

**SELF AWARENESS AND COMMUNITY INTEGRATION AFTER
TRAUMATIC BRAIN INJURY**

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Submitted to the Graduate Faculty of the
School of Health and Rehabilitation Sciences in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

University of Pittsburgh

2012

UNIVERSITY OF PITTSBURGH
SCHOOL OF HEALTH AND REHABILITATION SCIENCES

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AFTER TRAUMATIC BRAIN INJURY**

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Traumatic brain injury (TBI) is a prevalent cause of disability in the United States, resulting in ongoing cognitive and behavioral deficits that may result in poor community integration outcomes. While community integration has historically been measured through objective outcomes, such as frequency of participation in activities of the household, family, and community, the use of subjective measures, such as satisfaction, is necessary to capture the unique perspective of each individual. Therefore, this dissertation measures community integration from two perspectives – frequency of participation and satisfaction with participation – to provide a more holistic representation of community integration after TBI.

Using the framework of the International Classification of Functioning, Disability and Health (World Health Organization, 2001), both frequency of participation and satisfaction with participation can be described as products of functioning and contextual factors. To explore these factors and their association with community integration after TBI, three studies were conducted. The first study examined factors associated with community integration. The second study explored in greater depth one of these factors – self awareness. The third study explored the moderating effects of positive affect, negative affect, and age on the relationship between self awareness and community integration.

The combined findings from these studies suggest that frequency of participation and satisfaction with participation are each associated with different functioning and contextual

factors after TBI. Self awareness contributed independently to frequency of participation and this relationship was moderated by negative affect and age. Self awareness did not contribute to satisfaction with participation, but positive affect, negative affect, and age were all found to independently predict satisfaction with participation. These findings provide insights into factors associated with community integration after TBI that may be useful in informing future efficacious interventions addressing poor community integration.

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PREFACE

I would like to thank all those whose help was instrumental to the completion of this project. A special thank you to my committee chair, Elizabeth R. Skidmore, PhD, OTR/L, for her dedication to mentorship and for the hours of reading, directing, and guiding that has shaped all aspects of my scholarship and professional development. Thank you to my other committee members, Ketki D. Raina, PhD, OTR/L, Michael McCue, PhD, CRC, Patricia Arenth, PhD, and Christian Niyonkuru, MS, for their time and individual expertise, each of which was necessary for the development, implementation, and completion of this project.

I would also like to thank the following individuals and organizations for devoting their time and energy to various aspects of this project. Thank you to Katlyn Watkins, Lauren Kessler, Martina Santarsieri, and Joelle Scanlon, to all of my fellow doctoral trainees in the Department of Occupational Therapy, and especially to all of the local organizations who provide support and services to individuals who have had traumatic brain injuries.

To my husband, Jon, I owe a special debt of gratitude. Thank you for the hours you devoted to supporting me in every way, from the minutest details of this project to the broader encouragement and support of my academic pursuits.

This study was supported in part through funding received from the SHRS Research Development Fund, School of Health and Rehabilitation Sciences, University of Pittsburgh, and the Provost's Development Fund, Office of Cross Cultural and Leadership Development, University of Pittsburgh.

1.0 INTRODUCTION

Traumatic brain injury (TBI) is a prevalent cause of disability in the United States, with 1.7 million individuals sustaining a new TBI each year (Centers for Disease Control and Prevention, 2010). The cognitive and behavioral deficits that result from TBI contribute to poor community integration outcomes (Bush et al., 2003; Millis, Rosenthal, & Lourie, 1994; Novack, Bush, Meythaler, & Canupp, 2001; Reistetter & Abreu, 2005; Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Poor community integration is associated with poor quality of life, productivity, and health (Cicerone & Azulay, 2007; Stalnacke, 2007; Stalnacke, Elgh, & Sojka, 2007). Thus, it is necessary to develop rehabilitation interventions to improve community integration after TBI.

Community integration can be defined as participation in meaningful community-based activities and relationships. Community integration is a function of the complex relationship between functioning and contextual factors (personal characteristics and the environment (Sander, Clark, & Pappadis, 2010; Sander, Pappadis, Clark, & Struchen, 2010; World Health Organization, 2001).

Among the many factors contributing to poor community, I hypothesize that poor self awareness of TBI-related cognitive and behavioral deficits significantly contributes to reduced frequency of participation and increased satisfaction with participation. Poor self awareness, impairment in one's ability to see oneself objectively, occurs frequently after TBI (Prigatano,

1991). However, measuring self awareness is complex, as it has multiple components. Specifically, self awareness involves not only recognizing one's abilities and limitations objectively, but also recognizing how the environment influences those abilities and limitations and how those abilities and limitations influence engagement in meaningful activities. I plan to examine the association between self awareness and community integration, including knowledge of one's limitations and the effects of the environment on those limitations in the conceptualization of self awareness.

Several factors may influence the relationship between self awareness and community integration. I have chosen to examine the influence of two factors believed to be associated with both self awareness and community integration: 1) affect and 2) age. While affect and age have each been associated with self awareness and community integration separately, the influence of each of these factors on the relationship between self awareness and community integration is still unclear. Clarification of the associations among affect, age, self awareness, and community integration may inform the design of interventions targeting community integration.

Affect refers to an individual's emotional state and can be classified as either positive affect or negative affect. Negative affect has most frequently been explored in the presence of clinical syndromes. For example, it has previously been established that depression, anxiety, and psychosocial distress are associated with poor community integration following TBI (Anson & Ponsford, 2006; Felmingham, Baguley, & Crooks, 2001; Hoofien, Gilboa, Vakil, & Donovan, 2001; Jorge, Robinson, Arndt, Starkstein, et al., 1993; Jorge, Robinson, Starkstein, & Arndt, 1993; Morton & Wehman, 1995; Ownsworth & Fleming, 2005; Ruff et al., 1993). However, individuals with poor self awareness seem to demonstrate less psychological distress and maladaptive coping than those with good self awareness, despite having poorer community

integration (Anson & Ponsford, 2006; Cooper-Evans, Alderman, Knight, & Oddy, 2008; Fleming, Strong, & Ashton, 1998; Godfrey, Bishara, Partridge, & Knight, 1993; Malec, Testa, Rush, Brown, & Moessner, 2007). This raises the question of whether the relationship between self awareness and community integration may be moderated by negative affect, as indicated by distress or poor coping or whether lack of awareness moderates emotional response. Positive affect, as indicated by positive coping and good self-esteem, has been associated with better community integration (Fleming et al., 1998). Therefore, I will explore the moderating effect of negative affect and positive affect on the relationship between self awareness and community integration.

Findings for the association between age and community integration after TBI vary. Most research suggests that younger individuals demonstrate better community integration than older individuals after TBI (Fleming, Tooth, Hassell, & Chan, 1999; Goranson, Graves, Allison, & La Freniere, 2003; Heinemann, Hamilton, Linacre, Wright, & Granger, 1995; Willemse-van Son, Ribbers, Hop, & Stam, 2009), though the opposite has been reported as well (Winkler, Unsworth, & Sloan, 2006). Community integration for individuals who have established life roles (e.g. those who are older) may differ from community integration for individuals transitioning to adulthood (i.e. those who are 18-24 years old) who may not have established life roles. With regard to self awareness after TBI, younger individuals with cognitive impairments may be more likely to demonstrate poor self awareness than those who are older (Morton & Barker, 2010). However, individuals with more severe cognitive impairment demonstrate more impaired self awareness (McDaniel, Edland, & Heyman, 1995), and older individuals who sustain a TBI demonstrate more cognitive impairment than younger individuals (Schonberger, Ponsford, Reutens, Beare, & O'Sullivan, 2009; Senathi-Raja, Ponsford, & Schonberger, 2010).

Given these findings, one would expect that older individuals with TBI would have more impaired self awareness. Therefore, I will examine the potential effects of age on the relationship between self awareness and community integration.

1.1 SIGNIFICANCE

This project is particularly timely, due to the increase in community-dwelling individuals with TBI and the growing body of literature reporting poor community integration even in the absence of significant physical or cognitive impairments. At two years post-injury, approximately 91% of individuals who have sustained a TBI are living in the community (Traumatic Brain Injury Model Systems National Data and Statistical Center, 2011). However, while 69% of individuals were employed or students prior to their injuries, only 38% are employed or students at two years post-injury, signifying a dramatic decrease in gainful employment and productivity in this population, despite minimal physical disability (average Functional Independence Measure scores 115 of 126; Traumatic Brain Injury Model Systems National Data and Statistical Center, 2011). Furthermore, the 1.7 million new TBIs each year (an increase in incidence from 1.4 million in 2004; Langlois, Rutland-Brown, & Wald, 2006) do not account for those treated in military facilities, which are estimated at approximately 235,046 between 2000 and 2011 (Defense and Veterans Brain Injury Center, 2011). There is an increasing trend in the incidence of TBI in the military, with 10,963 new cases in 2000 and 32,001 new cases in 2011 (Defense and Veterans Brain Injury Center, 2011). Lost productivity from TBI is 14 times that of lost productivity due to spinal cord injury, with approximately 2%

of the United States population living with long-term disability associated with TBI (Langlois et al., 2006). The estimated cost of this lost productivity as a result of TBI is \$60 billion annually (Corso, Finkelstein, Miller, Fiebelkorn, & Zaloshnja, 2006).

In both the civilian and military populations, there are numerous consequences of TBI that negatively affect community integration. Decreased productivity as a result of TBI results in higher medical costs (medical treatment, long-term disability, increased risk for other health conditions). Life expectancy of those who survive TBI is reduced 7 years compared to individuals without TBI (Harrison-Felix, Whiteneck, Devivo, Hammond, & Jha, 2006). Furthermore, 17-22% of individuals with TBI are re-hospitalized each year, frequently due to physical complaints, but increasingly due to mental health complaints as time since injury increases (Cifu et al., 1999; Marwitz, Cifu, Englander, & High, 2001). Psychiatric and neurobehavioral sequelae of TBI result in a loss of productivity and high medical costs, as well as increased risk of suicide (Centers for Disease Control and Prevention, 2003). Socially, individuals with TBI are at high risk for loss of friendship and social support, and they tend to engage in more passive leisure activities than individuals without TBI (Mazaux & Richer, 1998; Morton & Wehman, 1995). Limited engagement in social roles may result in isolation and negative psychological consequences (Brown, Gordon, & Spielman, 2003; Leach, Frank, Bouman, & Farmer, 1994), which may in turn adversely affect satisfaction and quality of life (Jones et al., 2011; Stalnacke, 2007).

Historically, research into interventions targeting community integration after TBI has focused on productivity, with higher frequency of engagement in community-based activities (predominantly vocational) indicating better outcomes (Sander, Clark, et al., 2010). However, while full-time work has historically represented a more positive outcome than part-time work

following TBI, individuals who work full-time report having a less balanced lifestyle than those who work part-time (Doig, Fleming, & Tooth, 2001), suggesting that the subjective experience of community integration may differ from traditional objective measures. Furthermore, satisfaction with community integration differs based on numerous factors, such as race and culture or environmental barriers and supports (Arango-Lasprilla & Kreutzer, 2010; Sander, Clark, et al., 2010; Sander et al., 2007), again suggesting the need to consider the subjective experience of the individual (satisfaction) in addition to objective measures such productivity (frequency) with regard to long-term community-based outcomes after TBI.

The impact of TBI at the national, community, and individual levels cannot be denied. Individuals with TBI may have unique difficulties in accessing services and maintaining overall health and participation in the community (Langlois et al., 2006). This decreased frequency of participation may in turn result in poor satisfaction and quality of life. This project will provide a deeper understanding of factors that contribute to community integration by examining both objective (frequency of participation) and a subjective (satisfaction with participation) components of community integration and by investigating alternative explanations for poor outcomes. It will provide pilot data that can be used to inform the design and implementation of appropriate and effective interventions to improve these outcomes for individuals who have sustained TBI.

1.2 PURPOSE

The purpose of this study is to investigate the degree to which community integration – as defined by frequency of participation and satisfaction with participation - is explained by self awareness in individuals with TBI. The study has three specific aims:

- (1) To examine the association between self awareness and community integration among adults with a history of traumatic brain injury,
- (2) To examine whether the association between self awareness and community integration differs by positive and negative affect among adults with a history of traumatic brain injury, and
- (3) To examine whether the association between self awareness and community integration differs by age among adults with a history of traumatic brain injury.

The descriptive data and correlations presented in Chapter 2 provide a comprehensive summary of the sample characteristics and the factors associated with community integration, including both frequency of participation and satisfaction with participation. Methods of assessment are described in detail, and recommendations for future research are discussed.

Chapter 3 specifically addresses Aim 1 of this project, examining the relationships between self awareness and frequency of participation and self awareness and satisfaction with participation through simple linear regression analyses. I conducted additional adjusted regression analyses including known covariates of community integration in the models, to explore additional factors that may influence these relationships.

Chapter 4 specifically addresses Aims 2 and 3 of this project, examining potential moderating factors in the relationships between self awareness and frequency of participation and self awareness and satisfaction with participation. These moderating factors include both positive and negative affect and age.

In Chapter 5, the results of the previous 3 chapters are summarized, the implications of these results are discussed with regard to community integration after traumatic brain injury, and recommendations are provided for future research examining self awareness and community integration after traumatic brain injury.

2.0 CHAPTER TWO – FACTORS ASSOCIATED WITH COMMUNITY INTEGRATION AFTER TBI

2.1 BACKGROUND

Every year, approximately 1.7 million individuals in the United States sustain a new traumatic brain injury (TBI; Centers for Disease Control and Prevention, 2010). Following TBI, problems can arise with memory, reasoning, communication, personality, social behavior, mood, and self awareness (Brown et al., 2011; Centers for Disease Control and Prevention, 2003, 2010). These cognitive, emotional, and behavioral changes may persist and possibly worsen over time, with the potential to negatively impact community integration, including productivity and quality of life (Draper & Ponsford, 2008; Masel, 2009; Senathi-Raja et al., 2010). Therefore, anticipating these problems and understanding the mechanisms by which they occur may allow for early intervention to reduce barriers to community integration.

A high proportion of individuals with a history of mild to severe TBI living in the community and do not receive rehabilitative services directed at cognitive impairment, mood, behavior disruptions or loss of productivity (Vangel, Rapport, Hanks, & Black, 2005). Even those with mild TBI experience disabling conditions (Borgaro, Prigatano, Kwasnica, & Rexer, 2003; Williams, Levin, & Eisenberg, 1990), and those with complicated mild injuries are comparable to those with moderate injuries on cognitive testing (Williams et al., 1990). Recent

research suggests that post-acute interventions for TBI should focus on managing attention and concentration, improving memory strategies, addressing executive functioning deficits including self awareness and self-cuing, and attending to adjustment to disability (Mateer & Sira, 2006). This evidence represents a shift in the focus of rehabilitative services away from management of acute symptoms and towards long-term issues for individuals with TBI. Consistent with this shift, the Centers for Disease Control recently called for a stronger scientific and clinical focus on community integration and societal participation outcomes after TBI (Centers for Disease Control and Prevention, 2010). The current project responds directly to this call by addressing factors associated with community integration, both from an objective perspective and from the perspective of the individual.

2.1.1 Community Integration in TBI

Individuals with TBI demonstrate reduced probability of employment, independent living, social and family relationships, leisure and recreation activities, and quality of life (Cicerone & Azulay, 2007; Stalnacke, 2007; Temkin, Corrigan, Dikmen, & Machamer, 2009; Willer, Johnson, Rempel, & Linn, 1993; Willer, Ottenbacher, & Coad, 1994). Only 38% of individuals with TBI report a high level of productivity in the community (Doig et al., 2001). Socially, individuals with TBI are at high risk for loss of friendship and social support, and they tend to engage in more passive leisure activities than individuals without TBI (Mazaux & Richer, 1998; Morton & Wehman, 1995).

Community integration has traditionally been measured through objective outcomes, such as return to work (Brown, McCauley, Levin, Contant, & Boake, 2004). More recent research (discussed below) strongly suggests measuring the individual's perspective of community

integration, assessing satisfaction with participation in household, family, community, and societal activities. This provides a more holistic view of community integration. In addition to measuring the frequency of participation in meaningful personal activities and social relationships, incorporating the individual's subjective experience (satisfaction with participation) offers additional insight into the individual's needs and goals, allowing for more personalized outcomes and interventions to be developed.

