PREDICTIVE MODELS OF FUNCTIONAL PERFORMANCE FOLLOWING STROKE

By

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Abstract

Acquired Brain Injury (ABI) is defined as damage to the brain that occurs after birth and is not related to congenital or degenerative diseases. ABI is a serious health care concern due to the functional disability and psychosocial maladjustment it causes. Studying factors influencing recovery following ABI offers valuable information for improving the evaluation process, intervention planning, and care implementation. This dissertation work includes four components exploring factors associated with favorable functional outcomes following traumatic and non-traumatic forms of brain injury. The first component encompassed a narrative review of personal and environmental factors influencing recovery following a Traumatic Brain Injury (TBI). This review provides an overall perspective on the course of functional recovery after TBI. The next part was more focused on mild forms of TBI known as Post-Concussion Syndrome (PCS) which adversely influences participation in activities of daily living. The second component encompassed a systematic review of different interventions addressing physical, cognitive, and emotional functioning in adults with PCS. The third component evaluated how non-traumatic brain injury affects participation in daily activities in the long-term. More specifically, it assessed the relation among personal characteristics, perceived performance, and impact of injury on daily participation of community-dwelling adults with stroke who have had this condition for years. This led to the fourth and final component which explored factors predicting functional performance of individuals with stroke following inpatient rehabilitation. This component included two predictive models identifying distinct demographic and health characteristics that predicted motor and cognitive domains of functional performance after discharge from rehabilitation. Examples of these factors included age, comorbidities, and motor/cognitive status on admission. This dissertation presents several factors influencing recovery after brain injury and affirms the importance of individualized interventions for serving clients with ABI.

Keywords: brain injury, functional performance, recovery, predictive models, rehabilitation.

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Introduction

This dissertation research builds upon previous work completed in the Therapeutic Science program as a series of comprehensive projects. These comprehensive projects focused on different aspects of brain injury, using a series of different research methods to produce findings relevant for the clinical management of the brain-injured client. As a first exposure to mild traumatic brain injuries, I took the lead in a project focused on educating recreational soccer referees about sport-related concussions. This project culminated in a short training video for use by the Kansas chapter of the US Soccer Federation in the training of officials for youth soccer programs. This initial exposure to the complexity of brain injuries led to my first comprehensive project (see Appendix 1), exploring factors influencing recovery following brain injury. I was particularly interested in gaining a better understanding of factors influencing functional recovery after traumatic brain injury (TBI). I conducted a narrative review summarizing the state of evidence about the complex relations among personal characteristics, injury-related elements, environmental factors, and functional recovery following TBI. This review concluded that multiple demographic and environmental factors were associated with functional outcomes after TBI, either supporting or hindering recovery following injury (Jaber & Radel, unpublished mss.)

In developing my understanding of factors influencing functional after TBI, the factor that drew my attention, in particular, was the role of TBI severity in recovery prognosis. Individuals with TBI often are reported to demonstrate variable rates of recovery that appear uncorrelated with of severity of the injury. This observation led to my second comprehensive project, which focused on the course of recovery experienced after mild forms of TBI. Although the majority of individuals with mild TBI recover completely, some of these individuals experience prolonged symptoms for weeks or months (McCrea et al., 2013). This condition is known as post-concussion syndrome (PCS). Persistent symptoms in PCS can cause substantial physical and emotional discomfort, and often adversely affect participation in daily activities (Lundin, de Boussard, Edman, & Borg, 2006). My second comprehensive project (see Appendix 2) focused on interventions that support participation for individuals with PCS by reducing symptoms and by supporting daily participation. A systematic review of reports from the literature examined different interventions for the physical, cognitive, and emotional functioning of adults with PCS. This extensive and timely review concluded that psychotherapy, counseling, and social support interventions were most beneficial in supporting cognitive and emotional functions of adults with PCS (Chapter 1; Jaber, Hartwell, & Radel, 2017). I found there was, however, only limited research reported investigating the effectiveness of rehabilitation and self-management strategies for these individuals in the long-term.

This gap in the literature led to my third comprehensive project (see Appendix 3), in which I conducted a retrospective chart review of data collected years after the study participants had experienced their strokes. The individuals providing these data were living in the community, long after discharge from in-patient and from out-patient care. These individuals had sought long-term social or other supports through a local community-based activity center. Through this retrospective analysis, I explored demographic characteristics and self-perceived activity performance of these individuals, all of whom lived with chronic stroke at the time their data were collected. I also examined the relation among personal characteristics, perceived performance, and impact of injury on the daily participation of these individuals. I found the characteristics of these stroke survivors in this community setting were consistent with those described in stroke literature. Additionally, the top three self-perceived challenging activities for these participants were driving, seeking employment, and functional mobility (Chapter 2; Jaber, Sabata, & Radel, 2018). In addition, a correlation analysis revealed significant associations among personal characteristics, health factors, and self-perceived occupational performance of these people with chronic stroke. These findings are relevant in relation to those of my initial comprehensive project, which also revealed a relationship among similar personal characteristics and functional recovery after TBI. Both my first and third comprehensive projects demonstrate a clear link among personal demographics, health factors, and functional outcomes after brain injury (Jaber & Radel, unpublished mss.; Jaber et al., 2017).

The complex relations among personal factors and functional outcomes led to more refined questions about potential predictors of favorable outcome after brain injury, and the extent to which early predictions of favorable functional outcomes after brain injury not only may be beneficial for clients, but also helpful to for their health care providers in developing a tailored management plan. My dissertation research (Chapter 3) has focused on building two predictive models, one for motor performance after stroke and the other for cognitive performance after stroke, that together will guide occupational therapists and other health professionals in designing individualized interventions and in deciding an optimal path of implementation. A further goal of these models is to support counseling of families and caregivers throughout an informed decision-making process. The findings of my dissertation have documented significant predictors of discharge motor function subscores (model 1) which included baseline motor subscores, discharge stroke severity, age, right affected side, independence on admission, and comorbid electrolyte disorder. Further, significant predictors of discharge cognitive function subscores (model 2) were baseline cognitive function subscores, client cooperative behavior, age, comorbid obesity, and total number of comorbidities. In conclusion, these predictive models unequivocally demonstrate having a stroke when younger, possessing good motor and cognitive abilities on admission after stroke, a milder stroke severity, fewer comorbidities, and clients having a positive attitude all predict favorable functional outcomes after inpatient stroke rehabilitation. These specific personal and health characteristics are key factors that determine the course of recovery during in-patient rehabilitation, and thus are viable targets for guided interventions.

Chapter 1

INTERVENTIONS USED TO ADDRESS THE NEEDS OF ADULTS WITH POST-CONCUSSION SYNDROME: A SYSTEMATIC REVIEW

This chapter has previously been accepted for publication in whole without any adaptations and is reprinted here with permission. Jaber, A., Hartwell, J., & Radel, J. Interventions Used to Address the Needs of Adults with Post-Concussion Syndrome: A Systematic Review. *American Journal of Occupational Therapy* (accepted Nov 2017).

This chapter was developed from my 2nd comprehensive exam (see Appendix #2).

Abstract

Post-Concussion Syndrome (PCS) impacts physical, cognitive, and emotional functions of affected individuals. Existing reviews of intervention to address PCS are limited to psychological and rehabilitation interventions, and to children and adolescent populations. We conducted a systematic review integrating current evidence about interventions for adults with PCS. The inclusion criteria encompassed intervention studies of adults (≥18 years) with PCS, evaluated recovery from PCS symptoms, and focused on the functional outcomes; 10 intervention studies met the inclusion criteria. Included studies demonstrated medium to high levels of evidence, and investigated psychotherapy, counseling, social support, self-management strategies, individualized rehabilitation, hyperbaric oxygen interventions, and group-based cognitive behavioral therapy. Outcomes included reduced post-concussion symptoms, improved cognitive function, enhanced quality of life, and increased community integration. The evidence supports psychotherapy, counseling, and social support interventions as being beneficial for cognitive and emotional functions in adults with PCS.

Keywords: brain injuries, adult, intervention studies, review literature.

Introduction

Increased awareness about concussions has contributed to more research addressing this topic (Bonds, Edwards & Spradley, 2014). One emerging emphasis is on the persistent residual symptoms of concussions, referred to as Post-Concussion Syndrome (PCS). The Centers for Disease Control estimate that 1.4 to 3.8 million concussions occur each year in the United States (Laker, 2011). Although studies of PCS have reported major differences in the incidence of this syndrome among people with concussions, the most commonly reported incidence was between 10% and 15% of concussions (Jotwani & Harmon, 2010; Prigatano & Gale, 2011). Lingering PCS symptoms may last for months after a concussion and can impact daily life participation (Roe, Sveen, Alvsaker, & Bautz-Holter, 2009; Lundin, de Boussard, Edman, & Borg, 2006). Occupational therapy emphasizes participation in daily life for individuals with a head injury as an important intervention outcome (Golisz, 2009). There is a lack of comprehensive systematic reviews integrating evidence about interventions for adults with PCS. The objectives of this review were to search the current literature systematically and to synthesize findings objectively on different interventions addressing physical, cognitive, and emotional functioning in adults with PCS. This review will identify interventions that have produced favorable outcomes reducing PCS symptoms and supporting participation in daily activities.

Literature Review

Occupational therapy (OT) contribute to the fulfillment of participation in daily life for individuals with different conditions, including concussions and other forms of mild traumatic brain injury (mTBI) (Law, 2002). Participation in daily life includes many areas of occupation such as activities of daily living, work, education, and social participation (American Occupational Therapy Association [AOTA], 2014). PCS affects different aspects of participation and should be addressable through OT interventions. OT practitioners pursue individualized interventions by working with people having PCS to manage symptoms and hasten a return to daily life activities, through designing interventions meeting the unique needs and abilities of each individual. Identifying evidence-based updates for PCS management provides OTs with an opportunity to assist their clients more effectively. Using individualized interventions paired with new evidence, OTs can support individuals with PCS to face challenges to participation caused by diverse and lingering symptoms.

PCS is defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as being when 3 or more symptoms persist for at least 3 months after the precipitating concussion event (4th ed., DSM-IV ;American Psychological Association [APA], 1994), although researchers consider symptoms to be persistent as early as 10 days (McCrory et al., 2013) or 28 days (Rose, Fischer, & Heyer, 2015) after concussion. Symptoms of PCS vary in frequency and duration after a concussion. PCS symptoms include headache, fatigue, dizziness, irritability, sleep disturbance, reduced concentration, impaired memory, sensitivity to light and noise, slowed thinking, and anxiety (Ryan & Warden, 2003). The vast majority of concussion symptoms resolve within 10 days after injury (McCrory et al., 2013), although a subgroup of individuals with concussion experience symptoms for weeks or months and thus meet the criteria for PCS (Roe et al., 2009). The persistent symptoms of PCS cause physical discomfort, increase the risk of emotional sequelae, and limit participation in daily activities (Lundin et al., 2006).

PCS adversely influences participation in activities of daily living (ADLs) and quality of life of individuals across the lifespan, especially adults. Adults constitute 62.4% of the US population (US Consensus Bureau, 2014). The prevalence of PCS symptoms in adults was 6%-30% at 3 months and 0.9%-23% at 6 months after a concussion (Roe et al., 2009; Spinos et al., 2010). Persistent concussion symptoms can be challenging to manage, and this affects the individual's capability to assume a daily routine, keep a job, or engage in leisure activities (Bottari, Dutil, Dassa, & Rainville, 2008). For example, driving requires full attention and concentration to operate a motor vehicle. Impaired concentration and slowed reaction time risk a motor vehicle crash, endangering the driver, passengers, and others in the community. The repercussions of PCS on adults' daily routine and work productivity should not be underestimated; therefore, providing education and support for seeking medical advice are important.

Management of PCS includes a combination of medical, cognitive, and rehabilitation strategies that target lingering symptoms after a concussion. No comprehensive reviews have been done to establish the outcomes of interventions on working adult with PCS symptom resolution and functional improvements. Previous reviews that addressed PCS management have been limited to a specific intervention type such as psychological interventions (AL Sayegh, Sandford, & Carson, 2010) or rehabilitation interventions (Leddy, Sandhu, Sodhi, Baker, & Willer, 2012). They have also been restricted to specific age groups like children and adolescents (Gilmore et al., 2015). Adults over 18 years of age represent an important part of individuals with concussion, and yet no systematic reviews have been conducted to integrate the evidence on effective PCS interventions for this population. Additionally, the role of OT in the management of PCS was not clearly defined in this literature. This review provides OT practitioners and other health professionals with access to current literature about effective interventions for adults with PCS. This systematic review aimed to answer the following research question: what evidence supports the effectiveness of different intervention strategies for adults with PCS? We hypothesized that a comprehensive systematic review of published studies will identify all interventions effective in attenuating PCS symptoms and improving participation in activities of daily living.

Methods

Search Strategy and Data Sources

We applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for structured implementation of the systematic review process (Moher, Liberati, Tetzlaff, & Altman, 2009). The review process included comprehensive electronic and manual search for publications where PCS was the primary focus between 2005 and 2015. This 10-year period has marked a significant increase in research studies addressing post-concussion syndrome. The electronic search was led by a librarian co-author. The manual search was conducted by examining bibliographic lists of included data and other reviews looking for relevant articles. The search was implemented using a combination of keywords and search terms (see Table 1). The main search databases utilized in this review included PubMed, CINAHL, PsychINFO, ProQuest, and OT seeker. Database filters of data range, language, and age were applied to retrieve appropriate studies. Study design filters were applied when available to locate randomized controlled trials (RCT). Database search results were exported and saved to a citation management tool for review.

Inclusion and Exclusion Criteria

Articles for review involved participants 18 years of age or older with a PCS diagnosis. Disparities exist in the definition of PCS with two medical classification systems establishing different diagnostic criteria including the International Classification of Diseases (ICD-10; World Health Organization, 1992) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; APA, 1994). The ICD-10 and DSM-IV diagnostic criteria were selected to conduct this review and to control for the literature inconsistencies in defining PCS. Many intervention studies used an established diagnosis of mTBI to define their target sample, but not a diagnosis of PCS. Individuals with mTBI who have persistent concussion symptoms were also included in this review. We presented a full list of the inclusion and exclusion criteria in the appendices (see Table 2).

Eligibility criteria included published studies written in English. Included studies addressed medical, rehabilitative, cognitive, or supportive therapy for PCS treatment with outcomes evaluating the reduction of PCS symptoms, improvement in functional performance, or participation in ADLs. The primary outcomes in this review included the number and category of PCS symptoms. Lingering PCS symptoms are the main underlying cause of physical and emotional challenges for affected individuals. The secondary outcomes encompassed functional performance of daily activities and other related outcomes like community integration and quality of life. These outcomes are also important and reflect the impact of PCS on the individual's ability to assume a daily routine and engage in activities after injury.

The research team extracted the abstracts of all studies that resulted from the electronic and manual search. These abstracts were used for the initial review and screening based on the eligibility criteria. The initial review of abstracts assessed each article based on the title and content of the abstract to determine eligibility for inclusion in this project. Some abstracts could not be assessed due to lack of details in the body of the abstract. Those that could not be assessed based on the title or content of abstract were reviewed in full-text. Articles meeting inclusion criteria were downloaded in full-text to allow further analysis.

Quality Appraisal and Level of Evidence

We evaluated quality and level of evidence for all included studies. We appraised the study quality based on the study design. We used the 11-item Physiotherapy Evidence Database (PEDro) scale for assessing the quality of randomized controlled studies (Moseley, Herbert, Sherrington, & Maher, 2002). RCTs with a score of 9-11 on PEDro were considered to have “excellent” quality; 6-8 were “good” quality; 4-5 were “fair” quality; and below 4 were “poor” quality (Teasell et al., 2013). Included studies that did not use an RCT design could not be assessed using PEDro scale. We used the 9-item Newcastle-Ottawa scale (NOS) to assess the quality of nonrandomized and observational studies (Wells et al., 2009). Studies with a score of 7-9 on NOS were considered to be “excellent” quality; 4-6 were considered “good to fair” quality; and 0-3 were considered “poor” quality. We also assessed the level of evidence for included studies based on the Oxford Centre for Evidence-based Medicine (OCEBM) 2011 guidelines for levels of evidence (Howick et al., 2011). The OCEBM classifies the level of evidence on a scale of one to five in which level one represents systematic reviews (highest) and level five denotes mechanistic reasoning (lowest). All included studies were assigned a number indicating the level of evidence.

Results

Search Results

Systematic electronic and manual searches yielded 146 studies extracted from PubMed, CINAHL, PsycINFO, and the Cochrane Libraries. The initial review of titles and abstracts led to the exclusion of 83 articles. The remaining 51 articles were reviewed in full-text, with 10 articles meeting all inclusion criteria. A PRISMA flowchart presents the search results and articles’ selection (see Figure 1).

Included Studies

Ten studies were included for analysis in this review. The sample sizes and the number of participants per group varied (range= 20 - 395 participants). Altogether, these studies encompassed 858 adults with concussion/mTBI that resulted in persistent concussion symptoms. The mean age of all participants was 35 years (mean age range= 23 – 47 years). The majority of participants were males (mean = 65%; range 25%-100%) and were employed before the injury (mean = 78%; range = 30% - 100%). The majority of participants were civilians (n=675) in seven studies, while the remaining participants were military personnel (n=183) in three other studies. Main causes of the concussion/mTBI included motor vehicle crashes and falls for civilian participants and improvised explosives devices' blasts for military personnel. The study designs of included studies also varied; seven studies were randomized controlled trials, while three studies employed nonrandomized designs including one pretest-posttest, one cohort, and one cross-sectional design. All included studies employed prospective data collection and used different instruments to evaluate intervention outcomes.

Outcomes Measured

The outcomes of interest in this review were PCS symptoms and/or functional performance. Eight included studies focused on evaluating all PCS symptoms (Bergman, 2011; Cifu et al., 2014; Elgmark Andersson, Emanuelson, Bjorklund, & Stalhammar, 2007; Kjeldgaard, Forchhammer, Teasdale, & Jensen, 2014; Miller et al., 2015; Moore et al., 2014; Rees & Bellon, 2007; Wolf, Cifu, Baugh, Carne, & Profenna, 2012). By contrast, two studies examined only one category of PCS symptoms, that being either cognitive symptoms (Boussi-Gross et al., 2013) or emotional/behavioral symptoms (Tiersky et al., 2005).

Included studies also evaluated a variety of functional outcomes. These outcomes included functional health and well-being (Elgmark Andersson et al., 2007; Kjeldgaard et al., 2014; Miller et al., 2015; Moore et al., 2014), participation in ADL (Cifu et al., 2014), and community integration (Elgmark Andersson et al., 2007; Moore et al., 2014; Tiersky et al., 2005). Some studies evaluated the quality of life after implementation of the intervention (Elgmark Andersson et al., 2007; Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015).

Quality and Level of Evidence for Included Studies

The quality of included studies ranged from fair to excellent (see Table 3). Seven included RCTs' quality scores that ranged from five to ten points on PEDro indicating fair to excellent quality (Boussi-Gross et al., 2013; Cifu et al., 2014; Elgmark Andersson et al., 2007; Kjeldgaard, et al., 2014; Miller et al., 2015; Tiersky et al., 2005; Wolf et al., 2012). Elgmark Andersson et al. (2007) was the only randomized controlled study to score poorly with only 5 points for criteria met. This study had a high risk of bias (including attrition, performance, and reporting bias) for one or more key domains on PEDro (Higgins, Altman, & Stern, 2011). Three nonrandomized studies' scores ranged from five to seven on the NOS indicating good to high quality (Bergman, 2011; Moore et al., 2014; Rees & Bellon, 2007). The included studies had moderate to high scores on methodological research implementation. The OCEBM 2011 guidelines state the level of evidence ranged from fair (level 4) to high (level 2) for included studies.

Intervention Content

We grouped interventions into five different intervention strategies including psychotherapeutic interventions, social work intervention, rehabilitation/ individualized interventions, self-management strategies, and hyperbaric oxygen (HBO) therapy. Three studies included psychotherapeutic interventions (Kjeldgaard et al., 2014; Rees & Bellon, 2007; Tiersky et al., 2005). Four RCT studies tested the efficacy of HBO therapy (Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015; Wolf et al., 2012). The three remaining studies evaluated the effectiveness of one intervention strategy in each study. These three studies evaluated the effectiveness of social work intervention (Moore et al., 2014), individualized rehabilitation (Elgmark Andersson et al., 2007), or self-management strategies (Bergman, 2011). The control group in all included studies either received a different dose of the intervention being tested or conventional medical care. We provide a brief discussion of these interventions to offer insights into the effectiveness of each intervention for adults with PCS.

Psychotherapeutic Interventions. These interventions include psychodynamic, psychoanalytic, cognitive, and behavior therapies. Three studies evaluating psychotherapeutic intervention strategies possessed good quality; these were Kjeldgaard et al., 2014 (PEDro score = 8), Rees & Bellon, 2007 (PEDro score = 8), and Tiersky et al., 2005 (NOS = 5). Two of these studies evaluated the effectiveness of Cognitive Behavioral Therapy (CBT), which substitutes maladaptive patterns of thinking and behavior with desirable patterns. Tiersky et al., 2005 conducted an RCT to test the effectiveness of individualized CBT on a sample of 20 adults (mean age = 47 years) with PCS. The intervention group received 33 sessions of CBT over 11 weeks. Individualized CBT led to significant decrease in PCS symptoms and to increase in emotional functioning (Tiersky et al., 2005). Kjeldgaard et al., 2014 conducted an RCT in 90 individuals (mean age = 34 years) with mTBI who had lingering headaches. The intervention group received nine weekly sessions of group-based CBT. Group-based CBT did not alter post-concussion headaches, although it did yield improvements in quality of life, psychological distress, and the overall symptoms experienced (Kjeldgaard et al., 2014).

The third report of a psychotherapeutic intervention strategy evaluated psychotherapy coupled with counseling on recovery from PCS (Rees & Bellon, 2007). The researchers conducted a longitudinal pre-post test on 20 adults with PCS (mean age = 31 years). The results showed that both psychotherapy and counseling yielded a significant reduction of post-concussion symptoms including agitation, irritability, and suicidal thoughts. These interventions used a holistic approach with multiple therapeutic strategies, including sessions where information was given, counseling based on client-centered CBT was used, and problem-solving strategies were practiced. The outcomes included improvements in cognitive and affective symptoms after PCS. Adults with concussions benefit from other interventions that provide client education including social work interventions (Moore, 2014).

Social Work Intervention. Social work services include linking clients to support groups and counselors, to expand the client's social support network. One study having excellent quality (NOS score = 7) found providing social interventions led to improvements in symptoms after a concussion. Moore et al. (2014) tested the effectiveness of the Social Work Intervention for Mild Traumatic Brain Injury (SWIFT) program on 64 adults (mean age = 40 years) with mTBI. The intervention group received the SWIFT program while the control group received treatment as usual. The SWIFT program strategically provided clients with reassurance, education, and follow-up guidelines, leading to greater use of medical services. The results of this study showed that the intervention group maintained pre-injury community functioning; whereas the control group significantly declined in social functioning and community interactions. These findings suggest social work interventions can assist individuals with mTBI and post-concussion symptoms to resume roles in their community.

Self-management Strategies. Self-management strategies are techniques that individuals employ to reduce the effect of residual illness on daily functioning and quality of life. One study with high quality (NOS score = 8) explored different self-management strategies used by adults who had prolonged symptoms after concussion (Bergman, 2011). The sample had a mean age of 40 years and consisted of 30 individuals with symptomatic mTBI and 30 controls without head injury. Individuals with mTBI reported that self-management strategies were effective in relieving symptoms. In addition, there was a significant relation between overall reports of being bothered by symptoms and the use of self-management strategies. Examples of these self-management strategies included activities/thoughts (e.g., make a list, use a calendar, or rest), complementary therapies (e.g., prayer or relaxation), and exercise. The results suggested adults with PCS symptoms are more likely to use self-management strategies, and these led to symptom relief and reduced symptom severity.

Rehabilitation and Individualized Interventions. Although rehabilitation and individualized interventions have proven effective in addressing functional concerns related to many disorders, one study having fair quality (PEDro score = 5) evaluated the effect of early rehabilitation intervention (including OT, physical therapy, and social work) and did support such benefits for adults with PCS (Elgmark Andersson et al., 2007). The researchers conducted an RCT in 395 individuals (mean age = 33 years) with mTBI. The intervention group consisted of 263 participants who were examined by rehabilitation professionals. The control group encompassed 131 participants who received regular care. The results showed that individualized intervention did not appear to improve symptoms one year after injury when compared with a control group, although there were important limitations in the study, including a high dropout rate and variability in duration of baseline evaluation. A conclusive determination about the effectiveness of individualized rehabilitation for PCS based on one study is not, therefore, possible.

Hyperbaric Oxygen (HBO) Therapy. HBO therapy involves inhaling oxygen-enriched air in a closed chamber with increased atmospheric pressure (Gill & Bell, 2004). The human lungs absorb more oxygen under these conditions and transferring more oxygen in the bloodstream is hypothesized to trigger the release of growth factors, and thus support healing (Tibbles & Edelsberg, 1996). Four RCT studies with high quality (PEDro scores = 9-10) tested HBO therapy with individuals with PCS, mainly focusing on military personnel (Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015; Wolf et al., 2012). Three of four studies did not show significant improvements for using HBO therapy with adults having PCS (Cifu et al., 2014; Miller et al., 2015; Wolf et al., 2012). The intervention groups received varying doses of HBO therapy between 1.5 - 2.4 absolute atmospheric (ATA) pressure units (2 ATA = twice the atmospheric pressure at sea level). The results did not yield any significant improvements or differences between intervention and control groups.

One of four HBO intervention studies (Boussi-Gross et al., 2013) reported significant differences between the study groups. Boussi-Gross et al., 2013 conducted an RCT with a crossover design in a sample of 56 adults (mean age = 44 years) with PCS. The intervention group was evaluated once after 2 months of HBO therapy. The crossover group was evaluated twice: once after 2 months of control period and once after subsequent 2 months of HBO therapy. Both groups received 40 HBO sessions at 1.5 ATA. All individuals having PCS experienced significant improvements in cognitive functioning and quality of life but not following the control period (Boussi-Gross et al., 2013).

Discussion

Reports of therapies used to manage PCS exist in the literature. Examples of these interventions include physical-cognitive rest and exercise. Rest is very important after injury because physical exertion after concussions leads to exacerbation of symptoms (Majerske et al., 2008; Moser, Glatts, & Schatz, 2012). After adequate resting, light aerobic exercise such as walking on a treadmill or stationary cycling has been recommended to further reduce symptoms (Leddy, Hinds, Sirica, & Willer, 2016). Some studies addressing these interventions were not included in this systematic review due to not meeting our rigorous methodological eligibility criteria. For example, this review only included studies focusing on the adult population while excluding studies concentrating on children or adolescents like the studies conducted by Majerske et al. (2008) and Moser et al. (2012). These alternative interventions mainly rest followed by light exercise are commonly used for the management of PCS, and if combined with some of the interventions presented in this review they could yield greater benefits for adults living with lingering PCS symptoms.

This review examined the evidence supporting interventions effective in addressing needs of adults with post-concussion syndrome. Interventions demonstrating significant positive outcomes included psychotherapeutic interventions, social work intervention, and self-management strategies. Psychotherapeutic and social work approaches were the most effective interventions for adults with PCS. Cognitive-behavioral therapy and psychotherapy interventions educate and empower clients to understand and cope with their challenging health problems (Anson & Ponsford, 2006). These therapeutic strategies validate the client’s complaints of persistent symptoms and provide aid in identifying appropriate mechanisms to cope with lingering symptoms of PCS (Potter & Brown, 2012). Social work interventions were also beneficial for adults with PCS. The reviewed literature reports social workers providing PCS clients with education about lingering symptoms, the recovery process, and coping strategies to manage prolonged symptoms. Other research confirms a positive effect of social work interventions on psychological recovery after severe brain injuries (Gan, Campbell, Gemeinhardt, & McFadden, 2006).

Self-management interventions are reported to be beneficial for individuals with different health conditions (Funnell, 2010). Other studies have evaluated the effectiveness of self-management strategies in people with mTBI (Kendrick, Silverberg, Barlow, Miller, & Moffat, 2012) and acquired brain injury (Brenner et al., 2012; Damush et al., 2011). These studies yielded mixed results, with the majority supporting the effectiveness of self-management strategies for people with head injuries. For example, two studies suggested self-management strategies improve daily functioning (Kendrick et al., 2012) and enhance self-efficacy, self-management behaviors, and specific aspects of quality of life (Damush et al., 2011). A third study, however, did not show similar benefits (Brenner et al., 2012). Self-management strategies may provide promise; further studies are needed to confirm the effectiveness of such strategies for adults with PCS.

Studies specifically exploring the effectiveness of occupational therapy and rehabilitation interventions for adults with PCS are limited. Only one intervention study was identified as using occupational therapy in the management of PCS (Elgmark Andersson et al., 2007). A scoping review of occupational therapy literature for mTBI and PCS identified only three intervention studies that focused on occupational performance after injury (Cogan, 2014). These three studies tested the effectiveness of three interventions including Cognitive Orientation to Occupational Performance (Dawson et al., 2009), multidisciplinary rehabilitation (Ghaffar, McCullagh, Ouchterlony, & Feinstein, 2006), and a self-management program (Kendrick et al., 2012). Cognitive Orientation and self-management interventions yielded significant improvements in the occupational performance of individuals with PCS. These studies did not meet the inclusion criteria for analysis in this review due to including mixed diagnoses, severe head injury, and adolescents in the study sample. While the evidence is limited on the effectiveness of OT for PCS, clinical practice guidelines for mTBI management are available (Marshall et al., 2012). These guidelines provide OTs and other health professionals with information about care for individuals with mTBI and, by extension, PCS.

Studies of HBO therapy yielded mixed results with only one of four studies demonstrating a beneficial effect for adults with PCS (Boussi-Gross et al., 2013). In each of the four RCTs, investigators compared the HBO therapy intervention group to a control group that received either no HBO therapy or a lower dose of pressure. The results of two studies showed the comparison group had greater improvements in PCS symptoms than the intervention group (1.5 – 2.4 ATA) when the comparison group received a lower pressure dose (1.2 – 1.3 ATA) of HBO therapy (Miller et al., 2015; Wolf et al., 2012). This observation provides support for using lower pressure doses to test the efficacy of HBO therapy in future research.

Limitations

This review included studies that used a mix of research designs and analyses, with the majority having medium to high quality. Limitations of reviewed studies involved small sample size (more than 90% had less than 100 participants), unequal gender ratios (the majority of participants were men especially in the military population), and varying outcome measures, thereby limiting the ability to synthesize results across studies. However, this review integrates a variety of intervention strategies that have a beneficial effect on adults with PCS in terms of alleviating symptoms and improving functional performance. We recognize our findings will be enhanced by future research further examining the effectiveness of PCS interventions using large, representative samples.

Implications for Occupational Therapy Practice

PCS has diverse symptoms that adversely affect daily functioning and work productivity. Each case of PCS is unique and understanding the experience of adults with persistent symptoms is an important first step toward designing an optimal intervention plan, therefore:

- Occupational therapy practitioners are encouraged to follow an individualized approach to the management of PCS taking into consideration their client's preferences and needs.
- Occupational therapy interventions designed for adults with PCS should include education and counseling about persistent symptoms to enable their clients to understand their situation and to reduce the stress associated with lingering symptoms.
- Interventions for adults with PCS should also incorporate suggestions for self-management strategies to cope with symptoms and to be more active in everyday life.
- Occupational therapy practitioners should consider referring clients with PCS to trained psychologists who are able to provide psychotherapeutic interventions such as psychotherapy and cognitive behavioral therapy.
- Alternatively, working as part of a multidisciplinary team will promote advocacy and inter-professional collaboration among OTs and other health care professionals and assist clients with PCS to optimize successful management of their lingering symptoms and achieve a return to regular activities.

Implications for Future Research

Additional high-quality interventional studies of PCS management are needed to confirm the findings reported in this review for adults with PCS. Future studies of PCS interventions should use a unified PCS definition and diagnosis (e.g., using ICD-10 criteria for PCS), include larger sample sizes, evaluate outcomes of functional performance and work productivity of adults with PCS, and conduct repeated follow-up assessments. Future research should seek to develop and test the effectiveness of individualized, multidisciplinary interventions using a combination of strategies that have shown to be beneficial for adults with PCS.

Conclusion

The findings of this systematic review suggest that cognitive behavioral therapy, psychotherapy, social work, and self-management interventions are effective in the management of PCS and may offer adjunct therapies to enhance common intervention practices of cognitive and physical rest followed by a graded aerobic exercise program used in the treatment of uncomplicated concussion. HBO therapy requires trained technicians, special equipment, and physical space to deliver, which can be expensive and less feasible in some medical settings. Psychotherapeutic interventions do not require specialized tools although extensive and specialized training is required to provide these interventions. CBT, psychotherapy, social work, and self-management interventions appear to be beneficial for adults with lingering post-concussion symptoms, perhaps by helping individuals with PCS understand their condition, and supporting them to adopt alternative coping strategies to deal with persistent symptoms. Studies having rigorous designs are needed to evaluate the effectiveness of interventions for PCS in adults with mTBI or concussions, including occupational therapy interventions.

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Table 1

Criteria	Keyword and Search Terms
Population	“Post-Concussion Syndrome”, “PCS”, “TBI”, “18+”, “Adults”
Intervention	“Occupational Therapy”, “Cognitive Therapy”, “Physical Therapy Modalities”, “Exercise”, “Rehabilitation”, “Pain management”, “Therapeutics”
Outcome	“Recovery of Function”, “Community integration”, “Quality of Life”, “Return to work”, “Activities of daily living”, “Performance

Note. Keywords and search terms; PCS = Post-Concussion Syndrome; TBI = Traumatic Brain Injury.

Table 2

Criteria	Inclusion Criteria	Exclusion Criteria
Intervention study	Yes	No
Peer-reviewed	Yes	No
Publication status	Published and dissertations	No
Study design	Randomized controlled trials (RCT), experimental, qualitative, descriptive or case studies	Reviews, editorials, and opinion papers
Language	English	Any other language (e.g., German and French)
Participants	Human participants; 18 years of age or more; diagnosis of Post-concussion syndrome or mTBI with persistent concussion symptoms	Human participants less than 18 years of age; diagnosis of moderate to severe TBI; and animal subjects
Outcomes evaluated	Improvements in PCS symptoms and/or functional performance/participation.	Physiological or molecular changes
Publication year	2005 – 2015	2004 and earlier

Note. Studies inclusion and exclusion criteria; PCS = Post-Concussion Syndrome; mTBI = Mild Traumatic Brain Injury.

