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**THE IMPACT OF GENDER, AGE, AND PERFORMANCE ON
STROKE SURVIVORS' GOAL CONCEPTUALIZATION,
PRIORITIZATION, AND ATTAINMENT**

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PRIORITIZATION, AND ATTAINMENT**

by

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Dedication

To my parents, Ann and Don Cooper, who have always loved and supported me and who have led by example to demonstrate you are never too old to learn something new.

To Cooper and Elizabeth for your love, patience, and support over the past four years.

You continue to amaze me in all that you are and all that you do.

And to Mike- for believing in me when I doubted, for supporting me when I faltered, and for being a true partner in holding down our fort as I lived this new adventure.

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ABSTRACT: Background: Stroke is a leading cause of disability in the United States. Current stroke rehabilitation recommendations include an emphasis on patient centered care and the inclusion of the stroke patient during goal setting and treatment planning. A better understanding of how stroke patients approach goals and prioritize outcomes would facilitate patient centered care. **Methods:** We utilized qualitative and quantitative methods to improve our understanding of goal priorities and goal attainment after stroke. First, we conducted interviews with 45 individuals who had sustained a stroke. Second, we evaluated gender differences in goal attainment in a large population based sample of stroke patients. During the interviews, subjects were asked to categorize and prioritize stroke goals as well as report on their current performance on these goals. The large population based sample was utilized to measure the likelihood of each gender accomplishing goals identified as important to them, and determining which patient characteristics impact goal attainment. **Results:** Stroke survivors categorized goals into similar groupings, without significant difference by age or gender. Goals that were most important to stroke survivors included improved balance, walking independently, feeding, and bathing. Many of the goals that were reported as important to stroke survivors, such as upper and lower extremity strength, balance, depression assistance and hand function are not measured in current required rehabilitation documentation. In the large population based study, women were more likely to discharge at a supervision level or better for all FIM items except stairs and upper extremity dressing. Individuals who lived alone prior to their stroke were more likely to discharge from rehab at a supervision level on each FIM item. **Conclusion:** Further research is needed, with a survey of a larger sample of individuals to get a better understanding of goal priorities after a stroke and determine if the gender and age differences seen here remain true. The large population based study indicates the gender differences seen in rehabilitation outcomes after stroke are most likely secondary to premorbid health and independence.

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LIST OF ABBREVIATIONS

AHA	American Heart Association
BI	Barthel Index
COPM	Canadian Occupational Performance Measure
DME	Durable Medical Equipment
DVT	Deep Vein Thrombosis
FIM™	Functional Independence Measure
GSBS	Graduate School of Biomedical Science
ICD-9	International Classification of Diseases 9 th Revision
ICF	International Classification of Functioning, Disability and Health
IPA	Importance Performance Analysis
IRF-PAI	Inpatient Rehabilitation Facility Patient Assessment Instrument
LOS	Length of Stay
MCTRJCA	Middle Class Tax Relief and Jobs Creation Act
MDS	Minimum Data Set
MMSE	Mini Mental Status Exam
MOCA	Montreal Cognitive Assessment
NSG	Nursing
OR	Odds Ratio
OT	Occupational Therapy
PCOR	Patient Centered Outcomes Research
PCORI	Patient Centered Outcomes Research Institute
PT	Physical Therapy

SADI	Self-Awareness of Deficits Interview
SIS	Stroke Impact Scale
SLP	Speech and Language Pathologist
SNF	Skilled Nursing Facility
tPA	Tissue Plasminogen Activator
UTMB	University of Texas Medical Branch
WHO	World Health Organization

CHAPTER 1. BACKGROUND

INTRODUCTION

Stroke Incidence and Prevalence:

Stroke continues to be one of the leading causes of death and disability in the United States.¹ The incidence of new strokes in the United States is about 795,000 a year, with 610,000 of them being first time strokes, and 185,000 being recurrent.² As the population in the United States continues to age, the prevalence of stroke survivors will increase.³ One recent study projected an additional 3.4 million individuals in the United States will have had a stroke by 2030.⁴ The highest rates of increase in stroke are predicted for Hispanic men⁴ and elderly women.³ Stroke also occurs frequently in countries outside of the United States, affecting high income countries more than low income countries.⁵ In 2013, the prevalence of stroke around the world was 25.7 million.⁶

Gender differences exist in occurrence of stroke. In younger age ranges, men have a higher incidence of stroke, but in the oldest age groups, women's incidence rates are equal to or higher than men.⁷ Partially because of the longer lifespan of women, each year more women than men have a stroke,⁸ and the overall lifetime risk of a stroke is higher for women.⁷

Unfortunately, more young people in the United States are having strokes. About 1/10 of all strokes occur in individuals aged 18-50 years old.⁹ The incidence of stroke amongst the younger population is rising for all populations, but remains significantly higher for blacks.¹⁰ In 2010, 31% of first strokes around the world happened to individuals younger than 65 years of age.¹¹

Patient -Centered Outcomes Research:

Considering the continued global impact stroke will have, it is important to further investigate the goal priorities and goal attainment of stroke survivors so that we can address deficits and maximize recovery in areas that are most important to the stroke survivor. Utilizing patient-centered outcomes research (PCOR) and a common theoretical framework can increase our understanding of stroke survivor's goals and priorities, and help us structure their time in rehabilitation to maximize recovery.

The Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 to guide an emerging trend to improve the inclusion of patients and other stakeholders in research and treatment decisions. According to the PCORI website,

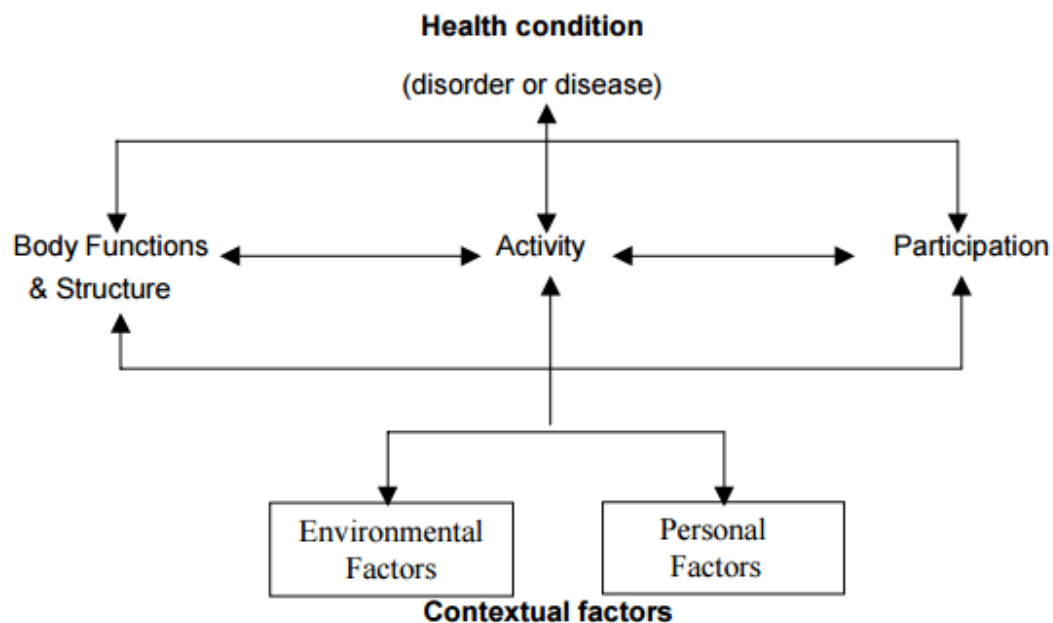
“Patient-Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions, such as: (1) “Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?” (2) “What are my options, and what are the potential benefits and harms of those options?” (3) “What can I do to improve the outcomes that are most important to me?” (4) “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?”¹²

Inpatient rehabilitation facilities provide a unique environment for the implementation of patient centered rehabilitation as they are guided by a multidisciplinary team approach for planning and implementing treatment after an injury. While it makes sense to include the patient and family when making rehabilitation decisions, it is still unclear how best to frame and facilitate these conversations to ensure the patient's needs are being met.

The ICF Model and Inpatient Rehabilitation:

For over 20 years, it has been required that inpatient rehabilitation facilities develop an interdisciplinary treatment plan that sets treatment goals for the patient while they are in rehabilitation.¹³ While including the patient and their background is an important part of the goal setting process, in practice it is sometimes challenging to do so. In the past each discipline contributed goals based on their training without always considering the patient and environmental factors beyond their scope of practice. Utilizing a common framework to discuss rehabilitation goals could help improve our understanding a stroke survivor's goal priorities. The International Classification (ICF) model was developed by the World Health Organization (WHO) as a framework to conceptualize the health and health related status of an individual.¹⁴ The ICF is the recognized framework for rehabilitation science and it directly aligns with many of the focus areas of PCORI

Figure 1.1: ICF Model



The ICF focuses not just on the impairment of the individual but also considers the context in which the individual lives and how the impairment or disability impacts the person's life. The ICF considers the impairment level deficits of the individual in the body functions and structure setting but then also includes what activity and participation deficits the individual has. The contextual components of the ICF include the environmental factors and the personal factors that either help or hinder an individual's participation. PCORI also recognizes the uniqueness of each individual and their circumstance and is funding research to help patients and the people who treat them come up with the best decisions for that individual person.

Shared decision making is another important component of PCOR that should be utilized during stroke rehabilitation. Shared decision making considers that the "right" choice for a patient may be different depending on the different components within the ICF. The goal of PCORI to address disparities also recognizes that not all individuals will respond to a specified intervention the same, and that other factors may be involved in determining the best recovery trajectory for that person.

While there has been an increase in use of the ICF and PCOR methods in stroke rehabilitation research, the inclusion of these frameworks within clinical practice has not always followed. Stroke rehabilitation research and practice can benefit from the more consistent inclusion of the ICF model and PCOR. Approaching the rehabilitation process as a collaboration, and framing the goal discussions in a way that makes sense to the stroke survivor, could improve the effectiveness of rehabilitation.

In order to successfully implement PCOR strategies into stroke rehabilitation we need a better understanding of what outcomes are important to stroke survivors and what methods are best to get a full understanding of stroke survivors' goal priorities. While best practice recommendations for stroke patients include the utilization of post-acute rehabilitation and the incorporation of patient centered practice during goal setting and treatment planning,¹⁵ it is unclear how and when to best include patients in rehabilitation planning. It is also unclear whether there are age or gender differences in goal priorities and how an individual's current performance impacts their goal priorities.

Another challenge to patient centered stroke rehabilitation is the typical front loading of rehabilitation services. Many individuals with an acute stroke are not clear on what goals are important to them or how different deficits may impact their daily life until they have been living outside of the hospital.¹⁶ Unfortunately, many individuals no longer qualify for therapy services at the time when they better understand what goals are most important to them.¹⁷

While previous qualitative studies have investigated goal priorities of stroke survivors, none have considered the individual's current performance on these tasks at the time of the interview. An individual's current performance could impact their perception about the importance of stroke related goals. Because rehabilitation professionals only have cross sectional views of the individual with a stroke, and recovery and adjustment after a stroke is longitudinal, it would be helpful for clinicians to have an understanding of how as performance changes on a task, goal priorities change.

Age and Gender Differences in Stroke Goals and Outcomes:

Having a better understanding of how age and gender impact goal prioritization can also lead to better patient centered care during rehabilitation. There are unique roles and needs at each stage of life, and it is important to better understand how these life roles may impact rehabilitation goals post stroke. Younger stroke survivors are typically working and managing a family at the time of their stroke and have different goal priorities. Younger stroke patients have reported rehabilitation did not address their needs, and the time spent there was meaningless.¹⁸ Because young stroke survivors are typically working at the time of their stroke there is a loss of financial income and a decrease in social participation afterwards.¹⁹ With a better understanding of typical goals for a certain individual, clinicians can guide goal discussion around areas that are typically of concern for that group, all let the discussion evolve from there.

It is also important to consider if there are gender differences in goal attainment after stroke. After stroke, women have been found to have poorer functional recovery²⁰ and more disability²¹ than men. This trend was also found in younger stroke survivors, with female gender found to be a strong baseline predictor for poor functional outcome.²² While previous investigations have examined outcomes by gender after stroke rehabilitation in the United States, it is still not clear how social support may or may not impact gender differences in outcomes post stroke rehabilitation. Also, many of the studies used a total disability score and didn't consider performance on individual activities. Having a better understanding of why there are differences in stroke outcomes by gender, and if these differences are present at the individual activity level can help guide clinical practice and treatment interventions.