Previous research has examined the relationship between various functional and contextual factors, terms defined by the ICF (World Health Organization, 2001) that are associated with community integration after TBI (See Figure 2.1).

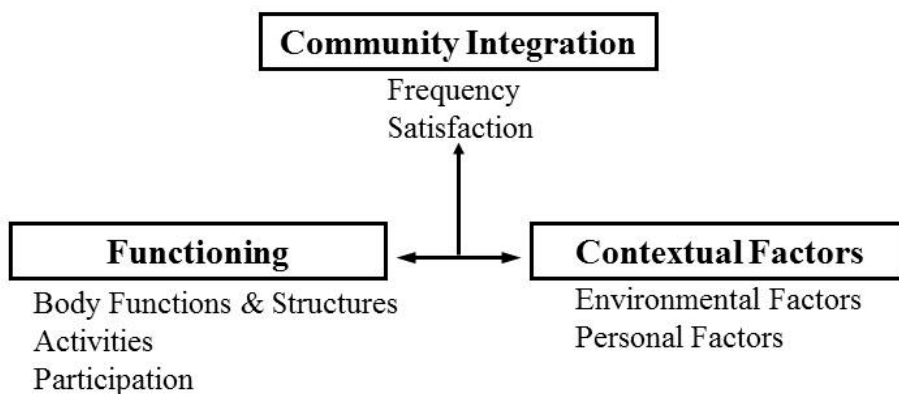


Figure 2.1. Model of Community Integration

Self awareness, injury severity, acceptance of disability, social relationships, education, ability to drive, marital status, and pre-injury productivity are factors most predictive of return to work, a common indicator of community integration after TBI (Ezrachi, Ben-Yishay, Kay, Diller, & Kattok, 1991; Gollaher et al., 1998; Kreutzer et al., 2003; Shames, Treger, Ring, & Giaquinto, 2007; Sherer, Bergloff, et al., 1998; Sherer et al., 2003). Other factors associated

community integration after TBI include cognition, disability, length of post-traumatic amnesia, and age (Fleming et al., 1999). This study will explore relationships among several of these factors and the two perspectives of community-integration proposed by the model: frequency of participation and satisfaction with participation.

2.1.2 Significance

Vocational outcomes have traditionally been a predominant measure of long-term community integration following brain injury, though other aspects of community integration, such as daily activities, recreation, and social relationships, are important objective measures as well (Sander, Clark, et al., 2010). Additionally, incorporating a subjective component (satisfaction) in community integration research has been recommended across the literature (Brown et al., 2004; Cicerone, 2004; Cicerone & Azulay, 2007; Johnston, Goverover, & Dijkers, 2005; Mascialino et al., 2009; Minnes et al., 2003; Sander, Clark, et al., 2010) and is increasingly important as clinical medicine shifts towards more client-centered interventions and outcomes. Satisfaction with participation in community-based activities differs based on numerous personal factors (Arango-Lasprilla & Kreutzer, 2010; Sander, Clark, et al., 2010; Sander et al., 2007), and understanding satisfaction is essential to understanding the individual's perspective with regard to long-term outcomes after TBI. The purpose of this study was to determine what factors are associated with community integration among community-dwelling adults with a history of complicated mild to severe TBI, taking into account both frequency of participation and satisfaction with participation.

2.2 METHODS

This cross-sectional study examined factors associated with community integration in a population of adults with a documented history of complicated mild to severe traumatic brain injury (TBI) at least 6 months post-injury. I recruited 65 participants, with a family member/caregiver if available, and assessed them once.

2.2.1 Participants

Individuals were recruited through existing collaborations with the University of Pittsburgh Departments of Occupational Therapy, Physical Medicine and Rehabilitation, and Psychiatry, as well as through key personnel within the University of Pittsburgh Medical Center Rehabilitation Institute. Through these collaborations, I had access to individuals with TBI who received services through Physical Medicine and Rehabilitation, had previously participated in research, and/or had enrolled in the University of Pittsburgh Medical Center Rehabilitation Institute Research Registry. Finally, individuals were recruited through advertisements and referrals at local brain injury support groups and agencies servicing individuals with TBI.

After referral, a brief telephone screening was completed to determine initial eligibility. If eligible, a study visit was scheduled, most often at the individual's home, though some chose to come to the University of Pittsburgh or to meet at a University of Pittsburgh Medical Center facility. Individuals who provided informed consent (or who provided assent with proxy informed consent) at the study visit were then screened to determine final eligibility. If eligible, participants completed the remaining assessments.

Inclusion criteria were: 1) a history of complicated mild to severe traumatic brain injury (Glasgow Coma Scale score 1-15 with evidence of neuroradiologic injury or significant functional compromise) greater than 6 months prior to assessment; 2) 18 years old or older; and 3) living in a private or group residential setting. Exclusion criteria were: 1) a history of any condition resulting in progressive cognitive decline (e.g. dementia); 2) current active psychotic or bipolar disorder; and 3) ongoing involvement in injury-related litigation.

2.2.2 Measures

2.2.2.1 Dependent Variable Measure: Community Integration

The Participation Assessment with Recombined Tools-Objective/Satisfaction (PART-OS) was used to measure community integration, including both frequency of participation and satisfaction of participation. The PART-OS was developed by the Participation Special Interest Group of the TBI Model Systems to address the lack of the subjective perspective of previously established measures of participation – the Craig Hospital Assessment and Reporting Technique and the Community Integration Questionnaire – in that these tools did not address a person’s subjective view of the engagement in activities being measured (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007). In an effort to evaluate both objective and subjective perspective of community integration, the PART-OS consists of two scales: the PART-O (objective items) and PART-S (satisfaction items). The PART-O consists of 24 items that measure frequency of engagement in various activities of the household, family, community, and wider society. A total score is calculated measuring a person’s level of participation. The PART-S addresses the subjective importance of 11 domains of participation. Domains are rated first as low, medium, or high importance, and then level of satisfaction is rated on a 0-10 point

scale for domains of medium or high importance. An average weighted satisfaction score is calculated based on these ratings. The PART-O is an established measure that has been validated and is being used as the gold standard participation measure in the TBI Model Systems (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007). The PART-S is currently undergoing validation in eight of the model systems of TBI (M. Dijkers, personal communication, July 27, 2010) and is included as a measure of subjective community integration, to capture the perspective of the individual with regard to participation.

2.2.2.2 Descriptive Measures

I collected demographic and injury-related data, as well as information about self awareness, positive and negative affect, self-efficacy, fatigue, behavior, disability, and cognition. Most measures were chosen from the Center for Measurement in Brain Injury (www.tbims.org/combi) compiled by the National Institute of Disability and Rehabilitation Research TBI Model Systems; these measures demonstrated strong psychometric properties – validity and reliability – when administered to individuals with TBI. In addition to these measures, I selected measures of behavior, affect, fatigue, and self-efficacy based on their psychometric properties in the TBI population. See Appendix A for a more detailed summary of the measures used in this study.

Demographic information

I collected demographic data including age, education, race, gender, marital status, time since injury, nature of injury, rehabilitation services received, ability to drive, and living situation and work status pre- and post-injury. Current mental health status and substance abuse were assessed using the PRIME-MD (Spitzer, Williams, Kroenke, Hornyak, & McMurray, 2000) and the Mini-International Neuropsychiatric Interview (MINI; Sheehan et al., 1998). I measured injury

severity at time of injury using the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974), a commonly used measure of injury severity in TBI (see Appendix B; Reistetter & Abreu, 2005). Participants were categorized as having had a complicated mild (GCS 13-15 with positive neuroradiologic findings or functional compromise requiring ongoing services), moderate (GCS 9-12), or severe (GCS \leq 8) injury.

Self Awareness

The Self-Regulation Skills Interview (SRSI) served as a measure of self awareness for this study. The SRSI is composed of 3 distinct subscales: Awareness, Readiness to Change, and Strategy Behavior (Ownsworth, McFarland, & Young, 2000). The SRSI demonstrated good inter-rater reliability ($r=.81-.92$) and test-retest reliability ($r=.69-.91$; Ownsworth et al., 2000). Individual subscale scores were used in this study, with higher scores indicating poorer self awareness, except in the case of Readiness to Change, where a higher score indicated greater motivation to change.

Affect

The Positive And Negative Affect Schedule (PANAS) is a valid and reliable measure of affect that consists of two 10-item mood scales: Positive Affect and Negative Affect (Watson, Clark, & Tellegen, 1988). Each scale includes 10 items rated on a five point scale and yielding total score for Positive Affect and for Negative Affect (ranges 10-50). Higher scores on the Positive Affect scale indicate high energy, concentration, and pleasurable engagement, whereas low scores indicate sadness and lethargy. Higher scores on the Negative Affect scale indicate high anger, disgust, guilt, fear, or nervousness, whereas low scores indicate calmness and serenity.

Self-efficacy

The General Self-Efficacy Scale (GSE) is a valid and reliable measure of general self-perceived self-efficacy (Luszczynska, Scholz, & Schwarzer, 2005). The scale consists of 10 items scored on a 4-point scale and yielding a total score ranging from 10-40 points. Higher scores indicate higher degrees of perceived self-efficacy.

Fatigue

The Modified Fatigue Impact Scale (mFIS) is a general scale that measures the impact of fatigue on everyday life in 3 dimensions – Cognitive, Physical, and Psychosocial (Fisk et al., 1994) - and has been validated in a TBI population (LaChapelle & Finlayson, 1998). The mFIS includes 21 items, each rated on a 5-point ordinal scale. It produces a total summed score ranging from 0-84, with higher scores indicating greater fatigue.

Behavior

The Frontal Systems Behavior Scale (FrSBe) assesses behaviors associated with damage to frontal systems, a common occurrence in TBI (Grace & Malloy, 2001). This is a valid and reliable tool when completed as a self-report or by a family member/significant other to measure behavior prior to and after injury. It is comprised of 46 items that contribute to three subscales- Apathy, Disinhibition, and Executive Dysfunction – and a total score (range 0-230). *T*-scores adjusted for age, gender, and education are derived, with higher scores indicating greater executive impairment. For this study, self-report total scores were used.

Disability

I assessed disability with the Mayo Portland Adaptability Inventory (MPAI; Malec, 2005; Malec et al., 2003). Items are rated on a 0-4 scale. The MPAI yields a total summed score, with higher

scores indicating more severe disability (Malec, 2005). It was administered both as a self-report form and to a family member/caregiver. For this study, the self-report total *T*-scores were used as a general measure of disability.

Cognition

I selected a brief neuropsychological test battery based on the battery validated by the TBI Model Systems (Hanks et al., 2008). It provided an overview of cognition that focused on cognitive domains most commonly affected by TBI. I selected 6 of 8 neuropsychological tests from the battery, as they were deemed most appropriate for a community-based sample. Each of these tests is listed and briefly described below. See Appendix A for further details.

California Verbal Learning Test II (CVLT-II). The CVLT-II is a 16-item list learning task that incorporates learning, short-term delayed recall, long-term delayed recall, and long-term delayed recognition (Delis, Kramer, Kaplan, & Ober, 2000). The adjusted *T*-score for learning (total trials 1-5) contributed to the cognitive composite score in this study.

Trail Making Test (TMT). The TMT is a timed, performance-based test that can be used as a measure of visuoconceptual and visuomotor tracking (Lezak, 1983). Time to complete Trails A and Trails B was converted to adjusted *T*-scores based on published norms, and both contributed to the cognitive composite score.

Symbol Digit Modalities Test (SDMT). The SDMT is a brief measure of visual perceptual skills, scanning, and psychomotor speed (Smith, 1982). The total written score on the SDMT was converted to an adjusted *T*-score and used in the cognitive composite score.

Letter and Category Fluency (FAS/Animal Naming). The FAS assesses word retrieval ability and executive functioning or frontal lobe functions (Benton & Hamsher, 1976). Total fluency scores for FAS and for Animal Naming were converted to adjusted T-scores based on published norms, and both contributed to the cognitive composite score.

Wechsler Test of Adult Reading (WTAR). The WTAR provides a brief measure of premorbid intellectual functioning (Wechsler, 2001). A standard score estimating premorbid verbal intelligence was calculated but was not used in the cognitive composite score (see Appendix C).

Wisconsin Card Sorting Test – 64-item version (WCST). The 64-item version of the WCST assesses executive functions, yielding subscale scores (adjusted T-scores) for perseverative responses and errors, total errors, and categories completed (Kongs, Thompson, Iverson, & Heaton, 2000). The T-score for total perseverative errors was used in calculating the cognitive composite score.

A single cognitive composite score was calculated to serve as an overall measure of cognition to maximize reliability and power (Green et al., 2008). Raw scores from the CVLT total trials 1-5, TMT A and B time, SDMT total, FAS total, Animals total, and WCST perseverative errors were transformed into normative scores using normative data for each test. These normative scores were then transformed into *T*-scores, which were averaged to produce a single cognitive composite *T*-score. Individual neuropsychological test data and correlations are detailed in Appendix C.

2.2.3 Statistical Analysis

To address the primary aim of the study, I first examined descriptive statistics and then computed Spearman and Pearson correlations, depending on the type of scale being assessed and the distribution of the measures, to assess which factors were associated with community integration after TBI. I set the overall significance level at $\alpha=.05$. Data were entered and maintained in a database using SPSS19.0™ for Windows. In compliance with the standards of the University of Pittsburgh Institutional Review Board, all data were de-identified, and personal information was stored separately to ensure confidentiality.

2.3 RESULTS

2.3.1 Recruitment

Out of 188 individuals contacted, 115 initially responded to recruitment letters, advertisements, outreach activities, and follow-up telephone calls. Upon initial telephone screening, 26 individuals were not interested in research, five did not meet injury severity criteria, 3 had passed away, 2 were currently involved in litigation, and 8 were not eligible for other reasons. 71 individuals were eligible after initial telephone screening, and 70 provided written informed consent. After consent and additional eligibility screening, two participants were determined to be ineligible due to active untreated bipolar/psychotic disorder, and three did not meet injury severity criteria after review of medical records. Thus, 65 individuals were deemed eligible to participate.

2.3.2 Descriptive Data

The descriptive data for this study are summarized in Table 2.1.

Table 2.1 Demographic and Descriptive Data

	(n=65)		
	Mean (SD)	Range	n
Self Awareness – SRSI			
Awareness Subscale*	7.63 (4.79)	0-20	65
Readiness to Change	7.30 (2.93)	0-10	65
Strategy Behavior Subscale*	14.54 (6.25)	0-30	65
Community Integration – PART-O/S			
Frequency of Participation	1.96 (0.51)	.70-3.26	65
Satisfaction with Participation	11.29 (3.51)	1.22-17.55	65
Affect - PANAS			
Positive Affect	32.67 (7.77)	10-48	64
Negative Affect*	18.80 (6.77)	10-35	64
Self Efficacy - GSE	30.46 (5.07)	17-40	64
Fatigue – mFIS (total)*	35.97 (21.15)	0-77	64
Self FrSBE (total T score)*	64.32 (21.11)	32-130	62
Other FrSBE (total T score)*	72.66 (20.38)	33-134	56
Disability – Self MPAI (total T score)*	44.27 (13.05)	-4-62	63
Disability – Other MPAI (total T score)*	41.58 (15.40)	-9-67	57
Cognition – Composite Score (average T Score)	44.54 (12.03)	-8.85-60.06	65
Age (years)	49.91 (16.54)	18-86	65
Age at injury (years)	38.92 (16.35)	16-85	65
Time Since Injury (months)†	55.00 (14.0, 104.5)	6-428	65
Education (years)	14.63 (2.63)	10-20	65
	n (%)		
Gender (male)	52 (80.0%)		65
Race (white)	63 (96.9%)		65
Married (yes)	26 (40%)		65
Ability to drive (yes)	45 (69.2%)		65
Vocational Status			65
Full-time	17 (26.2%)		
Part-time	9 (13.8%)		
Retired	6 (9.2%)		
Unemployed	10 (15.4%)		
Disability	23 (35.4%)		

Table 2.1 (continued)

	n (%)	
Injury Severity [‡]		65
Complicated Mild (GCS=13-15)	20 (30.8%)	
Moderate (GCS=9-12)	13 (20.0%)	
Severe (GCS≤3)	32 (49.2%)	
History of Inpatient Rehabilitation (yes)	48 (73.8%)	65
Depression History		65
Current Major Depressive Disorder	9 (13.8%)	
History of Major Depressive Disorder	30 (46.2%)	
Minor Depressive Disorder	5 (7.7%)	
No History	21 (32.3%)	
Alcohol History		65
No use	3 (4.6%)	
Past use	20 (30.8%)	
Current use	26 (40.0%)	
Past abuse – no current use	9 (13.8%)	
Past abuse – current use	5 (7.7%)	
Current abuse or dependence	2 (3.1%)	
Drug History		65
No use	32 (49.2%)	
Past use	18 (27.7%)	
Current use	8 (12.3%)	
Past abuse – no current use	4 (6.2%)	
Past abuse – current use	2 (3.1%)	
Current abuse or dependence	1 (1.5%)	

*Higher scores indicate poorer functioning

†Median, inter-quartile range

‡Based on Glasgow Coma Scale (GCS) score at time of injury

Participants' ages ranged from 18-86 years old, and time since injury ranged from 6 months to 35.7 years. On average, participants had completed some post-secondary education ($M=14.63$ years, $SD=2.63$). The majority of participants in the present sample were male (80%), white (96.9%), able to drive (69.2%), not married (60%), and had a history of inpatient (73.8%) and outpatient (78.5%) rehabilitation. The distribution of injury severity at time of injury varied, though the largest group was participants with a history of severe injury (49.2%). The majority of participants had current symptoms or history of major depressive disorder (60%), with an

additional 7.7% demonstrating current symptoms of minor depressive disorder. Current alcohol abuse (3.1%) or drug abuse (1.5%) were not prominent in the present sample, though history of alcohol abuse (21.5%) or drug abuse (9.3%) was more common.