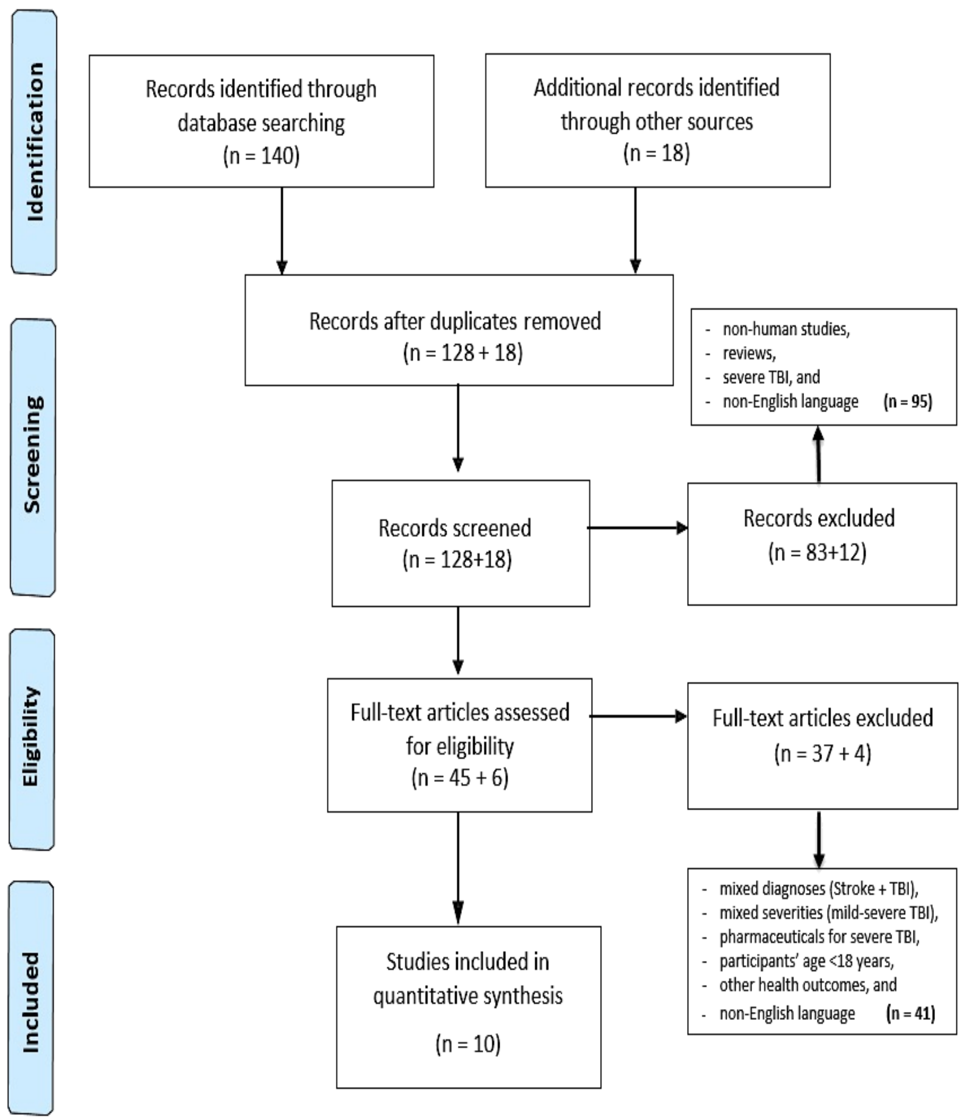
Table 3

Randomized Studies (PEDro Scale)												
Citation	Sampling and Randomization				Blinding			R ≥ 85%	ITT	OC ≥ 1	PM	Total
	1	2	3	4	5	6	7	8	9	10	11	
Boussi-Gross et al. (2013)	+	+	+	–	+	–	+	+	+	+	+	9
Cifu et al. (2014)	+	+	+	+	+	–	+	+	+	+	–	9
Elgmark Andersson et al. (2007)	+	+	+	–	–	–	–	–	–	+	+	5
Kjeldgaard et al. (2014)	+	+	+	+	–	–	–	+	+	+	+	8
Miller et al. (2015)	+	+	+	+	+	–	+	+	+	+	+	10
Tiersky et al. (2005)	+	+	+	+	–	–	+	+	–	+	+	8
Wolf et al. (2012)	+	+	+	+	+	–	+	+	+	+	+	10

Nonrandomized Studies (Newcastle-Ottawa scale)										
Citation	Selection				Comparability		Outcomes			Total
	1	2	3	4	5	6	7	8	9	
Bergman (2011)	+	+	+	–	+	+	+	+	+	8
Moore et al. (2014)	+	+	+	+	+	–	+	+	–	7
Rees & Bellon (2007)	+	+	+	+	+	–	+	+	–	5

Note. Quality appraisal of all included studies; R = response rate; ITT = intention to treat; OC = Outcomes; PM = Point Measure.

Figure 1



Note. PRISMA flowchart of search results and articles selection of eligible studies. The search results yielded 146 articles after removing duplicates. Articles were then screened for eligibility, and 95 articles were excluded for different reasons including non-human sample, reviews, mod-severe TBI, and non-English language. Fifty-one articles were reviewed in full-text articles, and 41 articles were excluded for having a mixed sample (Stroke + TBI), mixed severities (mild-severe TBI), pharmacological studies for severe TBI, other health outcomes, and non-English language. Ten studies met the eligibility criteria.

Chapter 2

SELF-PERCEIVED OCCUPATIONAL PERFORMANCE OF COMMUNITY-DWELLING ADULTS LIVING WITH STROKE

This chapter has previously been accepted for publication in whole without any adaptations and is reprinted here with permission. Jaber, A., Sabata, D., & Radel, J. Self-Perceived Occupational Performance of Community-Dwelling Adults Living with Stroke. *Canadian Journal of Occupational Therapy* (accepted Jan 2018)

This chapter was developed from my 3rd comprehensive exam (see Appendix #3).

Abstract

Background. Stroke has long-term consequences for functional performance of daily activities. Evaluating client-perceived occupational performance provides insight for designing stroke-specific programs supporting home and community participation. Purpose. This study described the personal characteristics and self-perceived occupational performance in community-dwelling adults with stroke. Methods. Retrospective chart review for 25 stroke survivors who sought services at a community-based center. The outcome measures encompassed the Canadian Occupational Performance Measure (COPM) to evaluate self-perceived occupational performance and the Montreal Cognitive Assessment (MoCA) to screen for cognitive impairment. The analysis included descriptive statistics. Findings. Mean participant age was 64 years and most were white males (72%). The mean cognitive function score was 22.1 on MoCA and the mean COPM performance and satisfaction subscores were 4.1 and 3.9, respectively. The top three challenging daily activities were driving, seeking employment, and functional mobility. Implications. Stroke-specific community programs should emphasize the diverse performance concerns important to stroke survivors.

Keywords: Stroke, Self-Perception, Occupational Performance, Community Support.

Introduction

Stroke encompasses a wide array of cerebrovascular disorders and represents a major healthcare concern worldwide (Feigin et al., 2014). Chronic stroke is a costly disease and a leading cause of disability in Canada (Dai et al., 2009). The prevalence of stroke in 2013 was 1.15% with an estimated 405,000 individuals living with chronic stroke (Krueger et al., 2015). In addition, estimated annual costs in Canada related to chronic stroke were $2.8 billion including direct medical costs, indirect costs of care, and absenteeism (Mittmann et al., 2012). The majority of individuals with chronic stroke possess some residual physical, cognitive, psychosocial, and/or behavioural challenges (DePaul, Moreland, & deHueck, 2013). These challenges affect participation in everyday life activities. Identifying clients' self-perceived challenges to daily participation assists occupational therapists in creating client-generated goals supporting long-term community participation after a stroke. This study describes the personal characteristics, self-perceived occupational performance, and performance challenges among community-dwelling adults living with a stroke.

Background

Individuals face challenges to daily participation during chronic stages of stroke (Haggstrom & Lund, 2008). These challenges encompass different areas of occupation, including activities of daily living (ADL), instrumental activities of daily living (IADL), work, leisure, and social participation (Harris & Eng, 2004). ADLs and IADLs are personal activities done on a daily basis to maintain health and well-being at home and in the community, such as eating, dressing, cooking, and driving (American Occupational Therapy Association [AOTA], 2014). The focus of occupational therapy, and rehabilitation more generally, in the longer-term after stroke emphasizes supporting on-going participation in home and community environments

(Winstein et al., 2016). A meta-analysis has suggested that individuals with chronic stroke who are receiving occupational therapy experienced both improvements in functional performance and reduced risk for poor health outcomes (Legg et al., 2007).

Client-centred occupational therapy services can be offered to stroke survivors through community-based programs, and these resources can provide tailored interventions to meet long-term needs of individuals after stroke. Community-based rehabilitation services are effective in creating positive recovery outcomes and opportunities for community integration for people with stroke (Ru et al., 2017). Examples of these services include multidisciplinary client-centred rehabilitation, exercise-based programs, stroke rehabilitation education, and self-management principles (Harrington et al., 2010; Ru et al., 2017). In addition, the Canadian Stroke Best Practice Guidelines state that individuals with stroke should be provided with information, support, and access to community services throughout transitions to the community to optimize the return to life roles and activities (Cameron et al., 2016). When individuals with stroke have access to community-based services they also report being more likely to stay engaged in the community, presumably due to personalized client-centred interventions that support achieving personal goals (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). Personalized interventions are most appropriate due to the considerable heterogeneity in the stroke presentation (Wiseman-Hakes, MacDonald, & Keightley, 2010), and healthcare professionals have been encouraged to consider their clients' perceived needs and priorities (Attree, 2001).

Assessing the client's perceived challenges in occupational performance provides valuable information about that individual's view of strengths and barriers to participation. This supports the development of personalized interventions to facilitate participation in daily activities, based on the client's own needs and priorities (Larson, 2010), to foster greater client motivation and engaged involvement, and to facilitate improved client satisfaction and intervention outcomes (Creel, Sass, & Yinger, 2002). The goal of the present study was to describe the demographic characteristics and self-perceived challenges to occupational performance for adults with chronic stroke who have sought long-term supports in a community-based center. We anticipate our findings will assist in identifying distinctive personal characteristics and perceived needs of the stroke population who choose to seek further supports after discharge from inpatient rehabilitation clinics. Recognizing challenges to occupational performance will help healthcare professionals, especially occupational therapists, in designing stroke-specific programs for supporting continued participation and community integration of individuals with chronic stroke.

Methods

Design

This study was based on a retrospective chart review of existing de-identified data from individuals with stroke and was approved by the University of Kansas Medical Center's Institutional Review Board.

Sample and Setting

The initial sample data included 68 individuals with chronic stroke who were randomly selected from a list of participants who had received services through *Next Steps*, a program of the American Stroke Foundation (ASF, 2017). *Next Steps* is a community-based activity program offered to all ASF clients. This program is intended to achieve individualized goals through involving a multidisciplinary approach and group support. Health professionals provided services and targeted activities to address participants' goals within four primary areas including communication, health behaviour, life after stroke, and physical fitness. Occupational therapists performed evaluations of self-perceived functional performance, cognitive function, and health status after stroke for clients in the *Next Steps* program. Program members participated in group-based physical activity training sessions supervised by a fitness trainer. Other activities provided by ASF included IADL training, community outings, support groups, and conversation classes.

The American Stroke Foundation has three locations within the Greater Kansas City metropolitan area. ASF clients participating in the *Next Steps* program at any of the three locations provided data for the analysis. The inclusion criteria encompassed individuals who a)were 18 years or older; b)had a diagnosis of stroke; c)participated in an ASF's *Next Steps* program; and d)completed assessment data on all or some of the target outcome measures. There were 43 individuals excluded due to missing data for all outcome measures. The final sample consisted of 25 individuals who met the eligibility criteria.

Instruments

a. Demographic Questionnaire: de-identified data previously collected from ASF clients characterized demographic profiles of individuals with chronic stroke. Data of interest included age, gender, ethnicity, comorbid conditions, duration of time between stroke and joining ASF, and duration of time between stroke onset and assessment on the Canadian Occupational Performance Measure.

b. Canadian Occupational Performance Measure (COPM): The ASF routinely administers this client-centred assessment tool to assess the self-perceived performance of ADLs and satisfaction with performance (Law et al., 1994). The COPM focuses on assessing challenges in the occupational performance of self-care, leisure, and productivity. This instrument also assesses satisfaction with performance, on a scale of 1-10 (1 = low satisfaction; 10 = high satisfaction). A change of two points or more on the COMP's performance or satisfaction score is considered clinically meaningful (Law et al., 2005). The COPM is a valid and reliable instrument (Cup, Scholte op Reimer, Thijssen, & van Kuyk-Minis, 2003).

c. *The Montreal Cognitive Assessment (MoCA)* is a standardized cognitive screening test assessing 8 domains of cognition including visuospatial/executive function, naming, memory, attention, language, abstraction, and orientation (Nasreddine et al., 2005). This cognitive test was routinely administered at ASF as a 10-minute interview. Scores on the MoCA range between 0-30, with a score of 26 or higher considered normal/healthy cognition. The MoCA is both valid and reliable (Wong et al., 2015).

Procedures

De-identified retrospective data from randomly-selected records were provided to the researchers by the American Stroke Foundation. The random selection of the initial sample occurred between January and March 2016 and included records of active members in the *Next Steps* program. Volunteers from the American Stroke Foundation entered the retrospective data using the Research Electronic Data Capture (REDCap) hosted at the University of Kansas Medical Center. REDCap is a secure, web-based application designed to support data capture for research studies (Harris et al., 2009). Assessments were completed at different times during participation in ASF activities, between April 2003 and March 2016. The demographic questionnaire was completed at the time each person joined the ASF, while the COPM assessments were completed at different times for each participant, with the majority having completed their assessments within the first three years after joining ASF. In this study, we used the demographic questionnaire to describe the characteristics of ASF clients and used the COPM scores to evaluate challenging occupations, occupational performance, and satisfaction of those clients when joining the ASF. One researcher applied the eligibility criteria on the initial sample of 68 records. Data from 25 records meeting the inclusion criteria were included in our analysis. We evaluated the reliability of data entry through checking 10 randomly selected records (15%) out of all 68. The accuracy of data entry exceeded our *a priori* criterion of 90%.

Data Analysis

The Statistical Package for the Social Sciences (SPSS, v.23) was used to analyze data. The analysis included descriptive statistics of the sample demographics, MoCA scores, and COPM subscores (*i.e.*, occupational performance and satisfaction with performance domains) to address the first aim of the study. The analysis included descriptions of daily activities perceived as important and challenging as reported on the COPM by ASF participants. These daily activities were classified into seven occupational performance categories (*i.e.,* areas of occupation) as defined by the Occupational Therapy Practice Framework, including ADL, IADL, work, education, leisure & play, rest & sleep, and social participation (AOTA, 2014). The occupational therapy practice framework provides a uniform definition for each occupational performance category addressed by occupational therapy services. We evaluated the reliability of classifying the performance challenges through checking five randomly-selected COPM responses (20%) out of all 25. Two researchers independently classified the occupational performance challenges based on the seven areas of occupation, with 96% agreement. Any disagreement in the classification was discussed until an agreement was reached between both researchers.

Findings

The sample consisted of data collected from 25 individuals with chronic stroke. The descriptive statistics confirmed the majority of participants were men (72%), white (72%), and averaged 64 years of age (range: 45 – 81 years). Participants reported having comorbidities, with hypertension (68%) and diabetes (16%) being the most prevalent. Almost half (48%) of these ASF participants joined the *Next Steps* program six months to six years after their stroke. See Table 1 for full demographic details. The MoCA cognitive function scores varied among participants over a range of normal to severe cognitive limitations ($\bar{x}$ = 22.1 ± 6.258 std. dev.; range: 3–30). The mean COPM performance subscore was 4.1 (± 2.220 std. dev; range 1.3 – 10.0) and the mean COPM satisfaction subscore was 3.9 (± 2.503 std. dev.; range: 1.0 – 10.0).

Participants reported 116 challenging daily activities when assessed on the COPM (see Figure 1). The top three challenges reported were in the areas of IADL, leisure participation, and ADL, respectively. Driving and community mobility were cited as the most frequent challenging activities in IADLs, with twelve participants (48%) citing this as an issue. Employment-seeking was cited by eight participants (36%) as the most frequent challenge in the area of work. Functional mobility was the most frequently reported in ADLs as indicated by seven participants (28%). Reading was most frequently reported in leisure participation by four participants (16%). Speaking and communication were the most reported challenges in social participation as cited by five participants (20%). Two participants (8%) reported difficulties in sleep patterns, and one participant (4%) reported challenges in completing the thesis requirement in graduate education (see Supplemental Table 2).

Discussion

The purpose of this study was to describe the personal characteristics, cognitive function, and self-perceived occupational performance of community-dwelling adults living with stroke. Our findings showed that stroke survivors who sought community-based support were mostly Caucasian men in their sixth decade of age with a history of common comorbidities like diabetes. Those individuals with stroke were not satisfied with their occupational performance and have reported several challenging occupational performance problems. The most frequently reported occupational performance challenges were related to three areas of occupation including instrumental activities of daily living (*e.g*., driving), work (*e.g*., seeking employment), and activities of daily living (*e.g*., walking), respectively.

The demographic and health characteristics of ASF participants with stroke are consistent with stroke literature; stroke frequency was higher in men compared to women, stroke frequency was higher in Caucasians compared to African Americans, and stroke risk was higher with advancing age (Mozaffarian et al., 2015). The files of ASF participants did not include data on other important demographic and health characteristics such as living arrangements, work status, or mobility. Some participants had common comorbidities (*e.g*., diabetes, hypertension), which are also consistent with the stroke literature (Hill, 2014; Magwood, White, & Ellis, 2017). Diabetes and hypertension are modifiable risk factors for stroke (Goldstein et al., 2001). Community-based stroke programs offer services to assist stroke survivors in controlling modifiable risk factors. The Canadian Stroke Best Practice Guidelines recommend that stroke survivors and their families should be assessed and prepared for transitions between care stages through patient education, provision of information, and awareness of community services (Cameron et al., 2016). Spreading awareness about the availability and benefits of long-term community supports could lead to increased utilization of such services by stroke survivors, and therefore provide enhanced opportunities for engagement in the community more rapidly after stroke.

Stroke survivors in this study reported a variety of daily activities they considered important yet found challenging to undertake. There was also a clear variability in reporting the priority and type of challenging daily activities among those individuals. The most frequently reported activities were driving, community mobility, seeking employment, and functional mobility. A common theme among these activities emphasizes personal autonomy and the client's desire to be independent both physically and financially. Prior reports of stroke survivors' experiences have identified the value of mobility (Kristensen, Tistad, Koch, & Ytterberg, 2016), employment (Roth & Lovell, 2014), and autonomy (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015) for people with stroke. One study reported 80% of stroke survivors identified mobility as their main concern for rehabilitation (Kristensen et al., 2016). Seeking employment also was reported as important by the younger participants (45-63 years old) in the Kristensen, et al. study (2016). The variability in reporting the type and priority of challenging daily activities reinforces the need for adopting a personalized client-centred approach in stroke-specific community programs to enhance client-perceived occupational performance and satisfaction.

Providing personalized client-centred service within a group context could also be beneficial for stroke survivors. Evidence from stroke studies of community-based programs has shown beneficial effects of group-based activities for individuals with chronic stroke (Harrington et al., 2010; Ru et al., 2017). Examples of these benefits include decreased social isolation and increased strength, ability to manage self-care needs, and life satisfaction. Our findings indicate that the majority of ASF participants reported leisure participation as an important element of their daily occupations. Leisure activities are enjoyable and provide social, physical, and cognitive health benefits (Pressman et al., 2009). Community-based stroke programs can follow a group-based approach to address occupational performance needs (*e.g.*, leisure activities) of stroke survivors.

The self-perceived performance and satisfaction scores of these ASF participants indicate clients were not satisfied with their occupational performance, yet these individuals were actively engaged in ASF. Contributing factors may include stroke severity, time since stroke onset, and support availability (*e.g*., spouse, family members, or friends). Published evidence suggests stroke severity and poor social support both are associated with reduced functional outcomes after stroke (Saver & Altman, 2012; Glass, Matchar, Belyea, & Feussner, 1993) and with reductions in health-related quality of life (Kruithof, van Mierlo, Visser-Meily, van Heugten, & Post, 2013). Accounting for these variables in future research could enhance understanding of underlying factors influencing perceived occupational performance and satisfaction in the months and years after a stroke.

Limitations and Future Directions

The present study was conducted on retrospective data and using a small sample of participants who voluntarily sought community-based services, and therefore may not be representative of the larger general population of stroke survivors living in their communities. Other limitations include the variability of assessment time on the outcome measures and the lack of information on the other important demographic and health characteristics such as physical abilities, living situation, and depression. However, the present study is important as it explored the needs of a defined population of stroke survivors who sought out and engaged with long-term community supports. These individuals report being determined to be active in their community regardless of the challenges they face on daily basis. We recognize our findings will be enhanced by future research examining longitudinal change in self-perception of the performance of daily activities as the individual progresses from acute to more long-term stages of stroke recovery, particularly if such studies employ a randomized controlled trial, cohort, qualitative, or similar robust designs. Further, using objective measures of functional performance will allow validation of self-reported occupational performance relative to the actual capacity of the individual in addressing these same tasks.

Conclusions

This study emphasizes the importance of understanding self-perceived challenges to occupational performance among a less-studied group of people at longer times following their stroke, who no longer are in the acute or early-recovery phases. The results of this study found individuals with stroke who sought long-term community supports have identified several meaningful yet challenging daily activities in different domains of occupation. These occupational performance challenges mainly encompassed community mobility, employment, functional mobility, and leisure participation. Understanding long-term perceived occupational performance provides direction for health professionals toward addressing possible needs (*e.g.*, physical and emotional) to improve occupational performance and lived experience after stroke. Though there were some study limitations, these results suggest occupational therapists should consider educating stroke survivors about community resources which provide stroke-specific programs for addressing their long-term physical, cognitive, social, and emotional needs.

Key Messages

- Occupational therapists should focus on enhancing community participation of adults with stroke through the development of a group-based, client-centred, and stroke-specific program to support the occupational needs of stroke survivors.
- Awareness efforts targeting first-time stroke survivors should encompass recommendations for gaining early access to community support resources after stroke.

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Table 1

Demographic Variables	Frequencies n, (%)
Mean Age	64 years
std. deviation	± 9.506
range	45 – 81
Gender	
Men	18, (72.0)
Women	7, (28.0)
Ethnicity	
Black or African American	2, (8.0)
White	18, (72.0)
Missing value	5, (20.0)
Other Conditions	
Hypertension	17, (68.0)
Diabetes	4, (16.0)
Seizures	5, (20.0)
Mean # Years between Stroke Onset and Joining ASF	1.0 year
Less 6 months (<0.5 Y)	10, (40.0)
6 months or more (≥ 0.5 Y)	12, (48.0)
Missing value	3, (12.0)
Mean # Years between Stroke Onset and COPM Assessment	2.7 years
Less 6 months (<0.5 Y)	2, (8.0)
6 months or more (≥ 0.5 Y)	17, (68.0)
Missing value	6, (24.0)
Mean MoCA Scores,	22.1
std. deviation	±6.258
range	3.0 – 30.0
Mean COPM Performance subscore	4.1
std. deviation	±2.220
range	1.3 – 10.0
Mean COPM Satisfaction subscore	3.9
std. deviation	±2.503
range	1.0 – 10.0

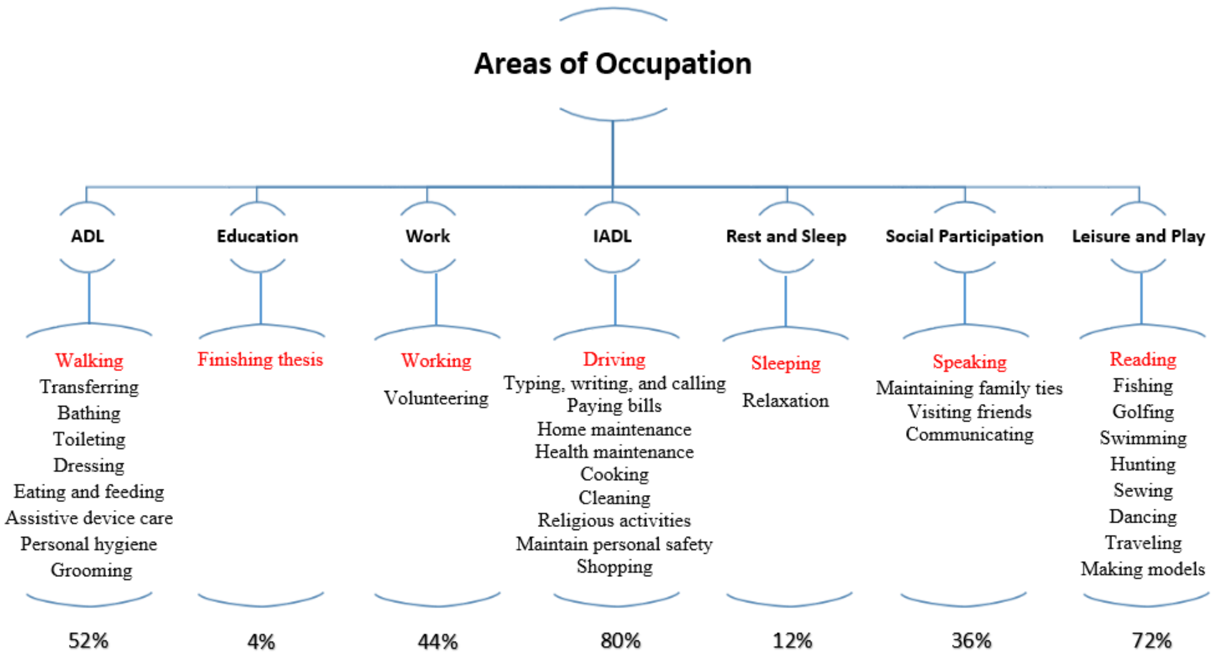
Note. Characteristics of the sample (N = 25); SD = Standard Deviation; Y = Years; ASF = American Stroke Foundation; COPM = Canadian Occupational Performance Measure; MoCA = Montreal Cognitive Assessment.

Table 2

Category	Number (%) of Participants	
1- Activities of daily living (ADLs)	13 (52)	
Functional mobility	3 (12) – Transfer;	4 (16) – Walking
Dressing	4 (16)	
Bathing	3 (12)	
Personal hygiene and grooming	2 (8)	
Toileting	1 (4)	
Swallowing/eating	1 (4)	
Feeding	1 (4)	
Personal device care	1 (4)	
2- Instrumental activities of daily living (IADLs)	20 (80)	
Driving and community mobility	11 (44) – Driving;	1 (4) – Bicycling
Meal preparation and cleanup	5 (20)	
Religious and spiritual activities and	5 (20)	
Communication management	4 (8) – Writing;	1 (4) – Phone calls
Home establishment and management	4 (16)	
Health management and maintenance	4 (16)	
Financial management	2 (8)	
Safety and emergency maintenance	2 (8)	
Shopping	1 (4)	
3- Rest and Sleep	3 (12)	
Sleep participation	2 (8)	
Rest	1 (4)	
4- Education	1 (4)	
Formal educational participation	1 (4)	
5- Work	11 (44)	
Employment seeking and acquisition	9 (36)	
Volunteer participation	4 (16)	
6- Leisure and Play	18 (72)	
Leisure participation	5 (20) – Playing sports	2 (8) – Fishing
	4 (16) – Reading;	2 (8) – Hunting
	4 (16) – Outdoor Act;	1 (1) – Comp. Games
	3 (12) – Golf;	1 (4) – Sewing
	2 (8) – Swimming	1 (4) – Dancing
	2 (8) – Making models;	1 (4) – Art
7- Social Participation	9 (36)	
Family and Friends	4 (16)	
Speaking and communicating	5 (20)	

Note. Occupational performance challenges classified based on the areas of Occupation in the Occupational Therapy Practice framework (N = 25).

Figure 1



Note. Challenging daily occupations reported by community-dwelling adults living with stroke. The percentages of each area of occupation represent the proportion of participants who reported having challenging activities under that particular area of occupation. Activities highlighted with red are the most frequently reported under each category.

Chapter 3

PREDICTIVE MODELS OF FUNCTIONAL PERFORMANCE FOLLOWING STROKE

Abstract

Cerebrovascular disease is a serious health care concern and a major cause of disability in the United States. Stroke is one form of cerebrovascular disease that impacts the individual's ability to perform activities of daily living. Predicting functional performance of people with stroke assists health care professionals in optimizing the delivery of health services to the affected individuals. The primary purpose of this study is to construct, internally validate, and test predictive models of Motor FIM and of Cognitive FIM subscores among individuals with stroke. A second purpose is to explore the relation among personal characteristics, health status, and functional performance of daily activities after stroke. This study used a retrospective chart review to conduct a secondary analysis of data obtained from the Healthcare Enterprise Repository for Ontological Narration (HERON) database. The initial HERON data extract encompassed 1192 records and the final sample consisted of 207 participants who were mostly white (74%) males (55%) with a diagnosis of ischemic stroke (77%). The outcome measures collected from HERON included performance scores on the National Institute of Health Stroke Scale (NIHSS), the Glasgow Coma Scale (GCS), and the Functional Independence Measure (FIM). The data analysis plan included descriptive statistics, Pearson correlation analysis, paired t-test, and Stepwise regression analysis. The results showed the significant predictors of discharge Motor FIM subscores were age, baseline Motor FIM subscores, discharge NIHSS scores, and comorbid electrolyte disorder ($R^2 = 0.57$, $p < 0.026$). Significant predictors of discharge Cognitive FIM subscores were age, baseline cognitive FIM subscores, client cooperative behavior, comorbid obesity, and the total number of comorbidities ($R^2 = 0.67$, $p < 0.020$). Functional performance on admission was significantly associated with age ($p < 0.01$), stroke severity ($p < 0.01$), and length of hospital stay ($p < 0.05$). Most stroke survivors exhibited significant improvements in functional performance after 2-4 weeks of acute inpatient rehabilitation ($p < 0.01$). In conclusion, our predictive models show that a younger age, good motor and cognitive abilities on admission, mild stroke severity, fewer comorbidities, and positive client attitude all predict favorable functional outcomes after inpatient stroke rehabilitation. This study provides health care professionals with evidence to evaluate predictors of favorable functional outcomes early at stroke rehabilitation, to tailor individualized interventions based on their client's anticipated prognosis, and to educate clients about the benefits of making lifestyle changes to improve their anticipated rate of functional recovery.

Keywords: Stroke, Rehabilitation, Predictors, Functional Performance, Electronic Medical Records, HERON.

Introduction

Stroke is a common medical condition among the elderly (Prince et al., 2015). The prevalence of stroke was 0.7-2 % among adults aged 18-64 years and 8.3% in older adults over the age of 65 years living in the United States in 2010 (Centers for Disease Control and Prevention, 2012). This condition impacts participation in activities of daily living (ADLs) and quality of life (Lynch et al., 2008; Sturm et al., 2002). Predicting functional performance of people with acute stroke assists health care professionals in designing proper intervention plans. The four objectives of this study were to 1) describe the functional independence level of people within two weeks of stroke onset; 2) explore the relation among personal characteristics, health status, and functional performance after discharge from inpatient rehabilitation; 3) evaluate changes in functional performance of people with stroke between admission to inpatient rehabilitation and discharge; and 4) construct, internally validate, and test predictive models of functional outcomes in people with stroke. The findings of this study will provide evidence-based recommendations for improving current stroke care practices.

Literature Review

Stroke encompasses a wide array of cerebrovascular disorders, representing a major healthcare concern in the United States (Santulli, 2013). More than 795,000 people have a stroke each year with estimated annual costs of $34 billion for medical care and lost wages (CDC, 2015; Mozaffarian et al., 2015). The vast majority of stroke cases are ischemic which constitutes (87%) of all strokes, while the remaining cases are mostly hemorrhagic strokes (CDC, 2105). Living with stroke can be challenging due to residual physical (Danielsson, Willen, & Sunnerhagen, 2012), cognitive (Schaapsmeerders et al., 2013), or psychosocial (Martinsen, Kirkevold, Bronken, & Kvigne, 2013) effects on functioning.

The International Classification of Functioning, Disability, and Health (ICF) is a common framework for describing the functional performance of individuals with different conditions including stroke (World Health Organization, 2001). Functional performance of daily activities encompasses a complex interaction among body structures, body functions, activities, and participation within environmental contexts according to the ICF (see Figure 1). The ICF highlights the multilayered effect of stroke on the individual's health and participation (Alguren, Lundgren-Nilsson, & Sunnerhagen, 2010; Leonardi et al., 2009). Studying factors influencing the functional performance of stroke survivors offers valuable information for improving the assessment process, care planning, and intervention implementation.

Stroke can adversely influence the functional performance of daily activities (Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Lee et al., 2015) and quality of life (Gbiri & Akinpelu, 2013; Haacke et al., 2006). Prior research has confirmed people with stroke participate less frequently in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) compared to people without stroke (Wolf, Chuh, Floyd, McInnis, & Williams, 2015). ADLs and IADLs are personal activities done on a daily basis to maintain health and well-being at home and in the community, such as eating, dressing, cooking, and driving (American Occupational Therapy Association, 2014). More than 50% of stroke survivors require assistance in performing ADLs within the first year after stroke onset (Hartman-Maeir et al, 2006). The poor functional performance of ADLs after stroke was linked to poor quality of life (Byeon & Koh, 2016; Heikinheimo & Chimbayo, 2015).

Functional performance is the ability to successfully carry out daily activities to maintain health and well-being. Examples of these daily activities include ADLs, IADLs, work, education, and leisure activities. This definition of functional performance is consistent with that provided by the ICF (World Health Organization, 2001). Many factors influence the functional performance of daily activities after stroke. These factors include the individual's demographic characteristics (van den Bos, Smits, Westert, & van Straten, 2002; Yan et al., 2017) and health status at stroke onset (Coupar, Pollock, Rowe, Weir, & Langhorne, 2012). Demographic characteristics include age, gender, educational level, and social and economic status, while health status includes clinical characteristics such as stroke severity, cardiac health, obesity, blood pressure, and initial motor score. Other factors that influence health outcomes post-stroke include functional performance abilities during the first few weeks of recovery after stroke onset (Hanger, Wilkinson, & Mears, 2010). These factors could serve as predictors of health outcomes after discharge from acute stroke rehabilitation.

Identifying early predictors of health outcomes after stroke help in tailoring appropriate rehabilitation interventions. Enabling people to participate in daily activities, routines, and roles within their home and community environments is the end goal of occupational therapy rehabilitation (American Occupational Therapy Association, 2014). Continuous development of evidence-based rehabilitation protocols to achieve these goals requires a clear understanding of how the client's overall health at stroke onset as well as post-stroke health affects functional outcomes. Previous studies of predictive models evaluated very specific health outcomes after stroke. These studies focused on health outcomes like survival (Counsell, Dennis, McDowall, & Warlow, 2002; Muir, Weir, Murray, Povey, & Lees, 1996; Wang, Rudd, Wolfe, & Wang, 2015), cognitive function (Suzuki et al., 2013), mobility (van de Port, Kwakkel, Schepers, & Lindeman, 2006), and functional performance as measured by Barthel Index (Adams et al., 1999; Baird et al., 2001; Bang et al., 2005; Counsell et al., 2002; Johnston et al., 2003; Tilling et al., 2001; Weimar et al., 2004). While other studies evaluated the overall functional performance using

Barthel Index, this study focused on evaluating motor and cognitive domains of function using the Functional Independence Measure.

Predictive models of functional outcomes after stroke have identified a variety of predictors, without unanimous agreement emerging on a set of best predictive variables. For example, commonly reported predictors have included age (Counsell et al., 2002; Johnston et al., 2000; Reid et al., 2010; Wang et al., 2015), stroke severity (Adams et al., 1999; Baird et al., 2001; Bang et al., 2005; Edwardson et al., 2016; Johnston et al., 2000; Muir et al., 1996), and comorbidities (Andersen, Andersen, & Olsen, 2011; Johnston et al., 2000; Saposnik et al., 2011). Other less frequently identified predictors have included living arrangement (Counsell et al., 2002), pre-stroke independence level (Reid et al., 2010), arm power (Counsell et al., 2002; Reid et al., 2010), stroke subtypes (Wang et al., 2015), and history of stroke (Johnston et al., 2000).

Rationale and Significance

Most prognostic studies of functional performance at early phases of stroke recovery have insufficient methodological quality, and therefore provide only limited evidence to support application in stroke rehabilitation (Veerbeek, Kwakkel, van Wegen, Ket, & Heymans, 2011). Veerbeek et al. (2011) suggested future studies should focus on the early prediction of functional performance using simple models leading to relevant clinical applications. The research study described here used stepwise regression modeling to investigate the early prognostic ability of many variables in predicting functional performance following inpatient stroke rehabilitation. In addition, the present research evaluated the predictive power of modifiable socioeconomic factors while previous studies focused on non-modifiable demographic characteristics. Accounting for social, economic, and medical predictors early in stroke recovery may enhance the ability of insightful clinicians to set attainable rehabilitation goals and to achieve optimal and shared decisions with stroke survivors and their caregivers.

This study applied a pragmatic approach of using pre-existing clinical data from electronic medical records (EMR) to conduct research. The novelty of the present study is the use of a large number of independent variables to develop predictive models, with variables including socioenvironmental factors based on the ICF framework. A recent review recommended building on the previous work of predictive modeling of outcomes after stroke (Fahey et al., 2018). We followed this approach by incorporating a group of demographic and health factors deemed predictive of survival in the stroke literature. We expanded our selection of potential predictors to include a variety of social and environmental factors present in a retrospective database obtained from a large, regional health system. This research study also evaluated the motor and the cognitive components of functional performance obtained with routine clinical assessments. These outcomes are used in the clinical evaluation of people with stroke during inpatient rehabilitation and are readily available in the electronic medical records of hospitalized stroke survivors.

Research Questions

This study was designed to address four principal research questions:

1. What is a typical level of functional performance in the initial 2 weeks after stroke onset?
2. What is the relation among personal characteristics, health factors, and functional performance status within the first 2 weeks after hospitalization because of stroke?

3. What changes in functional performance occur between admission to inpatient stroke rehabilitation and discharge (typically 4-6 weeks after stroke onset)?
4. What demographic, socioeconomic, or medical factors obtained acutely (1-2 weeks after stroke) predict favorable functional performance upon discharge from inpatient rehabilitation (typically 4-6 weeks after admission)?

I expected to find people with stroke to have varying levels of functional performance in the initial two weeks of stroke onset, consistent with numerous prior studies in this literature (question 1). I hypothesized some modifiable social (e.g. living arrangement), economic (e.g. employment), and health (e.g. body mass index) profiles at stroke onset will be correlated with functional performance (question 2). I further hypothesized people with stroke will demonstrate improvements in functional performance of daily activities after discharge from an inpatient rehabilitation setting (question 3). Additionally, I hypothesized some of these characteristics will predict the functional performance when assessed four to six weeks after a stroke (question 4). Implications of these findings for clinical practice then are discussed, followed by an exploration of protocol modifications for clinical management of acute stroke and for stroke rehabilitation procedures as they now may be practiced.