This research project provides insight into the stroke patient's approach and prioritization of goals and reports of gender and age differences in this approach. We also report of gender related differences in goal attainment in older adults, and how social support impacts this outcome. The results from this research provides clinicians with useful information on how best to approach goal setting and prioritization with stroke patients of different ages and genders, allowing them to be more patient centered in rehabilitation.

This is the first study to our knowledge to examine how stroke patients conceptualize and categorize their goals and to measure how current performance may impact an individual's perception of goal importance. By comparing goal priorities by gender and age we provide new information on possible differences in goal priorities in these groups. Finally, we report on gender differences in recovery on goals that are important to this group, and how social support influences gender differences in recovery.

For the purpose of this investigation, the variables will be operationally defined as follows. Gender will be dichotomized as male or female and will be by self-identification during the interviews and by medical record for the claims data. Age will be defined as the age of the individual at the time of the interview for the qualitative portion of the investigation and discharge from the rehabilitation hospital for the claims data. Goal conceptualization will be defined as the manner in which participants organize the stroke goals into groups that go together. Goal prioritization will be defined as the goals that are rated as most important to participants on a 5 point scale during the structured interviews. Finally, goal attainment will be defined as reaching a specific FIM cutoff score at discharge from inpatient rehabilitation.

The information from this study can help guide patient centered rehabilitation practice and inform clinicians of possible age and gender focus areas during stroke rehabilitation. Having a better understanding of how gender, age, current performance, and social support impact rehabilitation goals and goal attainment will lead to more patient centered care during stroke rehabilitation.

STUDY AIMS AND HYPOTHESES

AIM 1: Describe how stroke patients classify and organize stroke recovery goals and compare classification by age and gender. We completed pile sorts of a standard set of 40 rehabilitation goals by 38 stroke survivors. The 38 stroke survivors were stratified by age and gender into 4 groups as follows: (10 male <65, 10 male $\geq$ 65, 9 female <65, and 9 female $\geq$ 65). The list of patient centered goals was developed from prior interviews with patients and caregivers and a review of the items included in the IRF-PAI, MDS 3.0, and the stroke impact scale.

Hypothesis: Patient groupings of goals and description of goals will not follow typical FIM™ and rehabilitation discipline categorization of goals that is currently utilized by rehabilitation professionals (e.g. grouping by self-care, mobility, cognition, or by the discipline-OT vs NSG vs PT vs SLP who addresses each goal)

AIM 2A: Examine the effects of age (<65, 65+years) and gender on stroke patients' perceived importance rating of patient centered outcomes.

Hypothesis: Perceived importance ratings of the stroke specific patient centered outcomes will differ by age group and gender.

AIM 2B. Determine the relationship between perceived importance and current performance on specific goals among stroke patients.

Hypothesis: Items such as continence will have high perceived importance regardless of current performance. For other items, such as mood and fatigue, perceived importance will be negatively correlated with perceived current performance

AIM 3: Evaluate goal achievement following inpatient rehabilitation by gender in a large population based sample of older stroke patients.

Hypothesis: Female stroke survivors will be less likely to reach preferred goals and this will be partially explained by the presence or absence of social support.

CHAPTER 2. GOAL CONCEPTUALIZATION

INTRODUCTION

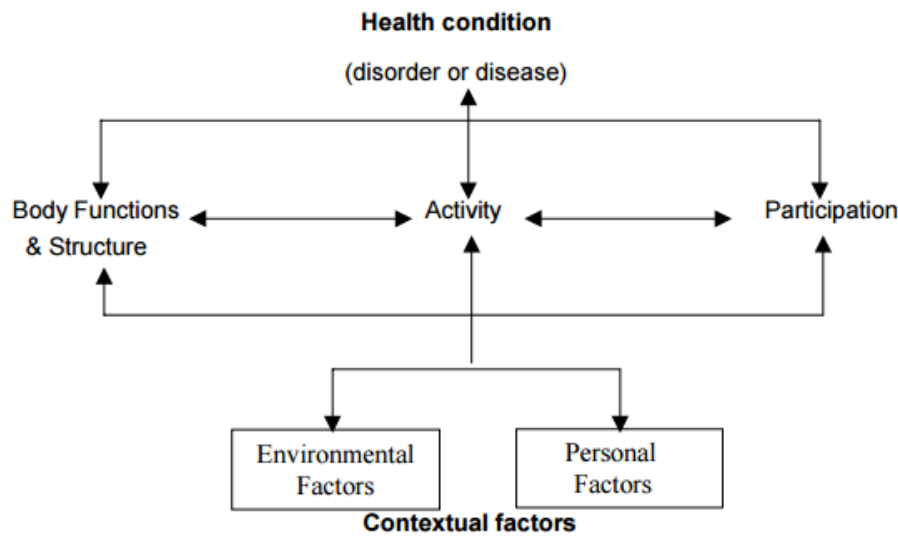
Stroke rehabilitation professionals are encouraged to follow patient-centered practice during post-acute rehabilitation.¹⁵ Clinicians are more patient centered when they can include the patient in their discussion about goals and discharge recommendations, and include in their discussions areas of the patient's life beyond the physical impairments.²³ Unfortunately, there are many barriers that make it difficult for patients to discuss and set goals that encompass all areas of function and participation while in rehabilitation.²⁴⁻²⁶ During inpatient rehabilitation, patients are often managing a new diagnosis, in a new environment and are working with clinicians from many different areas. Patients are unfamiliar with goal setting in this environment, and have difficulty stating goals beyond general terms.¹⁶ Having a framework to discuss goals that is organized around the stroke survivor's perception of outcome categories could lead to more beneficial goal discussions. Clinicians typically categorize stroke outcomes by using their discipline-specific goal areas, outcome measures, or an overarching framework.

Clinicians who typically work with individuals who have sustained a stroke and set goals for their recovery include Nursing (NSG), Occupational Therapy (OT), Physical Therapy (PT) and Speech and Language Pathologists (SLP). Each discipline sets goals for the patient and provides treatment within the boundaries of their practice act. In inpatient rehabilitation, the Functional Independence Measure (FIM™) is required to measure the level of assistance a rehabilitation participant requires in various areas of function. The FIM™ is broken down into motor (self-care, sphincter control, transfers, and locomotion) and cognitive (communication and social cognition) domains.^{27,28} Because the FIM™ is

required documentation for all rehabilitation facilities who are reimbursed by Medicare and it is used to compare facilities on rehab effectiveness, the FIM™ items are often used as the goal framework for the interdisciplinary rehabilitation care plans. While the FIM™ is a good measure to determine care requirements, there are many goals that are important to individuals after a stroke that are not captured in the FIM™ scale.

Another framework is the International Classification of Functioning, Disability, and Health (ICF).¹⁴ The ICF model was developed by the World Health Organization (WHO) as a framework to conceptualize the health and health related status of an individual (Figure 2.1). The ICF focuses not just on the impairment of the individual but also considers the context in which the individual lives and how the impairment or disability impacts the person's life. The ICF considers the impairment- level deficits of the individual in the body functions and structure setting but then also includes what activity and participation deficits the individual has. The contextual components of the ICF include the environmental factors and the personal factors that either help or hinder an individual's participation. Disability researchers recommend using the ICF as a common framework for disability classification and measurement.²⁹

Figure 2.1 ICF Model



It is unclear if patients approach goal outcomes according to an already established framework, or not. Before we can have effective discussions with stroke survivors about what goals are most important to them, we must have a better understanding of how they conceptualize goals after recovery. One method to understand how a group of individuals structure domains is through pile sorting and multidimensional scaling (MDS).³⁰ This method asks individuals to identify similarity among items in a domain through pile sorts.³⁰ Each individual has the freedom to sort the cards of items in as many categories as they think are necessary. Information from the individual pile sorts can be represented with MDS or clustering, and provide information on perceptions of goals, categories for goals, and be compared to the organization of outcomes in the FIM™ and ICF. The clusters that are revealed through MDS can also inform the structure of future surveys and discussions regarding the items.

This information on how stroke survivors categorize goals can help organize future surveys to a larger population of stroke survivors and inform clinicians on how to frame discussions about goals. Having a better understanding of how stroke survivors categorize goal topics can help facilitate patient centered goal discussions and lead to recommendations on how to frame a survey on goal priorities which can be administered to a larger sample of individuals. The objective of this study was to 1) determine how stroke survivors organize goals related to stroke recovery, and 2) compare young <65 vs old ≥ 65 and male vs female in their goal categorization.

METHODS

Participants:

We recruited 46 stroke survivors in the Houston and Galveston areas. Eligibility criteria included: age (>18), ability to communicate in English, history of hospitalization because of a stroke, discharged from hospital at time of interview, able to follow commands, and cognitively able to consent to the study.

Screening:

Participants were recruited from the Houston and Galveston areas through support groups, outpatient rehabilitation facilities and social media from January of 2017-October 2017. Purposive sampling was used with the goal of obtaining 10 participants in each of the following groups: (Female <65, Male <65, Female ≤ 65 , and Male ≤ 65). Flyer postings as well as presentations at support group meetings were utilized to communicate to potential participants the purpose of the study.

Patient eligibility was determined during an initial interview with the patient either in person, over the phone, or via secure email. The locations of the interviews was

determined by participant preference and included the following: a private room at a support group location, at the participant's home, or in a public location (i.e. library or coffee shop).

The consent form was reviewed with each participant prior to the interview. Participants were asked to demonstrate understanding of the study and the risks by repeating back to the investigator potential risks of the study and how they would terminate their participation if they chose to do so.

After the consent form was completed, the Montreal Cognitive Assessment (MoCA)³¹(Appendix C) was administered to all participants to assess if they had the cognitive capacity to understand and follow the instructions of the assessments. The MoCA is a brief cognitive screen that consists of 16 items that assess cognitive status across the following domains: visuo-spatial, executive function, naming, memory, attention, language, abstraction, and orientation.³¹ The MoCA has been found to have excellent internal consistency with stroke patients, and identified more mild cognitive impairments in stroke survivors than the Mini Mental Status Exam (MMSE).³²

The total possible score on the MoCA is 30, and while the standardized cut off to indicate no cognitive impairment is a score of 26 or above, a score of 22 or better has been recommended for individuals who have sustained a stroke.³³⁻³⁵ All participants who scored higher than a 22 on the MoCA were included in the study. Two individuals could not complete the visual perceptual and visual motor tests on the MoCA because of significant visual deficits, and they were administered the MoCA-BLIND. For these two individuals, the score was based on a total possible score of 22 rather than 30, with normal $\geq 18/22$. A total of 45 subjects consented to the study, seven of whom did not meet the MoCA cut off

score, and therefore were excluded. Therefore, a final group of 38 subjects was included in the structured interviews and analysis.

Each interview began with the administration of the Self-Awareness of Deficits Interview (SADI).³⁶ This interview evaluates an individual's self-awareness of deficits, the self-awareness of functional implications of deficits, and the ability of the individual to set realistic goals.³⁶ Scores on the SADI range from 1-9 with a score of 7-9 out of 9 indicating severe impairment of self-awareness and a score of 4-6/9 indicating moderate impairment. The SADI interviews were audio recorded, transcribed, and scored by two individuals with experience in working with individuals with neurological deficits (CCH & TR). The two SADI scores were averaged to obtain a final SADI score for each participant. All individuals who score ≥ 7 on the SADI were excluded from the analysis. In our sample, no individuals scored ≥ 7 , therefore no participants were excluded secondary to significant impairments in self-awareness.

Two individuals could not complete the SADI secondary to significant expressive aphasia deficits, but were included in the analysis secondary to their ability to demonstrate independent functioning in the community, and ability to gesture and communicate about their deficits through other means.

Following administration of the SADI and the MOCA, each participant was asked questions regarding demographic information, stroke history and current and previous social support.

Development of the 40 goals

The list of 40 goals for this project were developed from previously completed stroke patient and caregiver interviews.³⁷ The qualitative interviews consisted of open

ended questions designed to elicit information regarding stroke recovery outcomes important to participants. Transcripts of the first 10 interviews (5 caregiver interviews and 5 patient interviews) were coded for themes relating to an individual's goals or outcomes after having a stroke. Those coded interviews produced a list of 40 goals across a broad range of limitations (Table 1). The most frequently mentioned goals concerned walking, talking, and using the restroom independently. There were also goals mentioned regarding help with depression, and participation in a stroke support group as well as education goals regarding stroke prevention. The patients and caregivers included limitations at the impairment, activity and participation level.