With regard to the primary dependent variable of community integration, participants in the present sample demonstrated slightly higher frequency of participation ($n=65$, $M=1.96$, $SD=0.51$) than a large sample of individuals with TBI without depression who were enrolled in the TBI Model Systems ($n=815$, $M=1.8$, $SD=0.7$; Hart, Seignourel, & Sherer, 2009). Satisfaction with participation in the present sample ($M=11.29$, $SD=3.51$) varied greatly from 1.22 to 17.55 (N.B. no published data using the PART-S were available for comparison at the time of this data collection). With regard to the primary independent variable of self awareness, the present sample demonstrated slightly poorer scores and greater variation on the awareness subscale ($M=7.63$, $SD=4.79$) and much poorer scores on the strategy behavior subscale ($M=14.54$, $SD=6.25$) than a sample of individuals ($n=61$) with acquired brain injury used to validate the tool ($M=5.7$, $SD=1.5$ and $M=5.8$, $SD=1.4$, respectively; Ownsworth et al., 2000). Despite poorer awareness scores, the present sample reported much higher scores on the readiness to change subscale ($M=7.30$, $SD=2.93$) than the validation sample ($M=2.3$, $SD=1.8$; Ownsworth et al., 2000). Compared to a sample from the general population ($n=1,003$) who demonstrated average positive affect of 31.31 (7.65) and negative affect of 16 (5.9), the present sample had similar positive affect ($M=32.67$, $SD=7.77$) and slightly higher negative affect ($M=18.80$, $SD=6.77$; Crawford & Henry, 2004). Participants in this study reported comparable self-efficacy ($M=30.46$, $SD=5.07$) to a sample of individuals with chronic acquired brain injury who had received rehabilitation ($n=37$, $M=30.1$, $SD=7.0$), and higher self-efficacy than those who had not received rehabilitation ($n=13$, $M=26.4$, $SD=5.4$; Svendsen & Teasdale, 2006). Average fatigue

scores for the present sample ($M=35.97$, $SD=21.15$) suggested high fatigue, approaching the cut-off score of 38, which indicates significant fatigue (Flachenecker et al., 2002). FrSBe scores suggest impaired executive functioning, as average T -scores ($M=64.32$, $SD=21.11$) are greater than one standard deviation from the mean ($M=50$, $SD=10$); even greater impairment is suggested by the significant other reported FrSBe scores. The present sample reported low to average disability ($M=44.27$, $SD=13.05$) based on T -scores ($M=50$, $SD=10$), again with similar results for significant other reported disability. Finally, the cognitive composite score suggests that the present sample on average is within the range of normal cognitive functioning ($M=44.54$, $SD=12.03$), with a trend in the direction of cognitive impairment. There was a very wide range of cognitive impairment in the present sample (T_- -.85 to 60.06), from individuals with severe cognitive impairment to individuals with high average cognitive functioning.

2.3.3 Correlations

All correlations are presented in Table 2.2. Frequency of participation was significantly correlated with self awareness and strategy behavior (SRSI), positive affect (PANAS), self-reported disability (MPAI), and the cognitive composite score. Higher frequency of participation was associated with better self awareness and strategy behavior, more positive affect, less disability, and better cognition. Satisfaction with participation was significantly correlated with positive affect and negative affect (PANAS), fatigue (mFIS), self-efficacy (GSE), self-reported disability (MPAI), age, and behavior (FrSBe). Higher satisfaction was associated with more positive affect, less negative affect, less fatigue, higher self-efficacy, less disability, older age, and less behavioral impairment. Furthermore, frequency of participation and satisfaction with participation were significantly associated with each other ($r=.456$, $p<.001$).

Table 2.2 Pearson Correlations (Spearman Correlations)**

	2.	3.	4.	5.	6.	7.	8.	9.	10.**	11.	12.	13.**	14.**	15.	16.**
1. Frequency of Participation - PART-O	.456‡	-.290*	.059	-.331*	.372†	-.043	-.157	.139	-.261*	.006	-.087	.047	-.051	-.132	.416†
2. Satisfaction with Participation - PART-S		.090	-.011	-.080	.504‡	-.391†	-.428‡	.310†	-.437‡	.271*	.228	-.032	-.243	-.349†	.106
3. Awareness – SRSI			-.461‡	.719‡	.036	-.283*	-.213	-.043	-.110	-.132	-.125	.044	.227	-.013	-.451‡
4. Readiness to Change – SRSI				-.447‡	-.104	.137	.205	-.168	.222	.276*	.155	.224	-.144	-.076	.211
5. Strategy Behavior – SRSI					-.158	-.041	.008	-.157	.038	-.100	.003	-.154	-.087	.170	-.239
6. Positive Affect – PANAS						-.337†	-.350†	.450‡	-.477‡	.166	.115	.100	.037	-.444‡	.071
7. Negative Affect – PANAS							.524‡	-.374†	.650‡	-.043	-.007	-.112	.071	.513‡	.110
8. Fatigue - mFIS								-.470‡	.765‡	.107	.085	.023	.004	.544‡	-.096
9. Self Efficacy - GSE									-.537‡	.001	.030	-.149	.014	-.662‡	.136
10. Self Reported Disability – MPAI**										.012	-.101	.198	.247	.658‡	-.086
11. Age											.867‡	.348†	-.505‡	-.056	.166
12. Age at Injury												-.116	-.630‡	-.075	.264*
13. Time Since Injury**													.208	.084	-.112
14. Injury Severity at time of injury**														.083	-.347†
15. Self Reported Behavior – FrSBe															-.195
16. Cognition Composite Score**															

* p < .05 ; † p < .01 ; ‡ p < .001

2.4 DISCUSSION

The purpose of this study was to explore factors associated with community integration – both frequency of participation and satisfaction with participation – among community-dwelling adults with a history of complicated mild to severe TBI. Higher frequency of participation was found to be associated with less cognitive impairment, higher positive affect, higher self awareness, and lower disability. Higher satisfaction with participation was found to be associated with higher positive affect, less disability, less fatigue, less negative affect, fewer behavioral problems, higher self-efficacy, and older age.

Table 2.3 Factors Correlated with Community Integration

<u>Frequency of Participation</u>	<u>Satisfaction with Participation</u>
Cognition ($r=.416, p<.01$)	Positive Affect ($r=.504, p<.001$)
Positive Affect ($r=.372, p<.01$)	Disability ($r=-.437, p<.001$)
Strategy Behavior ($r=-.331, p<.05$)	Fatigue ($r=-.428, p<.001$)
Self Awareness ($r=-.290, p<.05$)	Negative Affect ($r=-.391, p<.01$)
Disability ($r=-.261, p<.05$)	Executive Behavior ($r=-.349, p<.01$)
	Self-Efficacy ($r=.310, p<.01$)
	Age ($r=.271, p<.05$)

Of note, positive affect and disability contributed to both frequency of participation and satisfaction with participation, though this sample demonstrated levels of positive affect

comparable to the general population and below average disability compared to a larger community-based TBI sample. The role of positive affect with regard to various outcomes among individuals with brain injuries has been demonstrated (Kalpakjian, Lam, Toussaint, & Merbitz, 2004; Ostir, Berges, Ottenbacher, Clow, & Ottenbacher, 2008). Individuals with higher positive affect may have greater motivation to compensate for barriers to participation. How positive affect influences the relationship between self awareness and frequency of participation is unclear and requires further exploration. One possible explanation for the contribution of disability to both outcomes is that individuals with less disability are able to participate more frequently in social activities, particularly those outside of the home. Additionally, they may derive more satisfaction from participating in those activities without the added burden of having to navigate through inaccessible environments or address attitudinal barriers. Another possible explanation is the tool chosen to measure disability; the MPAI subscale of participation is closely related to frequency of participation and may be measuring a similar construct.

Self awareness and cognition were associated only with frequency of participation. Previous studies have shown a relationship between impaired self awareness and poor participation outcomes (Bach & David, 2006; Ezrachi et al., 1991; Hammond et al., 2004; Hoofien et al., 2001; McAvinue, O'Keeffe, McMackin, & Robertson, 2005; Ownsworth & Clare, 2006; Sherer et al., 2003). One explanation for this relationship is poor self-reporting (under-reporting) of actual frequency of participation among individuals with impaired self awareness. The reliance on self-reported assessments in this study, given that, overall, the sample demonstrated poor self awareness, may limit the interpretability of some measures (e.g. frequency of participation). However, individuals and their significant others did report similar levels of disability on a tool that also incorporates a participation component, suggesting that poor

awareness may not have resulted in inaccurate reporting of frequency of participation. The relationship between self awareness and community integration, as well as potential moderating factors of this relationship, requires further exploration.

The association between cognition and frequency of participation may also be explained by the fact that frequency of participation was self-reported. An individual with impairments in memory, attention, and executive functions may not be able to accurately report how frequently in a typical week he/she engages in various activities. Perhaps more importantly, impaired cognition may directly influence an individual's ability to engage in various activities, from shopping to household management to social activities.

Satisfaction with participation was associated with several factors in addition to positive affect and disability. Of the demographic variables examined, the only one associated with satisfaction with participation was age. Participation outcomes have previously been found to be associated with both younger age (Fleming et al., 1999; Heinemann et al., 1995; Willer et al., 1994) and older age (Winkler et al., 2006), so the relationship between participation outcomes and age remains unclear (Yasuda, Wehman, Targett, Cifu, & West, 2001). The finding in this study that older age was associated with higher satisfaction with participation (while age was not significantly associated with frequency of participation) is unique in its focus on satisfaction. Older individuals may have different expectations of their level of participation, which may influence how satisfied they feel with the activities they are able to engage in. Older individuals may also have better social support systems established before their injuries, resulting in a more positive affective state and higher self-efficacy, which in turn may result in higher satisfaction with participation. The association between age and community integration should be explored further.

While positive affect was associated with both frequency of participation and satisfaction with participation, negative affect was associated only with satisfaction with participation. Participants demonstrated higher levels of negative affect than the general population, consistent with previous findings (Kalpakjian et al., 2004). While the relationship between satisfaction outcomes and depression after TBI has been well established (Evans, Sherer, Nick, Nakase-Richardson, & Yablon, 2005; Stalnacke, 2007; Underhill et al., 2003), little work has been done examining the influence of negative affect on satisfaction outcomes in the absence of depression. Given that high negative affect can occur in the absence of depression, findings of this study suggests that future research should examine negative affect – independently from depression – when considering community integration.

Fatigue was highly associated with satisfaction with participation, but not with frequency of participation. This is consistent with previous research suggesting that post-TBI fatigue does not reduce frequency of participation (Cantor et al., 2005), but still has a negative impact on lifestyle and health-related quality of life (Cantor et al., 2005; Ziino & Ponsford, 2005). Cantor et al. (2008) suggest that fatigue may affect satisfaction, even when not reducing frequency of participation. Results from this study support that hypothesis, as satisfaction with participation was negatively associated with fatigue. Again, this highlights the need to incorporate a subjective component into any research investigating community integration after TBI, as factors that may not influence frequency of participation may influence satisfaction. Future research should examine the influence of fatigue after TBI on satisfaction with participation.

Higher self-efficacy was associated with higher satisfaction with participation in this study. Again, this is consistent with previous research that has demonstrated a relationship between self-efficacy and more global satisfaction outcomes (Cicerone & Azulay, 2007;

Rutterford & Wood, 2006; Tsaousides et al., 2009). Research suggests self-efficacy may influence social aspects of community integration after TBI as well (Dumont, Gervais, Fougereyrollas, & Bertrand, 2004, 2005). Individuals with high self-efficacy may feel more control over their participation, therefore resulting in higher satisfaction even in situations where they might be participating less frequently. Conversely, individuals with higher satisfaction in their participation may have higher self-efficacy regardless of the frequency with which they are able to participate. The direction of the relationship between self-efficacy and satisfaction with participation should be explored further.

The final factor that was associated with satisfaction with participation impaired behavior associated with frontal systems, or behavioral manifestations of impairment in executive functions (measured with the FrSBe). Objectively measured cognitive impairments were associated with frequency of participation, but impairment in executive functions as it manifests behaviorally was associated with satisfaction with participation. These differences to be explored in future research. Behavioral impairments negatively affect social integration – the aspect of community integration specific to having close interpersonal relationships (Struchen et al., 2011) – and social integration has in turn been associated with life satisfaction after TBI (Burleigh, Farber, & Gillard, 1998; Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001). While this study cannot address this question specifically, future research should examine the potential moderating effect of social integration (social relationships) on the relationship between behavioral impairment and satisfaction with participation.

A significant limitation of this study was the lack of diversity with regard to race and geographical location. While the heterogeneity of the sample overall with regard to factors such as injury severity, time since injury, gender, and method of recruitment is a significant strength of

this study, the majority of this sample was white, and all were from the greater Pittsburgh region. This limits the generalizability of the study results, particularly as race has been shown to be a significant factor with regard to various community integration outcomes after TBI (Horner, Selassie, Lineberry, Ferguson, & Labbate, 2008; Sander, Pappadis, et al., 2010; Sander et al., 2009; Wehman, Gentry, West, & Arango-Lasprilla, 2009). Future research should therefore explore whether the relationships described in this study differ based on race.

The diversity of recruitment methods and the less restrictive inclusion and exclusion criteria when compared with many TBI studies recruiting community-based samples yielded a heterogeneous sample of adults living in the community after TBI. The diversity of factors examined, framed within the overarching concepts of the ICF, provides a holistic picture of community integration in this population. Perhaps the most significant and timely aspect of this study is the focus not only on frequency of participation in domains beyond productivity, but also on the incorporation of the subjective component of satisfaction with participation. As demonstrated by the study results, frequency and satisfaction represent two unique components of community integration, each influenced by different factors. These findings support the importance of incorporating a subjective measure such as satisfaction with participation into future research investigating community integration. Exploring the factors that influence frequency of participation and satisfaction with participation in greater depth will better inform outcomes to improve community integration for individuals after TBI.

3.0 CHAPTER THREE – SELF AWARENESS AND COMMUNITY INTEGRATION

3.1 INTRODUCTION

3.1.1 Community Integration in TBI

Traumatic brain injury is not only an acute but also a chronic condition, with problems in cognition, emotion, behavior, and productivity persisting and worsening over time (Draper & Ponsford, 2008; Masel, 2009; Senathi-Raja et al., 2010). As a result of these problems, individuals with TBI experience poor community integration, including reduced probability of employment, independent living, social and family relationships, leisure and recreation activities, and quality of life (Cicerone & Azulay, 2007; Stalnacke, 2007; Temkin et al., 2009). There are several factors that are associated with return to work, a common objective indicator of community integration after TBI. These factors are self awareness, injury severity, acceptance of disability, social relationships, education, ability to drive, marital status, and pre-injury productivity (Ezrachi et al., 1991; Gollaher et al., 1998; Kreutzer et al., 2003; Shames et al., 2007; Sherer, Bergloff, et al., 1998; Sherer et al., 2003). Little is known about factors associated with the subjective perspective of satisfaction with participation.