Methods

Design

This study used a retrospective chart review design. A secondary analysis was conducted on data extracted from the Healthcare Enterprise Repository for Ontological Narration (HERON; Waitman, Warren, Manos, & Connolly, 2011). The HERON database integrates de-identified clinical data from seven different regional sources including hospital electronic medical record systems (e.g. EPIC ™ & O2™), clinical billing system (e.g. IDX), the University of Kansas

(KU) Hospital Cancer Registry, KU Biospecimen Repository, Social Security Death Index, University of Kansas Health System (KUHS) Consortium, and the Research Electronic Data Capture (REDCap) web application (CTSA Award # UL1TR000001). The EPIC data from the University of Kansas Health System is one of the primary sources for HERON data and for this study.

Participants

The final sample included records of 207 individuals with acute stroke who were admitted to the University of Kansas Health System (KUHS) between January 2013 and July 2017. The KUHS is a full spectrum healthcare provider to urban, suburban, and rural settings in Kansas and Missouri. The inclusion criteria encompassed individuals who a) were 18 years or older; b) had a diagnosis of first-time stroke (The *International Classification of Diseases*, 9th revision [ICD-9] codes #430.x to #438.x and ICD-10 codes #I60.x to #169.x); c) had completed assessment data on measures of stroke severity and functional performance. Exclusion criteria covered individuals with stroke who a) have two or more strokes; b) have other diagnoses of neurological conditions which may mimic stroke symptoms or interfere with the individual's cognitive or physical abilities at the time of assessment (e.g. Traumatic Brain Injury, Alzheimer's disease, or Parkinson's disease); c) have severe physical limitations which affect functional performance (e.g. amputations, limited range of motion, low back pain, or fractures).

Setting

This study was conducted at the University of Kansas Medical Center (KUMC) in Kansas City, Kansas. The study was implemented in collaboration with 1) the Medical Informatics division, which oversees the HERON database at KUMC and 2) the University of Kansas Health

System, where clinical services were provided and which houses electronic medical records systems (Epic & O2).

Study Variables

The main study variables included the demographic, social, health factors at stroke onset (independent variables), and functional performance of daily activities (dependent variables) after stroke (see Figure 2).

Independent (Predictor) Variables. The independent variables included demographic characteristics, social and environmental factors, and health variables (see Table 1). The instruments used to collect data in client charts included a demographic questionnaire, the Glasgow Coma Scale (GCS) to assess the level of consciousness after head injury, and the National Institute of Health Stroke Scale (NIHSS) to evaluate stroke severity.

Dependent (Outcome) Variables. The dependent variables were related to the capacity for functional performance of daily activities as measured by the Functional Independence Measure (FIM). The composite FIM score may be separated into a motor and a cognitive subscale. The motor subscale has 13 items that evaluate domains of self-care, sphincter control, transfers, and locomotion. The cognitive subscale has 5 items that evaluate communication and social cognition. The motor and cognitive subscores served as the independent variables in this study.

Research Instruments

This study included a retrospective chart review of data collected using the following research instruments:

a. *Demographic and Health Questionnaire:* existing demographic and medical history data previously collected in HERON will be used to characterize the demographic profile of individuals with acute stroke. The demographic and medical characteristics of interest include age, gender, race/ethnicity, marital status, educational level, living arrangement, BMI, insurance status, diagnosis, comorbid conditions, and length of stay. This questionnaire is specific to the KU Health System and is not a standardized or published tool.

b. *Glasgow Coma Scale (GCS):* is a 15-item instrument to assess the level of consciousness after brain injury (Teasdale & Jennett, 1974). GCS has three subscales: 1) motor response; 2) verbal response; and 3) eye opening. The total GCS scores range between 3 and 15 with greater scores indicating higher levels of consciousness. Based on GCS score, brain injury is classified into three categories: severe (GCS score < 9), moderate (9-12), and mild (≥13). This observer rating scale takes about 15 minutes to administer and it has been found to be a reliable instrument (Reith, Van den Brande, Synnot, Gruen, & Maas, 2016).

c. *National Institute of Health Stroke Scale (NIHSS):* this 15-item tool is used to evaluate the severity of stroke (Brott et al., 1989). The NIHSS scores range between 0 and 42 with higher scores indicating greater severity. Stroke severity using this scale is classified into 4 categories: very severe (NIHSS score>25), severe (15-24), mild to moderate (5-14), and mild (1-5). It takes about 5 minutes to administer this instrument, which has been found to be both valid (Kasner et al., 1999) and reliable (Goldstein & Samsa, 1997).

d. *Functional Independence Measures (FIM):* is an 18-item instrument to assess the level of independence and functional ability to carry out daily activities (Granger, Hamilton, Keith, Zielezny, & Sherwins, 1986). FIM has two main subscales: 1) Motor FIM subscale (13 items); and 2) Cognitive FIM subscale (5 items). The Motor FIM subscale encompasses four domains of physical functioning including Self Care, Sphincter Control, Transfer, and Locomotion. The Cognitive FIM subscale contains two domains of cognitive functioning including Communication and Social Cognition. The composite score of FIM ranges from 18 to 126 with higher scores indicating a greater level of independence. It takes approximately 30 minutes to administer this instrument in an interview. This instrument has good psychometric properties and was found to be reliable, valid, and sensitive to change (Hsueh, Lin, Jeng, & Hsieh, 2002), and has good inter-rater reliability with kappa values of 0.56 to 0.95 (Haas, Mayer, & Evers, 2002; Ottenbacher, Hsu, Granger, & Fiedler, 1996).

Procedures

This study was approved by the KUMC's Internal Review Board (IRB). The Medical Informatics division at KUMC provided identifiable clinical data from HERON containing KUHS clients' medical record numbers. The HERON dataset included the predictor variables (demographic, social, and medical characteristics) of people with stroke, who had their assessments completed during hospitalization between January 2000 and July 2017.

The HERON dataset constituted clinical data for the development and validation of a predictive model. Despite being a rich reservoir of clinical data, the HERON database did not uniformly include all assessments (i.e. NIHSS & FIM) necessary for executing this study. The NIHSS assessments were performed during admission to the emergency department, while the FIM evaluations were administered during admission and discharge to inpatient stroke rehabilitation. These assessments only were documented in the medical charts of the stroke clients, as part of the KUHS electronic medical records system and separate from the HERON system. NIHSS and FIM assessments, therefore, were extracted manually from KUHS electronic medical records (Epic & O2) and integrated with information from the HERON database.

The initial HERON data extract encompassed 1192 record of individuals with stroke. After implementing the eligibility criteria, the number of records decreased to 579. These records were reviewed carefully, followed by manual data extraction of the NIHSS and FIM assessments. In addition, all missing HERON data was completed by manual review, leading to a perfectly complete dataset of 207 de-identified records with HERON, FIM, and NIHSS variables (see Figure 3). I conducted a comparison between the initial and final samples to confirm that our eligibility criteria did not affect the sample selection in this study. The results of this comparison revealed consistent similarities in all demographics (see Table 2). For example, the mean age of the initial sample was 66 years compared to 64 years in the final sample. Therefore, the demographic characteristics of the initial sample were similar to the final study sample.

Data Analysis

The Statistical Package for the Social Sciences (SPSS v.23) was used to analyze data. The data analysis plan included descriptive statistics of the sample demographics, health characteristics, and functional performance of daily activities. The descriptive statistics consisted of calculating means and standard deviations for continuous data (e.g. age) and calculating percentages for categorical data (e.g. gender). Prior to conducting further analyses, assumptions of normality, linearity, and homoscedasticity were evaluated. Preparing data for analysis also included inspecting outliers and handling missing data through 1) manual data extraction of missing values from the electronic medical records; and 2) case deletion of individual records having missing data on main outcome variables.

An accepted method for building a robust predictive model involves dividing the main dataset into parts for validation purposes (Raykar & Saha, 2015). This strategy is known as data splitting (Picard & Berk, 1990), and entails reserving one part of the dataset for model fitting and another part for model validation (Faraway, 2016). Using this split-sample approach allows objective evaluation of the model performance using similar, yet independent, data (Picard et al., 1990). The study dataset was divided into two components: a training set for fitting the predictive model and a validation set for selecting the best model. There is no definitive proportion used in splitting data, with common options being 80/20, 60/40, and 50/50 (Brown, 2014). I chose an 80/20 split, with the main dataset randomly sorted into the 80% for training and the 20% for validation (see Figure 3).

The analysis included descriptive statistics of stroke survivors' functional performance status after stroke onset to inform care providers about the immediate impact of stroke on the individual's functioning (aim 1). The next step was testing the associations between main study variables, done using Pearson correlation analysis (aim 2). Furthermore, a paired t-test incorporating multiple subscales evaluated changes in functional performance between admission and discharge from inpatient stroke rehabilitation (aim 3). Finally, predictive models of functional performance were constructed using stepwise regression analysis to identify the best set of independent predictors of motor and cognitive domains of functional performance on discharge from inpatient rehabilitation (aim 4). Stepwise regression analysis assesses a large number of independent variables for entry or removal from the model, to provide a product having the most predictive power (Alexopoulos, 2010). After fitting the regression model using the fitting subset (constituting 80% of the main dataset), the regression model was tested using testing subset (the remaining 20% of the main dataset). The performance of the final fitted model then was evaluated by reassembling the fitting and testing subsets (100% of the main dataset) for a final analysis of the model. The significance level for all analyses was set *a priori* at $\alpha = 0.05$.

Sample Size Determination

Multiple regression analysis requires an adequate sample size to achieve an accurate estimation of regression coefficients and to minimize bias in the analysis (Kelley & Maxwell, 2003). The first step in determining the required sample size was calculating the total number of independent variables used in the regression model. There were 8 continuous and 25 categorical variables used. Each categorical variable had two or more categories (e.g. marital status categories include single, married, and divorced). This resulted in a total of 65 variables in the final regression analysis, with eight continuous variables and 57 dummy-coded categorical variables. After running the univariate analysis, only 23 out of 65 dummy-coded variables were significantly associated with the outcome variables.

The second step in the analysis was to calculate the minimum number of participants required in the sample to achieve significance. Sample size in regression analysis often is based on the ratio of the number of participants to the number of variables (more accurately, the number of parameters). This ratio is referred to as subjects per variable (SPV; Austin & Steyerberg, 2015) or events per variable (EPV; Ogundimu, Altman, & Collins, 2016). A widely accepted rule of thumb for EPV is 10 (Harrell, Lee, Matchar, & Reichert, 1985; Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996; Vittinghoff & McCulloch, 2007). However, simulation studies of regression models suggested using a range of EPV from 5 to 20 may be suited for reliable model development (Harrell et al., 1985; Peduzzi, Concato, Feinstein, & Holford, 1995), although using a large sample with high EPV yields more reliable results with less estimation bias (Steyerberg, Eijkemans, & Habbema, 1999). The minimum required sample size for the main dataset was 230 participants. The main dataset was split as 80% (184 participants) for model fitting and 20% (46 participants) for model testing to demonstrate internal validation.

Results

Descriptive statistics of the final study sample confirmed a majority of participants were males (55%), white (74%), non-Hispanic (93%), and had a mean age of 64 years (see Table 3). Participants in this sample were mainly Kansas residents, living with their spouse, in a home setting within 50 of KU hospital, where they received medical and rehabilitation services for stroke management (see Table 4). The majority of our sample (77%) had an ischemic stroke affecting the left side of their body. Almost all participants (92%) had one or more comorbidity including diabetes, hypertension, anemia, and depression (see Table 5). The mean length of inpatient hospital stay was eight days ($\bar{x}$ = 8 ± 7 std. dev.; range: 1 - 52) and the mean length of stroke rehabilitation was sixteen days ($\bar{x}$ = 16 ± 15 std. dev.; range: 1 - 91).

The FIM composite score varied among participants upon admission to inpatient rehabilitation ($\bar{x}$ = 62.0 ± 19.9 std. dev.; range: 18 - 112). The mean motor FIM subscale was 41.4 (± 15.5 std. dev; range 7 - 85) and the mean cognitive FIM subscale was 20.7 (± 7.3 std. dev.; range: 5 - 35). Both subscales were significantly and proportionally associated with each other and with the composite score. A comparison of the FIM scores by the length of acute inpatient hospital stay showed that participants who stayed for less than four days had significantly higher FIM composite scores compared to participants who were hospitalized for eight or more days after stroke (p = 0.004). This comparison also revealed similar results for motor (p = 0.039) and cognitive (p = 0.009) FIM subscales when compared by length of acute inpatient stay (see Figures 4 & 5).

A Pearson correlation analysis evaluated the relation among personal characteristics, health status, and FIM scores on admission to inpatient rehabilitation (see Table 7). The correlation analysis revealed a strong positive association between FIM composite scores on admission to rehabilitation and both motor (rs =0.95, $p < 0.001$; n = 206) and cognitive (r = 0.73, $p < 0.001$; n = 207) FIM subscores (the motor subscore contributes disproportionately to the composite FIM with 91/126 points; the cognitive subscore contributes 35/126 points). There was a moderate negative association between FIM composite scores on admission to rehabilitation and NIHSS scores ($r = -0.50$, $p = 0.001$; n = 161) on admission to acute care. There also was a weak negative association between FIM composite score and age ($r = -0.14$, $p = 0.043$; n = 207), and between FIM composite score and acute inpatient length of stay ($r = -0.28$, $p < 0.001$; n = 207).

The correlation analysis also evaluated the relation between FIM composite scores on admission to inpatient rehabilitation and at discharge from that service. The results showed a strong positive association between FIM composite scores on admission and discharge ($r = 0.76$, $p < 0.001$; n = 207). Further analysis of this relation included a comparison of FIM scores using a paired *t*-test to evaluate the change in FIM scores between admission and discharge from rehabilitation (see Figure 6). The results showed that stroke survivors had significantly higher FIM composite scores on discharge from rehabilitation (t (205) = -21.7, $p < 0.001$). There was a significant increase in all FIM domains and subscale scores on discharge including motor subscale (t (205) = -11.5, $p < 0.001$) and cognitive subscale (t (205) = -21.5, $p < 0.001$). The mean difference between baseline and discharge FIM scores was both statistically significant ($p < 0.001$) and clinically meaningful for motor FIM subscale, cognitive FIM subscale, and composite FIM score (see Figure 7).

Motor FIM Model

Univariate and stepwise regression analyses evaluated the predictive ability of personal and health factors for estimating Motor FIM subscores at discharge from inpatient rehabilitation.

Univariate analysis of demographic and health variables revealed 23 predictors that were significantly associated with the motor FIM subscores (see Tables 7). Stepwise regression analysis then was used to build a predictive model of motor FIM subscores at discharge from inpatient rehabilitation, based on stroke survivors' demographic and health characteristics on admission (see Figure 8). A regression model was fitted for the motor FIM subscores ($R^2 = 0.65$, $p < .001$). There were six significant predictors of discharge motor FIM subscores; ranked in order of predictive strength these include baseline motor FIM subscore, stroke severity NIHSS score on discharge from acute care, age, having Fluid and Electrolyte Disorder, having a stroke to the left hemisphere that affects the right side of the body, and functional independence on admission to acute care (see Table 8). Considering the baseline motor FIM subscores alone explained 53% of the variance for the Motor FIM subscores (see Figure 9), while the remaining five predictors explained an additional 12% of that variance.

The fitted model for Motor FIM subscale was tested successfully using the reserved 20% sample, consisting of 42 participants (see Table 9). The motor FIM model yielded a significant regression model ($R^2 = 0.55$, $p < 0.001$). This model testing revealed two significant predictors of motor FIM subscore at discharge including baseline motor FIM subscore and right affected side, respectively. The fitted model was then validated using the whole combined sample of 207 participants. The results of the model validation yielded a final model of four significant predictors ($R^2 = 0.57$, $p < 0.026$). These four predictors are the baseline Motor FIM subscore, discharge NIHSS, age, and comorbid electrolyte disorder (see Table 10). The baseline motor FIM subscores remained the strongest predictor in the validation process as it accounted for 51% of the variance for motor FIM subscore at discharge. All variable inflation factor (VIF) values were less than 1.2 in the final fitted and tested models, indicating that multicollinearity among the predictors did not influence the regression estimates.

Cognitive FIM Model

Univariate and Stepwise regression analyses also were used to build and test a predictive model of Cognitive FIM subscores at discharge from inpatient rehabilitation using the same process outlined above. Univariate analysis showed that 21 personal and health factors were significantly associated with the cognitive FIM subscores (see Tables 11). Those variables were entered into Stepwise regression to build the predictive model (see Figure 10). A significant regression model was fitted for Cognitive FIM subscores ($R^2 = 0.70$, $p < 0.001$). The five significant predictors were baseline cognition FIM subscore, baseline age, cooperative client behavior, comorbid obesity, and the total number of comorbidities, respectively. The baseline Cognitive FIM subscore was the strongest predictor as it alone explained 61% of the variance for the Cognitive FIM subscores (see Figure 11). The remaining four predictors explained an additional 9% of that variance (see Table 12).

The fitted model for cognitive FIM subscores also was tested successfully (see Table 13). The model testing analysis yielded a significant regression model for cognitive FIM subscores ($R^2 = 0.53$, $p < 0.001$). However, there was only one significant predictor of cognitive FIM subscore at discharge among the five predictors from the model fitting model. Baseline cognitive FIM subscore was the only significant predictor in the tested model ($B = 0.65$, $p < 0.001$). The fitted and tested model was then validated using the whole combined sample of 207 participants. The results of the model validation yielded a final model of five significant predictors ($R^2 = 0.67$, $p < 0.020$). The five predictors were baseline cognition FIM subscore, baseline age, cooperative client behavior, comorbid obesity, and the total number of comorbidities (see Table 14). The baseline cognitive FIM subscores remained the strongest predictor in the validation process as it accounted for 61% of the variance for cognitive FIM subscore at discharge.

Discussion

This study aimed to explore demographic and health factors obtained early in post-stroke recovery that predict functional performance of stroke survivors after discharge from inpatient rehabilitation. Identifying these factors encompassed a comprehensive evaluation of the relation among potential predictors with functional performance to construct a robust predictive model of motor and cognitive domains of function. This research effort began with a thorough description of the demographic, environmental, and medical characteristics of our sample. The demographic characteristics of this study sample were similar to the general stroke population in the United States. The mean age of participants in this study was 64 years (SD = 13.9) and was similar to the mean age of the general stroke population (69 years, SD = 16.9; Kissela et al., 2012). Studies of temporal trends in stroke incidence have found rates observed in young adults are on the rise (Bejot, Bailly, Durier, & Giroud, 2016), with the mean age at first stroke decreasing by three years between 1994 and 2005 (Kissela et al., 2012). We compared our sample to Kissela et al. (2012) sample and found a trend toward increasing stroke cases at a younger age, with 25% of our sample in 2017 being less than 55 years old compared to 19% in 2005. This observation is of great public health significance because strokes in younger clients lead to a greater lifetime burden on individuals, families, and communities. The total annual burden of stroke in the United States is estimated at $33.9 billion including costs of care and lost wages (Benjamin et al., 2017).

Our findings showed 77% of the cases were ischemic strokes compared to 87% in the general stroke population (Benjamin et al., 2017), with our dataset having a higher proportion of hemorrhagic strokes. Hemorrhagic strokes are more severe in nature than ischemic strokes (Andersen, Olsen, Dehlendorff, & Kammersgaard, 2009). The stroke literature showed that greater stroke severity was associated with worse functional outcomes after stroke (Saver & Altman, 2012), and therefore, a sample population with a greater proportion of hemorrhagic strokes may have accounted for lower FIM scores in our sample upon admission to inpatient rehabilitation. On the other hand, individuals with hemorrhagic strokes exhibit a greater response to therapeutic rehabilitation and functional prognosis than individuals with ischemic stroke (Paolucci et al., 2003). In addition to the stroke type and severity, we compared the gender and race proportions between our sample and the general stroke population. The observed proportion of strokes in the present study was higher in men (55%) than women (45%), as has previously been reported (Appelros, Stegmayr, & Terent, 2009; Caso et al., 2010; Reeves et al., 2008). Moreover, the incidence of a first stroke was higher among African-Americans compared to Whites (Mozaffarian et al., 2015).

The presence of comorbidities is important to consider as these conditions may hinder functional recovery after stroke (Karatepe, Gunaydin, Kaya, & Turkmen, 2008). Analysis of the health characteristics reported by our participants showed many did have comorbidities. Some of these comorbidities have been reported in the stroke literature such as hypertension, diabetes, and obesity (O'Donnell et al., 2010; Pan, Sun, Okereke, Rexrode, & Hu, 2011). Other less commonly reported comorbidities reported by our study participants included peripheral vascular disease, valvular disease, hypothyroidism, psychosis, rheumatoid arthritis, and lymphoma. Co-occurring conditions such as these may mask or exacerbate the effects of the stroke (Institute of Medicine, 2011). At the same time, the presence of co-morbidities may delay the course of recovery due to added physical or cognitive limitations. For example, a client with both a pre-existing mental health condition (depression or schizophrenia) and a stroke may take a longer time in rehabilitation to achieve functional gains relative to a stroke client who has a comparable injury but does not have an associated psychological disorder (Chemerinski, Robinson, & Kosier, 2001). A comprehensive evaluation of the individual's comorbid conditions is crucial in determining the actual impact of stroke on the individual's life and skills. It allows health care professionals to make informed clinical decisions during the intervention planning, to anticipate the course of recovery and rehabilitation, and to anticipate challenges lingering in the home environment after discharge.

The first aim addressed in the present study was to describe the functional performance of stroke survivors upon admission to inpatient rehabilitation. The admission FIM scores varied among participants indicating different levels of functional performance. This finding is aligned with another report of functional performance post-stroke (Abdul-sattar & Godab, 2013), although these authors report higher admission FIM scores than exhibited by participants in our sample. Perhaps the lower admission FIM scores in our sample were because more of these participants had hemorrhagic strokes, which are known to cause more severe impairments. Almost one-quarter of our participants had hemorrhagic strokes and this high proportion might explain lower functional performance on admission to rehabilitation. Another interpretation includes the considerable heterogeneity in clinical characteristics among stroke survivors such as infarct size, hemorrhage location, vascular anatomy, premorbid conditions, affected brain region, previous brain function, and spontaneous recovery. Different brain regions control unique aspects of functioning and, therefore, the impact of stroke on functional performance is partially determined by the location of injury (Cheng et al., 2014), and spontaneous recovery occurs with substantial variability among stroke survivors during the first few weeks after stroke onset

(Cramer 2008). The present study identified factors which may explain the variability in functional performance scores including age, stroke severity, comorbid conditions, and length of stay in acute care.

Stroke also impacts functioning with a marked variability in the length of hospital stay during acute stroke management (Kim, Hwang, Oh, & Kang, 2013). Further analysis of admission FIM scores for our subjects revealed that participants with a hospital stay of fewer than four days had higher levels of performance compared to participants who stayed for weeks. By contrast, a prior report of the relation between acute LOS and admission FIM did not find any differences between FIM scores of individuals who had short or longer acute length of stay [LOS] (Ng et al., 2016). Our study defined a short acute LOS as four days or less compared to seven days in Ng et al. (2016). We divided LOS into four groups (i.e. 1-3 days, 4-7, 8-15, and 16 or more) in our sample to provide a more specific description of functional performance for participants in each group. Different definitions for short LOS lead to these inconsistent results; we obtained results having no significant findings when we used a similar definition of seven days as a “short” LOS. It is plausible that developments in stroke rehabilitation over the past decade also may have accounted for the conflicting results regarding LOS and FIM scores. Our data was collected for stroke survivors who received services between 2013 and 2017, whereas Ng et al. (2016) collected data for stroke participants between 2004 and 2009. The results of Ng et al. (2016) also indicate that acute rehabilitation and LOS were significantly shorter for stroke admissions after 2007. Changes in insurance coverage and fees may have contributed to shorter LOS among stroke survivors. For example, Medicare law limits the amount of money the government pays for medically necessary therapy services (e.g. occupational therapy and physical therapy) in one calendar year (Pergolotti, Lavery, Reeve, & Dusetzina, 2018). These limits are called “therapy caps” or “therapy cap limits”. Therapy limits are subject to change, and therefore, may affect access and choice of some stroke survivors about important rehabilitation services.

Based on our findings, stroke survivors who stay for a few days in acute care are expected to have high levels of functional performance upon admission to inpatient rehabilitation. Other contributing factors to short LOS in acute care include stroke severity. Our study findings showed that stroke severity was significantly associated with acute LOS indicating that stroke survivors who have milder strokes will likely have a short hospital stay in acute care. Health professionals can estimate the prognosis of stroke survivors more accurately by considering acute care LOS, and as a result, health professionals can anticipate the needed resources and frequency of rehabilitation services. This study provides an evidence-based strategy to support prognostic predictions.

The second aim of this study was to explore the association among demographic and health characteristics with functional performance on admission to inpatient rehabilitation. The correlation analysis confirmed an inverse relation among functional performance and factors such as age, NIHSS scores, acute LOS, and the number of comorbidities. These factors were inversely correlated with admission FIM scores. In other words, older age, severe stroke, longer acute LOS, and more comorbidities were all associated with worse functional outcomes upon admission to inpatient rehabilitation. A complex interaction between these variables may contribute to higher or lower levels of functional performance (Haselbach, Renggli, Carda, & Croquelois, 2014). For example, the strongest association was with the NIHSS scores indicating that stroke severity was the most influential factor on functional performance followed by LOS, age, and comorbidities, respectively. In addition, further analysis of NIHSS scores with FIM subscores showed that stroke severity was more closely linked to the motor aspect of functional performance rather than the cognitive domain. Acute LOS, however, was more closely associated with the cognitive aspect compared with the motor subscale on the admission FIM. These associations support the notion that factors correlated with overall functional performance may exert different influences on the motor and cognitive domains of function. Therefore, it is clinically relevant to account for the relation among these variables with specific domains of functional performance because this approach will assist health professional toward addressing motor and/or cognitive functional limitations of stroke survivors.

The third aim of this study was to evaluate changes in functional performance between admission and discharge to inpatient rehabilitation. The functional performance of stroke survivors markedly increased after inpatient rehabilitation. This finding supports other reports of functional gains after stroke rehabilitation (Ng et al., 2013; Rayegani et al., 2016). Changes in motor functioning, cognitive functioning, and overall functional performance all exceeded the predefined cutoff scores for clinically meaningful gains. FIM score changes defined as being minimal clinically important differences are 17 for motor FIM, 3 for cognitive FIM, and 22 for FIM composite score (Beninato et al., 2006). In the current study, the mean score differences were 20, 4, and 24 (see Figure 7). This is a clear indicator that inpatient rehabilitation services are effective in assisting stroke survivors to improve their functional skills. Not only are these functional improvements significant, but also encompass different aspects of motor and cognitive performance.

The most prominent improvements in functioning were in the self-care domain of motor FIM and in the social cognition domain of cognitive FIM (see Figure 7). The self-care domain includes basic daily life activities such as eating, bathing, and dressing. Self-care activities are essential for maintaining health and wellbeing. We previously reported self-care activities were among the top functional performance priorities to address among stroke survivors (Jaber, Sabata, & Radel, 2018). The social cognition domain encompasses skills of social interaction, problem-solving, and memory. Those social and cognitive skills are important for social participation and for the preservation of social roles and interpersonal relationships (Hewetson, Cornwell, & Shum, 2018).

These stroke survivors also exhibited improvements, although less substantial, in other domains of function on FIM including sphincter control and communication. The lesser degree of improvement conceivably may have been because recovery of these functions requires a longer time. For example, about 40-50% of stroke survivors have urinary and/or bowel incontinence issues during their acute care stay, dropping to 15% by the end of the first year after stroke (Kovindha, Wattanapan, Dejpratham, Permsirivanich, & Kuptniratsaikul, 2009; Thomas et al., 2008). Another potential and important interpretation, however, is a suboptimal management of urinary and bowel incontinence following stroke. In fact, one review of urinary incontinence among stroke survivors found less than two-thirds of stroke units have a documented plan to promote continence (Mehdi, Birns, & Bhalla, 2013), despite best practices guidelines for stroke rehabilitation stating management of bowel and bladder continence is a crucial part of the rehabilitation process. This reflects a recognition that social stigma, risk of skin breakdown, and burden of care associated with incontinence are important performance concerns (Winstein et al., 2016). More satisfactory patient outcomes may emerge when health care professionals regularly dedicate increased attention to promoting sphincter control and communication functions in addition standard aspects of function such as eating, dressing, and mobility.

The fourth aim of this study was to construct and test a predictive model of function after stroke. Two predictive models emerged, one focusing on motor function and one on cognitive function. The final versions of these fitted models identify two sets of significant predictors, one for motor FIM subscores and another set for cognitive FIM subscores.

Motor FIM Model

Factors influencing motor FIM subscores after rehabilitation included age, baseline motor subscores, NIHSS scores, rehabilitation duration, comorbidities, therapy frequency, assistive devices, independence on admission, and client/caregiver's behavior during rehabilitation. The univariate analysis confirmed these factors as significant independent predictors of motor FIM subscores at discharge from rehabilitation. These predictors included all three categories of independent variables (i.e. demographic, environmental, and health). For example, demographic characteristics included age, environmental factors encompassed family behavior, and health variables involved stroke severity. The most prominent category was health and medical as it yielded a considerable number of significant negative and positive predictors (see Table 7). For example, positive predictors included high admission motor FIM subscores, independence on admission, and normal cognition. Examples of negative predictors encompassed high stroke severity, uncooperative client behavior, age, and comorbidities. Health variables accounted for the majority (62%) of variance in the motor model and therefore were the most important to consider for treatment planning and implementation during inpatient rehabilitation.

Predictor variables in the fitted motor model partially accounted for variance in the discharge motor FIM subscores. About 40% of variance remained unexplained in the final model. Other factors that were found to be significant predictors in other studies may have accounted for the unexplained variance in the present study. For example, factors that did not influence motor FIM subscores in this study included stroke type, health insurance, body mass index, smoking status, hypertension, and diabetes. These factors did not correlate with the motor FIM subscores and were not included in the model fitting procedure for motor FIM subscores. The majority of these non-contributing factors were health-related variables which might increase the risk of having a stroke such as smoking, hypertension, and diabetes. Nonetheless, none of these health factors predicted motor FIM subscores. Potential reasons may include other characteristics of our sample such as higher proportion of young participants below 55 years, higher proportion of hemorrhagic strokes, and lower rates of smokers. Studies of motor recovery after stroke confirmed that young age, mild stroke severity, infrequent comorbidities, and diverse rehabilitation strategies positively affected the course of recovery (Alawieh, Zhao, & Feng, 2018; Hendricks, van Limbeek, Geurts, & Zwarts, 2002).

The final validated model for motor FIM subscores included a set of four significant predictors including baseline motor FIM subscores, discharge NIHSS scores, age, comorbid electrolyte disorder. Having a combination of positive predictors such as younger age, high admission motor FIM subscores, low discharge NIHSS score, and no comorbidities including electrolyte disorder are likely to yield higher motor FIM subscores at discharge from rehabilitation. The strongest predictor was admission motor FIM subscores, as it was eight times more predictive than all other factors combined. Fluid and electrolyte disorder was also predictive of motor recovery upon discharge from rehabilitation. This disorder is defined as shortage or excess of essential minerals and fluids in the human body. Examples of important bodily minerals include potassium and sodium. While other studies identified fluid and electrolyte disorders as a potential comorbidity after stroke (Alam et al., 2012; Marupudi &

Mittal, 2015), our findings identified this condition as predictive of motor recovery after rehabilitation.

Health care professionals can make estimate their client's motor functioning capabilities at discharge from rehabilitation using the baseline scores of motor function collected on admission. Our findings showed that admission motor FIM subscores were the strongest predictor of discharge motor FIM subscores as confirmed by the model testing procedure. The literature of factors predicting motor recovery following stroke showed that initial measures of motor function were the most significant predictors of recovery on discharge from rehabilitation (Coupar, Pollock, Rowe, Weir, & Langhorne, 2012). Our findings support those of Coupar et al. (2012) that admission subscores can be predictive of discharge subscores.

Cognitive FIM Model

Factors predicting cognitive FIM subscores after rehabilitation included age, baseline cognitive subscores, stroke type, acute care LOS, NIHSS scores, comorbidities, aphasia diagnosis, assistive devices, independence on admission, and client/caregiver's behavior during rehabilitation. Similar to the motor FIM model, the majority of cognitive FIM predictors were health factors mainly encompassing stroke-related variables (e.g. stroke severity, aphasia, and LOS). Positive predictors encompassed high cognitive FIM subscores on admission, positive client-caregiver behavior during rehabilitation, and independence on admission (see Table 10). Negative predictors included high stroke severity, aphasia, hemorrhagic stroke, and wheelchair use. Studies of cognitive recovery after stroke have found that older age, cognitive impairment and depression are negative determinants of rehabilitation outcome after stroke (Dusica, Devecerski, Jovicevic, & Platisa, 2015). Other studies have concluded that diabetes mellitus, hypertension, and stroke type were negative clinical determinants that also affected cognitive status after stroke (Mohd Zulkifly, Ghazali, Che Din, Singh, & Subramaniam, 2016).

Our findings are aligned with other reports of negative predictors of cognition after stroke such as age, cognitive impairment, and stroke type. On the other hand, there were differences between our findings and the findings of other studies about factors of depression, diabetes, and hypertension. We did not find these factors to be associated with the cognitive FIM subscores, and they were not included in the model fitting procedure. These conditions (i.e. diabetes and hypertension) develop at an older age and it is plausible the young participants in our sample did not have these conditions. The percentage of adults with diabetes increases with age, reaching as high as 25% of adults 65 years or older (CDC, 2017). The demographics of our sample showed the proportion of younger participants (less than 55 years) was higher compared to other stroke participants in previous studies. Another interpretation may be related to variability in the time of diagnosis for these comorbidities. For example, the incidence of depression after stroke was 25% among one sample of 157 thousand stroke survivors (Jorgensen et al., 2016), while the prevalence of preexisting depression was 10% in a different sample of 1819 stroke survivors (Aron, Staff, Fortunato, & McCullough, 2015). Having pre-existing comorbid depression has been reported to be more detrimental to the health of stroke survivors compared to newly developed depression post-stroke (Aron et al., 2015), as this condition limits the client's ability to participate actively in rehabilitation sessions (Chollet et al., 2013). Studies of depression have shown that people with depression have both an increased risk of stroke and increased morbidity after stroke (Dong, Zhang, Tong, & Qin, 2012; Pan et al., 2011).

Predictor variables in the cognitive FIM model partially accounted for variance in the discharge cognitive FIM subscores. About 30% of variance remained unexplained in the final model. Other factors that were found to be significant predictors in other studies may have accounted for the unexplained variance in the present study. Examples of factors in the present study that did not predict cognitive FIM subscores on discharge from rehabilitation included rehabilitation session's duration and therapy frequency. The intensity and duration of rehabilitation services (i.e. occupational and physical therapies) were associated with the discharge cognitive FIM subscores. Those predictor variables were also strongly associated with each other. Multicollinearity occurs when there are high inter-correlations between two or more predictor variables (Alin, 2010; Farrar & Glauber, 1967). Independent variables with multicollinearity reduce the precision of the estimate prediction coefficients and, therefore, have to be removed from the analysis. We removed those variables (e.g. therapy frequency and intensity) that were strongly associated with each other from the model fitting procedure. Inpatient rehabilitation total LOS was the only predictor we kept among those with collinearity. Although factors of intervention frequency and intensity were excluded from the analysis in the present study, they remain important practical factors for the clinician to consider in the design and implementation of intervention protocols.

The final validated model for cognitive FIM subscores indicated a group of five significant predictors including admission cognitive FIM subscores, age, client cooperative behavior, comorbid obesity, and the total number of comorbidities, respectively. The strongest predictor was admission cognitive FIM scores as it was ten times more predictive than other factors combined (see Table 11). The final model encompassed a combination of factors representing demographic, environmental, and health characteristics of stroke survivors. Having a combination of young age, high admission cognitive FIM subscores, low discharge NIHSS score, cooperative client behavior, and no comorbidities especially obesity will yield higher motor FIM subscores at discharge from rehabilitation. Health professionals may, therefore, be justified to consider the baseline cognitive FIM subscores as the best (but not the only) indicator of their client's anticipated cognitive recovery upon discharge from rehabilitation.

Baseline cognitive FIM subscores were the single strongest predictor of discharge cognitive FIM score. The literature of factors predicting cognitive recovery following stroke suggests that older age, aphasia, hemilateral neglect, spasticity, LOS, admission FIM scores were considered significant predicting factors of the neurorehabilitation outcome (Haselbach et al., 2014). Our study findings are supported by prior literature and contributed additional variables to the general repository of predictors of cognitive functioning after stroke rehabilitation. For example, our findings showed that positive client attitudes were predictive of enhanced cognitive recovery after stroke. Positive client behavior might be indicative of satisfaction with rehabilitation services received. It could also be a sign of milder forms of stroke among stroke survivors who received inpatient rehabilitation. Client behavior a modifiable factor and therefore is a very important potential target for intervention. Health care professionals may consider both emotional and physical status of stroke survivors on admission to assist clients in reaching optimal recovery of cognitive functions.

