Broadening the Scope of Community Participation in Traumatic Brain Injury Research

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Submitted to the Graduate Faculty of the

School of Health and Rehabilitation Sciences in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

University of Pittsburgh

2021

UNIVERSITY OF PITTSBURGH

SCHOOL OF HEALTH AND REHABILITATION SCIENCES

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March 11, 2021

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University of Pittsburgh, 2021

Community participation has traditionally been conceptualized as the frequency or difficulty of engagement in community activities. However, qualitative studies reveal that people with disabilities define community participation by the degree to which they feel included in society. This sense of "enfranchisement" is not well-represented among conceptualizations of community participation in rehabilitation research. That said, some suggest that enfranchisement may be a promising intervention target as a means of improving community participation.

Community participation is problematic following traumatic brain injury (TBI), and optimal interventions for and measurement of community participation are unclear. We need to specify which intervention elements show promise for restoring community participation. We also need an interpretable outcome measure of enfranchisement. This dissertation examined interventions associated with improved community participation outcomes, as they are currently measured, and examined the psychometric properties of the Enfranchisement Scale of the Community Participation Indicators (CPI), as a promising new measure.

First, we conducted a scoping review of interventions that address community participation outcomes after brain injury. We found that studied interventions focused more on the performance of community activities, rather than the enfranchisement, per se. Daily life skills interventions and metacognitive interventions showed the greatest promise for improving performance of home and community activities, highlighting the importance of focusing on personally meaningful activities rather than injury-related impairments.

Second, we examined existing and prospectively collected data to assess construct validity, cut points, and sensitivity to change of the CPI. We found that enfranchisement is strongly correlated with participation, environment, and depression; and weakly correlated with physical and cognitive impairments. Thus, interventions focused on environmental barriers and mood symptoms may be important for improving enfranchisement. We also found that the CPI had similar sensitivity to change as the Community Integration Questionnaire, the gold standard for assessing performance of community participation activities.

Overall, these findings suggest new directions for intervention research in TBI rehabilitation by identifying potential intervention elements (i.e., meaningful activities, environmental modifications, mood management) and new target outcomes (e.g., enfranchisement) as a means of improving community participation. These results will guide intervention development to address enfranchisement and assess intervention-related changes over time.

Table of Contents

List of Tables

List of Figures

Preface

My sincerest thanks go to my committee, who guided me and challenged me to advance my ideas, and without whom this work would not be possible. I am also grateful for my family, who have provided unending support and encouragement through this process. My thanks also go to the participants in the studies presented in this dissertation, as well as Joan Toglia, Michael O’Dell, and Allen Heinemann, who provided data and mentorship for some of the included analyses. Lastly, I owe great thanks to my colleagues in the Occupational Therapy Cognitive Performance Laboratory for their guidance and support.

This work was supported by the School of Health and Rehabilitation Sciences Dissertation Fund and the Department of Occupational Therapy.

1.0 Introduction

1.1 Significance

1.1.1 Traumatic brain injury results in low rates of community participation

Traumatic brain injury (TBI) is a prevalent and disabling condition. It is estimated that between 3 and 5 million people in the United States have some degree of disability caused by a TBI (1). The outlook is bleak for those whose injuries are severe enough to require inpatient rehabilitation: 20% do not survive 5 years post-injury, and 40% experience declines in function after discharge from rehabilitation services (1). Home management, employment, and social and community participation are often limited following TBI, because these activities are strongly influenced by social and environmental factors that are often beyond the person's control (2).

People with TBI experience restrictions in community participation compared to those without TBI (3). These community participation restrictions persist over time, even as abilities to complete self-care and mobility activities improve over time (3). Community participation, particularly engagement in social activities, has been linked with quality of life and personal health outcomes (4). This is unsurprising considering that adults with a range of disabilities report that community participation is the domain of function with the highest value to them and most closely tied to quality of life (5). Not only is community participation personally meaningful to those with TBI, but it is also important to their health. The World Health Organization (6) and Healthy People 2030 (7) have both identified public health goals of improving access and opportunities for people with disabilities so that they may have the same access to healthcare, community services, and social engagement that lead to better health. Addressing the barriers to community participation can help achieve these public health goals in the TBI population.

The consequences of TBI are broad and vary among individuals. Common consequences include impairments in cognitive skills, affect, and physical function (8). These impairments influence community participation outcomes (9). However, the relationship between each of these impairments and community participation outcomes is moderately strong at best (10), suggesting that there are factors beyond impairments that influence community participation after TBI. A few studies have examined the influences of environmental factors on community participation. These studies revealed that social support and "social obstacles" are important (2, 11-13). These environmental barriers help explain some of the variation in community participation outcomes that is not fully explained by impairments (2, 11-13).

1.1.2 Community participation is multifaceted

Community participation outcomes have traditionally been defined by either the frequency or difficulty of engagement in productivity (work or school), social activities, instrumental activities of daily living, and leisure activities (14-16). This definition conceptualizes community participation by the performance of complex home and community activities rather than the meaning of these activities. However, qualitative studies suggest that people with disabilities define community participation outcomes differently. Their definition entails more than just frequency of or difficulty in performing complex home and community activities (5). Rather, people with disabilities define community participation outcomes by the degree of "enfranchisement," or sense of belonging and inclusion that people derive from interactions with their communities. Enfranchisement describes the degree to which people feel valued by their community, contribute to their community, and feel a sense of choice and control over their lives. Community participation encompasses enfranchisement, social connectedness, and a sense of personal and social responsibility (5).

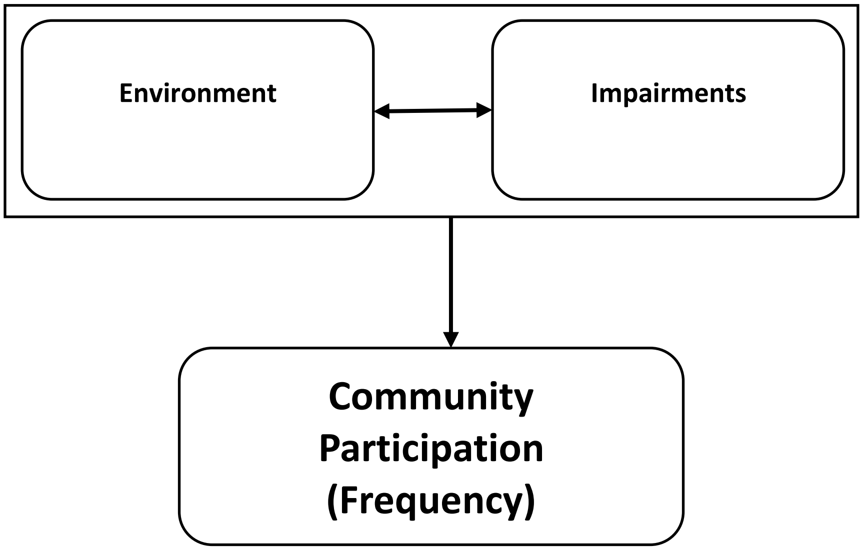

Figure 1. Community Participation: Traditional View

Our understanding of the factors that influence community participation is still developing, but our current knowledge is based on research conducted primarily with a traditional, performance-oriented view of community participation as depicted in Figure 1. This figure defines community participation outcomes in terms of frequency of participation in community activities and illustrates the factors that have been associated with community participation in previous studies. In this conceptualization, the degree of community participation is the culmination of an interaction between the person's capacity for community participation, as determined by impairments, and the immediate physical environment. However, this model fails to capture elements of community participation that are most valued by people with disabilities, in particular the sense of inclusion.

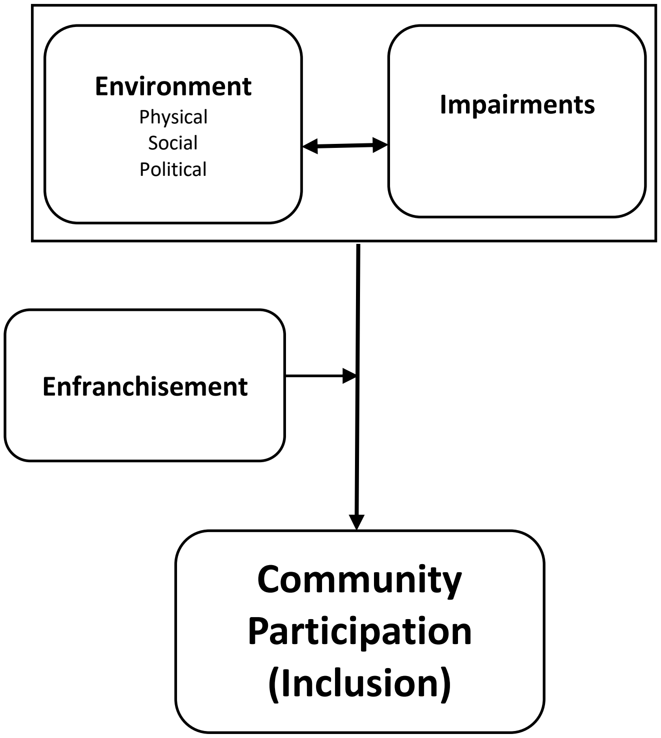

Figure 2. Community Participation: Novel Perspective

Alternatively, figure 2 presents a novel perspective on community participation. In this figure, community participation outcomes are characterized by the inclusion and connectedness that are valued by people with disabilities. The interaction between the person and the environment remains important, but the scope and influence of environmental considerations are broadened. Most importantly, this model also illustrates the likely role of enfranchisement, or the degree to which people feel valued by their community, contribute to their community, and feel a sense of choice and control. Enfranchisement is believed to moderate community participation. That is, enfranchisement influences how the interaction between the person and the environment bring about community participation outcomes. Enfranchisement may be the key to understanding these important, subjective components of community participation that are important to the disability community but are currently missing or under-represented in current rehabilitation science discussions of community participation.

1.1.3 Optimal intervention approaches are unclear

Currently, we know little about how to improve community participation (17, 18). One of the greatest limitations of current evidence exploring interventions to improve community participation is that most intervention studies have focused on the underlying deficits that affect community participation. Intervention studies that address cognitive skills, affect, and physical function (18-22) show promise for improving these underlying impairments but show limited success for improving community participation in a meaningful way. With little evidence to suggest that impairment-based interventions promote improvements in community participation, an alternative approach is needed. Interventions focused on the performance of meaningful home and community activities may show more promise. Exploration of a broader range of intervention targets is needed to identify the optimal approach to improving community participation outcomes.

1.1.4 Measurement of enfranchisement requires further development

While understanding elements associated with improvements in home and community activities is important, the existing literature is not likely to reveal insight into enfranchisement as a mechanism for improving community participation. Studies examining enfranchisement are few.

Because we believe that enfranchisement may warrant consideration in interventions seeking to optimize community participation, we sought to address some important gaps in current research.

While enfranchisement shows promise as a potential intervention target to improve community participation outcomes, we need a scientifically sound method for defining and measuring enfranchisement before we can define and test intervention. To our knowledge, the Enfranchisement Scale of the Community Participation Indicators is the only measure that directly assesses enfranchisement. The tool has been validated in a sample of adults with cognitive disabilities using a Rasch analysis approach (23). A factor analysis revealed two dimensions to this scale: importance and control. Yet, little was known about how to interpret the results. The Rasch analysis was useful in characterizing the degree of enfranchisement a person experiences compared to others (23). However, additional validation is needed. More analyses are needed to establish the construct validity and clinical interpretability of the measure (24). Construct validity (comparison against other measures) aids in interpretation of the severity, meaning, and impact of disenfranchisement. Clinical interpretability, established through clinically meaningful cut points, aids in identifying problematic levels of disenfranchisement.

Additionally, a measure that is sensitive to change is necessary if we are to evaluate the effects of interventions seeking to improve enfranchisement. Minimum Detectable Change (MDC) and the Minimal Clinically Important Difference (MCID) scores are helpful when determining whether changes over time are statistically or clinically meaningful (25-27). The identification and validation of these psychometric properties would be useful in the interpretation of intervention studies focused on improving enfranchisement and community participation.

1.2 Specific Aims

Considering these important gaps, the purpose of this dissertation was to explore a broad range of intervention approaches to address community participation, and to explore the psychometric properties of a measure of enfranchisement to be used in future longitudinal and intervention studies.

Aim 1: Scoping Review: Identify essential elements of interventions with the potential to influence community participation.

Aim 2: Measurement Analyses: Assess the psychometric properties of an existing measure of enfranchisement and validate findings.

Aim 2a: Examine the construct validity, responsiveness (minimal detectable change, MDC), and clinical interpretability (minimally clinical important difference, MCID; clinically important critical values) of the Community Participation Indicators Enfranchisement Scale.

Aim 2b: Validate the minimally clinical important difference (MCID), and clinically important critical values in adults with TBI through prospective data collection.

Together, these aims provide the groundwork for future research focused on developing and testing interventions aimed at improving community participation following TBI. This body of research identifies potential intervention elements for these future interventions and establishes the psychometric properties necessary for reliable interpretation of enfranchisement data. This dissertation is important and innovative in that it examines those intervention elements that may be most likely to improve community participation outcomes when considering a more innovative and stakeholder-driven definition of community participation. Furthermore, it expands the use of a measurement tool previously used to detect enfranchisement (or disenfranchisement) and enhances our ability to interpret longitudinal data. Establishing the validity of the Enfranchisement

Scale will aid in interpretation of the impact of disenfranchisement. Establishing the MDC and MCID will broaden its range of uses to include examinations of change over time and response to intervention. Collectively, the findings of this dissertation inform the design of future studies to determine whether enfranchisement changes over time, whether it does in fact moderate community participation outcomes, and whether interventions targeting enfranchisement affect overall community participation outcomes. This research study sets us up for a new trajectory in designing interventions for community participation by opening up a new intervention target.

2.0 Effect of Interventions on Activity Outcomes for Adults with Brain Injury

This chapter describes a scoping review examining intervention elements that show promise for improving community participation outcomes after brain injury. This chapter has been developed into a manuscript that is under review by a rehabilitation research journal.

2.1 Introduction

Activity and participation are important outcomes of rehabilitation following brain injury. Activity is described by the International Classification of Functioning, Disability and Health (ICF) as the performance of specific tasks (6). Participation is defined by the ICF as "involvement in a life situation" and is understood to encompass personally meaningful and contextually-driven engagement (6, 15). While many have argued that activity and participation are broad concepts (15, 28, 29), measures used in rehabilitation studies often examine the frequency or difficulty of performance of varied types of activities (14) in the home and the community (14-16). Together, activity and participation span a broad range of outcomes important in rehabilitation practice.

Activity and participation outcomes are often poor after brain injury with significant consequences (30). Poor activity and participation outcomes contribute to physical inactivity, social isolation, poor quality of life, and high rates of post-injury depression (4, 30-33). Clearly, improving activity and participation is an important component of brain injury rehabilitation. However, the optimal approaches for improving activity and participation outcomes in the home and community are unclear (17, 18).

Most interventions for adults with brain injury have focused on addressing the underlying impairments following injury (e.g., cognitive impairments, mood, motor impairments, balance impairments) with the hope that restoration of these elements would translate to improved performance of daily activities in the home and community. Some of the most frequently explored interventions include psychotherapy interventions (Cognitive Behavioral Therapy, mindfulness meditation)(19, 34), physical activity interventions, and cognitive remediation approaches (Attention Process Training, computerized training)(35, 36). These types of interventions can be considered impairment-focused interventions because they address an underlying injury-related impairment (mood, motor or balance impairments, cognitive impairments). While some of these interventions have shown promise for addressing underlying impairments, the impact of these impairment-focused interventions on activity and participation outcomes remains unclear (18-22).

Alternatively, activity-focused interventions are interventions that directly address the performance of specific, meaningful activities using approaches such as task-specific training and metacognitive training. While these intervention approaches have shown promise for improving activity-based outcomes in other diagnostic groups, their effectiveness for people with brain injury is unclear (37-39). One review examined several intervention approaches following brain injury, but few studies were included, and few conclusions could be drawn about the effectiveness of activity-focused and impairment-focused approaches (40). Furthermore, it remains unclear what specific intervention elements are associated with the most favorable activity and participation outcomes following brain injury. Therefore, the purpose of this scoping review was to characterize the intervention elements associated with improvements activity and participation outcomes for adults with brain injury.

2.2 Methods

2.2.1 Search Strategy and Inclusion Criteria

We conducted a comprehensive search using a strategy developed in collaboration with a health science librarian (Appendix A). The PRISMA checklist for scoping reviews was used to guide our methods and reporting (41). We searched PubMed, PsycINFO, and Ovid for RCTs published in English between 2000 and 2020, examining non-pharmacological interventions that address activity and participation outcomes for adults with acquired brain injury (ABI). Search terms included variations of brain injury combined with activities of daily living, community participation, social participation, community integration, social integration, leisure, employment, and work. Studies were excluded if they 1) did not describe a randomized controlled trial; 2) did not include participants with ABI; 3) did not examine a non-pharmacological intervention; and 4) did not include an activity or participation outcome measure. Our most recent search was conducted in November, 2020.

Title and abstract reviews were completed by the first author (JK). Full-text reviews were completed by two separate reviewers (JK, ES) to ensure accuracy and consistency. Discrepancies were settled by group discussion. Each study was appraised for quality by a minimum of two raters (JK, KH, EM, ES) using the Cochrane Risk of Bias Tool (42).

2.2.2 Data Extraction

Data were extracted from each study into an Excel spreadsheet by two raters (JK, ES): (1) study design; (2) sample characteristics; (3) experimental intervention and associated intervention elements; 4) comparison intervention; 5) activity or participation outcome measure; and 6) effect sizes. To permit synthesis of intervention elements across studies, we identified and classified intervention elements from each experimental intervention. Four raters (JK, KH, EM, ES) independently classified the intervention elements and discrepancies were discussed and resolved. All analysis was completed using Excel.

2.2.3 Data Analysis

2.2.3.1 Thematic analysis

We first conducted a thematic review of intervention elements and outcome measures across all studies. Our original intent was to examine intervention elements and outcome measures for activity and participation outcomes. However, an early scan of the included studies revealed that all studies examined performance of activities in the home and in the community, and relatively few studies examined participation, as defined by a sense of belonging or inclusion (5). Rather, the included studies used measures that examined performance of or satisfaction with performance of activities in the community. While some of these measures included "participation" in the name, we chose to frame these findings in terms of community activity outcomes. Therefore, we decided to examine intervention elements as they applied to two outcome levels: performance of home activities (mobility; activities of daily living; instrumental activities of daily living in the home such as medication management and financial management), and performance of community activities (social activities; leisure activities; work or volunteer activities; and instrumental activities of daily living in the community such as shopping). We examined these domains separately to determine whether intervention elements associated with favorable outcomes differed based on the outcome level. Studies have demonstrated that the factors that influence performance of home and community activities may differ, as social and environmental factors often play a smaller role in home activities than in community activities (2, 11, 12, 43). This suggests that different intervention elements may be needed to influence home and community activity outcomes.

2.2.3.2 Effect size extraction and calculation

After classifying intervention elements, we examined effect sizes associated with each intervention element. First, we examined effect sizes for all activity outcomes at the first follow-up after completion of the intervention. We gleaned effect sizes from the studies, if provided, or calculated them if not provided. For those studies that reported means and standard deviations, we calculated Cohen's d effect sizes between groups at follow-up using the following formula: $(\text{Mean}_{\text{Intervention}}\text{-}\text{Mean}_{\text{Control}})/\text{SD}_{\text{pooled.}}$ For those studies that reported medians and interquartile ranges, we calculated Cohen's d effect sizes using the procedure reported by Wan and colleagues (44). For those studies that reported F-statistics or chi-squared statistics, we transformed these into Cohen's d using Psychometrica online software (45). When effect sizes were not reported, we attempted to contact the authors to obtain the data necessary to compute them. We summarized effect sizes in activity outcomes associated with experimental interventions containing identified intervention elements. Effect sizes less than .2 were considered negligible; effect sizes .2-.5 were considered small; effect sizes .5-.8 were considered moderate; and effect sizes greater than .8 were considered large (46).

2.2.3.3 Effect sizes based on time of follow-up

Next, we examined effect size based on time of follow-up by plotting effect sizes on a dot plot to determine if the range of effect sizes varied by time since intervention. For consistent reporting and comparison, we examined the time from study admission to follow-up. For example, if a study examined a 12-week intervention and assessments were administered immediately after completing the intervention, we considered this a follow-up at 3 months. All activity outcomes at all available time points were included in the analysis of effect sizes by time of follow-up to obtain a clear picture of whether effect sizes varied over time.