3.1.2 Self Awareness in TBI

In previous investigations, self awareness, a prevalent factor after TBI, was found to be associated with community integration. Poor self awareness occurs frequently after TBI, as a result of the interaction between neurocognitive, psychosocial, and environmental factors (Ownsworth, Clare, & Morris, 2006). The prevalence of impaired self awareness among adults with TBI varies greatly, ranging from 45% to 97% (Sherer, Boake, et al., 1998). Inconsistencies in the prevalence of impaired self awareness may be due to differences in its definition and measurement.

Broadly defined, self awareness is objective knowledge of oneself or the capacity for self-reflection (Prigatano, 1991). More specifically, it involves the interaction of knowledge (objective) and interpretation of this knowledge (subjective; Prigatano, 1991), with impairments in self awareness often occurring at the level of application. Impaired self awareness is associated with poor recovery and rehabilitation outcomes, and conversely, better self awareness is associated with better rehabilitation outcomes (Clare, Wilson, Carter, Roth, & Hodges, 2006; Hoofien, Gilboa, Vakil, & Barak, 2004; Ownsworth & Clare, 2006; Ownsworth, Fleming, Desbois, Strong, & Kuipers, 2006; Prigatano, 2005). Individuals with impaired self awareness may have difficulty setting realistic goals, recognizing when to use compensatory strategies, and interacting appropriately in social situations (McGlynn & Schacter, 1989). In addition, impaired self awareness can affect motivation and treatment adherence in a rehabilitation program (Fleming et al., 1998; Prigatano & Wong, 1999).

Self awareness incorporates the knowledge one has of oneself (body functions and structures and personal factors) and one's context (environmental factors). Therefore, like community integration, be influenced by the interaction between functioning and contextual

factors as clarified by the ICF (see Figure 3.1). Since both community integration and self awareness are influenced by functioning and contextual factors, I hypothesize that they are, therefore, related to each other.

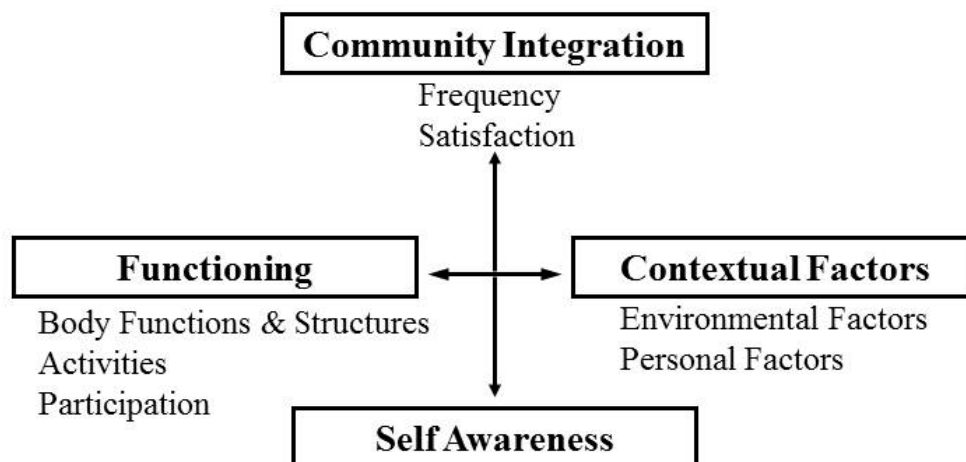


Figure 3.1 Model of Community Integration and Self Awareness

3.1.3 Significance

Community integration is recognized as an important measure of long-term outcome after TBI. Self awareness likely contributes to variability in community integration and was previously shown to be associated with frequency of participation (a component of community integration). The purpose of this study is to investigate the independent contribution of self awareness to community integration among community-dwelling adults with a history of complicated mild to

severe TBI. The study will examine two components of community integration: frequency of participation and satisfaction with participation. In addition, the contribution of other factors associated with community integration will be explored.

3.2 METHODS

This study used a cross-sectional design to examine the association between self awareness and community integration in a population of adults with a history of complicated mild to severe traumatic brain injury (TBI) at least 6 months post-injury. I recruited 65 participants, with a family member or significant other if available, and assessed them once.

3.2.1 Participants

Individuals were recruited through existing collaborations with the University of Pittsburgh Departments of Occupational Therapy, Physical Medicine and Rehabilitation, and Psychiatry, through the University of Pittsburgh Medical Center Rehabilitation Institute Research Registry, and through advertisements and outreach at local brain injury support groups and agencies servicing individuals with TBI.

After referral, a brief telephone screening was completed to determine initial eligibility, and if eligible, a study visit was scheduled, most often at the individual's home. After written informed consent was obtained, additional eligibility screening was completed, and if eligible, participants completed the remaining assessments.

Inclusion criteria were: history of complicated mild to severe traumatic brain injury (GCS score 1-15) greater than 6 months prior to assessment; 18 years old or older; and living in a private or group residential setting. Exclusion criteria were: a history of any condition resulting in progressive cognitive decline (e.g. dementia); current active psychotic or bipolar disorder; or ongoing involvement in injury-related litigation.

3.2.2 Measures

I collected demographic data, injury severity at time of injury, cognitive, affective, and disability status, and data on self-efficacy, fatigue, self awareness and frequency of and satisfaction with participation to address the study's aims. All assessments are summarized in detail in Appendix A.

3.2.2.1 Dependent Variable Measure: Community Integration

Community integration was measured using the Participation Assessment with Recombined Tools-Objective/Satisfaction (PART-OS; (2007). The PART-OS consists of two parts: the PART-O (frequency of participation) and PART-S (satisfaction with participation). The PART-O measures frequency of participation in activities of the household, family, community, and wider society, and has been validated for use with individuals with TBI (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007; Whiteneck et al., 2011). The PART-S measures satisfaction with participation in 11 domains and is currently undergoing validation in a TBI sample.

3.2.2.2 Independent Variable Measure: Self Awareness

The Self-Regulation Skills Interview (SRSI) served as the primary measure of self awareness for this study. The SRSI is composed of 3 distinct scales as determined by principle components analysis: Awareness, Readiness to Change, and Strategy Behavior. These scales are made up of six items that provide a detailed assessment of specific meta-cognitive skills, including emergent awareness, anticipatory awareness, readiness to change, strategy generation, degree of strategy use, and strategy effectiveness (Ownsworth, McFarland, & Young, 2000). These six items are applied to a main area of difficulty identified by the participant (e.g. lack of motivation, poor communication skills) and are scored on a 10-point Likert scale by the interviewer (except item 3 – readiness to change - which is a self-rating scored by the participant). Higher scores represent lower skill for all items. The SRSI is recommended for use with individuals who can demonstrate a basic level of intellectual awareness, which can be determined by a validated instrument such as the Self Awareness of Deficits Interview (SADI; Ownsworth et al., 2000). The SADI consists of a structured interview with questions designed to capture three components of self awareness: awareness of deficits, awareness of functional implications of deficits, and setting realistic goals (Fleming, Strong, & Ashton, 1996). It was used to assist individuals in identifying a main area of difficulty on which to focus for the SRSI. If unable to identify any areas of difficulty on the SADI, individuals were unable to complete the SRSI, and the highest possible score (poorest awareness) was assigned.

Both the SRSI and SADI have demonstrated good psychometric properties in a TBI population. The SRSI scales correlated as expected with measures of individual neuropsychological functioning (poor awareness being associated with poor neuropsychological functioning), demonstrating good convergent validity. The SRSI Self Awareness Index was

significantly ($p < .05$) correlated with all three sections and total score of the SADI ($r = .326$, $r = .379$, $r = .539$, and $r = .513$, respectively; Wise, Ownsworth, & Fleming, 2005). Furthermore, the SRSI demonstrated good inter-rater reliability ($r = .81-.92$) and test-retest reliability ($r = .69-.91$; Ownsworth et al., 2000). The SADI demonstrated fair to good inter-rater reliability on each of its three subscales and total score, with intra-class correlation coefficients (ICC) of 0.78, 0.57, 0.78, and 0.82 respectively (Fleming et al., 1996). Test-retest reliability in a TBI population was also good (defined as ICC over 0.75) for all three subscales (0.85, 0.86, and 0.86; Simmond & Fleming, 2003). The SADI demonstrated good concurrent validity with a modest correlation to the Dysexecutive Questionnaire discrepancy score ($r = .40$, $p < .05$; Bogod, Mateer, & MacDonald, 2003) and the Awareness Questionnaire, ($r = .498$ and $.352$, $p < .05$).

For this study, I used the SADI to help with identification of a primary problem and interpretation of scores for the SRSI. The Awareness subscale of the SRSI was used as the primary independent variable for all analyses.

3.2.2.3 Descriptive Measures

I collected demographic and injury-related data, as well as information on cognitive, affective, and behavioral characteristics. Most measures were chosen from the Center for Measurement in Brain Injury (www.tbims.org/combi) compiled by the National Institute of Disability and Rehabilitation Research TBI Model Systems; these measures demonstrate strong psychometric properties – validity and reliability – when administered to individuals with TBI. In addition to these measures, I selected the remaining measures based on their strong psychometric properties in a TBI population. These additional measures served to characterize the sample and as control

variables in the exploratory adjusted regression analyses. These variables were selected based on their previous correlations with the dependent variable measures and included disability, affect, cognition, behavior, fatigue, self-efficacy, and age.

Disability

I assessed disability with the Mayo Portland Adaptability Inventory (MPAI; Malec, 2005; Malec et al., 2003), which yields a total summed score that is converted to a *T-score*, with higher scores indicating more severe disability (Malec, 2005).

Affect

The Positive And Negative Affect Schedule (PANAS), a valid and reliable measure of affect (Watson, Clark, & Tellegen, 1988) yields two subscale scores: one for positive affect and one for negative affect.

Cognition

A cognitive composite score was calculated to describe overall cognitive status (Green et al., 2008). Details of individual neuropsychological tests are provided in Appendix B. Raw scores were transformed into normative scores using normative data for each test. These normative scores were then transformed into *T-scores*, which were averaged to produce a single composite cognitive *T-score*.

Behavior

The Frontal Systems Behavior Scale (FrSBe) assesses behaviors associated with damage to frontal systems, a common occurrence in TBI (Grace & Malloy, 2001). It yields a total score that is converted to a *T-score*.

Fatigue

The Modified Fatigue Impact Scale (mFIS) is a general scale that measures the impact of fatigue on everyday life (Fisk et al., 1994; LaChapelle & Finlayson, 1998). The mFIS produces a total summed score ranging from 0-84, with higher scores indicating greater fatigue.

Self-efficacy

The General Self-Efficacy Scale (GSE) is a valid and reliable measure of general self-perceived self-efficacy consisting of 10 items scored on a 4-point scale and yielding a total score ranging from 10-40 points. Higher scores indicate higher degrees of perceived self-efficacy.

3.2.3 Statistical Analyses

I needed 60 participants to provide adequate power (80%; $\alpha=.05$) to detect a moderate effect size ($f^2=.20$) for explaining a moderate amount of variance ($r^2=.25$) in the dependent variables of frequency of participation and satisfaction with participation. This sample size was determined based on the desire to detect a moderate effect size for rehabilitation research ($f^2=.20$) and was calculated using G*Power 3.0™. As this study was powered for only two covariates, all adjusted analyses are exploratory.

Data were entered and maintained in a database using SPSS19.0™ for Windows. In compliance with the standards of the University of Pittsburgh Institutional Review Board, all data were de-identified, and personal information was stored separately to ensure confidentiality.

Initially, I examined descriptive statistics. I then conducted two simple linear regression analyses to address the primary question of whether self awareness predicts frequency of and satisfaction with participation. I hypothesized that level of self awareness would be positively

associated with frequency of participation and negatively associated with satisfaction with participation. To further explore what factors may contribute to participation outcomes, I conducted two exploratory multiple regression analyses including the previously identified eligible control variables ($r > .25$).

3.3 RESULTS

3.3.1 Recruitment

Overall, 70 individuals provided informed consent for this study, of which 65 were found to be eligible to participate. See Figure 3.2 for a summary of recruitment results.

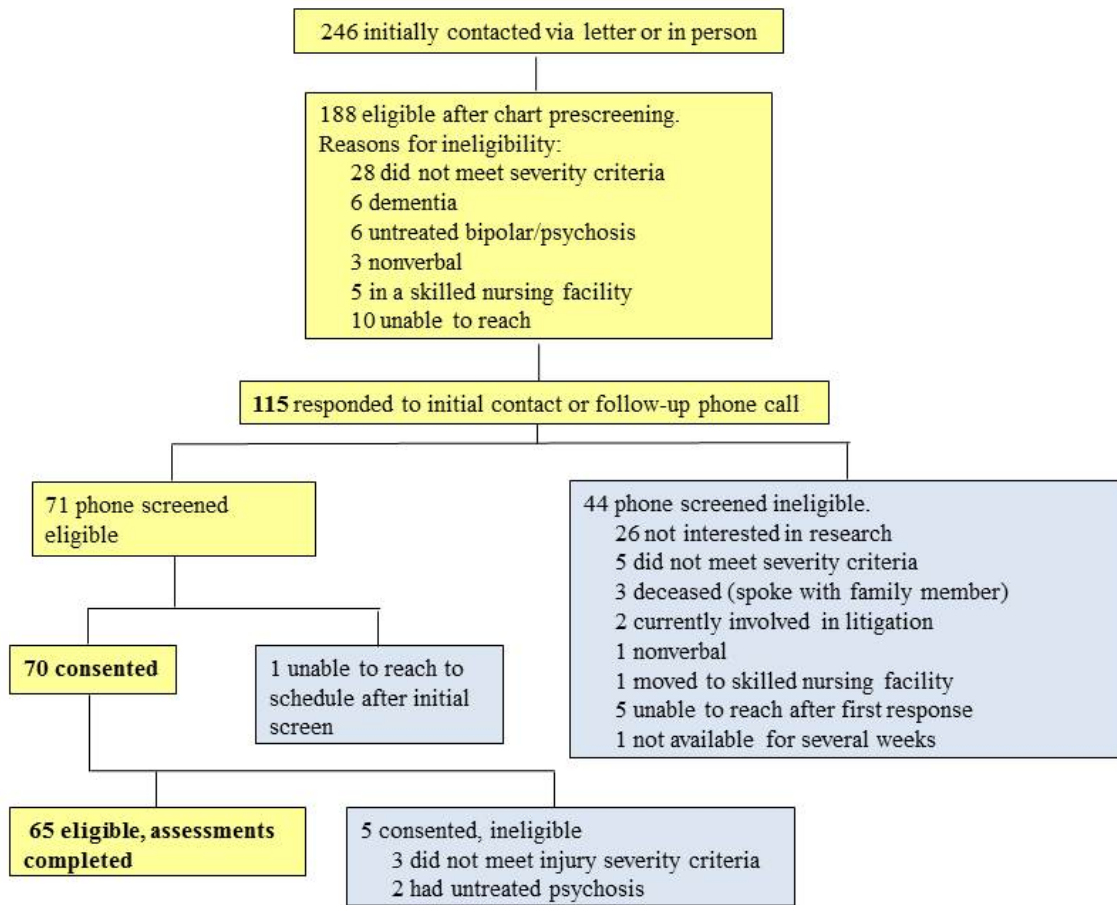


Figure 3.2 Recruitment Flowchart

3.3.2 Descriptive Data

Descriptive data for this sample have been presented previously (See Table 2.1). Participants ranged in age from 18-86 years old ($M=49.91$) and were 6-248 months post-injury (median 55 months). The majority of the sample was male (80%), white (96.9%), and not married (60%) and approximately one-half of the sample (49.2%) had a history of severe injury.

3.3.3 Regression Analyses

3.3.3.1 Self Awareness and Frequency of Participation

Results of the regression analyses addressing the question of the influence of self awareness on frequency of participation are summarized in Table 3.1. Self awareness was found to be a significant predictor, explaining 7% of the variance in frequency of participation among adults with TBI ($F_{1,63}=5.77$, $P=.019$), a “practically significant” amount for rehabilitation research (Ferguson, 2009). As predicted, better self awareness was associated with higher frequency of participation.