Implications for Practice

Predictive models have important application in the rehabilitation of stroke survivors. Our results integrate and extend the work of prior studies of predictive modeling after stroke. Taken together, this body of evidence represents a firm step toward implementation of predictive models in clinical practice. Examples include informing health professionals' clinical decisions, educating clients and caregivers about the expected rehabilitation outcomes, identifying clients who will likely benefit from rehabilitation, and improving the effectiveness of resource utilization in the clinic. This research study provides further suggestions below for improving intervention planning and client education aspects of stroke rehabilitation.

Health care professionals can tailor interventions to meet the needs of individuals with stroke. Stroke rehabilitation best practices include individualized client-centered interventions planned in collaboration with the client and family to address issues of motor recovery, cognitive impairment, and limitations in the functional performance of daily activities (Winstein et al., 2016). Enabling clients to make informed decisions is the new benchmark for high-quality care, which enables individuals to actively participate in the decision-making process at a level consistent with their preferences and believes (Lehmann, de Melker, Timmermans, & Mollema, 2017). At the same time, individualized interventions are inclusive of all personal, environmental, and health characteristics. Having a robust, effective, and accurate model predicting outcomes provides a useful and important tool to guide the process of providing health care to individuals with a stroke.

This study showed that many interrelated demographic and health factors predicted motor and cognitive performance after rehabilitation. Clients presenting in the clinic with mild ischemic stroke, limited cognitive impairment, good mobility, intact speech, young age, right hemiplegia, and no comorbidities (especially obesity and electrolyte disorders) are more likely to be exhibit the greatest functional improvements in motor and cognitive tasks of daily living. These are positive indicators that stroke survivors are likely to demonstrate favorable functional outcomes after inpatient rehabilitation. Therapists working with stroke survivors can identify which of their clients will likely to be independent. Beginning to reacquire the ability to carry out self-care activities of daily living represents the first stage in a stroke survivor's return to independence. Other positive indicators of favorable functional outcomes include early signs of independence on admission to rehabilitation such as showing good motor skills, intact cognition, and positive social interaction. Health care professionals are encouraged to consider these significant predictors of favorable functional outcomes upon admission to inpatient rehabilitation. In addition, client attitude, patient education about stroke, and socialization are valid targets for individualized interventions to maximize rehabilitation outcomes in terms of enhancing functional performance.

Our predictive models provide a clear list of factors that may limit function such as comorbid conditions and use of assistive devices. Fluid-electrolyte disorders and obesity were predictive of cognitive and motor functions after rehabilitation. Stroke rehabilitation best practices provide recommendations for addressing these comorbidities. For example, addressing these comorbidities warrants referral to physicians for the medical management of comorbid conditions and referral to community resources to increase physical activity (Winstein et al., 2016). Individualized rehabilitation interventions can be tailored to address these conditions.

Social and environmental influences have an impact on functional outcomes after stroke as they guide the path to recovery. Social factors include client/caregiver attitudes and behavior and social support. The present study showed positive client/family behaviors and supportive assistive devices were predictive of favorable motor and cognitive functional outcomes after stroke. For example, clients with stroke demonstrating signs of noncollaboration or maladaptive behavior should receive additional care to address these emotional signs. The therapist working with this client may consider emphasizing emotional regulation and behavioral control techniques to assist the client in overcoming emotional challenges. In addition, environmental factors include assistive equipment and informational education. It is essential to evaluate these factors during intervention planning to maximize participation in everyday life activities at home and in the community. This comprehensive approach to treatment empowers the client to regain control over their recovery process and to promote participation in everyday life activities.

Quality health care should be client-centered and family-inclusive. These concepts entail health services which are respectful of and responsive to client and family preferences to guide all clinical decisions (Groene, 2011). Social support plays a prominent role in promoting or hindering the functional performance of individuals after stroke. Positive family attitudes and support assist the client in coping with injury. Rehabilitation literature emphasizes the role of family involvement as an important factor in the promoting the success of stroke rehabilitation (Creasy, Lutz, Young, & Stacciarini, 2015; Fang et al., 2017). Thus, it is important to integrate the family members and caregivers in the rehabilitation process to promote recovery and favorable rehabilitation outcomes.

Research Implications

The strengths of the present study included exploring recovery of functional performance for stroke survivors using real-life clinical data produced by clinicians and extracted from medical records. This pragmatic approach to using clinical data for research can be adopted by clinicians and researchers for studying stroke rehabilitation. The number of medical records contained in the HERON database allowed access to a large volume of clinical data. Further, evaluating functional performance is important for identifying the impact of the stroke on the individual's health and well-being. The study design permitted an evaluation of complex relations among client factors and stroke outcomes after the onset of stroke. This study used a multiple regression analysis in the evaluation of a large number of predictors, to provide prognostic information and to inform rehabilitation professionals about client needs for medical assistance and supports. This study also used the ICF framework for guiding the selection of potential factors that predict functional performance after a stroke.

This study was an analysis of retrospective clinical data. A retrospective design has inherent limitations including having incomplete or missing data in the dataset, medical records lacking specific elements of patient data, imprecision in interpreting or verifying assessment documentation, and variability in the quality of the documentation itself (Gearing, Mian, Barber, & Ickowicz, 2006). Another limitation of the present study is the small sample size. Our final sample consisted of 207 participants which did not meet the minimum required sample of 230. Nonetheless, some of the study limitations we encountered were addressed through manual data extraction from medical records. For example, missing values were obtained through careful review of medical charts on case-by-case bases. Variability in the quality of documentation made the chart review process more challenging, nonetheless, all necessary data elements were obtained and analyzed. Despite these considerations, a retrospective design is valuable in allowing consideration of a wide number of variables in the development of models such as those presented here.

Conclusions

Baseline motor and cognitive subscores on FIM were the strongest predictors of functional outcomes upon discharge from inpatient stroke rehabilitation. Client behavior and comorbid electrolyte disorders proved to be important predictors, although they have not received much attention in the stroke literature. Accounting for factors influencing functional recovery of stroke survivors may enhance their lived experience as independent members of their home and community. I plan to evaluate the impact of these predictors on stroke rehabilitation including changes in physicians' practices, clients' outcomes, or care costs. A recent meta-analysis did not find any model impact studies assessing the ability of predictive models to improve client outcomes (Fahey et al., 2018).

Future studies should focus on evaluating the effect of using predictive models to improve care quality, outcome, and cost-effectiveness. These studies may employ an experimental design to compare patient outcomes (e.g., functional performance, length of stay, and client satisfaction) between intervention protocols designed based on the findings derived from predictive models of functional recovery following stroke. Comparative studies evaluating the length of stay also provide an indicator of cost-effectiveness associated with adopting these newly-developed intervention protocols based. Other suggested future directions include descriptive studies of physicians' perceptions or practices related to adopting new intervention protocols developed based on predictive models of stroke recovery.

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Table 1

Category	Variable
Demographic	Age Gender Race Ethnicity Marital state Employment status Health insurance
Social and Environmental	Living place Living arrangement Home type Caregiver Person present during visits Client behavior Caregiver behavior
Health and Medical	Stroke diagnosis Stroke severity Affected side Body mass index Smoking status Alcohol consumption Comorbidities Aphasia Prognosis Sensory status Strength status Cognitive function Assistive devices Assistance needed Independence on admission Upper and lower extremities tone Length of inpatient hospital stay Duration of inpatient rehabilitation Frequency of occupational and physical therapy services

Note. List of predictor variables.

Table 2

Demographic Variables	Initial Sample (N = 925)	Final Sample (N = 207)
Age in Years		
18 – 39	5%	5%
40 - 59	23%	32%
60 – 79	53%	51%
80 or higher	19%	12%
Sex		
Males	54%	55%
Females	46%	45%
Stroke Diagnosis		
Ischemic	72%	77%
Hemorrhagic	18%	22%
Transient Ischemic Attack	10%	1%
Race		
White or Caucasian	71%	74%
Black or African American	22%	20%
Asian	1%	4%
American Indian or Alaskan Native	0%	1%
Declined	0%	1%
Other	6%	0%
Marital Status		
Single	24%	29%
Married	46%	48%
Divorced	14%	12%
Widowed	15%	11%
Separated	1%	0%
Employment Status		
Full-time Employment	17%	23%
Part-time Employment	3%	4%
Retired	46%	50%
On Disability	6%	11%
Unemployed	10%	12%
Missing	18%	0%
State of Residence		
Kansas	59%	70%
Missouri	30%	27%
Other States (AR, CA, FL, NE, TE, TX, WI)	11%	3%

Note. Comparison of sample demographics between the initial and final samples.

Table 3

Demographic Variables	n	Statistics
Mean Age in Years (±SD, Range)	207	64 (±13.9; 18 - 97)
Sex		
Males	114	55%
Females	93	45%
Race		
White or Caucasian	154	74%
Black or African American	41	20%
Asian	8	4%
American Indian or Alaskan Native	1	1%
Declined	1	1%
Ethnicity		
Non-Hispanic	193	93%
Hispanic	12	6%
Declined	2	1%
Marital Status		
Single	59	29%
Married	99	48%
Divorced	26	12%
Widowed	23	11%
Employment Status		
Full-time Employment	49	23%
Part-time Employment	8	4%
Retired	103	50%
On Disability	22	11%
Unemployed	25	12%
Health Insurance Status		
Medicare	111	54%
Private	56	27%
Medicaid	27	13%
Veterans Affairs	4	2%
No insurance	9	4%
State of Residence		
Kansas	144	70%
Missouri	56	27%
Other States (AR, CA, FL, NE, TE, TX, WI)	7	3%

Note. Demographics of the sample (N = 207); M = Mean; SD = Standard Deviation; R = Range

Table 4

Demographic Variables	n	Percentage
Lives Arrangement		
Spouse or Significant Other	107	52%
Alone	45	22%
Family	28	13%
Son or Daughter	20	10%
Friend or Other	7	3%
Home Type		
House	172	83%
Apartment	24	12%
Mobile Home	7	3%
Assisted Living	4	2%
Receives Assistance From		
None Needed	142	69%
Spouse	32	15%
Family	26	12%
Home Health Nursing	6	3%
Friends	1	1%
Client Behavior		
Cooperative	81	39%
Withdrawn	43	21%
Flat affect	17	8%
Tearful	16	8%
Unspecified	15	7%
Uncooperative	14	7%
Hyper verbal	6	3%
Fearful	5	2%
Irritable	5	2%
Not interactive	4	2%
Liable	1	1%
Distance Away from KU Health System (miles)		
< 50	135	65%
50 - 100	44	22%
100 - 500	21	10%
500 - 1000	5	2%
> 1000	2	1%

Note. Social and environmental factors (N = 207)

Table 5

Demographic Variables	N	Statistics
Stroke Diagnosis		
Ischemic	162	78%
Hemorrhagic	45	22%
Affected Side		
Left	108	52%
Right	99	48%
Mean Number of Comorbidities (±SD, Range)	207	4 (±3, 0 - 16)
Mean Length of Hospital Stay in Days (±SD, Range)	207	8 (±7; 2 - 52)
Mean Length of Inpatient Rehabilitation in Days (±SD, Range)	207	16 (±15; 1 - 91)
Smoking Status		
Never	99	48%
Former	66	32%
Current	42	20%
Alcohol Consumption (oz/wk.)		
Abstinence (0)	157	76%
Light (0.1 – 10.5)	47	23%
Moderate (10.5 – 21.0)	1	1%
Mean BMI (±SD, Range)	125	28.4 (±7.0; 14.8 – 54.2)
Under weight (< 18.5)	7	3%
Normal (18.5 - 25)	61	30%
Over weight (25.1 - 30)	68	33%
Obesity Class I (30.1 - 35)	38	18%
Obesity Class II (35.1 - 40)	19	9%
Obesity Class III (> 40.1)	14	7%
Mean NIHSS Score on Admission (±SD, Range)	162	9.0 (±6.6; 0 - 27)
Mean NIHSS Score on Discharge (±SD, Range)	122	6.0 (±5.1; 0 - 23)
Mean Composite FIM Score on Admission (±SD, Range)	207	58.6 (±21.0; 18 - 112)
Mean Composite FIM Score on Discharge (±SD, Range)	207	84.8 (±25.3; 18 - 126)

Note. Health and medical characteristics of the sample (N = 207); M = Mean; SD = Standard Deviation; R = Range; FIM = Functional Independence Measure; BMI = Body Mass Index; NIHSS = National Institute of Health Stroke Scale; oz/wk = ounces per week.

Table 6

	Age	BMI	Dist.	Com.	NIHSS Adm.	NIHSS Dis.	GCS Adm.	LOS	Motor FIM 1	Cog. FIM 1	FIM 1 Com.
Age	1.00										
BMI	-0.19**	1.00									
Distance KU	-0.08	-0.02	1.00								
Comorbidities	-0.01	0.11	-0.03	1.00							
NIHSS Adm.	-0.10	-0.06	0.04	-0.08	1.00						
NIHSS Dis.	-0.17	0.02	-0.08	-0.04	0.72**	1.00					
GCS Adm.	0.09	0.05	0.11	-0.01	-0.42**	-0.43**	1.00				
Acute LOS	-0.21**	-0.10	0.02	0.07	0.25**	0.41**	-0.27**	1.00			
Motor FIM 1	-0.16*	0.06	0.00	-0.09	-0.43**	-0.59**	0.22*	-0.20**	1.00		
Cog. FIM 1	-0.43	0.36	0.00	-0.09	-0.45**	-0.49**	0.47**	-0.34**	0.48**	1.00	
FIM 1 Com.	-0.14*	0.06	0.00	-0.04	-0.50**	-0.62**	0.34**	-0.28**	0.95**	0.73**	1.00
FIM 2 Com.	-0.22**	0.15*	-0.02	-0.14*	-0.35**	-0.57**	0.22*	-0.20**	0.74**	0.52**	0.76**

Note. Pearson correlation matrix between predictors and FIM Motor and Cognitive subscores on admission (N = 207); FIM = Functional Independence Measure; BMI = Body Mass Index; KUHS = Distance between residence and University of Kansas Health System; Com = Comorbidities; NIHSS Adm. = National Institute of Health Stroke Scale score on Admission; GCS = Glasgow Coma Scale; Cog = Cognitive; LOS = Length of Stay in acute care; * $p < 0.05$; ** $p < 0.001$; the significance level was set at $\alpha = 0.05$.

Table 7

Negative Predictors						
Variable		Pearson's Correlation		Linear Regression		
		Correlation Coefficient	*P* value	Regression Coefficient	R^2	*P* value
1	NIHSS @ Discharge	-0.55	**0.000**	-2.00	0.31	**0.000**
2	NIHSS @ Admission	-0.34	**0.000**	-1.01	0.12	**0.000**
3	Assistive Device (wheelchair)	-0.32	**0.000**	-18.48	0.10	**0.000**
4	Patient Behavior: Not interactive	-0.31	**0.000**	-13.32	0.10	**0.000**
5	Comorbidity: Fluid & Elect. Disorder	-0.27	**0.000**	-11.09	0.07	**0.000**
6	Strength Status Flaccid	-0.27	**0.000**	-14.39	0.07	**0.000**
7	Age	-0.24	**0.001**	-0.34	0.06	**0.002**
8	Inpatient Rehab length of stay	-0.24	**0.002**	-0.53	0.06	**0.002**
9	Cognitive Status Impaired	-0.23	**0.002**	-9.21	0.05	**0.003**
10	All Comorbidities	-0.18	**0.010**	-1.34	0.03	**0.021**
11	Medicare Insurance	-0.17	**0.015**	-6.89	0.03	**0.030**
12	Retired Employment	-0.16	**0.019**	-6.60	0.03	**0.038**
13	Family Behavior: Un-cooperative	-0.16	**0.019**	-21.29	0.03	**0.039**

Positive Predictors						
Variable		Pearson's Correlation		Linear Regression		
		Correlation Coefficient	*P* value	Regression Coefficient	R^2	*P* value
1	Motor FIM Subscale @ Admission	0.76	**0.000**	0.99	0.58	**0.000**
2	Cognitive FIM Subscale @ Admission	0.36	**0.000**	0.98	0.13	**0.000**
3	Independence on Admission	0.28	**0.000**	14.68	0.08	**0.000**
4	Patient Behavior: Cooperative	0.27	**0.000**	11.41	0.08	**0.000**
5	Cognitive Status Normal	0.24	**0.001**	9.67	0.05	**0.002**
6	Receives Help From: None Needed	0.21	**0.003**	9.37	0.05	**0.007**
7	Family Behavior: Cooperative	0.17	**0.013**	18.70	0.03	**0.027**
8	Gait Distance	0.17	**0.036**	0.02	0.03	**0.036**
9	Assistive Device Walker	0.16	**0.019**	8.00	0.03	**0.039**
10	Affected Side Right	0.15	**0.030**	5.99	0.02	**0.050**

Note. Significant predictors of Motor FIM Subscores on discharge ranked by correlation coefficients using the 80 % fitting sample subset (n = 165); Selection of predictors was based on the results linear regression analysis for variables having low to high correlation (Pearson's Coefficient $r > 0.15$, $p < 0.05$) and a significant regression coefficients ($p < 0.05$); FIM = Functional Independence Measure; NIHSS = National Institute of Health Stroke Scale score; Pearson Correlation Coefficients = strength and direction of the relation between the predictor and outcome variables; Regression Coefficient = unstandardized coefficients; the significance level was set at $\alpha = 0.05$.

Table 8

Motor FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Motor FIM Subscore on Admission	0.48	5.68	**0.000**	0.651
NIHSS Score on Discharge	-0.31	-3.66	**0.000**	
Age	-0.20	-2.91	**0.005**	
Comorbidity: Fluid & Electrolyte Disorder	-0.17	-2.69	**0.009**	
Affected Side Right	0.15	2.37	**0.020**	
Independence on Admission	0.15	2.32	**0.023**	

Note. Model development for Motor FIM subscores on discharge from rehabilitation using the 80 % fitting sample subset (n= 165); significance level was set at $\alpha = 0.05$.

Table 9

Motor FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Motor FIM Subscore on Admission	0.72	6.20	**0.000**	0.547
NIHSS Score on Discharge	-0.37	-1.74	0.100	
Age	-0.08	-0.61	0.544	
Comorbidity: Fluid & Electrolyte Disorder	-0.07	-0.52	0.610	
Affected Side Right	-0.26	-2.19	**0.035**	
Independence on Admission	-0.03	-0.29	0.775	

Note. Model testing results for the fitted model of Motor FIM subscores using the 20% testing sample subset (n= 42); significance level was set at α = 0.05.

Table 10

Motor FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Motor FIM Subscore on Admission	0.53	6.82	**0.000**	0.574
NIHSS Score on Discharge	-0.26	-3.30	**0.001**	
Age	-0.16	-2.43	**0.017**	
Comorbidity: Fluid & Electrolyte Disorder	-0.14	-2.26	**0.026**	
Affected Side Right	0.06	1.05	0.297	
Independence on Admission	0.09	1.38	0.169	

Note. Model validation for the final fitted model of Motor FIM subscores using the whole sample (N= 207); significance level was set at α = 0.05.

Table 11

Variable		Pearson's Correlation		Linear Regression		
		Correlation Coefficient	*P* value	Regression Coefficient	R^2	*P* value
		Negative Predictors				
1	NIHSS @ Discharge	-0.47	**0.000**	-0.61	0.22	**0.000**
2	Cognitive Status Impaired	-0.47	**0.000**	-6.48	0.22	**0.000**
3	NIHSS @ Admission	-0.35	**0.000**	-0.36	0.12	**0.000**
4	Aphasia diagnosis	-0.32	**0.000**	-4.61	0.10	**0.000**
5	Patient Behavior: Not interactive	-0.36	**0.000**	-5.28	0.13	**0.000**
6	Acute Inpatient length of stay	-0.22	**0.004**	-0.23	0.05	**0.004**
7	Assistive Device Hand Held	-0.19	**0.007**	-3.95	0.04	**0.015**
8	Age	-0.18	**0.011**	-0.09	0.03	**0.021**
9	Strength Status Flaccid	-0.17	**0.014**	-3.12	0.03	**0.028**
10	Assistive Device (wheelchair)	-0.16	**0.021**	0.63	0.03	**0.042**
11	Receives Help - healthcare provider	-0.15	**0.024**	-6.25	0.02	**0.048**

Positive Predictors

Variable		Pearson's Correlation		Linear Regression		
		Correlation Coefficient	*P* value	Regression Coefficient	R^2	*P* value
1	Cognitive FIM Subscale @ Admission	0.80	**0.000**	0.75	0.64	**0.000**
2	Motor FIM Subscale @ Admission	0.52	**0.000**	0.23	0.27	**0.000**
3	Cognitive Status Normal	0.50	**0.000**	6.91	0.25	**0.000**
4	Glasgow Coma Scale @ Admission	0.38	**0.000**	1.11	0.15	**0.000**
5	Patient Behavior: Cooperative	0.38	**0.000**	5.36	0.14	**0.000**
6	Independence on Admission	0.28	**0.000**	5.05	0.08	**0.000**
7	Ischemic Stroke diagnosis	0.23	**0.002**	3.85	0.05	**0.004**
8	Comorbid Obesity	0.21	**0.004**	4.03	0.04	**0.007**
9	Receives Help From: None Needed	0.21	**0.004**	3.10	0.04	**0.009**
10	Body mass index	0.18	**0.010**	0.17	0.03	**0.021**

Note. Significant predictors of Cognitive FIM subscores on discharge ranked by correlation coefficients using the 80 % fitting sample subset (n = 165); Selection of predictors was based on the results linear regression analysis for variables having low to high correlation (Pearson's Coefficient $r > 0.15$, $p < 0.05$) and a significant regression coefficients ($p < 0.05$); FIM = Functional Independence Measure; NIHSS = National Institute of Health Stroke Scale score; Pearson Correlation Coefficients = strength and direction of the relation between the predictor and outcome variables; Regression Coefficient = unstandardized coefficients; the significance level was set at $\alpha = 0.05$.

Table 12

Cognitive FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Cognitive FIM Subscore on Admission	0.729	13.57	**0.000**	0.699
Age	-0.145	-2.91	**0.004**	
Patient Behavior: Cooperative	0.173	3.22	**0.002**	
Comorbid Obesity	0.193	3.71	**0.000**	
Number of Comorbidities	-0.137	-2.64	**0.009**	

Note. Model development for Cognitive FIM subscores on discharge from rehabilitation using the 80% fitting sample subset (n= 165); significance level was set at $\alpha = 0.05$.

Table 13

Cognitive FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Cognitive FIM Subscore on Admission	0.65	5.45	**0.000**	0.534
Age	0.01	0.10	0.923	
Patient Behavior: Cooperative	0.13	1.03	0.308	
Comorbid Obesity	0.14	1.12	0.269	
Number of Comorbidities	0.02	0.17	0.868	

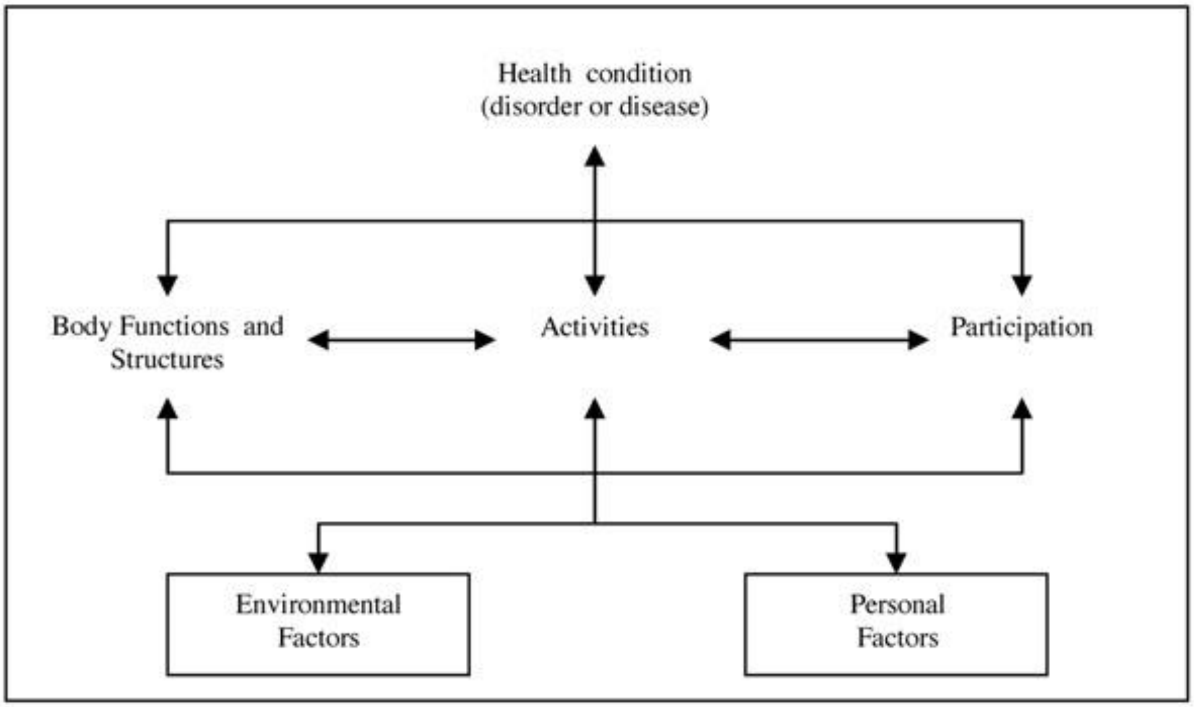
Note. Model testing results for the fitted model of Cognitive FIM subscores using the 20% testing sample subset (n= 42); significance level was set at $\alpha = 0.05$.

Table 14

Cognitive FIM Subscores Model				
Variable	Standardized Regression Coefficient (Beta)	*t* statistic	*p* value	R^2
Cognitive FIM Subscore on Admission	0.72	16.29	**0.000**	0.669
Age	-0.13	-3.07	**0.002**	
Patient Behavior: Cooperative	0.14	3.22	**0.001**	
Comorbid Obesity	0.18	4.07	**0.000**	
Number of Comorbidities	-0.10	-2.35	**0.020**	

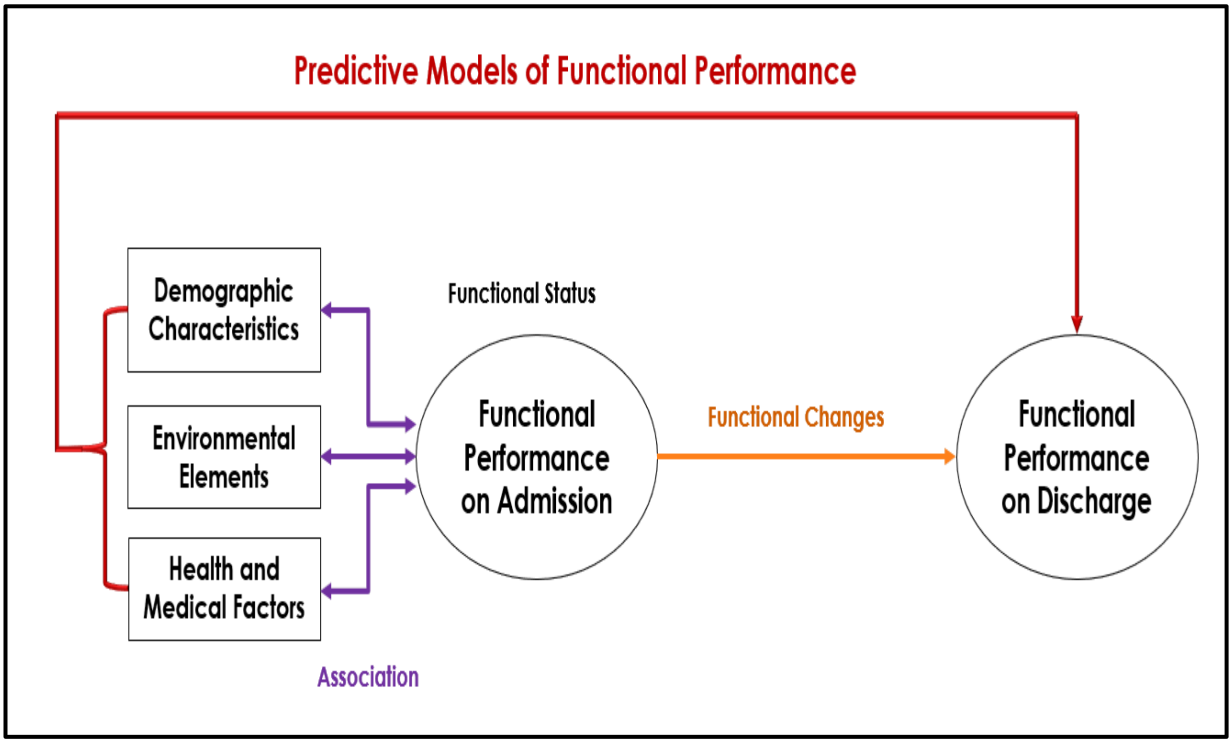
Note. Model validation for the final fitted model of Cognitive FIM subscores using the whole sample (N= 207); significance level was set at α = 0.05.

Figure 1



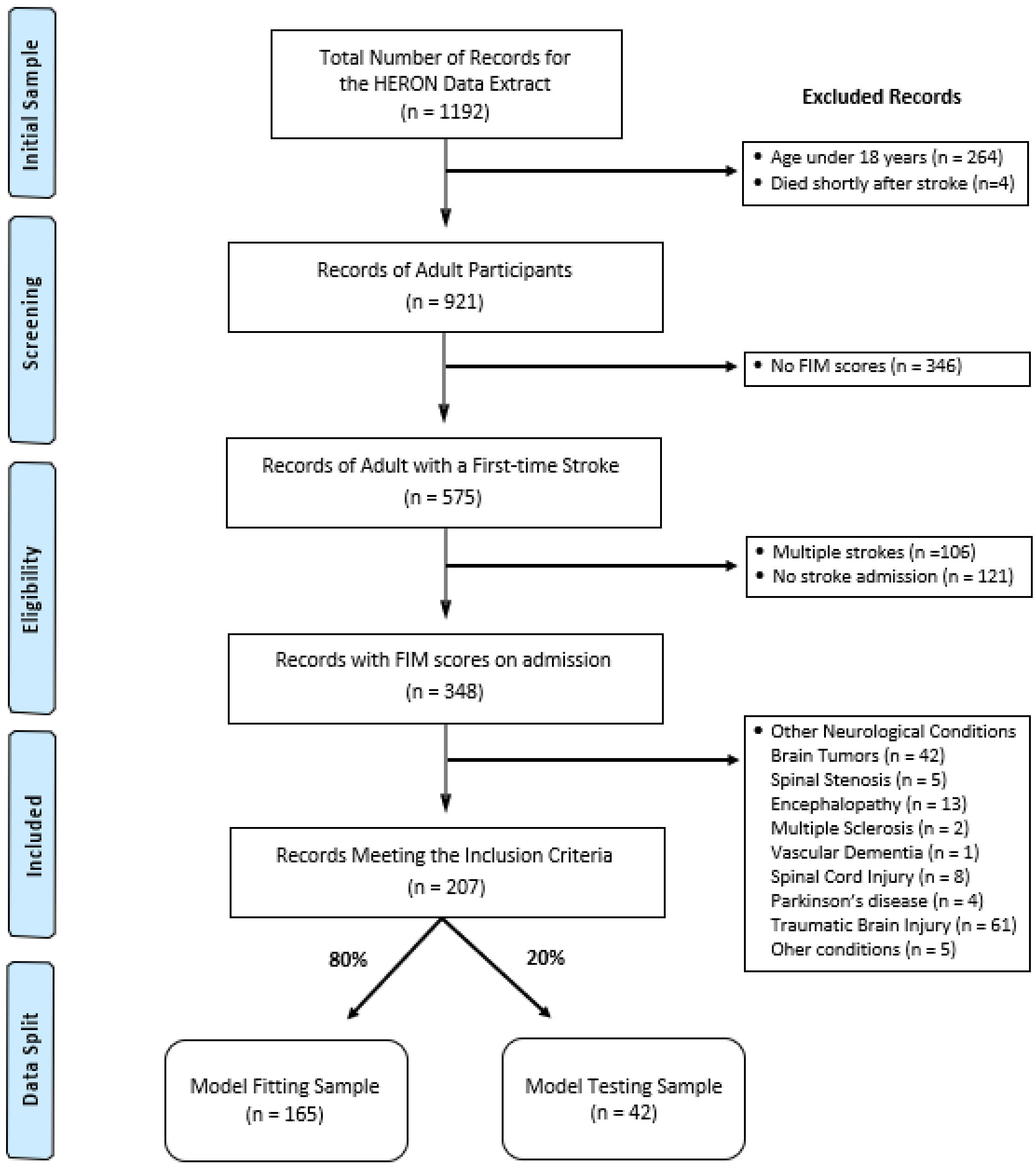
Note. Diagram of the International Classification of Function and Disability (ICF) framework (World Health Organization, 2001). This diagram demonstrates the complex interactions among personal, health, and environmental factors and how it influences the individual's participation and functioning.

Figure 2



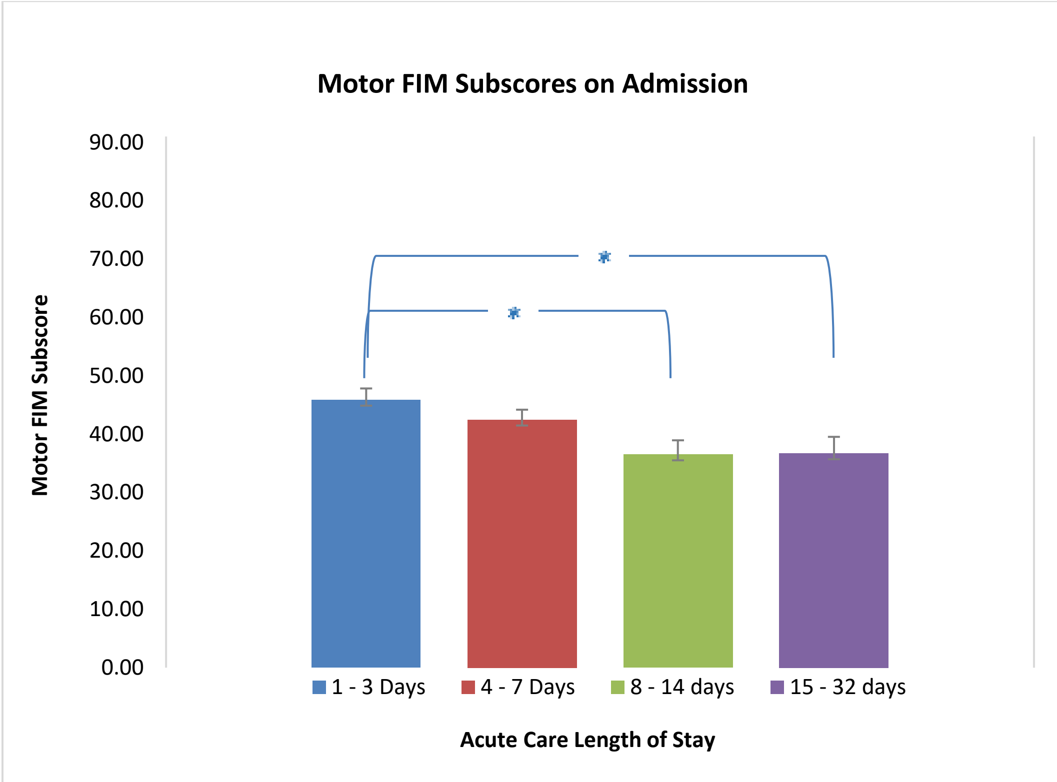
Note. This diagram presents the main predictor and outcome variables in the Regression Model. The main predictors were classified into three categories including demographic characteristics, social and environmental factors, and health variables. Functional performance was evaluated on admission and discharge to inpatient rehabilitation. The outcome variable in the regression model was functional performance after discharge from rehabilitation.

