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Disparities Between Native Americans and White Individuals in Trajectories of Community Participation over the 5 Years after Traumatic Brain Injury

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ABSTRACT

Traumatic brain injury (TBI) disproportionately affects minoritized populations within the U.S., especially Native Americans who are more likely to experience a more severe or fatal TBI than White individuals. Despite this disparity, little research has investigated the experience of Native Americans with TBI or outcome disparities following TBI. The current study used a subsample of 63 Native Americans with TBI from the TBI Model Systems (TBIMS) database matched by age, sex, and injury severity to 63 White individuals to examine disparities in community participation, as measured by the Participation Assessment with Recombined Tools—Objective (PART-O), over the five years following TBI. Analysis of variance (ANOVA) and chi-square tests revealed Native Americans were less likely to be employed prior to injury, less likely to have private insurance, more likely to report problematic alcohol use in the month prior to injury, and more likely to have lower education attainment compared to their demographically matched White counterparts. A series of hierarchical linear models (HLMs) revealed Native Americans demonstrated lower Out and About scores but statistically equivalent Social and Productivity scores compared to White individuals with TBI. The difference in Out and About scores did not change as a function of time, and the overall difference between the two groups dissipated with the inclusion of the statistically different sociodemographic variables. Both educational attainment and type of insurance were statistically significant predictors of Out and About trajectories. These results highlight important predictors that can help rehabilitation clinicians more accurately identify individuals who may be at risk for lower community participation following inpatient TBI rehabilitation. More research is needed to better understand the causal pathways underpinning disparities following TBI for Native Americans and strengths unique to the Native American community that might be bootstrapped to help bridge gaps in outcome.

Vita

Jack Watson was born on November 5th, 1989 in Henrico, Virginia. He received his bachelor's degree in medieval studies and English from the University of Virginia in May, 2012. Shortly thereafter, he worked as a law enforcement officer and air rescue fire fighter serving his local community in Charlottesville, Virginia for four years before pursuing a post-baccalaureate in psychology at VCU while working as a research coordinator for Dr. Paul B. Perrin at Virginia Commonwealth University. For Dr. Perrin, Jack worked on a number of studies, but his primary responsibility was coordinating Dr. Perrin's grant-funded *Randomized clinical trial of a telehealth transition assistance program for SCI caregivers*. He currently attends Virginia Commonwealth University, where he received his master's degree in psychology in 2023, in the health psychology doctoral program as part of the Distinguished Doctoral Scholars Program funded by the Southern Regional Education Board.

Positionality and Population of Interest

Jack Watson is a first-generation college student and first-generation American citizen from a rural community in Virginia. He has ties to the Native American and disability communities and serves as an informal caregiver for both of his parents. Due to these identities and experiences, Jack has chosen a research topic and approach that highlights the experiences and voices of individuals from within the disability community, particularly those from multiple marginalized identities. Through his research, he hopes to elucidate health inequities and contribute to increasing the quality of and access to care for medically underserved populations.

Introduction

Overview of the Literature Review

This literature review will begin by discussing the etiology and epidemiology of traumatic brain injury (TBI) including incidence and prevalence. The review will discuss common impairments following TBI including general disability, functional independence, depression, anxiety, reduced life satisfaction, suicide, social challenges, and community participation. The review will pay particular attention to community participation, the primary outcome of interest for the proposed study. The review will then address TBI epidemiology in racial/ethnic minorities with a strong focus on Native Americans and discuss disparities in outcomes for Native Americans with TBI. Importantly, the dearth of literature on the experience of Native Americans with TBI will be highlighted. Finally, the review will describe the purpose of this study, which is to examine possible race-based disparities in community participation over the first 5 years after TBI between Native Americans and White individuals.

Etiology of TBI

Traumatic brain injury (TBI) is a physical injury to brain tissue that causes temporary or permanent functional impairment (Parikh et al., 2007). More specifically, the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association [APA], 2013) requires a TBI to result in disorientation, confusion, loss of conscious, amnesia, or neurological defect. Clinical manifestations of TBI can vary widely, both with and without gross structural damage to the brain and as open or closed wounds (Parikh et al., 2007). Closed head wounds are characterized by a rapid acceleration, deceleration, or rotational force injuring the brain tissue (Greve & Zink, 2009; Parikh et al., 2007). Trauma to the head must be caused by an external force like a blow or fall (BIA, 2011; NDSC, March 2017). The TBI occurs when the trauma to the head is sufficient to interrupt typical brain function (BIA, 2011; NDSC, March, 2017).

In a TBI, virtually every structure of the brain is at risk for damage. Nerves and blood vessels can be crushed or torn with damaged blood vessels possibly leading to additional health complications including hemorrhages and hematomas (Ghajar, 2000; Parikh et al., 2007). TBI can place individuals at significant risk for hypoxemia, hypotension, and brain swelling, all of which can further exacerbate brain damage, increasing the likelihood for severe health complications or death (Ghajar, 2000). The temporal and frontal lobes, given their peripheral location within the brain, are especially vulnerable to linear forces (e.g., acceleration and deceleration; Greve & Zink, 2009) while deeper brain structures—white matter—are more likely to be injured by rotational forces, a type of injury known as diffuse axonal injury (Greve & Zink, 2009).

Impaired brain function may be immediate and caused by direct damage (e.g., an open wound lacerating brain tissue) or delayed and caused by subsequent events following the initial injury (e.g., a subdural hematoma; Ghajar, 2000; Parikh et al., 2007; Greve & Zink, 2009). Neurological damage especially may evolve secondary to the injury (Ghajar, 2000) and is often due to brain swelling—a particularly problematic sequelae of TBI given the brain is housed within the skull with largely non-compressible cerebrospinal fluid (Ghajar, 2000; Parikh et al., 2007). Most individuals with significant TBI lose consciousness at least briefly, may become irritable, and may demonstrate altered function ranging from confusion to coma (Ghajar, 2000; Parikh et al., 2007; Greve & Zink, 2009).

Individuals with TBI are classified based on mechanism of injury, structural change/damage, and clinical severity (Baalen et al., 2003). Clinical severity is typically measured by degree and length of impairment and ranges from mild to severe, with the majority being mild (ICD-11; World Health Organization, 2019). Concussions are synonymous with mild TBI (Parikh et al., 2007). The Glasgow Coma Scale (GCS) is a common measure of injury severity during initial examination based on eye opening, verbale response, and motor response (Jennett et al., 1981; Teasdale & Jennett, 1976). A common indicator of clinical severity is time spent in posttraumatic amnesia (PTA), a state in which a person experiencing a TBI is unable to form and retain new memories (Baalen et al., 2003). It is common to define the clinical severity of TBI by either the GCS or PTA; however, computed tomography (CT) scans are often used to identify physical evidence of TBI (Baalen et al., 2003; Ghajar, 2000; Greve & Zink, 2009; Jennett et al., 1981; Parikh et al., 2007).

Prevalence of TBI

TBI is a global health crisis (Maas et al., 2017). It is one of the leading causes of death and disability worldwide and is the leading cause of death and disability for young people in the United States (U.S.; Maas et al., 2017; Ghajar, 2007). TBI burdens the global healthcare system substantially with estimated costs in excess of $400 billion a year (Correa et al., 2022; IBRD, 2020; Maas et al., 2017). Globally, there are 69 million new TBIs each year (Dewan et al., 2018) with 61,000 yearly TBI-related deaths in the U.S. alone (Centers for Disease Control, 2019). North America has the highest reported incidence of TBI; however, this number may be more reflective of disparities in reporting and access than real numbers (Dewan et al., 2018). Indeed, dating as far back as 1988, the U.S. government, through the Centers for Disease Control and Prevention (CDC), established a system to report and monitor TBIs while encouraging research and prevention (Coronado, 2012).

Americans experienced over 200,000 TBI related hospitalizations in 2018 (CDC, 2021a). Unfortunately, these numbers only include individuals admitted overnight to a hospital and do not account for untreated TBIs or those treated through urgent care, primary care, emergency room visits, federal facilities (e.g., prisons, military bases), or other outpatient care centers (CDC, 2021a). Total TBI estimates within the U.S. exceed 2 million per year (CDC, 2019). Within the U.S., falls (47.9%), collision with an object (17.1%), and motor vehicle accidents (13.2%) account for the main causes of TBI (CDC, 2019; Roozenbeek et al., 2013).

Common TBI Impairments

Thanks to advances in medicine, our understanding of TBI, and, especially, critical first-response care, individuals are surviving TBI and living longer following injury than ever before (Hammond et al., 2019; Greve and Zink, 2009; Parikh et al., 2007). In fact, estimates from the late 2010s have seen mortality following a severe TBI dip by more than 50% (CDC, 2019; Ghajar et al., 2000). Older age and greater injury severity are the chief demographic predictors of mortality following TBI (Hammond et al., 2019; Parikh et al., 2007). Most individuals with mild TBI make a full recovery or at least return to near pre-injury levels of function (Hammond et al., 2019; Parikh et al., 2007). The GCS, one of the most common early-stage assessments of injury severity, has five possible outcome categories: good recovery (return to pre-injury function), moderate disability (the so called “independent but disabled”), severe disability (incapable of self-care), vegetative (no cognitive function), and death (Jennett et al., 1981; Teasdale & Jennett, 1976). Over 50% of individuals with a severe TBI have a good recovery or moderate disability (Parikh et al., 2007). Still, many individuals with TBI face a life-long alteration to their quality of life and independence.

Physical Challenges. Individuals with TBI may experience a host of physical impairments and challenges following their injury including: bladder and bowel problems, reduced or muted sensations, compromised movement, memory difficulties, amnesia, excessive fatigue, chronic headaches, slow processing speed, and cognitive decline (CDC, 2014; Jennett et al., 1981; Moretti et al., 2012; Parikh et al., 2007; Smith et al., 1997). Individuals with TBI may also develop subsequent neurological disorders like epilepsy, dyssomnia, parasomnia, and other sleep disorders (Moretti et al., 2021; Smith et al., 1997), all of which can exacerbate the cognitive deficits caused by brain damage. Similarly, a TBI places an individual at a heightened risk to develop even more severe neurological disorders like Alzheimer’s disease, Parkinson’s disease, chronic traumatic encephalopathy, and dementia (CDC, 2014; Hammond et al., 2019). Each of these diseases brings its own difficulties, challenges, and life-expectancies all of which compound the negative aspects of a TBI.

Individuals with TBI frequently develop comorbid conditions like diabetes, high cholesterol, arthritis, hypertension, respiratory diseases, and fluid component imbalances virtually all of which increase the likelihood for a second injury (e.g., a fall leading to a fracture) and heighten the risk of premature mortality (Caplan et al., 2018; Hammond et al., 2019). Pain, especially back and neck pain, is a common problem following TBI (Hammond et al., 2019) as are headaches and migraines (Hoffman et al., 2011; Mayer et al., 2013). Both headaches, particularly migraines, and chronic pain are linked to reduced life satisfaction and health-related quality of life (Eskin et al., 2013; McNamee & Mendolia, 2014; Taşkapilioğlu & Karli, 2013) and further exacerbate the cognitive difficulties faced by individuals with TBI (Arciniegas et al., 2002).

Greater levels of disability and the presence of comorbid conditions have been linked to reduced levels of community participation, decreased life satisfaction, and poorer physical and mental health (Hammond et al., 2019; Fuhrer et al., 1992; Mailhan et al., 2005; Pierce & Hanks, 2006; Williams et al., 2014). Lower physical function and decreased independence is associated with a higher risk for depression, lower life satisfaction, anxiety, and health-related quality of life (Rivers et al., 2018). Functional independence—the ability to regularly and independently perform basic tasks associated with daily living (Curzel et al., 2013; Heinemann et al., 1993)—is a key predictor of return to pre-injury levels of function and is an especially useful metric for predicting life satisfaction for individuals with TBI (Fuhrer et al., 1992; Rivers et al., 2018; Hartman-Maeir et al., 2007). Functional independence is also useful for forecasting an individual's likely supervision needs from a caregiver (Corrigan et al., 1997).