Exploratory analysis: To explore further, a second model was fit including previously identified covariates that correlated ($R>0.25$) with frequency of participation. These covariates included the cognitive composite score, disability (MPAI), and positive affect (PANAS). This model explained 29% of the variance in frequency of participation ($F_{4,58}=7.34$, $P<.001$). With the addition of these variables, self awareness no longer achieved statistical significance ($P=.390$). Cognition ($P=.005$) and positive affect ($P=.002$) were both statistically significant independent predictors in this model.

3.3.3.2 Self Awareness and Satisfaction with Participation

Results of the regression analyses addressing the question of the influence of self awareness on satisfaction with participation are summarized in Table 3.2. Overall, self awareness was not significantly associated with satisfaction with participation ($F_{1,63}=.52$, $P=.476$). Given that the overall model was not significant, I failed to reject the null hypothesis that self awareness is not associated with satisfaction with participation.

Exploratory analysis: To further explore possible contributing factors to satisfaction with participation, a second regression model was fit including previously identified variables associated with satisfaction with participation. In addition to self awareness, these variables included positive affect, negative affect, disability, self-efficacy, fatigue, and age. The overall model was found to be significant ($F_{7,55}=5.04$, $P<.001$), with all of these factors combining to explain 31% of the variance in satisfaction with participation. The only two statistically significant factors after controlling for all others, however, were positive affect ($P=.010$) and age ($P=.043$).

Table 3.1 Linear Regression Analyses: Frequency of Participation

	Frequency of Participation Model 1 (n=65)			Frequency of Participation Model 2 (n=63)	
	B	P		B	P
Intercept	-	<.001	Intercept	-	<.001
Self Awareness	-.031	.019	Self Awareness	-.011	.390
			Cognition	.015	.005
			Positive Affect	.025	.002
			Disability	-.003	.524
	R ² =.08	<0.001		R ² =.34	<0.001
	R ² _{Adj} =.07			R ² _{Adj} =.29	

Table 3.2 Linear Regression Analyses: Satisfaction with Participation

	Satisfaction with Participation Model 1 (n=65)			Satisfaction with Participation Model 2 (n=63)	
	B	P		B	P
Intercept	-	<.001	Intercept	-	.078
Self Awareness	.066	.476	Self Awareness	.045	.608
			Positive Affect	.147	.010
			Negative Affect	-.050	.479
			Disability	-.018	.675
			Self Efficacy	-.009	.920
			Fatigue	-.038	.150
			Age	.050	.043
	$R^2=.01$.476		$R^2=.37$	<0.001
	$R^2_{Adj}=.01$			$R^2_{Adj}=.30$	

3.4 DISCUSSION

The purpose of this study was to explore whether self awareness contributes significantly to community integration, including frequency of participation and satisfaction with participation, among adults with a history of TBI living in the community. Findings indicate that self awareness is a significant predictor of frequency of participation but is not a significant predictor of satisfaction with participation. This is consistent with previous research demonstrating an association between self awareness and poor rehabilitation and participation outcomes (Bach & David, 2006; Ezrachi et al., 1991; Hammond et al., 2004; Hoofien et al., 2001; McAvinue et al., 2005; Ownsworth & Clare, 2006; Sherer et al., 2003). Individuals with poor self awareness have difficulty setting goals, recognizing when to use compensatory strategies, and engaging in appropriate social behavior (McGlynn & Schacter, 1989), which may hinder participation in various community-based activities, including work, leisure, and social relationships. Another possible explanation for the relationship between self awareness and frequency of participation is that individuals with poor self awareness may be more likely to engage less frequently in activities or to underreport frequency of participation in activities as a result of associated cognitive impairment, such as poor memory or impairments in executive functions. This is supported by findings from the secondary exploratory analyses, as the addition of cognition to the model negated the significant contribution of self awareness to frequency of participation. This suggests a hypothesis for future exploration that self awareness is a mediating factor in the relationship between cognition and frequency of participation. More specifically, individuals

with impaired cognition may only demonstrate lower frequency of participation if they have poor self awareness and are unable to recognize the need for or when to use compensatory strategies. Conversely, if they have good self awareness, they may be able to circumvent their cognitive impairments and participate more frequently in community based activities. Additionally, impairments in memory may influence an individual's ability to accurately report frequency of participation, resulting in underreporting. Future research may explore some measure of frequency of participation that does not rely on the participant having to remember, such as proxy report or activity logs.

Little research has been done investigating the relationship between self awareness and satisfaction with participation. A study by Evans and colleagues (2005) indicated that more impairment in self awareness was associated with higher life satisfaction early during inpatient rehabilitation (Evans et al., 2005); this was consistent with the hypothesis of this study. Furthermore, higher levels of depression are associated with poorer satisfaction after TBI (Corrigan et al., 2001; Evans et al., 2005; Underhill et al., 2003), and depressive symptoms increase as self awareness improves (Fleming et al., 1998; Malec et al., 2007); though this may only be the case among individuals who have poor self awareness from the start (Ownsworth & Oei, 1998)), supporting the hypothesis that self awareness is negatively associated with satisfaction. However, this study found no association between self awareness and satisfaction with participation. One possible explanation is that the relationship between self awareness and satisfaction with participation differs as a function of affective state (such as is suggested above with regard to depression). In this sample, only a very small percentage of participants (21.5%) were experiencing current major or minor depressive symptoms. Given that rates of current depression may not be as high in a more chronic TBI population (as compared to the first few

years post-injury), it is important to examine the influence of negative affect, in the absence of depression, as it interacts with self awareness to influence satisfaction with participation. This requires further exploration.

The exploratory adjusted analysis revealed additional factors that require further investigation. Based on the previously established correlations, positive affect, negative affect, disability, self-efficacy, fatigue, and age were included in the adjusted model examining the relationship between self awareness and satisfaction with participation. After including these covariates in the model, positive affect and age were the only statistically significant predictors. While these results should be interpreted with caution, future research should explore the influence of both positive affect and age on the relationship between self awareness and satisfaction with participation.

The most significant limitation of this study was the sample size. The study was originally powered for the primary question of how self awareness contributes to frequency of participation and not for the secondary exploratory analyses. Therefore, failure to achieve statistical significance in the exploratory analyses may be due to lack of sufficient power to detect an effect, and results should be interpreted with caution. While these findings are not conclusive, they do serve to generate additional hypotheses for further exploration. A second limitation of this study is the reliance on self-report measures, especially given the potentially confounding factor of impaired self awareness. Future research should consider ways to measure frequency of participation beyond self-report (though satisfaction with participation can only be a self-reported variable).

In summary, self awareness is an independent significant contributing factor to frequency of participation but does not significantly contribute to satisfaction with participation. Given the

complexity of both self awareness and community integration after TBI, it is likely that there are additional contributing factors that may moderate either or both of these relationships. Further exploration into potential moderating factors is warranted.

4.0 CHAPTER FOUR – AFFECT AND AGE AS MODERATORS OF THE RELATIONSHIP BETWEEN SELF AWARENESS AND COMMUNITY INTEGRATION

4.1 INTRODUCTION

Poor community integration, as measured by employment, independent living, social and family relationships, leisure and recreation activities, and quality of life, is common after TBI (Cicerone & Azulay, 2007; Stalnacke, 2007; Temkin et al., 2009). This may result in isolation and negative psychological consequences. Conversely, improved vocational and social participation outcomes are related to improvement in self-worth and psychological well-being (Johnstone, Vessell, Bounds, Hoskins, & Sherman, 2003). Overall, returning to activities of the household, family, community, and wider society after TBI influences various health outcomes (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007).

Previous research demonstrated that self awareness is associated with community integration. Furthermore, individuals with impaired self awareness may set unrealistic goals, fail to recognize when to use compensatory strategies, and behave inappropriately in social situations (McGlynn & Schacter, 1989). Self awareness predicts negative social behavior, regardless of the severity of cognitive or executive impairment (Bach & David, 2006; O'Keeffe, Dockree, Moloney, Carton, & Robertson, 2007), which may explain the reduction in social interactions 1-5 years post-injury (Hammond et al., 2004).

4.1.1 Affect

Affect is another factor that may contribute significantly to community integration outcomes after TBI. Numerous studies have reported the relationship between depression, anxiety, or psychosocial distress and poor psychosocial and community integration following TBI (Anson & Ponsford, 2006; Felmingham et al., 2001; Hoofien et al., 2001; Jorge, Robinson, Arndt, Forrester, et al., 1993; Jorge, Robinson, Arndt, Starkstein, et al., 1993; Morton & Wehman, 1995; Ownsworth & Fleming, 2005; Ruff et al., 1993). Furthermore, community integration is positively associated with self-esteem and positive coping (Lubusko, Moore, Stambrook, & Gill, 1994; Tate & Broe, 1999). This suggests the influence of not only negative affect, such as that associated with depression, anxiety, or distress, but positive affect as well, such as that associated with self-esteem and positive coping. The association between positive and negative affect and community integration was previously identified in this sample and further exploration of these constructs as they relate to community integration is needed.

The relationship between affect and self awareness after TBI is less clear. While much evidence suggests that poor self awareness is associated with poorer community integration, poor self awareness has also been associated with less maladaptive coping, less psychological distress, and better self-esteem after TBI (Anson & Ponsford, 2006; Cooper-Evans et al., 2008; Fleming et al., 1998; Godfrey et al., 1993; Malec et al., 2007). The question has been raised whether the relationship between self awareness and community integration may differ because of emotional distress or poor coping (Fleming et al., 1998). To further investigate the complex relationship between self awareness, affect, and community integration, I examined whether affect moderates the relationship between self awareness and community integration. Furthermore, whereas previous studies investigating this question focused primarily on depression or anxiety, I have

chosen to measure negative affect more broadly and positive affect as well, to examine whether negative and positive affect separately moderate the relationship between self awareness and community integration.

4.1.2 Age

TBI affects individuals of all ages, though the two highest risk groups are ages 15 to 24 years and 60 years and older. Several studies suggest that community integration is associated with age, with those who are younger having better outcomes, including higher productivity and less disability (Fleming et al., 1999; Goranson et al., 2003; Heinemann et al., 1995; Willemsse-van Son et al., 2009). However, the opposite has also been found to be true (Winkler et al., 2006), and a review by Yasuda et al. (2001) suggested that with regard to return to work as a measure of community integration, the impact of age varied by study (Yasuda et al., 2001). Previous investigation in this sample demonstrated that older age was associated with higher satisfaction with participation. These inconsistencies suggest there may be other factors interacting with age to yield differing community integration outcomes. One possible factor is self awareness. The relationship between patterns of self awareness deficits and age is also unclear. In a healthy population, accuracy of self-evaluations (self awareness) improves over the lifespan (Demetriou & Bakracevic, 2009). However, in TBI, younger and older individuals do not differ significantly with regard to total symptoms reported, despite evidence that suggests greater impairment and disability in older individuals with TBI (Breed, Flanagan, & Watson, 2004). This suggests the possibility of poorer self awareness among older individuals with TBI. Given that cognitive impairment increases with age at time of injury and impairments in self-awareness are associated with severity of cognitive impairment, I would expect older individuals to have poorer self-

awareness. However, some findings suggest that older individuals with TBI have more accurate self awareness than younger individuals (Sherer et al., 2003), and that the relationship between executive dysfunction and behavioral insight (self awareness) is only present in younger individuals (< 25 years) with TBI (Barker, Andrade, Morton, Romanowski, & Bowles, 2010). To address these discrepancies, I will investigate whether age is a moderating factor in the relationship between self awareness and community integration.

4.1.3 Significance

In summary, community integration is an important long-term outcome after TBI, and self awareness is a factor that most likely explains differences in community integration. Furthermore positive affect, negative affect, and age may moderate the relationship between self awareness and community integration (frequency of participation and satisfaction with participation). Understanding what factors are associated with each of these components of community integration, as well as how these factors may interact, will inform clinical practice and provide meaningful and effective targets for client-centered and personalized interventions. Therefore, the purpose of this study was to investigate the degree to which community integration is explained by the interaction between self awareness and both positive affect and negative affect and the interaction between self awareness and age among community-dwelling adults with a history of complicated mild to severe TBI.

4.2 METHODS

This cross-sectional study examined the association between self awareness and community integration in a sample of adults with a history of complicated mild to severe traumatic brain injury (TBI). Sixty-five participants completed interviews and assessments selected to describe the sample and to measure frequency of participation and satisfaction with participation (components of community integration), self awareness, and positive and negative affect.

4.2.1 Participants

Details of recruitment strategies were discussed previously in detail. Briefly, individuals were recruited through existing collaborations with previous research studies, through the University of Pittsburgh Medical Center Rehabilitation Institute Research Registry, and through local agencies and support groups for individuals with TBI.

Individuals were included if they demonstrated evidence of a complicated mild to severe traumatic brain injury (GCS score 1-15 with neuroradiologic findings or significant functional compromise) sustained longer than 6 months ago, were 18 years old or older, and lived in a private or group residential setting. Individuals were excluded if they had a history of any condition resulting in progressive cognitive decline (e.g. dementia), current active psychotic or bipolar disorder, or were currently involved in injury-related litigation.

Individuals first completed a brief telephone screening to determine initial eligibility. If eligible, an assessment time was scheduled, and consent forms were sent via mail to be reviewed. Assessments took place in the individual's home, at the University of Pittsburgh, or at a

University of Pittsburgh Medical Center facility. Individuals (or their proxies) who provided informed written consent were then screened to determine final eligibility, prior to completion of study assessment. All participants were assessed by the same individual.

4.2.2 Measures

I selected measures from the Center for Measurement in Brain Injury (www.tbims.org/combi) and the Rehabilitation Research TBI Model Systems; these measures demonstrate strong psychometric properties in a TBI population. All measures completed for this study are thoroughly described in Appendix A and are summarized in Table 4.1. The dependent variables – frequency of participation and satisfaction with participation – were measured using the Participation Assessment of Recombined Tools, Objective-Satisfaction (PART-OS). The independent variables in this study were self-awareness, positive and negative affect, and age. Self-awareness was measured using the Self Regulation of Skills Interview (SRSI) Awareness subscale. The Positive and Negative Affect Schedule (PANAS) was used to measure affect.

Table 4.1 Assessment Selection and Rationale

<i>Assessment Tool</i>	<i>Explanation/Rationale</i>
<u>Community Integration:</u> Participation Assessment with Recombined Tools- Objective/Satisfaction (PART-OS)	Valid and reliable tool for assessing community integration in a traumatic brain injury population. PART-O consists of 24 items that quantify level of participation, and the PART-S consists of eleven domains that indicate level of satisfaction with participation. A total participation score and an average satisfaction score are derived from these measures (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007).
<u>Awareness: Self Regulation Skills</u> Inventory (SRSI)	Valid and reliable tool for assessing self-awareness. The SRSI is a structured interview, with six items scored on a 0-10 scale resulting in 3 subscales with higher scores indicating poorer awareness: Awareness (0-20), Readiness to change (0-10; higher is better), and Strategy behavior (0-30). Total scores on each subscale were used as measures of domains of self awareness (Ownsworth et al., 2000).
<u>Affect: Positive And Negative</u> Affect Schedule (PANAS)	Valid and reliable tool for assessing positive and negative affect. It consists of two 10-item scales (10-50) that yield total scores. Higher scores on the positive affect subscale indicate higher positive affect. Higher scores on the negative affect subscale indicate higher negative affect (Watson, Clark, & Tellegen, 1988).

4.2.3 Statistical Analyses

Sample size was determined using G-Power 3.0™. To provide 80% power with an alpha level of .05 and to detect a moderate effect size ($f^2=.20$) explaining a moderate amount of variance in frequency of participation ($r^2=.25$) with two covariates, a sample size of 60 was required.

Statistical analyses were performed using SPSS19.0™ for Windows. I first examined descriptive statistics, including means and standard deviations for continuous variables and frequencies and percentiles for categorical variables. I then conducted multiple regression analyses for each of the dependent variables characterizing community integration: frequency of participation and satisfaction with participation. Unadjusted regression analyses with the independent variables of interest and an interaction term were performed for each of the dependent variables. If the interaction term was not statistically significant, the unadjusted regression was run again examining the main effects of the two independent variables in the model.