Figure 3



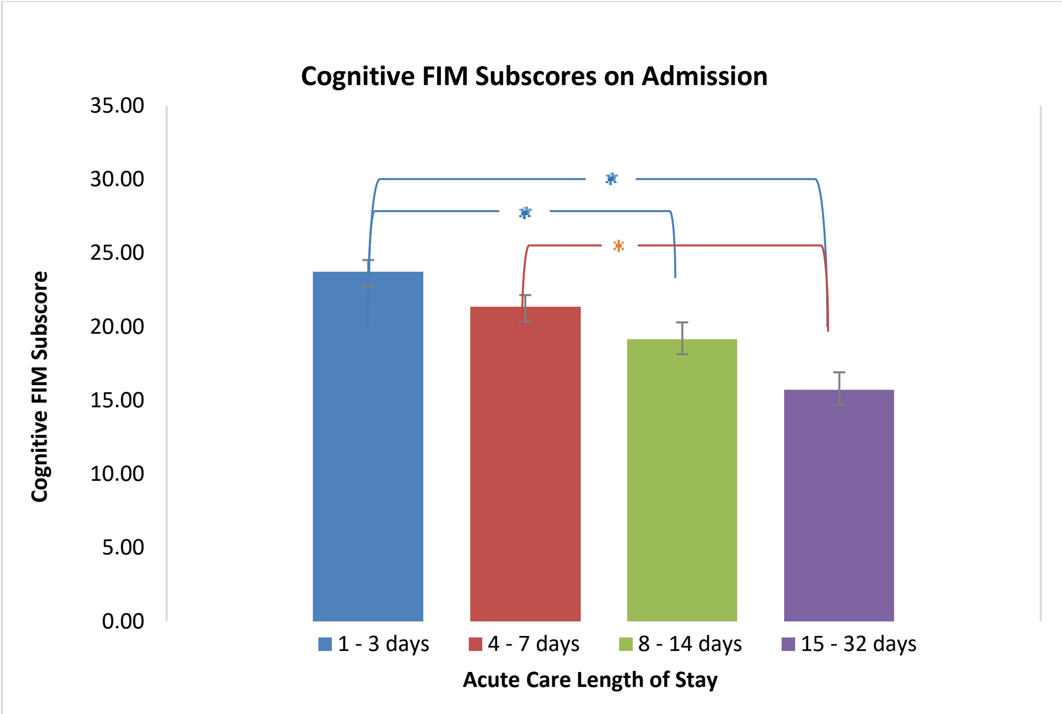
Note. Flowchart presenting the sample selection and data splitting. The initial sample consisted of 1192 records. The final sample was comprised of 207 participants with stroke meeting all inclusion criteria.

Figure 4



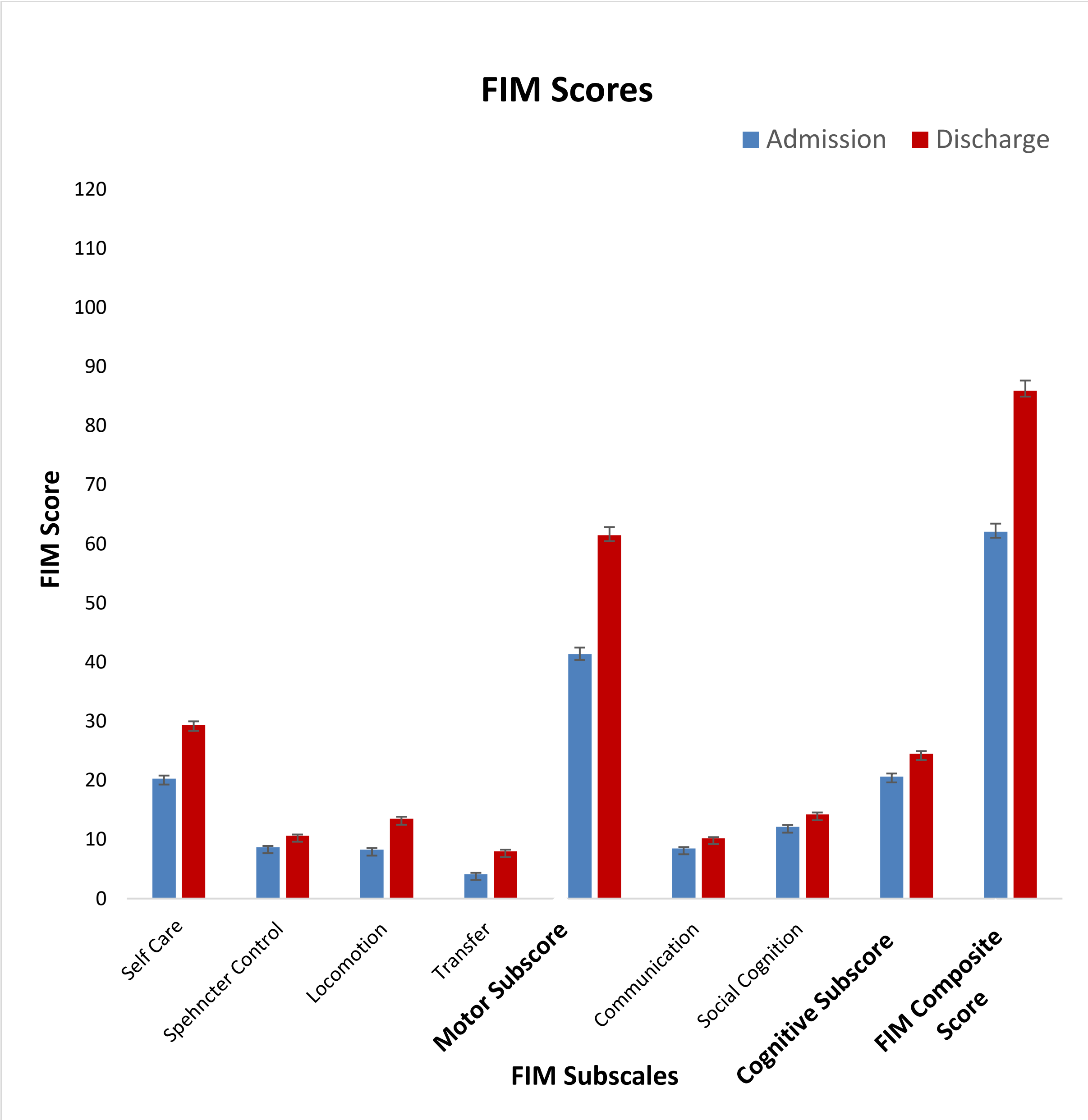
Note. Comparison of Motor FIM subscores on admission to inpatient Rehabilitation by length of stay in acute care. Motor FIM subscores were divided into four categories based on length of stay. Individuals who stayed for less than four days had significantly higher motor subscores compared to individuals who stayed for 8 or more days. Individuals with shorter length of stay in acute care (< 4 days) are expected to demonstrate significantly improved motor recovery compared to those who stay for longer periods in acute care (≥ 8 days). * = $p < 0.05$.

Figure 5



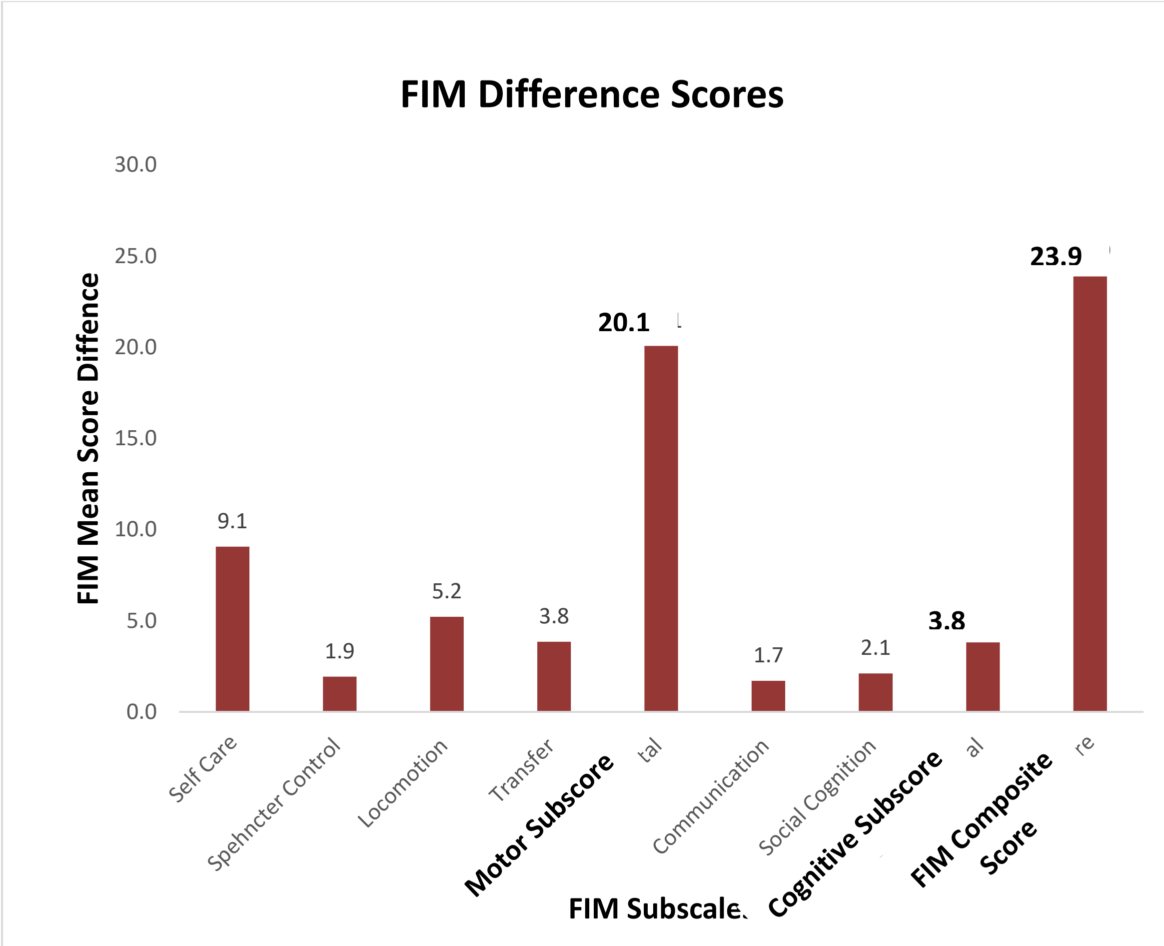
Note. Comparison of Cognitive FIM subscores on admission to inpatient Rehabilitation by length of stay in acute care. Cognitive FIM subscores were divided into four categories based on length of stay. Individuals who stayed for less than seven days had significantly higher cognitive subscores compared to individuals who stayed for 8 or more days. Individuals with shorter length of stay in acute care (< 4 days) are expected to demonstrate significantly improved cognitive recovery compared to those who stay for longer periods in acute care (≥ 8 days). * = $p < 0.05$.

Figure 6



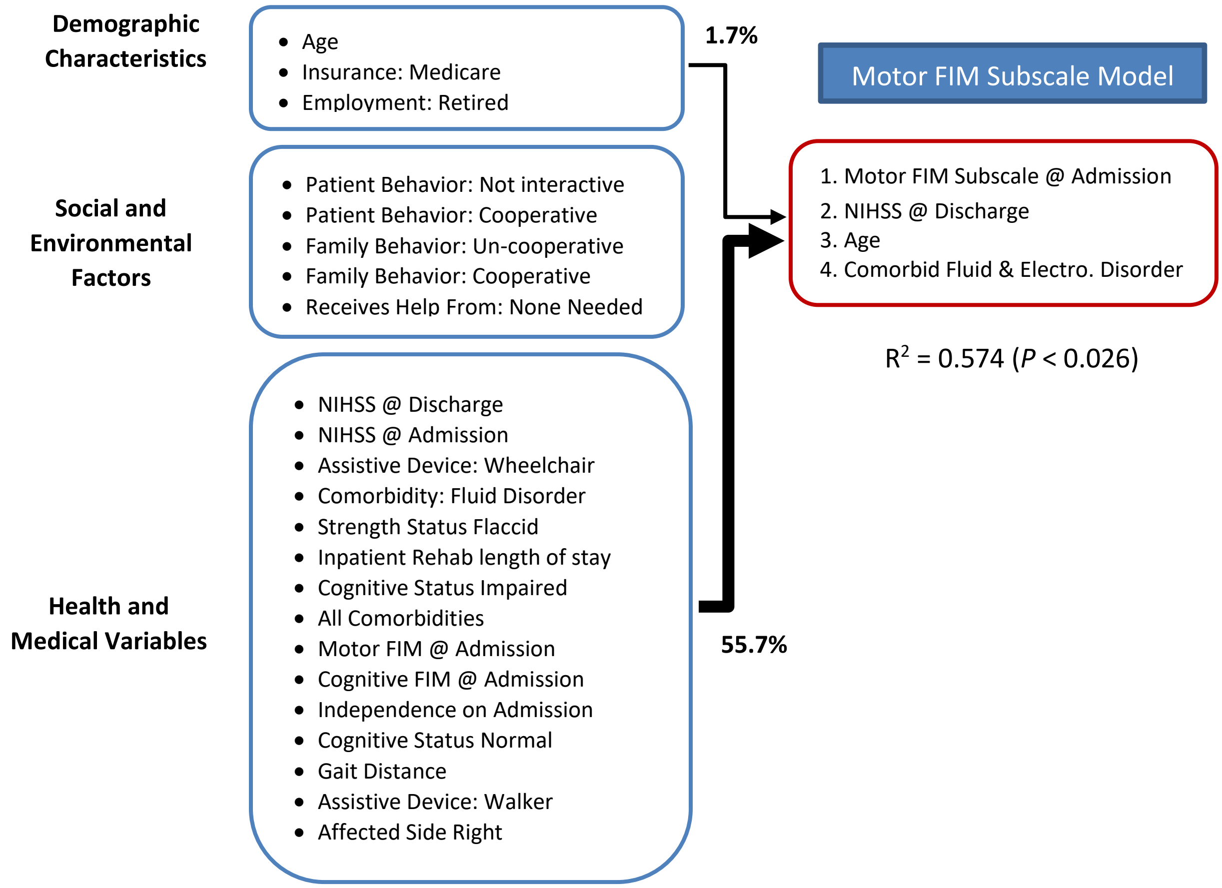
Note. A comparison of Functional Independence Measure (FIM) scores on admission and discharge from inpatient rehabilitation. The comparison included FIM subscales and composite score. All FIM subscores were significantly higher on discharge from inpatient rehabilitation ($p < 0.001$). Inpatient rehabilitation was effective as it yielded significant improvements on all domains of functional performance of stroke survivors. The significance level was set at $\alpha = 0.05$.

Figure 7



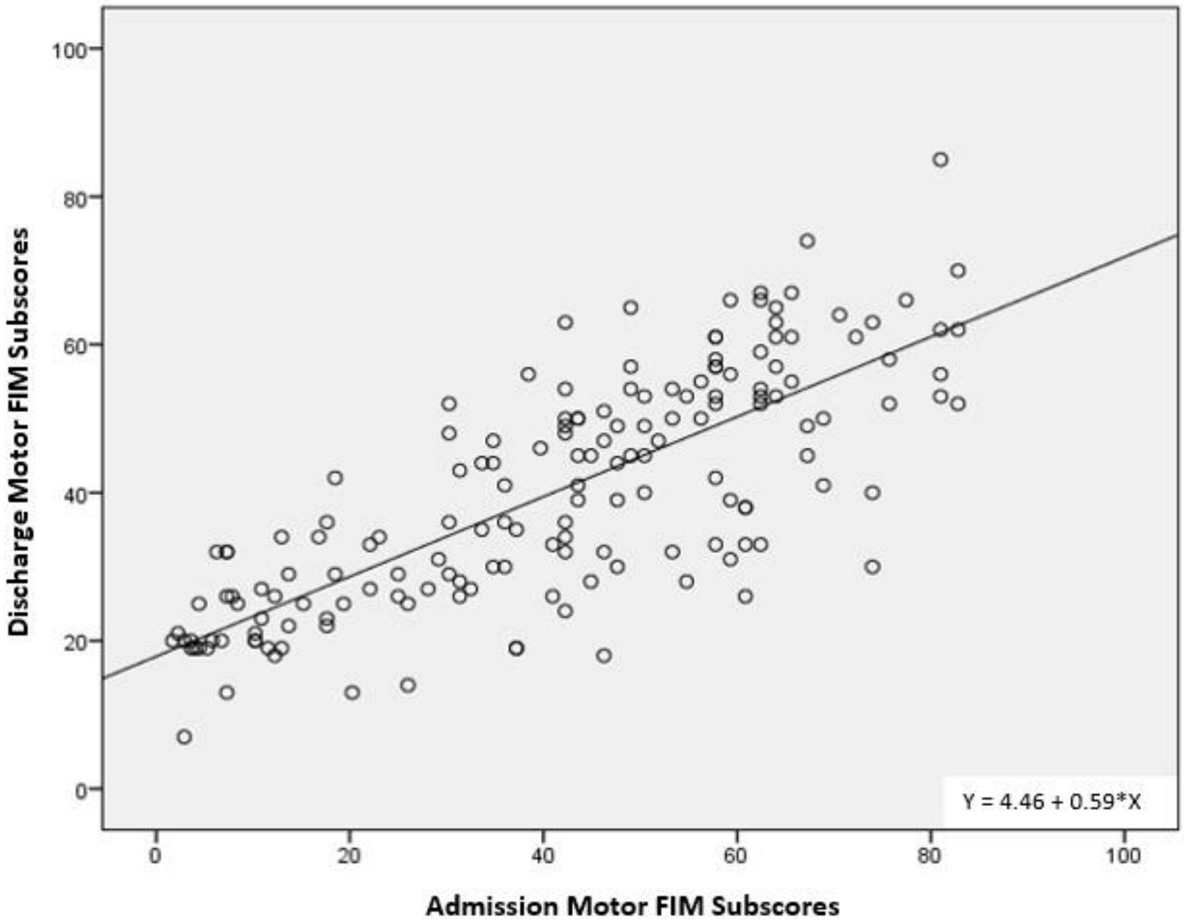
Note. Mean score difference of Functional Independence Measure (FIM) when compared between admission and discharge from inpatient rehabilitation. The comparison included FIM subscales as well as the composite score. The mean difference was statistically significant and clinically meaningful (a change >17, 3, and 22 points) for Motor FIM subscores, Cognitive FIM subscore, and FIM composite score, respectively.

Figure 8



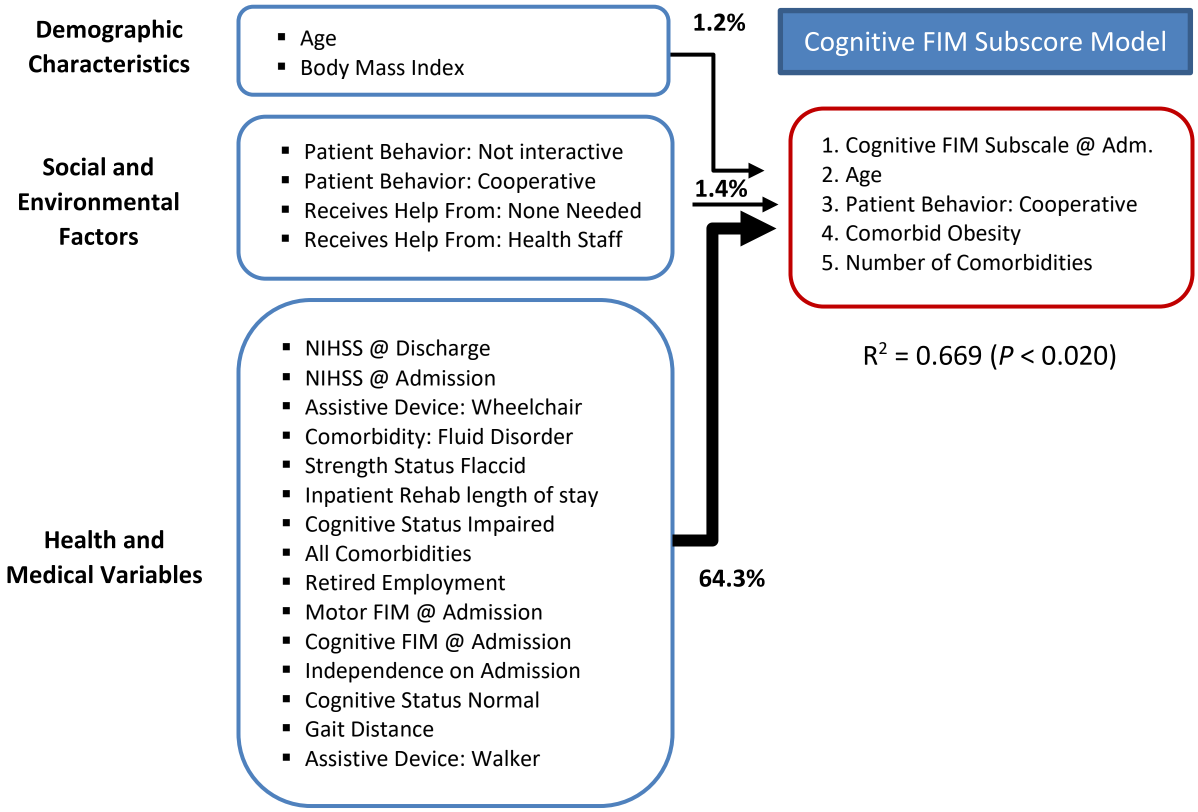
Note. Final fitted model for Motor FIM subscale. Significant predictors under the 3 major categories were analyzed using Stepwise regression. Four significant predictors (right column, #1-#4) survived to be included in the final validated model for Motor FIM subscore. Together, baseline Motor FIM subscores, discharge NIHSS scores, age, and comorbid electrolyte disorder accounted for 57% of the total variance in Motor FIM scores upon discharge from inpatient rehabilitation. The strongest predictor was the baseline Motor FIM subscores. Health professionals should evaluate these predictors upon admission to inpatient rehabilitation to identify clients who will likely improve and to tailor individualized interventions.

Figure 9



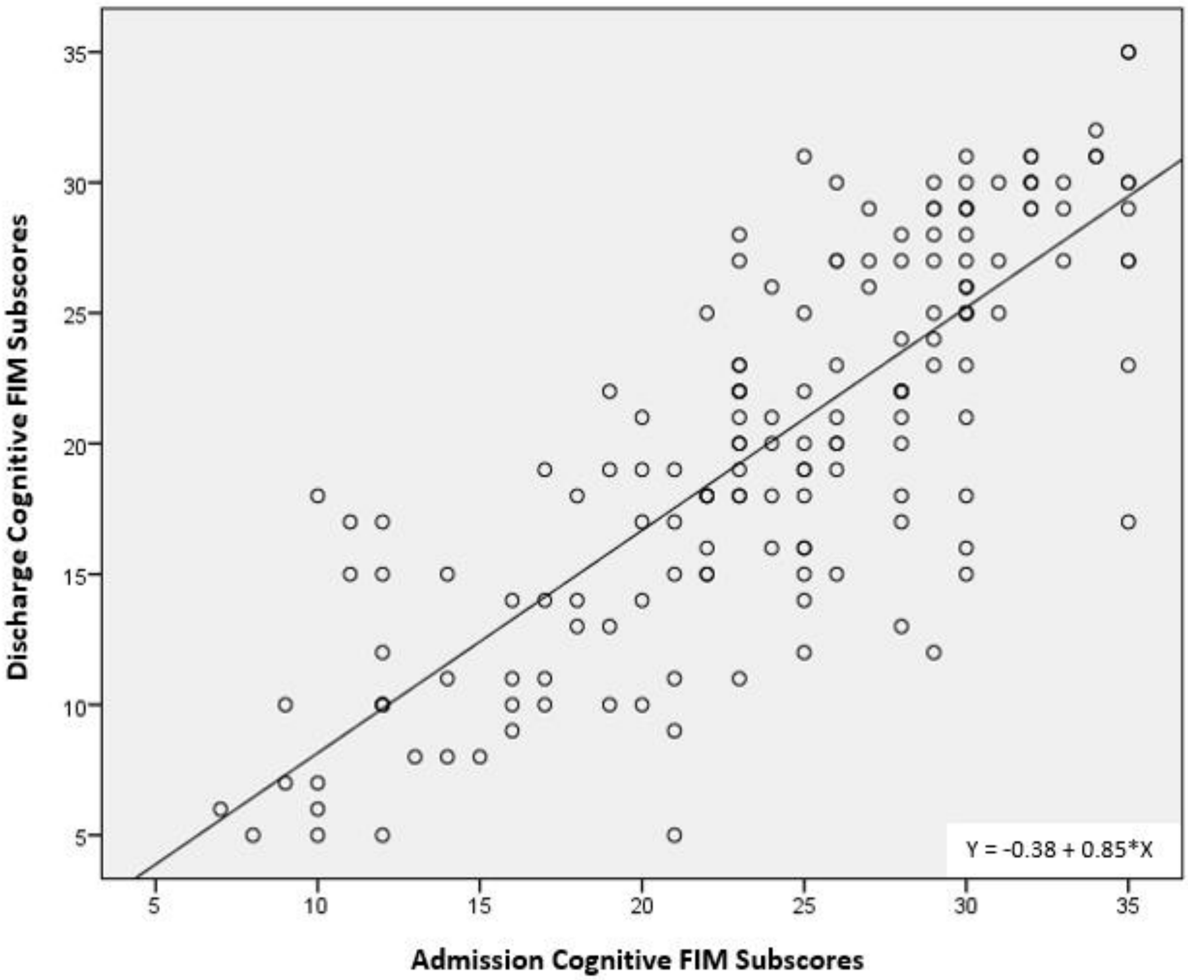
Note. Scatter plot of admission Motor FIM subscores vs. discharge Motor FIM subscores. Admission Motor FIM subscore is the strongest predictor of discharge Motor FIM subscores as evident by the model fitting and testing results.

Figure 10



Note. Final validated model for Cognitive FIM subscale. Predictors under the 3 major categories (i.e. demographic, social, and health) were analyzed using Stepwise regression. Five significant predictors (right column, #1-#5) were included in the final validated model for Cognitive FIM subscore. Baseline Cognitive FIM subscores, age, cooperative client behavior, comorbid obesity, and total number of comorbidities accounted for 66% of the total variance in Cognitive FIM scores upon discharge from inpatient rehabilitation. The strongest predictor was the baseline Cognitive FIM subscores. Health professionals should evaluate these predictors upon admission to inpatient rehabilitation to identify clients who will likely improve and to tailor individualized interventions.

Figure 11



Note. Scatter plot of admission Cognitive FIM subscores vs. discharge Cognitive FIM subscores. Admission Cognitive FIM subscore is the strongest predictor of discharge Cognitive FIM subscores as evident by the model fitting and testing results.

Chapter 4

GENERAL SUMMARY: CONCLUSIONS AND FUTURE DIRECTIONS

General Summary

My dissertation research demonstrates that demographic, environmental, and health characteristics influence the course of functional recovery following acquired brain injury (ABI). Functional recovery after traumatic forms of ABI depends on many inter-related factors associated with favorable outcomes such as young age, male gender, high educational level, and higher income. Access to health care, health insurance, and social support are also associated with recovery, whereas physical environmental barriers accounted for worse outcomes after traumatic brain injury (TBI). Moreover, injury severity and rehabilitation strategies are important determinants of functional recovery following a TBI. This dissertation work included a systematic review of rehabilitation interventions for individuals with mild forms of TBI known as post-concussion syndrome (PCS). Interventions demonstrating significant positive functional outcomes following PCS included psychotherapeutic interventions, social work intervention, and self-management strategies. These interventions alleviate symptoms and facilitate return to daily life routines after brain injury.

My dissertation research also examined long-term effects of non-traumatic brain injury on the self-perceived functional performance of stroke survivors. Individuals with stroke identified several meaningful daily activities that were challenging to perform in the years following injury. These challenges activities encompassed community mobility, employment, functional mobility, and leisure participation. After studying factors influencing functional recovery following brain injury, the final piece examined factors predicting favorable functional outcomes. Early prediction of functional outcomes following brain injury is extremely valuable as it helps health care professionals in designing individualized client-centered interventions and allows for informed counseling of families and caregivers.

The final part of this dissertation research included the development and validation of two predictive models of Motor and Cognitive FIM subscores among individuals with stroke. These models identified significant predictors of motor and cognitive domains of function following stroke rehabilitation. Baseline motor FIM and the baseline cognitive FIM subscores are the strongest predictors of discharge FIM subscore after inpatient rehabilitation. Secondary predictors of functional performance include a combination of personal, social, and medical characteristics including stroke severity, age, client behavior, independence on admission, and comorbidities. Comorbid conditions were both prevalent and diverse among stroke survivors. The research I have pursued during my doctoral program supports my firm belief that individualized interventions are essential for serving clients with stroke, to maximize their recovery and participation in daily activities. Therefore, it is important to consider predictors of favorable functional outcomes along with the client preferences when working with adults with stroke at the hospital, at home, or in the community.

Future Research

This dissertation research effort explored factors associated with functional outcomes following brain injury including TBI and stroke. Future research should focus on examining the influence of various demographic and health factors on longitudinal changes in functional performance of daily activities following brain injury. Using objective measures of functional performance will allow validation of self-reported functional performance relative to the actual capacity of the individual in addressing these same tasks. Further research should also focus on exploring the influence of significant predictors of motor and cognitive performance of stroke survivors in the long-term after rehabilitation. Evidence regarding this topic accumulating yet the effect of the information generated by predictive models has not been tested in clinical practice.

Impact studies exploring the impact of predictive models on physician's decisions and client outcomes are scarce (Fahey et al., 2018). Therefore, future research should evaluate the impact of knowledge derived from predictive models of functional capacity on stroke rehabilitation practice, client health, and costs of care.

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Appendix 1

FACTORS INFLUENCING FUNCTIONAL RECOVERY FOLLOWING A TRAUMATIC BRAIN INJURY

Comprehensive Project #1

By

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Factors Influencing Functional Recovery Following a Traumatic Brain Injury

Introduction

Traumatic brain injury (TBI) is a significant health care problem that continues to affect the lives of millions of people each year. This condition causes a wide range of physical, cognitive, and emotional symptoms. When these symptoms continue to exist, it interferes with the individual's ability to perform activities of daily living activities (ADLs) leading to functional limitations and disability. These consequences are more evident in people with severe degrees of injury who do not attain full functional recovery and continue to live with functional limitations. Functional recovery denotes the individual's ability to perform ADLs independently within the individual's natural environment after injury. Occupational therapists work with their clients to achieve functional recovery and to maximize participation in daily occupations after TBI. Formulating a comprehensive understanding of the client's personal and environmental factors crucial for serving clients. These factors may support or hinder functional recovery after TBI. The purpose of this review is to explore the influence of personal and environmental factors on functional recovery following a TBI.

Studying factors influencing functional recovery after TBI helps occupational therapists in tailoring intervention plans that meet the needs of their clients with TBI. In addition, understanding the effect of these factors may assist in reducing the economic burden of TBI. This can be achieved through careful design of effective interventions to reduce the length of stay in hospitals and to increase employee retention after injury. TBI is highly predictable and preventable, and thus prevention strategies can be effective. Identifying factors relevant to prevention may increase awareness and reduce the incidence of TBI.

Background

TBI is a serious public health problem in the United States (US) and worldwide

(Corrigan, Selassie, & Orman, 2010; Puvanachandra & Hyder, 2009). An estimated 1.74 million people in the US (Coronado et al., 2011) and more than 10 million people worldwide (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007) sustain a TBI each year leading to hospitalization or death. TBI is a major cause of long-term disability in industrialized and developing countries (Hydar et al., 2007). It is expected to exceed many diseases as a leading cause of disability and death by the year 2020 (Chan, Thurairajah, & Colantonio, 2013; Zitnay, 2005). TBI continues to receive the attention of many researchers, health care professional, and legislators. It should be noted that the true number of TBI cases exceeds the figures in current US national and military reports. TBI cases that receive medical services in departments other than the emergency rooms are not included. Other TBI cases co-occur with other injuries, and the diagnosis may be registered as a polytrauma, not as a TBI (Ribbers, 2010). In addition, many cases of mild TBI often goes undetected, undiagnosed, or underreported (Buck, 2011). Underdiagnosed mild TBI puts these individuals at higher risk for successive brain injuries and potentially leads to functional impairment, lower quality of life, and increased financial burden.

The economic burden of TBI is significant. In 2010, the total annual costs of TBI were $76.5 billion including direct medical expenses and indirect societal costs (Centers for Disease Control and Prevention [CDC], 2013). Ma et al. (2014) reviewed the literature on the economic burden of TBI compared to other conditions. The researchers used the Consumer Price Medical Index to estimate the annual costs of TBI and concluded that the total cost was $78.1 billion (Ma, Chan, & Carruthers, 2014). The inflation-adjusted annual direct costs of TBI were estimated to be $13.1 billion. This includes services provided in a formal health care facility like physician visits, emergency room visits, and acute hospitalization. In addition, the indirect costs were $64.7 billion and accounted for the value of lost work hours and unpaid care provided to the individual with a TBI by caregivers. TBI continues to cost billions of dollars each year not to mention the intangible costs due to reduced quality of life for both individuals with TBI and their caregivers (Ribbers, 2010).

TBI and Functional Impairment

The consequences of TBI can be devastating for the individual's functional skills as the injury causes alterations in brain functions, and thus may result in long-term functional impairment. Functional impairment after TBI happens due to the multifaceted physical, cognitive, sensory, or emotional symptoms generated by the injury. Physical symptoms of TBI include motor problems such paresis, ataxia, apraxia, and postural instability. Other symptoms include headaches, nausea, and fatigue (Dikmen, Machamer, & Temkin, 2009). These symptoms adversely influence the individuals' mobility, participation in the community, and performance of ADLs. Although physical impairment is frequent after TBI, it is not the sole cause of functional limitations after TBI.

Other forms of functional impairment happen due to deficits in cognitive functions like memory, attention, and reasoning (Arciniegas, Held, & Wagner, 2002; Walker & Pickett, 2007). These cognitive skills are very important for successful engagement in ADLs. The inability to remember previous events or formulate new memories can lead functional limitations. This is also true when individuals with TBI have a reduced attention span. In addition to cognitive deficits, Individuals with TBI can have sensory processing deficits such as problems with the five senses, communication (receptive and expressive), and psychological problems.

Psychological problems are prevalent after TBI (Schwarzbold et al., 2008). It includes depression, anxiety, personality changes, aggression, social inappropriateness, and posttraumatic stress (Jorge et al., 2004; Rogers & Read, 2007). These disorders appear after TBI, and mixed factors can play a role in the development of these disorders. Examples of these factors include disturbances of brain structures and circuitry, personal traits like age and genetic predisposition, and pressure generated by environmental demands. A combination of such factors might lead to psychological disorders after TBI, yet the evidence is not definite about one unique factor in terms of causality. Depression and other psychological disorders associated with TBI disrupts the individuals' engagement in meaningful activities and social relationships leading to functional impairment and potentially reduced the quality of life of injured individuals as well as their families (Arango-Lasprilla et al., 2008).

The impact of functional impairment upon the lives of individuals with TBI extends to touch other aspects of their life such as employment. It can result in loss of employment, and thus increases the financial burden on the individual. About 20% of people with TBI lose their jobs because of a work-related disability that resulted from the head injury (Finkelstein et al., 2006). These disabilities limit the individual's ability to work and participate in ADLs, but with intensive interdisciplinary rehabilitation, clients can gain improvements in their ADL task performance and can increase their chances for employment (Waehrens & Fisher, 2007). Such improvements emphasize the importance of client-centered Occupational Therapy (OT) services to assist individuals with TBI overcome these functional limitations and maximize participation in daily life activities.

Although TBI can influence the individual's participation in daily life activities, some people live an active and engaged life after rehabilitation. Many people with TBI living with functional impairment have many skills, which have not been influenced by the injury like feelings toward family and friends, long-term memories, and the ability to perform some ADLs (e.g.; drive, dress, or cook). Even people with a moderate to severe injury can still employ their intact skills and functions, along with their numerous personal characteristics to supports functional engagement in ADLs. For this reason, occupational therapists are encouraged to use a strength-based approach to intervention planning and implementation. This approach focuses on the individual's retained skills to support functional recovery and reintegration in the community.

Functional Recovery after TBI

Many outcomes can be used to gauge functional recovery after TBI. These outcomes include the degree and success in the performance of ADLs, return to work or school, and community re-integration. These outcomes were the most important from the perspective of individuals with TBI and their families (Golisz, 2009). Achieving independence, community integration, and maximum participation in daily life is the ultimate goal of rehabilitation for individuals with TBI (Sander, Clark, & Pappadis, 2010).

Occupational therapists follow a holistic approach to evaluation and treatment planning for individuals with TBI. This approach mandates a comprehensive assessment and understanding of the client's condition and all related factors that could support or hinder functional recovery. It will assist occupational therapists in deciding the course of the intervention and will increase the likelihoods of predicting prognosis, determining follow-up plans, and anticipating outcomes of therapy.

Occupational therapists work with individuals who have TBI during all stages of recovery. They offer a comprehensive assessment of the individual's strengths and limitations. Occupational therapists utilize many assessment tools to evaluate and monitor their client's functional capacity, outcomes, and recovery after TBI. These measures include, but not limited to, Functional Independence Measure (FIM), Disability Rating Scale (DRS), Glasgow Outcome

Scale-Extended (GOS-E), and the Community Integration Questionnaire (CIQ; Ottenbacher, Hsu, Granger, & Fiedler, 1996; Rappaport, Hall, Hopkins, Belleza, & Cope, 1982; Willer et al., 1993; Wilson, Pettigrew, & Teasdale, 1998). The Rivermead Post-Concussion Questionnaire (RPCQ) measures post-concussion symptoms, which may persist for weeks or months after mild TBI or concussions (King, Crawford, Wenden, Moss, & Wade, 1995). The heterogeneity of TBI presentation and outcomes may justify the availability of so many assessment tools to evaluate the outcomes after TBI.