Functional independence can be affected by a host of physical, mental, and social sequelae of TBI (Arcinegas et al., 2002; Carpuso & Levin, 1992; Cowen et al., 1995; Erler et al., 2018; Levin et al., 1988). Cognitive impairments are a particularly disabling consequence of TBI, often the most impactful symptom in terms of function (Carpuso & Levin, 1992). Reduced information processing speed is an especially salient and disabling cognitive impairment that frequently accompanies TBI (Carpuso & Levin, 1992). Long-term memory deficits may also reduce an individual's independence (Arcinegas et al., 2002; Levin et al., 1988), and it is not uncommon for individuals to face language difficulties, problems with attention, and deficits in perceptual reasoning (Carpuso & Levin, 1992), all of which may hamper an individual's ability to appropriately and safely navigate their daily life.

Compromised motor functions are an incredibly common sequela of TBI (CDC, 2014; Cowen et al., 1995; Erler et al., 2018; Zarshenas et al., 2019), so it is no surprise that individuals with TBI demonstrate significant difficulty with motor tasks compared to the general populace (Caeyenberghs et al., 2011). Bladder and bowel management, self-care tasks (e.g., dressing, bathing), fine motor tasks (e.g., brushing teeth, buttoning a shirt, writing), ambulating, and balance can all be negatively affected by a TBI (Caeyenberghs et al., 2011; Centers for Disease Control, 2014; Erler et al., 2018). Virtually all of these motor impairments place individuals with TBI at a significantly higher risk for a post-injury fall (McKechnie et al., 2015) than an individual with little to no motor impairment.

Perhaps not surprisingly, the level of physical impairment/difficulty experienced by a person with TBI is highly predictive of their community participation (Huebner et al., 2003; Mailhan et al., 2005; Pierce & Hanks, 2006; Williams et al., 2014). Poor motor function along any domain also limits an individual’s ability to return to pre-injury roles and levels of activity (Erler et al., 2018). In fact, significant increases in functional independence, particularly motor function, accomplished through targeted community-based therapy has proven to drastically increase an individual’s ability and willingness to engage with their community (Huebner et al., 2003; Sloan et al., 2009).

Psychological Challenges. A myriad of emotional and psychological symptoms can also accompany TBI (CDC, 2014). Compared to the general populace, individuals with TBI typically score lower on measures of life satisfaction (Jacobsson et al., 2010) with reduced community participation and greater levels of disability being strong indicators of lower scores (Fuhrer et al., 1992; Hartman-Maeir et al., 2007; Mailhan et al., 2005; Pierce & Hanks, 2006; Rivers et al., 2018; Williams et al., 2014). Indeed, an individual’s ability to return to a productive lifestyle (e.g., work, social interaction) and maintain good health are both key predictors of life satisfaction (Corrigan et al., 2001). Motor independence, gainful employment, depressive symptoms, social integration, and marital status have all been shown to be strongly associated with life satisfaction for individuals with TBI (Corrigan et al., 2001). Perhaps surprisingly, individuals with moderate disability demonstrate worse life satisfaction scores than either folks who experience a good recovery (as determined by the GCS) or severe disability (Mailhan et al., 2005). Individuals who self-assess as being social and vocationally productive (important aspects of community participation) are more likely to report greater life satisfaction, health-related quality of life, and self-perceived importance of health values (Jacobsson et al., 2010).

TBI is a unique risk factor for depression with some estimates placing the comorbid prevalence of depression at 50% for those with moderate to severe TBI (Bombardier et al., 2010; Jean-Bay, 2000). The significantly reduced physical function experienced by individuals with moderate-to-severe TBI has been linked to an increase in both the presence and severity of symptoms associated with depression and anxiety (Rivers et al., 2018). It is important to note that the rates of anxiety and depression as well as the severity can vary widely for the TBI population and are impacted by a plethora of variables including pre-injury functioning (e.g., education) and condition (e.g., mental health, substance use; Albrecht et al., 2019; Bombardier et al., 2016; Davis et al., 2012; Jorge et al., 2004). Nonetheless, given the frequency and impact of depression and anxiety that can accompany TBI, intense and recurrent mood changes are common and often exacerbated by heighted anxiety and irritability (Holsinger et al., 2002). This can be an incredibly disorienting experience for the person with TBI and those close to them as they may notice changes in relational patterns, impulsiveness, interests, and personality (Holsinger et al., 2002; CDC, 2014; Milders et al., 2003).

Anxiety disorders are another comorbid mental health condition with a high prevalence for individuals with TBI (CDC, 2014). A systematic review found as many as 36% of individuals with TBI meet the criteria for an anxiety disorder at any given time (Scholten et al., 2016). In fact, lifetime prevalence rates for anxiety disorders accompanying TBI make it one of the most common and disabling sequelae (Mallya et al., 2015; Mayou et al., 1993) with PTSD developing in as many as 24% and GAD in as many as 28% (Mallya et al., 2015). The literature on anxiety disorders in mild TBI is scant and inconsistent with wide ranging prevalence estimates (Moore et al., 2006). In general, anxiety disorder rates increase over time following TBI, with individuals who had a pre-injury history of mental health disorders or those who do not return to pre-injury levels of community participation and productivity being at a much higher risk for developing an anxiety disorder at some point following their injury (Scholten et al., 2016). Notably, the presence of an anxiety disorder post-injury is highly predictive of an individual's likelihood to return to work and social interaction (van der Horn et al., 2013). Further, anxiety and depression disorders often cooccur in individuals with TBI (Hart et al., 2016; Jorge et al., 2004; Jorge et al., 1993) further compounding the negative and disabling effects of TBI. Some estimates indicate that as many as 70% of individuals having a diagnosis of either major depressive disorder or generalized anxiety disorder will be diagnosed with both at some point during their rehabilitation from TBI (Rao & Lyketsos, 2002; Fann et al. 1995).

As one of the leading causes of physical-trauma-related mental health disorders (CDC, 2019; Bryant et al., 2010), TBI places individuals at a drastically increased risk for suicide (CDC, 2021b; Madsen et al., 2018; Simpson & Tate, 2007; Teasdale et al., 2001; Wadhawan et al., 2019; Wasserman et al., 2008). More than 25% of people experiencing a TBI will have suicidal ideation at some point post-injury (Mackelprang et al., 2014). Estimates of suicide rates in TBI populations indicate that individuals with TBI are, at a minimum, twice as likely to die by suicide than the average person (Madsen et al., 2018). This likelihood increases drastically when certain conditions are met. For instance, individuals with severe disability following TBI are more than four times as likely to die by suicide than individuals without a TBI; this risk is increased even further if, for instance, the person also has a substance use disorder (Madsen et al., 2018; Teasdale et al., 2001; Wasserman et al., 2008). Multiple sustained TBIs also significantly compound the risk of suicide (Richard et al., 2015).

Importantly, research has shown that many aspects of community participation (e.g., increased social interaction, self-perceived productivity, decreased feelings of isolation) act as a buffer against suicidality (Madsen et al., 2018; Teasdale et al., 2001; Tsaousides et al., 2007; Wasserman et al., 2008). Many of the treatments for reducing suicidality in individuals with TBI focus on increasing social interconnectedness and general social support, further accentuating the vital role of community participation in creating a stable and healthy post-injury life (Tsaousides et al., 2007). One qualitative study using community-based participatory research showed that individuals with TBI self-identified that informal relationships (i.e., friends, family, other individuals with disability) was one of the most important factors in preventing suicide (Kuipers & Lancaster, 2000).

Social Challenges. Individuals with TBI face a host of social and life development challenges following their injury. While many people do live healthy and productive lifestyles (Corrigan et al., 2001), it is often in the face of significant adversity. People with TBI are less likely to be employed and less likely to have stable, long-term employment (Catalano et al., 2006; Hoofien et al., 2001). They are less likely to be married and more likely to be divorced (Hoofien et al., 2001; Stevens et al., 2017). Individuals who experience a TBI, particularly at a young age, are less likely to have high educational attainment than the average person and may face significant learning challenges due to permanent neurobiological changes to the brain for which our education system is not adequately prepared (D'Amato & Rothlisberg, 1996; Sharbafshaaer, 2018). Each of these aforementioned disparities represents significant divergence from national averages, further reinforcing the fact that individuals with TBI face unique social challenges post-injury (Hoofien et al., 2001).

In fact, across nearly all life domains, individuals with TBI encounter difficulties unique to their brain injury and disability with which the average person does not have to contend (Liss & Willer, 1990). These difficulties can, particularly in intimate relationships, add a level of burden that would not otherwise be present. Individuals with a TBI frequently endorse feelings of loneliness and lower social interaction and functioning and regularly view themselves as a burden to loved ones, particularly if they have an informal caregiver (e.g., spouse or other family member who provides a significant portion of care; Hoofien et al., 2001). All of this is to demonstrate that a TBI can and often does drastically impact a person's social life and interaction with their community.

Community Participation

Community participation is a general construct within the disability literature that refers to overall functioning at the societal level post-injury (Bogner, 2013; Takada et al., 2016;). While community participation has been assessed in a variety of ways in the literature, it generally comprises social interaction (e.g., visits with friends or social interactions like providing support for another), productivity (e.g., work or education), and the number of times the person left the home to engage with their community (e.g., attended church or a sporting event; Bogner, 2013; Whiteneck et al., 2011). Community participation, in all its facets, is a primary outcome focus for many TBI rehabilitation programs (Takada et al., 2016; Williams & Willmott, 2012). As far back as World War I, the importance of community participation was recognized as the U.S.

federal government instituted programs to help injured soldiers, particularly those with TBI, return to work (Sander et al., 2010). The importance of the transition to home then back into the community has only grown in recent years as more people are surviving TBI and living longer than ever before (Hammond et al., 2019; Greve and Zink, 2009; Parikh et al., 2007; Sander et al., 2010).

Community participation, sometimes called community integration, community reintegration, or community engagement in the literature, has been found to be one of the most important aspects of rehabilitation post-TBI (Jacobsson et al., 2010; Kuipers & Lancaster, 2000; Lee et al., 2001) and has a plethora of important benefits like acting as a protective factor against suicide (Madsen et al., 2018; Teasdale et al., 2001; Tsaousides et al., 2007; Wasserman et al., 2008). The construct of community participation can be conceptualized as the degree to which an individual is able to engage in a normal pattern of social and community life following rehabilitation (Lee et al., 2001; Wood et al., 2010) and should generally be accompanied by an increase in one's quality of life (Kuipers & Lancaster, 2000; Malek et al., 2013; Parvaneh et al., 2015). This often consists of the resumption of former roles and relationships post-discharge (e.g., fulfilling familial tasks, working).

The earliest model of community participation is the "Whatever It Takes" (WIT) developed by Willer and Corrigan (1994). This model was created to specifically consider environmental barriers for disabled individuals and the importance of natural supports (e.g., friends and family). It also represented a significant shift in concepts of rehabilitation as it marked the first time long-term community participation was established as a specified goal of post-disability rehabilitation (Willer and Corrigan 1994). The model centers on self-determination and sets standards for rehabilitation programs and goals—for instance, that community integration (i.e., participation) be holistic in nature and that rehabilitation programs should attempt to create learning environments that reflect the environments in which learned skills will be used (Willer and Corrigan, 1994).

Since the WIT's inception, a small body of literature has advanced the cause of community participation following acquired disability, and it has become an important, though still underutilized, metric for rehabilitation outcomes (Takada et al., 2016; Williams & Willmott, 2012). In 1998, McColl and colleagues expanded on the work of Willer and Corrigan through the first major qualitative study on community participation for individuals living with TBI (1998). The study highlighted nine possible indicators of community participation that have been used to inform subsequent research, scale development, and implementation of rehabilitation programs.

Inability to participate in one's community is one of the key aspects of disability according to the World Health Organization (WHO); however, despite its documented importance, community participation is one of the least assessed outcomes post-TBI (Mellick, 2000). One of the earliest assessments of community integration, the Craig Handicap Assessment and Reporting Technique (CHART) was designed to assess the degree to which physical and organ-based impairments (two other key aspects of disability according to the WHO) impacted an individual's ability to fully engage with their community (Mellick, 2000; Whiteneck, 1992). The latest version of the CHART assesses six domains of "handicap" (i.e., absence of social participation): 1) physical independence—ability to live without supervision or assistance, 2) mobility—capacity for unassisted ambulation, 3) occupation—ability to occupy time in a manner appropriate for their age, sex, and culture, 4) social integration—ability to maintain appropriate and expected social relationships, 5) economic self-sufficiency—ability to be economically independent through appropriate earning activity, and 6) orientation—ability to orient to one's self and one's surroundings (Mellick, 2000, Whiteneck, 1992).