2.2.3.4 Effect sizes associated with home and community outcomes

We then examined effect sizes on home and community activity outcomes separately to determine if different intervention elements were associated with different levels of outcomes. To analyze home-level outcomes specifically, we selected a single measure to include in the analysis so that each study would only be represented once in the analysis, regardless of the number of outcomes included in the study. For consistency, when more than one measure was collected in a single study, we selected the measure used most frequently across all studies. Studies that included only a measure of community-level outcomes and no measure of home-level outcomes were excluded from this portion of the analysis. If data were provided for multiple time points of follow-up, we used data from the first administration of assessments following the completion of the intervention. For instance, if follow-up assessments were administered at 3- and 6- months, we used data from the 3-month follow-up. For these outcomes, we calculated the percentage of participants in studies with negligible, small, moderate, and large effect sizes for each intervention element. These data were presented in stacked bar charts (47).We chose to analyze based on the percentage of the total overall sample of participants receiving each intervention element, because many of the included studies were feasibility studies with small samples. Intervention elements with higher percentages of participants in studies with larger effect sizes were considered to be associated with better outcomes. For each intervention element we calculated the range of effect sizes across studies and an I^2 statistic to determine the degree of heterogeneity among studies (48, 49). We calculated I^2 in Excel using the approach described by Neyeloff (50).

We repeated this procedure to analyze community-level outcomes. When more than one measure of community-level outcomes was collected in a study, we selected the measure that relied on patient report or satisfaction, rather than therapist report or frequency measures. Studies that only included measures of home-level outcomes and no measures of community-level outcomes were excluded from this portion of the analysis.

2.3 Results

2.3.1 Study Characteristics

Our initial search found 4,636 studies. After reviewing titles, abstracts, and full texts, we identified 39 studies that met criteria. Figure 3 details the reasons for exclusion at each stage of review. Table 1 and Table 2 summarize the included studies. The 39 studies recruited participants with traumatic brain injury (TBI) only (n=23), stroke only (n=10), or participants with any acquired brain injury (ABI) (n=6). Studies included participants in the acute stage of recovery (n=15), chronic stage of recovery (n=18), or regardless of chronicity (n=4). Two studies did not specify the time since injury of included participants. Twenty-one of the thirty-nine studies examined interventions delivered in an outpatient or research laboratory (n=13) or inpatient rehabilitation setting (n=8). The most frequently employed comparison condition was usual care (n=19), followed by active control interventions (n=10) and no control intervention (n=10). Eleven studies (28.2%) had a low risk of bias and the remaining 28 (71.8%) had a high risk of bias

(Appendix B). The most common sources of bias were lack of blinding and limited reporting on allocation concealment.

The included studies examined effect sizes of intervention on 20 different activity or participation outcome measures. The studied outcome measures most frequently assessed performance of home and community activities, or the burden of care required for performance of those activities. The most common outcome measure examining home-level outcomes was the Functional Independence Measure (n=8), and the most common outcome measure examining community-level outcomes was the Community Integration Questionnaire (n=7). There was only one study that examined participation using a measure of inclusion and belonging and data were not provided for this study (51). Therefore, we analyzed results of intervention elements on home and community activity outcomes. Table 3 summarizes outcome measures and their frequency of use. Full data from included studies are available (Appendix C).

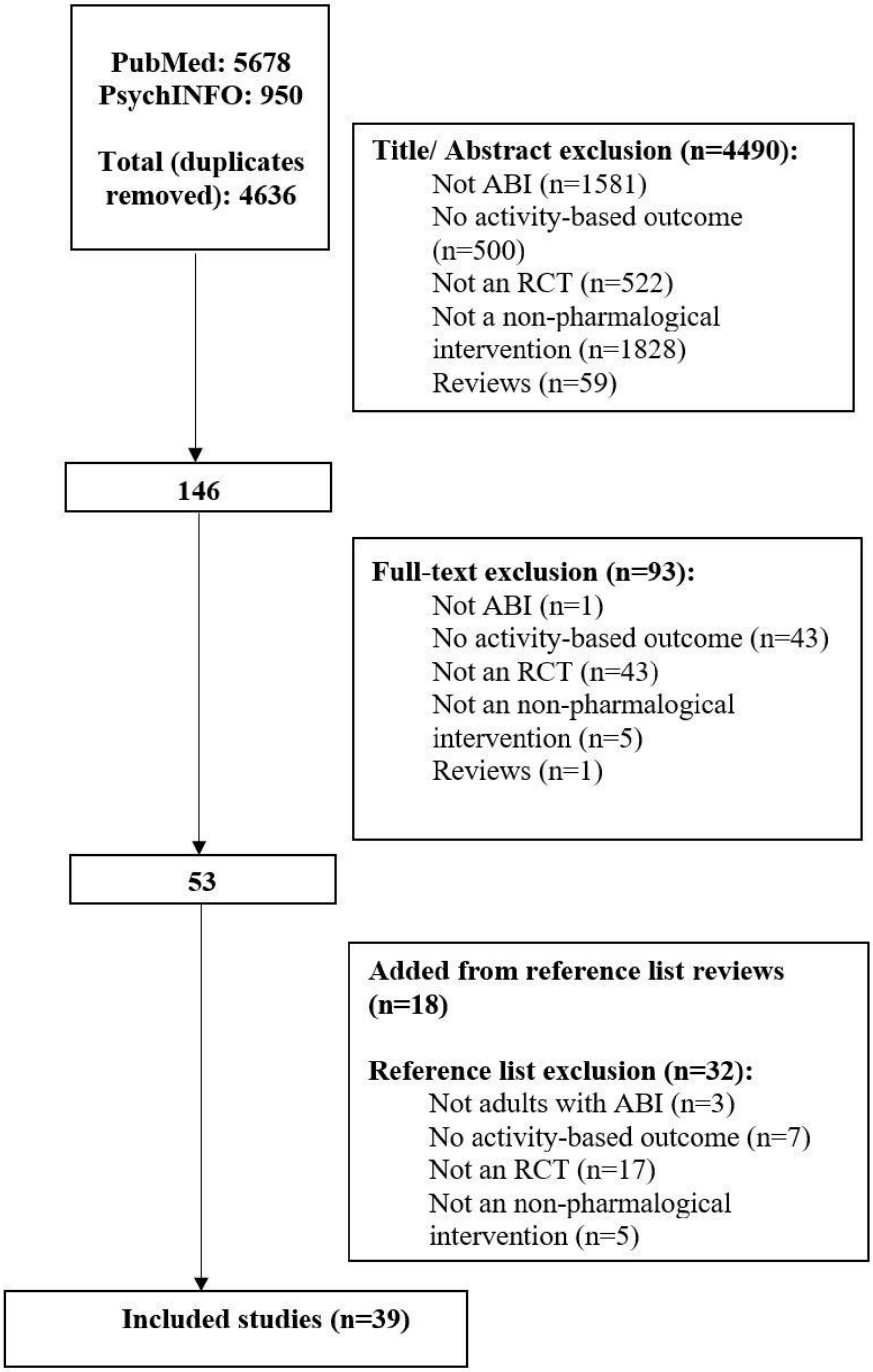

Figure 3. Flow Chart

Table 1. Summary of Identified Studies

Citation	Sample	Chronicity	Comparator	Baseline	Follow-up	Outcome Measure(s)
			Inpatient Rehabilitation Interventions			
Bovend'Eerdt, T. (2010)	30 adults with CNS disorders (stroke, TBI, MS)	Acute	Usual Care	Admission to inpatient rehabilitation	6 weeks 12 weeks	Barthel Index Nottingham Extended ADL Scale
Cheng, S. (2006)	46 adults with TBI	Acute	Usual Care	Admission to inpatient rehabilitation	Discharge	Functional Independence Measure Lawton IADL
Skidmore, E. (2015)	30 adults with acute stroke	Acute	Control Intervention	Admission to inpatient rehabilitation	3 months 6 months	Functional Independence Measure
Skidmore, E. (2017)	41 adults with stroke	Acute	Usual Care	Admission to inpatient rehabilitation	3 months 6 months 12 months	Functional Independence Measure
Trevena-Peters, J. (2018)	104 adults with TBI	Acute	Usual Care	Admission to inpatient rehabilitation	Discharge 2 months	Functional Independence Measure Community Integration Questionnaire
Vanderploeg, E. (2008)	366 Veterans with moderate to severe TBI	Chronic	Control Intervention	Pre-intervention	1 year	Return to work
Wang, T. (2007)	44 adults with stroke	Acute	Usual Care	Admission to inpatient rehabilitation	4 weeks	Barthel Index
Wilson, D. (2006)	40 adults with TBI	Acute	Usual Care	Admission to inpatient rehabilitation	8 weeks	Functional Independence Measure
			Home Interventions			
Bell, L. (2005)	171 adults with moderate-severe TBI	Acute	Usual Care	Admission to inpatient rehabilitation	1 year	Functional Independence Measure Community Integration Questionnaire
Bell, K. (2011)	433 adults with moderate-severe TBI	Acute	Usual Care	Admission to inpatient rehabilitation	2 years	Functional Independence Measure Participation Measure with Recombined Tools-Objective
Bourgeois, M. (2007)	51 adults with chronic TBI	Chronic	Control Intervention	Pre-intervention	1 week 1 month	Community Integration Questionnaire
Lundqvist, A. (2010)	21 adults with ABI	Chronic	No Intervention	Pre-intervention	20 weeks	Canadian Occupational Performance Measure

Table 1 continued

Tefertiller, C. (2019)	63 adults with severe TBI	Chronic	Usual Care	Pre-intervention	6 weeks 12 weeks 24 weeks	Participation Measure with Recombined Tools-Objective
			Clinic Interventions			
Brenner, L. A. (2012)	74 adults with chronic TBI	Chronic	No Intervention	Pre-intervention	3 months 6 months	Participation Measure with Recombined Tools-Objective
Cantor, J. (2014)	98 adults with TBI	Chronic	No Intervention	Not specified	12 weeks	Participation Objective Participation Subjective
Cicerone, K. (2008)	69 adults with TBI	Chronic	Usual Care	Pre-intervention	4 months 10 months	Community Integration Questionnaire
Dahlberg, C. A. (2007)	52 adults with chronic TBI	Chronic	No Intervention	Pre-intervention	3 months	Community Integration Questionnaire Craig Hospital Assessment and Reporting Technique
das Nair, R. (2012)	72 adults with ABI	Both	Control Intervention	Not specified	5 months 7 months	Nottingham Extended ADL Scale
Goverover, Y. (2007)	20 adults with ABI	Both	Usual Care	Pre-intervention	3 weeks	Community Integration Questionnaire
Guidetti, S. (2011)	40 adults with stroke	Acute	Usual Care	Pre-intervention	3 months 12 months	Stroke Impact Scale- Participation
Hanks, R. A. (2012)	96 adults with TBI	Acute	No Intervention	Pre-intervention	1 year	Community Integration Measure
Hart, T. (2017)	8 adults with moderate to severe TBI	Chronic	Control Intervention	Pre-intervention	2 months	Participation Measure with Recombined Tools-Objective
McDonald, S. (2008)	51 adults with chronic TBI	Chronic	Control Intervention	Pre-intervention	12 weeks	Sidney Psychosocial Reintegration Scale
O'Connor, M. (2016)	18 Veterans with mild TBI	Unspecified	Control Intervention	Pre-intervention	1 year	Employment Status
Rath, J. (2003)	60 adults with TBI	Chronic	Usual Care	Pre-intervention	3 months 6 months	Community Integration Questionnaire
Trexler, L. (2016)	44 adults with ABI	Unspecified	Control Intervention	Pre-intervention	15 months	Mayo-Portland Adaptability Index- Participation

Table 1 continued

			Community Interventions			
Corr, S. (2004)	26 adults with chronic stroke	Chronic	No Intervention	Pre-intervention	6 months 12 months	Canadian Occupational Performance Measure Nottingham Extended ADL Scale Nottingham Leisure Questionnaire
Powell, J. (2002)	112 adults with severe TBI	Both	Usual Care	Pre-intervention	12 weeks	Barthel Index Functional Independence Measure Brain Injury Community Rehabilitation Outcome
Struchen, M. (2011)	45 adults with TBI	Both	No Intervention	Pre-intervention	3 months	Craig Hospital Assessment and Reporting Technique
Wolf, T. (2016)	185 adults with stroke	Chronic	Wait List Control	Pre-intervention	3 months 6 months 9 months	Community Participation Indicators Reintegration to Normal Living Index Stroke Impact Scale
			Multiple Settings			
Bertens, D. (2015)	67 adults with TBI and executive dysfunction	Chronic	Control Intervention	Pre-intervention	8 weeks	Everyday task performance Goal Attainment Scaling
Dawson, D. (2013)	13 adults with chronic TBI	Chronic	Control Intervention	Pre-intervention	10 weeks	Mayo-Portland Adaptability Index- Participation Canadian Occupational Performance Measure
Kessler, D. (2017)	21 adults with stroke	Acute	Usual Care	Pre-intervention	6 months 12 months	Reintegration to Normal Living Index Canadian Occupational Performance Measure
Langhammer, B. (2008)	75 adults with stroke	Acute	Usual Care	Pre-intervention	3 months 6 months 12 months	Barthel Index
Langhammer, B. (2014)	37 adults with stroke	Acute	Usual Care	Pre-intervention	4 years	Barthel Index
Ownsworth, T. (2008)	84 adults with ABI	Chronic	Control Intervention	Pre-intervention	8 weeks 3 months	Canadian Occupational Performance Measure

Table 1 continued

Polatajko, H. (2012)	20 adults with stroke	Chronic	Usual Care	Pre-intervention	5 weeks	Canadian Occupational Performance Measure
			Unspecified Setting			
Tiersky, L. A. (2005)	29 adults with mild-moderate TBI	Chronic	No Intervention	Pre-intervention	3 months 4 months 7 months	Community Integration Questionnaire
Scheenen, M. (2017)	91 adults with mild TBI	Acute	Usual Care	Pre-intervention	3 months 6 months 12 months	Return to work

Table 2. Synthesis of study characteristics

	n=39
Chronicity, n(%)	
Acute	15 (38.5%)
Chronic	18 (46.2%)
Both	4 (10.3%)
Unspecified	2 (5.1%)
Diagnosis, n(%)	
TBI only	23 (59.0%)
Stroke only	10 (25.6%)
All ABI	6 (15.4%)
Setting, n(%)	
Inpatient	8 (20.5)
Home	5 (12.8%)
Clinic	13 (33.3%)
Community	4 (10.3%)
Multiple	7 (17.9%)
Unspecified	2 (5.1%)
Comparators, n(%)	
Usual Care	19 (48.7%)
Control	10 (25.6%)
No intervention	10 (25.6%)

TBI: Traumatic Brain Injury; ABI: Acquired Brain Injury

Table 3. Outcome Measures

Outcome Measures	n
Functional Independence Measure	8
Community Integration Questionnaire	7
Barthel Index	5
Canadian Occupational Performance Measure	5
Participation Assessment with Recombined Tools	4
Employment Status	3
Craig Hospital Assessment and Reporting Technique	2
Nottingham Extended ADL Questionnaire	2
Stroke Impact Scale Participation	2
Reintegration to Normal Living Index	2
Brain Injury Community Rehabilitation Outcome	1
Goal Attainment Scaling	1
Nottingham Leisure Questionnaire	1
Participation Objective Participation Subjective	1
Lawton Instrumental Activities of Daily Living	1
Community Integration Measure	1
Sydney Psychosocial Reintegration Scale	1
Mayo-Portland Adaptability Index- Participation Index	1
Vocational Independence Scale-Revised	1
Community Participation Indicators	1

2.3.2 Thematic Analysis

The included studies examined a broad range of interventions. We characterized these intervention elements using the following classifications: metacognitive interventions, behavioral interventions, cognitive training interventions, social skills interventions, daily life skills interventions, peer mentoring, job coaching/vocational skills interventions, physical activity interventions, education/resource facilitation, and support/encouragement (Table 4 provides definitions used to support classification). Classification of study interventions was not mutually exclusive; in fact, all but 8 studies examined interventions containing more than one element. Metacognitive interventions were present in the most studies (n=22), followed by daily life skills interventions (n=20). Job coaching/vocational skills interventions were present in the fewest (n=3).

Table 4. Intervention Elements

Intervention Elements	n	Description/Examples
Metacognitive Strategies	22	Use of an explicit strategy to structure approach to task completion; incorporates problem-solving, self-assessment, self-monitoring, self-management, goal-setting, generalization of skills
Behavioral Strategies	10	Cognitive Behavioral Therapy (CBT), Motivational Interviewing, other types of psychoeducation
Cognitive Strategies	10	Cognitive remediation, errorless learning, rote practice of cognitive tasks
Social Skills Training	7	Participants are trained in mechanics of social interaction
Daily Life Skills Training	21	Daily activities are completed within the intervention session; incorporates task-specific and activity-based training; compensatory strategies for completing daily activities
Job Coaching, Vocational Skills Training	3	Vocational rehabilitation; strategies for successful job acquisition and performance
Physical Activity Training	6	Exercise, motor control interventions, gait training
Education, Resource Facilitation	9	Therapist-directed teaching, identification of relevant supports and resources; case management
Support, Encouragement, Mentoring	10	Support or encouragement are provided to encourage participation in activities; mentoring may be provided by therapist, peer, or other expert

2.3.3 Effect sizes of intervention element on activity-based outcomes

Metacognitive interventions included elements of problem-solving, self-monitoring or self-assessment, self-management, metacognitive strategies (most frequently, goal-plan-do-check), goal-setting, and explicit strategies for generalization of new skills. The 22 studies that examined metacognitive interventions included a total of five measures of home-level outcomes and 29 measures of community-level outcomes. Four studies did not report effect sizes or data for activity measures (51-54). Effect sizes ranged from .08 to 2.9. When considering all available activity outcome measures, seven (20.6%) resulted in negligible effect sizes (55-59), 10 (29.4%) resulted in small effect sizes (35, 56, 60-65), six (17.6%) resulted in moderate effect sizes (61, 63, 66, 67), and 11 (32.4%) resulted in large effect sizes (56, 61, 67-71).

Ten studies examined behavioral interventions, which included elements of cognitive behavioral training (CBT), motivational interviewing, or other forms of psychoeducation. Combined, these studies examined effect sizes on one measure of home-level outcomes and nine measures of community-level outcomes. Two studies did not report effect sizes or data for activity outcomes (34, 54). Effect sizes ranged from .04 to .98. When considering all available activity outcomes, five (50.0%) resulted in negligible effect sizes (58, 72-74), four (40.0%) resulted in small effect sizes (35, 60, 64), and one (10.0%) resulted in a large effect size (70).

Studies of cognitive training interventions included interventions incorporating elements of cognitive remediation, computerized cognitive training, and errorless learning to train cognitive skills or compensatory strategies using a rote practice approach. Ten studies examined cognitive training using two measures of home-level outcomes and 13 measures of community-level outcomes. All studies reported effect sizes or data for activity outcomes. Effect sizes ranged from .04 to 1.76. When considering the 15 outcome measures, two (13.3%) resulted in a negligible effect size (74, 75), seven (46.7%) resulted in small effect sizes (35, 61-64, 76, 77), four (26.7%) resulted in moderate effect sizes (36, 61, 63, 77), and two (13.3%) resulted in large effect sizes (36, 61).

Eight studies examined social skills interventions, which focused on training participants in mechanics of social interaction. None of these studies included measures of home-level outcomes. Eleven measures of community-level outcomes were used across studies. One study did not report effect sizes or data for activity outcomes (54). Effect sizes ranged from .00 to .98. Of the 11 outcome measures, six (54.5%) resulted in negligible effect sizes (56, 58, 72, 73, 78), three (27.3%) resulted in small effect sizes (56, 64), and two (18.2%) resulted in large effect sizes (56, 70).

Studies examining daily life skills interventions included intervention elements incorporating activity-based training, task-specific training, and training on compensatory strategies for completing daily activities or other activity-based goals. Twenty studies examined the effect sizes of daily life skills interventions, using four measures of home-level outcomes and 28 measures of community-level outcomes. One study did not report effect sizes or data for activity outcome measures (51). Effect sizes ranged from .00 to 1.86. Of the 32 outcome measures, nine (28.1%) resulted in negligible effect sizes (57-59, 73-75, 78, 79), 10 (31.3%) resulted in small effect sizes (35, 61-63, 65, 76, 77, 79), seven (21.9%) resulted in moderate effect sizes (61, 63, 66, 67, 77), and six (18.8%) resulted in large effect sizes (61, 67, 68, 71).

Peer mentoring interventions involved learning through peer education or feedback, modeling, observation of peers, and group problem-solving. Six studies examined peer mentoring interventions with a total of seven measures of community-level outcomes. No studies examined the effect of peer mentoring interventions on home-level outcomes. Two studies did not report effect sizes or data for activity outcomes (51, 52). Effect sizes ranged from .00 to .72. Of the seven outcome measures, three (42.9%) resulted in negligible effect sizes (56, 72, 78), three (42.9%) resulted in small effect sizes (56, 64), and one (14.3%) resulted in a large effect size (56).

Three studies examined job coaching or vocational skills interventions. These studies examined vocational rehabilitation approaches or training on strategies for successful job acquisition and performance. These studies included two measures of community-level outcomes and no measures of home-level outcomes. One study did not have data available for calculation of effect sizes (34). Of the two measures of community-level outcomes, one (50.0%) resulted in a negligible effect size (73) and one (50.0%) resulted in a small effect size (64). No studies resulted in moderate or large effect sizes.