This intricate nature of TBI complicates the diagnosis process and makes it difficult to find effective interventions (Saatman et al., 2008). For example, individuals do not necessarily present with an open head wound, skull fracture, or loss of consciousness to be diagnosed with a TBI. These signs and symptoms are not evident in mild forms of TBI, which makes the diagnostic process more complex and challenging. In mild TBI, it may take days or weeks before the individual seeks medical services, not until the individual begins to experience problems in performing routine daily tasks or in social situations. Establishing a formal TBI diagnosis provides validation of the client’s complaints about the lingering symptoms. Moreover, it provides an opportunity to seek proper treatment to manage subsequent symptoms and/or functional limitations.

Occupational therapists tailor interventions that meet the needs of individuals with TBI. OT individualized interventions begin with assisting the client during recovery from coma and end with community re-integration after rehabilitation. Occupational therapists collaborate with the client and family on addressing issues of motor recovery, cognitive impairment, and limitations in occupational performance. Some of the interventions occupational therapists focus on addressing social and coping skills, education and work activities, community mobility, and environmental modifications. For example, a client with TBI demonstrates signs of uncontrolled anger and maladaptive behavior. The occupational therapist working with this client may consider using emotional regulation and behavioral control techniques to assist the client to overcome these signs. In this instance, an occupational therapist would consider using therapeutic strategies such as situation modification to regulate emotions and to avoid anger bursts. These strategies suggest avoiding known situations that trigger anger and modifying such situations to make it more appealing to the client. This comprehensive approach to treatment empowers the client to regain control over the client's life and to promote participation in everyday life activities.

Factors Influencing Functional Recovery after TBI

There are many factors influencing functional recovery after TBI. One of the most important factors is the severity and causes of injury including civilian and military TBI. Other factors include the personal and demographic characteristics of the injured individuals (Mushkudiani et al., 2007), environmental factors (Whiteneck, Gerhart, & Cusick, 2004), successive head injury, and post-concussion syndrome. Understanding the relationship between these factors and recovery will assist occupational therapists in the clinical decision-making process. In addition, it will serve as the foundation for designing intervention plans that meet the needs of clients with TBI and promote participation in daily life activities.

Severity and Causes of Injury

Each case of TBI is unique because affected individuals have different causes of injury, degrees of severity, and regional patterns of injury. For this reason, some individuals with TBI exhibit different functional recovery profiles. One of the factors influencing functional recovery after TBI is the severity and extent of damage that results from the injury. The severity of injury is a strong predictor of patient outcomes and recovery after TBI (National Institute of Neurological Disorders and Stroke [NINDS], 2014). Increased severity predicts worse functional and cognitive outcomes in affected individuals across the age span. Injury severity predicted functional outcomes two years after injury in children with TBI (Chevignard et al., 2012). Children with severe TBI had poor adaptive skills and outcomes, with deficits greatest for cognition (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012; Catroppa, Godfrey, Rosenfeld, Hearps, & Anderson, 2012). Adults and older adults with severe TBI are at higher risk for dementia, functional limitations, and disability (Gardner et al., 2014). A combination of older age and increased injury severity lead to worse outcomes in the elderly group. It may lead to increased length of hospitalization, increased risk of medical complications, longer recovery time, and lesser quality of life.

The severity of injury encompasses the extent of damage generated by the injury. Severe TBI involves more brain damage, and thus worse recovery outcomes and functional limitations. Researchers classified damage that results from TBI into primary and secondary injuries. In primary injuries, the damage primarily occurs due to mechanical forces acting on the brain at the time of impact, and this generally takes 100 milliseconds or less to occur (Greve & Zink, 2009; Prins, Greco, Alexander, & Giza, 2013). Primary injuries cause cortical contusions, hemorrhage, deep cerebral lesions, and diffuse axonal injuries (Blumbergs et al., 1994; Thibault & Gennarelli, 1990). Deep and diffused injuries cause more damage leading to disability and worse prognosis in terms of functional recovery. Secondary injuries happen due to physiological events stemming from the primary injury, with a time course of minutes, hours, or days (Greve & Zink, 2009; Prins et al., 2013). Secondary injuries lead to extensive degeneration of affected neurons and glial cells because of the hematoma or edema generated by the primary injury (Gentry, 1994). A brain hematoma is a clot that forms when a blood vessel ruptures in the brain. It can develop in different locations and sizes inside the skull and leads to elevated intracranial pressure. The prolonged compressive forces of edema and hematoma can lead to neural damage by deforming the brain tissue, raising intracranial pressure, and decreasing cerebral blood flow (Greve & Zink, 2009). These consequences of edema and hematoma often cause temporary and possibly permanent impairment of brain functions depending on the size, location, damage, and treatment of the clot. Permanent impairment of cognitive functions affects the individual's ability to assume their life roles because of difficulty in planning, in remembering, in making decisions, in keeping track of time, in coordinating complex events, and in adapting to life changes.

The extent of brain damage in TBI depends on many factors including the location and nature of injury in the brain (e.g. intensity, direction, and duration of the injury-inducing force; Anderson, Spencer-Smith, & Wood, 2011; Maas, Stocchetti, & Bullock, 2008; NINDS, 2014). Location of injury plays a major role in determining symptoms and functional outcomes after injury. Injury to specific structures of the brain results in distinct signs and symptoms related to that structure's function. For example, injury to the frontal lobes may cause impairment of decision-making and impulse control leading to inappropriate social behavior. Injury to the cerebellum can cause loss of motor coordination and balance. The brainstem controls vital functions such as breathing and heart rate, and thus injury to this area could inhibit any of these processes. Identifying the location of injury determines subsequent symptoms, and thus guides the selection of intervention strategies to achieve the best functional outcomes. In addition, identifying brain structures at higher risk of injury in TBI is important in determining the influence of injury location on functional recovery.

Evidence suggests that specific areas of the brain are more susceptible to damage in TBI. Frontal and anterior temporal brain lesions occur more often in head injuries than lesions in the posterior cerebral hemispheres (Lux, 2007). Factors that could contribute to this phenomenon include the facts that the frontal lobes have a relatively large size and are less constrained inside the skull compared to the posterior lobes. Symptoms and signs observed in the evaluation can help health care professionals pinpoint possible areas of the brain damaged in the course of TBI. Further, health care professionals can anticipate symptoms based on the affected area of the brain. Identifying specific areas of the brain damaged in TBI helps occupational therapists in determining the course of treatment and in anticipating prognosis following rehabilitation.

The cause of injury is equally important to the severity of injury, the extent of damage, and the location of injury in determining the functional outcome and recovery after TBI. Different causes of injury account for different mechanisms of injury, and thus contributes to the variability in the functional recovery patterns. Examples of different causes of injury include penetrating or non-penetrating injury and civilian or military TBI. TBI can be caused by penetrating or non-penetrating injury to the head. Penetrating brain injury destroys the brain tissues in the path of the projectile and yields significant structural damage to adjacent tissues. The trajectory and location of the wound are the most significant factors in determining outcomes post-injury. Penetrating injuries may cause limited functional impairment due to the localized nature of injury compared to diffused injuries. In diffused brain injuries, the damage is widespread in the brain, and thus the functional recovery outcomes are worse. Other causes of TBI include civilian and military injuries.

Civilian and Military TBI

Civilian and military TBI is a unique classification of brain injuries in which TBI occurs due to different exposures. Civilian and military TBI have different causes of damages and course of recovery. In civilian TBI, falls were the leading cause of injury in the US accounting for 40% of cases (CDC, 2014). In contrast, the leading cause of combat-related TBI among active duty military personnel is explosive blasts (Brahm et al., 2009; Elder & Cristian, 2009). The mechanism of injury and damage caused by falls are different from injuries caused by blast waves. Falls involves a localized brain injury that results from acceleration-deceleration head movement, or direct impact of the head with the ground or object. Explosive blasts generate pressure waves, which lead to sudden fluctuations in the atmospheric pressure outside the head. These fluctuations result in increased intracranial pressure as the evidence suggests from animal studies (Leonardi, Bir, Ritzel, & VandeVord, 2011). The increased intracranial pressure that results from explosive blasts can lead to diffused brain injury (Magnuson, Leonessa, & Ling, 2012). Civilian and military TBI results in different degrees of functional limitations and disability.

The course of recovery and retention of functional skills varies and requires individualized occupational therapy intervention plan that meets the needs of the client with TBI. The occupational therapist must consider the preinjury lifestyle, personality, goals, values, resources, and the individual's ability to adapt to changes in order to minimize the impact of TBI upon the individual’s life.

Personal and Demographic Factors

The demographic characteristics vary among individuals with TBI, and it contributes to the potential variability in functional recovery outcomes among different populations. Some of the personal and demographic attributes of interest in this review include age, gender, socioeconomic status (SES), race/ethnicity, and educational level.

Age seems to have associations with the individual's susceptibility to TBI and recovery after injury. Adolescents and people older than 75 years of age are at higher risk of sustaining a TBI (Coronado et al., 2011). These age groups are different in terms of practices, performance capacity, and life roles. Adolescents are more engaged in activities that increase their risk of TBI such as sports and recreational activities. Older adults are more susceptible to other age-related changes such as cerebrovascular atherosclerosis and the adherence of dura to the skull with advancing age, they receive aspirin and anticoagulant therapies, and they are more suitable to other co-morbidities like which increase the chances of worse brain injuries (Thompson, McCormick, & Kagan, 2006; Timiras, 2003). In addition, Hukkelhoven et al. (2003) found an association between older age and worse outcomes after TBI, the possibility of having worse outcomes increased by 45% for every 10 years of age.

A combination of older age and other factors contribute to these worse outcomes. For example, older age combined greater TBI severity increased the risk of developing dementia in people 55 years or more (Gardner et al., 2014). A possible interpretation of this phenomenon is that the individual's physical and cognitive abilities to recover from TBI decline with age. Marquez de la Plata et al. (2008) conducted a longitudinal study to evaluate the relationship between age and risk of functional decline within five years after TBI. The findings indicated that age of 27 years or more was associated with greater functional decline and disability compared to a younger age (16-26 years). Younger adults showed the greatest amount of improvement and least decline measured using FIM and DRS. The body of evidence suggests that older age is associated with worse outcomes in terms of functional recovery. Nonetheless, individuals with older age have acquired more skills, social relationships, and resources over the years. Occupational therapists can utilize a strength-based approach that emphasizes their client's skills and social support system to facilitate restoration of functional skills necessary for everyday activities. For example, the therapist can integrate different family members and friends in the intervention planning and implementation to increase the client's motivation to participate in therapy. Another example is capitalizing on the client's skills and abilities. Having more skills means more opportunities to engage the client in meaningful activities that can promote functional recovery and participation.

Studies have revealed a link between gender and outcomes after TBI. Women have poorer outcomes after mild TBI (Bazarian, Blyth, Mookerjee, He, & McDermott, 2010). Gender is also a significant predictor of post-concussion symptoms three months after mild TBI. Researchers have linked post-concussion symptoms to increased functional impairment and decreased the quality of life after mild TBI (Lundin et al., 2006; Stalnacke et al., 2005). Women are at higher risk of developing post-concussion symptoms than men (Ryan & Warden, 2003). Niemeier et al. (2014) examined gender differences in self-awareness of injury-related deficits during acute TBI recovery. The authors concluded that women had better self-awareness of their performance limitations than men did. One interpretation of this conclusion is that increased awareness of deficits may decrease self-confidence and determination eventually leading to worse functional outcomes. A second interpretation is that women have a greater deficit and thus they are more aware of their limitations. A third interpretation is that men have less self-awareness of their deficits after TBI because they have a higher risk of sustaining a substantial injury than women. In fact, men have twice the risk of sustaining a brain injury compared to women due to differences in lifestyle and exposures (CDC, 1999). Sustaining a substantial brain injury in men may lead to inappropriately high self-confidence, which leads to engagement on risky behaviors that increase the possibility of sustaining secondary or subsequent injuries.

Men and women had differences on reported symptoms and perceived challenges in ADLs after TBI. Colantonio et al. (2010) found that men reported symptoms of agitation and difficulty setting goals. In contrast, women reported symptoms of headaches, dizziness, and low self-esteem more frequently than men did. Both men and women have difficulties in daily functioning due to different problems associated with TBI. Men perceived having a sensitivity to noise and insomnia as more problematic in daily functioning, whereas women considered lack of initiative and needing supervision more problematic (Colantonio, Harris, Ratcliff, Chase, & Ellis, 2010). Studies of gender differences in functional recovery after TBI suggest that women are prone to worse outcomes after TBI. In addition, men and women reported having challenges with different TBI symptoms. These findings suggest that occupational therapists must design individualized treatment plans that meet the needs of each client. These interventions can address the problems perceived by each client. For example, men may benefit from intervention strategies that employ environmental modifications to reduce the noise in the home and work environments. Women may find it more helpful to engage in daily routines that require less supervision from others.

Other personal factors that influence functional recovery include the individual's Socioeconomic Status (SES). SES denotes a combination of factors -education, income, and occupation- that contribute to the social and financial standing of individuals/families in a community (American Psychological Association, 2015). The income piece of SES seems to influence recovery after TBI. Low income decreases the individual's ability to obtain health insurance coverage and thus limits access to care. Heffernan et al. (2011) found that lack of health insurance coverage decreased the chances of getting rehabilitation service in people with TBI. In other words, individuals with TBI who do not have insurance coverage were less likely to seek medical service in rehabilitation centers. In addition, having higher income and private insurance were associated with lower rates of leaving the hospital against medical advice. These findings suggest that having higher income and medical insurance increased the chances of seeking important medical and rehabilitation services after TBI. In addition, a comparison of TBI outcomes between high, middle, and low-income countries revealed higher survival rates among people with severe TBI in high-income countries. Middle and low-income countries had lower rates of disability due to mild-moderate TBI (De Silva et al., 2009). A possible interpretation of these results could mean that advanced medical care in high-income countries may have contributed to a higher proportion of patients surviving TBI with a functional impairment and disability, whereas social and cultural support could explain lower functional impairment and disability rates after mild to moderate TBI in middle-low income countries.

Sociodemographic factors include race/ethnicity in which individuals with different racial backgrounds have reported different experiences of TBI outcomes. Arango-Lasprilla and Kreutzer (2010) reviewed the literature on the relationship between race/ethnicity and TBI outcome. Researchers concluded that minorities (African Americans, Hispanics, and Asians) reported more functional limitations than Caucasians up to 5 years after TBI. Hydar et al. (2007) found that African American children (≤16 years) had more functional limitations and disabilities compared to Caucasians and Asians. In the same sample, African Americans had increased pre-morbidities and severe injuries. In another study, African Americans had more functional disabilities than Caucasians (Hart et al., 2007). African Americans also reported less life satisfaction than Caucasians and Asians one year after TBI (Arango-Lasprilla et al., 2009). Possible explanations for this phenomenon include differences in access to health care, access to transportation, financial status, and culture-specific behaviors and customs. Accounting for these sociodemographic differences allows for optimized planning and implementation of therapeutic interventions.

As a part of SES, the educational level also has an influence on recovery following TBI. Educational level was a strong predictor of disability-free recovery in the first year after TBI (Schneider et al., 2014). In other words, people with more education have increased odds of recovering from serious brain injuries without residual disability. Schneider and colleagues concluded that the proportional relationship between education and functional recovery indicates that cognitive reserve might contribute in facilitating neural adaptation after TBI. Cognitive reserve theories suggest that higher educational level and intelligence may increase the individual’s ability to cope with brain damage after TBI. Individuals with TBI who had higher educational levels (mean = 14.1) scored better on measures of intelligence than others with lower educational levels (mean =12.3; Kesler, Adams, Blasey, & Bigler, 2003). This finding suggests that more education might be related to adaptation of cognitive capacity after injury. Higher educational level predicts better functional and cognitive outcomes after TBI. Accounting for educational level assists occupational therapists in predicting recovery outcomes following rehabilitation.

Environmental and Contextual Factors

According to the Occupational Therapy practice framework, the term environment denotes the external physical surroundings and the social elements at which participation in ADLs takes place (American Occupational Therapy Association [AOTA], 2014). The context refers to the less noticeable elements around the client that have a strong influence on performance. There are many environmental and contextual factors influencing recovery after TBI including the physical environment, social environment, and cultural context. Other environmental factors include employment, pre-existing conditions, and lifestyle. Understanding the role of the multifaceted environmental and contextual factors on functional recovery is pivotal in supporting individuals with TBI. Occupational therapists aim to increase the individual's participation in their natural environment. This may require making some adaptations and modifications to the environment to support functional performance and to enable occupational engagement.

Environmental influences have an impact on outcomes after TBI as it guides the path to recovery (Anderson et al., 2011). Examples of these environmental factors include home environment, family support, cultural customs, and interventions tailored to the individual's needs and preferences. It is essential to evaluate the influence of these factors on recovery after injury in an effort to attain healthy living and maximize participation in everyday life activities. The first goal of this process is identifying the positive aspects of the environment that promotes performance and recovery. Positive elements of the environment may include physical objects or immaterial components that support participation. For example, training equipment that the client likes to use, or social events that the client likes to attend. The second goal is recognizing barriers hindering participation in everyday life activities. Barriers include any objects or circumstances that hinder participation and reduces engagement in meaningful activities.

The physical environment includes the natural and artificial surroundings like buildings, landscapes, streets, and transportation means. The social environment consists of different types of social variables such as socioeconomic status (SES), family functioning and behavior, social resources and stressors, employment and expectations of persons and organizations (AOTA, 2014; Gerring, Taylor, Wade & Yeates, 2011). In addition to the physical and social environments that influence the individual's performance, the cultural context is equally important. The cultural context includes customs, beliefs, and expectations accepted by the individual's society.

A well-balanced physical environment customized to embrace the needs of individuals with TBI will provide a suitable medium for enhancing performance and increasing participation. For example, home modifications that are implemented by occupational therapist promote safety and independence (Fagan & Sabata, 2011). Although affected by injury, individuals with TBI retain some of their physical and cognitive skills. From a strength-based approach, occupational therapists shed the light on these skills alongside the environmental modifications that can increase the individual's chances of overcoming the challenges associated with TBI.

The physical environment also includes access to health care and access to transportation. These factors may contribute to improved or worsening outcomes after TBI (CDC, 2014b). Access to health care services is affected by many factors such as the availability of specialty providers, availability of financial resources to individuals with TBI, access to transportation, and geographical location of residence, and level of insurance coverage (CDC, 2014b). The availability of these factors improves access to health care services, and thus may increase the likelihood of achieving favorable rehabilitation outcomes. Occupational therapists may consider consulting with the client or family if they believe that any of these conditions apply to the client. Identification of the individuals at risk of worse outcomes due to access limitations provides opportunities for targeted prevention efforts to increase access to health care and to reduce the burden of environmental demands.

Physical environmental demands can increase the burden on individuals with TBI. Work demands, family responsibilities, and financial obligations generate pressure that can be difficult to manage, and in some cases, lead to psychiatric problems including depression. Whether it is trauma or environmental factors, individuals with TBI might face additional challenges of dealing with psychological disorders. Occupational therapists should educate individuals with TBI and their families about the possibility of developing such conditions. Individuals diagnosed with any of these disorders should receive appropriate intervention to attenuate the influence of psychological ailment.

Identifying the physical environmental barriers that individuals with TBI face in their daily lives is essential in facilitating functional recovery and community integration. Physical barriers may limit the individual's ability to move, work, play sports, or even perform simple ADLs. Individuals with TBI reported many environmental barriers that limited community integration with physical barriers being the most influential (Fleming et al., 2014). Whiteneck et al. (2004) identified many environmental barriers that influenced outcomes 1 year after sustaining a TBI. These barriers included transportation, governmental policies, family members' attitudes, and some aspects of the surrounding physical environment including lighting, noise, and crowdedness (Whiteneck et al., 2004). In addition, the findings of FIM indicated that individuals with TBI who required physical assistance reported more barriers that those who did not require assistance. These results suggest that people with TBI with severe physical disability face more challenges in terms of handling their physical environment. Having a severe TBI may reduce the individual's awareness of the surrounding physical environment, or it may decrease the individual's ability to interact with the surrounding physical environment.

In addition to the physical environment, the social environment also plays a role in promoting or hindering the functional performance of individuals with TBI. The family environment and social support assist the client in coping with injury. Rehabilitation literature strongly emphasizes the role of family involvement as an important factor in the potential success or failure of the long-term rehabilitation of clients with different conditions. Yeates et al. (1997) examined the environmental factors as predictors of recovery after TBI in children 6-12 years-old. The researchers concluded that the quality of the pre-injury family environment was a significant predictor and moderator of the effect of TBI during recovery post-injury. Additionally, having a supportive, involved family attenuated the effect of TBI whereas in low-functioning, detached families it was exacerbated. Individuals who have severe TBI are at high risk for a significant decrease in friendships and social support (Izuate, Durozard, Aldigier, Teissedre, Perreve, & Gerbaud, 2008). Thus, it is imperative to integrate the family members, caregivers, and loved ones in the rehabilitation process to promote recovery and favorable rehabilitation outcomes.

Social support does not stop at the family level but extends to incorporate the community. Societal views of disability associated with TBI are also important as it influences how individuals with TBI are treated in the community. The availability and quality of social support is likely to influence the subjective feeling of health and well-being experienced by individuals with TBI. One study showed that individuals with TBI who had minimal feelings of belonging, being valued, and being involved with others are more likely to report difficulty with regulating emotions, managing interpersonal interactions, displaying confidence, and showing sensitivity to the feelings of others (Bay, Blow, & Yan, 2012). Researchers recommended employing community-based programs and using supported-relationship interventions to improve the level of independence of individuals with TBI (McCabe et al., 2007).

Community re-integration is best fit for individuals with TBI who are living with a residual disability, require assistance with ADLs and care needs, or face difficulties in returning to their home and work environments (Trudel, Nidiffer, & Barth, 2007). It encompasses work or other productive activity, independence in daily living, and social participation (Sander et al., 2010). The value of community integration stems from the notion that full community integration and participation in society is the ultimate goal of rehabilitation for individuals with TBI. Some of these individuals live with long-term challenges even after 10 years of injury (Lefebvre, Cloutier, & Levert, 2008). In part, these challenges are due to different barriers that contribute to this difficulty including not going back to work, depressed mode, and problems in relationships. It is also important to indicate that coping with the changes after injury is important for a successful community reintegration. These coping abilities of individuals with TBI decrease as the severity increases, which may limit community involvement. One study revealed that approximately 50% of individuals with TBI are not satisfied with their community integration (Lefebvre et al., 2008). The authors suggest that health care professionals should consider this aspect when designing intervention plans to increase community involvement. Health care professionals should also consider the cultural background of the individual and community.

The cultural context plays a crucial role in shaping peoples' views and ways of living. People from different cultures have unique expectations and views about illness and disability (Diaz, 2013). Social scientists estimate the minority groups will constitute 45% of the US population by 2050 (Rameriz & de la Cruz, 2002). This means that a growing diverse group of TBI survivors will be receiving rehabilitation services, and therefore health care professionals must consider the cultural backgrounds when working with these clients to maximize participation in the community and to facilitate a safe return to work.

Employment is another important factor to consider when working with individuals with TBI. About one-third of individuals with TBI who received treatment in emergency departments were at a working age (15-65 years) in 2010 (CDC, 2014c). In some cases, TBI results in career transfer, reassignment, or termination as the affected individuals are less efficient or have a reduced ability to produce skilled work due to the TBI or resulting disability (Power & Hershenson, 2003). Individuals with TBI are not fully aware of the extent of their disability, and thus makes efficient work more challenging for them. Other barriers can make obtaining a new job or retaining an old one after TBI difficult. These include lack of knowledge and acceptance of TBI on the part of employers may prevent them from hiring individuals with a TBI. Another barrier to employment after TBI is underestimating the challenges that individuals with mild-moderate TBI face. Some state organizations had a history of providing inadequate assistance to these individuals in finding work opportunities (Brain and Spinal Cord, 2013). At the same time, those who return to work would find it difficult to retain their jobs. One study found that more than 50% of individuals with a TBI who return to work lose their job within 1 year after returning to work (Johnstone, Mount, & Schopp, 2003). The annual economic burden of this turnover is approximately 22 billion dollars in lost wages and continued health care costs (Yasuda, Wehman, Targett, Cifu, & West, 2001). A history of unemployment or sick leave predicted worse long-term outcomes in people with severe TBI. In addition, this population faced more challenges with ADLs and had a poor health-related quality of life post-injury (Ulfarsson, 2013).

Premorbid and post-incident factors could hinder functional recovery after TBI. Some individuals who sustain TBI may have preexisting physical, cognitive, or psychological conditions. These conditions could mask or exacerbate the effects of the head injury (Institute of

Medicine, 2011). At the same time, it may delay the course of recovery due to the added physical or cognitive limitations caused by the presence of preexisting condition. For example, a TBI client with preexisting schizophrenia may take longer time in rehabilitation to achieve functional gains compared to a TBI client who has a comparable injury but does not have a psychological disorder. Pre-existing psychological disorders increase the risk of sustaining a future TBI. Vassallo et al (2007) conducted a study to evaluate this risk and concluded that individuals with pre-existing psychiatric disorders are two times more likely to develop a TBI in the future than others. This applies to individuals with depression, anxiety and conduct disorder. For this reason, early detection and management of these psychological disorders may decrease the incidence of TBI. A comprehensive evaluation of the individual's current and past medical histories is crucial in determining the actual impact of TBI upon the individual's life and skills. It allows occupational therapists to make informed clinical decisions during the intervention planning, and to anticipate the course of recovery and the outcomes of rehabilitation.

The individual's lifestyle and context in which the injury happens are important factors that influence functional recovery after TBI. Civilian and military TBI fall into this category of factors in which lifestyle and context define the causes of damages and course of recovery. Active military personnel are susceptible to TBI due to combat-related injuries, whereas civilians are more susceptible to other causes of TBI such as falls and motor vehicle crashes. Other examples of lifestyle influences include athletes, truck drivers, and many other occupational roles that puts the individual at higher risk for TBI. Different lifestyle and contextual influences play a role in determining the risk for TBI and the subsequent degrees of functional limitations. The course of functional recovery is also influenced by the continuous exposure to the daily occupations and practices that increase the risk for successive head injuries. Occupational therapists are encouraged to evaluate the contextual exposures and lifestyle practices that may support or hinder functional recovery after rehabilitation. The individualized occupational therapy intervention plans must account for these practices to promote participation in ADLs and to prevent successive brain injuries.

Successive TBI injuries

Individuals with mild TBI are at higher risk of sustaining a second injury, and the risk increases with repeated injuries. The symptoms of the first head injury take time to resolve, and in some cases, the individual remains undiagnosed and returns to routine daily activities. The unresolved symptoms and unhealed brain increase the risk of sustaining a second head injury by three times. The cumulative effect of repetitive mild TBI may lead to increased risk of cognitive impairment and neurodegenerative conditions (Aungst, Kabadi, Thompson, Stoica, & Faden, 2014). This risk of impairment increases in later-life and with repeated injuries of a mixed-severity (Gavett, Stern, & McKee, 2011; Guskiewicz et al., 2005). Repeated TBI has been linked to higher incidence of dementia (Alzheimer's Association, 2012; Bower et al., 2003), chronic traumatic encephalopathy (McKee et al., 2009) and Parkinson's disease (Hutson et al., 2011).

Evidence derived from animal research and human studies suggest that a brain recovering from a concussion is at higher risk of sustaining a second head injury with less force. It takes the brain longer time to fully recover and, in some rare cases, it leads to life-threatening outcomes (e.g., Second Impact Syndrome [SIS]; Bey & Ostick, 2009; Simma, Lutschg, & Callahan, 2013; Slobounov, Slobounov, Sebastianelli, Cao, & Newell, 2007). SIS is particularly a concern for the child and adolescent populations because they are more susceptible to injury and the consequence of injury are most damaging to them. Repetitive mild TBI was associated with increased risk of suicide among service members (Bryan & Clemans, 2013). Health care professionals must apply all prophylactic measures to prevent successive mild TBI. One strategy is the early detection and evaluation of TBI cases. This can be achieved through spreading awareness about TBI symptoms and evaluation among groups with a higher risk of TBI such as athletes, military personnel, and the elderly. Another strategy dictates close supervision and follow-up of confirmed mild TBI cases. For example, strategies to limit progressive injury might include avoiding daily routines that places individual with TBI at higher risk of injury (e.g. play sports) before the physician determines they are clear of the initial TBI injury. These strategies could save lives especially for children at risk of SIS, and individuals with a long history of repeated head injury, which puts these individuals at higher risk for depression and suicide. Successive brain injuries are not the only concern that may influence functional recovery after TBI. Post-concussion syndrome can also develop after mild TBI and can influence the course of functional recovery as well.

Post-Concussion Syndrome

Post-concussion syndrome refers to the emergence and persistence of a group of lingering symptoms following a TBI. Post-concussion symptoms may develop following a TBI of any severity, particularly mild TBI (Emanuelson, Andersson Holmkvist, Bjorklund, & Stalhammar, 2003). The classification of these symptoms includes three categories: cognitive, physical, and emotional/behavioral symptoms. It is also important to distinguish between mild TBI and post-concussion syndrome. Post-concussion syndrome is different from a subclinical concussion. Both conditions have similar effects of concussions, but subclinical concussions cannot be diagnosed and often goes unrecognized. A mild TBI refers to the initial TBI severity and denotes a type of injury whereas a post-concussion syndrome describes a group of symptoms that stemmed from TBI. Symptoms of TBI can persist for three months or more. This condition falls under the umbrella of post-concussion syndrome (McHugh et al., 2006). Clinicians use many instruments to quantify post-concussion symptoms including Neurobehavioral Symptoms Inventory, Post-Concussion Symptoms Inventory, the Post-Concussion Syndrome Checklist, the Post-Concussion Syndrome Symptoms Scale, and the Rivermead Post Concussion Symptoms Questionnaire. The degree of severity of post-concussion symptoms are mild, moderate, severe, and very severe (Soble et al., 2014). These symptoms can start within days after TBI and it may take weeks to develop. The gradual development of post-concussion symptoms creates a problem of linking the symptoms to TBI. In some cases, post-concussion symptoms may arise after days of not being present earlier from the injury. This situation makes it more difficult for the client to link the new emerging symptom to the initial injury. Post-concussion symptoms may decline or resolve within three months. It can also persist for one year or more. Understanding the influence of post-concussion symptoms on the affected individuals' lives is crucial for health care professionals to be able to provide support and service to attenuate the lingering symptoms.

Post-concussion symptoms may influence recovery, quality of life, and perceived abilities to perform ADLS in affected individuals (Emanuelson et al., 2003; Sveen, Bautz-Holter, Sandvik, Alvsaker, & Roe, 2010). Common post-concussion symptoms reported in research studies include headaches, fatigue, dizziness, poor memory, and sleep disturbance (Lundin et al., 2006; Stalnacke, Elgh, & Sojka, 2007; Stalnacke et al., 2005). These symptoms can hinder participation in ADLs and decrease quality of life (Lundin et al., 2006; Stalnacke et al., 2005). Cognitive symptoms include loss of concentration, and sensitive to light or noise. These symptoms cause limitations in performing instrumental activities of daily living (IADL) such as driving and shopping to name a few. Driving requires meticulous coordination of multiple skills including concentration, and shopping happens in environments full of visual and auditory stimuli. Moreover, individuals with symptoms of anxiety or irritability may find it challenging to participate in social events. A combination of post-concussion symptoms leaves the individual with overwhelming feelings of frustration and discomfort. These findings emphasize the importance of follow-up after TBI. Identifying individuals at risk of developing post-concussion symptoms facilitates early detection and management of these symptoms.

Conclusion

The expected outcomes and recovery after a TBI are captured in the Hippocratic aphorism "No head injury is so serious that it should be despaired of nor so trivial that it can be ignored" (Olivecrona & Olivecrona, 2013). Functional recovery after TBI depends on many factors. Demographic criteria associated with better outcomes include younger age, male gender, high educational level, and higher income. The severity of injury predicted outcomes and functional recovery after TBI. Severe degrees of TBI are associated with worse outcomes and functional limitations across all ages. Environmental factors also contribute to the improvement or decline in the individual with TBI recovery. Environmental barrier may hinder recovery and lead to unwanted outcomes. Access to health care and health insurance support functional recovery, whereas physical environmental barriers accounted for worse outcomes in terms of community reintegration. Strong social support system promotes community integration of individuals with TBI. Early prediction of survival and functional outcomes following a TBI is extremely important as it helps occupational therapists in designing individualized interventions and in deciding the path of implementation (Chamoun, Robertson, & Gopinath, 2009). Moreover, it allows for informed counseling of families and caregivers who are influential in the decision-making process.

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Appendix 2

A SYSTEMATIC REVIEW OF INTERVENTIONS USED TO ADDRESS THE NEEDS OF ADULTS WITH POST-CONCUSSION SYNDROME

Comprehensive Project #2

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Abstract

Post-Concussion Syndrome (PCS) impacts physical, cognitive, and emotional functions of affected individuals. Previous research has investigated several effective interventions for managing PCS. Existing reviews of PCS interventions are limited to psychological and rehabilitation interventions, and to children and adolescent populations. We conducted a systematic review integrating current evidence about interventions for adults with PCS. This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The search included peer-reviewed research articles, published in English between 2005 and 2015. Inclusion criteria encompassed intervention studies of adults (≥18 years) with PCS, evaluated recovery from PCS symptoms, and focused on the functional outcomes. Results of the systematic search identified 146 articles after removing duplicates. Ten intervention studies met the inclusion criteria. Included studies demonstrated medium to high levels of evidence, and investigated psychotherapy, counseling, social support, self-management strategies, individualized rehabilitation, hyperbaric oxygen interventions, and group-based cognitive behavioral therapy in adults with PCS. Outcomes included reduced post-concussion symptoms, improved cognitive function, enhanced quality of life, and increased community integration. In conclusion, the evidence supports psychotherapy, counseling, and social support interventions as being beneficial for cognitive and emotional functions in adults with PCS. Additional research is needed investigating the effectiveness of occupational therapy interventions and self-management strategies on adults with PCS.

Keywords: Post-concussion Syndrome, Interventions, Review.

A Systematic Review of Interventions Used to Address the Needs of Adults with Post-Concussion Syndrome

Introduction

Increased awareness about concussions has contributed to more research addressing this topic. One emerging emphasis is on the residual physical, cognitive, and emotional symptoms of concussions, referred to as Post-Concussion Syndrome (PCS). Lingering PCS symptoms last for months and impact daily life participation after a concussion. The objectives of this review were to systematically search the current literature and to objectively synthesize findings on different interventions addressing physical, cognitive, and emotional functioning in adults with PCS. More specifically, this review will identify interventions that have produced favorable outcomes in terms of reducing PCS symptoms and in supporting daily participation.

Literature Review

Symptoms of PCS vary in frequency and duration after a concussion. PCS symptoms include headache, fatigue, dizziness, irritability, sleep disturbance, reduced concentration, impaired memory, sensitivity to light and noise, slowed thinking, and anxiety (Burton, 2011; Ryan & Warden, 2003). Headaches, fatigue, and sleep disturbances are most common in terms of frequency of occurrence and severity of symptoms (Blinman, Houseknecht, Snyder, Wiebe, & Nance, 2009; Carroll et al., 2004; Guskiewicz, Weaver, Padua, & Garrett, 2000). Although the vast majority (80%-90%) of concussion symptoms resolve within 2 weeks after injury (Makdissi et al., 2010; McCrory et al., 2013; McCrea et al., 2013), some symptoms can persist for weeks or months. About 50% of individuals with PCS report lingering symptoms for up to 3 months after injury, with 10%-15% reporting symptoms for more than a year (Binder, Rohling, & Larrabee, 1997). Persistent symptoms in PCS cause substantial physical and emotional discomfort and affect participation in daily activities (Lundin, de Boussard, Edman, & Borg, 2006; Reddy, Collins, Lovell, & Kontos, 2013).

PCS adversely influences participation in activities of daily living (ADLs) and quality of life of affected individuals. Persistent concussion symptoms can be challenging to manage which in turn affects the individual's capability to assume a daily routine, keep a job, or engage in leisure activities (Bottari, Dutil, Dassa, & Rainville, 2008). For example, driving requires full attention and concentration to operate a motor vehicle. Impaired concentration and slowed reaction time risk a motor vehicle accident, endangering the driver's life and the life of others in the community. PCS also affect sleep patterns and work productivity. Good quality of sleep is important to maintain physical and emotional well-being. When people do not get enough sleep, they may not have the energy in the next morning to participate in daily activities including work. Abnormal sleep patterns in PCS include difficulty in initiation and maintenance of sleep leading to insomnia and lack of sleep (Perlis, Artiola, & Giles, 1997). Insomnia affects participation and complicates the course of recovery from PCS (Orff, Ayalon, & Drummond, 2009). Lack of sleep also affects perception and judgment (Kostyun, Milewski, & Hafeez, 2015), and leads to reduced work efficiency, productivity, errors, and accidents in the workplace (Gaultney & Collins-McNeil, 2009). Maintaining good sleep is important for all age groups especially working adults.