To better interpret the interaction between self awareness and affect, both positive and negative affect were dichotomized into two groups: high and low (e.g. high positive affect and low positive affect). Mean scores from a large sample of the general population ($n=1,003$) on both the positive affect and negative affect subscale determined cut points for the groups (Crawford & Henry, 2004). The high positive affect group had scores of 31 or greater on the positive affect subscale. The high negative affect group had scores of 17 or greater on the negative affect subscale. To better interpret the interaction between self awareness and age, age was split into three group, using cut offs based on the two highest risk groups for TBI: 18-24 years, 25-59 years, 60 years and older.

4.3 RESULTS

4.3.1 Recruitment

Of 115 individuals who initially responded or were contacted to participate in the study, 71 were found to be eligible after initial telephone screening. Seventy participants provided informed consent, of which 65 were found to be eligible and completed study assessments. One participant failed to complete the PANAS. Therefore, 64 participants were included in the regression analyses examining the moderating effects of affect, and 65 participants were included in the regression analyses examining the moderating effects of age.

4.3.2 Descriptive Data

Descriptive data for this sample were presented previously (See Table 2.1). Participants had a mean age of 49.1 years and a median time since injury of 55 months. The sample was 80% male, 96.9% white, and 60% unmarried. Approximately one-fifth (21.5%) of the sample had current major or minor depressive symptoms, with an additional 46.2% reporting a history (but no current symptoms) of depression.

4.3.3 Regressions

4.3.3.1 Frequency of Participation

Three regression analyses were conducted to examine further the relationship between self awareness and frequency of participation. The first examined the moderating effect of positive

affect, the second examined the moderating effect of negative affect, and the third examined the moderating effect of age. Each is summarized in Table 4.2.

Table 4.2 Analysis of Variance for Frequency of Participation

Source	df	F	η^2	p
<i>Self Awareness x Positive Affect → Frequency of Participation</i>				
Corrected Model	3	3.85	.16	.014
Self Awareness (SRSI)	1	2.28	.04	.136
Positive Affect (PANAS)	1	4.86	.08	.031
Self Awareness x Positive Affect Interaction	1	1.77	.03	.189
Within-group error	60	(.225)		
<i>Self Awareness x Negative Affect → Frequency of Participation</i>				
Corrected Model	3	2.90	.13	.042
Self Awareness (SRSI)	1	3.33	.05	.073
Negative Affect (PANAS)	1	3.07	.05	.085
Self Awareness x Negative Affect Interaction	1	3.25	.05	.076
Within-group error	60	(.234)		
<i>Self Awareness x Age → Frequency of Participation</i>				
Corrected Model	5	3.41	.22	.009
Self Awareness (SRSI)	1	8.70	.13	.005
Age	2	5.24	.15	.008
Self Awareness x Age Interaction	2	3.22	.10	.047*
Within-group error	59	(.216)		

Note. Values enclosed in parentheses represent mean square errors; * p < .05

The interaction between self awareness and positive affect was not significant, and demonstrated a negligible effect size ($P=.189$, partial $\eta^2=.03$). However, both self awareness and positive affect were significant predictors of frequency of participation when the main effects were examined (see Table 4.3, Model 1). Overall, self awareness and positive affect combined to explain 11% of the variance in frequency of participation.

The interaction between self awareness and negative affect was not significant at the alpha of .05 level. However, it did approach significance ($P=.076$) and demonstrated an effect size (partial $\eta^2=.05$) above the level of “practical significance” defined by Ferguson ($\eta^2=.04$; Ferguson, 2009). This interaction is demonstrated in Figure 4.1.

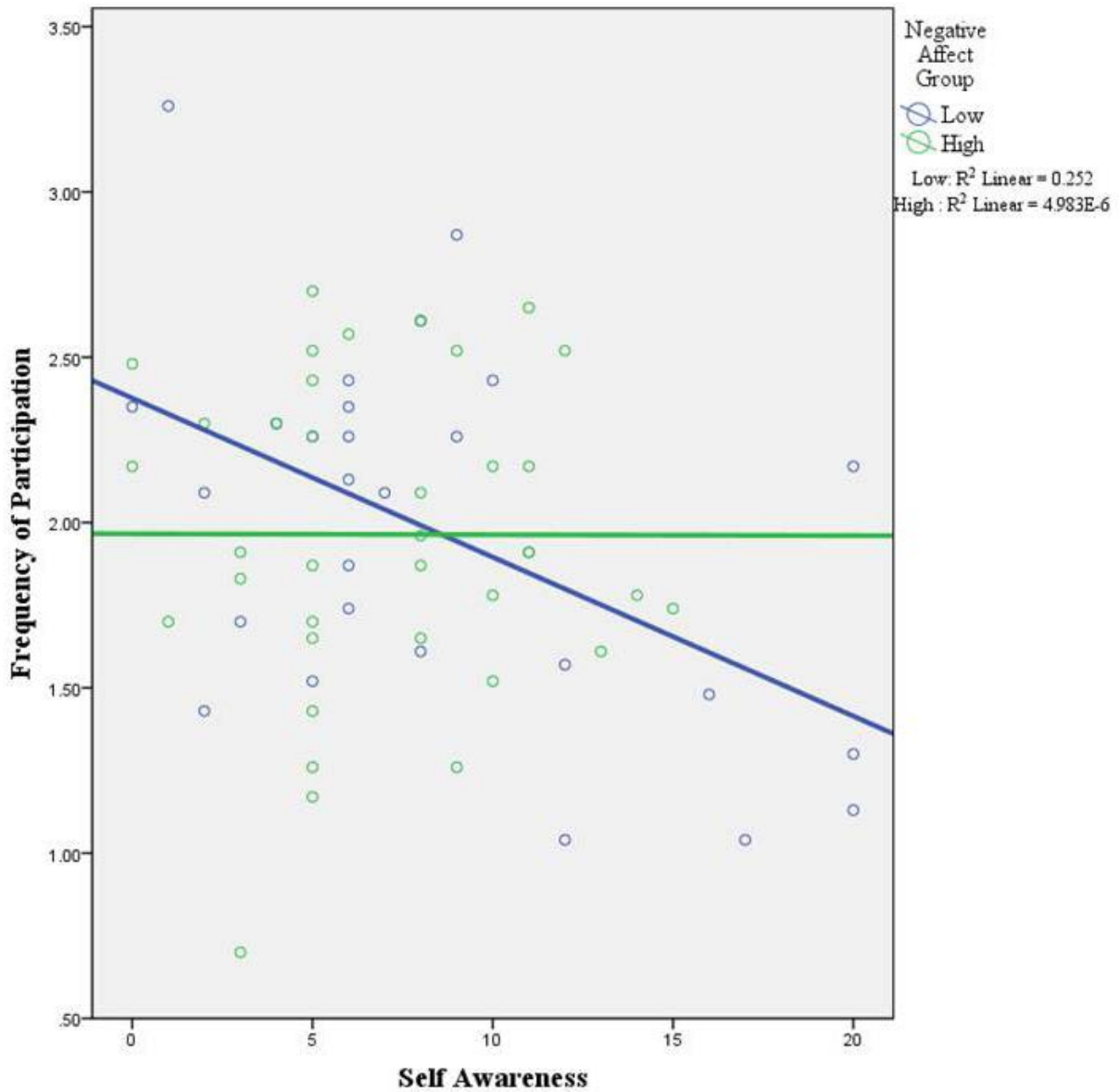


Figure 4.1 Frequency of Participation: Self Awareness by Negative Affect

Among those with high negative affect, there is no relationship between self awareness and frequency of participation ($R^2 < .001$); when negative affect is high, frequency of participation remains consistent regardless of self awareness. However, among those with low negative affect,

there is a moderate relationship between self awareness and frequency of participation ($R^2=0.25$); when negative affect is low, better self awareness is associated with higher frequency of participation.

Model 2 in Table 4.3 summarizes the main effects for self awareness and negative affect. Negative affect was not a significant predictor of frequency of participation ($P=.684$), while self awareness was a significant predictor even when controlling for negative affect ($P=.025$). The interaction suggests, however, that this is only the case among those who are not experiencing high negative affect.

Table 4.3 Frequency of Participation: Main Effects

	Model 1:		Model 2:	
	Positive Affect		Negative Affect	
	(n=64)		(n=64)	
	B	P	B	P
Intercept	2.296	<.001	Intercept	2.173 <.001
Self Awareness	-.032	.015	Self Awareness	-.030 .025
Positive Affect	-.259	.044	Negative Affect	.052 .684
	$R^2=.14$		$R^2=.08$	
	$R^2_{Adj}=.11$		$R^2_{Adj}=.05$	

Note: Referents are High Positive Affect, High Negative Affect

The interaction between self awareness and age group was statistically significant, demonstrating a small effect ($P=.047$, partial $\eta^2=.10$). Figure 4.2 depicts this interaction. For those in the 18-24 years old age group, self awareness and frequency of participation have a strong relationship ($R^2=0.79$). For participants between the ages of 24 and 59, there was no relationship between self awareness and frequency of participation ($R^2=0.01$). Finally, for participants in the 60 years and older age group, there was a weak relationship between self

awareness and frequency of participation ($R^2=0.12$). Again, in cases where there was an association, better self awareness was associated with higher frequency of participation.

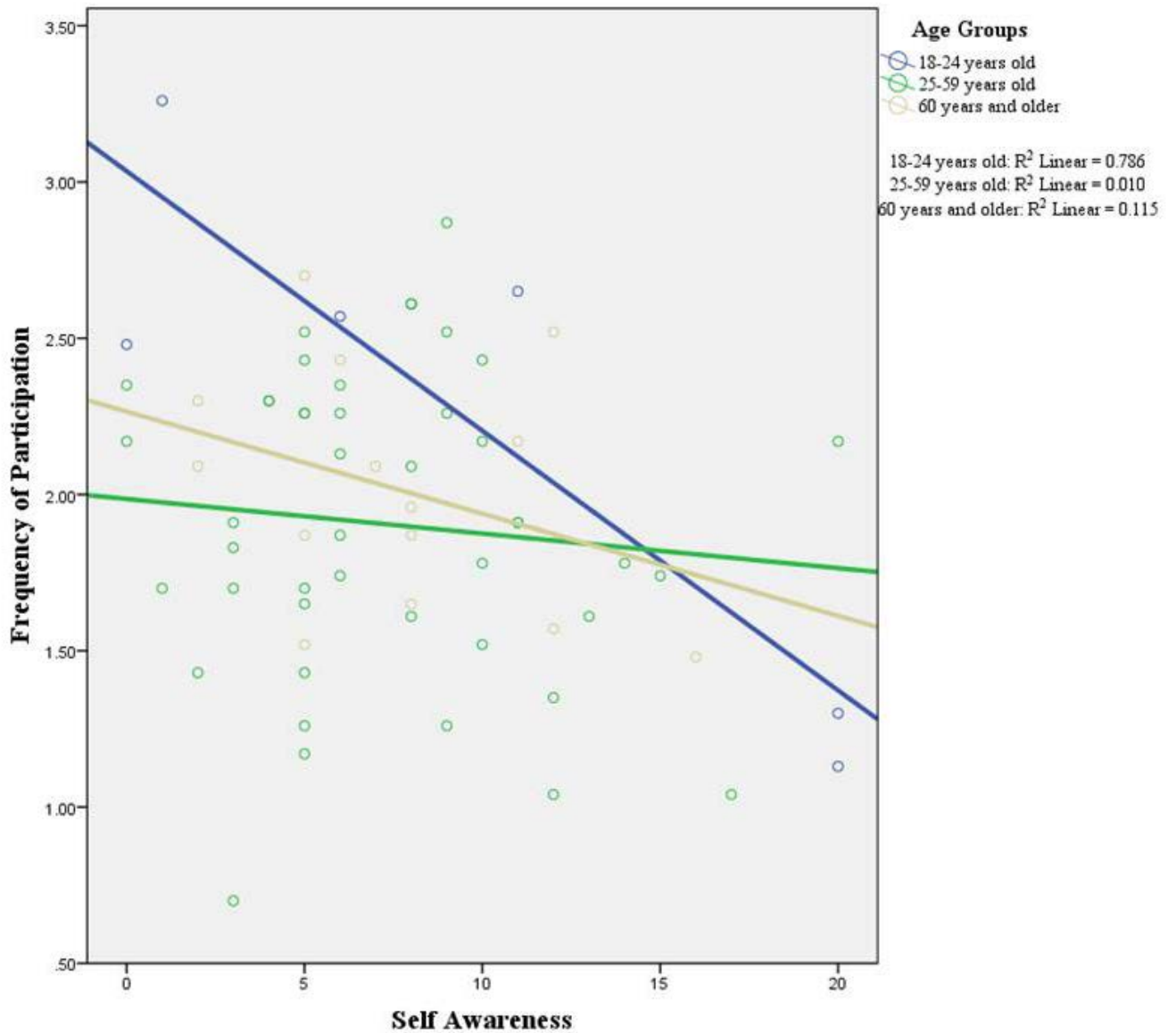


Figure 4.2 Frequency of Participation: Self Awareness by Age Group

4.3.3.2 Satisfaction with Participation

Three regression analyses were conducted to examine further the relationship between self awareness and satisfaction with participation. The first examined the moderating effect of positive affect, the second examined the moderating effect of negative affect, and the third examined the moderating effect of age. Each is summarized in Table 4.4.

Table 4.4 Analysis of Variance for Satisfaction with Participation

Source	df	F	η^2	p
<i>Self Awareness x Positive Affect → Satisfaction with Participation</i>				
Corrected Model	3	4.03	.17	.011
Self Awareness (SRSI)	1	0.64	.01	.429
Positive Affect (PANAS)	1	4.14	.07	.046
Self Awareness x Positive Affect Interaction	1	0.15	.00	.700
Within-group error	60	(10.422)		
<i>Self Awareness x Negative Affect → Satisfaction with Participation</i>				
Corrected Model	3	3.63	.15	.018
Self Awareness (SRSI)	1	0.39	.01	.536
Negative Affect (PANAS)	1	4.02	.06	.050
Self Awareness x Negative Affect Interaction	1	0.18	.00	.674
Within-group error	60	(10.597)		
<i>Self Awareness x Age → Satisfaction with Participation</i>				
Corrected Model	5	1.84	.14	.118
Self Awareness (SRSI)	1	0.42	.00	.837
Age	2	1.87	.06	.164
Self Awareness x Age Interaction	2	0.38	.01	.686
Within-group error	59	(11.554)		

Note. Values enclosed in parentheses represent mean square errors; * p < .05

The interaction between self awareness and positive affect was not significant, and demonstrated no effect ($P=.700$, partial $\eta^2=.00$). Only positive affect was a significant predictor ($P=.001$) of satisfaction with participation when the main effects were examined (see Table 4.5, Model 1). Satisfaction with participation was lower for those with low positive affect than for those with high positive affect. Overall, self awareness and positive affect combined to explain 14% of the variance in satisfaction with participation.

The interaction between self awareness and negative affect was not significant, and demonstrated no effect ($P=.674$, partial $\eta^2=.00$). Only negative affect was a significant predictor ($P=.003$) of satisfaction with participation when the main effects were examined (see Table 4.5, Model 2). Having low negative affect predicted higher satisfaction with participation scores. Overall, self awareness and negative affect combined to explain 12% of the variance in satisfaction with participation.

The interaction between self awareness and age group was also not significant, and demonstrated no effect ($P=.686$, partial $\eta^2=.01$). Only being in the 25-59 year old age group was a significant predictor ($P=.003$) of satisfaction with participation when the main effects were examined (see Table 4.5, Model 3).

Table 4.5 Satisfaction with Participation: Main Effects

	Model 1:		Model 2: Negative			Model 3:		
	Positive Affect		Affect			Age		
	(n=64)		(n=64)			(n=65)		
	<i>B</i>	<i>P</i>		<i>B</i>	<i>P</i>		<i>B</i>	<i>P</i>
Intercept	11.904	<.001	Intercept	9.939	<.001	Intercept	7.678	<.001
Self Awareness	0.059	.486	Self Awareness	0.046	.592	Self Awareness	0.014	.768
Positive Affect	-2.819	.001	Negative Affect	2.595	.003	Age 16-24 years	- 0.568	.509
						Age 25-59 years	-1.649	.003
	$R^2=.17$			$R^2=.15$			$R^2=.15$	
	$R^2_{Adj}=.14$			$R^2_{Adj}=.12$			$R^2_{Adj}=.11$	

Note: Referents are High Positive Affect, High Negative Affect, Age Group 60 years and older

To explore further how age group was related to satisfaction with participation, a one-way ANOVA was conducted to explore between-group differences. The over 60 years old group had the highest satisfaction with participation ($M=13.38$), followed by the 18-24 years old group ($M=12.23$), and finally the 25-59 years old group ($M=10.51$). Only the 25-59 years and over 60 years groups differed significantly ($P=.020$) from each other. Group differences are shown in Figure 4.3.