Physical activity interventions included interventions addressing motor control, gait training, or exercise. Six studies examined physical activity interventions, using five measures of home-level outcomes and one measure of community-level outcomes. One study did not report effect sizes or data for activity outcome measures (80). Effect sizes ranged from .00 to .35. Of the six outcome measures, four (66.7%) resulted in negligible effect sizes (81-83) and two (33.3%) resulted in small effect sizes (84, 85). No studies resulted in moderate or large effect sizes.

Studies of education or resource facilitation included interventions incorporating therapist-directed teaching, structured education, identification of relevant resources and supports, or formal case management. Eleven studies examined this category of interventions using three measures of home-level outcomes and 12 measures of community-level outcomes. Two studies did not report effect sizes (51, 52). Effect sizes ranged from .00 to .70. Of the 15 outcome measures, eight (53.3%) resulted in negligible effect sizes (55, 58, 72, 73, 78, 86), three (20.0%) resulted in small effect sizes (60, 63), and four (26.7%) resulted in moderate effect sizes (63, 66).

Six studies examined broad types of support or encouragement provided by a therapist, using two measures of home-level outcomes and nine measures of community-level outcomes activities. One study did not report effect sizes or data for activity outcomes (53). Effect sizes ranged from .10 to 2.9. Of the 11 outcome measures, two (18.2%) resulted in negligible effect sizes (55), three (27.3%) resulted in small effect sizes (60, 64), three (27.3%) resulted in moderate effect sizes (66), and three (27.3%) resulted in large effect sizes (69).

In summary, the 39 included studies addressed a broad range of intervention elements. Of these, metacognitive interventions, daily life skills interventions, and support/encouragement resulted in the highest frequency of large effect sizes, suggesting that these may play an important role in addressing home and community activity outcomes following ABI. Physical activity interventions resulted in the poorest overall outcomes, suggesting that physical activity alone may be insufficient to achieve meaningful changes in home and community activity outcomes.

2.3.4 Effect sizes by time

Figure 4 illustrates the effect sizes of interventions on all home and community outcomes based on the time of follow-up assessments. Most frequently, outcomes were assessed within 6 months of study admission with another cluster of assessments completed one year following study admission. Effect sizes were largest 1-6 months from study admission, with no large effect sizes and only two moderate effect sizes seen beyond 6 months. (Both moderate effect sizes were seen at one year and both were associated with studies of metacognitive strategies). It is possible that the decrease in effect sizes after 6 months was due to the lower number of studies examining outcomes beyond 6 months. However, this may also suggest that the included interventions may be associated with improved outcomes in the short term but may not be sufficiently potent to achieve lasting change. It may also suggest that interventions that address home and community activity outcomes may need to include the securing of long-term, reliable support.

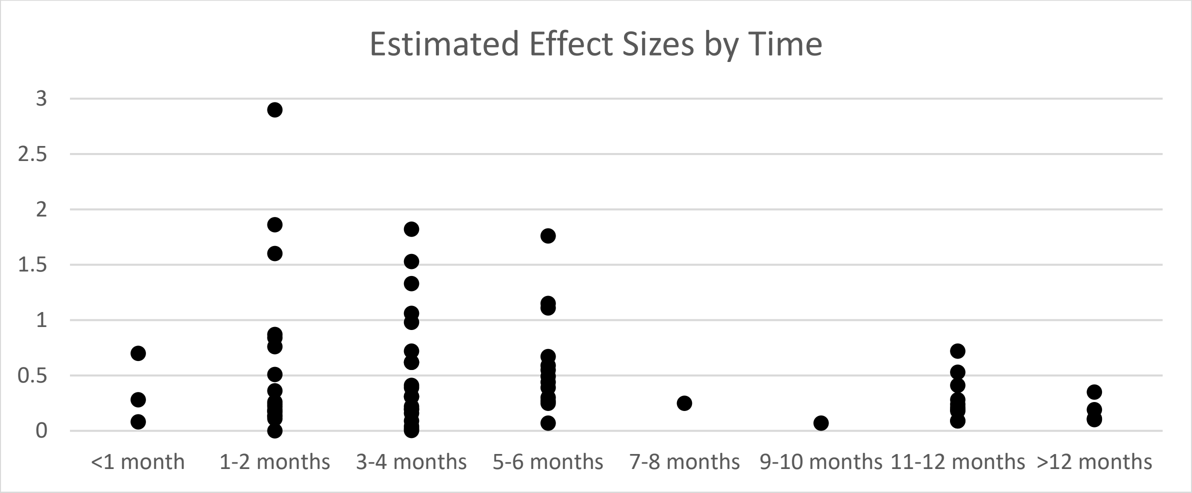

Figure 4. Effect sizes by Time

2.3.5 Effect sizes on home activities

Our analysis of home-level outcomes is presented in Table 5. When considering studies that assessed home-level outcomes (n=12), metacognitive interventions and physical activity interventions were the most prominent (n=5), followed by daily life skills interventions (n=4). No studies examining home-level outcomes used social skills interventions or vocational skills interventions, which is unsurprising considering the community nature of social activities and work. Overall, there were few studies in each category, in some instances making thematic synthesis difficult.

Metacognitive interventions and daily life skills interventions had the broadest range of effect sizes. Daily life skills interventions had the largest proportion the total sample in a study with large effect sizes (13.6%). The only other intervention element associated with large effect sizes was metacognitive interventions (4% of the total sample). Daily life skills interventions (47.1%) and cognitive training interventions (69.3%) were the only intervention elements to result in moderate effect sizes. Support and encouragement (60.5%) and education and resource facilitation (66.6%) were mostly associated with negligible effect sizes and no moderate or large effect sizes in home-level outcomes.

Most intervention elements were associated with studies that had high rates of heterogeneity ranging from 17% to 100%. Physical activity interventions and support and encouragement had the highest rates of heterogeneity (100%), suggesting that the studies included in each category may be too different to reasonably be combined. Still, each of these was associated with only negligible or small effect sizes, suggesting that interventions that even fall loosely within these two categories may be insufficient to achieve change in performance of home-level outcomes.

In summary, daily life skills interventions appear to show the greatest promise for improving independence in home-level outcomes. Metacognitive interventions and cognitive training interventions may also show promise. These results should be interpreted cautiously in light of the small number of studies included in this portion of the analysis.

Table 5. Effect sizes of intervention elements on home activities

Active Ingredient	# of studies	Sample size	I^2	Range of Effect sizes	Magnitude of Effect Sizes: Not Reported	Negligible (d<.2)	Small (d=.2-.5)	Moderate (d=.5-.8)	Large (d>.8)
Metacognitive Training	5	833	56.1%	.10-1.06	13.4%	56.9%	26.1%		4
Behavioral Training	1	171	-	.21			100.0%		
Cognitive Training	2	150	17.1%	.26-.75			30.7%	69.3%	
Daily Life Skills Training	4	221	71.5%	.16-1.06		18.6%	20.8%	47.1%	13.6%
Physical Activity Training	5	226	100%	0-.35		50.4%	49.6%		
Education, Resource Facilitation	3	650	73.4%	.10-.26		66.6%	33.4%		
Support, Encouragement, Mentoring	2	716	100%	.10-.21	15.6%	60.5%	23.9%		
Total	12	1163	-	0-1.06	9.6%	50.6%	28.2%	8.9%	3

2.3.6 Effect sizes on community activities

Our analysis of community-level outcomes is presented in Table 6. When considering only studies that included a measure of community-level outcomes (n=31), metacognitive interventions were still examined by the largest number of studies (n=20) followed by daily life skills interventions (n=17). Physical activity interventions (n=2) and vocational skills interventions (n=3) were examined by the fewest studies. In fact, physical activity was examined by only one study with effect sizes available, and vocational skills interventions were examined by only two studies with effect sizes available, thus limiting our understanding of the generalizability of these results.

All categories of intervention elements showed wide ranges of effect sizes. Social skills interventions had the largest proportion of the total sample associated with large effect sizes (10.7%), but also had a high proportion with negligible effect sizes (51.2%) suggesting mixed results. Behavioral interventions were also associated with high proportion of participants with large effect sizes (6.7%), followed by metacognitive interventions (5.8%), and daily life skills interventions (3.6%). Physical activity interventions and vocational skills interventions showed the least promise, with only negligible effects reported. Peer mentoring and vocational skills interventions also showed the weakest results, with only negligible and small effect sizes. However, the studies associated with all three of these intervention elements had few included studies and high rates of missing data. Further study is required.

Among studies of community-level outcomes, I^2 statistics ranged from 48.9% to 100%. Several intervention elements had high heterogeneity, including vocational skills training (100%), metacognitive interventions (83.4%) and cognitive interventions (81.0%). This is unsurprising considering the variation in sample sizes, outcome measures, and effect sizes across studies. Those intervention elements that may be considered more complex (metacognitive interventions, cognitive interventions) had larger I^2 values than less complex intervention elements (education/resource facilitation, support/encouragement).

In summary, when considering community-level outcomes social skills interventions, behavioral interventions, metacognitive interventions, and daily life skills interventions all show some promise. Physical activity interventions and vocational skills interventions showed the least promise, but also the least amount of data. However, all analyses revealed a wide range of effect sizes and the true effectiveness of these intervention elements are unclear.

Table 6. Effect sizes of intervention elements on community activities

Active Ingredient	# of studies	Sample size	I^2	Range of Effect Sizes	Magnitude of Effect Sizes: Not Reported	Negligible (d<.2)	Small (d=.2-.5)	Moderate (d=.5-.8)	Large (d>.8)
Metacognitive Training	20	1675	82.4%	.04-1.82	25.7%	32.1%	32.7%	3	6.8
Behavioral Training	8	658	73.5%	.04-.98	9.1%	31.8%	51.4%		7.8%
Cognitive Training	9	557	80.6%	.04-1.76		23.9%	64.1%	8.3%	4
Social Skills Training	6	388	64.2%	.003-.98	15.5%	58.0%	13.4%		13.1%
Daily Life Skills Training	17	990	74.5%	.003-1.82	18.7%	28.5%	42.7%	5	6
Job Coaching, Vocational Skills	3	178	-	.31	61.2%	38.8%			
Physical Activity Training	2	93	-	.13	67.7%	32.3%			
Education, Resource Facilitation	10	1199	64.6%	.003-1.15	21.6%	58.6%	14.3%	4	2
Support, Encouragement, Mentoring	10	1207	62.3%	.003-1.15	24.6%	53.5%	18.5%		2
Total	31	2255	-	.003-1.82	26.4%	37.4%	28.3%	2	5.9

2.4 Discussion

We aimed to examine interventions addressing community participation but the included articles for the most part examined interventions addressing performance of home and community activities. The distinction between community participation and the performance of home and community activities is important. Personal values and priorities, contextual factors, and social connection are important elements of community participation, as are the sense of belonging and inclusion (5, 28, 87). Performance of activities in the home and community on its own does not necessarily signify community participation. Rather, in qualitative studies, people with disabilities have revealed that a sense of belonging and inclusion in society is a more important component of community participation than performance of community activities per se (5). Few of the measures of community-level activities included in this review assess these important components of community participation, and instead focus on the performance of community activities alone.

This suggests an important shortcoming in measurement of participation. In light of the critical input from stakeholders gleaned from qualitative studies, it is clear that our measures of participation are limited in scope and rarely reflect the values of stakeholders in regards to community participation (5). To illustrate this point, the most commonly used measure of community-level outcomes in this review was the Community Integration Questionnaire. While this is often considered to be the gold standard in measurement of community participation, the measure examines specific community activities, but not satisfaction, sense of belonging, or inclusion in society. While we prioritized measures of satisfaction over measures of frequency of or burden required for community activity performance, few of the included measures assessed the sense of belonging and inclusion. Ultimately, our ability to understand the implications of our results for comprehensively addressing community participation is limited by the assessment tools used in the included studies. Future studies may include measures that assess inclusion in society, such as the Enfranchisement Scale of the Community Participation Indicators (51, 88), to better understand the effect of interventions on a broader range of community participation outcomes.

That said, it is reasonable to expect that some of the intervention elements that appear to be the most promising for improving community activities may also hold potential for improving holistic community participation outcomes. Across all analyses, daily life skills interventions and metacognitive interventions showed the greatest promise for influencing activity and participation outcomes following brain injury, while physical activity interventions, education, and resource facilitation showed the least promise. This suggests that activity-focused interventions may have more potential for improving activity and participation outcomes than providing education or addressing the underlying injury-related impairments. That said, all intervention elements resulted in wide ranges of effect sizes, and most studies resulted in negligible or small effect sizes. Additionally, most included studies were small pilot or feasibility studies, limiting the generalizability of the results. Therefore, while daily life skills interventions and metacognitive interventions show promise, more evidence is needed to better understand the broader effectiveness of these interventions. Similarly, more evidence is needed to understand the roles of activity-focused interventions and impairment-focused interventions in achieving holistic rehabilitation outcomes.

Our analysis revealed that the optimal intervention elements may depend on the outcome of interest. Our overall analysis of activity and participation outcomes revealed similar patterns, but ultimately different results than our analyses of home-level and community-level outcomes, separately. Social skills interventions were associated with improvements in community outcomes; this makes sense considering the social nature of many community activities. Similarly, education, resource facilitation and support, and encouragement were also associated with in community outcomes, which may emphasize the importance of social supports and services in improving access to and performance of community-level activities. Cognitive training interventions were associated with improvements in home outcomes. This may suggest that cognitive training interventions are useful in addressing performance of cognitive instrumental activities of daily living such as medication management, meal preparation, and financial management in the home, but are less useful for socialization and leisure activities in the community. Performance of community-level activities may be more heavily influenced by social and environmental factors and performance of home-level activities may be more heavily influenced by cognitive impairments. This has important implications for rehabilitation practice. Different approaches may be needed for addressing home-level activities such as self-care, and home management than are needed for the dynamic and complex factors that affect performance of community-level activities.

An important finding of this study was that the magnitude of effect sizes seemed to decrease after six months. This may have been because several of the studies with the largest effect sizes were feasibility studies without long-term follow-up. It is also possible that longer periods of follow up (greater than one year) are needed to achieve significant change in activity and participation outcomes, particularly to achieve patterns of greater engagement in community activities. However, it should be considered that meaningful changes seen immediately following intervention are not maintained over the long-term. This may suggest that most of the studied interventions are not potent enough to lead to long-term change, and higher dosages are required.

There may be an important role for booster sessions in rehabilitation practice to promote long-term behavior change and maintenance of learned skills. Few studies examine the effects of booster sessions, but these show promising results for clinical feasibility and maintenance of effects (89-93). Studies have examined booster sessions in a range of behavioral interventions, cognitive interventions, and physical activity interventions, but the feasibility and effectiveness of booster sessions for daily skills interventions and metacognitive interventions are unclear. Future studies of these interventions may explore the role of booster sessions and whether they can contribute to better long-term outcomes.

2.4.1 Study Limitations

This review had several limitations. First, most of the included studies were feasibility studies with small sample sizes. Several of these studies showed moderate-large effect sizes that were clinically meaningful but not statistically significant. It is possible that these studies were under-powered and that larger sample sizes would have led to statistical significance. However, it is also possible that feasibility studies had favorable inclusion criteria and intervention protocols, and that larger effectiveness studies may not show similar effects (94, 95). This is particularly evident in the examination of support and encouragement, which showed promising effects when simply looking at the overall effect sizes but showed less promise when weighting effect sizes by sample size in our sub-analyses. Second, several of the examined intervention categories showed high rates of heterogeneity. It is possible that interventions included in each category of intervention elements were not similar enough to reliably compare. This precluded our ability to conduct a more rigorous synthesis, such as a meta-analysis. Differences across studies in time of follow up, number of follow ups, number and type of assessment tools, and sample sizes make direct comparison difficult. That said, a strength of this study is the multiple approaches to summarizing the data to account for these differences.

Finally, the results of this study are based on the available RCTs in the brain injury rehabilitation literature. Other bodies of literature suggest additional intervention elements that may serve to improve community participation following brain injury, and these require additional exploration. For example, social learning was not well-represented in this study, but may show promise for improving community participation outcomes. It has been explored in similar populations and promising outcomes, and may be relevant to brain injury rehabilitation (96, 97).Similarly, elements of supported employment have been explored in brain injury research, but few RCTs are available (98, 99). Studies examining methods for improving empowerment may also reveal insights into approaches for improving community participation outcomes (100, 101). Future research may explore these and other intervention elements which have been examined with different study designs and target populations for their effectiveness on improving community participation outcomes after brain injury.

2.4.2 Conclusions

In conclusion, we found that when broadly addressing activity and participation outcomes, daily life skills interventions and metacognitive interventions resulted in the strongest effect sizes. When specifically addressing home-level outcomes, daily life skills training, metacognitive training, and cognitive training show the most promise. When specifically addressing community-level outcomes, social skills interventions, behavioral interventions, daily life skills interventions and metacognitive interventions all show promise. These results can guide rehabilitation practitioners in selecting the optimal approach to treatment depending on the client's individual goals, needs, and supports. These results can also guide rehabilitation researchers in fine-tuning intervention approaches for activity-based outcomes over time. Larger studies are needed to better understand the effectiveness of the interventions examined. A broader range of outcome measures assessing the full scope of participation are needed to better understand the optimal approach to comprehensively address participation outcomes.

3.0 Construct validity and severity measurement properties of the Enfranchisement Scale of the Community Participation Indicators

This chapter describes an analysis of previously collected data that aimed to establish construct validity and clinically meaningful cut points of the Enfranchisement Scale of the Community Participation Indicators. This chapter has been developed into a manuscript that is under review by a rehabilitation research journal.

3.1 Introduction

Rehabilitation researchers have frequently conceptualized community participation as a person's ability to engage in meaningful activities within their communities (15, 28, 87). Community participation is difficult to measure (15, 16). Measurement approaches have focused on the *frequency* with which people engage in specific community, work, or social activities; or the *difficulty* that they experience with those activities (14). However, qualitative studies have revealed that people with disabilities view community participation as a sense of inclusion and membership within the community (5). These concepts are not well-represented in current measures of community participation.

Hammel and colleagues labeled this sense of inclusion or membership in the community as "enfranchisement" (5, 102). Enfranchisement encompasses choice and control in community participation, feeling valued by the community, and contributing to the community (5). Enfranchisement, the sense of inclusion in society, may be a distinct, more meaningful measure of community participation, than frequency of activities. Guided by these findings, Heinemann and colleagues developed the Enfranchisement Scale of the Community Participation Indicators (CPI), to assess this important dimension of community participation (102).

The Enfranchisement Scale of the CPI was developed using Rasch analysis in a sample of adults with disabilities (23, 102). Prior to Rasch analysis, this team conducted a factor analysis that revealed two factors within the Enfranchisement Scale: Control and Importance (23). The Control subscale measures the sense of choice and control. The Importance subscale measures the feelings of being valued by the community and contributing to the community. Both subscales demonstrated good reliability and discriminated between groups based on disability severity (23).

Additional research is needed to inform the interpretation of these subscales. While Heinemann et al. established that the subscales of the Enfranchisement Scale can discriminate between groups based on disability severity, convergent and discriminant validity must be established to understand what each subscale is measuring. Additionally, we do not know whether there are clinically meaningful cut points that would indicate when enfranchisement is restricted enough to warrant clinical intervention. Without a better understanding of the scale’s construct validity and cut points, interpretation of results is limited. Therefore, the purpose of this analysis was to establish construct validity (convergent and discriminant validity) and clinically meaningful cut points for each Enfranchisement subscale of the CPI.

3.2 Methods

3.2.1 Participants

We conducted a secondary analysis of data collected in a cross-sectional study of community-dwelling adults with a diagnosis of stroke, traumatic brain injury (TBI), or spinal cord injury (SCI)(103, 104). Inclusion criteria were age at least 18 years old, one year or more post-injury, and fluency in English. Details of inclusion criteria based on medical diagnosis and severity can be found in an earlier report (103, 104). Participants were recruited through research registries and flyers in three Midwestern cities. Research procedures were approved by the Institutional Review Board.

3.2.2 Measures

The Enfranchisement Scale contains two subscales: Control and Importance. The Control subscale contains 13 items (raw score range 13-65) and the Importance subscale contains 14 items (range 14-70). Each item is scored on a 5-point Likert scale, with lower scores indicating greater enfranchisement. Subscale scores are computed by summing responses to each item. While previous studies of this measure have used Rasch analysis, in this study we used classical test theory methods and subscale raw scores to conduct the analyses, consistent with best practices in convergent and discriminant validity methods (105).