PCS affects the lives of individuals across the lifespan including adults of working age (18 -64 years). Adults in this age group constitute 62.4% of the US population and the workforce in the community (United States Consensus Bureau, 2014). The prevalence of PCS symptoms in adults with concussions was 6% at 3 months and 0.9% at 6 months after injury (Spinos et al., 2010). Adults of age 40 years are particularly at higher risk for developing PCS (McCauley, Boake, Levin, Contant, & Song, 2001) with the symptoms becoming more severe at age 50 compared to younger adults (Fenton, McClelland, Montgomery, MacFlynn, & Rutherford, 1993; Radanov, di Stefano, Schnidrig, & Ballinari, 1991; Williams, Levin, & Eisenberg, 1990). Having worse symptoms could be related to the reduced brain and cognitive reserve associated with aging. Persistent PCS symptoms increase the stress associated with peer pressure, societal expectations, and complex job demands. The repercussions of PCS on adults' daily routine and work productivity could be worsened not only by their age but also by their job setting and work demands.

Working adults with dangerous professions are at higher risk for brain injury and subsequent sequelae such as PCS. For example, active duty military personnel (e.g., paratroopers) are at a higher risk of having a traumatic brain injury (TBI) compared to their civilian peers (Defense and Veterans Brain Injury Center, 2014; Ivins et al., 2003). This is due to the physical and dangerous nature of military training and battlefield risks. Other examples of high-risk professions include construction workers (Tiesman, Konda, & Bell, 2011) and police officers (United States Department of Labor, 2006). Working adults with PCS find it challenging to meet the work demands with troublesome lingering symptoms, and thus seeking medical advice is appropriate when needed.

Management of PCS includes a combination of medical, cognitive, and rehabilitation strategies that target lingering symptoms after a concussion. No comprehensive reviews have been done to establish the outcomes of interventions on working adult with PCS in terms of symptom resolution and functional improvements. Previous reviews that addressed PCS management have been limited to either a specific intervention type (e.g., psychological interventions; AL Sayegh, Sandford, & Carson, 2010; and rehabilitation interventions; Leddy, Sandhu, Sodhi, Baker, & Willer, 2012) or a specific age group (e.g., children and adolescents; Gilmore et al., 2015; Winkler & Taylor, 2015). The purpose of this review was to provide health care professionals with access to current updates in the literature published during the last decade about effective interventions for adults with PCS. This review will answer the following research question: what is the evidence for the effectiveness of different intervention strategies (e.g. rehabilitation, cognitive, medical...etc.) for adults with PCS? We hypothesized that rehabilitation interventions will be more helpful than other forms of interventions in reducing PCS symptoms and improving participation in ADLs.

Methods

In keeping with methods suited to rigorous and unbiased reporting, we applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines consisting of a 27-step plan for structured implementation of the systematic review process (Moher, Liberati, Tetzlaff, & Altman, 2009).

Search Strategy and Data Sources

The review process included comprehensive electronic and manual search for publications where PCS was the primary focus between 2005 and 2015. The electronic search was led by a librarian at the University of Kansas Medical Center. The manual search was conducted by examining bibliographic lists of included articles and other reviews looking for relevant articles. The search was implemented using a combination of keywords and search terms (see Table 1). The main search databases utilized in this review included PubMed, CINAHL, PsychINFO, ProQuest, and OT seeker.

Eligibility Criteria

Articles for review involved participants 18 years of age or older with a PCS diagnosis. Disparities exist in the definition of PCS with two medical classification systems establishing different diagnostic criteria including the International Classification of Diseases (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). In the ICD-10, PCS is confirmed when 3 or more concussion symptoms persist after a head injury which caused loss of consciousness (World Health Organization, 1992). The DSM-IV criteria establish a PCS diagnosis when an individual has at least 3 concussion symptoms last for 3 months or more after a concussion (American Psychiatric Association [APA], 2000). The latest version of the DSM manual (DSM-V) removed PCS definition and replaced it with Neurocognitive Disorders (APA, 2013).

The ICD-10 and DSM-VI diagnostic criteria were selected to conduct this review and to control for the literature inconsistencies in defining PCS. Many intervention studies used an established diagnosis of mTBI to define their target sample, but not a diagnosis of PCS. Individuals with mTBI who have persistent concussion symptoms were also included in this review. Eligibility criteria included published intervention studies written in English. Included studies addressed medical, rehabilitative, cognitive, or supportive therapy for PCS treatment with outcomes evaluating the reduction of PCS symptoms, improvement in functional performance, or participation in ADLs. We presented a full list of the inclusion and exclusion criteria in the appendices (see Table 2).

The research team extracted the abstracts of all studies that resulted from the electronic and manual search. This list was used for the initial review and screening based on the eligibility criteria. The initial review of abstracts assessed each article based on the title and content of the abstract to determine eligibility for inclusion in this project. Some abstracts could not be assessed due to lack of details in the body of the abstract. Abstracts that could not be assessed based on the title or content of abstract were reviewed in full-text. Articles meeting inclusion criteria were downloaded in full-text to allow further analysis.

Quality Appraisal and Level of Evidence

We evaluated quality and level of evidence for all included studies to formulate conclusions about these study findings. We appraised the study quality based on the study design. We used the Physiotherapy Evidence Base Database (PEDro) scale for assessing the quality of randomized controlled studies (Moseley, Herbert, Sherrington, & Maher, 2002). The 11-item PEDro scale was developed by the Centre for Evidence-Based Physiotherapy to assess the methodological quality of RCTs (Maher, Sherrington, Herbert, Moseley, & Elkins, 2003). Included RCTs were graded based on the 11 domains in PEDro. RCTs with a score of 9-11 on PEDro were considered to have “excellent” quality; 6-8 were “good” quality; 4-5 were “fair” quality; and below 4 were “poor” quality (Teasell et al., 2013).

Included studies that did not use an RCT design could not be assessed using PEDro scale. We used the Newcastle-Ottawa scale (NOS) scale to assess nonrandomized and observational studies (Wells, et al., 2009). The 9-item NOS evaluates the quality of studies based on 3 domains (selection of groups; comparability of groups; and exposure or outcome). Nonrandomized studies with a score of 7-9 on NOS were considered to be “high” quality; 4-6 were considered “medium” quality; and 0-3 were considered “low” quality (Zhou et al., 2016). We used similar score interpretations for both NOS and PEDro to maintain consistency in assessing quality, and thus we considered “high” quality on NOS to be “excellent”, “medium” quality to be “fair to good”, and “low” quality to be “poor”.

We also assessed the level of evidence for included studies based on the Oxford Centre for Evidence-based Medicine (OCEBM) 2011 guidelines for levels of evidence (Howick et al., 2011). The OCEBM classifies the level of evidence on a scale of one to five in which level one represents systematic reviews (highest) and level five denotes mechanistic reasoning (lowest). All included studies were assigned a number indicating the level of evidence.

Results

Search Results

Systematic electronic and manual searches yielded 146 studies extracted from PubMed, CINAHL, PsycINFO, and the Cochrane Libraries. The initial review of titles and abstracts led to the exclusion of 83 articles. The remaining 51 articles were reviewed in full-text, with 10 articles meeting all inclusion criteria. A PRISMA flowchart presents the search results and articles' selection (see Figure 1).

Included Studies

Ten studies were included for analysis in this review. Summary of the 10 interventional studies was provided in the appendices (see table 3). These studies did identify different intervention strategies for the management of PCS and persistent concussion symptoms. The sample sizes and number of subjects per group varied (range= 20 - 395 subjects). Altogether, these studies encompassed 858 individuals with concussion/mTBI that resulted in persistent concussion symptoms. Seven studies were randomized controlled trials, while three studies employed nonrandomized designs including one pretest-posttest, one cohort, and one descriptive design. All included studies employed prospective data collection and used different instruments to evaluate intervention outcomes.

Outcome Measures

The outcomes of interest in this review were PCS symptoms and/or functional performance. PCS symptoms are grouped under three categories including physical, cognitive, and emotional/ behavioral symptoms. Eight included studies focused evaluating all PCS symptoms (Bergman, 2011; Cifu et al., 2014; Elgmark Andersson, Emanuelson, Bjorklund, & Stalhammar, 2007; Kjeldgaard, Forchhammer, Teasdale, & Jensen, 2014; Miller et al., 2015; Moore et al. 2014; Rees & Bellon, 2007; Wolf, Cifu, Baugh, Carne, & Profenna, 2012). By contrast, two studies examined only one category of PCS symptoms including cognitive symptoms (Boussi-Gross et al., 2013) or emotional/behavioral symptoms (Tiersky et al., 2005).

Included studies also evaluated a variety of functional outcomes. These outcomes included functional health and well-being (Elgmark Andersson et al. 2007; Kjeldgaard et al. 2014; Miller et al., 2015; Moore et al. 2014), participation in ADL (Cifu et al., 2014), and community integration (Elgmark Andersson et al. 2007; Moore et al. 2014; Tiersky et al., 2005). Some studies evaluated the quality of life after implementation of the intervention (Elgmark Andersson et al. 2007; Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015).

Quality of Included Studies

The quality of included studies ranged from fair to excellent (see table 4). Seven included RCTs' quality scores ranged from five to ten points on PEDro indicating fair to excellent quality (Boussi-Gross et al., 2013; Cifu et al., 2014; Elgmark Andersson et al., 2007; Kjeldgaard, et al., 2014; Miller et al., 2015; Tiersky et al., 2005; Wolf et al., 2012). Elgmark Andersson et al. (2007) was the only randomized controlled study to score poorly with only 5 points for criteria met. This study had a high risk of bias (including attrition, performance, and reporting bias) for one or more key domains on PEDro (Higgins, Altman, & Stern, 2011).

Three nonrandomized studies scores ranged from five to seven on the NOS indicating good to high quality (Bergman, 2011; Moore et al. 2014; Rees & Bellon, 2007). Overall, the included studies had moderate to high scores on methodological research implementation. The OCEBM 2011 guidelines indicate the level of evidence ranged from fair (level 4) to high (level 2) for included studies.

Intervention Content

We grouped interventions into psychotherapeutic interventions (i.e., cognitive behavioral therapy [CBT] and psychotherapy), social work intervention, rehabilitation/ individualized interventions, self-management strategies, hyperbaric oxygen (HBO) therapy, and medical interventions.

Three studies included psychotherapeutic interventions (Kjeldgaard et al., 2014; Rees & Bellon, 2007; Tiersky et al., 2005). Four RCT studies tested the efficacy of HBO therapy (Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015; Wolf et al., 2012). The three remaining studies evaluated the effectiveness of one intervention strategy in each study. These three studies evaluated the effectiveness of social work intervention (Moore et al. 2014), individualized rehabilitation (Elgmark Andersson et al., 2007), or self-management strategies (Bergman, 2011). Medical interventions represented conventional care provided to participants mainly including medications to alleviate PCS symptoms. The control group in all included studies either received no treatment, a different dose of the intervention being tested, or conventional medical care. We provide a brief discussion of these interventions to offer insights about the effectiveness of each intervention for adults with PCS.

Discussion

This review addressed whether recent evidence exists to support interventions are differentially effective in addressing needs of adults with PCS. The findings did not provide support for our hypothesis that rehabilitation interventions were more effective than other forms of intervention for PCS. In fact, interventions that showed significant positive outcomes included psychotherapeutic interventions, social work intervention, and self-management strategies. HBO therapy had mixed results with only one study out of four providing evidence for significant improvements for participants receiving this intervention. Studies investigating rehabilitation interventions were limited. One study evaluated individualized rehabilitation but did not provide support for benefits of this approach compared to conventional medical care.

Psychotherapeutic Interventions

Psychotherapies encompass different intervention techniques to help individuals manage a specific emotional or behavioral problem. Therapists using psychotherapeutic approaches inform the individual about the nature of the problem and provide advice on proper management. Psychotherapeutic approaches include psychodynamic, psychoanalytic, cognitive, and behavior therapies (APA, 2016). Cognitive-behavioral therapy and psychotherapy interventions educate and empower clients to understand and cope with their challenging health problems (Cicerone, 1989; Cicerone, Levin, Malec, Stuss, & White, 2006; González-Prendes & Brisebois, 2012; National Association of Cognitive Behavioral Therapies, 2016). These therapeutic strategies validate the client's complaints of persistent symptoms and provide aid in identifying appropriate mechanisms to cope with lingering symptoms of PCS.

Three studies with good quality evaluated two psychotherapeutic intervention strategies (Kjeldgaard et al., 2014; Rees & Bellon, 2007; Tiersky et al., 2005). The first intervention was cognitive behavioral therapy, a treatment derived from psychotherapy. CBT aims to substitute maladaptive patterns of thinking and behavior with desirable patterns (Davis, 2016). Two studies with good quality (PEDro score = 8) evaluated CBT's effectiveness when provided to clients with PCS individually or in a group setting (Kjeldgaard et al., 2014; Tiersky et al., 2005). Individualized CBT led to significant decrease in PCS symptoms and increase in emotional functioning (Tiersky et al., 2005). Group-based CBT did not alter post-concussion symptoms (headaches specifically), although CBT did lead to improvements in quality of life, psychological distress, and the symptoms experienced (Kjeldgaard et al., 2014). These findings are consistent with findings of another report exploring the effects of CBT on individuals with brain injury (Bradbury et al., 2008; Leonard, 2002).

The second psychotherapeutic intervention strategy is psychotherapy, coupled with counseling. One study with good quality (NOS score = 5) explored the effectiveness of psychotherapy on recovery from PCS (Rees & Bellon, 2007). The researchers reported that both psychotherapy and counseling resulted in significant reduction of post-concussion symptoms including less agitation, irritability, and suicidal thoughts. Psychotherapy and counseling interventions in this study used a holistic approach with multiple therapeutic strategies, which included information giving sessions, counseling interventions based on client-centered CBT, and problem-solving interventions. These strategies aimed to improve cognitive functions and assist in symptom resolution. The outcomes of this intervention led to improvements in cognitive and affective symptoms after PCS. Adults with PCS also benefit from other interventions that provide client education including social work interventions.

Social Work Intervention

Social workers provide PCS clients with education about the lingering symptoms, recovery process, and coping strategies to manage prolonged symptoms. Social work services also include linking clients to support groups and counselors to expand the social support network for these adults with PCS. One included study with excellent quality (NOS score = 7) found that social interventions led to improvements in symptoms after a concussion. Moore et al. (2014) found that Social Work Intervention for Mild Traumatic Brain Injury (SWIFT) resulted in successful community functioning after injury. This program provided clients with reassurance, education, and follow-up guidelines, which led to greater use of medical service. These findings suggest social work interventions can assist individuals with mTBI and post-concussion symptoms in resuming roles in the community after injury. It is also consistent with a previous report showing a positive effect of social work interventions on psychological recovery after severe brain injuries (Gan, Campbell, Gemeinhardt, & McFadden, 2006). Other intervention strategies that have resulted in positive outcomes include self-management strategies.

Self-management Strategies

It is well established in the literature that self-management interventions are beneficial for individuals with different health conditions (Funnell, 2010; McCorkle et al., 2011; Reid et al., 2008; van Grieken, Kirkenier, Koeter, & Schene, 2014). Self-management strategies are techniques which individuals employ to reduce the effect of residual illness on daily functioning and quality of life. One included study with high quality (NOS score = 8) explored different self-management strategies used by adults with concussions who had prolonged symptoms (Bergman, 2011). The results showed that adults with PCS symptoms are more likely to use self-management strategies when bothered by lingering symptoms. Self-management strategies reported by participants also led to symptom relief and reduced symptom severity. Examples of self-management strategies used by adults with PCS include activities/thoughts (e.g., make a list, use a calendar, or rest), complementary therapies (e.g., prayer or relaxation), and exercise. Other studies evaluated the effectiveness of self-management strategies in people with mTBI (Kendrick, Silverberg, Barlow, Miller, & Moffat, 2012) and acquired brain injury (Brenner et al., 2012; Damush et al., 2011). These studies provided mixed results with the majority supporting the effectiveness of self-management strategies for people with head injuries. For example, two studies suggest that self-management strategies improve daily functioning (Kendrick et al., 2012) and enhance self-efficacy, self-management behaviors, and specific aspects of quality of life (Damush et al., 2011), while a third study did not show benefits for self-management strategies (Brenner et al., 2012). Self-management strategies provide promising results, but further studies are needed to confirm its effectiveness for adults with PCS.

Rehabilitation and Individualized Interventions

Occupational therapy (OT) practitioners work with individuals who have PCS to manage symptoms and return to daily life activities. OTs design interventions that meet the needs and abilities of clients; health care practitioners refer to this approach as individualized interventions. This intervention approach proved to be effective with some disorders, however, the findings of one study with fair quality (PEDro score = 5) in this review did not provide support for benefits in adults with PCS. That study evaluated the effect of early rehabilitation intervention (including OT, physical therapy, and social work) for adults with PCS (Elgmark Andersson et al., 2007). The results showed individualized intervention does not appear to change the consequences one year after injury compared with the control group. Nonetheless, there were many limitations in design and implementation of this study including a high dropout rate and variability in duration of baseline evaluation. With only one study, we are unable to reach a conclusive decision about the effectiveness of individualized rehabilitation for PCS.

Studies exploring the effectiveness of occupational therapy interventions for adults with PCS are limited. This review identified only one intervention study using occupational therapy for the management of PCS (Elgmark Andersson et al., 2007). A scoping review of occupational therapy literature for mTBI and PCS identified only three intervention studies that focused on occupational performance after injury (Cogan, 2014). These three studies tested the effectiveness of three interventions including Cognitive Orientation to Occupational Performance (Dawson et al., 2009), multidisciplinary rehabilitation (Ghaffar, McCullagh, Ouchterlony, & Feinstein, 2006), and self-management program (Kendrick et al., 2012). Cognitive Orientation and self-management interventions yielded significant improvements in the occupational performance of individuals with PCS (Gaffar et al., 2006; Kendrick et al., 2012). These studies did not meet the inclusion criteria for analysis in this review due to including mixed diagnoses, severe head injury, and adolescents in the study sample. The evidence is limited on the effectiveness of OT for PCS, however, clinical practice guidelines for mTBI management are available (Marshall, Bayley, McCullagh, Velikonja, & Berrigan, 2012). These guidelines provide OTs and other health professionals with information about care for individuals with mTBI and PCS.

Other rehabilitation interventions include physical and cognitive exercise programs for people with post-concussion symptoms. These interventions yielded benefits for participants with PCS. For example, aerobic exercises on the treadmill led to reduction in PCS symptoms and improved cerebral blood flow to the brain (Leddy et al., 2010; Leddy & Willer, 2013). Another intervention for PCS includes Hyperbaric Oxygen therapy.

Hyperbaric Oxygen (HBO) Therapy

HBO therapy is used for the treatment of individuals with different illnesses including brain injury. This intervention involves inhaling oxygen-rich air in a closed chamber with increased atmospheric pressure (Gill & Bell, 2004). The human lungs absorb more oxygen under these conditions and transferring more oxygen in the bloodstream has been hypothesized to trigger the release of growth factors, and thus support healing (Tibbles & Edelsberg 1996). The atmosphere absolute (ATA) is a unit to measure the degree of compressed air in the room compared to the normal air. Four studies with high quality (PEDro scores = 9-10) tested HBO therapy with individuals with PCS, mainly with military personnel (Boussi-Gross et al., 2013; Cifu et al., 2014; Miller et al., 2015; Wolf et al., 2012). The researchers used different doses of HBO ranging between 1.2 and 2.4 ATA. In each randomized controlled trial, the investigators compared the HBO therapy intervention group to a control group that received either no HBO therapy or a lower dose of pressure.

Only one of four HBO intervention studies produced significant differences between the intervention and control groups (Boussi-Gross et al., 2013). In that study, individuals with PCS had significant improvements in cognitive functioning and quality of life compared to the control group (Boussi-Gross et al., 2013). This is also the only study that used a crossover design to account for possible placebo effect as suggested by a previous similar study (Wolf et al., 2012). In addition, two of the four studies compared the HBO group (pressure range: 1.5 – 2.4 ATA) to a sham group (pressure range: 1.2 – 1.3 ATA) in which the pressure dose was lower in the sham group (Miller et al., 2015; Wolf et al., 2012). In both studies, the sham group demonstrated greater improvements in PCS symptoms than the intervention group (Miller et al., 2015; Wolf et al., 2012). This observation provides support for using lower pressure doses to test the efficacy of HBO therapy. The HBO intervention technique, therefore, showed mixed results in research studies, and more studies are needed to validate the benefits of HBO therapy unequivocally.

Medical Interventions and Control Groups

Medical interventions help individuals with mTBI and PCS in managing symptoms. Examples of medical interventions include medications. Medications prescribed to relieve symptoms like headaches include divalproex sodium (Packard, 2000). Other medications for PCS include antidepressants like Amitriptyline (Dinan & Mobayed, 1992), Dexamethasone (Saran, 1985), Topiramate, Triptans, and Dihydroergotamine.

Other PCS Interventions

The management of PCS includes other therapies that have been established in the literature. These techniques were not included in this systematic review due to our rigorous inclusion and exclusion criteria. Examples of these alternative interventions include physical-cognitive rest and exercise. Rest is very important after injury because physical exertion after concussions leads to exacerbation of symptoms (Majerske et al., 2008; Moser, Glatts, & Schatz, 2012). After adequate resting, light aerobic exercise such as walking on a treadmill or stationary cycling is recommended to further alleviate symptoms (Leddy et al., 2010). These alternative interventions are commonly used for the management of PCS, and if combined with some of the interventions presented in this review could yield greater benefits for people living with lingering PCS symptoms.

Conclusion

The findings of this systematic review suggest that psychotherapeutic and self-management interventions are more effective than individualized rehabilitation in the management of PCS. Studies of psychotherapeutic interventions (i.e., CBT and psychotherapy), social work intervention, and self-management strategies are more effective than HBO therapy and individualized rehabilitation. HBO requires special equipment/space to deliver this intervention, which can be expensive and less feasible in some medical settings. By contrast, psychotherapeutic interventions such as CBT and psychotherapy do not require specialized tools, while also relieves stress associated with PCS. Psychotherapeutic techniques may have helped individuals with PCS understand their condition, potentially helping them find alternative coping strategies to deal with persistent symptoms. CBT, psychotherapy, and social work interventions can be beneficial for adults with lingering post-concussion symptoms.

Clearly, more studies with rigorous design are needed to evaluate the effectiveness of current interventions for PCS in adults with mTBI or concussions, including occupational therapy intervention and self-management strategies. There is also a need for studies exploring the effectiveness of novel emerging interventions such as computer-based programs and rehabilitation exercise programs, which could influence both physical and cognitive symptoms of PCS. Moreover, intervention strategies that proved to be effective in adults with PCS should be evaluated in pediatric populations.

Implications for Practice

PCS has diverse symptoms that can adversely affect daily functioning and work productivity. Each case of PCS is unique and understanding the experience of adults with persistent symptoms is an important first step toward designing the best intervention plan. Health care professionals are encouraged to follow an individualized approach to the management of PCS. Intervention designed for individuals with PCS should include education and counseling about persistent symptoms and self-management strategies to cope with symptoms. Other interventions may require modifying daily routines or surrounding environment to reduce the impact of PCS symptoms. Health care professionals should be encouraged to refer individuals with PCS, as needed, to trained psychologists who provide psychotherapeutic interventions. Another approach is working within a multidisciplinary team in which health professionals work side-to-side to meet the needs of individuals with lingering PCS symptoms. Inter-professional collaboration and advocacy among health care professionals are warranted to assist clients with PCS manage lingering symptoms.

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Table 1

Criteria	Keyword and Search Terms
Population	“PCS”, “Adults”, “TBI”, “Head injuries”, “Brain Injuries”, “Traumatic brain injury”, “Post-concussion symptoms”, “Post-Concussion Syndrome”
Intervention	“Occupational Therapy”, “Cognition Therapy”, “Physical Therapy Techniques”, “Exercise”, “Rehabilitation”, “Intervention”, “Pain management”, “Treatment”, “Pharmacologic Actions”, “Antidepressants”, “Prescription”, “Drugs”, “Drug therapy”
Outcome	“Recovery”, “Outcome”, “Community integration”, “Improve quality of life”, “Daily life activities”, “Return to work”, “Function”, “Activities of daily living”, “Performance

Note. Keywords and search terms; PCS = Post-Concussion Syndrome; TBI = Traumatic Brain Injury.

Table 2

Criteria	Inclusion Criteria	Exclusion Criteria
Intervention study	Yes	No
Peer-reviewed	Yes	No
Publication status	Published and dissertations	No
Study design	Randomized controlled trials (RCT), experimental, qualitative, descriptive or case studies	Reviews, editorials, and opinion papers
Language	English	Any other language (e.g., German and French)
Participants	Human participants; 18 years of age or more; diagnosis of Post-concussion syndrome or MTBI with persistent concussion symptoms	Human participants less than 18 years of age; diagnosis of moderate to severe TBI; and animal subjects
Outcomes evaluated	Improvements in PCS symptoms and/or functional performance/participation.	Physiological or molecular changes
Publication year	2005 – 2015	2004 and earlier

Note. Studies inclusion and exclusion criteria; PCS = Post-Concussion Syndrome; MTBI = Mild Traumatic Brain Injury.

Table 3

Citation	Design	Participants	Intervention	Outcome Measures	Results	Lvl
Bergman (2011)	Descriptive observational study	30 individuals with mTBI during the first 3 months and 30 controls without head injury age 18-71 years	Self-management strategies included complementary therapy, activities /thoughts, and exercise.	Self-Management for MTBI questionnaire, and the Problem Checklist	Self-management strategies relieve symptoms. Examples are activities/ thoughts, complimentary therapies, and exercise have a significant relationship between overall reports of being bothered by symptoms (p = 0.008).	4
Boussi-Gross et al. (2013)	RCT - Crossover	56 individuals with PCS due to mTBI 1–5 years after injury mean age 44.1 years	HBO Therapy: 40 HBO sessions at 1.5 ATA 5 days a week	Mindstreams (cognitive function) and EQ-5D questionnaire (QOL).	Significant improvements in cognitive function and QOL in both groups following HBOT but not following the control period.	2
Cifu et al. (2014)	RCT - Double-blinded	61 military personnel with PCS and a history of mTBI mean age of 23 years	HBO Therapy: 40 sessions at 2.0 ATA, or 40 sessions at 1.5 ATA	RPQ-16, Mayo-Portland Adaptability Inventory-4 Participation Index, and Satisfaction with Life Scale	No significant interaction time by intervention group for improvement on the RPQ-16. No significant time by intervention interaction was found for any functional, cognitive, or psychomotor secondary outcome measures.	2
Elgmark Andersson et al. (2007)	RCT	395 individuals with mTBI, 78 participants had PCS mean age of 33 years	Individualized OT plan plus counseling and medications as needed. Control got treatment as usual.	Post-Concussion Symptoms Questionnaire, the Life Satisfaction Questionnaire (LiSat-11), CIQ, and SF-36	No statistical differences were found between the intervention and control groups. Participants who reported several PCS and accepted rehabilitation did not recover after one year.	2

Kjeldgaard, et al. (2014)	RCT	90 individuals with Chronic post-traumatic headache after mild head injury age 18-65 years	Group-based CBT intervention for 9 weeks. Control group	RPQ, Short-Form Health Survey (SF-36), The Symptom Checklist (SCL-90-R), and a headache diary	CBT had no effect on headache and pressure pain thresholds and only a minor influence on quality of life, psychological distress, and the overall experience of symptoms.	2
Miller et al. (2015)	RCT - Double-blinded	72 military personnel with post-concussion symptoms at least 4 months after mTBI mean age of 31 years	HBO Therapy: 40 HBO sessions at 1.5 ATA, 40 sham sessions at 1.2 ATA, or Control	RPQ, SF-36, and Global Satisfaction with Life Scale	No clinically significant differences observed between groups defined as improvement of at least 2 points on the RPQ-3 subscale. Yet, both groups showed improvement in symptoms on the RPQ.	2
Moore et al. (2014)	Cohort	64 individuals with mTBI age >18 years, mean age = 39	Social Work Intervention for Mild Traumatic Brain Injury (SWIFT-Acute) and Usual Care groups	RPQ, Community Integration Questionnaire (CIQ), Patient Health Q-4, PTSD Checklist-Civilian.	The intervention group maintained pre-injury community functioning; whereas Usual Care significantly declined in functioning on the CIQ. Both groups significantly increased medical service use.	3
Rees & Bellon (2007)	Pretest - posttest	20 individuals with PCS age 18-52 years	Counseling and psychotherapy intervention within 2 years after trauma.	Concussion symptoms questionnaire, and Beck Depression Inventory	Participants reported a significant decrease in overall post-concussion symptoms most noticeably in reduction of agitation, irritability and suicidal wishes.	3
Tiersky et al. (2005)	RCT - Single-blinded	20 individuals with persisting complaints after mTBI age 19-62 years	CBT and cognitive remediation: 50 minutes 3 times a week for 11 weeks. The control group received treatment as usual	Symptom Check List–90R General Symptom Index, plus scales of depression, anxiety, coping, and CIQ.	Significant improvements in emotional functioning, including reduced anxiety and depression 1 - 3 months after treatment. No changes in community integration scores.	2

Wolf et al. (2012)	RCT - Double-blinded	50 military personnel with PCS due to mTBI age 20-51 years	HBO Therapy: 30 sessions HBO at 2.4 ATA, or sham at 1.3 ATA over an 8-week period	ImPACT and Post-traumatic Disorder Check List-Military Version (PCL-M)	No significant effect for HBO at 2.4 ATA. Eight participants in the Sham group showed improvements on the ImPACT and PCL-M composites compared to 2 participants in the intervention group.	2

Note. Summary table of included studies; Lvl = level of evidence; PCS = post-concussion syndrome; TBI = traumatic brain injury; RCT = Randomized Controlled Trial; HBO = Hyperbaric Oxygen Therapy; PTSD: Posttraumatic Stress disorder RPQ = Rivermead Post-Concussion Symptoms Questionnaire; PCSQ = Post-Concussion Symptoms Questionnaire; LiSat-11 = the Life Satisfaction Questionnaire; CIQ = Community Integrated uestionnaire; and SF-36 = Short-Form Health Survey; ImPACT = Immediate Post-Concussion Assessment and Cognitive Testing; PCL-M = Post-traumatic Disorder Check List-Military Version; QOL = questionnaire to measure quality of life; (SF-36); SCL-90-R = The Symptom Checklist.

Table 4

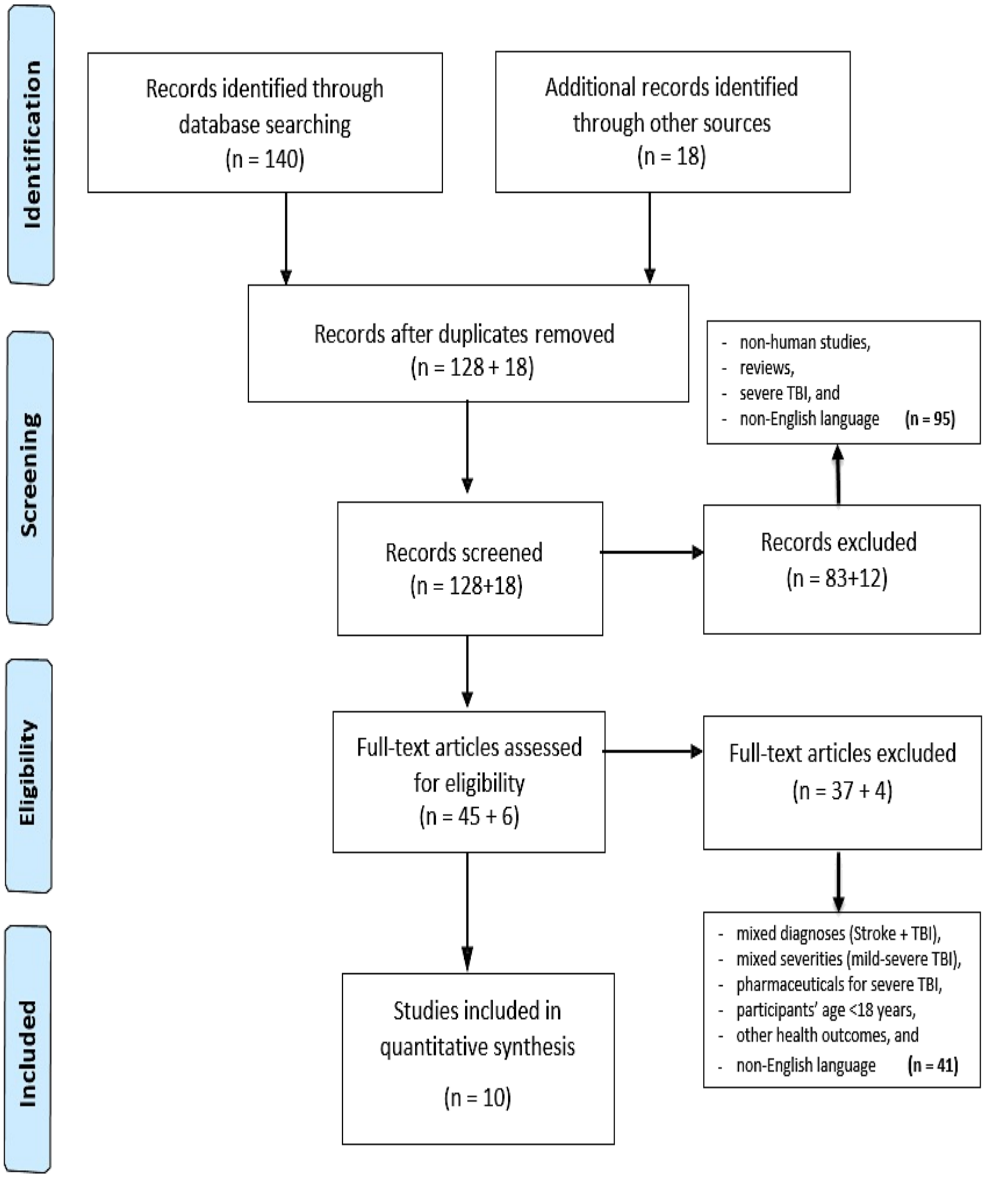
Randomized Studies (PEDro Scale)												
Citation	Eligibility Criteria	Randomization	Concealed Allocation	Comparable Groups	Blinded Participants	Blinded Therapists	Blinded Assessors	Response rate ≥85% on ≥1 Measure	Intention to treat	Results reported for ≥ 1 Outcome	Point measures provided	Total Number of Criteria Met
Boussi-Gross et al. (2013)	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	9
Cifu et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	9
Elgmark Andersson et al. (2007)	Y	Y	Y	N	N	N	N	N	N	Y	Y	5
Kjeldgaard et al. (2014)	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	8
Miller et al. (2015)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	10
Wolf et al. (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	10
Tiersky et al. (2005)	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	8

Non-Randomized Studies (Newcastle-Ottawa scale)

	Selection				Comparability		Outcomes			
Citation	1	2	3	4	5	6	7	8	9	Total
Moore et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	N	7
Rees & Bellon (2007)	Y	N	Y	N	N	N	Y	Y	Y	5
Bergman, (2012)	Y	Y	Y	N	Y	Y	Y	Y	Y	8

Note. Quality appraisal of all included studies; ITT = intention to treat; OC = Outcomes; PM = Point Measure; Y = Yes; N = No.

Figure 1



Note. Flowchart of search results and articles selection of eligible studies. The search results yielded 146 articles after removing duplicates. Articles were then screened for eligibility, and 95 articles were excluded for different reasons including non-human sample, reviews, mod-severe TBI, and non-English language. Fifty-one articles were reviewed in full-text articles, and 41 articles were excluded for having a mixed sample (Stroke + TBI), mixed severities (mild-severe TBI), pharmacological studies for severe TBI, other health outcomes, and non-English language. Ten studies met the eligibility criteria.