While some consistent themes emerged from these initial interviews, 17 of the 40 statements were only said by one participant. To ensure an exhaustive list of potential goals was included, the FIM™ and the Stroke Impact Scale (SIS) were also reviewed to see if additional goals could be identified that had been mentioned by previous stroke survivors during the development of those scales. The FIM™ scale measures caregiver burden by scoring an individual on various functional tasks.^{27,28} There are 13 motor categories and 5 cognitive categories in the FIM™. The SIS is a patient centered survey that asks an individual who has had a stroke to rate the impact the stroke has had on various daily activities, strength, mood, communication, mobility, cognition, and participation.^{38,39} The SIS was developed from stroke patient interviews and has a wide range of activities and tasks that stroke patients themselves have said are difficult after a stroke.

From the interviews, SIS and FIM™ a total of 57 potential survey items were developed. Appendix A includes a table with information on each of the potential questions, and where the question was developed. The list of potential questions was

reviewed and some items were removed to make the list of goals shorter and more manageable for the participant. Items were removed if they were seen as redundant, or if an item was said only once in an interview and did not come up on the FIM™ or SIS. Appendix A also includes which items were removed and the reasoning for not including them. The final list of goals has 40 items. Twenty seven of the items came directly from patient and caregiver interviews and 11 items were from the FIM or SIS. One item, sexual intimacy, was not mentioned in the interviews or included in either of the scales. However, it was added to the list of 40 goals as previous studies have shown this to be an important area of focus during stroke rehabilitation and an area that is not always discussed during rehabilitation.^{40,41}

Table 2.1: List of Rehabilitation Priorities After Stroke

Number of Participants Mentioning Each Stroke Goal During Initial 10 Interviews		
	After 5 interviews	After 10 interviews
I want to be able to walk	3	5
I want to be able to talk again- to communicate what I want or need	3	5
I want to be able to go to the bathroom by myself	1	5
I want my hand to work better	4	4
I want to get my strength back	2	4
I want help with my depression	1	4
I want to drive again	3	3
I want more rehabilitation- more therapy	2	3
I want to be a part of a support group	2	3
I want my balance to be better	2	3
I want to get back home again	1	3
I want to be able to get in and out of bed by myself		3
I want to know how to prevent another stroke	2	2
I want to be able to do projects around the house	2	2
I want to have better stamina/endurance, to not get tired so easily	2	2
I want to be able to take care of myself	1	2
I want to get back to normal again- to be able to do all the things I used to do	1	2
I want my vision to be better	1	2
I want more information about my stroke- to sit down with the doctor and have them explain things to me		2
I want more information about what equipment is available and best for me		2
I want to be independent- to not have to rely on others for things		2
I want to be able to move around by myself more		2
I want to get back to work	1	1
I want to be social, to date again	1	1
I want to do more activities- to get out of the house more	1	1
I want a new brace or equipment to make things easier for me	1	1
I want to be able to put on my pants and socks	1	1
I want clear communication from by doctors	1	1
I want a neurologist to follow up with me right after discharge from the hospital	1	1
I want the pain and hypersensitivity in my arm to go away	1	1
I want less intensive rehabilitation to start out		1
I want to be able to swallow my food		1
I want more education and training from the therapists		1
I want my home set up so it is easy and safe to get around		1
I want my doctor to consider the cost of medications when deciding what I should take		1
I want my skin to stay healthy		1
I want help stretching my muscles		1
I want to be able to get in and out of the car		1
I want my arm to work better		1
I want information about resources available to stroke patients- free clinics, support groups, etc.		1

FINAL LIST OF 40 GOALS from interviews (Table 2.1) and Standardized Evaluations (Appendix A)

I want to drive again
I want my vision to be better
I want to be able to concentrate
I want to remember things (keep appointments, take medications, etc.)
I want to be able to communicate what I need and want
I want to be able to understand what is being said to me in a conversation
I want my arm to be stronger
I want my hand to work better
I want the pain in my arm to go away
I want to go through my day without having a bowel or bladder accident
I want my home set up so it is safe and easy for me to get around
I want to be able to get dressed by myself
I want to be able to feed myself
I want to be able to solve daily problems without help
I want to do more activities- to get out of the house more
I want to be able to bathe myself
I want to be able to go to the bathroom by myself
I want to be able to get in and out of bed by myself
I want my balance to be better
I want my leg to be stronger
I want to be sexually intimate with my partner
I want to be able to do projects around the house
I want to participate in a conversation with a group of people
I want to be part of a support group
I want to be social, to see my friends or date again
I want to get back to work again
I want a new brace or equipment to make things easier for me
I want help with my pain
I want to be able to move around by myself
I want to have better stamina/endurance, to not get tired so easily
I want to be able to walk on my own without a cane or a walker
I want help with my anxiety
I want to be able to control my mood and not yell at my family when I am frustrated
I want help with my depression
I want to know how to prevent another stroke
I want to know more about my stroke- to have my doctor explain it to me
I want information on resources available to stroke patients
I want my skin to stay healthy
I want to be able to get in and out of the car by myself
I want to be able to climb one flight of stairs by myself

This investigation utilized these 40 goals to further our understanding of how stroke survivors in the community categorize these goals. Having an understanding of how stroke survivors group goals will help clinicians approach goal setting from the client's perspective. This information will help inform patient centered-practice during goal discussions and guide how best to set up a survey in a way that makes sense to stroke survivors that can be implemented with a larger sample of stroke survivors.

Participant Instructions:

Participants were provided a stack of 40 cards with a single goal related to stroke written on each card. First, the investigator reviewed each goal with the participant and asked for confirmation that the participant understood the goal statement. Next, the participant was handed the stack of 40 cards and read the following instructions:

"Please put the cards into groups that go together. There is no right or wrong answer- we are interested in how you think these cards go together. There is not a specific number of groups required."

Once the participant finished sorting the cards into piles they were asked to name each grouping. The group names and cards within each pile were recorded for analysis. The cards were shuffled in between subjects so that each subject was presented each goal in a random order.

Analysis:

The analysis for the card sort utilized methods previously used in anthropological investigations.^{30,42} The pile sort data was imported into ANTHROPAC and analyzed using multidimensional scaling and clustering to provide information on the grouping of items. The resultant aggregate proximity matrix was examined for the overall sample of 40

subjects as well as by group (male vs female, young vs old). Kruskal's STRESS coefficient was used to measure goodness of fit.

RESULTS

A total of 45 subjects were recruited and consented for participation in the study. Seven subjects were excluded secondary to scores on the MOCA < 22. The remaining 38 subjects (10 male < 65, 9 female < 65, 10 male ≥ 65 and 9 female ≥ 65) continued with the structured interviews and were included in the analysis. Table 2.3 describes the sample characteristics of the 38 individuals who completed the structured interviews. The groups of men and women were similar in all sample characteristics. While more male stroke survivors (63%) had a spouse as their primary source of assistance than female stroke survivors (32%), and female stroke survivors were more likely to have a child assisting in their care (26%) than male stroke survivors (0%), the differences between groups on social support was not significant. ($X^2(df\ 2)=4.7767$, $p<.0918$)

Table 2.4 contains the sample characteristics of each of the subgroup of participants.

Table 2.3: Sample Characteristics

SAMPLE CHARACTERISTICS				
	Total Sample	Men	Women	p value
N	38	19	19	
Age Mean (SD)	63.9 (12.6)	63.1 (12.73)	64.9 (12.76)	p=0.67
Race/Ethnicity n (%)				
African American	14 (36.8)	7	7	p=0.85
Asian	2 (5.26)	1	1	
Caucasian	19 (50.0)	11	8	
Hispanic	1 (2.63)	0	1	
Biracial	2 (5.26)	1	1	
Time Since Stroke (months) Mean (SD)	98.6 (87.7)	82.35 (72.70)	116.7 (100.9)	p=0.23
MOCA Mean(SD)	24.90 (2.02)	25.25 (1.97)	24.50 (2.07)	p=0.25
SADI Mean (SD)	1.10 (0.92)	1.03 (.88)	1.20 (.99)	p=0.58
Current Social Support				
Spouse	18	12	6	p=0.09
Parent/Child/Provider	9	2	7	
None	11	6	5	

Table 2.4: Sample Characteristics of Subgroups

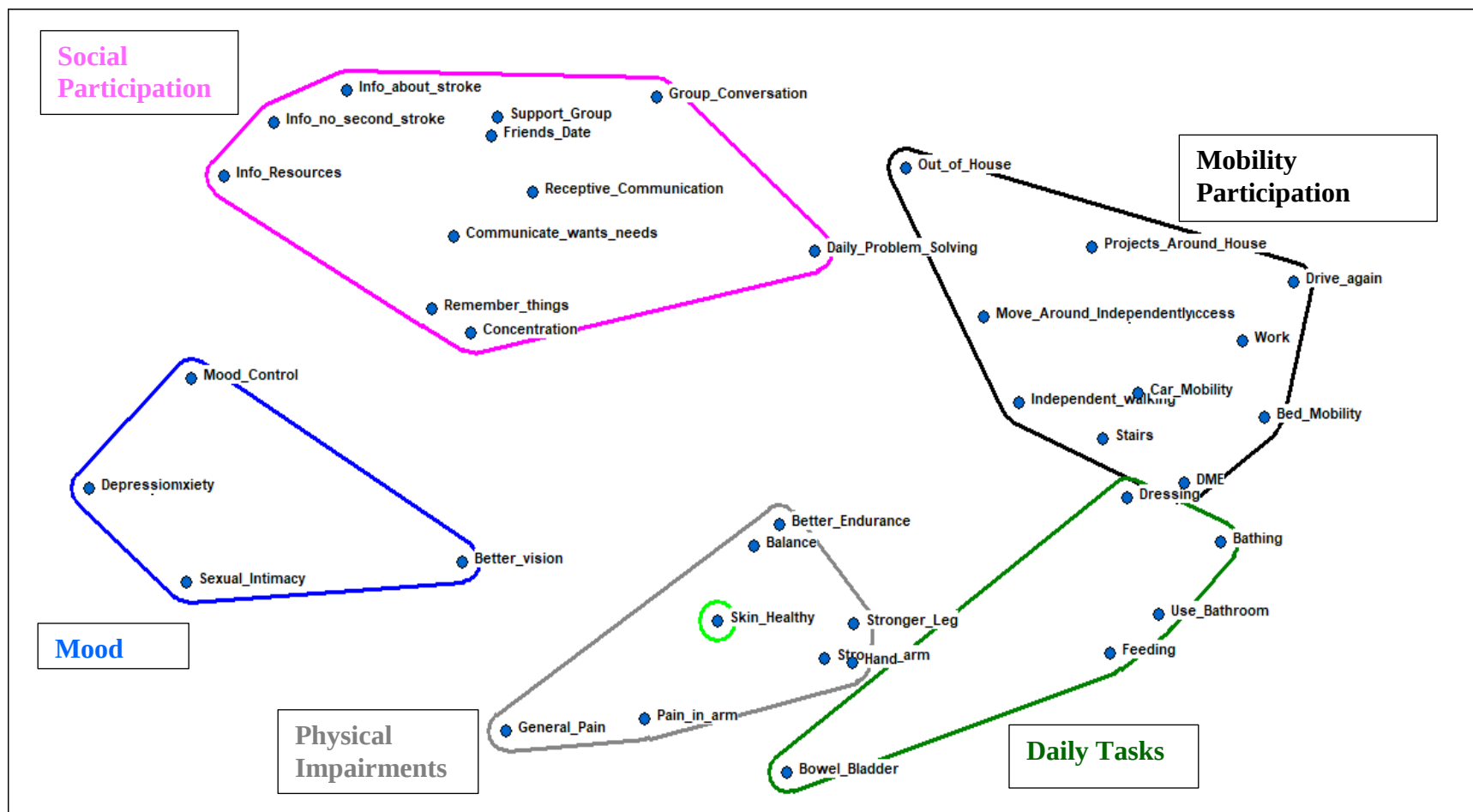
	Male < 65 N=10	Female < 65 N=9	Male ≥ 65 N=10	Female ≥ 65 N=9
Age, M years (SD)	53.5 (7.79)	55.44 (8.40)	72.7 (8.78)	74.33 (8.67)
Race/Ethnicity n(%)				
African American	(4)40%	(5) 55.56%	(3)30%	(2) 22.2%
Asian	(1) 10%	0%	0%	(1) 11.1%
Caucasian	(4) 40%	(3) 33.33%	(7) 70%	(5) 55.6%
Hispanic	0%	0%	0%	(1) 11.11%
Biracial	(1) 10%	(1) 55.6%	0%	0%
Time Since Stroke, M Months (SD)	64.7 (32.48)	132.11 (96.33)	100 (96.9)	101.33 (108.82)
MOCA Score, Mean (SD)	25.8 (2.35)	24.56 (2.30)	24.7 (1.42)	24.44 (1.94)
Current Social Support n(%)				
Spouse	(6) 60%	(2) 22%	(6) 60%	(4) 44.4%
Parent/Child/Provider	(2) 20%	(4) (44%)	0%	(3) 33%
None	(2) 20%	(3) 33%	(4) 40%	(2) 22%

Five main areas or subgroups of items were evident in the multidimensional scaling of the group as a whole (Figure 2.2) as well as the groups compared by gender (Figure 2.3 and Figure 2.4) and by age (Figure 2.5 and Figure 2.6). The consistent pattern that emerged was a clustering of items in the following 5 categories. 1) Information, Communication, and Social Participation; 2) Physical Impairments; 3) Daily Tasks; 4) Mood & Sexual Intimacy; and 5) Mobility, with a stress coefficient for the group of 0.19. Items within the first group included communication items, support groups, participation in activities in the community and information about resources.