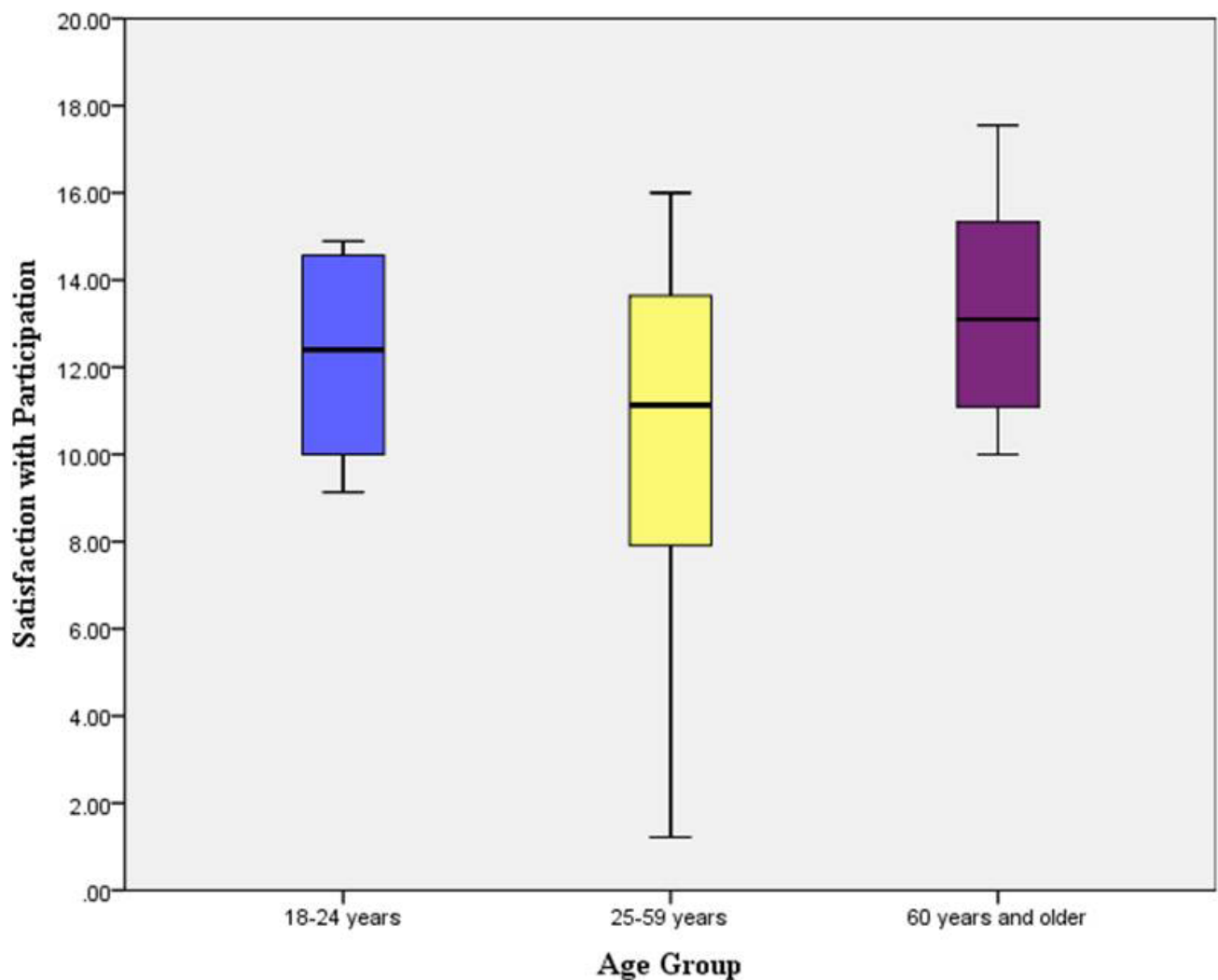


Figure 4.3 Satisfaction with Participation by Age Group

4.4 DISCUSSION

The purpose of this study was to examine whether positive affect, negative affect, or age moderate the relationships between self awareness and community integration, measured both by frequency of participation and satisfaction with participation. With regard to frequency of participation, positive affect did not moderate the contribution of self awareness, but both self awareness and positive affect were independent predictors of frequency of participation. While not achieving statistical significance, negative affect appeared to moderate the contribution of self awareness, as only those with low negative affect demonstrated a relationship between self awareness and frequency of participation. Age group was also a moderating factor, with individuals in the 18-24 years old group demonstrating the strongest relationship between self awareness and frequency of participation. There were no significant interactions with regard to the relationship between self awareness and satisfaction with participation. For the main effects, self awareness was not a significant predictor of satisfaction with participation. However, being in the low positive affect, high negative affect, and 25-59 years old age groups each significantly predicted lower satisfaction with participation, after controlling for self awareness.

Self awareness and positive affect both significantly contributed to frequency of participation, when controlling for one other. The contribution of self awareness to frequency of participation was demonstrated previously. This study suggests that the relationship between self awareness and frequency of participation does not differ as a result of positive affect. The correlation between positive affect and frequency of participation has been demonstrated; these findings further support this association. Positive affect includes emotions such as interest, pride, alertness, and determination. Individuals experiencing these emotions may be more motivated to participate in activities and may push through barriers to participation. Conversely, it is possible

that participating more frequently in activities may lead to increased pride and interest. Given that this was a cross sectional study, no causal relationships could be determined. It remains unclear whether higher positive affect leads to higher frequency of participation, or whether higher frequency of participation results in higher positive affect. Future research should investigate the direction of the relationship between positive affect and frequency of participation. Additionally, potential confounding factors that may be related to individual items on the positive affect scale should be addressed and controlled for, such as fatigue, self-efficacy, and cognition.

Negative affect was not an independent predictor of frequency of participation after controlling for self awareness. However, the interaction between self awareness and negative affect approached significance; given that the analyses were powered for two covariates and included three, it is possible that this interaction would have achieved significance with more participants. Given that it demonstrated a practically significant effect size, I chose to explore it further. The interaction indicates that the relationship between self awareness and frequency of participation was only present among individuals with low negative affect (a more positive mood state). Among those with low negative affect, as self awareness increases, there may be more recognition and therefore more motivation to improve frequency of participation. Among those with high negative affect, frequency of participation remains even across all levels of self awareness. This suggests that in the presence of negative affect – emotions such as distress, shame, nervousness, and hostility – self awareness does not contribute to differences in frequency of participation. An important factor to consider is what it means to have low and high negative affect; low negative affect is not positive affect, but is instead the *absence* of negative affect. Therefore, this interaction would indicate that in the *absence* of negative affect, self awareness is a driving factor in frequency of participation, whereas in the *presence* of negative affect it is not.

To understand the underlying factors driving this interaction, further investigation into the potentially moderating effects of satisfaction with participation and other factors is needed.

Neither positive affect nor negative affect moderated the relationship between self awareness and satisfaction with participation. However, each was a statistically significant independent predictor of satisfaction with participation, after controlling for self awareness. Again, the direction of these relationships – whether higher positive affect and lower negative affect lead to higher satisfaction or are a result of higher satisfaction – should be explored. What is clear from these findings is that mood state – both positive and negative affect – is an important factor to consider for all individuals who have sustained a TBI, even at the subclinical level (in the absence of depression or anxiety).

The final factor considered was age. The relationship between self awareness and frequency of participation differed as a function of age group. More specifically, there is a strong relationship between self awareness and frequency of participation among those between the ages of 18-24 years old, a weak relationship among those over 60 years old, and no relationship among those between 25 and 59 years old. This interaction between self awareness and age may account for the varying relationship found between age and community integration seen throughout the literature. There are several potential explanations for this interaction. For those in the youngest age group, poor self awareness may result in social isolation from peers, influence the ability to obtain new employment, and increase dependence on family (i.e. parents) for completing various activities, hence reducing overall frequency of participation. Those with good self awareness in this age group may be more motivated to work past barriers, use compensatory strategies, and easily adapt to a new way of functioning as they were still in the process of transitioning to these adult roles and creating new habits. For those in the middle age group, their roles and activities

are likely to have been more established and less likely to change as a result of poor self awareness. They may have had long-term social relationships (e.g. spouse, children, professional, etc.) that could better withstand some of the problems associated with poor self awareness (and therefore not be as affected by it) or that could help to facilitate participation (e.g. cues to initiate, prompts for follow-through), they may have had established jobs that were more likely to be flexible, and they may have had more established habits and routines (compensatory strategies) upon which to rely, therefore not requiring self awareness to recognize the need to learn and use these strategies. For individuals in the oldest age group, again the influence of self awareness on frequency of participation begins to emerge. Individuals in this age group may have shrinking social support, as a result of retirement, illness, or death of a spouse or friends. They may therefore have to be more self-reliant than their younger peers. Poor self awareness may have a greater impact on those who are more self-reliant and who do not have the social network and supports to help them to compensate.

Another factor that may contribute to this finding is satisfaction with participation. While the interaction between self awareness and age did not contribute to satisfaction with participation, the main effect of age did. Exploring this further, being in the middle age group (25-59 years old) predicted lower satisfaction with participation. Those in the middle age group also demonstrated the widest range of satisfaction with participation. One possible explanation for this is the level of expectation for participation for each age group. Those who are 18-24 years old are just transitioning to adult roles and less may be expected with regard to how independent they are in performing various activities. Many may still be living with their parents who take care of household activities for them and they may still be establishing social connections and vocational paths. Those who are over 60 years old are more likely to be retired,

are likely beyond the age of actively raising children, and may engage in more passive leisure activities. The expectations for frequency of participation – not to mention the demands – are lower than for individuals between 25 and 59 years old, who may be working to support a family, raising children, or caring for older family members. As a result, the lower satisfaction in this middle age group may be a direct result of feeling as if they have not lived up to those expectations. A second possible explanation is the importance of a balanced lifestyle to satisfaction with participation. Earlier, I argued that vocational outcomes are not the only important community-integration measure, particularly with regard to satisfaction with participation. Additionally, individuals with a history of TBI who work full-time have reported a less balanced lifestyle than those who work part-time. Taken together, it could be that those in the middle age group are more likely to be working – or need to be working – full time, which doesn't allow for participation in social relationships or leisure activities, reducing satisfaction with participation. This is supported by previous findings that fatigue was highly associated with satisfaction with participation; those experiencing more fatigue are less satisfied, perhaps as a result of having to devote all their energy to only a select number of activities and not achieving a balanced lifestyle.

Overall, these explanations view age as a proximal measure of the broader construct of life roles. It has already been mentioned that participation may be very different for individuals who are younger than those who are older, again alluding to this idea of changing life roles across the age span. This is further complicated by the question of whether current life roles, or life roles at the time of injury, are more important factors to consider. These findings clearly point to differences in the relationship between self awareness and frequency of participation as a result of

age group as well as differences in satisfaction with participation by age group, though further exploration is required to explain what other contextual factors may be contributing to these relationships.

One limitation of this study was use of current age. Given the study design and that all other variables addressed current functioning and contextual factors, the decision was made to use current age. However, as discussed above, age at time of injury may be an important factor to consider as well. Future studies could explore age at time of injury and how it influences the trajectory of community integration across the lifespan. A second limitation of the study was the single time point assessment of affect. Affect – unlike psychiatric diagnosis – may fluctuate significantly from day to day, or even hour to hour. Multiple measurements of affect across a span of time may produce a more meaningful measure of affective traits of an individual. Again, this is a possibility to be explored in future longitudinal studies.

This project is particularly timely, due to the increase in community-dwelling individuals with TBI and the growing body of research about poor community integration outcomes even in the absence of significant physical or cognitive impairment. It provides a deeper understanding of factors that contribute to community integration by investigating alternative explanations for poor outcomes, such as positive and negative affect and age. More importantly, these findings support the argument for including a subjective component to the conceptualization of community integration and the idea that contextual factors – both personal and environmental – are necessary to account for in community integration research.

5.0 CHAPTER FIVE - CONCLUSION

Traumatic brain injury (TBI) survivors often experience poor community integration outcomes, including decreased productivity, poor health, limited social engagement, and poor quality of life. While, historically, community integration after TBI has been measured by frequency of participation in various activities and relationships, the subjective experience of each individual (i.e., the individual's satisfaction with his participation) is essential to consider as well. Broadly, this project sought to investigate factors that contribute to community integration, including both frequency of participation and satisfaction with participation, after TBI.

5.1 SPECIFIC AIMS

This study had three specific aims:

1. To examine the association between self awareness and community integration.
2. To examine whether the association between self awareness and community integration differs as a function of both positive and negative affect.
3. To examine whether the association between self awareness and community integration differs as a function of age.

5.2 SUMMARY OF FINDINGS

To address these aims, Chapter 2 described what factors were associated with both frequency of participation and satisfaction with participation among adults with a history of TBI. Findings indicated that self awareness, positive affect, disability, and cognition were all associated with frequency of participation, and positive affect, negative affect, fatigue, self-efficacy, disability, age, and behavior were all associated with satisfaction with participation. While frequency of participation and satisfaction with participation were moderately associated with one another, these findings support previous research suggesting that these are distinct indicators of community integration, each influenced by different factors.

Chapter 3 addressed the first specific aim of this project by exploring the independent contribution of self awareness to community integration. Self awareness contributed significantly to frequency of participation but did not contribute to satisfaction with participation. Exploratory analyses revealed that, after controlling for other relevant factors identified in Chapter 2, self awareness was no longer a significant predictor of frequency of participation. These exploratory analyses suggested that positive affect was an independent predictor of community integration that should be explored further.

Chapter 4 expanded on findings from Chapter 3 and addressed the second and third specific aims of this project by investigating the moderating effects of positive affect, negative affect, and age on the relationship between self awareness and community integration. I found that negative affect and age were moderating factors in the relationship between self awareness and frequency of participation. Specifically, there was a moderate relationship between self awareness and frequency of participation among participants with low negative affect but there was no relationship among participants with high negative affect. With regard to age, the

relationship between self awareness and frequency of participation was strong among those 18-24 years old but weak to not present in the older age groups. There were no moderating factors in the relationship between self awareness and satisfaction with participation, though positive affect, negative affect, and age all independently predicted satisfaction with participation.

Overall, these findings confirmed that frequency of participation and satisfaction with participation are likely distinct indicators of community integration, each associated with different functioning and contextual factors. Among the numerous factors that contribute to community integration after TBI, self awareness contributes significantly to frequency of participation among individuals with low negative affect and those 18-24 years old, but does contribute to satisfaction with participation. Positive affect, negative affect, and age all independently predict satisfaction with participation.

5.3 SIGNIFICANCE

The prevalence of TBI continues to grow, with an ever-increasing number of individuals experiencing long-term negative consequences as a result. As the goals of rehabilitation and healthcare continue to shift towards community-based and client-centered interventions and services, understanding community integration from both an objective and subjective perspective becomes increasingly important. The findings of this project begin to clarify what factors contribute to objective and subjective community integration, and by doing so, take a step towards the development of effective interventions to improve community integration.

5.4 LIMITATIONS

While the findings of this project are timely and significant, there were limiting factors to consider. First, the design of this project was a cross-sectional cohort study. While this design is appropriate to the exploratory aims of the project, it does not allow for investigation into changes and trends over time or temporal relationships between factors.

Second, the assessments in this project relied heavily on self-report. While subjective constructs such as satisfaction with participation and positive and negative affect can only be obtained through self-report, objective constructs such as frequency of participations, disability, and behavior may be biased by self-report (particularly in cases of poor self awareness).

Third, the two primary constructs being measured – community integration and self awareness – are broad and complex constructs that are difficult to define and measure. While a significant innovation of this project was its incorporation of a subjective perspective of community integration (satisfaction), the measurement of this construct is still early in its development. Though currently undergoing validation, the PART-S has not yet demonstrated its level of validity and reliability as a measure of satisfaction with participation. The difficulties in measuring self awareness, by contrast, have been an ongoing challenge in research investigating this construct. Strategies for measuring self awareness include measuring differences between some objective measure, such as family or clinician report or neuropsychological testing, and an individual's self report, predicted performance compared to actual performance, and clinician administered interview. For this project, I chose a clinician administered interview, as this included components of self report, as well as assessment by the clinician based on all information available including reports from family members and data from neuropsychological

test performance. There are limitations to this approach, including a high level of subjectivity on the part of the clinician administering the assessment and a particular conceptualization of self awareness specific to the questions asked during the interview.