Table 7. Measures

Measure	Description
CPI Enfranchisement-Control	12-item assessment of the degree of sense of choice and control in community participation; range 12-65, lower scores are better
CPI Enfranchisement-Importance	12-item assessment of the degree of meaningful community participation; range 13-70, lower scores are better
PROMIS Ability to Participate in Social Roles and Activities	Computer Adapted Test of participation abilities. Reported as t-scores, but with lower scores indicating better ability to participate in social roles and activities.
PROMIS Satisfaction with Participation in Social Roles and Activities	Computer Adapted Test of satisfaction with participation. Reported as t-scores, but with lower scores indicating greater satisfaction with participation.
IADL	11-item measure of difficulty performing IADLs; range 11-34; lower scores indicate better IADL performance
Perceived Social Support	16-item measure of social support; range 16-80; higher scores indicate greater social support
CHIEF	12-item measure of environmental barriers and the severity of their impact on daily functioning.
PROMIS Depression	4-item questionnaire examining depressive symptoms; range 4-20, lower scores indicate fewer depressive symptoms
PROMIS Physical Function	4-item questionnaire examining difficulty with physical activities; range 4-20, higher scores indicate greater function
NIH Toolbox Cognition	Age-corrected composite score integrating scores from subtests examining performance in a range of cognitive domains. Reported as t-score, with higher scores indicating better cognitive performance.
Environmental Factors Item Bank	5 subtests each measuring a different domain of the environment. Higher scores indicate greater environmental barriers.

CPI: Community Participation Indicators; IADL: Instrumental Activities of Daily Living; CHIEF: Craig Hospital Inventory of Environmental Factors; NIH: National Institutes of Health

To evaluate construct validity, we included measures which span the domains of the *ICF*, including measures of participation, activity, impairment, and environment. The PROMIS Ability to Participate in Social Roles and Activities and the PROMIS Satisfaction with Participation in Social Roles and Activities (Computer Adapted versions) assess participation (106, 107). The Craig Hospital Inventory of Environmental Factors (CHIEF) assesses environmental factors and their degree of influence on daily function (108). The PROMIS Depression and Physical Function scales measures emotional status and the influence of physical impairments on daily living (109-111). Measures were also included to examine IADL performance and perceived social support. Finally, the NIH Toolbox Cognition age-corrected composite score was used to characterize cognitive function (112). Table 7 summarizes the structure and scoring of these measures.

For our analysis of cut points, we used a Measure of Social Attitude- Barriers and Facilitators (113, 114). This measure focuses on the degree of social acceptance, and the degree to which others treat the person with respect, dignity, and autonomy (114). From a content perspective, this measure aligns most closely to the construct of enfranchisement and was therefore used to provide evidence of convergent validity.

3.2.3 Analysis

We examined construct validity by evaluating Spearman's rho correlations between each Enfranchisement subscale and measures of participation, activity, environment, and impairment (115). We hypothesized that enfranchisement would be more strongly associated with measures of participation, environment, and social support (0.4-0.6), demonstrating convergent validity, and less strongly associated with measures of activity and impairment (<0.3), demonstrating discriminant validity. We hypothesized that all of these comparisons would reveal positive relationships, with negative correlations only seen when the directionality of the included measures was reverse scored (environment, physical function, cognition).

We included the CHIEF as our primary measure of environment because it is commonly used in rehabilitation research (104, 116). However, we hypothesized that the environment plays an important role in enfranchisement and also wanted to understand which environmental domains are related to enfranchisement. Therefore, we examined the relationship between enfranchisement and the environment at a more granular level. We compared each Enfranchisement subscale with measures examining: 1) the built and natural environment; 2) systems, services, and policies; 3) barriers in the social environment; 4) facilitators in the social environment; and 5) the economic and financial environment. These measures were developed to represent the domains of the environment present in the International Classification of Functioning, Disability and Health (104).

To identify clinically important cut points, we compared the results of each Enfranchisement subscale to results on a measure of facilitators in the social environment (114). In the absence of established norms on this tool, participants were classified as experiencing good enfranchisement if they had a score above the mean on the measure of facilitators in the social environment, and poor enfranchisement if they were at or below the mean.

We used SAS software with PROC Logistic and the macro %ROCPlot to define cut points at varying levels of sensitivity, specificity, and overall level of classification accuracy (117). Sensitivity refers to the ability of the tool to classify someone as having a restriction when they do in fact have the restriction; specificity refers to the ability of the tool to classify someone as not having a restriction when they in fact do not have the restriction (118). We chose to prioritize high sensitivity to ensure that most of those who have low rates of enfranchisement would be identified for rehabilitation services. Therefore, we selected cut points with a minimum sensitivity of 0.8.

Sensitivity of 0.8 indicates that 80% of those who have restricted enfranchisement would have a score on the Enfranchisement Scale that indicates a restriction. Classification accuracy was examined using the area under the ROC curve (AUC). Higher AUC indicates greater accuracy (119-121). Generally, an AUC of 0.7 is considered acceptable, and an AUC of 0.8 is considered excellent (119-121).

Due to the high rates of missing item-level data in both subscales, we imputed missing data for cases with <20% of items missing. We replaced missing items with each person's item mean score (122, 123). Cases with more than 20% of items missing were excluded from the analysis. We then compared the results with imputed cases to results using complete cases only. We used the COSMIN checklist (115) to guide our analysis and reporting.

3.3 Results

The sample had a mean age of 64.1 years and two-thirds were males. The majority had some college education (67.2%) and were unmarried (59.8%). This sample included a high proportion of minorities. The sample included participants with stroke (34.9%), TBI (30.5%) and SCI (34.6%) with a range of disability levels in each of these groups. Overall, the sample demonstrated high scores (indicating poor enfranchisement), particularly on the Control subscale (Control: M=56.0, SD=6.0; Importance: M=44.4, SD=14.9). The sample had greater variance on the Importance subscale. No clinically meaningful differences were noted between the samples who were included and excluded from the analysis. Similarly, there were no differences in mean scores on either Enfranchisement Scale among the diagnostic groups. Table 8 summarizes the sample's demographic, injury, and clinical characteristics.

Table 8. Participant Characteristics

	Full sample (n=604)	Control (imputed sample) (n=391)	Control (complete cases) (n=281)	Importance (imputed sample) (n=219)	Importance (complete cases) (n=83)
Sex, male, n(%)	387 (64.1)	239 (61.1)	175 (62.3)	137 (62.6)	54 (65.1)
Age, m(SD)	47.34 (16.3)	47.06 (16.8)	46.9 (17.3)	47.3 (16.7)	45.3 (17.2)
Race, n(%)					
White	354 (58.6)	221 (56.5)	152 (54.1)	118 (53.9)	46 (55.4)
Black	193 (32.0)	127 (32.5)	95 (33.8)	70 (32.0)	25 (30.1)
Asian	14 (2.3)	11 (2.8)	9 (3.2)	9 (4.1)	3 (3.6)
Native American	2 (0.3)	1 (0.3)	0 (0)	1 (0.5)	0 (0)
Multiple races	7 (1.2)	6 (1.5)	5 (1.8)	4 (1.8)	2 (2.4)
Pacific Islander	1 (0.2)	1 (0.3)	1 (0.4)	0 (0)	0 (0)
Other	33 (5.5)	24 (6.1)	19 (6.8)	17 (7.8)	7 (8.4)
Ethnicity, n(%)					
Not Hispanic/Latino	558 (92.4)	363 (92.8)	255 (90.7)	194 (88.6)	74 (89.2)
Hispanic/Latino	42 (7.0)	26 (6.6)	24 (8.5)	23 (10.5)	8 (9.6)
Unknown	4 (0.7)	2 (0.5)	2 (0.7)	2 (0.9)	1 (1.2)
Marital Status, n(%)					
Married/Partner	191 (31.6)	126 (32.2)	86 (30.6)	68 (31.1)	29 (34.9)
Other	361 (59.8)	239 (61.1)	178 (63.3)	142 (64.8)	51 (61.4)
Unknown	52 (8.6)	26 (6.6)	17 (6.0)	9 (4.1)	8 (9.6)
Education, n(%)					
Less than high school	62 (10.3)	41 (10.5)	29 (10.3)	22 (10.0)	9 (10.8)
High school	136 (22.5)	80 (20.5)	60 (21.4)	45 (20.5)	16 (19.3)
Some college	221 (36.6)	143 (36.6)	108 (38.4)	80 (36.5)	27 (32.5)
College degree	185 (30.6)	127 (32.5)	84 (29.9)	72 (32.9)	31 (37.3)
Diagnosis, n(%)					
Spinal Cord Injury	209 (34.6)	132 (33.8)	96 (34.2)	65 (29.7)	23 (27.7)
Para Complete	56 (26.8)	36 (27.3)	24 (25.0)	19 (29.2)	5 (21.7)
Para Incomplete	45 (21.5)	29 (22.0)	24 (25.0)	14 (21.5)	4 (17.4)
Tetra Complete	46 (22.0)	30 (22.8)	20 (20.8)	15 (23.1)	7 (30.4)
Tetra Incomplete	61 (29.2)	36 (27.3)	27 (28.1)	16 (24.6)	6 (26.1)
Unknown	1 (0.5)	1 (0.8)	1 (1.0)	1 (1.5)	1 (4.3)
Stroke	211 (34.9)	138 (35.3)	98 (34.9)	95 (43.4)	39 (47.0)
Mild	60 (28.4)	45 (32.6)	35 (35.7)	23 (24.2)	10 (25.6)
Moderate	57 (27.0)	35 (25.4)	19 (19.4)	28 (29.5)	11 (28.2)
Severe	93 (44.1)	58 (42.0)	44 (44.9)	44 (46.3)	18 (46.2)
Unknown	1 (0.5)	0 (0)	0 (0)	0 (0)	0 (0)
Traumatic Brain Injury	184 (30.5)	121 (30.9)	87 (31.0)	59 (26.9)	21 (25.3)
Complicated mild	67 (36.4)	44 (36.4)	31 (35.6)	20 (33.9)	6 (28.6)
Moderate	16 (8.7)	11 (9.1)	7 (8.0)	9 (15.3)	3 (14.3)
Severe	99 (53.8)	65 (53.7)	48 (55.2)	29 (49.2)	12 (57.1)
Unknown	2 (1.1)	1 (0.8)	1 (1.1)	1 (1.7)	0 (0)
Enfranchisement- Control	-	56.0 (6.0)	58.4 (4.7)	57.7 (6.7)	59.0 (8.5)
Enfranchisement- Importance	-	52.1 (11.4)	53.4 (11.0)	44.4 (14.9)	48.3 (19.0)
Participation Ability	19.8 (13.5)	22.7 (15.1)	24.8 (16.5)	21.5 (15.5)	24.5 (18.0)
Participation Satisfaction	20.53 (16.6)	24.71 (18.1)	27.4 (19.1)	21.6 (18.1)	26.83 (22.0)
Instrumental ADLs	16.8 (5.9)	16.4 (5.9)	15.8 (5.8)	16.8 (5.9)	16.9 (6.1)
Social Support	63.6 (13.2)	67.7 (11.3)	69.3 (10.3)	62.7 (14.2)	64.8 (13.7)
Environmental Barriers	10.1 (12.0)	7.9 (9.4)	7.7 (9.9)	11.2 (13.8)	10.3 (12.3)
Depression	6.8 (3.4)	5.7 (2.6)	5.6 (2.6)	7.1 (3.9)	7.2 (4.1)
Physical Function	13.5 (5.4)	13.8 (5.6)	14.0 (5.6)	13.8 (5.2)	14.1 (5.5)
Cognition (Theta)	-1.3 (0.9)	-1.5 (0.9)	-1.6 (0.9)	-1.3 (1.1)	-1.3 (1.1)

Of the 604 participants in the database, 30 did not complete the Control subscale and 31 did not complete the Importance subscale. The Control subscale included 281 complete cases and the Importance subscale included 83 complete cases. The remaining cases had at least one item missing. Those with more than 20% of items missing were excluded from the analysis (Control=183; Importance=354). The final analysis included 391 participants for the Control subscale and 219 participants for the Importance subscale. See table 9 for a summary of missing data and imputed values.

Table 9. Missing Data Summary

	Not administered	Complete cases	Imputed cases	Excluded from analysis
Control	30	281	391	213
Importance	31	83	219	385

3.3.1 Construct Validity

The results of the construct validity analysis supported our hypothesis that enfranchisement was most closely related to participation, followed by social support. The Importance subscale was strongly associated with depressive symptoms. Cognition, physical function, and environmental factors were least strongly related to enfranchisement. Table 10 presents the correlations between the Enfranchisement subscales and its comparators. A more detailed analysis of the associations between enfranchisement and cognition are presented in Appendix E.

Table 10. Construct Validity

	Ability to Participate$^+$	Satisfaction with Participation$^+$	IADL$^+$	Social Support$^+$	Environmental Factors	Depression$^+$	Physical Function	Cognition
Control$^+$	.41*	.43*	.25	.30*	-.17*	.28	-.16*	.06
Importance$^+$	.54*	.56*	.28*	.56*	-.08	.49*	-.25*	.09

Facilitators in the social environment were closely related to both Enfranchisement subscales. Importance was also closely related to systems, services, and policies, and the economic and financial environment. The built and natural environment, which is most heavily represented in the CHIEF, demonstrated the weakest relationship with enfranchisement. Table 11 presents the correlations between the Enfranchisement subscales and the environment.

Table 11. Enfranchisement and Environment

	Built and Natural Environment$^+$	Systems, Services, and Policies	Social Attitude-Barriers	Social Attitude-Facilitators	Economic and Financial Environment
Control$^+$	-.22*	.30*	.31*	.42*	.17
Importance$^+$	-.25*	.48*	.31*	.47*	.37*

Overall, these results suggest that enfranchisement was most closely related to participation, the social environment, and social support. Additionally, the Importance subscale was closely related to depressive symptoms and services, systems, and policies, and the economic and financial environment. Enfranchisement was least closely related to cognition, physical function, and the built and natural environment. Apart from the strong relationship between enfranchisement and depressive symptoms, our hypotheses were supported.

3.3.2 Cut points

For the Control subscale, we defined a cut point of 53. This cut point resulted in sensitivity of 0.81 and specificity of 0.61, with an area under the ROC curve of 0.67 (Wald χ^2=29.96, p<.001, 95% CI: .63-.72), just below the minimum acceptable AUC of 0.7. Few participants scored on the lower (better) end of this scale, with most participants indicating poor control over what they do and how they do it. This resulted in a cut point at the higher (worse) end of the scale to achieve a minimum sensitivity of 0.8. For the Importance subscale, we found a cut point of 26. This cut point resulted in sensitivity of 0.82 and specificity of 0.18 with an area under the ROC curve of 0.73 (Wald χ^2=29.60, p<.001, 95% CI: .68-.78), which indicates acceptable classification accuracy. While the mean score on this subscale was much higher than this cut point (44.4), few participants scored around the mean. There was a bimodal distribution of scores with a cluster of participants scoring on the low end (up to a score of 26) and a cluster of participants scoring on the higher end (above a score of 56).

3.4 Discussion

Our hypotheses regarding the construct validity of the Enfranchisement Scale were supported in part. The moderately strong relationship between the Enfranchisement subscales and community participation measures provides evidence of convergent validity. This result indicates that these concepts are related but not perfectly overlapping (sense of belonging vs abilities or satisfaction). This finding suggests that a comprehensive assessment of community participation should include assessment of enfranchisement.

While most of our hypotheses were supported, there was one notable exception. There was a stronger than expected association between enfranchisement and depressive symptoms. While these two constructs are distinct, this relationship is unsurprising and aligns with the findings of a previous study examining the relationship between depressive symptoms and enfranchisement (43), and other studies examining the relationship between depressive symptoms and community participation more generally (124-126). If one does not feel a sense of inclusion and connection with the community, this may contribute to a lower sense of fulfillment or enjoyment in life, resulting in higher rates of depressive symptoms. It is also possible that individuals with depressive symptoms may not initiate community activities and engagement that would lead to greater experience of enfranchisement.

Still, the weak relationship between enfranchisement and both physical function and cognition provides evidence of discriminant validity between enfranchisement and common TBI-related impairments. These weak relationships are interesting, because physical function and cognition are impairments that are often the focus of rehabilitation interventions (35, 64, 80, 125-127). The stronger relationship between enfranchisement and social support may be what matters more than these specific impairments. Perhaps, individualized social support can address the challenges imposed by varying degrees of impairments in cognitive and physical functioning. With good social support, community participation may not be as affected by these impairments as they otherwise would be. Alternatively, it is possible that other environmental factors mitigate this relationship.

Our analysis of the association between enfranchisement and environmental domains also helps us better understand the construct of enfranchisement. The social environment was strongly associated with both subscales, while the built and natural environment was weakly associated. This makes sense, because enfranchisement depends on the level of acceptance a person feels from the people in their community. Discrimination, social barriers, and few opportunities for social interaction may all affect enfranchisement. Physical barriers in the environment are less likely to influence a person's sense of belonging and inclusion. This possibility is supported by studies that reported a relationship between the social environment and community participation more generally (2, 11, 128).

Evidence of construct validity was similar for the Control and Importance subscales, reflecting their correlation. There were only a few differences: social support, depressive symptoms, services/systems/policies, and economic and financial environment. All of these had a stronger association with the Importance subscale than the Control subscale. It is possible that the similarities observed between the two subscales is the result of few available comparators that measure precisely enough the factors that make control and importance distinct from each other. Still, we learned that differences in social support, local policies and services, and economic and financial characteristics of the person and the community may influence the experience of control and importance. Depressive symptoms may play a distinct role in the experience of importance and control. Future studies should seek to distinguish these constructs further.

We identified a cut point of 53 on the Control subscale and a cut point of 26 on the Importance subscale. These values are different even though the raw score range of the two scales is similar. This difference is noteworthy considering that there was a mean difference of only 11.6 points. Perhaps differences in the constructs influence the cut points. The Importance subscale may include items that, even with mild impairment, make a larger difference in peoples' experience with participation than those on the Control subscale. Future studies should investigate this possibility.

The logistic regression that determined our selected cut points revealed an acceptable area under the ROC curve on the Importance subscale (.73) and a slightly lower area under the ROC curve on the control subscale (.67). These findings provide some evidence that the Importance and Control subscales can be used to identify clients in need of rehabilitation services to address low enfranchisement. However, these results should be interpreted with caution until more research is done to confirm our findings.

3.4.1 Study Limitations

There were high rates of item-level missing data in the original combined dataset that, if not missing, could have influenced the findings. We used a conservative approach to minimize the risk of bias, but it is possible that missing scores could have affected the results, particularly with the cut point analysis of the Importance subscale. A confirmatory analysis with a large prospective dataset may provide additional insight. Furthermore, the absence of a gold standard for comparison affects both analyses. Because enfranchisement is a novel concept and this is the first measure of enfranchisement, the selected comparators were the best available. This study still provides valuable insights into the validity evidence of this scale and helps us understand the construct of enfranchisement. Finally, the distributions of both subscales were non-normal. Future studies may consider using measures of empowerment as a closer construct for comparison (129). While few measures of empowerment have been validated in samples of adults with disabilities, they are widely used in educational settings, among family members of people with disabilities, and in other healthcare contexts. The close alignment of constructs may suggest that measures of empowerment can be used as a close comparator. The results of the Control subscale were negatively skewed (poor enfranchisement), and the results of the Importance subscale were bimodally distributed. Non-normal distributions may have influenced the cut points. The diversity of this sample in terms of diagnostic groups, race, education, and marital status is a strength of this analysis, as it enhances external validity.

3.4.2 Conclusions

We found evidence of convergent validity between the Enfranchisement Scale and measures of participation, and discriminant validity between the Enfranchisement Scale and measures of disability-related impairments. The cut points (Control: 53; Importance: 26) provide acceptable sensitivity and moderate classification accuracy, which is a place to start considering the lack of a gold standard for comparison. Future studies should seek to replicate these findings. Results aid in the interpretation of enfranchisement measures and help us identify individuals in need of rehabilitation interventions to enhance participation.

4.0 Detecting change in community participation with the Enfranchisement Scale of the Community Participation Indicators

This chapter describes an analysis of previously collected data that examines the sensitivity to change of the Enfranchisement Scale of the Community Participation Indicators. This chapter was developed into a manuscript that is under review by a rehabilitation research journal.

4.1 Introduction

Participation, or meaningful engagement in life events, is an important component of the International Classification of Functioning, Disability and Health, and an important outcome of rehabilitation intervention for people with disabilities (6, 15, 28, 87). However, little is known about the trajectory of change in participation over time, making it difficult for rehabilitation practitioners to determine the right intervention at the right time (10). Most frequently, participation is examined more than one year after the onset of disability and is most often examined in cross-sectional studies (10, 130-132). The few longitudinal studies examining participation trajectories have shown no change or changes that were statistically significant but not clinically meaningful (3, 10, 133). However, it is unclear if these findings are because 1) participation generally does not change, 2) participation has been measured for the most part in the chronic phase of recovery when little change may be expected, or 3) participation outcome measures are not sensitive to change.

Numerous assessment tools measure varying domains of participation. The most frequent tools in published studies include the Community Integration Questionnaire (CIQ)(134), the Craig Handicap Assessment and Reporting Technique (CHART)(135), the Community Integration Measure (CIM)(136), the Participation Assessment with Recombined Tools- Objective (PART-O)(88) and the Participation Objective Participation Subjective (POPS)(137). While each of these have been validated in populations with disabilities, only the CIQ has an established minimum clinically important difference (MCID). A team led by van Baalen reported a MCID of 6.18 (20.6% of the full scale) for the CIQ(138). The PART-O, also commonly used in TBI Model Systems studies, does not have an established MCID, but does has a reported Standard Error of Measurement of .40 (139). Without a clear MCID, it is difficult to interpret changes over time in most measures of participation.