The Community Integration Questionnaire (CIQ) is another of the earliest and most widely used assessments of community participation (Willer et al., 1994). The CIQ specifies three important domains of community participation: (1) home—the degree to which the person takes an active role in the function of the home/family, (2) social—the degree to which the person resumes social activities like visiting friends, attending religious services, or leisure activities within the community, and (3) productivity—the degree to which the person engages with work, education, or volunteer activities (Willer et al., 1994). The Participation Objective, Participation Subjective (POPS) is yet another commonly used measure (Brown, 2006; Brown et al., 2004) which assesses community participation in both objective and subjective ways. To accomplish this, the POPS assesses 26 "items" of community participation, each with three questions. The first question is objective, asking, for instance, how many hours a week the person works, with two subjective follow-ups geared toward enjoyment and satisfaction (for instance, how satisfied the person is with the number of hours worked; Brown, 2006; Brown et al., 2004). In this way, the POPS is able to both quantitatively and qualitatively assess community participation.

The PART-O is another commonly used assessment of community participation and one of the most recently developed (Bogner et al., 2013; Bogner, 2013). It is a combined and modified version of the CHART, CIQ, and POPS. It was specifically designed to be used within the TBIMS and is the primary measure for the proposed study. The PART-O will be discussed later in the methods section.

With the study and use of community participation still in its relative infancy—only a part of the disability literature for about 25 years—it can be difficult to determine exactly how to operationalize and utilize the construct. Definitions of community participation vary widely and can include the degree to which a person resumes their typical roles following acquired disability, comprehensive day services, inpatient and outpatient rehabilitation services, the degree to which individuals engage with their social support network, and an investigation of environmental factors impacting post-rehabilitation life and recovery (Evans & Brewis, 2008; Goranson et al., 2003; Jette et al., 2005; Keysor et al., 2006; Lee et al., 2001; Pollard & Sakellariou, 2008 Sharma, 2007). Further, the means with which these programs and outcomes are assessed vary, often assess dissimilar aspects of community participation, and have different metrics for success (Bogner et al., 2013; Brown, 2006; Brown et al., 2004; Mellick, 2000; Whiteneck, 1992; Willer et al., 1994).

Finally, community participation can have a deeply cultural context. For instance, Sander and colleagues found that Hispanic individuals whose primary language is Spanish scored worse on measures of community participation (as measured by the PART-O) than for those who spoke English as their primary language (2021). The PART-O, like all other popular measures of community participation, was designed and normed on White, English-speaking individuals; even the Spanish version of the PART-O is a direct translation from English rather than culturally specific (Sander et al., 2021). It is also likely that such measures of community participation are unable to detect variations in cultural conceptions of community participation. Hispanic and Black individuals with TBI have been shown to endorse different aspects of community participation as more important than White individuals with TBI (Sander et al., 2011). Specifically, Black and Hispanic individuals were more likely to view their environment as integral to community participation, and Hispanics were more concerned with others making them feel loved and how social barriers might impact community participation than either White or Black individuals (Sander et al., 2011). While this research does not exist for Native Americans with disabilities, it is not unreasonable to assume that differences in culture may cause Native Americans and White individuals to have partly divergent views on community participation and what specific aspects are most important.

Native American Disparities

Native Americans are a severely underserved and marginalized group in the U.S. They face significant health disparities when compared to White individuals in diseases, injuries, acquired disabilities, and premature death across all age groups (Sarche & Spicer, 2008). They also experience a number of social and economic disparities like increased poverty rates, lower education and employment, higher rates of violence and trauma, and higher rates of substance use (Sarche & Spicer, 2008). Five of the seven poorest counties in America are at least partly incorporated into Native American land (i.e., a federally recognized Native American "Reservation;" Brockie et al., 2013; DePietro, 2022). A sizeable portion of Native American land has also been ravaged by hard rock mining and is now peppered with abandoned mines, leading to increased health risk (e.g., higher rates of kidney disease, hypertension, and the development of multiple comorbid chronic diseases) for those exposed (Lewis et al., 2016). This can be particularly problematic as the presence of multiple comorbid conditions with TBI can prevent recovery or increase functional deficits (Zarshenas et al., 2019).

Native Americans face some of the worst health conditions in the U.S. (Jones, 2006). Premature mortality rates in Native Americans communities, largely due to chronic disease-related complications, is roughly twice as bad as the worst Organization of Economic

Cooperation and Development country (Murray et al., 2005). Native Americans face significantly elevated rates of diabetes (Burrows et al., 2000; Newman et al., 1993) which research has partly linked to having experienced severe malnutrition, both personally and intergenerationally (Benyshek et al., 2001). They also experience heightened rates of cancer over and above other racial and ethnic minorities within the U.S.; though the specific rates and disparities vary be region and tribe (Baquet, 1996; Wiggins et al., 2008). Native Americans report greater frequency and severity of chronic pain compared to the general populace (Zajacova et al., 2022).

Native Americans are significantly more likely to die prematurely due to chronic disease than White Americans (Clements et al., 2020). Sadly, the prevalence of increased premature mortality due to chronic disease and infection has a history dating back at least 500 years (Jones, 2006). Compared to the general populace, Native Americans were 4x more likely to die during the Spanish flu of 1918, more likely to die from H1N1, more likely to die from hantavirus pulmonary syndrome, and experience a host of disparities related to other dangerous chronic diseases and infections like HIV, hepatitis A, and hepatitis C (Ehrenpreis & Ehrenpreis, 2022).

Alcohol abuse and alcoholism are leading causes of death and disability among Native Americans (Koss et al., 2003; May et al., 1994). In the late 1990s, the alcohol-related mortality rate among Native Americans was seven times that of the general U.S. population (Indian Health Service, 2000; Koss et al., 2003; May et al., 1994). Native American men are far more likely to have a long-term alcohol misuse problem than Native American women—up to five times the lifetime prevalence, and typically start drinking at a young age, developing dependency sometime in their twenties (Leung et al., 1993). Estimates of lifetime alcohol abuse prevalence rates range from 36.4% to 52%; however, one cohort-based study found three quarters of the

Native American men followed in the study developed alcohol dependency at some point in their life (Flores, 1985; Leung et al., 1993). Native American men are also far less likely to stop drinking alcohol than women, and those who do cease alcohol use typically do so absent medical treatment (Leung et al., 1993). Research from the early 2000s and mid 2010s is conflicted on current rates of alcohol use, dependency, and alcohol-related disparities, with some research showing greater alcohol use among Native Americans compared to other ethnic/racial minorities (Szlemko et al., 2006) and other research showing lower or comparable rates (Cunningham et al., 2016). More research must be conducted to understand the actual rates of consumption as, despite some research showing comparable rates of use, mortality due to alcohol-related diseases far exceeds the national average (e.g., 4.9 times more likely to die from alcoholic liver disease than the general populace) and may indicate significant disparities in quality of healthcare and healthcare access rather than alcohol use (Cunningham et al., 2016).

Native Americans, particularly women, report significantly higher than average rates of intimate partner violence (IPV), roughly five times the national average (Malcoe et al., 2004). The high rates of violence and IPV are especially concerning as assault is a leading cause of TBI (CDC, 2021b), and this translates to a causal disparity for Native Americans as they are three times as likely to have violence as a cause of TBI (Linton & Kim, 2014). Indeed, research has documented the association between IPV and TBI with estimates suggesting more than 30% of women who experience IPV also receive a head injury (Luna-Firebaugh et al., 2002; Evans-Campbell et al., 2006). Some research places this estimate far higher with as many as 92% of abused women receiving a TBI at some point as a direct result of IPV (Ivany & Schminkey, 2016).

For Native American women, this can be particularly problematic. Prior research has shown that Native American women experience higher rates of violence than any other racial/ethnic group in the U.S. (Wahab & Olson, 2004). Qualitative research suggests that IPV is often deeply entrenched and repressed within Native American families (Finfgeld-Connett, 2015). Survivors may be reluctant or even prevented from seeking medical assistance, further exacerbating the systemic barriers to access already prevalent in many Native American communities (Cromer et al., 2019; Finfgeld-Connett, 2015; Sarche & Spicer, 2008).

Native Americans face profound barriers to reliable and adequate healthcare services (Cromer et al., 2019). Given the poverty levels of many Native American communities, concerns around the high cost of medical care or lack of insurance are rampant (Liddell, 2020; Marrone, 2007). Cultural differences, suspicion of western medicine practices, and provider distrust were key barriers uncovered by a qualitative study of 31 Native American women in the Gulf Coast region of the U.S. (Liddell, 2020). Further, research indicates health literacy, communication difficulties (e.g., English as a second language), and distance to the nearest medical facility all impede healthcare access for Native Americans (Marrone, 2007). It is unsurprising, then, that Native Americans are significantly less likely than the general populace to utilize healthcare resources (Whitfield & Lloyd, 2008).

Even when Native Americans do choose to engage with the healthcare system, many of their facilities are woefully inadequate (Cromer et al., 2019; Sequist et al., 2011). Particularly for more severe or complicated conditions, the facilities within geographical reach are ill-equipped to provide adequate care (Cromer et al., 2019; Sequist et al., 2011). Rural Indian Health Service (IHS) facilities will often lack vital specialists (e.g., endocrinologists and oncologists) or have long wait times (Cromer et al., 2019; Liddell, 2020; Sequist et al., 2011). Serious concerns exist within the Native American community that the care they receive from their local IHS facilities will be poor, inaccurate, and inadequate (Liddell, 2020). Unfortunately, there is little research on the quality of care received by Native Americans, but what does exist paints a bleak picture, especially for Native Americans with TBI.

TBI in Native Americans

Very little research exists on Native Americans with TBI. In 2017, two separate systematic reviews of TBI in indigenous populations, one focusing on just North America and the other worldwide, found only 8 studies meeting inclusion criteria that even mentioned Native Americans (Lakhani et al., 2017; Zeiler & Zeiler, 2017). Since these reviews, only one other paper, also utilizing the TBIMS database, has been published that examines disparities between Native Americans and White individuals with TBI and found that Native Americans with TBI had generally worse cognitive and motor function following TBI than their demographically matched counterparts (Watson et al., in press). The few studies that do include Native Americans with TBI are often larger TBI studies covering numerous racial/ethnic minoritized communities and/or have very small samples (Bazarian et al., 2003; Daugherty et al., 2019; Linton, 2015; Linton & Kim, 2014). There are very few studies examining outcomes following TBI for Native Americans, even fewer examining health disparities, and only one to date examining health disparities in a demographically matched sample (Lakhani et al., 2017; Watson et al., in press; Whitfield & Lloyd, 2008; Zeiler & Zeiler, 2017).

Injury, like TBI, is the primary cause of preventable death in Native Americans under the age of 45 (Peterson et al., 2019). Despite this, only a small number of studies have examined preventable injuries in the Native American community, and even fewer investigate longitudinal outcomes following injury or acquired disability (Peterson et al., 2019). As of the early 2000s, incidence for TBI requiring hospitalization for Native Americans was 75/100,000 people (Langlois et al., 2003; Rutland Brown et al., 2005); however, research in the mid-2010s indicates an increase in TBI and TBI-related deaths (Peterson et al., 2019). From 2008-2014, TBI-related hospitalizations for Native Americans grew by 32%, and TBI-related deaths increased by 13% (Peterson et al., 2019). Lifetime prevalence of TBI is higher for Native American men (~26%) than women (8%-26% depending on the estimates). Further, some research places the incidence of TBI for Native Americans at 1026.2/100,000 (Bazarian et al., 2003); however, accurately quantifying TBI in Native Americans is difficult as prevalence rates vary widely based on Native American tribe and geographic location within the U.S. (Nelson et al., 2007). This makes sense as Native American tribes are often geographically and culturally distinct from each other.