Appendix 3

PERCEIVED PERFORMANCE OF ACTIVITIES BY ADULTS WHO SOUGHT COMMUNITY-BASED SUPPORT AFTER STROKE

Comprehensive Project #3

By

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SPRING 2017

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Abstract

Stroke has long-term consequences for the functional performance of daily activities. Evaluating client-perceived occupational performance provides insight for designing stroke-specific programs supporting home and community participation. This study explored associations among personal characteristics and self-perceived activity performance in community-dwelling adults with stroke. This study also evaluated how changes in health status may impact self-perceived activity performance of individuals who received services at a community support center. This study was a retrospective chart review design. The sample included 68 individuals with stroke ($\bar{x}$ = 67 ± 11.6 years) who received services at American Stroke Foundation sites. Outcome measures included the Canadian Occupational Performance Measure and the Stroke Impact Scale. The data analysis plan included bivariate Pearson correlation analysis and paired t-tests. There were positive correlations between sex and perceived activity performance ($r=0.40$, $p=0.041$; $n=27$) and between perceived recovery and satisfaction ($r=0.56$, $p=0.013$; $n=19$), and a negative correlation between perceived recovery and cognition ($r=-0.37$, $p=0.040$; $n=31$). The paired t-test revealed a significant decrease in Mobility subscore of the SIS at follow-up ($p = 0.017$). In conclusion, men's perception of their functional performance was higher than women's perceptions; we plan to evaluate the accuracy of these perceptions using objective measures. Participants' perceptions about their overall recovery were associated with higher satisfaction and lower cognition. Participants' perceptions of their mobility were lower at follow-up than at baseline. Accounting for factors influencing the perceived performance of stroke survivors may enhance their lived experience as active members of their community.

Keywords: Stroke, Self-Perception, Occupational Performance, Community Support.

Perceived Performance of Activities by Adults Who Sought Community-Based Supports after Stroke

Introduction

Stroke encompasses a wide array of cerebrovascular disorders, representing a major health care concern in the US (Soldner, Upton, & Dunlap, 2009). Chronic stroke is among the leading causes of disability in the US and worldwide (Faul, Xu, Wald, & Coronado, 2010; Mozaffarian et al., 2015; Rosenberg, Simantov, & Patel, 2007). The majority of individuals with chronic stroke have some residual cognitive, psychosocial, behavioral, or physical challenges (DePaul, Moreland, & deHueck, 2013; Kersel et al., 2001). These challenges affect participation in everyday life activities for individuals with chronic stroke

The long-term consequences of stroke have their greatest impact on individuals' health and well-being (Ribbers, 2010). Individuals with stroke encounter challenges to participation in activities of daily living (ADL) because of the wide array of physical, sensory, and psychosocial effects on functioning (Hackman et al., 2014). In addition to acute management and timely rehabilitation services, it is imperative to also consider long-term supports to facilitate optimal independent functioning and quality of life for individuals during the chronic stages of their recovery (Black & Hanspal, 2003; Malec, 2001; Ownsworth, McFarland, & Young, 2000; Powell, Heslin, & Greenwood, 2002).

Community-based programs and resources can provide client-centered interventions to meet long-term support needs of individuals with stroke. Accumulating evidence suggests community-based rehabilitation services create positive outcomes for recovery and community integration of individuals with brain injury (Altman, Swick, Parrot, & Malec, 2010; McCabe, Lippert, Weiser, Hilditch, Hartridge, & Villamere, 2007; Thomas, 2008). Examples of these services include multidisciplinary client-centered rehabilitation, exercise-based programs, stroke rehabilitation education, and self-management principles (Harrington et al., 2010; Ru et al., 2017). Further, when individuals with stroke have access to community-based services, which provide personalized client-centered interventions that support achieving their goals, they are more likely to stay engaged in the community (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). Personalized interventions are most appropriate due to the considerable heterogeneity in the stroke presentation (Wiseman-Hakes, MacDonald, & Keightley, 2010). Health care professionals are encouraged to tailor interventions based on each clients' perceived needs and priorities (Gage, 1995).

The client's self-perception of performance challenges plays an important role in determining actual health status. Assessing the client's perceived challenges and changes in occupational performance provides health care professionals with valuable information about the client's view of strengths and barriers to participation. When health care professionals recognize these strengths and barriers, an individualized intervention can be developed to facilitate participation in ADLs based on the client needs and priorities (Larson, 2010), to foster greater client motivation and involvement, and to facilitate improved client satisfaction and intervention outcomes (Creel, Sass, & Yinger, 2002; Kols & Sherman, 1998). Previous studies explored challenges and changes in perceived participation in chronic stroke after receiving specialized exercise interventions (Fernandez-Gonzalo et al., 2014; Flansbjer, Lexell, & Brogardh, 2012), cognitive therapy (Lee, Bae, Jeon, & Kim, 2015), computer-based intervention (Beckelhimer, Dalton, Richter, Hermann, & Page, 2011), yet more studies are needed to investigate these changes after participation in a community-based support program.

The primary aim of the current study was to describe demographic characteristics and self-perceived activity performance of individuals with chronic stroke who have sought long-term supports in a community-based center. A second aim was to evaluate self-perceived impact of injury on of health among individuals with chronic stroke who received services at a community-based support center. We hypothesized clients with stroke will report changes in the perception of their health after participating in a community-based program. Our third aim was to compare self-perceived impact of injury on daily activities in individuals with chronic stroke in a community-based program and other individuals with chronic stroke. We hypothesized self-perceived impact of injury will be different when individuals with stroke have ongoing support in the community. This comparison will assist in identifying distinctive characteristics of the stroke population seeking further supports after discharge from inpatient rehabilitation clinics. This study will also provide insights into how community-based chronic disease management programs can be more effective in designing stroke-specific programs and in supporting participation and community integration of individuals with chronic stroke.

Methods

Design

This study includes a retrospective chart review of existing de-identified data from individuals with stroke. The institutional review board at the University of Kansas Medical Center approved this study.

Sample and Setting

The sample data selection for the retrospective analysis included 68 individuals with chronic stroke currently receiving rehabilitation services through the American Stroke Foundation (ASF) Next Step program. The inclusion criteria encompassed individuals who a) are

18 years or older; b) have a diagnosis of stroke; c) participated in an ASF Next Step Program; and d)completed assessment data on the target outcome measures. The exclusion criteria included ASF client who a) have missing data on all outcome measures.

The Next Step program is a community-based program involving a multidisciplinary approach and group support intended to achieve individualized goals. Members in this program participated in group-based physical activity training sessions supervised by a fitness trainer. The duration and frequency of exercise sessions were 30-45 minutes of exercise 2-3 days a week. Other activities provided in the ASF includes IADL training (e.g., shopping and cooking), community outing, volunteering in the community, board games, support groups, and conversational classes. The ASF Next Step Program has three locations within the Greater Kansas City Area: 1) Mission, KS; 2) Kansas City, MO; and 3) Blue Springs, MO. The sampling and data analysis processes incorporated data from ASF clients participating in any of the three programs.

Instruments

a. *Demographic Questionnaire:* demographic data previously collected from ASF clients (de-identified) was used to characterize the demographic profile of the individuals with chronic stroke. The demographic characteristics of interest included age, gender, ethnicity, comorbid conditions, duration between stroke and joining ASF, and duration spent in the ASF.

b. *The Montreal Cognitive Assessment (MoCA) is a* standardized cognitive screening test which assesses 8 domains of cognition, including visuospatial/executive function, naming, memory, attention, language, abstraction, and orientation (Nasreddine et al., 2005). MoCA takes 10 minutes to administer in an interview. This instrument is both valid and reliable (Hoops et al., 2009; Koski, 2013) and is a feasible cognitive screening tool for detecting mild cognitive impairment in stroke (Cumming, Bernhardt, & Linden, 2011).

c. *Canadian Occupational Performance Measure (COPM):* this client-centered assessment tool assesses self-perceived performance in ADLs and satisfaction with performance over time (Law et al., 1994). The COPM particularly focuses on assessing challenges in occupational performance of self-care, leisure, and productivity. This instrument also assesses satisfaction with performance on a scale of 1-10, where 1 indicates low satisfaction and 10 indicates high satisfaction. The COPM is a valid and reliable instrument (Cup, Scholte op Reimer, Thijssen, & van Kuyk-Minis, 2003; Jenkinson, Ownsworth, & Shum, 2007; McColl, Paterson, Davies, Doubt, & Law, 2000).

d. *Stroke Impact Scale (SIS):* this stroke-specific, self-report instrument includes 59 items and assesses 8 domains of health and functioning (Duncan et al., 2003). These domains include strength, hand function, ADL/IADL, mobility, communication, emotion, memory and thinking, and participation. The last question in the SIS asks clients to rate their recovery from a stroke on a scale from 0-100. The SIS has good psychometric properties. The second version of this instrument was tested with stroke clients, and was found to be reliable, valid, and sensitive to change (Duncan et al., 1999; Edwards & O'Connell, 2003). We obtained normative data of SIS subscores from 2 studies. One study recruited a sample of individuals (N = 287) with acute stroke (Duncan et al., 2002). The sample in Duncan et al. (2002) consisted of individuals with a mean age of 72.6 years, 53% females, and < 28 days post-stroke (range 90-120 days). The other study employed individuals (N = 58) with chronic stroke (Huang, Wu, Hsieh, & Lin, 2010). The sample in Huang et al. (2010) consisted of individuals with a mean age of 56.42 years, 34% females, and 17.85 months post stroke (range 7-88 months). The comparison of SIS scores with the norms includes calculating the difference between subscores on the 8 domains.

Procedures

De-identified client assessments were provided by the American Stroke Foundation. The assessments were completed at different time points during participation in ASF activities, between April 2003 and March 2016. In this study, we used baseline COPM scores to evaluate activity performance and satisfaction of ASF clients when joining the Next Step Program (aim 1). One time point was included in the analysis for the COPM (baseline) to determine the activity performance level and satisfaction with performance at the time of joining the ASF. The follow-up COPM scores contained too many missing data to be entered in the analysis. The SIS assessments included two time points (baseline and follow-up). We used the SIS scores to compare self-perceived impact of stroke on daily activities between ASF stroke clients and normative data obtained from other clients with chronic stroke (aim 2). The baseline assessment was taken on admission and the follow-up was conducted 1-3 years on average after the initial assessment. All assessments meeting enrollment criteria were included in our analysis. We evaluated the reliability of data entry through checking 10 randomly selected records (15% of all records). The accuracy of data entry exceeded 90%, and any identified errors in data entry were corrected. Access to this dataset was limited to authorized study personnel.

Data Analysis

The Statistical Package for the Social Sciences (SPSS V.23) was used to analyze data. The data analysis plan included descriptive statistics of the sample demographics, and a bivariate Pearson correlation analysis between sample demographics, MoCA, SIS, and COPM scores (aim 1). We conducted a post hoc analysis using independent t-tests in order to interpret the relationship accurately between variables with significant correlations. Further, the analyses included paired *t*-tests to assess changes in the SIS scores overtime (aim 2), and independent t-test to compare SIS scores with normative data (aim 3).

We compared the baseline SIS data with normative data established for acute stroke (Duncan et al., 2002), and compared the follow-up SIS data with normative dataset for chronic stroke (Huang, Wu, Hsieh, & Lin, 2010). Published normative data included only the mean and standard deviation of the SIS domain subscores. We used GraphPad software to calculate the *t* statistic and *p* value based on means and standard deviations (Motulsky, 2016). The descriptive analyses included all 68 participants. The remaining analyses included part of the sample due to missing or incomplete assessments. For example, out of the 68 individuals in the sample, 65 had completed baseline SIS, 30 had completed baseline and follow-up SIS, and 27 had completed baseline COPM assessments.

Results

The sample consisted of data collected from 68 individuals with chronic stroke. The descriptive statistics confirmed the majority of participants were males (60%), white (67%), and had an average age of 67 years (range: 45 – 92 years). Participants reported having comorbidities, with hypertension (44%) and diabetes (32%) being the most prevalent. Approximately half (44%) of these ASF participants joined the Next Step program within one year of having a stroke; the other half (56%) joined the program within 2 to 9 years after injury. Additionally, about 20% of participants have been receiving support in the program for at least 1 year, while the remaining majority received support for a duration that spans between 2 to 12 years.

The cognitive function scores varied between participants with a mean of 20.7 and standard deviation of 6.9 (range: 3 and 30) indicating normal to severe cognitive limitations. After the injury, participants heard about the ASF from different sources with the rehabilitation team being the most common source of information about community-based supports after discharge from inpatient care. Table 1 displays the demographic characteristics of the sample. The table also presents past medical history and cognitive evaluation scores for study participants.

We conducted a Pearson correlation analyses to examine the relationship between sample demographics, cognitive function, self-perceived activity performance and satisfaction, and impact of injury after stroke at baseline. Table 2 displays the results of the correlation analyses. We found a weak correlation between ethnicity and time since stroke onset and joining the Next Step program (r = -0.38, p = 0.007; n = 49) with African Americans joining the program later than Caucasians. Further analysis of this relationship using independent t-tests revealed that African Americans joined the Next Step program 4.6 years on average after their stroke onset compared to 1.7 years for Caucasians, yet this difference was not significant (p = 0.052). Ethnicity was also weakly associated with time spent in the Next Step program (r = 0.28, p = 0.031; n = 58) with Caucasians spending more time in the program compared to African Americans. African Americans participated in the Next Step program for an average of 1.4 years compared to 3.7 years for Caucasians (p= 0.015). Figure 1 presents the time comparison between African Americans and Caucasians.

The correlation analysis also revealed a weak association between sex and time between stroke onset and joining the Next Step program (r = -0.34, p = 0.012; n = 55), and there was a significant difference between men and women in which men joined the Next Step program 2 years earlier than women after having a stroke (1.4 vs 3.3 years, respectively; $p = 0.019$). Additionally, we found a moderate positive correlation between sex and activity performance ($r = 0.40$, $p = 0.041$; n = 27) with men being more active. Further analysis of the baseline performance scores on the COPM revealed a significant difference between men and women ($p = 0.041$) using an independent *t*-test. On average, men's perception of their functional performance was higher than women's by 2 points, indicating their perception of activity performance was better. Figure 2 displays the comparison of performance scores between both genders at baseline.

The recovery score on the SIS was strongly and positively correlated with the SIS total score ($r = 0.62$, $p < 0.001$; n = 55) and performance scores ($r = 0.71$, $p < 0.001$; n = 20). Individuals reporting higher recovery scores on the SIS tend to report lower impact of stroke on performance as reported on the SIS. Further, there was a moderate negative correlation between recovery score and cognitive function ($r = -0.37$, $p = 0.040$; n = 31) in which individuals with higher cognitive function reported lower recovery scores. We also found a moderate positive correlation between recovery score and satisfaction scores on the COPM ($r = 0.56$, $p = 0.013$; n = 19) with individuals reporting higher recovery scores being more satisfied with their performance.

The satisfaction scores on the COPM were strongly and positively correlated with performance and satisfaction scores ($r = 0.94$, $p < 0.001$; n = 25) with individuals having better perception of their performance being more satisfied with their activity performance. Additionally, we found a moderate negative correlation between hypertension and satisfaction ($r = -0.57$, $p = 0.005$; n = 23), with those who have hypertension being less satisfied. We compared the SIS scores between baseline and follow-up and found significant differences between the mean scores of ASF clients in the SIS domain Mobility ($p = 0.017$) subscores. Participants' perceptions about their mobility decreased at follow-up. Further analysis of the mobility subscores of 30 participants showed that the perception of 21 decreased, 2 maintained same levels, and 7 increased. Individuals who reported a decrease in their perceptions about mobility were on average 9.6 years older than individuals who reported increased perceptions (67.8 vs. 58.1, respectively). In addition, men constituted the majority of participants who reported decline in mobility perceptions (66.7%) and improvements (85.7%). Additionally, the duration of time between SIS baseline and follow-up assessments varied and averaged 2.2 years (0.2 – 10.9 years). Table 3 presents the results of the paired t-tests for the SIS scores.

We conducted two comparisons for SIS scores with normative data. First, a comparison of the baseline SIS scores with the normative data for acute stroke using independent t-test showed that clients in the Next Step program had significantly higher scores on Mobility domain (p=0.016) and significantly lower scores on five other domains including Strength (p=0.030), Emotion (p=0.001), Communication (p =0.024), Hand Function ($p < 0.001$), and Participation (p=0.030). Overall SIS scores were not significantly different between the ASF group and the normative data for acute stroke. A second comparison evaluated the difference between the follow-up SIS scores and normative data for chronic stroke. The results of this comparison showed that clients in the ASF had significantly lower scores on 3 domains including Memory (p=0.018), Communication (p =0.013), and Mobility ($p = 0.012$). Overall SIS scores were not significantly different between the ASF group and the normative data for chronic stroke. Figure 3 shows the two comparisons using baseline (n = 65) and follow-up (n= 30) SIS scores for ASF clients and SIS norms for acute (n = 287) and chronic (n = 58) stroke.

Discussion

Our first aim was to describe demographic characteristics and self-perceived activity performance of individuals with chronic stroke who sought long-term supports in a community-based center. The demographic characteristics were consistent with stroke literature; the frequency being higher in men compared to women, higher in Caucasians compared to African Americans, and having increased risk with advancing age (Mozaffarian et al., 2015). African Americans and Caucasians showed different patterns in seeking long-term community support after stroke, in which African Americans sought these supports years after stroke onset compared to Caucasians, while Caucasians were more adherent to attending support programs after joining compared to African Americans. Spreading awareness about long-term community supports could lead to increased utilization of such services at earlier years after stroke. Some participants had common comorbidities (e.g., diabetes, hypertension), which are well-documented and modifiable risk factors for stroke (Goldstein et al., 2001), and associated with reduced quality of life among individuals with cardiovascular disease including stroke (Chin, Lee, & Lee, 2014). Our study found community-dwelling adults with stroke who also had hypertension experienced reduced satisfaction with activity performance. Medical treatments, physical exercise, counseling, patient education, and behavior change all are available strategies to reduce the risk of stroke recurrence and to improve the quality of life for affected individuals.

The mean time since stroke onset to admission to the Next Step program was 26.4 months (SD = 35.4), so spontaneous recovery is not likely a confounding factor for our observations. The long-term phase of recovery requires services and supports with a different emphasis than the medical and rehabilitation services available in more acute phases of recovery. We believe it is important to note that participants, once they joined ASF, continued to engage in activities provided in the Next Step program for months or years; some participants have actively participated in the program for more than 10 years. Being engaged in meaningful activities within a social context seems to attract these participants with stroke. The program provided participants with unique opportunities to participate in personalized activities that address physical, emotional, and social aspects of performance.

We found a significant association between self-perceived activity performance, self-perceived recovery, and satisfaction in performance coupled with a gender difference in reporting these perceptions; men in our study reported higher levels of activity performance than did women. This is consistent with reports of evaluated gender differences in perceived physical and cognitive functions among people with stroke (Roding, Glader, Malm, Eriksson, & Lindstrom, 2009). These researchers found significant differences between genders with women reporting greater deterioration in functioning than did men. Other researchers, however, report mixed results regarding gender differences in activity performance of individuals with stroke, ranging from no observed gender differences (Vincent-Onabajo, Hamzat, & Owolabi, 2014) to men achieving significantly higher scores than women on subjective measures of functional performance (e.g., Functional Independence Measure and Barthel Index; Gargano, et al., 2007; Wyller, Sodring, Sveen, Ljunggren, & Bautz-Holter, 1997). Possible contributing factors to these differences in men and women perceptions about activity performance may include differences in stroke severity and support availability (e.g. spouse, family members, or friends). Published evidence suggests social support is associated with improved functional outcomes after stroke (Glass, Matchar, Belyea, & Feussner, 1993) and with health-related quality of life after stroke (Kruithof, van Mierlo, Visser-Meily, van Heugten, & Post, 2013). Understanding the gender differences in perceived activity performance provides direction for researchers and health professionals toward addressing possible underlying factors (e.g., physical and emotional needs) to improve perceived activity performance and life experience, and recovery after stroke.

Self-perceived recovery was proportionally associated with positive perceptions about activity performance, satisfaction with activity performance, and less impact of injury after stroke. This is congruent with another report of the relation between self-perceived recovery and impact of injury on individuals with stroke. Vanhook (2007) found a positive association between perceived recovery and reduced impact of injury 1-3 years after stroke. We also found self-perceived recovery to be inversely associated with cognitive function in which stroke participants with better cognitive function reported worse perceptions about their recovery.

Our second aim was to evaluate changes in self-perceived impact of stroke on aspects of health. We hypothesized that participating in long-term community support programs will yield changes in self-perceived impact of injury after stroke. Our findings provide support for our hypothesis; self-perceived impact of stroke was significantly different on the mobility domain. ASF participants reported lower scores on the mobility domain at follow-up indicating a reduction in their perceptions about mobility. Functional mobility was the 3rd most frequently reported performance problems by participants in this study. Individuals who reported decline in perceptions about mobility were mostly men, and about one decade older on average than individuals who reported improved perceptions about mobility. Although men tend to report higher scores on perceived performance than women, they seem to report lower scores on perceived mobility. Some of these individuals had joined the Next Step program years before they received their follow-up assessment. Advancing age, age-related decline in motor control, and long duration between assessments may have contributed to these differences on perceived mobility. One report of actual mobility using objective measures provided evidence about decline in mobility years after stroke. The results showed that 21% of individuals with chronic stroke demonstrated decline in mobility status 1-3 years after stroke (van de Port, Kwakkel, van Wijk, & Lindeman, 2006). The findings of van de Port et al. (2006) study provides support for our findings, nonetheless, using objective measures to assess actual mobility of the current study is warranted. The presence of cognitive impairment, physical inactivity, and depression 1 year after stroke were significant predictors of decline in mobility 3 years post stroke (van de Port et al., 2006). Individuals who reported a decline in their perceptions about own mobility should be screened for physical inactivity, cognitive problems, and depression. Detection and management of these problems could protect against further decrease in perceptions about health in general and mobility in particular.

Our third aim was to conduct a comparison with normative data on self-perceived impact of stroke. We hypothesized that individuals seeking long-term community support will have different views of self-perceived impact of stroke when compared to other individuals with acute (Duncan et al., 2002) and chronic stroke (Huang et al., 2010). The first comparison between the baseline scores in our study and normative data for acute stroke showed that our sample had a higher score on the Mobility domain and a lower score on five other domains including Strength, Emotion, Communication, Hand Function, and Social Participation. Further comparison between both samples revealed that participants in the normative data study have had a stroke for less than 4 weeks at the time of data collection compared to 27 months on average for our sample. This introduces many potential confounders to this comparison including varying duration from stroke onset, spontaneous recovery, and Anosognosia. Published evidence from a systematic review suggests that individuals with stroke may overestimate their abilities or lack awareness about the impact of injury on functioning (i.e. Anosognosia), especially within the first 3 months after injury with an incidence of 7%-77% in people with stroke (Orfei et al., 2007). In addition, the sample in Duncan et al. (2002), was considerably larger, which statistically augments the difference when compared with our sample.

The second comparison between the follow-up scores on self-perceived impact of stroke and normative data for chronic stroke revealed that participants in the normative data study had higher scores on domains of Memory, Communication, and Mobility, yet the overall SIS scores were not significantly different between the ASF group and the normative data. These findings provided support for our hypothesis that individuals seeking community support demonstrated different results compared to the normative data. The characteristics of both samples did not match on age and onset of stroke. For example, participants in the normative data study averaged 12 years younger and have had a stroke for less time (2.8 years lesson average) at the time of assessment. In addition, the normative sample size was almost twice as large. These differences could have confounded the comparison.

The present study was conducted on retrospective data; we were not able to control for potential confounding factors including socioeconomic status, marital status, education level, the presence of other neurological conditions, the nature and location of stroke, the lack of a control group, concurrent rehab services from other disciplines, duration of treatment, frequency and adherence to the exercise sessions, and restricting some analyses to subsets of the data due to missing data on certain outcome measures. *Although these limitations exist*, this study is still meaningful and has produced valuable information about individuals with stroke who have sought long-term support in a community-based program. This report provided useful information about the relationship between demographics, self-perceived activity performance, and long-term impact of stroke.

Conclusion

Our findings document this community-based center does provide supportive programs and environment for individuals with stroke to individually address their physical, cognitive, social, and emotional well-being. This study emphasizes the importance of understanding changes in the individuals' perceptions about their activity performance, satisfaction, and impact of injury on performance after chronic stroke. It also sheds some light on potential benefits of pursuing long-term community-based supports to maintain the emotional and functional gains after discharge from acute care rehabilitation. Health care practitioners can support their clients at discharge by directing them toward community resources offering these or similar long-term programs. We recognize the findings we report may be enhanced by future research examining longitudinal changes in self-perceived activity performance in chronic stroke particularly if these studies employ a randomized controlled trial, cohort, qualitative, or similarly robust designs. Further, using objective measures of functional performance will allow validation of self-reported activity performance with the actual capacity to address these tasks. The activities provided in a community-based center should be defined clearly, have a pre-determined duration and frequency of visits, and address potential confounding factors we identified in the course of this research to yield an accurate assessment of effectiveness in producing satisfactory client outcomes.

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Table 1

Demographic Variables	Frequencies
Mean Age (±SD, Range)	67 years (±11.6; 45 – 92)
Sex	
Females	27 (39.7%)
Males	41 (60.3%)
Ethnicity	
African American	13 (19.1%)
American Indian or Alaskan	1 (1.5%)
Caucasian	46 (67.6%)
Missing value	8 (11.8%)
Stroke Diagnosis	68 (100%)
Other Conditions	
Hypertension	30 (44.4%)
Diabetes	22 (32.4%)
Seizures	10 (14.7%)
Mean MoCA Scores, (±SD; Range)	20.7 (±6.9; 3 – 30)
Mean # Years between Stroke and Joining ASF (± SD; Range)	2.3 (±3.0; 0.3 – 11.4)
Less than a year (<1)	28 (41.2%)
One year or more (≥ 1)	27 (39.7%)
Missing value	13 (19.1%)
Mean # Years in ASF (± SD; Range)	3.5 (3.4; 0.1 – 12.6)
Less than a year (<1)	14 (20.6%)
One year or more (≥ 1)	51 (75.0%)
Missing value	3 (4.4%)

Note. Characteristics of the sample (N = 68); SD = Standard Deviation; MoCA = Montreal Cognitive Assessment; ASF = American Stroke Foundation.

Table 2

	Age	Sex	Ethn.	DM	HTN	Seiz.	Years in ASF	Time since Stroke	Cog.	Rec. Score	SIS Score	Perf. Score
Age	1.00											
Sex	-0.02	1.00										
Ethnicity	0.23	0.26*	1.00									
DM	0.13	0.09	-0.02	1.00								
HTN	-0.07	0.04	-0.22	0.01	1.00							
Seizures	-0.17	0.07	0.12	-0.05	0.04	1.00						
Years in ASF	0.12	-0.03	0.28*	-0.22	0.09	0.19	1.00					
Time since Stroke	-0.14	-0.34*	-0.38**	0.17	-0.12	0.09	-0.28*	1.00				
Cognition	-0.10	-0.11	- 0.15	-0.04	0.31	-0.10	0.19	0.09	1.00			
Recov. Score	0.05	0.05	0.10	-0.16	-0.15	-0.21	0.02	0.08	-0.37*	1.00		
SIS Scores	0.15	0.22	0.09	0.09	0.13	-0.18	-0.24	0.04	0.00	0.62**	1.00	
Perf. Score	0.11	0.40*	-0.05	-0.35	-0.39	-0.18	-0.06	-0.24	0.03	0.71**	0.25	1.00
Satisf. Score	0.05	0.22	0.15	-0.32	-0.57**	-0.05	-0.03	-0.08	-0.04	0.56*	0.12	0.94**

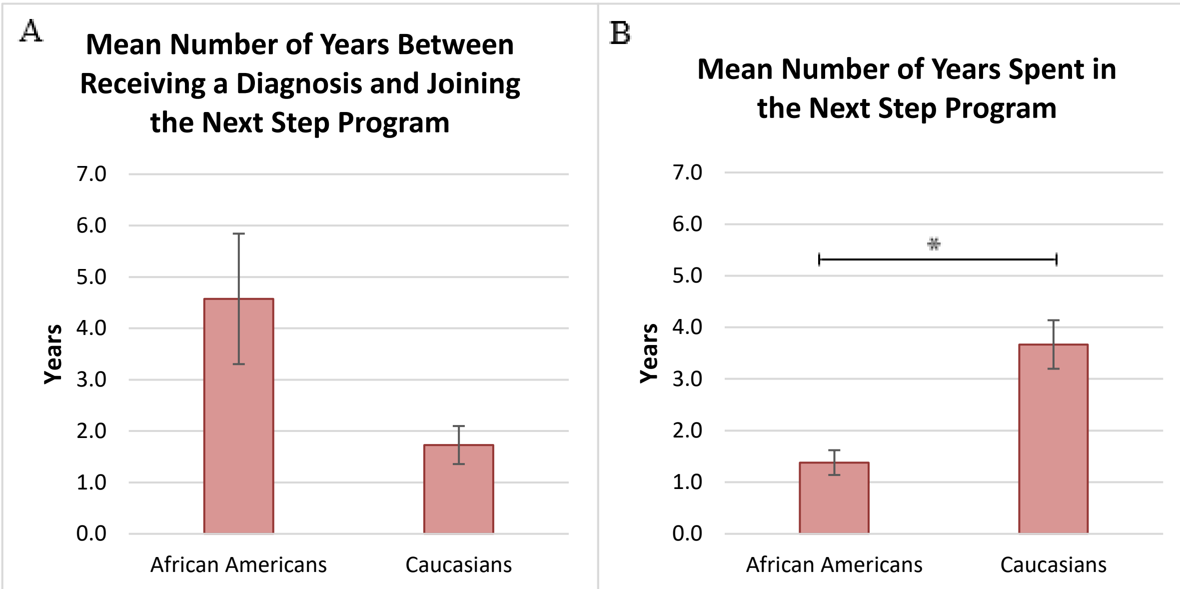
Note. Correlation matrix; * $p < 0.05$; ** $p < 0.01$; ASF = American Stroke Foundation; Cog = Cognition; DM = Diabetes Mellitus; HTN = Hypertension; Recov. = Recovery; Seiz. = Seizures; SIS = Stroke Impact Scale; Perf. = Performance; Satisf. = Satisfaction.

Table 3

SIS Domains	SIS 1 Mean	Mean Diff.	*t*	*p*
Strength	55.81	7.54	1.61	0.120
Memory	73.51	2.56	0.75	0.458
Emotions	64.62	-2.23	-0.70	0.492
Communication	80.11	0.48	0.19	0.850
ADL/IADL	78.14	4.51	1.50	0.146
Mobility	73.85	5.56	2.55	0.017*
Hand Function	41.21	0.69	0.14	0.889
Participation	54.35	-0.89	-0.22	0.831

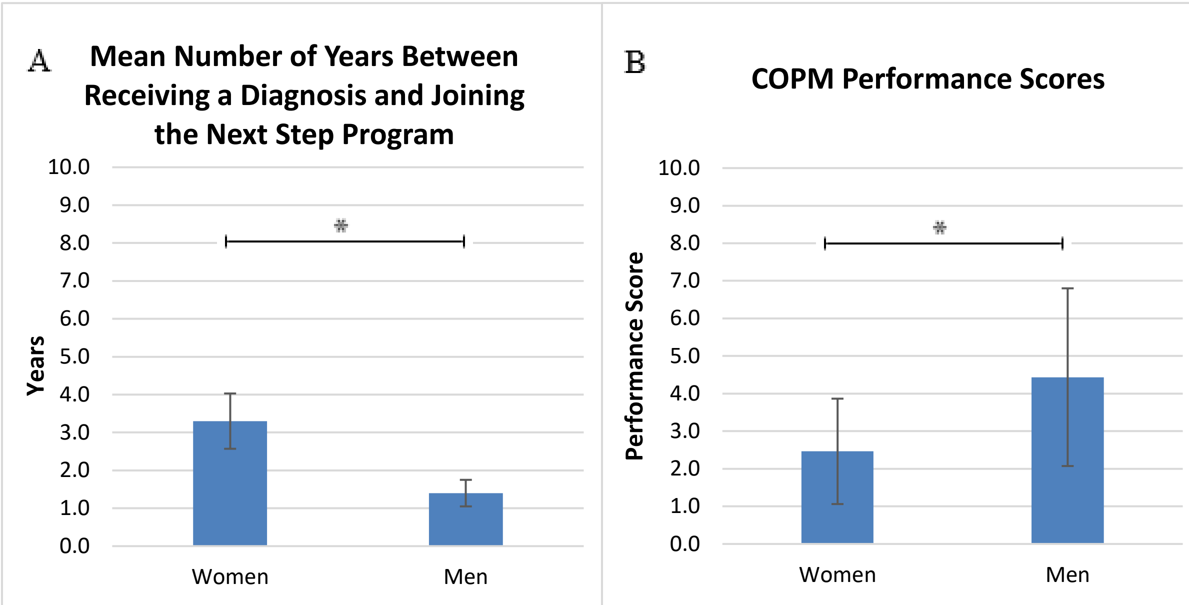
Note. Paired sample t-tests for the SIS domains (n=30); SIS = Stroke Impact Scale; Diff = difference; IADL = Instrumental Activities of Daily Living; t = t statistic; * = $p < 0.05$.

Figure 1



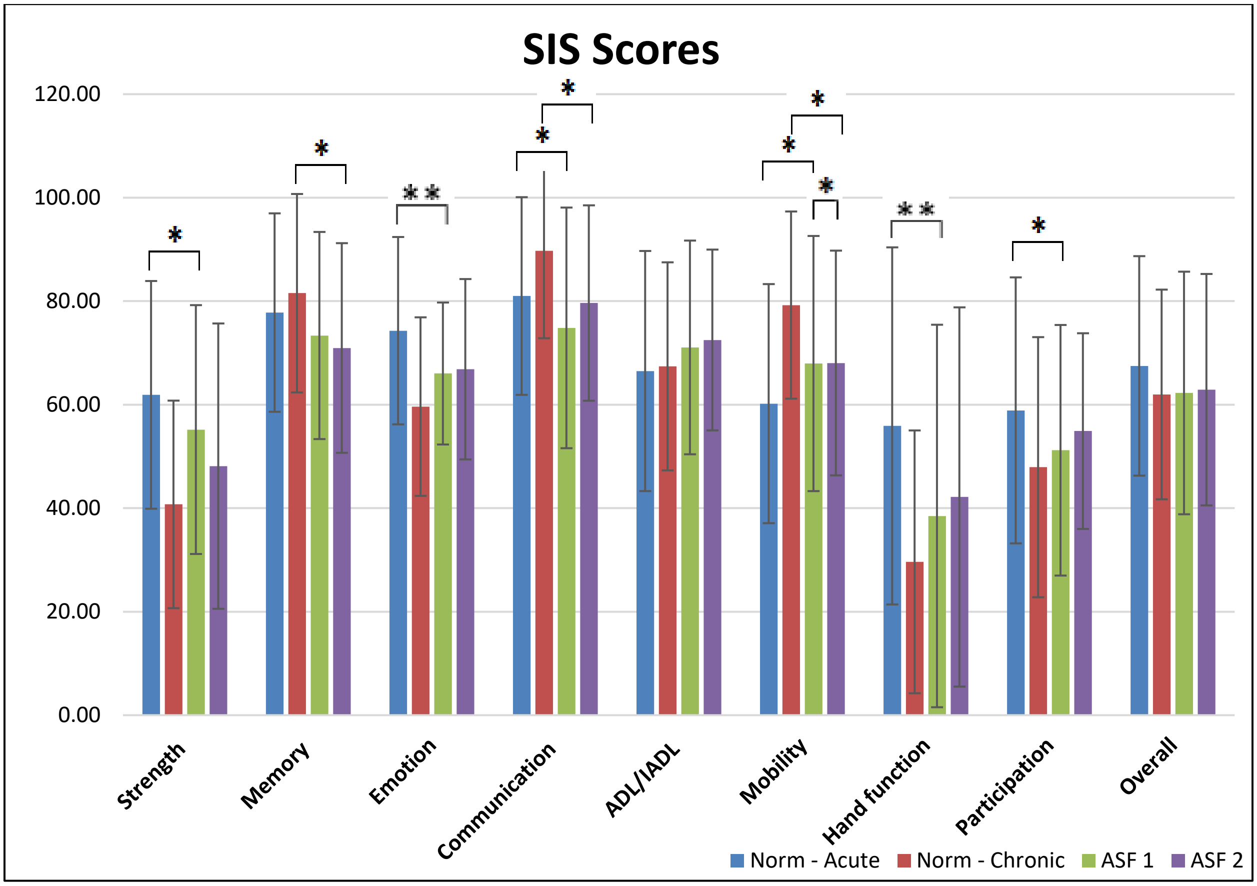
Note. A) Mean number of years between receiving a stroke diagnosis and joining the Next Step Program divided by ethnicity with no significant difference between African Americans and Caucasians. B) Mean number of years spent the Next Step Program divided by ethnicity). Caucasians spent significantly more years relative to African Americans in the program. * = p <0.05; error bars = standard error.

Figure 2



Note. A) Mean number of years spent the Next Step Program separated according to sex. Men spent significantly more years in the program relative to women B) Mean performance scores separated according to sex. Men reported significantly higher perceived performance relative to women. * = p <0.05; error bars = standard error.

Figure 3



Note. Mean SIS scores of ASF clients who took part in Next Step at baseline and at follow-up 2 years later, compared to normative SIS data (Duncan et al., 2002) for individuals with acute and with chronic stroke. * = $p < 0.05$ (one-tailed); error bars = standard deviation.