The physical impairment items, such as stronger extremities, better balance, and better endurance were consistently grouped together. The pain items were always grouped together, but did not always end up in the same category. The pain items were sometimes grouped with the physical impairment items (total group, young stroke) with the mood items (female), with vision and skin (male) or in a category by themselves (older stroke). Interestingly, sexual intimacy was grouped with the mood items rather than the mobility or impairment items, across all groups except the female subgroup. One item, healthy skin, was not consistently grouped with other items, and in some (total and older stroke) ended up as a one item category.

Figure 2.2 MDS FOR TOTAL SAMPLE

Stress Coefficient =.189



These 5 categories were also present in age and gender subgroups, with the exception of the pain items. When comparing the male vs female groupings, the following differences were found. Males grouped the information items in a separate category, whereas they were included in the communication and social participation group for the females. The final male groupings that were similar to the overall group included: 1) Information; 2) Communication and Social Participation; and 3) Mood & Sexual Intimacy. Males had separate groupings of 4) Cognitive Items; 5) Pain; and 6) Impairments, Daily Tasks and Mobility were grouped together.

When comparing the older and younger stroke survivors, both had similar groupings for the 1) Information; 2) Communication and Social Participation 3) Daily Tasks and 4) Mood & Sexual Intimacy categories. In the older stroke group, the physical impairment items were divided with upper extremity impairments falling in the group with self-care items, and the lower extremity impairments along with balance and endurance falling with the mobility items. Also, the pain items were in a separate group. For the younger stroke group, pain was included in the physical impairment group and the self-care and mobility items were grouped differently.