Motor vehicle crashes were the chief cause of TBI in Native Americans under the age of 55, with falls, intentional self-harm, and assault representing the other leading causes for all Native Americans (Peterson et al., 2019). Substance use and violence (i.e., assault and IPV) are uniquely significant factors for TBI within the Native American population and represent a significant disparity in cause compared to White Americans (Blackmer & Marshall, 1999; Linton & Kim 2014; Linton, 2015; Linton et al., 2016). Research has identified that, for Native Americans, living in a rural location, being male, and having a history of substance use are all significant risk factors for experiencing a TBI (Zeiler & Zeiler, 2017).

TBI leads to higher post-injury hospitalization rates for Native Americans than other individuals with TBI (Rutland-Brown et al., 2005). Native Americans living with TBI are far more likely to develop a mood or anxiety disorder (Nelson et al., 2007), and, as would be expected, following TBI, they face challenges with healthcare access, employment, and functional independence (Fuentes et al., 2016; Watson et al., in press; Whitfield & Lloyd, 2008).

However, despite these negative impacts, Native Americans spend less on purchased services and rehabilitation and spend less time in rehabilitation programs than non-Native American individuals with TBI (Whitefield & Lloyd, 2008). The specific reasons for this disparity in services and use has not been fully examined.

The literature on outcomes following TBI for Native Americans is scant. There is very little from which to draw meaningful conclusions. Indeed, researchers who specialize in TBI in underrepresented populations have called for a more complete investigation into the factors contributing to, sequelae of, and best rehabilitation practices for TBI in Native Americans (Arango-Lasprilla & Niemeier, 2007; Watson et al., in press). The few researchers specifically focusing on the Native American population with TBI have also highlighted the urgent need for more research to support Native Americans (Lakhani et al., 2017; Nelson et al., 2007, Linton, 2015; Linton et al., 2016; Watson et al., in press; Zeiler & Zeiler, 2017). Linton (2015) and colleagues (2014) have stressed the need for research that centers the unique cultural and contextual factors that may impact recovery post-TBI for Native Americans, a lens that is sorely lacking in the sparse TBI literature. Several researchers have also underscored the importance of race as a factor for research in TBI, especially for research that intends to uncover cultural and contextual factors that may impact aspects of disability (Arango-Lasprilla & Niemeier, 2007; Linton et al., 2016; Meade et al., 2015).

Community Participation in Native Americans

To date, no research has examined community participation within a Native American sample, and no culturally informed or culturally specific measure of community participation exists for Native Americans (Sander et al., 2021). There is also no literature on community structure or characteristics within Native Americans. What little information that does exist is often from Native American authors writing fiction, non-fiction, or poetry (Hall, 1989). Applying these first-hand accounts to a general picture of Native American community is rife with difficulty due to the culturally distinct nature of Native American tribes (Sarch & Spicer, 2008). It may be best, then, to examine recent events and related research (e.g., research on spirituality) to approach a discussion on community within Native Americans and highlight important strengths that might be leveraged in research.

In 2016, the Dakota Access pipeline (DAPL) brought thousands of Native Americans from across the country to stand in solidarity with the Standing Rock Sioux to protest the appropriation of Sioux land for the pipeline (Levin, 2016) as it encroached upon a Sioux sacred burial ground and threatened contamination of their water supply (Whyte, 2016). Protesters remained unarmed and peaceful, and protest methods included establishing camps, ceremonial dances, and prayer circles (Levin, 2016; Whyte, 2016). In 2016, a relay run conducted by Oceti Sakowin Youth and Allies ran nearly 2,000 miles from North Dakota to Washington D.C., arriving with over 140,000 signatures requesting a halt to the DAPL (Joseph, 2016). A simple internet search of the DAPL protests will show a diverse group of Native Americans from across the U.S. ranging in age from young children to tribal elders and chiefs braving harsh weather and possible arrest to help protect Sioux lands. This speaks to a profound sense of community that transcends tribal identity and geographic location and shows the perseverance of Native Americans in the face of adversity and persecution. Additionally, tribal elders and chiefs demonstrated stalwart leadership as they shepherded their people through a difficult, months-long protest.

While there is no culturally specific measure of community participation for Native Americans, there is a measure of spirituality, the Native American Spirituality Scale (NASS;

Greenfield et al., 2015). The NASS was developed in conjunction with members of a Native American tribe to help capture aspects of spirituality that are contextually relevant to Native Americans (Greenfield et al., 2015). Given the importance of spirituality to Native Americans and the way in which spirituality was salient (e.g., Sioux burial ground) and present throughout the DAPL protests (e.g., dancing, prayer circles) it is not unreasonable to link spirituality as an important aspect of Native American community. Unfortunately, the TBIMS database does not assess spirituality, nor in any way that might better reflect Native American beliefs and practices, nor their sense of community. Nonetheless, Greenfield and colleagues (2015) found that spirituality, especially spiritual behaviors, was strongly associated with both tribal identity and lower substance use. This indicates that spirituality may be an important strength and buffer for Native Americans against negative sequalae.

The research on Native American cultural/ethnic identity is similarly lacking, with most research being decades old (Jones & Galliher, 2015). The little research that does exist suggests that Native Americans are proud of their cultural/ethnic identity and have a roughly “average” cultural identification, i.e., neither particularly strong nor weak culturally identity (Jones & Galliher, 2015). Given the close ties of spirituality and cultural/ethnic identity, it possible that both aspects may play a role in defining community for Native Americans; however, this has not been explored in the literature. Research with other racial/ethnic minority communities has suggested that racial/ethnic identity might be a protective factor against a host of negative outcomes (Butler-Barnes et al., 2018; Forest-Bak & Jenson, 2015; Neblett et al., 2012). Similar results have been found within the disability community as well, suggesting that strong disability identity and/or pride may protect against negative experiences (e.g., discrimination) and outcomes (e.g., lower self-esteem; Bogart et al., 2018).

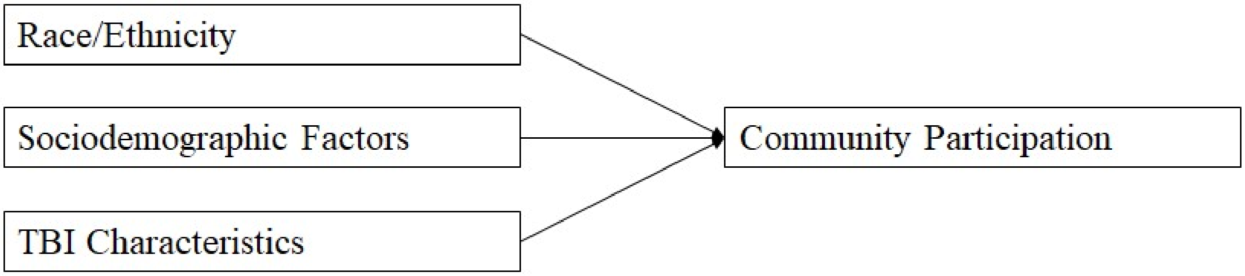
No research exists on community participation for Native Americans following TBI (Lakhani et al., 2017; Zeiler & Zeiler, 2017). Research on the general TBI population indicates that experiencing a TBI makes individuals less likely to engage with their community (Huebner et al., 2003; Mailhan et al., 2005; Pierce & Hanks, 2006; Williams et al., 2014), less likely to return to pre-injury roles (Erler et al., 2018), less likely to be able to live independently (Corrigan et al., 1997), more likely to feel lonely (Hoofien et al., 2001), and more likely to experience social interaction difficulties (Hoofien et al., 2001). It is not uncommon for individuals with TBI to face increased likelihood for divorce (Catalano et al., 2006; Hoofien et al., 2001), difficulty attaining and maintaining employment (Hoofien et al., 2001; Stevens et al., 2017), and decreased involvement in leisure activities (Sander et al., 2011). It is not unreasonable to assume that Native Americans would face similar difficulties following TBI even if this has not been explicitly documented within the literature as of yet.

Race has been indicated as a unique predictor of community participation, though this research did not examine Native Americans (Gary et al., 2009). Disparities in community participation following TBI have been documented for both Black and Hispanic populations (Arango et al., 2007; Arango et al., 2008; Hart et al., 2007; Gary et al., 2009). Research has indicated that Black and Hispanic individuals tend to score lower on measures of community participation than White individuals (Arango-Lasprilla et al., 2007), and lower employment trajectories following TBI for Black and Hispanic individuals have also been documented (Arango-Lasprilla et al., 2008). Black individuals with TBI are significantly less likely to resume productive lifestyles compared to White individuals with TBI (Sander et al., 2011) due in large part to systemic barriers experienced following acquired disability. While these specific disparities have not been documented with the Native American population, it is not unreasonable to assume that some parallels exist. However, Native Americans are a culturally distinct group of individuals, even from tribe to tribe. It is, therefore, necessary to explicitly investigate possible disparities in community participation within the Native American community.

Study Purpose and Theoretical Model

The purpose of this study is to identify disparities in community participation, and their potential causes, between Native Americans and White individuals following TBI. The proposed study uses a theoretical framework designed by Meade and colleagues (2015) in which demographic and injury-related characteristics are envisioned as two of three aspects accounting for health-outcomes following injury or disability (Figure 1).

Figure 1. *Current Study Theoretical Model.*



The Model of Healthcare Disparities and Disability (MHDD) was chosen because it was specifically designed to work for and be applied to the disability community (Meade et al., 2015) and has been used in research on Native Americans with TBI from the TBIMS database (Watson et al., in press). In their work, Meade and colleagues (2015) noted that virtually all of the existing theoretical models for healthcare disparities were designed using primarily non-disabled individuals and did not account for cultural or contextual factors specific to the disability community (e.g., disability itself or the stress caused by multiple marginalized identities). Thus, this key gap in existing theoretical models undermined their generalizability to the disability community and led to inaccurate assumptions about access, particularly to resources and healthcare services (Meade et al., 2015). For instance, two individuals living within the same community with roughly the same annual income may be assumed to have roughly the same access; however, an individual with a disability, particularly with high functional impairment, may be unable to leave the home, thus drastically limiting access. Meade and colleagues developed the MHDD to help fill this gap (2015). They suggest that longitudinal outcomes are the result of a highly complex interaction of personal factors (e.g., race, personality, sex, age), sociodemographic characteristics (e.g., income, marital status, education level), and disability characteristics (e.g., severity, type of disability, cause of injury; Meade et al., 2015).

Thus, based on this model, the purpose of this study is to evaluate the degree to which a disparity in community participation exists between Native Americans and White individuals with TBI at 1, 2, and 5 years after injury and to determine if this disparity changes over time. The study will then attempt to account for the disparity through demographic or injury related characteristics that differ significantly between the two groups. Whatever disparity remains after the inclusion of covariates can be attributed, at least partly, to culturally and contextually specific factors unique to Native Americans with TBI (e.g., unmeasured systematic biases).

Aims and Hypotheses

Aim 1

Identify differences in community participation between Native Americans and White individuals with TBI at 1-, 2-, and 5-years post-injury.

Hypothesis 1. Given that previous research has documented that non-White groups with TBI report lower function and mental health outcomes following TBI (Blackmer & Marshall, 1999; Bowman et al., 2007; Shiho, 2018; Watson et al., in press; Whitfield & Lloyd, 2008) than

Whites, it is hypothesized that Native Americans will show generally worse outcomes across community participation at all time points when compared to their White counterparts.

Hypothesis 2. Further, it is expected that Native Americans will show worse community participation trajectories as a function of time (i.e., the disparity will grow larger overtime).

Aim 2

Identify differences in demographic and injury-related characteristics following TBI between Native Americans and White individuals.

Hypothesis 3. There will be significant differences, with White individuals faring better, across some of the aforementioned demographic and injury-related variables (e.g., education, violence as a cause of injury, substance abuse).

Aim 3

Establish whether demographic or injury-related characteristics account for some (or all) of the community participation disparities (if any are found).

Hypothesis 4. Previous studies have demonstrated that racial/ethnic disparities exist across a plethora of outcomes following TBI (though little literature has documented this phenomenon with Native Americans) and that such disparities persist even after accounting for a number of socio-demographic variables (Blackmer & Marshall, 1999; Linton et al., 2016; Whitfield & Lloyd, 2008). Thus, if any differences in community participation between Native Americans and White individuals from Aim 1 are uncovered, some, but not all of the variance, will be accounted for by demographic and injury-related variables (Figure 1), suggesting at least some additional variance due to culturally and contextually specific variables that are not measured in the current study.