While the CIQ does have an established MCID, its content measures only certain dimensions of the construct of participation. Whiteneck and colleagues identified limitations with participation measurement tools, like the CIQ, that only focus on frequency of involvement selected community activities. Specifically, these measures do not always address the context or personal significance of the selected activities (15). The context and personal significance are critical components of community participation (5, 15, 28, 87).

Enfranchisement is a dimension of participation that describes a person’s sense of belonging within their community. It is composed of three components: feeling valued by the community, contributing to the community, and feeling a sense of choice and control (5, 23, 102). Enfranchisement encompasses the context and personal significance elements that are missing in many conceptualizations and measures of participation. There is one measure of enfranchisement: the Enfranchisement Scale of the Community Participation Indicators. This measure has been validated in a sample of adults with disabilities (23, 102). Previous research has also established its construct validity and clinically important cut points (Kersey, under review). However, before this measure can be used clinically or in intervention trials, we need to understand its sensitivity to change.

The purpose of this analysis is to examine the minimum detectable change (MDC) and the minimum clinically important difference (MCID) of the Enfranchisement Scale of the Community Participation Indicators in a sample of adults with stroke. These analyses are needed to aid in interpretation of naturally occurring change and intervention response in clinical and research settings.

4.2 Methods

4.2.1 Participants

We conducted a secondary analysis of data previously collected from two separate studies. One study was a wait-list randomized controlled trial of a self-management intervention for adults with stroke (n=97)(51). Participants were recruited from the community using stroke registries across multiple midwestern sites and were included if they were community-dwelling adults who had mild-moderate strokes more than 3 months prior and had completed their acute and inpatient rehabilitation. The dataset was selected because all participants received an intervention between testing time points and would be expected to improve. Data from a second prospective, observational study were also used. The second study enrolled participants in inpatient rehabilitation within an academic medical center, and completed follow-up assessments six and

12 months after discharge to the community (n=149)(140). The participants were within their first year since stroke, and natural recovery or recovery from ongoing rehabilitation services, was expected. Together, the datasets included 246 community-dwelling adults with stroke. Research procedures for both studies were approved by an Institutional Review Board.

4.2.2 Measures

The Enfranchisement Scale is composed of two subscales: Control and Importance. Each subscale was administered twice in each study, 6 months apart. The Control subscale includes 13 items evaluating the person's sense of choice and control over their participation (range 13-65). The Importance subscale includes 14 items evaluating the degree to which the person feels valued by the community and contributes to the community (range 14-70). Each item is measured on a 5-point Likert scale, with lower scores indicating greater enfranchisement. While initial research on this tool was completed with Rasch analysis, to aid in clinical use of the MDC and MCID we conducted these analyses using subscale raw scores (105).

4.2.3 Analysis

We calculated MDC using the following formula: MDC= $1.96 * \text{SEM} * \sqrt{2}$ where standard error of measurement (SEM) = $\text{SD}_{\text{baseline}}\sqrt{1 - \text{reliability}}$ (141, 142). We used an Intraclass Correlation Coefficient (two-way mixed model) as the test-retest reliability coefficient, including participants who did not receive the intervention. The MDC provides the minimum amount of change needed to trust that the change is statistically reliable. Alternatively, the MCID provides the minimum amount of change needed to trust that the change is clinically meaningful (25, 27).

Anchor-based and distribution-based approaches can be used to calculate the MCID (25-27, 142, 143). In the absence of a strong reference assessment to use as a comparator for an anchor-based approach, we used a distribution-based approach. We calculated the MCID using the following formula: MCID=.5SD$_{\text{baseline}}$ (127, 143). We selected cases with complete data on each subscale. We used the COSMIN checklist to guide our analysis and reporting (115).

4.3 Results

In the combined dataset, 121 out of 246 participants had complete data at two time points on the Control subscale and 116 had complete data at two time points on the Importance subscale. Incomplete or missing cases were excluded from the analysis. Most cases with missing data came from the observational study (Control: n=103; Importance; n=107), with participants missing one or both subscales at one or both timepoints. The reasons for missing data are unclear, but the Enfranchisement Scale was not a primary outcome and likely not a priority for administration in either parent study. Additionally, in some cases a proxy completed the assessment battery if the participant had cognitive or communication impairments. In this case, the Enfranchisement Scale was not administered due to its subjective and personal nature.

Table 12 presents the characteristics of the participants included and excluded from the Control analysis and Table 13 presents the characteristics of the participants included and excluded from the Importance analysis. The combined sample (n=246) was diverse in race and education and was equally comprised of men and women. Overall, the combined sample had participants with moderate stroke severity and moderate disability. Participants in each of the studies had some important differences. Participants in the observational study had greater stroke severity and greater disability, possibly related to the more acute nature of the sample. Participants in the intervention study were an average of 10 years younger and had a greater rate of pre-stroke employment.

At baseline, participants demonstrated high scores (poorer performance) on the Control subscale (M=51.43, SD=10.37, Median=54, IQR=34) and slightly lower (better) scores on the Importance subscale (M=44.12, SD=12.70, Median=44, IQR=18.75). Scores on both subscales were negatively skewed at both time points, particularly on the Control subscale. At baseline, no participants received the lowest (best score) on either subscale. Eight participants (6.5%) received the highest (worst) score on the Control subscale and 2 (1.6%) received the highest score on the Importance subscale. At follow-up, no participants received the lowest (best) score on either subscale. Twelve (9.6%) of participants received the highest (worse) score on the Control subscale and 4 (3.2%) received the highest score on the Importance subscale.

Table 12. Participants Analysis: Control Subscale

	Included n=121	Excluded n=125	
Sex, male, n(%)	58 (47.9)	67 (53.6)	$\chi^2(1)=0.79$, $p=.37$
Age, m(SD)	61.2 (11.8)	66.3 (14.9)	$t(235)=3.03$, $p=.003$
Race/ethnicity, n(%)			$\chi^2(4)=14.80$, $p=.005$
White	56 (46.3)	66 (52.8)	
Black	50 (41.3)	29 (23.2)	
Hispanic/Latino	10 (8.3)	12 (9.6)	
Asian	5 (4.1)	11 (8.8)	
Other	0 (0)	6 (4.8)	
Unknown	0 (0)	1 (0.8)	
Education, n(%)			$\chi^2(3)=6.42$, $p=.09$
Less than high school	10 (8.3)	14 (11.2)	
High school	41 (33.9)	57 (45.6)	
College	54 (44.6)	37 (29.6)	
Graduate degree	16 (13.2)	17 (13.6)	
Pre-Stroke Employment, n(%)			$\chi^2(4)=19.79$, $p=.001$
Full-time	78 (64.5)	51 (40.8)	
Part-time	1 (0.8)	7 (5.6)	
Disability/leave	0 (0)	2 (1.6)	
Retired	29 (24.0)	54 (43.2)	
Unemployed	13 (10.7)	11 (8.8)	
Stroke Severity (NIHSS), M(SD)	5.4 (5.2)	7.4 (6.9)	$t(216)=2.51$, $p=.01$
Disability (FIM), M(SD)	97.9 (24.7)	71.1 (28.3)	$t(243)=-7.90$, $p<.001$
Cognitive impairment*, n(%)	28 (23.1)	48 (38.4)	$\chi^2(1)=1.26$, $p=.26$
Participation (SIS), M(SD)	69.3 (24.3)	56.8 (26.3)	$t(219)=-3.65$, $p<.001$

NIHSS: National Institutes of Health Stroke Scale; FIM: Functional Independence Measure; SIS: Stroke Impact Scale- Participation Index

Table 13. Participant Characteristics: Importance Subscale

	Included **n=116**	**Excluded** **n=130**	
Sex, male, n(%)	56 (48.3)	68 (52.7)	$\chi^2(1)=0.39$, $p=.53$
Age, m(SD)	60.7 (11.6)	66.6 (14.9)	$t(238)=3.49$, $p=.001$
Race/ethnicity, n(%)			$\chi^2(4)=11.17$, $p=.03$
White	53 (45.7)	68 (52.7)	
Black	47 (40.5)	32 (24.8)	
Hispanic/Latino	10 (8.6)	12 (9.3)	
Asian	6 (5.2)	10 (7.8)	
Other	0 (0)	6 (4.7)	
Unknown	0 (0)	1 (0.8)	
Education, n(%)			$\chi^2(3)=8.12$, $p=.04$
Less than high school	10 (8.6)	14 (10.9)	
High school	38 (32.8)	59 (45.7)	
College	54 (46.6)	37 (28.7)	
Graduate degree	14 (12.1)	19 (14.7)	
Pre-Stroke Employment, n(%)			$\chi^2(4)=25,62$, $p<.001$
Full-time	78 (67.2)	50 (38.8)	
Part-time	1 (0.9)	7 (5.4)	
Disability/leave	0 (0)	2 (1.6)	
Retired	25 (21.6)	58 (45.0)	
Unemployed	12 (10.3)	12 (9.0)	
Stroke Severity (NIHSS), M(SD)	5.5 (5.3)	7.1 (6.9)	$t(221)=1.94$, $p=.05$
Disability (FIM), M(SD)	98.9 (24.5)	71.2 (28.0)	$t(243)=-8.15$, $p<.001$
Cognitive impairment*, n(%)	27 (23.3)	46 (35.7)	$\chi^2(1)=4.30$, $p=.04$
Participation (SIS), M(SD)	68.9 (24.0)	57.9 (26.8)	$t(219)=-3.20$, $p=.002$

NIHSS: National Institutes of Health Stroke Scale; FIM: Functional Independence Measure; SIS: Stroke Impact Scale- Participation Index

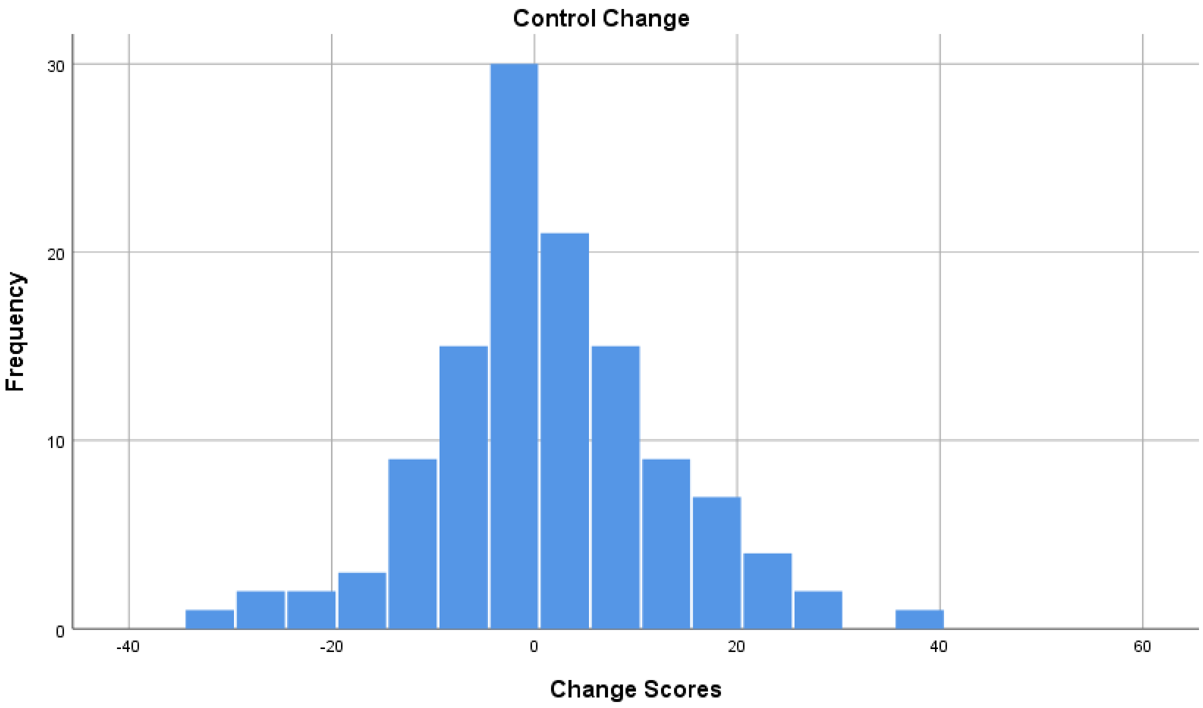

Figure 5. Control Change Scores

Overall, the sample demonstrated minimal change over time, but there was variability in the sample's change scores (Control d=.17; Importance d=.13). Change scores on the Control subscale were normally distributed and ranged from -32 to 38 (M=1.31, SD=11.5, Median= 0.0, IQR= 14.0, 95% CI: -.66-3.72)). Figure 5 presents the distribution of change scores on the Control subscale. Change scores on the Importance subscale were slightly positively skewed and ranged from -31 to 44 (M=1.08, SD=12.6, Median=0.0, IQR=13.0, 95% CI: -1.03-3.66). Figure 6 presents the distribution of change scores on the Importance subscale. The range and distribution of change scores was similar for participants from each study. Table 14 presents baseline scores, follow-up scores, change scores, effect sizes, MDC, and MCID for each subscale.

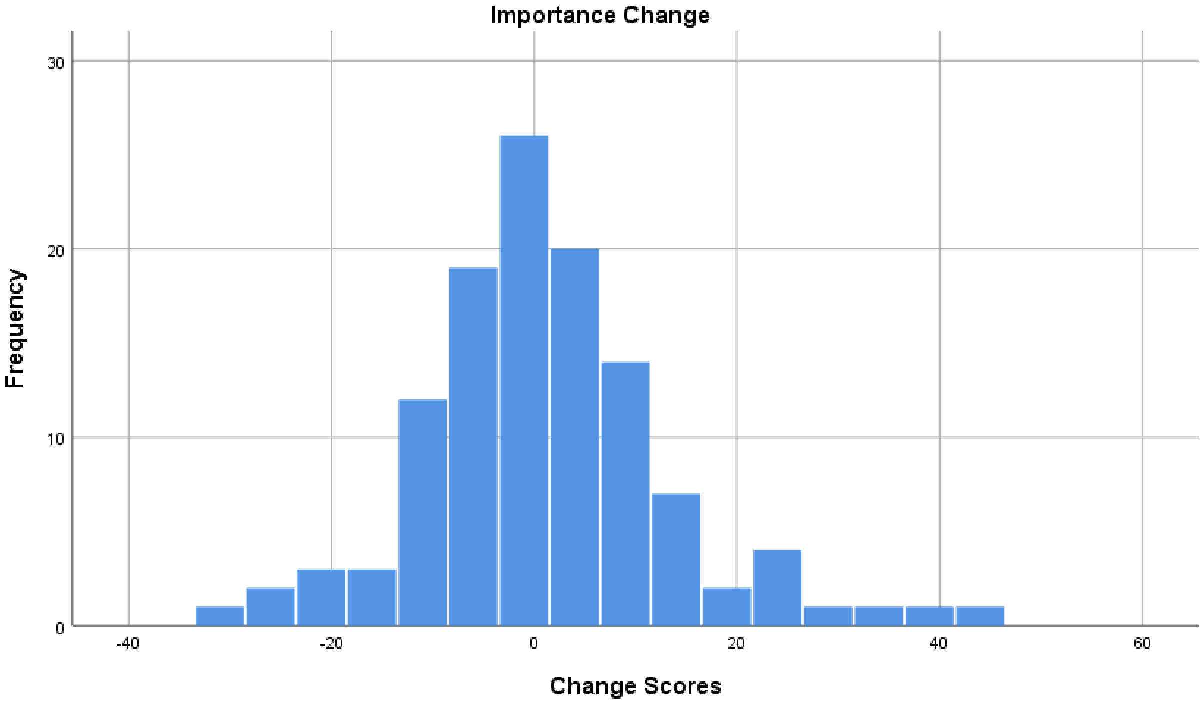

Figure 6. Importance Change Scores

For the Control subscale, we found an ICC of 0.91, which resulted in a SEM of 3.1 and a MDC_{95} of 9 (95% CI: 7-11). With a standard deviation of 10.37 we computed a MCID of 6. Taking the greater of the MDC and MCID, our findings suggest that a change of 9 points may be required to ensure that the person's change is both statistically and clinically significant on the Control subscale. This represents 17.3% of the scale's total range. For the Importance subscale, we found an ICC of 0.91 which resulted in a SEM of 3.81 and a MDC_{95} of 11 (95% CI: 8-13). With a standard deviation of 12.70 we computed a MCID of 7. Taking the greater of the MDC and MCID, our findings suggest that a change of 11 may be required to ensure that the person's change is both statistically and clinically significant on the Importance subscale. This represents 19.6% of the scale's total range.

Table 14. Sensitivity to Change Results

	Baseline	Follow-up	Change Scores	Effect Size (d)	MDC	MCID
Control, M (SD)	51.43 (10.37)	53.24 (11.05)	1.31 (11.51)	0.17	9	6
Median (IQR)	54.00 (34.00)	56.50 (13.75)	0.0 (14.0)	-	-	-
95% CI	-	-	-.66-3.72	-	7-11	-
Importance, M (SD)	44.12 (12.70)	45.83 (13.74)	1.08 (12.59)	0.13	11	7
Median (IQR)	44.00 (18.75)	48.00 (18.00)	0.0 (13.0)	-	-	-
95% CI	-	-	-1.03-3.66	-	8-13	-

MDC: Minimum Detectable Change; MCID: Minimal Clinically Important Difference

4.4 Discussion

We found MCID values (Control: 6, Importance: 7) that were lower than the MDC values (Control: 9; Importance: 11). While typically the MCID should be larger than the MDC, considering the content of these two subscales, it is unsurprising that larger values are needed for statistical significance than clinical significance on these scales. Participation, and enfranchisement in particular, is context-dependent, and each individual’s perception of and satisfaction with participation varies considerably. What two different people consider meaningful change can be very different. To ensure that change scores are both statistically and clinically meaningful, we determined that 9 points of change on the Control subscale and 11 points of change on the Importance subscale are needed. Considering the percentage of the two subscales needed to achieve important change (Control: 17.3%; Importance: 19.6%), both scales may have similar sensitivity to change as the CIQ. This information will aid in interpretation of change over time, building our understanding of changes in participation.

There was very small mean change over time in enfranchisement, but wide variability in change scores across the sample in the magnitude and direction of change. This finding informed our use of a formula including standard deviations rather than means to calculate the MCID. The small mean change is similar to that reported in previous longitudinal studies of participation, as is the detection of large standard deviations of change scores (3, 133). Rather than concluding that participation is stable over time, an alternate explanation may be that trajectories of change in participation vary among people with disabilities, perhaps based on select moderators (3, 133). This bears further examination in larger samples that are followed for longer periods of time and measured at more than two time points. Understanding the factors that predict trajectories of participation is essential to more precise participation intervention.

4.4.1 Study Limitations

The primary limitation of this study was the lack of a strong reference assessment to use as a comparator in the dataset. While the dataset did include the Stroke Impact Scale Participation Index, the relationship between these two assessments was not strong enough to produce acceptable classification accuracy (Control: Spearman’s rho=.52; Importance: Spearman’s rho=.32). This finding may indicate that enfranchisement measures a different dimension of participation than the Stroke Impact Scale. Without a strong reference assessment, we were unable to examine the MCID using an anchor-based approach. An anchor-based approach may have given us more confidence that the MCID truly represents meaningful change in participation. Another limitation was the rate of missing data. This measure was not the primary outcome of either parent study, which may have contributed to fewer participants completing the scale at both time points. Missing data are particularly important because the sample analyzed had important differences from those who were excluded from the analysis, including greater severity of disability, greater participation restrictions, older age, and lower rates of employment prior to stroke. The generalizability of our results may be limited to those meeting these characteristics. That said, our analyzed sample sizes of 121 and 116 were still sufficient to capture a range of participation change scores and trajectories.

4.4.2 Conclusions

We found that the Enfranchisement Scale may have similar sensitivity to change as the CIQ, while providing a different approach for measuring the personal and contextual elements of community participation that are missing from the CIQ. More work is needed to examine the sensitivity to change of other measures of participation to understand how the Enfranchisement Scale compares to measure of other domains and dimensions of participation. Understanding differences in sensitivity to change across domains and dimensions of participation will help us understand which of these tends to naturally change over time, respond more readily to intervention, or remain stable. This will help us more precisely target our intervention efforts moving forward.

5.0 Cut Points and Sensitivity to Change of the Enfranchisement Scale of the Community Participation Indicators in Adults with Traumatic Brain Injury

This chapter describes the results of an analysis of prospectively collected data on adults with traumatic brain injury. This chapter is being developed into a manuscript for submission to a rehabilitation research journal.

5.1 Introduction

Community participation has been described as meaningful engagement in the community (15, 87). Community participation is often measured by the frequency with which people engage in community activities or the difficulty they experience in completing those community activities (14). Yet, this approach misses an important component of community participation: inclusion and belonging (5, 15). "Enfranchisement" describes this component of community participation. Enfranchisement is defined as the degree to which a person feels valued by their community, contributes to their community, and feels a sense of choice and control (5).