Figure 2.3 MDS FEMALES

Stress Coefficient .211

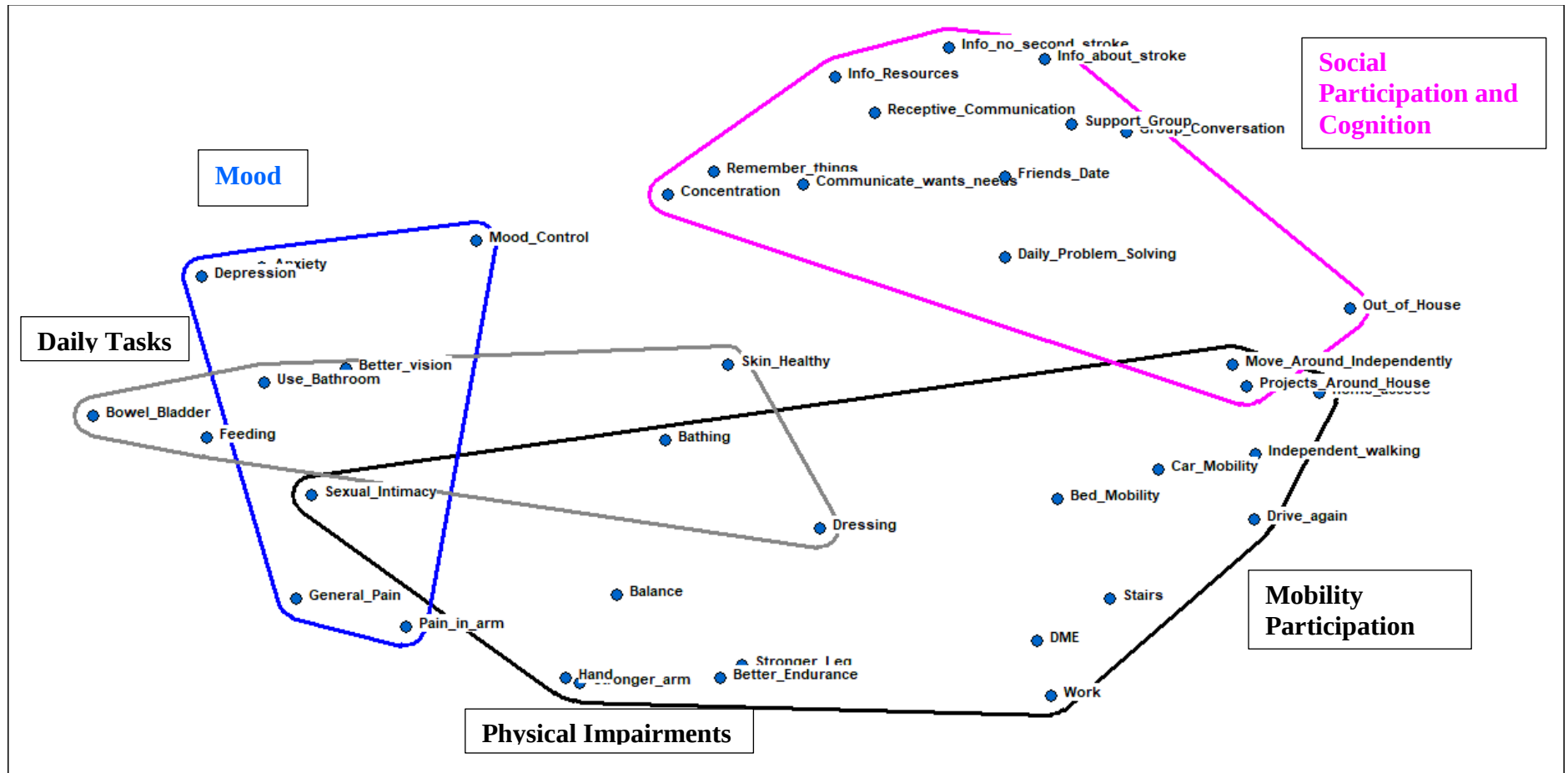


Figure 2.4 MDS MALES

Stress Coefficient .171

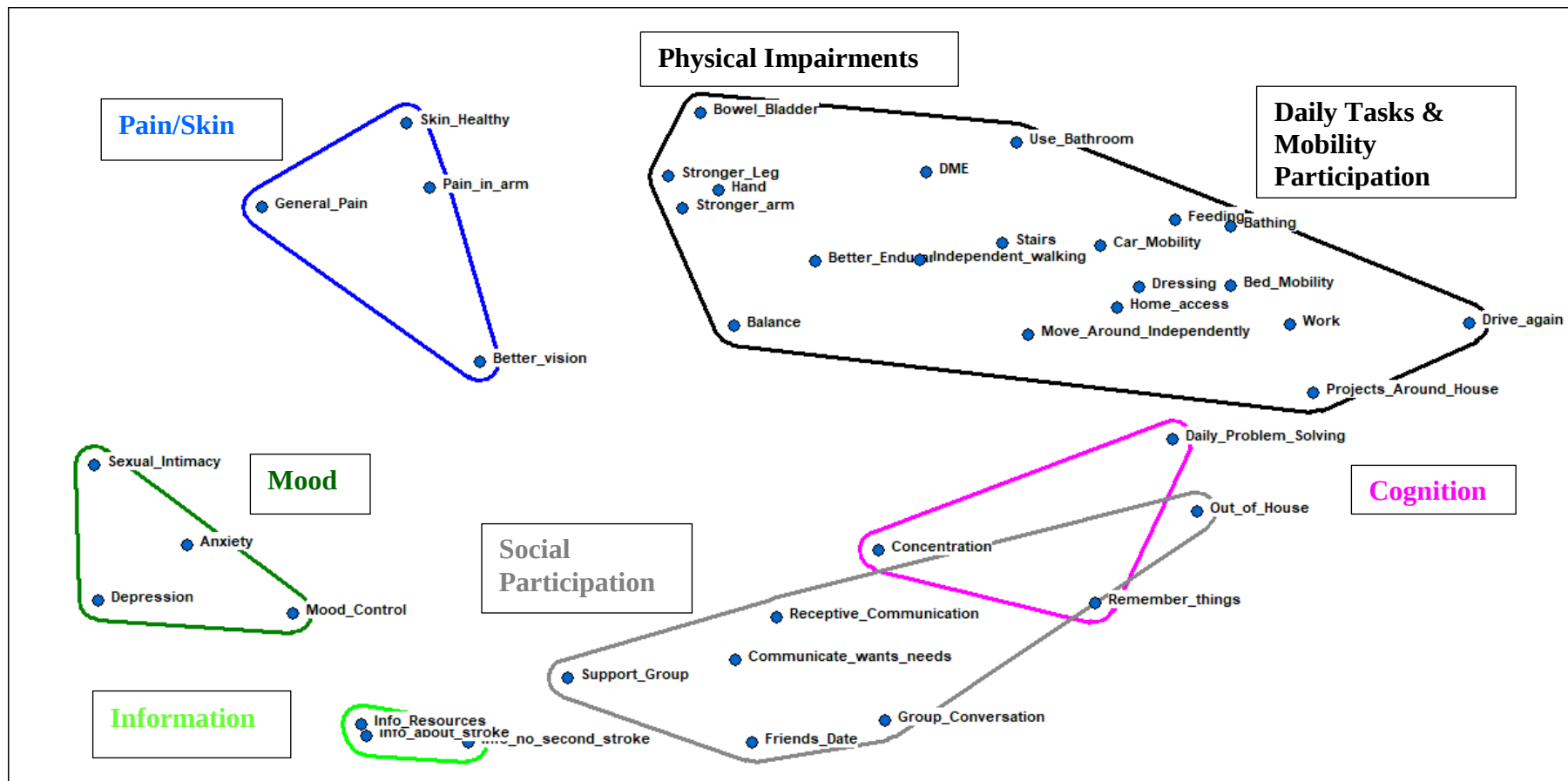


Figure 2.5 MDS ≥ 65
Stress Coefficient .181

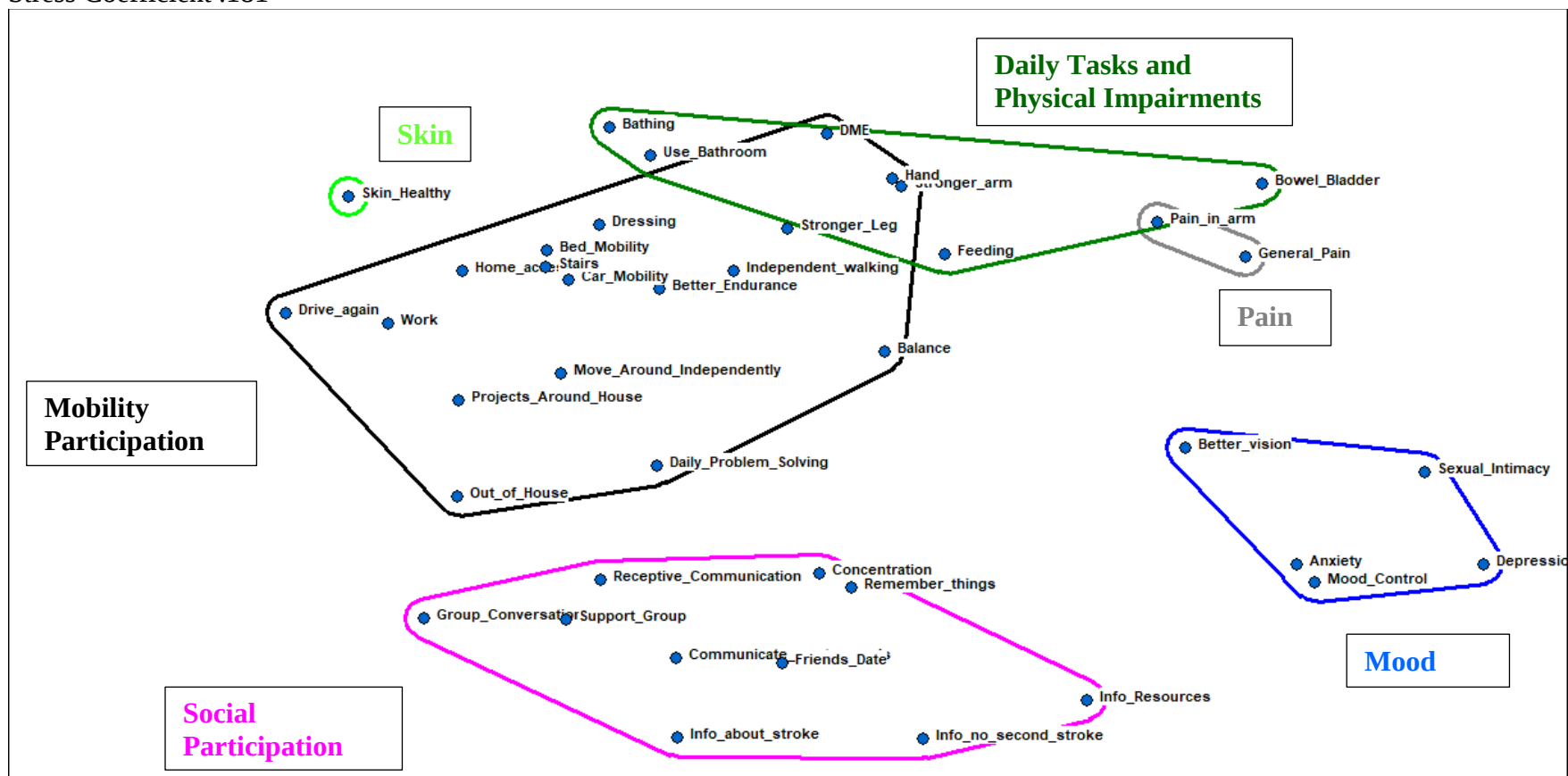
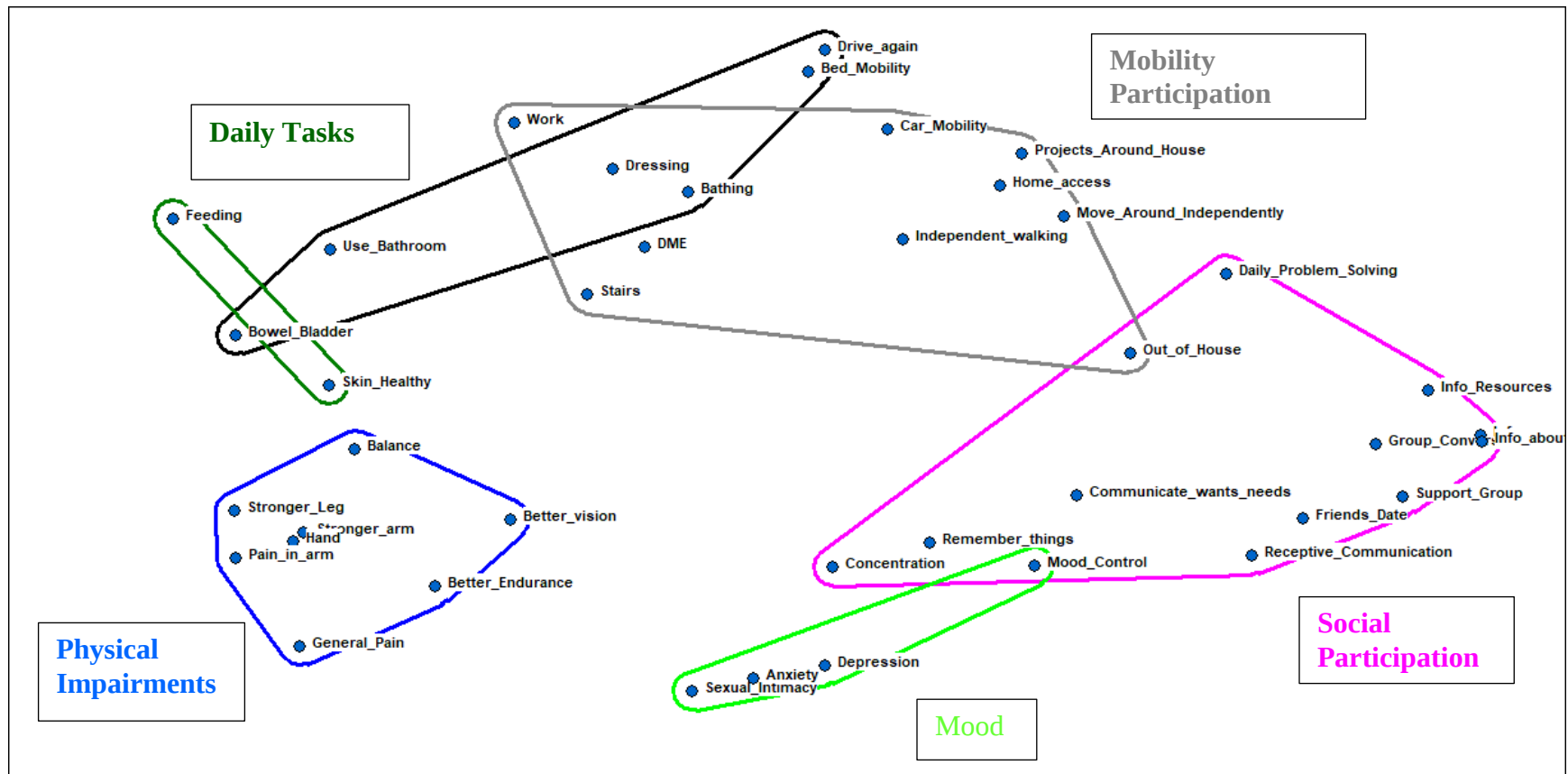


Figure 2.6 MDS <65

Stress Coefficient .203



DISCUSSION

The results of this study show a framework for how stroke survivors conceptualize goals and can be used as a foundation for developing a survey that can be disseminated to a larger group of stroke survivors. A larger scaled survey could lead to a better understanding of the importance of different goals after a stroke. This information can help guide outcome discussions amongst clinicians, stroke survivors, and their caregivers and help improve patient centered care during and after stroke rehabilitation.

As a group as a whole, stroke survivors grouped goals in a patterns similarly across groups. It is recommended that future surveys following this same framework and group items in the following categories: 1) Information; 2) Communication and Social Participation; 3) Physical Impairments; 4) Daily Tasks; 5) Mood & Sexual Intimacy; and 6) Mobility.

The FIM™ scale consists of 18 items which can be broken down into 5 categories: Self-care, sphincter control, transfers/locomotion, communication and social cognition.^{27,28} The goals included in this study that are included in each FIM™ category are: self-care (eating, bathing, toileting, dressing and bowel/bladder control); transfer/locomotion (walking, moving around independently, bed mobility and stairs); communication (comprehension and expression); and social cognition (remembering things, daily problem solving, and mood control). While all FIM™ items were not grouped together, participants did follow the FIM™ categories when grouping most items. For example, all self-care items were grouped together by the group as a whole and for the groups of women and men. Communication and expression were always grouped together, but there were many

other items related to social communication and information that were included as well.

The social cognition items followed a different pattern. Memory and problem solving were consistently grouped together, but mood control, was grouped with the other mood related items such as depression and anxiety rather than with the other cognitive items. The participants in this study are chronic stroke survivors and the majority had received rehabilitation and therapy services, so their groupings could have been influenced by their experiences with different therapy disciplines. It would be beneficial to complete the same pile sorting with individuals who have not yet received therapy services to see if acute stroke survivors also group the goals in this pattern.

The ICF considers the impact of an injury from the activity, participation and impairment categories while also considering the contextual influence of the person and their environment.¹⁴ The participants in this study did follow the ICF model by grouping similar impairments, or activities together, but the overall groups were guided more by the activity. For example, all physical impairments were grouped together, but impairments related to communication and cognition were grouped in a social participation category, and impairments related to mood were grouped together in a separate category. Similar activities were also grouped together, but again were guided more by the overall category, so that all self-care activities were together, and all mobility activities were together. The participation goals, were grouped at the activity level as well. For example, the goal of seeing friends was consistently grouped in the social participation category, and the work and driving goals were grouped in the mobility category. In summary, the participants did not group the items in a pattern that followed directly either the FIM scale or the ICF model.

Therefore, it is recommended that future surveys and communications regarding goals with stroke survivors follow the groupings identified by this sample of individuals.

The two pain items included in this analysis did not consistently remain in one particular group. While pain is frequent after a stroke^{43,44} for the majority of these individuals, pain was not a part of their daily lives. It would be interesting to continue this investigation with another group of stroke survivors who are currently experiencing pain to determine where these items are categorized.

It is worth considering that sexual intimacy was the one activity that was consistently grouped with the mood items rather than the other daily activity items. While in the recent past, sexual functioning after stroke was not always considered, it is now recognized as an important aspect of an individual's quality of life that should be addressed.⁴⁵ Stroke and medications can negatively affect sexual expression and intimacy because of physical impairments, changes in cognition, changes in emotional expression, and depression.⁴⁶ Recommendations for addressing sexual functioning after a stroke include providing a program which includes educational information, emotional counseling and training on techniques to manage challenges.⁴⁷ These results indicate that for chronic stroke survivors, it could be beneficial to begin conversations regarding sexual intimacy around mood discussions as that is where the stroke survivors group this item.

Skin health was not consistently grouped with any of the other goals in any of the groups. This group of individuals was high functioning, most were ambulatory, and none reported skin issues. Stroke survivors with more limited mobility are at risk for developing skin breakdown and wounds. A future study should investigate where skin health is categorized amongst individuals who have a history of skin breakdown.

LIMITATIONS

This study is the first to utilize card sorting methods to determine how stroke survivors conceptualize goals. This information can be utilized when developing surveys for stroke survivors and when communicating with stroke survivors during patient centered goal discussions. There are some limitations to this study that should be considered. This group was a small sample of chronic stroke patients who had received rehabilitation. Because the sample was a group of chronic stroke survivors who had been living in the community for months to years post stroke, it is unclear if the findings here could be generalized to include acute stroke survivors. Also, this group's experiences in rehabilitation could have impacted their goal categorization. Also, including such a large number of goals (40) during the card sort exercises increased the stress coefficient.

CONCLUSIONS

In this study we found stroke survivors grouped items into the following categories: 1) Information; 2) Communication and Social Participation; 3) Physical Impairments; 4) Daily Tasks; 5) Mood & Sexual Intimacy; and 6) Mobility. Utilizing these categories when beginning discussions related to post stroke goals could facilitate patient centered care and give clinicians a better understanding of how to approach goal discussions and treatment interventions.

CHAPTER 3. PATIENT-CENTERED GOALS IN REHABILITATION

INTRODUCTION

The majority of clinicians recognize the importance of setting goals for their clients as part of the treatment plan, but the lack of clear guidelines on how best to incorporate the client into goal setting makes the actual practice of patient-centered care in rehabilitation difficult.⁴⁸ Clinicians from different disciplines report different goal priorities for patients who have had a stroke.⁴⁹ While most clinicians say that they are patient-centered in their approach to goal setting, the majority of the goals are established and led by the therapy team.^{24,25}

Clinicians report there are more barriers than facilitators when seeking to include the individual in goal setting.^{24,26} Some of the barriers to patient-centered goal setting in rehabilitation include, a lack of knowledge about goal setting for the patient²⁵, and organizational requirements.²⁶ Another challenge is the difference in how patients and clinicians approach goal setting. Patients typically set more global goals, and tend to focus on the areas of participation, whereas clinicians are more specific in their goals and focus on the areas of impairment and activity limitations.⁵⁰ A disconnect between what the patient and the clinician see as a priority can add to the challenge of patient inclusion during goal setting.⁵¹ Many of the goals that are appropriate in the hospital setting may not address the goals that are important to the individual once they are back in the community.