Method

Procedure

The proposed study has received approval from the TBIMS National Data and Statistical Center to use the public database and conduct this study. The study will use the TBI Model Systems (TBIMS) U.S. National Database to conduct a secondary data analysis. The TBIMS began in 1987 and is the largest longitudinal study of TBI in the world (though the database used for the proposed study focuses only on individuals within the U.S.). The TBIMS has 16 multidisciplinary level 1 trauma centers and 3 follow-up centers within the U.S. Data cover a variety of factors including pre-injury data, demographics, injury profiles, acute care, rehabilitation, and longitudinal outcomes on more than 15,000 individuals with TBI.

All TBIMS medical and follow-up centers received relevant institutional review board approval. Informed consent was obtained during inpatient rehabilitation or prior to study enrollment from all TBIMS participants or, when necessary, a legal proxy (e.g., spouse). All data were collected through medical records, patient interviews, direct examination of patients, data collection forms, or interviews with a legal proxy. Data were collected at baseline then 1, 2, 5, and every 5 years thereafter following discharge. Follow-up data collection was done by phone, in-person, or by mail. For the proposed study, only data from the first 5 years following discharge will be used. The U.S. Department of Health and Human Services funds the TBIMS program through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; MSKTC, 2020; NDSC, March 2017).

Participants

To be eligible for enrollment in the TBIMS, individuals are required to meet the following criteria: (1) sustained a TBI which resulted in (a) Glasgow Coma Scale (GCS) score < 13, (b) post traumatic amnesia (PTA) > 24 hours, (c) loss of consciousness > 30 minutes, or (d) neuroimaging evidence of abnormality caused by intracranial trauma, (2) received medical care for the TBI within 72 hours of the injury, (3) enrolled and completed inpatient rehabilitation at an approved TBIMS site, and (4) was 16 years of age or older at the time of the injury.

The current study included all individuals who identified as solely Native American (i.e., did not select more than one race/ethnicity) in the TBIMS database who had complete data for sex, age, and injury severity (as measured by time spent in PTA) as well as at least one complete data point for community participation (as measured by the PART-O) at years 1, 2, or 5. Each Native American participant was demographically matched on sex, age, and PTA category to a White individual with TBI for comparison. Further, White matched participants needed to have at least one complete data point for community participation (as measured by the PART-O), with preference given to having the same time point of data (e.g., the Native American participant had year 2 but not years 1 or 5 then the White participant who most closely resembles this was matched). In the event that multiple people fit these criteria, the White person appearing first in the database was selected to ensure consistency. The order of people in the database was randomized to account for possible selection bias based on time of enrollment.

There was initially a total of 90 Native American identifying individuals in the original dataset; however, this number was reduced to 63 as participants were included for the proposed study only if they had at least one complete community participation data point (years 1, 2, or 5) and complete data for age, sex, and PTA. Demographic and injury-related characteristics of the 126 demographically matched individuals can be seen in Table 1.

Table 1
Characteristics of Individuals with TBI

Variable	Native American	White	*p-value*
Age at Injury, M (*SD*)	37.84 (16.16)	37.84 (16.12)	*p* = 1.000

Sex, n (%)			*p* = 1.000
Male	40 (63.50%)	40 (63.50%)	
Female	23 (36.50%)	23 (36.50%)	
Years of Education Pre-Injury, M (*SD*)	12.00 (2.44)	13.26 (3.05)	*p* = 0.015
Employment at Injury, n (%)			*p* = 0.002
Employed	31 (49.20%)	48 (76.20%)	
Not Employed	32 (50.80%)	15 (23.80%)	
Annual Earning, n (%)			*p* = 0.759
<9,999	7 (19.40%)	8 (21.10%)	
10,000-19,999	8 (22.20%)	6 (15.80%)	
20,000-29,999	10 (27.80%)	8 (21.10%)	
30,000-39,999	4 (11.10%)	5 (13.20%)	
40,000-49,999	2 (5.60%)	2 (5.30%)	
50,000-59,999	1 (2.80%)	3 (7.90%)	
60,000-69,999	-	2 (5.30%)	
70,000-79,999	1 (2.80%)	-	
80,00- 89,999	1 (2.80%)	-	
90,000-99,999	1 (2.80%)	1 (2.60%)	
> 100,000	1 (2.80%)	3 (7.90%)	
Type of Work, n (%)			*p* = 0.302
Blue Collar	25 (80.60%)	33 (70.20%)	
White Collar	6 (19.40%)	14 (29.80%)	
Cause of Injury, n (%)			*p* = 0.187
Non-Violent	56 (88.90%)	60 (95.20%)	
Violent	7 (11.10%)	3 (4.80%)	
Insurance Type, n (%)			*p* = 0.047
Private	23 (37.10%)	34 (54.80%)	
Non-Private	39 (62.90%)	28 (45.20%)	
Marital Status, n (%)			*p* = 0.177
Married	40 (63.50%)	47 (74.60%)	
Not Married	23 (36.50%)	16 (25.40%)	
Language Spoken at Home, n (%)			*p* = 0.291
English	50 (94.30%)	54 (98.20%)	
Other than English	3 (5.70%)	1 (1.80%)	
Illicit/Non-Prescription Drug Use, n (%)			*p* = 0.056
Reported Problematic Use	35 (57.40%)	24 (40.00%)	
Did Not Report Problematic Use	26 (42.60%)	36 (60.00%)	
Cigarette Use, n (%)			*p* = 0.966
Smoked Prior to Injury	9 (42.90%)	3 (37.50%)	
Did Not Smoke Prior to Injury	12 (57.10%)	5 (62.50%)	
Alcohol Use, n (%)			*p* = 0.040

Reported Problematic Use	28 (44.40%)	13 (20.70%)	
Did Not Report Problematic Use	32 (50.80%)	45 (71.40%)	
Days Spent in PTA, M (*SD*)	25.70 (27.33)	21.94 (13.92)	*p* = 0.367

Information on completeness of data can be found in Table 2. Missing data could occur for many reasons such as: refusal to participate, not available at time of collection, incorrect contact information at follow-up, not being physically or cognitively able to participate, discontinued use of the variable, and death.

Table 2
Data Missingness

Variable	Native American		White	
	# With Data	% Missing	# With Data	% Missing
One-Year Out and About	50	20.63%	46	26.98%
Two-Year Out and About	48	23.81%	49	22.22%
Five-Year Out and About	33	47.62%	49	22.22%
One-Year Productivity	50	20.63%	46	26.98%
Two-Year Productivity	49	22.22%	50	20.63%
Five-Year Productivity	33	47.62%	49	22.22%
One-Year Social	50	20.63%	46	26.98%
Two-Year Social	48	23.81%	50	20.63%
Five-Year Social	33	47.62%	49	22.22%

Sample Size Justification

The literature on acceptable sample size for HLM is mixed with some research indicating that sample size can depend on the variable of interest (Von Davier & Hastedt, 2009). Research generally suggests that larger sample sizes are needed for multiple cluster levels of HLM (e.g., students, nested within classrooms, nested within schools, nested within school districts, nested within counties, and so on; Hoyle & Gottfredson 2015). For single-level (i.e., cluster) HLMs—which the proposed study is only a single cluster (within an individual over time)—smaller sample sizes are acceptable (Hoyle & Gottfredson 2015; UCLA Statistical Consulting Group, nd; Von Davier & Hastedt, 2009). Statistical simulation has shown that for most single-level HLMs, a sample size of 50 is sufficient (Maas & Hox, 2005; UCLA Statistical Consulting Group, nd). Given that the proposed study is targeting a sample size of 126 individuals, this should be more than enough to uncover the relevant effects. Further, the TBIMS is the largest longitudinal database of TBI in the world. There is no other known database that has more nuanced longitudinal data on Native Americans with TBI than the TBIMS. As such, regardless of the sample size, it is important to use the available resources to uncover health disparities and their sources in Native Americans with TBI.

Measures

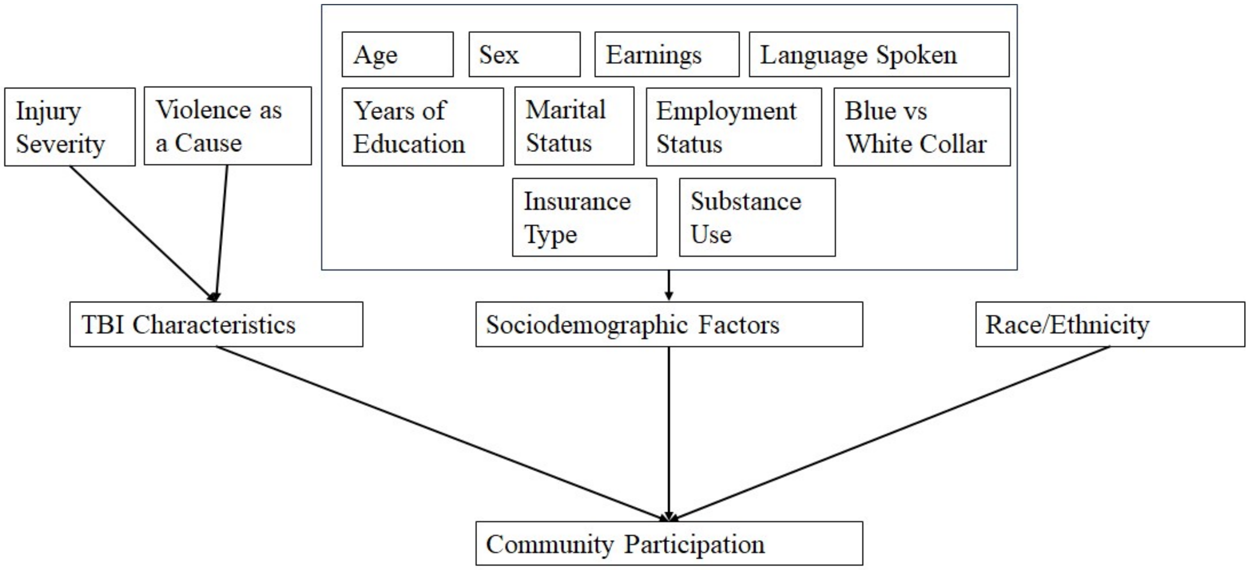
Demographic and Injury-Related Variables

The TBIMS assesses a large number of demographic, injury-related, and outcome variables. For the current study, Native American and White participants were matched according to sex, age, and injury severity (defined as time spent in PTA). Further, the following demographic and injury-related characteristics were examined: marital status, years of education, annual earnings, employment status at the time of injury, type of employment (blue vs white collar), violence as a cause of injury, language spoken at home, insurance type (private vs other), and substance use (alcohol, drugs, and tobacco).

All of these variables were examined through single-item assessment or an electronic health records system (EHRS). Age was calculated based on the participant’s date of birth. Sex was a binary choice between male and female. Injury severity was split into 3 categories defined by PTA (mild: 0-1 days, moderate: >1 - <7 days, and severe: >7 days; O’Neil et al., 2013). For the remainder of the other possible covariates, coding was as follows. Employment was coded to reflect a dichotomy between being employed and unemployed (e.g., retired, homemaker). Type of employment was dichotomized between white and blue collar to capture differences based on physical labor. Partnership status (i.e., marital status) was also be dichotomized between married and all other possible answers. The TBIMS does not have an option for committed, non-married relationships. Insurance type was divided into two categories: private vs all other forms of payment. Language spoken at home was dichotomized between English and all other languages. Cause of injury was divided between violent (e.g., assault) and non-violent (e.g., motor vehicle accident) mechanisms of injury. Country of origin is already dichotomized within the dataset as U.S. vs non-U.S. Finally, annual earnings (continuous), education (continuous), and substance use disorder (binary choice between having a diagnosis or not or exhibiting problematic use or not) were not be recoded.