Enfranchisement was identified as an important component of community participation through qualitative research conducted with people with disabilities (5). This research led to the development of the Enfranchisement Scale of the Community Participation Indicators (23, 102). The content of this measure was developed using stakeholder perspectives and was refined using factor analysis and Rasch analysis (5, 23, 102). Recent research by our team has also examined construct validity and cut points in a sample of adults with disability (stroke, spinal cord injury and traumatic brain injury) and sensitivity to change in a sample of adults with stroke (Kersey, under review).

Enfranchisement may be particularly problematic for survivors of traumatic brain injury (TBI). Our previous analysis of construct validity revealed that enfranchisement is associated with social and environmental barriers and depressed mood (Kersey, under review). These factors are also among the most common barriers to community participation for people with TBI (2, 8, 12, 13). These linkages suggest that enfranchisement and community participation outcomes are associated with one another, and thus measurement of enfranchisement may be important when seeking to improve community participation outcomes for people following TBI.

It has been suggested that psychometric properties should be established separately for each diagnostic group, as different patterns of disability may differentially affect outcomes (144, 145). Considering the relevance of enfranchisement to people with TBI, there is a need to determine whether the psychometric properties established in previous samples are the same or different for people with TBI. Therefore, the purpose of this study was to examine the psychometric properties (cut points, sensitivity to change) of the Enfranchisement Scale of the Community Participation Indicators in a sample of adults with TBI.

5.2 Methods

We conducted a repeated measures observational study with assessments administered at study admission and again 3 months later. Baseline data were used for examination of cut points. Change scores from baseline to follow-up were used for examination of sensitivity to change (minimum detectable change, MDC; minimal clinically important difference, MCID).

5.2.1 Participants

We recruited community-dwelling participants with TBI who were expected to experience change in enfranchisement over 3 months. Participants were eligible if they: 1) were age 18 or older; 2) were diagnosed with a TBI; and 3) *either* a) had experienced their TBI within the prior 12 months, *or* b) were receiving outpatient, community, or home health rehabilitation services at the time of study enrollment. These criteria were selected to include participants likely to experience either natural change or intervention-related change in enfranchisement during study participation. Participants were excluded if they: 1) had a diagnosis of dementia; 2) did not speak English sufficiently to provide informed consent; 3) resided in a non-community setting; or 4) had an injury severity score of 1 or 2 on the Glasgow Outcome Scale- Extended, which would indicate disordered consciousness. We recruited participants from community-based brain injury rehabilitation programs, research registries, brain injury support groups, and discharging patients from inpatient brain injury rehabilitation programs.

5.2.2 Procedures

Participants who expressed interest in study participation were screened over the phone to determine eligibility. If participants were eligible based on the phone screen, we obtained informed consent for participation in the full study. If participants were unable to provide informed consent due to cognitive impairments, we obtained informed consent from a proxy and verbal assent from the participant. Baseline and follow-up assessments were administered either in person, over the phone, or using video conference technology.

5.2.3 Measures

Our primary outcome measure was the Enfranchisement Scale of the Community Participation Indicators (23, 102). This scale includes two subscales: Control (choice and control over participation) and Importance (feeling valued by and contributing to the community). The Control subscale contains 13 items and has a total range of 13-65. The Importance subscale contains 14 items and has a total range of 14-70. Each item is scored on a 5-point Likert scale and subscale scores are computed by summing item scores on each subscale. Lower scores indicate greater enfranchisement. We administered both subscales at baseline and again 3 months later to assess sensitivity to change.

In addition to administering the Enfranchisement Scale, we asked participants 3 additional questions: 1) do you feel a sense of choice and control over your community participation? 2) do you feel valued by your community? 3) do you contribute to your community? Participants were asked to provide a yes or no answer to each question and responses were used as reference criteria for establishing cut points. Question 1 was used as a reference criterion for the Control subscale and questions 2 and 3 were used as reference criteria for the Importance subscale (participants were classified as having good enfranchisement on the Importance subscale if they answered “yes” to *both* question 2 and question 3).

Table 15. Measures

Measure	Description
CPI Enfranchisement- Control **(23)**	13-item assessment of the degree of sense of choice and control in community participation; range 13-65, lower scores are better
CPI Enfranchisement- Importance **(23)**	14-item assessment of the degree of meaningful community participation; range 14-70, lower scores are better
Glasgow Outcome Scale- Extended **(146)**	Assessment of injury severity; range 1-8; 1 indicates death; 2 indicates disordered consciousness; 3-4 indicate severe injuries; 5-6 moderate; 7-8 mild
Reintegration to Normal Living Index **(147)**	11-item report of engagement in home and community activities measured on a 10-point Likert Scale; higher scores are better.
Environmental Factors: CHIEF **(108)**	12-item measure of the environmental factors and the severity of their impact on daily functioning; higher scores indicate greater barriers.
Social Support: Multidimensional Scale of Perceived Social Support **(148)**	12-item measure of emotional support received from a close other, family, and friends. Measured on a 7-point Likert Scale. Higher scores indicate greater support.
Depression: PROMIS Depression Short Form **(110)**	8-item self-report questionnaire examining depressive symptoms over the last week. Measured on a 5-point Likert Scale. Lower scores indicate fewer depressive symptoms.
Cognition: PROMIS Cognitive Function Abilities Short Form **(149)**	8-item self-report questionnaire examining perceived cognitive impairments over the last week. Measured on a 5-point Likert Scale. Higher scores indicate better cognitive function.
Word List Recall (Immediate) **(150)**	Participants are verbally presented with a list of 15 words and asked to immediately recall as many as possible. Validated for telephone administration as part of the Brief Test of Adult Cognition by Telephone
Self-Awareness- Discrepancy Scores **(151)**	Performance on the Word List Recall is scored by the participant and the assessor on a 1-10 scale and the difference is calculated. Higher scores indicate greater impairment in self-awareness.

CPI: Community Participation Indicators; CHIEF: Craig Hospital Inventory of Environmental Factors

We administered additional measures at baseline and follow-up to characterize the sample. Table 15 provides details on all included assessments. To classify injury severity, we administered the Glasgow Outcome Scale Extended (146). This measure is scored from 1-8 with lower scores indicating greater severity. A score of 1 or 2 indicates disordered consciousness, and participants with these scores were excluded from the study. To analyze disability, we administered the Reintegration to Normal Living Index, which assess performance on a variety of home and community activities (147). To analyze environmental factors, we administered the Craig Hospital Inventory of Environmental Factors (CHIEF)(108). We also administered the Multidimensional Scale of Perceived Social Support to assess social support (148). To analyze depressive symptoms, we administered the PROMIS Depression Short-Form (110).

Finally, to analyze cognition, we administered the PROMIS Cognitive Function Abilities Short-Form as a self-report measure of cognitive skills (149), the Word List Recall subtest of the Brief Test of Adult Cognition by Telephone (150), and discrepancy scores to assess self-awareness. To calculate discrepancy scores, participants were asked to score their own performance on the Word List Recall task on a scale of 1-10. The assessor then also scored their performance and the difference between scores was calculated. We selected these cognitive measures to gain an understanding of the participant's own perspective on how their cognition affects their daily life (PROMIS), an objective measure of the participant's cognitive performance (Word List Recall), and a measure of self-awareness (discrepancy scores) to determine whether self-awareness impairments may affect the reliability of our included self-report measures. Because we were interested in the relationship between cognition and enfranchisement outcomes, we explored these in more depth using a larger variety of cognitive performance assessments. The methods and results of this analysis are presented in Appendix F.

5.2.4 Data Analysis

First, we examined clinically meaningful cut points. We used SAS software with PROC Logistic and the macro %ROCPlot for this analysis (117). We classified participants as having good or bad enfranchisement on each subscale using the criteria established above. We then used this classification scheme to examine recommended cut points at varying levels of sensitivity (accurate identification of someone with good enfranchisement) and specificity (accurate identification of someone who does not have good enfranchisement) (118). We only considered cut points with a minimum sensitivity of 0.8 (accurate identification of 80% of those with disenfranchisement) to ensure that those with disenfranchisement would be identified as needing rehabilitation services. We also used SAS software with PROC Logistic to perform a logistic regression to determine the predictive value of each subscale in determining good or bad enfranchisement according to the established criterion. We calculated the area under the Receiver Operating Characteristics (ROC) curve to determine the strength of the relationship between each subscale and its criterion (119-121). We considered an area under the curve (AUC) of .7 to be acceptable and .8 to be excellent (119-121).

Finally, we examined sensitivity to change. We first calculated MDC, which describes the minimum change on each subscale that is statistically significant. We calculated the MDC using the established formula: $\text{MDC} = 1.96 * \text{SEM} * \sqrt{2}$ with standard error of measurement (SEM) calculated with the following formula: $\text{SEM} = \text{SD}_{\text{baseline}}\sqrt{1 - \text{reliability}}$ (141, 142). We previously found an Intraclass Correlation Coefficient (ICC) of 0.91 for both the Control subscale and the Importance subscale (Kersey, under review). We used these ICC values as the reliability statistic in the SEM formula. We then calculated the MCID, which describes the minimum change needed on each subscale that is clinically meaningful (25, 27). To align our analysis approach with our previous study analyzing the MCID in a sample of adults with stroke (Kersey, under review), we replicated the method for calculating MCID. We therefore calculated the MCID as: MCID=.5$SD_{baseline}$ (127, 143). We selected cases with complete data on each subscale. We used the COSMIN checklist to guide our analysis and reporting (115).

We estimated the needed sample size using MedCalc Online software for ROC curve analyses to achieve 80% power with an alpha level of .05. We estimated our sample size using the following assumptions: 1) minimum AUC of .70, and 2) estimated attrition of 10%. We found that our assumptions had been met after enrolling 44 participants so we ceased recruitments.

5.3 Results

We enrolled 44 participants. All participants completed baseline assessments and 32 completed follow-up assessments (one lost to follow-up; the remainder are pending follow-up assessments 3 months after completion of baseline assessments). Our sample had an average age of 49.0 years (SD=16.1, range 22-90). The sample was equally split on gender, was primarily white (88.6%) and lived primarily in urban areas (77.3%). Though our sample was highly educated, few had returned to their prior level of employment (18.2%) and 65.9% of the sample reported an annual income below $25,000 per year. All levels of injury severity were represented aside from disordered consciousness, and the sample overall had moderate-severe injuries (M=4.7, SD=1.6, range 3-8). Participants had levels of disability, environmental barriers, social support, depression, and cognition similar to established norms (148, 152, 153). This sample was also similar to the sample in our previous study (chapter 3) except that the current study's sample experienced greater environmental barriers. Table 16 presents the characteristics of the current sample. We found very little discrepancy between participant and assessor scoring of cognitive performance (M=0.2, SD=1.5), indicating that the sample had good self-awareness of deficits, and suggesting that the self-report measures were reliable.

The results of this study are presented in Table 17. There were no missing data on either of the Enfranchisement subscales. On the Control subscale, 27 of 44 participants were classified as having good enfranchisement at baseline, and 17 were classified as having poor enfranchisement. The sample had an average baseline Control subscale score of 27.5 (SD=9.6, median=28.0, IQR=11.0). Scores on the Control subscale were positively skewed, indicating that overall, the sample had good enfranchisement (low scores). On the Importance subscale, 33 participants were classified as having good enfranchisement at baseline and 11 were classified as having poor enfranchisement. The sample had an average baseline Importance subscale score of 36.3 (SD=9.9, median=35.5, IQR=13.8). On both subscales, the sample overall demonstrated little or no change over time but had large variation in change scores. The mean change score on the Control subscale was 1.5 (SD=7.0) and the mean change score on the Importance subscale was 0.0 (SD=9.2).

Table 16. Participant Characteristics

	n=44
Sex, male, n(%)	22 (50.0)
Age, M(SD)	49.0 (16.1) (range 22-90)
Race/ethnicity, n(%)	
White	39 (88.6)
Black	2 (4.5)
Hispanic	3 (6.8)
Income Range, n(%)	
Less than $10,000	12 (27.3)
$10,000-$25,000	17 (38.6)
More than $25,000	14 (31.8)
Unknown	1 (2.3)
Employment Status, n(%)	
Previous job or similar	8 (18.2)
Reduced work capacity	12 (27.3)
Unable to work/unemployed	24 (54.5)
Education, n(%)	
Less than high school	2 (4.5)
High school	15 (34.1)
Some college	5 (11.4)
College degree	8 (18.2)
Graduate degree	14 (31.8)
County, n(%)	
Rural	10 (22.7)
Urban	34 (77.3)
Injury severity, M(SD)	4.70 (1.6) (range 3-8)
Disability (RNLI), M(SD)	74.3 (15.8)
Environmental Barriers (CHIEF), M(SD)	17.6 (16.1)
Social Support (MSPSS), M(SD)	66.8 (11.3)
Depression (PROMIS), t-scores, M(SD)	52.6 (9.4)
Cognition (PROMIS), t-scores, M(SD)	49.8 (10.3)
Word List Recall, M(SD)	4.9 (3.3)
Word List Recall Discrepancy (Self-Awareness), M(SD)	0.2 (1.5)

RNLI: Reintegration to Normal Living Index; CHIEF: Craig Hospital Inventory of Environmental Factors; MSPSS: Multidimensional Scale of Perceived Social Support

Table 17. Results

	Control	**Importance**
Baseline, M(SD)	27.5 (9.6)	36.3 (9.9)
Median, IQR	28.0 (11.0)	35.5 (13.8)
Follow-up, M(SD)	27.0 (8.2)	36.5 (10.3)
Median, IQR	25.5 (10.8)	35.0 (11.8)
Change Score, M(SD)	1.5 (7.0)	0.0 (9.2)
Median, IQR	1.0 (9.0)	1.0 (10.5)
Cut point	44	39
SEM	2.9	3.0
MDC_{95}	8	8
MCID	5	5

SEM: Standard Error of Measurement; MDC: Minimum Detectable Change; MCID: Minimal Clinically Important Difference

We identified a cut point of 44 on the Control subscale. This cut point was associated with sensitivity of 0.97 and specificity of 0.55. The area under the ROC curve was 0.75 (95% CI: .57-.94, Wald χ^2=6.17, p=.01), exceeding the minimum acceptable AUC of 0.7. The Control subscale baseline standard deviation of 9.6 led to a SEM of 2.9, a MDC_{95} of 8 (95% CI: 5-11) and a MCID of 5. Together, these results suggest that 8 points of change may ensure a statistically and clinically significant change on the Control subscale. This amount of change represents 15.4% of the scale's total range.

We identified a cut point of 39 on the Importance subscale. This cut point was associated with sensitivity of 0.89 and specificity of 0.47. The area under the ROC curve was 0.81 (95% CI: .68-.94, Wald χ^2=8.52, p=.003), achieving excellent classification accuracy. The Importance subscale baseline standard deviation of 9.9 led to a SEM of 3.0, again a MDC_{95} of 8 (95% CI: 5-11) and again a MCID of 5. Together, these results suggest that 8 points of change may ensure a statistically and clinically significant change on the Control subscale. This amount of change represents 14.3% of the scale's total range.

5.4 Discussion

We found cut points of 44 on the Control subscale and 39 on the Importance subscale. This suggests that a person needs to score on the higher (worse) end of the Control subscale to be identified as having poor enfranchisement, but nearer the middle of the Importance subscale to be identified as having poor enfranchisement. It is possible that restrictions in choice and control are more tolerable than restrictions in feeling valued by and contributing to the community. People may be more sensitive to the constructs represented on the Importance subscale. We had a similar finding in our previous study; however, the discrepancy between cut points on the two subscales was much larger in the previous study (Control: 53, Importance: 26). In our previous study, we used a different reference criterion to classify participants has having good or bad enfranchisement, which may have contributed to the different observations. The finding of our current study resulted in greater classification accuracy and narrower AUC confidence intervals, suggesting that the current criteria were better classifiers. Still, the current study had a much smaller sample size. More research with a larger sample size and the stronger reference criteria may help reconcile the differences in cut points. That said, the confidence intervals in each study overlapped, and these differences may not be statistically reliable.

On both subscales, we found a MDC_{95} of 8 and a MCID of 5, suggesting that a minimum change score of 8 is needed to ensure that change is both statistically and clinically meaningful. Again, our results matched an important pattern found in our previous study of adults with stroke.

On both subscales, in both studies, the MCID was smaller than the MDC. While this is unusual, it may reflect the subjective and contextual nature associated with enfranchisement and changes in enfranchisement over time. Despite this similarity across studies, the MDC and MCID in this study were different than what we found previously (Control: 9, Importance: 11). Again, the confidence intervals associated with the results in each study overlapped, and these differences may not be statistically reliable. Still, this study supports our previous results which found that both enfranchisement subscales were at least as sensitive to change as the gold standard for community participation, the Community Integration Questionnaire (138).

An important similarity across our studies of sensitivity to change, and other longitudinal studies of community participation, was a lack of mean change over time, but with significant variation in change scores (3, 133). Our sample in both studies of sensitivity to change included participants who made no change, participants who experienced improvements in enfranchisement, and participants who experienced worsening enfranchisement over the study period. This pattern among studies provides further support to suggest that there may be important modifiers that predict trajectories of community participation generally, and enfranchisement specifically. Exploration of the predictors of the trajectory of enfranchisement should be a priority for future rehabilitation research to better understand the implications of this for targeting rehabilitation interventions.

That differences between this study in a sample with TBI and our previous studies are interesting. It is possible that there are important differences in the experience of enfranchisement across diagnostic groups. However, previous studies have shown that there are few differences in enfranchisement scores across diagnostic groups (TBI, stroke, spinal cord injury) in samples larger than ours (23, 102, 103)(chapter 3). Therefore, it is also possible that our results differed due to variances in sampling approaches. We specifically targeted people with recent brain injuries, or who were still undergoing rehabilitation therapies, while previous studies have intentionally sought participants who were in a more chronic or stable phase of recovery. It is possible that people who are no longer experiencing changes in disability patterns have a different experience of enfranchisement than those who are earlier in the recovery process. Future studies should examine the effect of time on patterns of enfranchisement, particularly now that we have an estimated MCID to help us better interpret change over time.

It is also likely that the differences in results were at least partially due to unmeasured differences among samples. Our sample overall demonstrated lower mean scores on both subscales than samples from our previous studies. Our Control subscale mean of 27.5 was far lower than the means of 56.0 (chapter 3, n=391, mixed sample) and 51.4 (chapter 4, n=103, stroke sample). In fact, the mean from the current study is near the low end of the scale (better enfranchisement), and the means of our previous studies are near the high end (worse enfranchisement). We found a similar, though less severe, difference in means on the Importance subscale. Our mean score of 36.3 was lower than the means of 44.4 (chapter 3, n=219, mixed sample) and 44.1 (chapter 4, n=107, stroke sample) in our previous studies. The different means and distributions of scores was certainly an important factor in the observed differences in results, but the sample characteristics driving the difference in enfranchisement outcomes is unclear. That said, the samples from our previous studies, each collected independently of each other and in different regions of the country, were much larger than this sample and were similar to each other. Those samples may be more representative of norms in the population of people with disabilities than the sample in this study. Future research should include larger samples of adults specifically with TBI to refine our estimate of the true population mean.

5.4.1 Study Limitations

This study had some limitations. First, our sample was predominantly white, highly educated, and low income. This limits our understanding of the generalizability of our results to other racial and socioeconomic groups. Second, to match our methodology to our previous study for comparison, we did not use an anchor-based approach to measuring MCID. An anchor-based approach may have provided a more reliable measure of what is truly patient-reported meaningful change over time. We did not use an anchor-based approach because we lack a strong reference assessment to use as a gold standard for measuring enfranchisement that would allow us to reliably compare magnitudes of change. Additionally, the approach we used allowed us to match the method used in our previous, retrospective study for a more reliable comparison. Future studies may consider the use of a participant-reported rating scale as a way of anchoring change scores. Finally, this study had a small sample size. More research with larger samples is necessary to confirm our findings.

5.4.2 Conclusions

We found that a score on the higher end of the Control subscale (44) indicates poor enfranchisement, and a score nearer the middle of the Importance subscale (39) indicates poor enfranchisement. We also found that both subscales were as sensitive to change as they were in a sample of adults with stroke, and as sensitive to change as the Community Integration Questionnaire. Future work in larger samples is necessary to confirm our findings, reconcile or confirm differences among diagnostic groups, and better understand the factors that influence enfranchisement outcomes.

6.0 Discussion

Traditional rehabilitation models have conceptualized community participation as the frequency or difficulty of performance of community activities. This conceptualization is at odds with the values and priorities expressed by stakeholders, who inform us that the most important component of community participation is inclusion in society. Enfranchisement plays an important role in this stakeholder-driven conceptualization, and is described as feeling valued by the community, contributing to the community, and having choice and control. Yet, enfranchisement has not been well-represented in rehabilitation science. This dissertation sought to explore a new approach to treating and measuring community participation that incorporates existing evidence and stakeholder views. We examined intervention elements that may improve community participation outcomes following traumatic brain injury and examined the psychometric properties of the Enfranchisement Scale of the Community Participation Indicators (CPI). Together, these aims were designed to provide the groundwork needed to develop and test interventions to improve enfranchisement as a mechanism for improving community participation.