Despite the many barriers to including patients in the goal setting process, both clinicians and patients feel it is beneficial to do so. Having a patient-centered approach has been shown to lead to a more positive rehabilitation experience from the patient's perspective.^{52,53}

It is still not clear however, when is the most appropriate time to include the patient in the goal setting. Some stroke patients who were in the early stages of recovery reported they didn't know the appropriate language or have a sufficient understanding of their deficits to set realistic goals.¹⁶ Other stroke patients describe early in rehab a clinician-led approach to goal setting was beneficial.²⁶ However, one study has shown that including the patient in the goal setting during early rehabilitation is feasible and resulted in a broader range of goals than when the clinicians alone were setting the goals.⁵² Having a framework to begin the dialogue about goals during rehabilitation could facilitate goal discussions and lead to increased patient inclusion during goal decisions.

Age Differences Post Stroke:

There are different life roles and expectations for individuals before and after retirement age. Individuals who sustain a stroke in their 40's or 50's typically have work and family obligations that are different than individuals who are past retirement age. The majority of the research investigating young stroke recovery focuses on return to work goals.⁵⁴⁻⁵⁶ While this is a major role for individuals who are below retirement age, there are other adult life roles that may be of importance to these individuals.

Some young stroke survivors report their time in rehabilitation was meaningless because it did not address their age specific needs.¹⁸ Unmet needs reported by young stroke survivors include information about the stroke, help with finances, assistance with social activities, and help with maintaining intellectual fulfilment.¹⁹ Young stroke survivors have reported financial issues, psychological issues, and challenges with interpersonal support.⁵⁷ Other unique challenges to the young stroke patient include marital breakup, and child care responsibilities.⁵⁸

Adding to the challenge for young stroke survivors is that many of the goals that are important to them are not able to be addressed during acute inpatient rehabilitation. Return to work goals often do not emerge until 6 to 12 months post stroke, when most individuals are no longer regularly receiving rehabilitation services.⁵⁷ Factors that contribute to return to work for these individuals include vocational rehabilitation, employer flexibility, social benefits, and support from family and coworkers.⁵⁹ However, only a small portion of these individuals receive a referral for vocational services.⁵⁷ The unique needs of both age groups should be considered when developing a rehabilitation plan of care.

Goal Importance:

Previous investigations have considered the importance of certain goals after a stroke. When a recent survey of stroke survivors asked them to list their top two goals in recovery after a stroke, the most frequent responses were walking (41%), better use of arm (13%), better use of hand (12%), improving speech (21%), driving (10%), and return(ing) to work (8%).⁶⁰ For this survey, 504 stroke survivors (or caregiver proxy) were interviewed by telephone. The sample was 42% male and 57% female. 44% were ≥ 65 years old and 57% were < 65 years of age. The results were presented as a summary of the entire sample, without separation of results by gender or age.⁶⁰ It would be helpful to know if there are different goal priorities by age or gender, and how an individual's current performance might impact their importance ratings.

While there is some information about what goals are important to stroke survivors, it is unclear how an individual's current performance may or may not impact their rating of the importance of goals. This is an important consideration because it can impact the

goal discussions. For example, if a clinician knows that walking is an important goal for an individual whether they need supervision or a lot of assistance, then this can remain a focus area whenever the individual receives therapy. By having a better understanding of how current performance impacts importance ratings on various goals, we can answer the following questions: Are there certain impairment, activity, or participation limitations that are recognized as important regardless of if an individual has a major deficit in that area? Are there other areas of functioning that are only recognized as important when an individual experiences that deficit? This information can help guide patient-centered practice in a couple of ways. First, a clinician can anticipate which deficits are going to be most important to address during their limited time with a patient to have the greatest impact on their lives in the years post stroke. Also, if there are areas that are identified that become most important when they show up, a clinician can provide information on strategies or resources for these areas that the patient can access in the years to come if these deficits appear when they are no longer receiving rehabilitation services.

Importance Performance Analysis:

Importance Performance Analysis (IPA) is a way to integrate and visualize how performance and importance are related. It was first developed and utilized in the automobile industry.⁶¹ It has since been used primarily by process improvement teams, to prioritize what areas of a practice are most important to address for patient⁶² or employee satisfaction.⁶³ IPA has also been used to determine what psychosocial factors most impact stress levels.⁶⁴ The Canadian Occupational Performance Measure (COPM) has been utilized in rehabilitation and research to measure current importance and performance on patient selected goals.^{65,66} However, on the COPM, importance and performance are

analyzed separately as a change in score over time, and the relationship between the two values, which IPA analysis provides, is not done on the COPM.

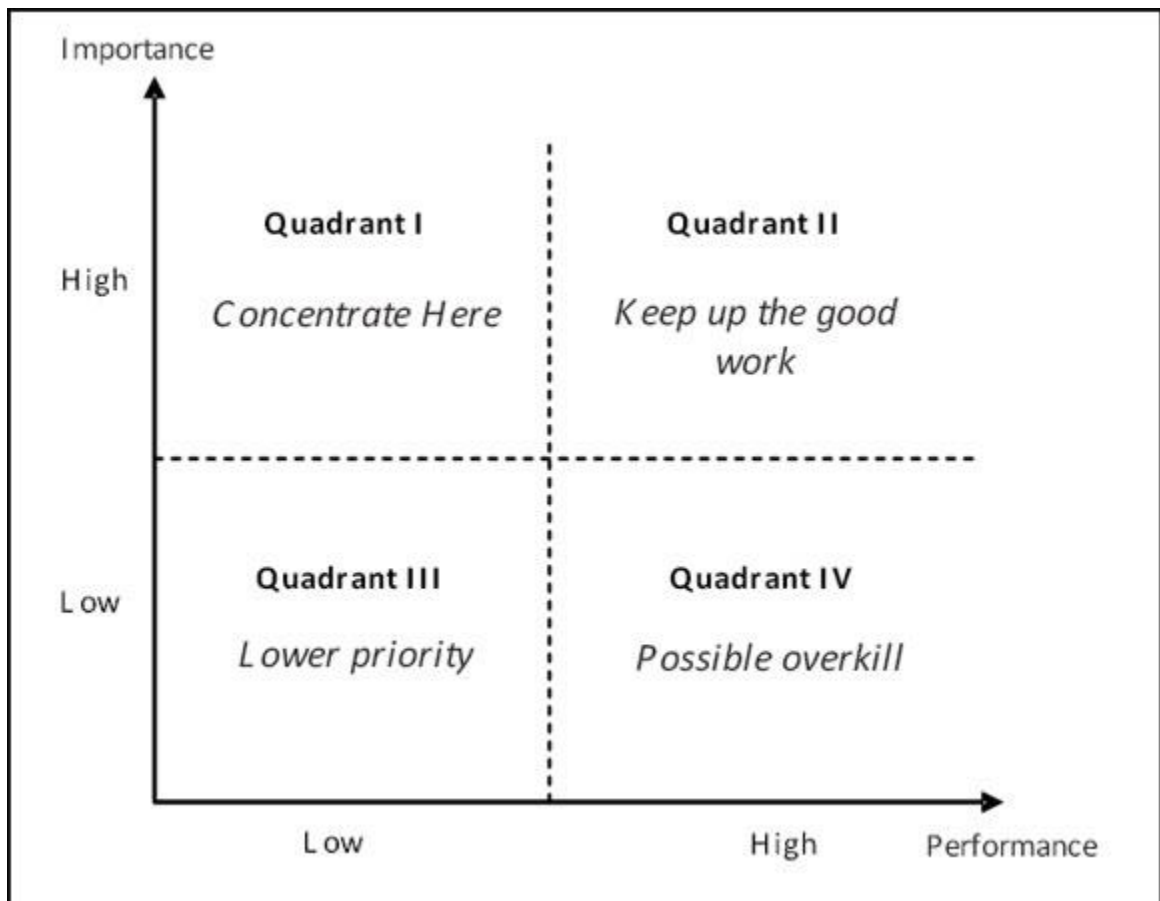
To our knowledge, IPA has not been used in rehabilitation, but it shows promise as an effective way to communicate with patients and other clinicians about what areas of rehabilitation should be prioritized at different stages of recovery and could provide a common framework for patients and clinicians to discuss their goals. For this investigation, the analysis was at one point in time, but in the future it could be used longitudinally to determine how performance impacts importance ratings over time.

IPA plots a 2-dimensional representation of importance and performance/function, creating a visualization of each goal in the four quadrants. (Figure 3.1) When IPA is used for process improvement, each of the four quadrants is labeled as follows. Quadrant 1: The quadrant with goals that are of low performance and high importance is labeled “Concentrate Here.” Quadrant II: The quadrant with goals that are of high performance and high importance is labeled “Keep Up the Good Work.” Quadrant III: The quadrant with goals that are of high performance and low importance is labeled “Possible Overkill.” Quadrant IV: Finally, the quadrant with goals that are of low performance and low importance is labeled “Lower Priority.”

More recent suggestions on how to visualize the relationship between importance and performance suggest using a linear line where performance=importance as the delineation for the focus areas, with anything above this line being something to draw focus towards.⁶⁷ For the overall sample, we also considered which goals should be a focus area if this diagonal line was used.

While each of these named quadrants has an important message for process improvement decisions, it does not seem appropriate to label the goals regarding inpatient rehabilitation in this manner as we anticipate these goals will be more fluid and will most likely move from quadrant to quadrant depending on the patient's current level of performance and where they are in their recovery. For our purposes, we will use the results from the IPA to focus on the upper left quadrant and begin goal discussions with the goals that end up there.

Figure 3.1 Importance Performance Grid



METHODS

The same group of participants who participated in the card sorting task described in chapter 3 were included here. More detailed information about subject recruitment and eligibility are included in chapter 3. Briefly, we recruited 46 stroke survivors in the Houston and Galveston areas. The participants were screened for self-awareness and cognitive status. Eligibility criteria included: age (>18), ability to communicate in English, history of hospitalization because of a stroke, discharged from hospital at time of interview, able to follow commands, and cognitively able to consent to the study. Purposive sampling was used with the goal of obtaining 10 participants in each of the following groups: (Female <65 , Male <65 , Female ≤ 65 , and Male ≤ 65).

There were 3 ranking tasks completed for this investigation. First, participants rated each goal on (1) current performance and (2) current importance, which were used for the importance performance analysis. Then, participants completed the third ranking task when they were asked to rate each goal on (3) overall importance when considering all individuals who have had a stroke. This ranking was used for the overall importance analysis. The methods and analysis for ranking tasks 1 and 2 will be described in the importance performance sections and the methods and analysis for rating task 3 will be described in the overall importance sections.

Importance Performance Analysis Methods:

Open ended interviews with 10 participants were used along with common outcome measures to gather the 40 patient goals. The development of the goals has been described previously, in chapter two. The three goals related to stroke education, were excluded from the IPA analysis because in initial trials participants viewed these responses as either a

yes/no answer rather than on the ordinal performance Likert scale. Therefore, there were 37 goals utilized in this analysis.

For the IPA, each goal statement was read to the individual, and they were asked to rate their current performance on each goal and then rate the goals in terms of their importance. The participant was read the following instructions:

“Now, I would like for you to think about how you are doing right now with your stroke recovery. For each of these goal statements, I would like for you to rate how well you are performing this goal right now on this 1-5 scale, with 1 being ‘unable to perform’ and 5 being ‘able to perform as well as before my stroke’. Next, I would like for you to indicate how important the goal is to you right now. Just like in the last group, you have to place at least one card on each of the 5 importance levels.”

The evaluator wrote in the score for each goal as the subject states it, utilizing the IPA form (Appendix D). The subjects were asked to rate their current performance (using the performance scale below) on each goal as well as how important this goal is to them (using the importance scale below) at the current time.

Figure 3.2: Importance Likert Scale

IMPORTANCE LIKERT SCALE

Not at all important	Somewhat important	Important	Very Important	Extremely important
1	2	3	4	5

Figure 3.3 Performance Likert Scale

PERFORMANCE LIKERT SCALE

Unable to perform the activity	Can complete activity with a lot of help	Can complete activity with a moderate amount of help	Can complete activity with a little help, or I need extra time	Can complete activity as well as before my stroke
1	2	3	4	5

Important Performance Analysis:

All participants scored <7 on the SADI and were therefore all included in the IPA analysis. The importance performance analysis was conducted as follows. For both the importance and performance results, overall reliability of the respondents was measured using Cronbach's alpha, but for the group as a whole and for each subgroup. Next, the mean scores of importance and performance for the entire sample were calculated and then plotted. The quadrants were established based on the median score for performance and importance. Goals that are in Quadrant I, indicating low performance and high importance were identified. IPA graphs were plotted and compared for the overall sample, and by group (male, female) (young, old).