These items were selected as they are typically used within rehabilitation research as either predictors of an outcome or explanations for health disparities (Arango-Lasprilla, Watson, Ertl, et al., 2023; Arango-Lasprilla, Watson, Merced, et al., 2023; Arango-Lasprilla et al., 2022; Davis et al., 2012; Erler et al., 2018). In reference to the study's theoretical model (Figure 1), all of these variables fall into either the demographic or injury-related characteristics. Thus, these variables were also chosen to be in line with the study's theoretical model and to help account for variance in community participation to increase the likelihood of uncovering a disparity due to unique cultural and contextual factors (e.g., race; Figure 2).

Figure 2. *Expanded Study Theoretical Model.*



Community Participation

Participation Assessment with Recombined Tools (PART-O; Bogner et al., 2013). The PART-O is a 17-item measure developed specifically to measure community participation for TBIMS participants; however, it has found ample use outside the TBIMS. The scale, originally developed by the TBIMS Participation Special Interest Group, is a shortened version of the original 24-item PART-O. The original 24-item measure was developed by incorporating or modifying items from three commonly used measures of social function: the Craig Handicap Assessment and Reporting Technique (Whiteneck, 1992), the Community Integration Questionnaire (Willer et al., 1994), and the Participation Objective, Participation Subjective (Brown et al., 2004; Bogner, 2013; Bogner et al., 2013).

The PART-O was developed to examine long-term community participation and social function. It measures three domains of community participation: productivity (e.g., hours spent working or in education), out and about (e.g., how frequently the participant leaves their home to engage with their community), and social relations (e.g., quality of friendships or frequency of visitation with friends/family). To score the PART-O, each domain subscale is averaged, producing a score of 0-5, then summed for a total score. For the proposed study, all three individual subscales will be used; however, the overall score will not.

Data Analysis Plan

Preliminary Analyses

All analyses were conducted using IBM SPSS Statistics version 29. Descriptive statistics were calculated and examined for the study sample (Table 1). The following demographic variables were examined: age, sex, annual earnings, language spoken at home, years of education, marital status, employment status, type of employment (blue vs white collar), type of insurance (private vs other), and substance use (presence of a diagnosed substance use disorder). Additionally, descriptive statistics also reported the injury-related variables of injury severity (as measured by time spent in PTA) and whether or not violence was the cause of injury. ANOVA tests and chi-squared analyses were used where appropriate to examine the demographic and injury-related characteristics for significant differences between the two groups.

Normality tests were performed on the outcome variable (Community Participation as measured by the PART-O) to assess the shape of the distribution and transform if necessary. The percent of missing data at 1-, 2-, and 5-years post-discharge was reported (Table 2), and Little's Missing Completely at Random (MCAR) was used to assess the degree these data were missing at random. HLMs full information maximum likelihood (FIML) estimation procedure was conducted to include participants with missing data.

Primary Analyses

An unconditional growth model was conducted with only the intercept, time, and time*time as fixed effects predictors to determine the best curvature model (e.g., straight or quadratic). A -2 log likelihood (-2LL) for each successive model with a critical $\chi 2$ value of significant difference at = .05 and > 3.841 drop from the previous model (at 1 degree of freedom) was used to determine adequate model curvature. Time was recoded as 0 (1 year), 1 (2 years), and 4 (5 years).

Primary Set 1. The next set of HLMs assessed whether there was a difference in the three community participation subscales over time between the Native American and White groups (Hypothesis 1). A follow-up HLM for each subscale incorporated an interaction term between time and race/ethnicity to determine if the difference in community participation outcomes occur differentially as a function of time (Hypothesis 2).

Primary Set 2. For the second primary set, the same analyses were conducted with the addition of the demographic and injury-related covariates that differ significantly between the two groups (Hypothesis 3) which were centered or given a reference of zero. This HLM determined the degree to which these covariates accounted for some of the disparity in community participation (Hypothesis 4). Potential covariates included: marital status, years of education, annual earnings, employment status at the time of injury, type of employment (blue vs white collar), violence as a cause of injury, language spoken at home, type of insurance, and substance use (alcohol, drugs, and tobacco); however, only years of education, employment at the time of injury, type of insurance, and alcohol use were significantly different between the two groups (Table 1). Therefore, this final set of HLMs only used those four covariates.

Results

Descriptive and Normality Analyses

Means (*M*s) and standard deviations (*SDs*) for all three Part-O subscales (Out and About, Productivity, and Social) separated by race are shown in Table 3.

Table 3
Part-O Subscale Means and Standard Deviations by Race

Variable	Native American	White
One-Year Out and About, *M (SD)*	1.314 (0.678)	1.738 (0.826)
Two-Year Out and About, *M (SD)*	1.460 (0.746)	1.832 (0.765)
Five-Year Out and About, *M* (*SD*)	1.434 (0.762)	1.663 (0.889)
One-Year Productivity, *M (SD)*	1.047 (0.844)	1.341 (0.944)
Two-Year Productivity, *M (SD)*	1.034 (0.782)	1.447 (0.961)
Five-Year Productivity, *M (SD)*	1.162 (0.993)	1.327 (1.060)
One-Year Social, *M (SD)*	2.263 (0.953	2.437 (0.823)
Two-Year Social, *M (SD)*	2.340 (0.934)	2.526 (0.792)
Five-Year Social, *M (SD)*	2.033 (1.194)	2.243 (1.015)

Normality tests on all three subscales demonstrated they were normally distributed. Skewness and kurtosis statistics appear in Table 4.

Table 4
Skew and Kurtosis of PART-O

Variable	Skew	Kurtosis
One-Year Out and About	0.218	0.099
Two-Year Out and About	-0.022	-0.179
Five-Year Out and About	0.017	-0.354
One-Year Productivity	0.644	-0.371
Two-Year Productivity	0.438	-0.944
Five-Year Productivity	0.499	-0.792
One-Year Social	0.215	0.190
Two-Year Social	-0.151	-0.518
Five-Year Social	-0.023	-0.529

Correlation coefficients between all potential covariates demonstrated no problematic multicollinearity (all $r < .70$). Further, of the potential covariates (Table 1; Figure 2) assessed via ANOVA or chi-squared tests, only years of education ($p = .015$), employment at the time of injury (*p* = .002), type of insurance held (*p* = .047), and alcohol use (*p* = .040) were significantly different between Native Americans and White individuals with TBI at baseline (Table 1).

Preliminary Curvature Analysis and Missing at Random

Results from Little's MCAR suggested that data for all three subscales were missing completely at random (χ^2 [3] = 4.99, *p* = .173). For the missing data, HLM's FIML was used to retain all participants despite missingness. FIML helps avoid bias due to listwise deletion and is a common practice in research using both HLM and longitudinal outcomes (Arango-Lasprilla, Watson, Ertl, et al., 2023; Arango-Lasprilla, Watson, Merced, et al., 2023; Larsen, 2011; Niehaus et al., 2014; Shin & Raudenbush, 2023).

An unconditional growth model was conducted with only the intercept and time as fixed effect predictors and then a second model with the addition of time*time to determine the best curvature model (e.g., straight or quadratic) for the HLMs. A -2 log likelihood (-2LL) for each successive model with a critical χ^2 value of significant difference at α = .05 and > 3.841 drop from the previous model (at 1 degree of freedom) was used to determine the best fitting model curvature for each subscale over time. The curvature comparisons can be seen in Table 5 and indicated that a straight line best fit all three subscales of the PART-O.

Table 5

Curvature Comparisons for PART-O Subscales

	Linear Model	Quadratic Model	Difference
	-2LL	-2LL	
Out and About	**566.464**	563.354	3.11
Productivity	**689.436**	689.409	0.027
Social	**687.304**	684.829	2.475

Note. Critical χ^2 value for significant difference at α = .05 is a > 3.841 drop from the previous model. No models surpassed this threshold. Bolded values represent the best model fit.

Primary Analyses

The first set of HLMs ("primary set 1") assessed whether there was a difference in the three community participation subscales between Native Americans and White individuals with TBI and whether these trajectories changed as a function of time. For the Out and About scores only, a second set of HLMs ("primary set 2") was run to attempt to account for the difference in Out and About scores through sociodemographic and injury-related covariates that differed significantly between the two racial groups. All relevant statistical results for the HLMs appear in Table 6.

Table 6
Predictors of the PART-O Subscales

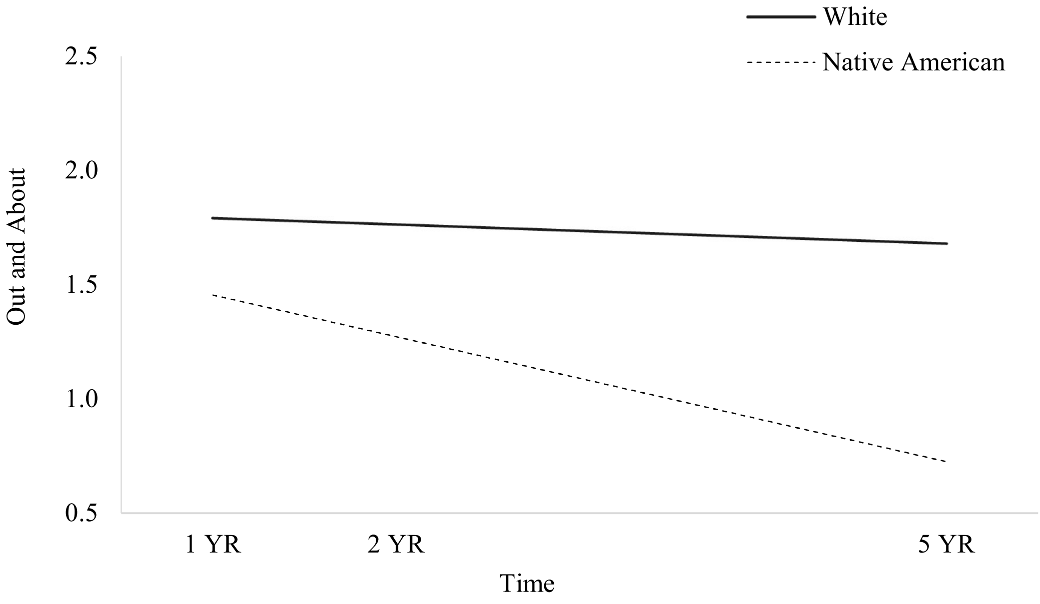
	Out and About		Productivity		Social	
Predictor	*b*-weight	*p*-value	*b*-weight	*p*-value	*b*-weight	*p*-value
Set 1: Race						
Intercept	1.753	< .001	1.329	< .001	2.478	< .001
Time	-.022	.274	.015	.567	-.050	.049
Native American vs. White	-.339	.006	-.259	.077	-.202	.180
Set 1: Race Interaction with Time						
Intercept	1.780	< .001	1.378	< .001	2.494	< .001
Time	-.037	.152	-.013	.697	-.059	.074
Native American vs. White	-.398	.004	-.362	.030	-.2374	.164
Time*Race	.037	.355	.067	.198	.022	.660
Set 2: Race with Covariates						
Intercept	.832	.005	-	-	-	-
Time	-.012	.551	-	-	-	-
Native American vs. White	-.108	.390	-	-	-	-
Education	.053	.015	-	-	-	-
Employment at Injury	.067	.612	-	-	-	-
Type of Insurance	.323	.009	-	-	-	-
Alcohol Use	-.001	.890	-	-	-	-

Part-O Out and About

Primary Set 1.

There was a significant main effect of race on Out and About trajectories (*p* = .006), indicating that Native Americans generally had worse Out and About trajectories over time than White individuals with TBI (Figure 3).

Figure 3. *Main effect of race on Out and About trajectories*.



There was not, however, a significant interaction effect for time*race (Table 6; *p* = .355), indicating that the slopes of these Out and About trajectories did not differ significantly by race (Figure 3).

Primary Set 2.