6.1 Studies of interventions do not measure inclusion in society

We found that activity-focused interventions (daily life skills interventions, metacognitive interventions) showed more promise than impairment-focused interventions (cognitive skills training, physical activity interventions) in improving performance of home and community activities after brain injury. However, few studies examined the effects of interventions using measures that assess inclusion in society as a component of community participation. It is unclear whether the improvements observed in performance of community activities as a result of these activity-focused interventions would also translate to improvements in enfranchisement.

Considering this gap in our findings, there is a critical need to begin assessing enfranchisement and its association with community participation outcomes. Until the TBI rehabilitation research community broadly adopts the conceptualization of community participation driven by people with disabilities and includes a measure that reflects this conceptualization in intervention studies, we will continue to lack data on this outcome and the question of the most appropriate intervention elements will remain unanswered.

While enfranchisement was not measured in the studies in our scoping review, it is reasonable to expect that some of the intervention elements that influence enfranchisement may be similar to those intervention elements that influence community participation. These intervention elements may be a reasonable starting place to guide future intervention development. Our findings suggest that interventions addressing the underlying injury-related impairments (cognitive impairments, physical function) appear to be unlikely to robustly influence community participation outcomes. Rather, activity-focused interventions showed the most promise, which suggests that skilled training and practice of daily activities may be key to improving community participation. Furthermore, it appears that education about strategies, resources, and skills for improved community participation is insufficient, without structured practice using and applying those learned skills to different contexts. Given the associations between 1) community participation outcomes, as they are currently measured, and enfranchisement (chapter 3), as well as the associations between 2) activity-focused interventions and selected community participation outcomes - it appears that activity-focused interventions may be a starting place for future studies seeking to influence enfranchisement.

6.2 Enfranchisement is associated with participation, environment, and depression

Through our measurement analyses, we were able to learn more about the construct of enfranchisement, and patterns of enfranchisement in populations of people with disabilities. We found evidence of convergent validity through moderate-strong correlations between enfranchisement and measures of community participation. We found evidence of discriminant validity through weak correlations between enfranchisement and measures of disability-related impairments, such as physical function and cognitive function. Together, these results suggest that the Enfranchisement Scale may in fact measure the construct of enfranchisement that is closely linked to community participation with validity.

We found that both Enfranchisement subscales were closely associated with measures of the environment. In particular, both subscales were strongly related to measures of facilitators and barriers in the social environment. This is unsurprising considering that feeling valued by the community may result from a supportive and welcoming social environment, while discrimination and lack of social support may lead to disenfranchisement. Additionally, both subscales were closely associated with services, systems, and policies. The Importance subscale was also closely associated with the economic and financial environment. This tells us that the availability of social, community, and financial resources may be an important factor in the experience of enfranchisement.

This also suggests that intervention elements focused on optimizing environmental factors, or the management thereof, are likely to be important when seeking to improve enfranchisement. In our scoping review, only one study directly incorporated strategies for management of environmental factors in the intervention (51). This study intervention addressed a broad scope of environmental factors, including the social environment; services, systems, and policies; and the economic and financial environment; using a combination of structured education and social learning. This study may provide a model for addressing environmental barriers relevant to enfranchisement. Several studies incorporated elements of resource facilitation that may serve to mitigate environmental barriers (51, 55, 60, 72). These studies included referrals to community resources and services, legal services, and medical services. The effect sizes of these interventions on community activity performance were negligible or small. There may be a role for resource facilitation in improving enfranchisement when enhanced with other promising intervention elements.

We also found a close relationship between enfranchisement and depression. This is unsurprising considering that community participation has been linked with quality of life and mental health outcomes (4). While the nature this relationship is unclear, it is likely that relationship between enfranchisement and mood is bi-directional. If so, there may also be a role for mood altering intervention elements when seeking to improve enfranchisement outcomes. (Of course, the inverse may also be true; intervention elements that improve enfranchisement may also improve mood). Our scoping review (chapter 2) revealed that behavioral interventions such as Cognitive Behavioral Therapy may lead to improvements in community participation outcomes. There were several studies of behavioral interventions associated with moderate and large effect sizes on community activity outcomes. These effect sizes were more robust in community outcomes compared to home outcomes. An interesting finding is that those studies examining behavioral interventions resulted in greater than negligible effect sizes when combined with metacognitive interventions (35, 58, 60, 64, 70). It is possible that this combination of intervention elements may influence enfranchisement outcomes by both managing the depressive symptoms that often co-occur with disenfranchisement, and by providing the opportunity to “do” or practice learned skills. Behavioral and metacognitive intervention elements, along with management of environmental factors, may be a promising combination of elements for influencing enfranchisement outcomes.

While we found a strong association between enfranchisement and depression, we found a weak association between enfranchisement and cognition. It is possible that there may in fact be a stronger relationship than what we found, and that limitations in measurement of cognition obscured the true association. We measured cognition in the prospective analysis (chapter 5) using only phone-administered cognitive testing. Each of these subtests had a weak association with enfranchisement (Appendix F). It is possible that we would have found different results if we had administered assessments in person or had used alternate approaches to cognitive testing (for example, performance-based testing of functional cognition or stronger measures of initiation and self-regulation). We used a broader range of measures for comparison in the retrospective analysis (chapter 3, Appendix E) and found similar results. However, we still did not have a measure of self-regulation, which is problematic following TBI and may contribute to community participation outcomes (154). Further exploration of this relationship using different approaches to measure cognition is warranted. Still, considering the pattern of very low correlations between cognitive skills and enfranchisement, it is likely that cognition does not robustly influence enfranchisement outcomes. Cognition may instead have a stronger influence on the performance of complex activities, but do not influence sense of belonging in the community.

These findings help to clarify our understanding of enfranchisement. Enfranchisement is defined as a sense of inclusion and belonging in society, and incorporates feeling valued by society, contributing to society, and having choice and control. The close association among enfranchisement and the social environment and systems, services, and policies, emphasizes that enfranchisement is strongly associated with factors external to an individual, perhaps even more strongly associated than individual competency or skill. Enfranchisement may be better described as living with the acceptance and support of the community and having decisional autonomy, rather than the degree to which a person is able to complete important community activities. The results of the construct validity analysis provide support for the definition of enfranchisement and the 3 domains that it encompasses, as described by Hammel, et al., (2008) and Heinemann, et al, (2011)(5, 102).

6.3 The Enfranchisement Scale of the CPI has adequate measurement properties

The Enfranchisement Scale of the CPI may be a useful tool to examine the effect of interventions on community participation in future clinical trials. Through our examination of its psychometric properties, we learned that the Enfranchisement Scale has adequate sensitivity to change and we were able to establish cut points that resulted in acceptable or excellent classification accuracy. While additional examination of the psychometric properties of this scale is needed to refine these results in larger samples, we were able to obtain a good estimate of the cut points and minimum change scores to ensure reliable and meaningful change.

We examined the psychometric properties of the Enfranchisement Scale with two retrospective analyses and one prospective analysis. These studies yielded similar patterns, but ultimately different results. Differences in the strengths and limitations of study methodologies may have contributed to these differences in findings. Both of our retrospective analyses had missing data on both Enfranchisement subscales and lacked a strong reference assessment for establishing cut points and minimal clinically important difference. However, the retrospective analyses had larger, more diverse samples that were demographically representative of the general population. On the other hand, the prospective analysis had stronger reference criteria, higher classification accuracy, and complete data on both subscales. Nonetheless, this study examined a much smaller sample, which was predominantly White and highly educated, limiting the generalizability of the results. Considering that each of these studies had strengths and limitations, it is possible that the true results lie somewhere in between those found in each of these studies. This is an important consideration, given that the confidence intervals in each study overlapped in both the analyses of cut points and the analyses of sensitivity to change. The differences in results may not be statistically reliable. Additional research in large, diverse samples using the stronger reference criteria may give us more precise results.

Another important complication affecting the interpretability of our results is that the mean scores on each subscale were dramatically different between our retrospective analyses (which were similar to each other) and our prospective analysis. In particular, there was a dramatic difference in means on the Control subscale. While we designed our prospective analysis with the assumption that the distribution of scores and the psychometric properties may be different in a sample of adults specifically with TBI, it is not clear if diagnosis was the driving factor in the differing results. The sample used in our retrospective analysis of cut points (chapter 3) included participants with TBI, stroke, and spinal cord injury. In that large sample, there was no difference in Enfranchisement means based on diagnosis. Additionally, there were similar means across diagnostic groups in the retrospective analyses (chapter 3 and 4). Thus, the differences in Enfranchisement Scale findings between our retrospective analyses and prospective analyses (chapter 5) may be due differences in sampling approaches (acute vs chronic stages of recovery), differences in unmeasured demographic or clinical characteristics, or some other factor. Larger samples are needed to complete advanced modelling analyses to shed light on factors that may influence the measurement of enfranchisement.

Despite the limitations of these studies, we still have useful findings to guide the interpretation of our assessment results. Taking the more conservative estimate of sensitivity to change, we would need to see a change score of 9 on the Control subscale and 11 on the Importance subscale to trust that observed change is reliable and meaningful. If there is indeed a difference in sensitivity to change due to person or clinical factors, these more conservative estimates would still ensure reliable and meaningful change in adults with TBI. For cut points, it may be prudent to select the cut points that are closest to good enfranchisement to ensure that as many people as possible who need intervention are properly identified. This would indicate a cut point of 44 on the Control subscale and 26 on the Importance subscale. Together, these results provide guidance on interpreting the results of this scale. Thus, we can use the Enfranchisement Scale to begin characterizing patterns of enfranchisement, natural change over time, and intervention-related change over time.

6.4 Future Directions

The findings of this dissertation point to several directions for future research. First, our measurement studies suggest that the Enfranchisement Scale of the CPI can be used as an important outcome measure in the testing of interventions to determine whether they result in improvements in critical, stakeholder-identified community participation outcomes. Future studies are needed to refine our understanding of the psychometric properties of this tool within and across diagnostic groups, patterns of enfranchisement over time, and predictors of trajectory of change in enfranchisement. Future studies are also needed to refine our understanding of the associations between enfranchisement and personal characteristics, injury characteristics, and injury-related impairments, including cognition. Answers to these questions can help us better identify those most in need of intervention, and the optimal time to intervene.

Second, data from the scoping review and measurement analyses suggest that the combination of environmental management, mood management, and metacognitive strategies with hands-on practice of learned skills may be promising for improving enfranchisement outcomes. That said, our scoping review did not specifically explore the effect of intervention elements on either environmental factors or depressive symptoms; our search strategy would need to be expanded. Additional reviews of the literature focused on specific environmental and behavioral intervention elements most likely to influence responses to environmental factors and mood is warranted.

While our scoping review and measurement analyses identified some useful starting points for intervention exploration, there are additional steps required to supplement these findings. To gain additional insights that can guide intervention development, we must incorporate stakeholders. People with brain injury have given us critical insights into their own conceptualization of community participation and can certainly give us insights into approaches that they feel may be the most relevant and useful given their experiences. An important next step will be to engage survivors of TBI in the discussion through qualitative and survey research. This may help us further refine these ideas and narrow intervention elements (what) and delivery features (how, when) to test in this population.

Engaging those who receive rehabilitation interventions will inform the relevance of intervention approaches (155, 156). In addition, engaging those who provide rehabilitation interventions will inform the feasibility and relevance of intervention elements across practice settings (155, 156). Rehabilitation therapists in multiple practice settings (inpatient, outpatient, home, community) may provide important insights into barriers and facilitators that will affect the usability of a new intervention approach. This type of stakeholder engagement will also provide insights into the optimal timing for interventions designed to improve enfranchisement outcomes. There may also be value in engaging healthcare organizations, community programs, and funding agencies to determine which intervention elements are of interest considering varied institutional and community priorities (155-158).

We can integrate stakeholder perspectives with the findings from this dissertation, additional observational studies of enfranchisement patterns and predictors, and review of the literature related to environment and behavioral interventions, to refine a holistic approach to improving enfranchisement after brain injury.

6.5 Conclusion

We conducted a scoping review of interventions that address community participation outcomes after brain injury and found that activity-focused interventions (daily life skills interventions, metacognitive interventions) showed the greatest promise for improving performance of home and community activities. Few studies examined enfranchisement as an intervention outcome. We examined the construct validity, cut points, and sensitivity to change of the Enfranchisement scale of the CPI. We found evidence of convergent and discriminant validity, statistically reliable cut points, and adequate sensitivity to change. We also learned that enfranchisement is strongly correlated with community participation, environment, and depression, and is weakly correlated with physical and cognitive impairments. Future studies should focus on exploration of patterns of enfranchisement over time, predictors of enfranchisement trajectories, research into behavioral and environmental interventions that may improve enfranchisement outcomes, and stakeholder perspectives on promising intervention elements to refine an intervention to improve community participation outcomes.

Appendix A Scoping Review Search Strategy

This appendix details the search strategy used to identify articles included in the scoping review presented in chapter 2.

Table 18. Scoping Review Search Strategy

Search Terms	Brain injur*, TBI, ABI (AND) Activities of daily living, community participation, social participation, community integration, social integration, leisure, employment, work
Databases	PubMed, PsychINFO/Ovid
Inclusion	Non-pharmacological intervention to address an activity-based outcome following ABI
Exclusion	Does not describe an RCT Does not include participants with ABI Does not examine a non-pharmacological intervention Does not include an activity-based outcome
Time Frame	2005 to present

*ABI- acquired brain injury; RCT- randomized controlled trial

Appendix B Risk of Bias

This appendix details the risk of bias assessments of each study included in Chapter 2. Risk of bias assessments were completed using the Cochrane Risk of Bias Tool. Assessments were completed by two independent raters and discrepancies were discussed and resolved.

Table 19. Risk of Bias

Study	Random sequence generation	Allocation concealment	Selective reporting	Other sources of bias	Blinding (participants, personnel)	Blinding (outcome assessment)	Incomplete outcome data
Bell, L. (2005)	-	-	-	-	X	-	-
Bell, K. (2011)	-	-	-	X	X	-	-
Bertens, D. (2015)	-	-	-	-	-	-	-
Bourgeois, M. (2007)	-	X	-	-	X	-	X
Bovend'Eerdt, T. (2010)	-	-	-	-	X	-	-
Brenner, L. A. (2012)	-	-	-	X	-	X	-
Cantor, J. (2014)	X	X	-	-	-	-	-
Cheng, S. (2006)	X	X	-	-	-	X	X
Cicerone, K. (2008)	-	-	-	-	-	-	-
Corr, S. (2004)	-	-	-	-	X	-	X
Dahlberg, C. A. (2007)	-	X	-	-	X	-	-
das Nair, R. (2012)	-	-	-	X	X	-	-
Dawson, D. (2013)	X	X	-	X	X	X	-
Goverover, Y. (2007)	X	X	-	-	-	X	-
Guidetti, S. (2011)	-	-	-	-	-	-	-
Hanks, R. A. (2012)	X	X	-	X	X	X	-
Hart, T. (2017)	-	-	-	-	-	-	X
Kessler, D. (2017)	-	-	-	-	-	-	-
Langhammer, B. (2008)	-	-	-	-	-	-	-
Langhammer, B. (2014)	-	-	-	-	-	-	-
Lundqvist, A. (2010)	-	X	-	-	-	X	-
McDonald, S. (2008)	-	-	-	X	-	X	X
O'Connor, M. (2016)	X	X	-	X	X	X	X
Ownsworth, T. (2008)	-	-	-	-	-	-	-

Table 19 continued

Polatajko, H. (2012)	X	X	-	-	X	X	X
Powell, J. (2002)	-	-	-	-	-	-	-
Rath, J. (2003)	X	X	X	-	X	X	X
Scheenen, M. (2017)	X	X	-	-	X	X	-
Skidmore, E. (2015)	-	X	-	-	-	-	-
Skidmore, E. (2017)	-	-	-	-	-	-	-
Struchen, M. (2011)	X	X	-	-	X	X	-
Tefertiller, C. (2019)	X	X	-	-	X	-	-
Tiersky, L. A. (2005)	-	-	-	X	X	-	-
Trevena-Peters, J. (2018)	-	-	-	-	-	-	-
Trexler, L. (2016)	-	-	-	-	X	-	-
Vanderploeg, E. (2008)	-	-	-	-	-	-	-
Wang, T. (2007)	-	X	-	X	X	X	X
Wilson, D. (2006)	-	X	-	-	X	-	-
Wolf, T. (2016)	-	X	X	-	X	X	X

Appendix C Scoping Review Supplementary Data

This appendix provides all data (effect sizes, time of follow-up, intervention element classifications) for each study included in Chapter 2.

Table 20. Scoping Review Supplementary Data

Citation	Results	Metacognitive Training	Behavioral Training	Cognitive Training	Social Skills Training	Daily Life Skills Training	Physical Activity Training	Job Coaching, Vocational Skills Training	Education, Resource Facilitation	Support, Encouragement, Mentoring
Bell, L. (2005)†	Functional Independence Measure, 12-months: p=.025, d=.21	0.21	0.21						0.21	0.21
	Community Integration Questionnaire, 12-months: p>.05, d=.28	0.28	0.28						0.28	0.28
Bell, K. (2011)†	Functional Independence Measure, 2 years: p>.05, d=.10	0.10							0.10	0.10
	Participation Assessment with Recombined Tools, 2 years- Objective: p>.05, d=.11	0.11							0.11	0.11
Bertens, D. (2015)	Everyday task performance, 8 weeks: p=.003, d=.57	0.57		0.57		0.57				
	Participant report, 8 weeks: p>.05, d=.36	0.36		0.36		0.36				
	Therapist report: p=.001, d=.87	0.87		0.87		0.87				

Table 20 continued

Bourgeois, M. (2007)	Community Integration Questionnaire, 1 week: p>.05, d=.28	0.28		0.28		0.28				
	Community Integration Questionnaire, 1 months: p>.05, d=.22	0.22		0.22		0.22				
Bovend'Eerdt, T. (2010)	Barthel Index, 6 weeks: p>.05 d=0						0			
	Nottingham Extended ADL Scale, 6 weeks: p>.05 d=.13						0.13			
	Barthel Index, 12 weeks: p>.05, d=.19						0.1			
	Nottingham Extended ADL Scale, 12 weeks: p>.05, d=.02						0.02			
Brenner, L. A. (2012)	Participation Assessment with Recombined Tools- Objective, 3 months: p>.05	NR							NR	
	Participation Assessment with Recombined Tools- Objective, 6 months: p>.05	NR							NR	
Cantor, J. (2014)	Participation Objective Participation Subjective, 12 weeks: p>.05, d=.41	0.41	0.41	0.41		0.41				
Cheng, S. (2006)	Functional Independence Measure, discharge: p>.05, d=.26	0.26		0.26		0.26			0.26	
	Lawton IADL, discharge: p>.05, d=.51	0.51		0.51		0.51			0.51	
Cicerone, K. (2008)	Community Integration Questionnaire, 4 months: p>.05, d=.31	0.31	0.31	0.31		0.31		0.31		
	Community Integration Questionnaire, 10 months: p>.05, d=.07	0.07	0.07	0.07		0.07		0.07		
Corr, S. (2004)^	Nottingham Extended ADL Scale, 6 months: p>.05, d=.25					0.25				
	Nottingham Leisure Questionnaire, 6 months: p>.05, d=.44					0.44				
	Canadian Occupational Performance Measure- Performance, 6 months: p>.05, d=.07					0.07				
	Canadian Occupational Performance Measure- Satisfaction, 6 months: p>.05, d=.27					0.27				
	Nottingham Extended ADL Scale, 12 months: p>.05, d=.24					0.24				
	Nottingham Leisure Questionnaire, 12 months: p>.05, d=.09					0.09				
	Canadian Occupational Performance Measure- Performance, 12 months: p>.05, d=.18					0.18				
	Canadian Occupational Performance Measure- Satisfaction, 12 months: p>.05, d=.09					0.09				
Dahlberg, C. A. (2007)	Community Integration Questionnaire- Social, 3 months: p>.05, d=.39	0.39			0.39					0.39
	Community Integration Questionnaire- Productivity, 3 months: p>.05, d=.09	0.09			0.09					0.09
	Craig Hospital Assessment and Reporting Technique- Occupation, 3 months: p>.05, d=.31	0.31			0.31					0.31
	Craig Hospital Assessment and Reporting Technique- Social, 3 months: p>.05, d=.72	0.72			0.72					0.72
das Nair, R. (2012)	Nottingham Extended ADL Scale, 5 months: p>.05, d=.49			0.49		0.49				
	Nottingham Extended ADL Scale, 7 months: p>.05, d=.25			0.25		0.25				
Dawson, D. (2013)	Mayo-Portland Adaptability Index- Participation, 3 months: p=.01, d=1.82	1.82				1.82				
	Canadian Occupational Performance Measure- Performance, 3 months: p=.04, d=1.33	1.33				1.33				
	Canadian Occupational Performance Measure- Satisfaction, 3 months: p=.03, d=1.53	1.53				1.53				