Overall Goal Importance Methods:

To measure overall importance of each goal during stroke recovery, and compare by age and gender individuals were provided a new stack of 40 cards with the same goal statements written on them. They were asked to sort the cards into groups based on overall importance of the goals. The participant were read the following instructions

“We just finished rating these goals on how important they are to you. Now, I would like for you to consider what goals you think are most important in overall stroke recovery when you consider everyone who has ever had a stroke. There is a scale here from 1-5 with 1 being ‘not important at all’ and 5 being ‘extremely important critical’ please place each of these cards on the scale to indicate how important this goal is in overall recovery from a stroke. You have to place at least one card on each of the 5 levels.”

The same importance scale (FIGURE 3.2) was utilized for this portion of the investigation, and all 40 goals were used.

Overall Importance Analysis:

First, the mean and standard deviation for the importance rating of each goal was measured. The internal consistency/reliability of each respondent was evaluated as a group as a whole and by subgroup. (men vs women, old vs young, women <65, women ≥65, men <65 and men ≥65). Pearson correlations using the mean score for each goal was calculated to compare groups on reliability. Finally, the goals were ranked and compared by group and spearman correlation coefficients were calculated to compare rank order of the goals by group. The rank of goals was also compared descriptively by the group as a whole and by subgroup.

RESULTS

Overall, 38 individuals completed the importance/performance ratings and the overall importance ratings. The sample characteristics were reported previously, in chapter two, with the table for both the overall sample characteristics (Table 3.1) and the sub group sample characteristics (Table 3.2) included here as well.

Table 3.1: Sample Characteristics

SAMPLE CHARACTERISTICS				
	Total Sample	Men	Women	p value
N	38	19	19	
Age Mean (SD)	63.9 (12.6)	63.1 (12.73)	64.9 (12.76)	p=0.67
Race/Ethnicity n (%)				
African American	14 (36.8)	7	7	p=0.85
Asian	2 (5.26)	1	1	
Caucasian	19 (50.0)	11	8	
Hispanic	1 (2.63)	0	1	
Biracial	2 (5.26)	1	1	
Time Since Stroke (months) Mean (SD)	98.6 (87.7)	82.35 (72.70)	116.7 (100.9)	p=0.23
MOCA Mean(SD)	24.90 (2.02)	25.25 (1.97)	24.50 (2.07)	p=0.25
SADI Mean (SD)	1.10 (0.92)	1.03 (.88)	1.20 (.99)	p=0.58
Current Social Support				
Spouse	18	12	6	P=.09
Parent/Child/Provider	9	2	7	
None	11	6	5	

Table 3.2: Subgroup Sample Characteristics

	Male <65	Female <65	Male ≥ 65	Female ≥ 65
Age	53.5 (7.79)	55.44 (8.40)	72.7 (8.78)	74.33 (8.67)
Race/Ethnicity				
African American	40% (4)	55.56% (5)	30% (3)	22.2% (2)
Asian	10% (1)	0	0	11.1% (1)
Caucasian	40% (4)	33.33% (3)	70% (7)	55.6% (5)
Hispanic	0%	0	0	11.11% (1)
Biracial	10% (1)	55.6% (1)	0%	0%
Time Since Stroke	64.7 (32.48)	132.11(96.33)	100 (96.9)	101.33 (108.82)
MOCA Score	25.8 (2.35)	24.56 (2.30)	24.7 (1.42)	24.44 (1.94)
Current Social Support				
Spouse	60% (6)	22% (2)	60% (6)	44.4% (4)
Parent	20% (2)	0	0	0
Child	0	33% (3)	0	22% (2)
Provider	0	11% (1)	0	11% (1)
None	20% (2)	33% (3)	40% (4)	22% (2)

The mean scores for each goal and the internal consistency score for importance for each group are included in table 3.2 below. The agreement within the sample as a whole and within each group indicates a reliable overall preference pattern, with Cronbach's alpha of 0.77 for the entire group, 0.66 for females, 0.60 for males, and 0.66 for both the young (<65) and old (≥ 65) groupings. When the smaller subgroups were compared, there was good reliability in all groups except the men <65. Women <65 Cronbach's alpha=0.56, women ≥ 65 alpha=0.57, men <65 0.28 and men ≥ 65 0.50. The men <65 appear to be less reliable and more variable in their responses.

The overall ranking of the goals by total sample and individual group are included in the charts 3.3-3.5 below. Items that are currently captured by the required FIM™ documentation are indicated by an *. While many of the items ranked as most important are included in the FIM™ documentation, there are many others such as balance, information, stronger arm, stronger leg, and vision that are consistently in the top 10 of items and are not included in the FIM™ documentation.

Table 3.2: Overall Importance Mean Score for Each Goal and Agreement

Subject Goal	Total N=38	All women N=18	all men n=20	<65 M+F n=19	≥65 M+F n=19
Drive Again	3.66	3.61	3.70	3.63	3.68
Better Vision	3.89	3.94	3.85	3.95	3.84
Concentration	3.82	3.94	3.70	3.58	4.05
Remember Things	4.00	4.17	3.85	3.84	4.16
Communicate Wants/Needs	3.87	4.11	3.65	3.63	4.11
Receptive Communication	3.71	3.67	3.75	3.47	3.95
Stronger Arm	3.95	4.11	3.80	4.11	3.79
Hand Function	3.61	3.61	3.60	3.84	3.37
Pain In Arm	3.58	3.61	3.55	3.95	3.21
B&B	3.87	3.61	4.10	4.05	3.68
Home Access	3.61	3.28	3.90	3.79	3.42
Dressing	3.87	3.78	3.95	3.89	3.84
Feeding	4.05	4.06	4.05	4.11	4.00
Daily Problem Solving	3.34	3.39	3.30	3.26	3.42
Out of House More	3.21	3.17	3.25	3.00	3.42
Bathing	3.79	3.78	3.80	3.79	3.79
Bathroom I'll	4.05	3.83	4.25	4.05	4.05
Bed Mobility	3.63	3.44	3.80	3.42	3.84
Balance	4.26	4.39	4.15	3.95	4.58
Stronger Leg	3.76	4.06	3.50	4.05	3.47
Sexual Intimacy	3.08	2.44	3.65	3.21	2.95
Projects Around the House	2.95	2.83	3.05	2.63	3.26
Group Conversation	3.26	3.56	3.00	3.00	3.53
Support Group	3.32	3.44	3.20	3.16	3.47
Socialize/Date	3.66	3.78	3.55	3.42	3.89
Work	2.97	2.83	3.10	3.26	2.68
DME	2.74	2.56	2.90	3.11	2.37
General Pain	3.61	3.44	3.75	3.79	3.42
Move Around Ind.	4.03	3.94	4.10	4.05	4.00
Better Endurance	3.68	3.72	3.65	3.53	3.84
Independent Walking	4.16	4.17	4.15	4.21	4.11
Anxiety	3.21	3.06	3.35	3.26	3.16
Mood Control	3.45	3.17	3.70	3.26	3.63
Depression	3.39	3.17	3.60	3.53	3.26
Info_No_Second_Stroke	4.18	4.00	4.35	3.95	4.42
Info About Stroke	3.79	3.72	3.85	3.63	3.95
Info Resources	3.66	3.94	3.40	3.16	4.16
Skin	2.92	2.67	3.15	2.63	3.21
Car Mobility	3.71	3.89	3.55	3.53	3.89
Stairs	3.08	3.28	2.90	2.95	3.21
Cronbach Coefficient Alpha	0.77	0.66	0.60	0.66	0.66

Table 3.3 Overall mean importance score and rank of goal items for total sample

*=FIM™ ITEM

Subject Goal	Total N=38
Balance	4.26
Info_No_Second_Stroke	4.18
*Independent Walking	4.16
*Feeding	4.05
*Bathroom I'll	4.05
*Move Around Ind.	4.03
*Remember Things	4.00
Stronger Arm	3.95
Better Vision	3.89
*Communicate Wants/Needs	3.87
*B&B	3.87
*Dressing	3.87
Concentration	3.82
*Bathing	3.79
Info About Stroke	3.79
Stronger Leg	3.76
*Receptive Communication	3.71
Car Mobility	3.71
Better Endurance	3.68
Drive Again	3.66
Socialize/Date	3.66
Info Resources	3.66
*Bed Mobility	3.63
Hand Function	3.61
Home Access	3.61
General Pain	3.61
Pain In Arm	3.58
*Mood_Control	3.45
Depression	3.39
*Daily Prob Solving	3.34
Support Group	3.32
Group Conversation	3.26
Out Of House More	3.21
Anxiety	3.21
Sexual Intimacy	3.08
*Stairs	3.08
Work	2.97
Projects Around the House	2.95
Skin	2.92
DME	2.74

Table 3.4: Mean overall importance score and ranks by gender

*=FIM item

Subject Goal	All women N=18
Balance	4.39
*Remember Things	4.17
*Independent Walking	4.17
*Communicate Wants/Needs	4.11
Stronger Arm	4.11
*Feeding	4.06
Stronger Leg	4.06
Info_No_Second_Stroke	4.00
Better Vision	3.94
Concentration	3.94
*Move Around Ind.	3.94
Info Resources	3.94
Car Mobility	3.89
*Bathroom I'll	3.83
*Dressing	3.78
*Bathing	3.78
Socialize/Date	3.78
Better Endurance	3.72
Info About Stroke	3.72
*Receptive Communication	3.67
Drive Again	3.61
Hand Function	3.61
Pain In Arm	3.61
*B&B	3.61
Group Conversation	3.56
*Bed Mobility	3.44
Support Group	3.44
General Pain	3.44
*Daily Prob Solving	3.39
Home Access	3.28
*Stairs	3.28
Out Of House More	3.17
*Mood_Control	3.17
Depression	3.17
Anxiety	3.06
Projects Around the House	2.83
Work	2.83
Skin	2.67
DME	2.56
Sexual Intimacy	2.44

Subject Goal	All men n=20
Info_No_Second_Stroke	4.35
*Bathroom I'll	4.25
Balance	4.15
*Independent Walking	4.15
*B&B	4.10
*Move Around Ind.	4.10
*Feeding	4.05
*Dressing	3.95
Home Access	3.90
Better Vision	3.85
*Remember Things	3.85
Info About Stroke	3.85
Stronger Arm	3.80
*Bathing	3.80
*Bed Mobility	3.80
*Receptive Communication	3.75
General Pain	3.75
Drive Again	3.70
Concentration	3.70
*Mood_Control	3.70
*Communicate Wants/Needs	3.65
Sexual Intimacy	3.65
Better Endurance	3.65
Hand Function	3.60
Depression	3.60
Pain In Arm	3.55
Socialize/Date	3.55
Car Mobility	3.55
Stronger Leg	3.50
Info Resources	3.40
Anxiety	3.35
*Daily Prob Solving	3.30
Out Of House More	3.25
Support Group	3.20
Skin	3.15
Work	3.10
Projects Around the House	3.05
Group Conversation	3.00
DME	2.90
*Stairs	2.90

Table 3.5: Mean overall importance score and rank by age group

*=FIM™ item

Subject Goal	<65 M+F n=19
*Independent Walking	4.21
Stronger Arm	4.11
*Feeding	4.11
*B&B	4.05
*Bathroom I'ly	4.05
Stronger Leg	4.05
Move Around Ind.	4.05
Better Vision	3.95
Pain In Arm	3.95
Balance	3.95
Info_No_Second_Stroke	3.95
*Dressing	3.89
*Remember Things	3.84
Hand Function	3.84
Home Access	3.79
*Bathing	3.79
General Pain	3.79
Drive Again	3.63
Communicate Wants/Needs	3.63
Info About Stroke	3.63
Concentration	3.58
Better Endurance	3.53
Depression	3.53
Car Mobility	3.53
*Receptive Communication	3.47
*Bed Mobility	3.42
Socialize/Date	3.42
*Daily Prob Solving	3.26
Work	3.26
Anxiety	3.26
*Mood_Control	3.26
Sexual Intimacy	3.21
Support Group	3.16
Info Resources	3.16
DME	3.11
Out Of House More	3.00
Group Conversation	3.00
*Stairs	2.95
Projects Around the House	2.63
Skin	2.63

Subject Goal	≥65 M+F n=19
Balance	4.58
Info_No_Second_Stroke	4.42
*Remember Things	4.16
Info Resources	4.16
*Communicate Wants/Needs	4.11
*Independent Walking	4.11
Concentration	4.05
*Bathroom I'ly	4.05
*Feeding	4.00
*Move Around Ind.	4.00
*Receptive Communication	3.95
Info About Stroke	3.95
Socialize/Date	3.89
Car Mobility	3.89
Better Vision	3.84
*Dressing	3.84
*Bed Mobility	3.84
Better Endurance	3.84
Stronger Arm	3.79
*Bathing	3.79
Drive Again	3.68
*B&B	3.68
*Mood_Control	3.63
Group Conversation	3.53
Stronger Leg	3.47
Support Group	3.47
Home Access	3.42
Daily Prob Solving	3.42
Out Of House More	3.42
General Pain	3.42
Hand Function	3.37
Projects Around the House	3.26
Depression	3.26
Pain In Arm	3.21
Skin	3.21
*Stairs	3.21
Anxiety	3.16
Sexual Intimacy	2.95
Work	2.68
DME	2.37

Table 3.6 below provides a comparison by group of the Pearson correlation coefficients of average importance score and the spearman correlation coefficients of rank order of importance scores. The biggest subgroup difference in score and ordering of the goals is between young and old (Pearson correlation coefficient 0.53 and Spearman correlation coefficient 0.51) and this difference is greatest in young and old women (Pearson correlation coefficient 0.33, Spearman correlation coefficient 0.28). Because of the low agreement amongst participants in the smaller subgroups (young women vs old women) we did not include comparisons of goals by the smaller groups.