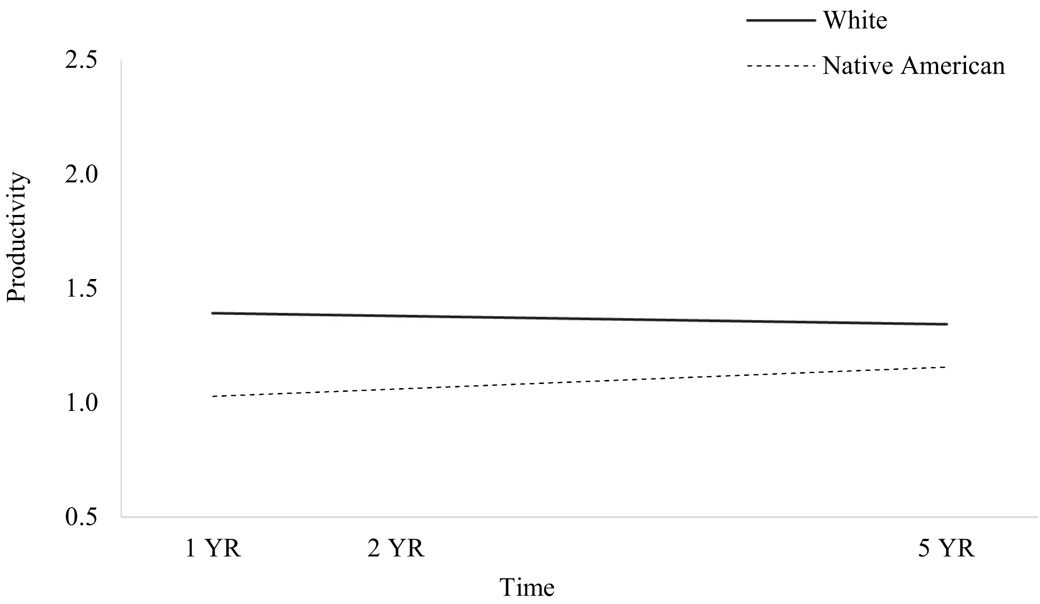
Given that Out and About trajectories differed significantly as a function of race, a follow-up HLM was run to attempt to account for this difference through sociodemographic and injury-related characteristics that differed significantly between the two groups (Table 1). Years of education, employment at the time of injury, type of insurance, and alcohol use patterns were entered as covariates to the HLM (Table 6). Results indicated that these covariates accounted for the statistically different Out and About trajectories between the two racial groups, reducing the significance of race as a predictor ($p = .390$). Both education ($p = .015$) and type of insurance (private vs other; $p = .009$) were significant predictors of Out and About trajectories (Table 6), likely accounting for the predictive power of race in differences in Out and About trajectories. Because the Out and About trajectory slopes did not differ significantly by race (i.e., the time*race effect was not significant), no respective follow-up model including the covariates was run.

Part-O Social

Primary Set 1.

There was no significant main effect of race on Productivity trajectories (Table 6; $p = .077$), though it was marginally significant. This suggests that Native Americans and White individuals with TBI have statistically equivalent Productivity scores over time, though the effect was generally in the anticipated direction of higher Productivity scores for the White group (Figure 4).

Figure 4. *Main effect of race on Productivity trajectories*.



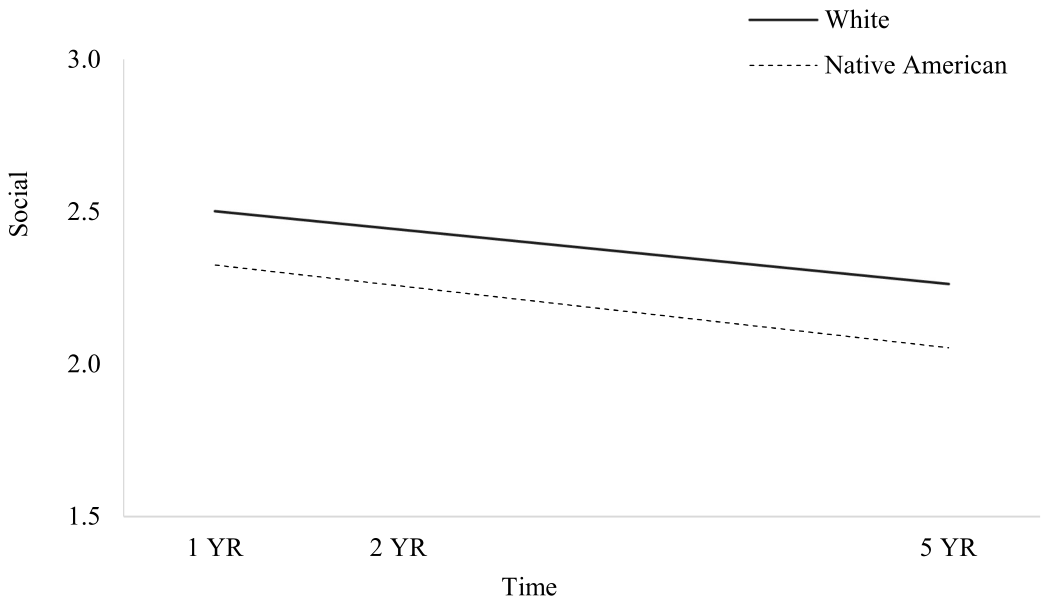
Additionally, there was no significant interaction effect for time*race, again suggesting that Productivity scores did not diverge significantly over time as a function of race. Because neither model was significant, no follow-up models with the statistically different covariates were run.

Part-O Productivity

Primary Set 1.

There was no significant main effect of race on Social trajectories (Table 6; *p* = .180). This suggests that Native Americans and White individuals with TBI had statistically equivalent Social scores over time (Figure 5).

Figure 5. *Main effect of race on Social trajectories*.



Again, there was no significant interaction effect for time*race, indicating that Social scores did not diverge significantly over time as a function of race. Because neither model was significant, no follow-up models with the statistically different covariates were run.

Discussion

The purposes of the current study were (a) to determine if differences in community participation over the 5 years following TBI exist between Native Americans and White individuals and, if so, (b) attempt to explain these differences using sociodemographic and injury-related covariates. To accomplish this, 63 Native Americans were demographically matched to 63 White individuals across age, sex, and injury severity (defined as time spent in PTA). ANOVAs and χ^2 tests examined differences between the two groups in years of education, employment at the time of injury, annual earnings, blue vs. white collar work, cause of injury, type of insurance, marital status, language spoken at home, illicit/non-prescription drug use, cigarette use, and alcohol use. Results indicated that Native Americans were generally less likely to have private insurance, less likely to be employed at the time of injury, more likely to have lower education attainment, and more likely to engage in binge drinking in the month prior to experiencing a TBI. Over the 5 years following TBI, Native Americans demonstrated lower Out and About scores but statistically equivalent Social and Productivity scores compared to their demographically matched White counterparts. The difference in Out and About scores did not change as a function of time, and the overall difference between the two groups dissipated with the inclusion of the statistically different sociodemographic variables. Both educational attainment and type of insurance were statistically significant predictors of Out and About trajectories, likely accounting for the difference in Out and About scores over time between the two groups.

Sociodemographic Differences

Very little research has examined sociodemographic and injury-related differences between Native Americans and other racial/ethnic populations in the U.S. Previous research utilizing the TBIMS database suggests that Native Americans are less likely to have private health insurance, and this may at least partly account for some of the disparities experienced by Native Americans with TBI (Watson et al., in press). The current study reinforces this limited literature by indicating Native Americans with TBI in this sample were also less likely to have private insurance and that this at least partly accounted for the difference in Out and About scores when compared to their demographically matched White counterparts. Further, this finding makes sense given the disparities in both healthcare quality and access experienced by Native Americans more broadly (Cromer et al., 2019). Research also suggests the cost of medical care is a serious concern within the Native American community (Liddell, 2020; Marrone, 2007), and Native Americans are far less likely to engage with the healthcare system than all other racial/ethnic groups in the U.S. (Whitfield & Lloyd, 2008). This can make living with and surviving chronic disease or severe injury particularly difficult for Native Americans who are much more likely to die prematurely due to disease or injury than White Americans (Clements et al., 2020), and the lack of private insurance found in the current study may exacerbate these difficulties.

Previous research using the TBIMS national database and therefore some overlap with the current sample also has found that Native Americans with TBI are less likely to be employed at the time of TBI compared to White individuals (Watson et al., in press). This finding was replicated in the current study and coincides with larger sociodemographic research indicating Native Americans have lower employment rates compared to the general U.S. populace (Sarche & Spicer, 2008). This finding also makes sense with the limited literature on Native Americans that indicates greater rates of poverty and lower rates of education for Native Americans (Brockie et al., 2013; DePietro, 2022; Sarche & Spicer, 2008). It is possible that employment status may also be linked to whether the participant has private insurance, as one’s place of employment is often a primary means of acquiring health insurance. Further, employment has a plethora of ancillary benefits beyond financial well-being like social interaction and sense of purpose which could act as a buffer against some of the negative sequelae of TBI.

The current study found that Native Americans with TBI had lower educational attainment than White individuals with TBI. This is a novel finding within the TBI rehabilitation literature given that no other study has uncovered a significant difference in education rates between Native Americans and White individuals with TBI. The only other study utilizing demographically matched Native American and White individuals in the TBIMS national database to examine rehabilitation disparities found that education was marginally different between the two groups (Watson et al., in press) and not a significant predictor of disparities in functional outcomes or life satisfaction. However, non-TBI research on Native Americans has shown they generally have lower educational attainment than the average U.S. populace (Sarche & Spicer, 2008). It may be possible that education can act as a buffer against some of the negative sequelae of TBI, particularly cognitive impairments, which is one of the most disabling consequences of TBI (Carpuso & Levin, 1992; Watson et al., in press). Thus, lower educational attainment may be a risk factor for other sequelae that can inhibit community participation.

Results suggested that Native Americans were more likely to engage in binge drinking in the month prior to experiencing a TBI than their White counterparts. While the research on general alcohol use rates within the Native American community is mixed (Cunningham et al. 2016; Szlemko et al. 2006), the limited research on TBI within the Native American population suggests that they are more likely to have substance use, especially alcohol, as a contributing factor for experiencing a TBI, with rates twice that of other racial/ethnic minorities (Linton et al., 2016). The only other study within the TBIMS national database using demographically matched

Native American and White individuals found that alcohol use differed marginally between the two groups, but the sample size was estimated to be too small to uncover a meaningful effect (Watson et al., in press). While not assessed in the present study, it is possible that binge drinking contributed to or exacerbated other negative sequelae of TBI (e.g., mental health) that then contributed to community participation outcomes. For instance, binge drinking has been independently associated with higher rates of depression, a very common comorbidity with TBI (Paljärvi et al., 2009).

Community Participation

The current study showed Native Americans with TBI had generally lower Out and About scores compared to White individuals over the 5 years after injury and that this difference remained relatively stable over time. Social and Productivity scores were statistically equivalent and did not change significantly overtime. As a general construct that measures overall functioning within society post-injury, community participation is an important metric to gauge an individual's success in rehabilitation (Bogner, 2013; Takada et al., 2016; Whiteneck et al., 2011). Indeed, community participation is a primary focus of many rehabilitation programs and, despite the relatively small body of literature, has been recognized as one of the most important aspects of rehabilitation for individuals with TBI (Jacobsson et al., 2010; Kuipers & Lancaster, 2000; Lee et al., 2001). Disparities in aspects of community participation, like Out and About scores, may be indicative of important gaps in rehabilitation care, especially for minoritized communities like Native Americans who experience TBI at disproportionately high rates (CDC, 2019a; Langlois et al., 2003).

Both educational attainment and type of insurance remained significant predictors of Out and About trajectories in the model including the covariates that differed significantly between the two groups. Thus, it is possible these either account for the racial differences in Out and About trajectories or are indicators of other unmeasured sources of variance (e.g., lack of access to healthcare). While not assessed in the present study, it is possible that individuals who had lower educational attainment were less likely to be employed following rehabilitation. Employment provides a host of benefits including a sense of community, feeling of productivity, greater financial stability, an opportunity to socialize, and sense of purpose (Modini et al., 2016). Conversely, unemployment has been linked to a plethora of negative outcomes like anxiety, depression, and stress (Bordea, 2017; Modini et al., 2016; Montgomery et al., 1999). This may also partly explain the variance in employment rates prior to TBI between the two groups.