Fourth, there were other limitations resulting from the individual assessments. For example, the community integration measure only accounts for current frequency of and satisfaction with participation but does not account for level of community integration prior to injury. Also, positive and negative affect were measured one time, with reference to the past four weeks, and may, therefore, have reflected a state characteristic rather than a trait characteristic.

Finally, while the study sample was heterogeneous with regard to recruitment methods, age, time since injury, injury severity, and numerous other factors, it was very homogeneous with regard to race, ethnicity, and geographical location. Additionally, volunteer bias is always a limitation to consider, particularly in a population of adults with TBI where initiation, motivation, and follow-through may be of greater concern than in the general population.

5.5 FUTURE RESEARCH

Future research should continue to incorporate both objective and subjective measures of community integration. The contribution of functioning and contextual factors should be explored in greater depth; specifically, both positive and negative affect, fatigue, self-efficacy, and behavior should be explored further. As discussed in Chapter 4, age may be a proximal measure for a variety of life roles, either individually or in combination. Therefore, exploring life roles that may be associated with age (e.g. work, caregiver status, marriage status, health status, etc.) may clarify the specific contributing factors to community integration. Incorporating

longitudinal data, measurements of pre-injury as well as post-injury community integration, and objective measures of frequency of participation, disability, and behavior (e.g. activity logs, performance assessments, or proxy reports) would address several of the limitations of this project. Finally, there is a need for research into effective interventions that incorporate community integration as an outcome measure and target one or more of the various factors found to contribute to community integration after TBI.

APPENDIX A

MEASUREMENT TOOLS

Demographic Questionnaire

A demographic questionnaire was completed to collect descriptive data for all participants. This questionnaire included the following information: Age, Race, Education, Gender, Pre-injury vocational status, Post-injury vocational status, Pre-injury residential status, Post-injury residential status, Marital status, Driving ability, Injury date, Mechanism of injury, Rehabilitation history (inpatient, outpatient, home health), Handedness, Hearing and Visual impairments, and total number of medications currently being taken.

Injury Severity: Glasgow Coma Scale (GCS)

Valid and reliable tool for determining injury severity in TBI (Teasdale & Jennett, 1974). GCS scores range from 3-15, with scores in the 3-8 range indicating severe injury, 9-12 range indicating moderate injury, and 13-15 indicating mild injury. Scores were calculated for injury severity at time of injury and were obtained from the medical chart, medical record review, or through participant and/or family member interview (See Appendix A for details on how scores were obtained).

Mental Health Status: PRIME-MD and Mini-International Neuropsychological Interview (MINI)

PRIME-MD: Valid and reliable diagnostic interview for assessing current and recent history of major depressive disorder, dysthymia, and mania (Spitzer et al., 2000). MINI: Valid and reliable diagnostic interview assessing current and recent history of psychosis and substance abuse (Sheehan et al., 1998);

Subsections will be used to augment the PRIME-MD. These assessments were used for screening purposes and to classify participants' depression, alcohol use, and drug use status. Depression status was classified as Current Major Depression, History of Major Depression, Current Minor Depression, No History of Major Depression. Alcohol and Drug use status were each classified as No Use or History of Use, Past Use No Abuse, Current Use No Abuse, No Current Use Past Abuse, Current Use Past Abuse, or Current Abuse or Dependence.

Community Integration: Participation Assessment with Recombined Tools-Objective/Satisfaction (PART-OS)

Valid and reliable tool for assessing community integration in a traumatic brain injury population (Mount Sinai School of Medicine Department of Rehabilitation Medicine, 2007). The PART-O consists of 24 items that quantify frequency of participation (Bogner et al., 2011; Whiteneck et al., 2011), and the PART-S consists of eleven domains that indicate level of satisfaction with participation (currently undergoing validation). The PART-OS was developed from previously established measures of participation, but improves upon these measures by including a subjective component of satisfaction with participation. A frequency of participation score is computed by totaling scores on the 24 items of the PART-O (each rated on a 0-4 or 0-5 point scale). A satisfaction with participation score is derived by averaging the weighted scores on up to 11 items (including only those rated as medium or high importance by the participant). These two measures serve as dependent variables in this study.

Self Awareness:

Self Awareness of Deficits Interview (SADI)

Valid and reliable tool for assessing self-awareness (Bogod et al., 2003; Simmond & Fleming, 2003; Wise et al., 2005). The SADI is a structured interview, with questions designed to capture three components of awareness. Each of the three questions is scored on a 0-3 point scale, with a higher score indicating greater impairment in self-awareness. The SADI was used as a measure of basic intellectual awareness and as the

	<p>basis for completing the Self Regulation of Skills Interview. If a participant was unable to identify any significant problems on the SADI, the SRSI could not be completed and the highest score (most impaired self awareness) was assigned on the SRSI.</p>
<p>Self Regulation Skills Inventory (SRSI)</p>	<p>Valid and reliable tool for assessing self-awareness (Ownsworth et al., 2000; Wise et al., 2005). The SRSI is a structured interview that requires the participant to identify a main area of difficulty upon which to focus for all of the items. There are a total of six items scored on a 0-10 scale resulting in 3 subscales, with higher scores indicating poorer awareness: Awareness (0-20), Readiness to change (0-10; higher is better), and Strategy behavior (0-30). The Awareness subscale score was used as the primary measure of self awareness for all analyses in this study, as it was the most direct measure of self awareness.</p>
<p><u>Affect</u>: Positive And Negative Affect Schedule (PANAS)</p>	<p>Valid and reliable tool for assessing positive and negative affect (Crawford & Henry, 2004; Watson, Clark, & Carey, 1988; Watson, Clark, & Tellegen, 1988). It consists of two 10-item subscales administered with reference to the past 4 weeks. Each item is rated on a 1-5 Likert Scale and then the 10 items are summed to produce a total subscale score. Total scores from the positive affect subscale and the negative affect subscale were used. Higher scores on the positive affect subscale indicate higher positive affect and higher scores on the negative affect subscale indicate higher negative affect.</p>
<p><u>Self Efficacy</u>: General Self Efficacy Scale (GSE)</p>	<p>Valid and reliable measure of general self-perceived self-efficacy (Luszczynska et al., 2005). The scale consists of 10 items scored on a 4-point scale and yielding a total score ranging from 10-40 points. Higher scores indicate higher degrees of perceived self-efficacy.</p>
<p><u>Fatigue</u>: Modified Fatigue Impact Scale (mFIS)</p>	<p>Valid and reliable tool that measures the impact of fatigue on everyday life in 3 dimensions – Cognitive, Physical, and Psychosocial (Fisk et al., 1994; LaChapelle & Finlayson, 1998). The mFIS includes 21 items each rated on a 5-point ordinal scale ranging</p>

Behavior: Frontal Systems Behavior Scale (FrSBe)

from 0 (no problem) to 4 (extreme problem). It produces a total summed score ranging from 0-84, with higher scores indicating greater fatigue. Scores greater than 38 indicate clinically significant fatigue (Flachenecker et al., 2002).

Valid and reliable tool for assessing behaviors associated with frontal dysfunction (Grace & Malloy, 2001; Malloy & Grace, 2005). It consists of 46 items each rated on a 1-5 Likert scale; ratings are made on each item for before injury and the present time. Items are summed to yield three subscales (Apathy, Disinhibition, and Executive Function) and a total score for before injury and for the present time. These raw scores are then converted to standardized *T*-scores. The FrSBe can be administered to the individual with a TBI or to a family member or significant other. Self-reported total *T*-scores were used as a broad measure of behavioral executive function.

Disability: Mayo Portland Adaptability Inventory (MPAI)

Valid and reliable tool for measuring level of disability in a post-acute brain injury population (Bohac, Malec, & Moessner, 1997; Malec, 2005; Malec, 2004a; Malec et al., 2003). Twenty-nine items are scored on a 4 point ordinal scale. This scale produces an Abilities subscale, an Adjustment Subscale, and Participation subscale; the Participation subscale has been independently validated (Malec, 2004b). A scoring rubric is provided to generate subscale scores and a total score. Raw scores are then converted to standardized *T*-scores. Total score *T*-scores were used as a global measure of disability.

Cognition: Neuropsychological Test Battery

This neuropsychological test battery is based on the battery trialed by the TBI Model System in 2003 (Hanks et al., 2008). It provides an overview of cognition, focusing on areas specific to TBI. Six of eight tests were selected from the battery, as they were deemed most appropriate to a community-based sample, including the California Verbal Learning Test (CVLT-II), the Trail Making Test (TMT), The Symbol Digit Modalities Test (SDMT), the Controlled Oral Word Association Test (FAS/Animals), the Weschler

Test of Adult Reading (WTAR), and the Wisconsin Card Sorting Test (WCST). The CVLT-II and the WCST were scored using a computerized program that provides both raw scores and *T*-scores for various components of each test. The SDMT, TMT, FAS/Animals, and WTAR produce raw scores that were first converted to *Z*-scores using published norms and then transformed to *T*-scores. *T*-scores from the CVLT long-delay recall, the WCST perseverative errors, the SDMT, the TMT Trails A and B, and the FAS and Animals were averaged to create a cognitive composite *T*-score (Green et al., 2008).

APPENDIX B

GLASGOW COMA SCALE SCORE DETERMINATION

Initial injury severity was assessed using the Glasgow Coma Scale (GCS), a validated measure of injury severity after traumatic brain injury (TBI; Kornbluth & Bhardwaj, 2011; Teasdale & Jennett, 1974). GCS scores were determined using a hierarchy of described below.

1. Priority was given to GCS scores obtained from the participant's medical chart. Emergency department notes and nursing notes for the first 24 hours after injury were examined first, and GCS scores as recording in these notes were used if available.
 - a. If multiple scores were available, the highest GCS score within a 24-hour period was recorded.
 - b. There has been some debate regarding the scoring of participants who are intubated or pharmacologically paralyzed. Given that highest scores within the first 24 hours were recorded, a participant's GCS prior score prior to intubation or induced paralysis may have been available and if so, was used. If not available, the GCS score recorded after intubation or induced paralysis was recorded as it was the best data available.

2. If the participant's medical chart was not accessible or if there was no GCS score recorded in the medical chart, GCS scores were determined via any clinical information available.
 - a. Clinical information used is listed below, in order of highest priority first.
 - i. Clinical information available in the medical chart, including emergency room evaluations, progress notes, and neuroimaging.
 - ii. Clinical information available via other source (e.g. doctor's letter, documentation in participant's possession, etc.)
 - iii. Significant other report/Participant report
 1. Loss of consciousness and duration
 2. Duration of PTA
 3. Neuroimaging evidence (e.g. report of "bleed" and location)
 4. History of inpatient rehabilitation and duration
 - b. GCS scores in each domain and then summed to produce a total score.
3. Participants were then categorized as having an initial complicated mild, moderate, or severe injury based on diagnosis definitions defined by the TBI Model Systems National Database (Harrison-Felix, Newton, Hall, & Kreutzer, 1996).
 - a. Participants were classified as having had a complicated mild injury if their GCS scores were between 13 and 15 and they had evidence of neuroradiologic findings or functional compromise to require inpatient rehabilitation. In the cases where this information was unavailable (n=3), participants were determined to have a complicated mild injury based on the GCS score between 13 and 15 and functional compromise to require participation in a specialized rehabilitation program for individuals with TBI (specifically, ReMed of Pittsburgh).

- b. Participants were classified as having had a moderate injury if their GCS scores were between 9 and 12.
 - c. Participants were classified as having had a severe injury if their GCS scores were less than or equal to 8.
4. Given the diversity of methods for obtaining GCS scores and the debate regarding the influence of intubation or pharmacological paralysis, GCS scores were not used as a continuous variable but instead only used to categorize participants as having initial mild, moderate, or severe injuries.

APPENDIX C

INDIVIDUAL NEUROPSYCHOLOGICAL TEST DATA

	Mean (SD)	Range	T-Score Mean (SD)*	Range	n
CVLT Total Trials 1-5	44.23 (12.98)	12-67	47.48 (14.40)	11-72	64
CVLT Short Delay Free Recall	8.61 (4.53)	0-16	-.48 (1.71)*	-4.5-2.5	64
Trails A Time	39.69 (24.49)	14-147	44.06 (23.67)	-82-65	65
Trails B Time	86.06 (50.77)	36-254	43.85 (23.40)	-64-66	65
Symbol Digit Modalities Test Total	41.33 (13.34)	10-76	40.13 (14.94)	-1-70	64
WCST Perseverative Errors	9.95 (7.57)	3-46	46.67 (11.39)	20-80	64
WCST Number of Categories Completed	3.34 (1.50)	0-6	n/a	n/a	64
Verbal Fluency (FAS) Total	36.56 (12.72)	5-67	44.97 (10.20)	15-75	64
Semantic Fluency (Animals)	18.22 (5.91)	4-30	45.75 (12.48)	17-76	64
WTAR	36.59 (8.05)	11-49	105.56 (12.31)	66-125	63
Cognitive Composite Score (average T Score)	n/a	n/a	44.54 (12.03)	-9-60	65

NOTE: CVLT=California Verbal Learning Test; WCST=Wisconsin Card Sorting Test; WTAR=Wechsler Test of Adult Reading
 *For CVLT Short Delay Free Recall and WTAR, values reported is a standard scores not T-Scores

Individual Neuropsychological Test Correlations

	CVLT Total	CVLT SD Free	Trails A	Trails B	SDMT	WCST Errors	WCST Categories	Fluency - FAS	Fluency - Animals	WTAR	Cognitive Composite
Frequency of Participation	.307*	.345†	-.363†	-.346†	.373†	.161	.006	.221	.181	.312*	.408‡
Satisfaction with Participation	.258*	.270*	-.084	-.099	.190	.206	-.153	-.114	.056	-.064	.169
SRSI - Awareness Subscale	-.379†	-.224	.403‡	.473‡	-.236†	-.196	-.218	-.527‡	-.342†	-.475‡	-.504‡
SRSI - Readiness to Change Subscale	.276*	.216	-.285*	-.376†	.215	-.036	.022	.261*	.382†	.100	.352†
SRSI - Strategy Behavior Subscale	-.183	-.124	.326†	.405‡	-.198	-.170	-.176	-.309*	-.217	-.320	-.364†
Positive Affect	-.052	-.051	.138	.099	.010	.288*	.069	-.134	.011	.026	-.059
Negative Affect	.005	-.037	-.172	-.087	.117	-.150	-.016	.281*	.198	.007	.140
Age	.297*	.210	-.045	-.167	.204	.163	-.206	.018	-.036	.059	.162
Injury Severity**	-.358†	-.349†	.110	.201	-.369†	-.280*	.017	-.264*	-.196	-.176	-.347†
CVLT Total T-Score		.863‡	-.513‡	-.538‡	.559‡	.068	.027	.392‡	.390†	.295*	.710‡
CVLT Short Delay Free Standard Score			-.395‡	-.415‡	.518‡	.071	.058	.304*	.352†	.236	.589‡
Trails A Z-Score				.779‡	-.631‡	-.045	-.167	-.342†	-.370†	-.431‡	-.858‡

Individual Neuropsychological Test Correlations continued

	CVLT Total	CVLT SD Free	Trails A	Trails B	SDMT	WCST Errors	WCST Categories	FAS Total	Animals	WTAR	Composite
Trails B Z-Score					-.649‡	-.254*	-.289*	-.385†	-.403‡	-.437‡	-.884‡
Symbol Digit Modalities Z-Score						.148	.093	.524‡	.411‡	.328†	.798‡
WCST Perseverative Errors T-Score							.534‡	.153	.183	.306*	.345†
WCST Number of Categories								.167	.120	.302*	.293*
Verbal Fluency (FAS) Total T- Score									.540‡	.394†	.587‡
Semantic Fluency (Animals) T-Score										.107	.616‡
WTAR Standard Score											.511‡

* p≤.05 ; † p≤.01 ; ‡ p≤.001

NOTE: SRSI=Self Regulation of Skills Interview; CVLT=California Verbal Learning Test; WCST=Wisconsin Card Sorting Test; WTAR=Wechsler Test of Adult Reading

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