Table 20 continued

Goverover, Y. (2007)	Community Integration Questionnaire, 3 weeks: p>.05, d=.08	0.08				0.08				
Guidetti, S. (2011)	Stroke Impact Scale, 3-months: p>.05, d=.22	0.22				0.22				
	Stroke Impact Scale, 12 months: p>.05, d=.22	0.72				0.72				
Hanks, R. A. (2012)	Community Integration Measure: p>.05, d=.19		0.19		0.19				0.19	0.19
Hart, T. (2017)	Social relations subscale, 2 months: p=.01, d=1.6	1.6								1.6
	Out and about subscale, 2 months: p=.009, d=.84	0.84								0.84
	Productivity subscale, 2 months: p>.05, d=2.9	2.9								2.9
Kessler, D. (2017)°	Reintegration to Normal Living Index, 6 months: p>.05, d=.67	0.67				0.67			0.67	0.67
	Canadian Occupational Performance Measure- Performance, 6 months: p>.05, d=.59	0.59				0.59			0.59	0.59
	Canadian Occupational Performance Measure- Satisfaction, 6 months: p>.05, d=1.15	1.15				1.15			1.15	1.15
Langhammer, B. (2008)	Barthel Index, 3 months: p>.05, d=.20						0.2			
	Barthel Index, 6 months: p>.05, d=.30						0.3			
	Barthel Index, 12 months: p>.05, d=.41						0.41			
Langhammer, B. (2014)	Barthel Index, 4 years: p>.05, d=.35						0.35			
Lundqvist, A. (2010)	Canadian Occupational Performance Measure- Performance, 5 months: p=.02, d=.55			0.55						
	Canadian Occupational Performance Measure- Satisfaction, 5 months: p<.001, d=1.76			1.76						
McDonald, S. (2008)	Sidney Psychosocial Reintegration Scale, 12 weeks: p>.05, d=.98	0.98	0.98		0.98					
O'Connor, M. (2016)	Employment status, 1 year: NNT=4		-		-	-		-	-	
Ownsworth, T. (2008)	Canadian Occupational Performance Measure- Performance, 8 weeks: p>.05, d=.14	0.14	0.14		0.14	0.14			0.14	0.14
	Canadian Occupational Performance Measure- Satisfaction, 8 weeks: p>.05, d=.18	0.18	0.18		0.18	0.18			0.18	0.18
	Canadian Occupational Performance Measure- Performance, 3 months: p>.05, d=.62	0.62	0.62		0.62	0.62			0.62	0.62
	Canadian Occupational Performance Measure- Satisfaction, 3 months: p>.05, d=.62	0.62	0.62		0.62	0.62			0.62	0.62
Polatajko, H. (2012)*	Canadian Occupational Performance Measure- Performance, 5 weeks: p<.05, d=1.86	1.86				1.86				
	Canadian Occupational Performance Measure- Satisfaction, 5 weeks: p<.05, d=.76	0.76				0.76				
Powell, J. (2002)	Barthel Index, 12 weeks: p>.05	NR								NR
	Functional Independence Measure, 12 weeks: p>.05	NR								NR
	Brain Injury Community Rehabilitation Outcome, 12 weeks: p>.05	NR								NR
Rath, J. (2003)	Community Integration Questionnaire, 3 months: p>.05	NR	NR		NR					
	Community Integration Questionnaire, 6 moths: p>.05	NR	NR		NR					
Scheenen, M. (2017)	Return to work, 3 months: p>.05		NR					NR		
	Return to work, 6 months: p>.05		NR					NR		

Table 20 continued

	Return to work, 12 months: p>.05		NR					NR		
Skidmore, E. (2015)*	Functional Independence Measure, 3 months: p=.006, d=1.06	1.06				1.06				
	Functional Independence Measure, 6 months: p=.004, d=1.11	1.11				1.11				
Skidmore, E. (2017)*	Functional Independence Measure, 3 months: p<.001, d=.16	0.16				0.16				
	Functional Independence Measure, 6 months: p=.006, d=.39	0.39				0.39				
	Functional Independence Measure, 12 months: p=.006, d=.53	0.53				0.53				
Struchen, M. (2011)	Craig Hospital Assessment and Reporting Technique- Social, 3 months: p>.05, d=.003				<.01	<.01				<.01
Tefertiller, C. (2019)	Participation Assessment with Recombined Tools, 6 weeks: p>.05						NR			
	Participation Assessment with Recombined Tools, 12 weeks: p>.05						NR			
	Participation Assessment with Recombined Tools, 24 weeks: p>.05						NR			
Tiersky, L. A. (2005)	Community Integration Questionnaire, 3 months: p>.05, d=.04		0.04	0.04		0.04				
	Community Integration Questionnaire, 4 months: p>.05, d=.04		NR	NR		NR				
	Community Integration Questionnaire, 7 months: p>.05, d=.04		NR	NR		NR				
Trevena-Peters, J. (2018)*	Functional Independence Measure, Discharge: p=.001, d=.75			0.75		0.75				
	Community Integration Questionnaire, 2 month follow-up: p>.05, d=.17			0.17		0.17				
Trexler, L. (2016)°	Mayo-Portland Adaptability Index, 15 months: p=.74, d=.19									
Vanderploeg, E. (2008)	Return to work, 1 year: p>.05			NR		NR				
Wang, T. (2007)	Barthel Index, 4 weeks: p>.05, d=.11						0.11			
Wilson, D. (2006)	Functional Independence Measure, 8 weeks: p>.05, d=.19						0.19			
Wolf, T. (2016)	Community Participation Indicators, 3 months: p>.05	NR				NR			NR	NR
	Stroke Impact Scale, 3 months: p>.05	NR				NR			NR	NR
	Reintegration to Normal Living Index, 3 months: p>.05	NR				NR			NR	NR
	Community Participation Indicators, 6 months: p>.05	NR				NR			NR	NR
	Stroke Impact Scale, 6 months: p>.05	NR				NR			NR	NR
	Reintegration to Normal Living Index, 6 months: p>.05	NR				NR			NR	NR
	Community Participation Indicators, 9 months: p>.05	NR				NR			NR	NR
	Stroke Impact Scale, 9 months: p>.05	NR				NR			NR	NR
	Reintegration to Normal Living Index, 9 months: p>.05	NR				NR			NR	NR

*Effect sizes were calculated by the authors using change scores; †Provided directly by authors, not reported in manuscript; ^Calculated from medians and ranges; °Calculated from partial-eta squared

Appendix D Factor Analysis

The appendix describes a factor analysis designed to answer the following research questions:

1) Is the Enfranchisement Scale of the Community Participation Indicators unidimensional or multi-dimensional?
2) If the scale is multi-dimensional, are the items on each subscale the same as were found in the previously published factor analysis?

Appendix D.1 Methods

This factor analysis was conducted using data from the studies presented in chapters 3 and 4. We conducted an exploratory factor analysis, which has been suggested as the best practice for accurately determining the number of underlying factors (159-161). We used the principal axis factor extraction method because the data were not normally distributed (159-161). First, we examined a scree plot to determine which factors would be retained in the model. Factors with item loadings above 0.3 and a minimum of 3 items were retained (159, 161). We used an oblique (Promax) rotation, as this method allows items to correlate, which is likely considering the outcomes of interest (159-161).

Appendix D.2 Results

Our factor analysis initially revealed 3 factors. However, one factor contained only one item with an item loading above 0.3, and this factor loaded more strongly on a separate factor. Therefore, the final analysis included a two-factor model with results similar to those previously published (23). Factor 1, with items measuring the construct of importance, contained 13 items, and accounted for 45.3% of the variance. Factor 2, which items measuring the construct of control, contained 11 items, and accounted for 9.9% of the variance. An additional 3 items cross-loaded and did not fall solely on one factor in this analysis. Figure 7 presents the scree plot from our analysis. Table 21 illustrates the factor loadings of each item. Because our results were nearly identical to those found in the larger, previously published factor analysis, the analyses contained in this dissertation used the subscales published by Heinemann and team (23). Table 22 illustrates the differences between our findings and those that were previously published.

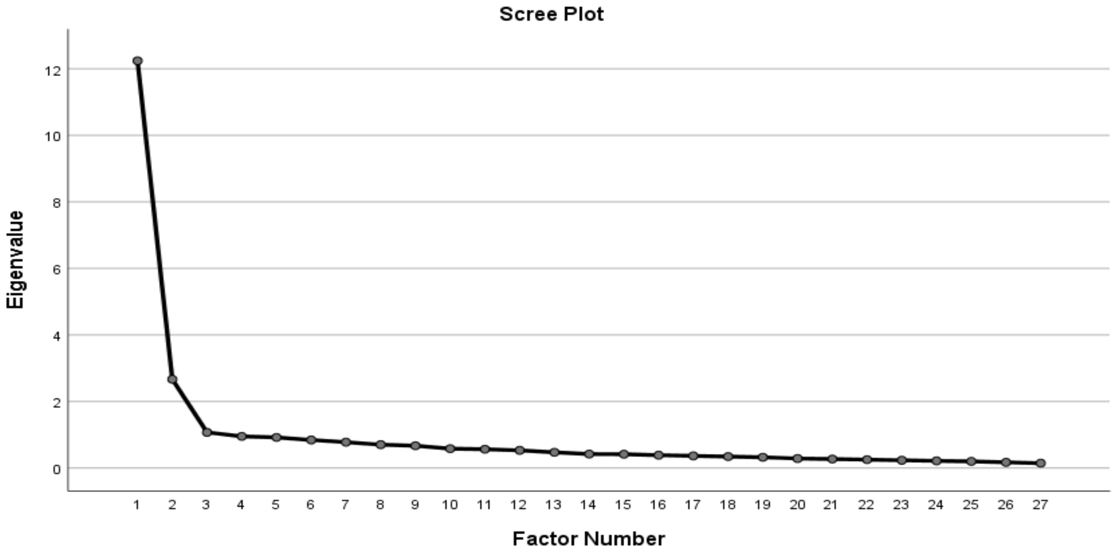

Figure 7. Scree Plot

Table 21. Factor Loadings

	Factor 1	**Factor 2**
I live my life the way that I want	.032	**.695**
I participate in activities that I choose	.204	**.570**
I have the freedom to make my own decisions	-.268	**.818**
I live my life fully	.069	**.735**
I have choices about the activities I do	-.011	**.609**
I actively pursue my dreams and desires	.340	.484
I do things that are important to me	.057	**.732**
I am able to go out and have fun	.195	**.570**
I have opportunities to make new friends	.362	.358
I take responsibility for my own life	-.079	**.674**
I am in control of my own life	-.127	**.796**
I have control over how I spend my time	-.167	**.703**
I participate in activities when I want	.148	**.627**
I do important things with my life	.500	.382
I participate in a variety of activities	**.531**	.253
I spend time doing things that improve my community	**.841**	-.155
I spend time helping others	**.701**	.112
I regularly seek out new challenges	**.506**	.271
I have a say on decisions in my community	**.744**	-.137
I contribute to society	**.723**	.111
I assume leadership roles in organizations	**.805**	-.100
I have influence in my community	**.803**	-.125
I feel safe participating in community activities	**.582**	.068
People count on me	**.491**	.165
People see my potential	**.606**	.047
I contribute to the well-being of my community	**.860**	-.082
I am actively involved in my community	**.984**	-.193

Table 22. Subscale Composition

	Kersey	Heinemann
I live my life the way that I want	Control	Control
I participate in activities that I choose	Control	Control
I have the freedom to make my own decisions	Control	Control
I live my life fully	Control	Control
I have choices about the activities I do	Control	Control
I actively pursue my dreams and desires	NONE	Control
I do things that are important to me	Control	Control
I am able to go out and have fun	Control	Control
I have opportunities to make new friends	NONE	Control
I take responsibility for my own life	Control	Control
I am in control of my own life	Control	Control
I have control over how I spend my time	Control	Control
I participate in activities when I want	Control	Control
I do important things with my life	NONE	Importance
I participate in a variety of activities	Importance	Importance
I spend time doing things that improve my community	Importance	Importance
I spend time helping others	Importance	Importance
I regularly seek out new challenges	Importance	Importance
I have a say on decisions in my community	Importance	Importance
I contribute to society	Importance	Importance
I assume leadership roles in organizations	Importance	Importance
I have influence in my community	Importance	Importance
I feel safe participating in community activities	Importance	Importance
People count on me	Importance	Importance
People see my potential	Importance	Importance
I contribute to the well-being of my community	Importance	Importance
I am actively involved in my community	Importance	Importance

Appendix E Retrospective Analysis of the Relationship Between Enfranchisement and Cognition

This appendix describes an analysis to answer the following research question: What was the relationship between the Enfranchisement Scale and measures of cognitive function in the retrospective analysis?

Appendix E.1 Methods

We analyzed the relationship between each enfranchisement subscale and multiple measures of cognitive function using previously collected data in a sample of adults with traumatic brain injury, stroke, or spinal cord injury (chapter 3). We assessed cognition using 3 approaches: self-report of cognitive function (PROMIS)(110); "functional cognition" assessed in the context of complex daily activities (Executive Function Performance Test)(162); and with traditional cognitive testing (National Institutes of Health Toolbox)(112). Because all cognitive measures had non-normal distributions, we calculated Spearman's Rho correlations for all measures.

Appendix E.2 Results

The correlations between Enfranchisement and self-report of cognition were the strongest among the measures of cognitive function. The correlation between Control and self-report of cognitive abilities was .17 and the correlation between Importance and self-report of cognitive abilities was .39.

Table 23 presents the results of the correlations between the Enfranchisement scale and the Executive Function Performance Test, a measure of functional cognition. Correlations between the Enfranchisement scale and all domains of functional cognition were less than .1, indicating a weak relationship.

Table 23. Executive Function Performance Test

	Total Construct Score	Initiation	Organization	Sequencing	Judgement and Safety	Completion
Control	.019	.025	.026	.003	.025	.073
Importance	.041	.031	.071	.050	.032	.008

Table 24 presents the results of the correlations between the Enfranchisement scale and the NIH Toolbox measure of Crystallized cognition. Crystallized cognition describes the person's pre-existing knowledge, as measured by reading, vocabulary, and a composite score. The correlation between enfranchisement and each Crystallized cognition subscale was again less than .1 suggesting a weak relationship.

Table 24. Crystallized Cognition

	Reading	Vocabulary	Total Crystallized
Control	.017	.000	.016
Importance	.074	.097	.089

Table 25 presents the results of the correlations between the Enfranchisement scale and the NIH Toolbox measure of Fluid cognition. Fluid cognition describes those skills that are more likely to be influenced by neurological disorders, such as memory, attention, and executive function. Again, the correlation between the Enfranchisement scale and all domains of Fluid cognition were below .1, suggesting a weak association.

Table 25. Fluid Cognition

	Cognitive Flexibility	Inhibitory Control	Working Memory	Processing Speed	Episodic Memory	Total Fluid
Control	.008	.028	.017	.014	.016	.016
Importance	.036	.019	.049	.012	.054	.031

In addition to the Crystallized and Fluid composite scores, the NIH Toolbox provides a total score, which weights the results on the Fluid composite score by the results on the Crystallized composite score. The correlation between the total score and the Control subscale was .01 and the correlation between the total score and the Importance subscale was .06.

Together, these results suggest that the association between Enfranchisement and both traditional cognitive tests and naturalistic cognitive tests is very weak. That said, it is possible that there are domains of cognition not measured in this study that does correlate with enfranchisement. It is also possible that no cognitive domain on its own makes a difference in enfranchisement, but that a combination of cognitive skills may show a stronger association with enfranchisement. Still, given the very low correlations, unmeasured cognitive skills are unlikely to robustly influence enfranchisement outcomes.

On the other hand, self-report of cognitive abilities was more closely associated with enfranchisement than actual cognitive performance. This association was still small for the Control subscale and was moderately strong for the Importance subscale. Considering the highly subjective nature of enfranchisement, it is unsurprising that self-report of cognitive function may influence how someone feels they are valued by and able to contribute to their community. Enfranchisement, as a sense of belonging and inclusion in society, perhaps depends less on what a person’s cognitive skills allow them to do and depends more on subjective experiences.

Appendix F Prospective Analysis of the Relationship Between Enfranchisement and Cognition

This appendix describes an analysis to answer the following research question: What was the relationship between the Enfranchisement Scale and measures of cognitive function in the prospective analysis?

Appendix F.1 Methods

We analyzed the relationship between each enfranchisement subscale and multiple measures of cognitive function using data collected in a sample of adults with traumatic brain injury (chapter 5). Appendix Table 6 summarizes the included measures of cognition. We included a self-report measure of cognitive function, a measure of self-awareness, and multiple tests of cognitive performance. Because all cognitive measures had non-normal distributions, we calculated Spearman's Rho correlations for all measures.

Table 26. Cognitive Assessments

Measure	Description
Cognition: PROMIS Cognitive Function Abilities Short Form **(149)**	8-item self-report questionnaire examining perceived cognitive impairments over the last week. Measured on a 5-point Likert Scale. Higher scores indicate better perceived cognitive function.
Brief Test of Adult Cognition by Telephone **(150)**	Performance-based cognitive assessment validated for telephone use using 7 subtests
Word List Recall	Participants are verbally presented with a list of 15 words and asked to immediately recall as many words as possible. Score reflects the number of words accurately recalled immediately after the list is read.
Digits Backward	Participants are verbally presented with strings of numbers increasing in length and are asked to repeat each string of numbers in backward order. Score reflects the largest string of numbers accurately repeated.
Category Fluency	Participants name as many animals as possible within one minute. Score reflects the number of animals named.
Go/No-Go (Time)	Normal, reversed, and mixed responses. Scores reflect summed response time for all 3 components.
Number Series	Participants are given a series of numbers following a pattern and are asked to determine the next number in the series based on that pattern. Score reflects the number of correct answers out of 5.
Backwards Counting	Participants are asked to count backward from 100 as quickly as possible. Score reflects the number reached in 30 seconds of counting backward.
Delayed Word List Recall	Participants are later asked to recall as many words as possible from the initial Word List Recall.
Oral Trail Making Test **(163)**	Assessment of executive function (verbal version of Trails B)- validated for telephone use.
Errors	Total number of errors requiring prompting or re-direction from the assessor.
Time	Total time required to reach the standardized end point, reported in seconds.
Self-Awareness- Discrepancy Scores **(151)**	Performance on each cognitive test is scored by the participant and the assessor on a 1-10 scale and the difference is calculated. Higher scores indicate greater impairment in self-awareness.
Total Discrepancy Score	Sum of the participant-assessor discrepancies of all cognitive performance tests. Possible range of 8-80.
Average Discrepancy Score	Average of the participant-assessor discrepancies of all cognitive performance tests. Possible range of 1-10.

Appendix F.2 Results

Appendix Table 7 presents the results of each included cognitive measure and Appendix Table 8 presents the correlations between each included cognitive measure and the enfranchisement subscales. We found moderate associations between the PROMIS self-report of cognitive function abilities and both the Control subscale (Rho=-.43) and the Importance subscale (Rho=-.31). On all measures of cognitive performance (BTACT subtests, Oral Trail Making Test, self-awareness discrepancy scores), associations were negligible (Rho≤.2). Together, these results suggest that self-report of cognitive function may play a role in enfranchisement outcomes, but actual cognitive performance may not. These results reflect the findings of our analysis in chapter 3, and other studies examining the relationship between enfranchisement and cognition (43). These results should be considered with caution, as all included cognitive measures used traditional testing approaches over the phone. Results may be different when assessing performance in person in a formal testing environment, in a natural setting to examine naturalistic performance, or when testing other domains of cognition not assessed in this study.

Table 27. Cognitive Assessment Results

Measure	Mean (SD)	Median (IQR)
PROMIS Cognitive Function Abilities	49.8 (10.3)	50.2 (12.1)
Word List Recall	4.9 (2.6)	5.0 (3.3)
Digits Backward	4.8 (1.6)	4.0 (2.0)
Category Fluency	19.1 (6.3)	18.0 (8.0)
Go/No-Go (Time)	106.1 (40.2)	100.9 (34.5)
Number Series	2.2 (1.7)	2.0 (3.0)
Backwards Counting	66.2 (13.9)	69.0 (20.5)
Delayed Word List Recall	2.6 (2.4)	2.0 (4.0)
OTMT Errors	1.1 (2.1)	0.0 (2.0)
OTMT Time	47.7 (27.4)	37.5 (41.3)
Self-Awareness- Total Discrepancy	9.4 (11.3)	9.0 (20.0)
Self-Awareness- Average Discrepancy	1.2 (1.4)	1.1 (2.5)

OTMT: Oral Trail Making Test

Table 28. Correlations between enfranchisement and cognition

	PROMIS Self-Report	Word List Recall	Digits Backward	Category Fluency	Go/No-Go	Number Series	Backward Counting	OTMT Errors	Discrepancy
Control	-.43*	-.11	.19	.11	-.13	-.05	.11	.06	-.05
Importance	-.31*	-.02	.05	-.03	.16	-.03	.20	.10	.07

OTMT: Oral Trail Making Test; *p<.05

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