Education provides several important benefits (e.g., larger crystalized knowledge) and is associated with a number of positive outcomes (e.g., higher lifetime earning potential; McMahon, 2004). Relevant to TBI, education has been shown to be a buffer against cognitive decline by increasing cognitive fluidity prior to a TBI (Clouston et al., 2012). Some research suggests that higher levels of education attainment are associated with increases in all cognitive abilities and especially with verbal memory, ability, and fluency in later life (Hatch et al., 2007). Thus, lower levels of education prior to experiencing a TBI may predispose Native Americans to worse cognitive decline following TBI. Indeed, using data from the TBIMS, such a disparity was uncovered, with Native Americans generally having lower cognitive function over the 5 years post-TBI than White individuals with TBI (Watson et al., in press). This may partly explain the results of the present study. That is, possibly due in part to lower levels of education (or other unmeasured variables associated with education), Native Americans were more likely to experience worse cognitive symptoms and, therefore, were less likely to participate within their community post-rehabilitation.

Type of insurance has also been identified as a key predictor of health disparities facing Native Americans within the TBIMS database, predicting worse cognitive and motor function over the 5 years post-injury (Watson et al., in press). Thus, the current study reinforces both the vital role of private insurance and the need to accurately assess insurance coverage and resources available for Native Americans with TBI post-rehabilitation. Indeed, the limited literature on Native Americans indicates they experience significant disparities in functional outcomes after TBI (Watson et al., in press) and barriers to accessing care including long distances to healthcare centers (Marrone, 2007), inadequate facilities (Cromer et al., 2019; Sequist et al., 2011), facilities lacking necessary specialists (Cromer et al., 2019; Liddell, 2020; Sequist et al., 2011), and ineffective or reduced quality care (Liddell, 2020). Further, Native Americans endorse significant concern over the cost and reliability of healthcare services, suspicion of western medicine practices, and general provider distrust (Liddell, 2020; Marrone 2007). Lack of private insurance, or lack of insurance entirely, may play a role in creating or exacerbating many of these concerns.

While not assessed in the current study, it is important to note that many Native Americans report experiencing cultural dissonance with their healthcare provider (Liddell, 2020; Marrone, 2007). Cultural differences and suspicion of western medicine practices may also negatively impact the provider relationship (Liddell, 2020; Marrone, 2007). Of the Native Americans who do wish to seek medical attention, cultural and community biases/pressure and provider distrust may prevent them from doing so (Finfgeld-Connett, 2015; Liddell, 2020). Unfortunately, racism has a long and deeply entrenched history within the American healthcare system (Fauci, 2001). Research suggests that racism plays a major role in the continued healthcare disparities experienced by many non-White groups within the U.S. (Yearby, 2018).

Race is one of the most important social determinants of health within the TBI literature (Johson & Diaz, 2023); therefore, failure to appropriately consider the race/ethnicity/culture of an individual with TBI may lead to a host of incorrect assumptions or mismatches in expectations between the provider and care recipient.

Any discussion of community participation for Native Americans with TBI is challenged by the lack of culturally sensitive and informed measures (Sander et al., 2021). Further, the culturally distinct and geographically isolated nature of many Native American tribes makes generalizability difficult (Sarche & Spicer, 2008). Scant research exists exploring concepts of community within Native Americans, and what little does exist is often isolated to a singular tribe or geographical region, is decades old, or examines a sample that is hardly representative of the general Native American population (e.g., professors with Native heritage; Dvorakova, 2018; Hall, 1989; Rumbertone, 2000). Authors and researchers have, for decades, wrestled with how one defines Nativeness or "Indianness," a topic rife with dysfunction due to decades of U.S. government interference and legalism (Weaver, 1997). At present, perhaps the best place to look for guidance on conceptualization of Native American community or Indianness is to the liberal arts and literature. But even here, there is hardly consensus. Conceptualizations of Indianness can include: (a) blood quantum levels, (b) place of birth, (c) the degree to which a person is nested or enrolled within a Native American community, and (d) identifying as Indian and wrestling with the totality of that identity (Weaver, 1997). Researchers have cautioned against both attempting to describe a culture in which one was not intimately raised as well as using a specific tribal conceptualization to generalize to all Native Americans, lest the research participants and community at large be made to feel like specimens (Holkup et al., 2004). With research on and measures of community lacking, especially within the rehabilitation literature, it is difficult to say how accurately the PART-O maps onto Native American conceptualizations of community or even what community following TBI looks like for Native Americans.

Clinical Implications

Given the dearth of literature on conceptualizations of community within Native Americans, rehabilitation clinicians should exercise caution when using community participation as key a metric of rehabilitation success. While community participation is undoubtedly an important metric (Bogner, 2013; Takada et al., 2016; Whiteneck et al., 2011), clinicians are encouraged to conduct a thorough assessment of community needs for Native Americans with TBI as current measures may not be adequate. Such a thorough assessment is even more important in light of the current study's findings that Native Americans had lower Out and About scores than White individuals.

The current study highlighted educational attainment, employment at the time of injury, type of insurance, and binge drinking in the month prior to experiencing a TBI as possible risk factors for reduced community participation. Rehabilitation clinicians may use these constructs as indicators for Native Americans who may need additional resources or early intervention to help bolster community participation post-discharge. Educational attainment and lack of private insurance appear to be especially predictive of lower Out and About scores for Native Americans relative to White individuals with TBI. As noted earlier, education has several benefits that may act as protective factors against negative sequelae of TBI; thus, lower education may predispose individuals to experience a larger number of and more severe negative outcomes. Type of insurance may be an indicator of the quality and availability of resources post-rehabilitation and should be considered when planning post-discharge care.

The lack of culturally sensitive and informed research on Native Americans with TBI can make providing culturally specific care difficult. While the body of literature is small, studies are beginning to show significant gaps in outcomes for Native Americans with TBI and suggest that a transformation in care is needed. Rehabilitation clinicians are therefore encouraged to conduct detailed assessments of the specific needs of Native Americans, include family members in medical conferences and decision making, and ensure that Native American patients have an active voice in their care. Given that Native Americans are significantly less likely to engage with the healthcare system and have appropriate resources provided to them post-discharge (Marrone, 2007; Whitfield & Lloyd, 2008), it is recommended that clinicians bear these disparities in mind and advocate appropriately for their patients.

Limitations and Future Directions

The current study has several limitations and thus future directions that should be considered when interpreting the findings. First, control norms do not exist for the PART-O, meaning there is no baseline "norm" with which to compare Native Americans with TBI. Future research may wish to examine how the PART-O functions within the general population for a more accurate reference with which to compare individuals with TBI. As noted before, appropriate measures for and research on conceptualizations of community do not currently exist for Native Americans. It is therefore possible that with a culturally sensitive and informed measure, the results might be different. It is also worth noting that some of the items in the PART-O may not be overly applicable to the Native American community. For instance, the item measuring religious or spiritual engagement ("In a typical month, how many times do you attend religious or spiritual services? Include places like churches, temples, and mosques.") lists religious symbols that may not be the most prevalent among Native Americans. Future research may wish to incorporate culturally specific indicators for Native Americans across all items, not just the religious question. Given that both Social and Productivity scores were equivalent between the two groups, it is possible that a different measure may find that Out and About scores are also statistically equivalent (or that Social and Productivity scores differ between the two groups). Future research may wish to (1) create a culturally specific measure of community participation and (2) use a culturally informed measure to more accurately assess community participation outcomes longitudinally post-TBI.

Native Americans with TBI are also somewhat uniquely situated within the U.S. in that they may have ties to multiple forms of identification that may act as either a buffer against negative outcomes or a generator of positive outcomes. Native Americans with TBI may have multiple cultural/ethnic identities (e.g., Native American or Native American and some other race/ethnicity), tribal affiliation, and disability identity. Tribal affiliation is a unique identity category for Native Americans that may offer additional benefits beyond Native American identity. Future research may wish to explore how tribal identity in addition to general Native American identity or the intersection of Native American, tribal, and disability identity might affect rehabilitation outcomes.

As noted earlier, the Native American community has a plethora of important and unique characteristics (e.g., spirituality, strong sense of kinship that transcends tribal or geographic ties, stalwart leadership, racial/ethnic and tribal identity) that may act as buffers against negative outcomes or generators of positive outcomes. Such positive characteristics were not assessed in the present study due to lack of inclusion of these constructs within the TBIMS database. Future research may wish to take a more targeted strengths-based approach to uncover the best culturally and contextually specific characteristics of Native Americans to bootstrap to assist with recovery and rehabilitation. Such research may be useful in creating culturally sensitive rehabilitation programs that lean on the strengths of the Native American community to increase quality of care and rehabilitation outcomes.

Native American participants were only included in the present study if they self-identified as solely Native American (i.e., did not select more than one race/ethnicity). This decision was made because it was impossible to differentiate between individuals who identified as mostly Native American or those who identified as mostly non-Native American. Thus, it is possible that this selection criteria may have overlooked some individuals who should have been included. Additionally, the ability to self-identify one's race does not allow for factors like acculturation or geographic location (e.g., living on tribal land) to be fully considered despite how important they might be in predicting outcomes. Native American participants were not identified by tribe which may have important implications for generalizability as well as cultural specificity. Future research may wish to more accurately identify Native American participants (perhaps through geotagging). Additional samples may wish to also include more robust data at year 5 and beyond. While the Little's MCAR indicated data were missing completely at random, a visual inspection of Table 2 raises questions around differential attrition. The specific reason for the lower participant count for Native Americans at year 5 is unknown but could be due to any of the reasons listed for missing data.

The TBIMS rehabilitation centers are all located within major metropolitan areas, far from most Native American tribal lands. This could indicate that the Native Americans included in the current study are not representative of the larger Native American population. That is, they may not live on tribal lands and may have access to more resources by proximity to a major urban area. It is possible that a process like geotagging may assist future research in more accurately identifying both the participants as well as their access to healthcare resources and may enable specifically examining certain subsections of the Native American with TBI population (e.g., only those living within tribal land).

The current study matched on three demographic variables and examined 11 other possible covariates; however, a plethora of possibly important variables were not investigated. Research suggests that access to healthcare resources, acculturation status, racism, and comorbid conditions (e.g., diabetes) may have a significant impact on outcomes for Native Americans with TBI (Findling et al., 2019; Marrone, 2007; Whitfield & Lloyd, 2008; Zarshenas et al., 2019). While the sample size for the current study was adequate for the conducted analyses, a larger sample size may help to uncover more nuanced results and allow the examination of a larger number of possible covariates (e.g., comorbidities, distance to the nearest healthcare facility).

Finally, the exact mechanism through which education, employment at the time of injury, type of insurance, and binge drinking in the month prior to experiencing a TBI might impact differences in community participation trajectories between Native American and White individuals is unclear. The nature of HLM does not allow for causal inference, and the aforementioned variables may be indicators of other unmeasured sources of variance (e.g., educational attainment may be an indicator of cognitive function or type of insurance may be an indicator of quality of care received). While the current study highlighted the predictive utility and relation among these variables and Out and About disparities over the 5 years post-injury, future research may wish to examine possible causal pathways to better inform rehabilitation care and early intervention.

Conclusion

The current study was the first to examine longitudinal trajectories and disparities of community participation for Native Americans with TBI when compared to a demographically matched sample of White individuals. This study builds on previous literature also utilizing the TBIMS database examining disparities within a demographically matched sample of Native Americans and White individuals with TBI (Watson et al., in press). The current study demonstrated that Native Americans were generally less likely to have private insurance, less likely to be employed at the time of injury, more likely to have lower education attainment, and more likely to engage in binge drinking in the month prior to experiencing a TBI. Over the 5 years following TBI, Native Americans within the current sample had lower Out and About scores but statistically equivalent Social and Productivity scores compared to their demographically matched White counterparts. The difference in Out and About scores did not change as a function of time, and the inclusion of the statistically different sociodemographic variables accounted for the predictive power of race between the two groups. Both educational attainment and type of insurance were statistically significant predictors of Out and About trajectories and at least partly account for the difference in scores over time between the two groups. It is also likely they are indicators of other sources of unmeasured variance that impact Out and About scores. The current study emphasized the important need for early assessment and intervention across key sociodemographic predictors and highlighted gaps in the literature, particularly the lack of a culturally informed measure of community participation and a dearth of research on culturally and contextually specific strengths that rehabilitation programs might target to improve outcomes.

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