Table 3.6: Pearson and Spearman Correlations Comparisons By Group

	Pearson Reliability	Spearman Rank Order
Male/Female	0.64	0.61
Old/Young	0.53	0.51
Old/Total	0.88	0.86
Young/Total	0.86	0.84
Male/Total	0.89	0.87
Female/Total	0.92	0.89
Male<65/Male≥65	0.49	0.54
Female<65/Female≥65	0.33	0.28

The average score for goals within the total sample ranged from 2.74(DME) to 4.26 (balance). All items were seen as important to the participants and should continue to be addressed in rehabilitation. Table 3.7 contains the goals that scored >4 on overall importance in the overall sample and within each of the subgroups. The goals that scored >4 in all groups included independent walking and feeding. Balance and information about how to prevent another stroke received a score of >4 in all groups except for the young

stroke survivors. Using the bathroom independently scored >4 in all groups except the grouping of all women.

Table 3.7: Goals with mean overall importance score >4

GOALS WITH AVERAGE SCORE >4					
GOAL	Total Sample n=38	All women n=18	All men n=20	All <65 n=19	ALL ≥ 65 n=19
balance	*	*	*		*
info no second stroke	*	*	*		*
independent walking	*	*	*	*	*
feeding	*	*	*	*	*
bathroom independently	*		*	*	*
move around independently	*		*	*	*
remember things	*	*			*
communicate wants and needs		*			*
stronger arm		*		*	
stronger leg				*	
bowel and bladder			*	*	
info on resources					*
concentration					*

There were not many items that received a score of ≤ 3 indicating all goals were seen as important to the stroke survivors. The goals that did receive a score ≤ 3 for the entire sample include work, completing projects around the house, skin health and DME. None of the goals were consistently ranked at the bottom in all groups. Sexual intimacy was ranked lower for both the ≥ 65 group and the women. Group conversations were ranked towards the bottom for men and those <65.

Table 3.8: Goals with average overall importance score of <3

GOALS WITH AVERAGE SCORE OF ≤ 3					
GOAL	Total Sample n=38	All women n=18	All men n=20	ALL <65 n=19	ALL $\geq$ 65 n=19
work	*	*			*
projects around the house	*	*		*	
skin	*	*		*	
DME	*	*	*		*
sexual intimacy		*			*
stairs			*	*	
group conversations			*	*	
out of the house more				*	

IMPORTANCE PERFORMANCE ANALYSIS RESULTS:

After considering the overall importance ratings for overall stroke recovery for each goal, we examined the importance ratings for each individual and how they were associated with their current performance. Table 3.9 has the reliability of respondents as an overall group and by subgroup. For the group overall, the reliability for performance was very high (.89) indicating the group was similar in their overall performance level and performance ratings. The subgroups also had good overall reliability for performance (women .80, men .81, young .80, and old .81)

Table 3.9: Reliability of Performance and Importance Ratings

IPA RELIABILITY		
	IMPORTANCE IPA RELIABILITY (Cronbach's Alpha)	PERFORMANCE IPA RELIABILITY (Cronbach's Alpha)
Total	0.79	0.89
All Men (n=20)	0.57	0.81
All Women (n=18)	0.71	0.80
All <65 (n=19)	0.67	0.80
All ≥65 (n=19)	0.72	0.81

Table 3.10: Correlations for Importance Ratings for IPA

	Pearson Correlation	Spearman Rank Correlation
Male/ Female	.668	.729
<65 / ≥65	.440	.470
Young Men/Old Men	.219	.315
Young Women/Old Women	.389	.243

The importance ratings for the overall group had good reliability (Cronbach's alpha =.79). The subgroups also had good reliability with their importance ratings (women Cronbach's alpha=.71, young Cronbach's alpha= .67, and old Cronbach's alpha= .72), but the men were less reliable than the other groups (Cronbach's alpha=.57) indicating that for some goals they did not agree on the importance. When the men were further divided into old and young groups, their reliability decreased slightly (Cronbach's alpha for men <65 =0.513 and for men ≥65= 0.461. For the men, the goals that had the most variability in

scoring included depression, driving, support group, work, DME, and sexual intimacy. Young men also had high variability in their responses on anxiety, concentration and socialization whereas old men had variable ratings on stairs.

Importance averages and ranks were also compared for the young and old groups and male and female groups. Men and women agreed more (Pearson correlation =.668) on scores than the young and old groups (Pearson correlation =0.440).

Because of the decreased reliability amongst the smaller sub groups, IPA graphs were plotted for the sample a whole (n=38) and for the men (n=20)/women (n=18) and old (n=19)/young (n=19), but not for the smaller groups (i.e. young men (n=10), young women (n=9)).

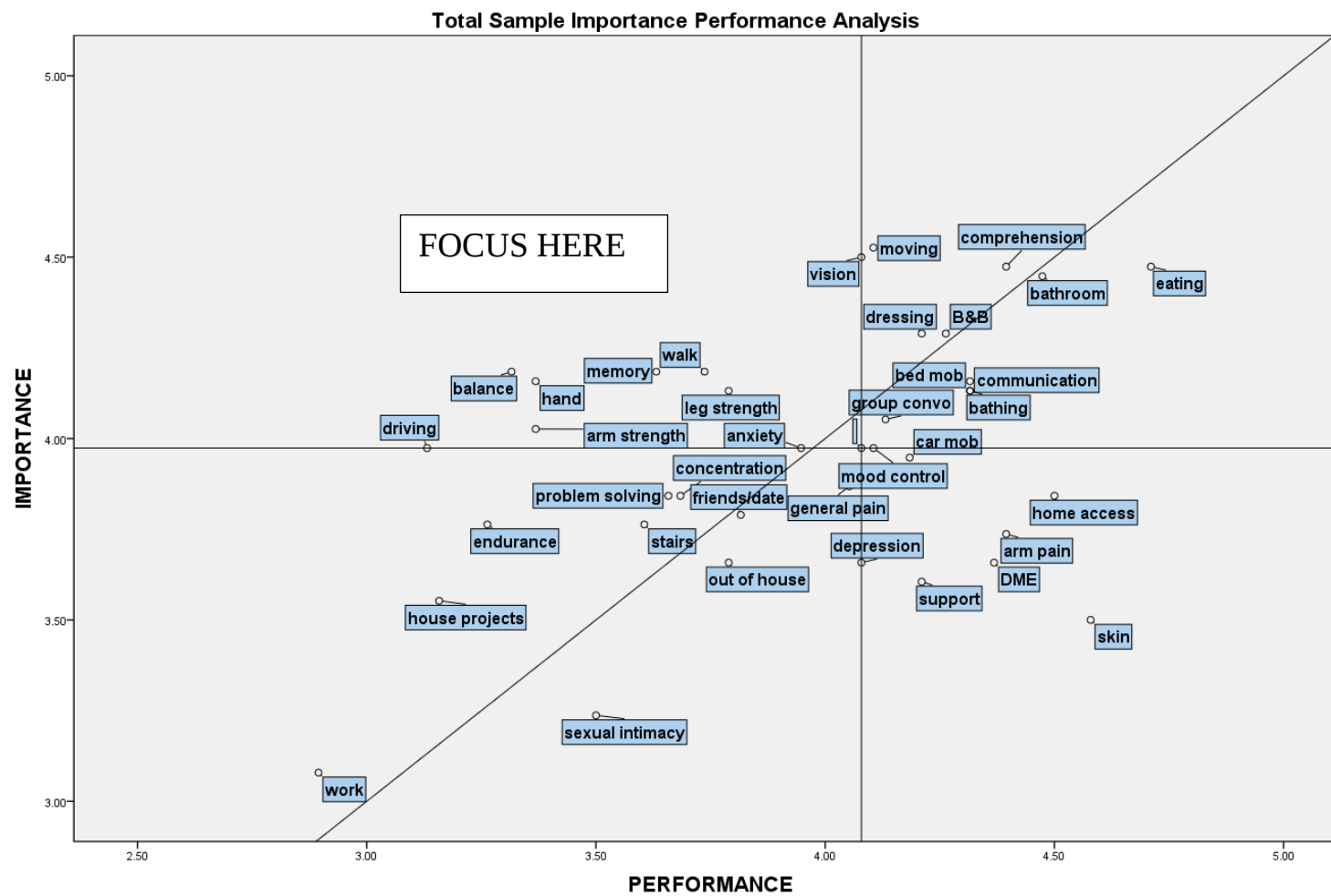
Figure 3.4 has the IPA for the entire sample (median score for importance = 3.97 and median score for performance = 4.08). The goals that are in the “focus here” quadrant include: leg strength, balance, hand function, driving, arm strength, memory, and walking. All FIM™ items except stairs are above the importance median line indicating they are all important items for the individuals. Items that were in the poor performance low importance area included work, sexual intimacy, and house projects. Items that were in the high performance, but low importance category included skin, home access, arm pain and DME.

When the diagonal line where performance=importance was included in the graph, there are more goals included as focus areas, including the majority of the goals that are in the “low priority” area in the traditional IPA graph. For the whole sample, the additional goals should be focused on including work, house projects, endurance, problem solving, stairs, concentration, and seeing friends or dating more.

Similarly, with each of the subgroup samples, more goals were identified as important when the diagonal line of performance=importance is utilized. For women, driving, getting out of the house, stairs, house projects, problem solving, and seeing friends/dating were included as goals to focus on. For men work, sexual intimacy, house projects, stairs, concentration, and problem solving were also included.

Recall that there were two importance ratings, the first the subjects were asked to rate importance of the goals for all stroke survivors and for the IPA they were asked to rate the importance of the goals for them specifically. The subjects agreed more on the importance rating for the entire stroke population (Table 3.6) than they did for their personal importance rating (Table 3.10).

Figure 3.4: TOTAL SAMPLE IPA



The male and female subgroup IPA are included here in Figures 3.2 and 3.3 respectively. (Male median performance= 4.0 and median importance= 3.95, Female median performance = 4.17 and median performance = 3.94). Similar to the overall groups, both men and women ranked all FIM™ items above the median importance score, except for stairs. In the “focus here” quadrant, both men and women included balance, memory, hand function and walking. Women also included concentration and bowel and bladder goals whereas the men included driving, arm strength, hand function, and vision. Sexual intimacy and work were rated as lower importance for females despite having similar performance ratings to males.

The median performance value for old stroke participants was 4.00 and the median importance value was 4.11. For young stroke survivors the median performance value 4.05 and the median importance value was 3.95. When comparing older stroke survivors to younger stroke survivors, (Figure 3.4 and 3.5) both included memory, arm, strength, and leg strength in their focus here quadrant. Young stroke survivors also had driving, hand function and balance, whereas older stroke survivors had bowel and bladder and problem solving. Sexual intimacy and work had lower importance ratings in older stroke survivors despite having similar performance ratings on these items to the younger stroke survivors.

Figure 3.5: Male IPA

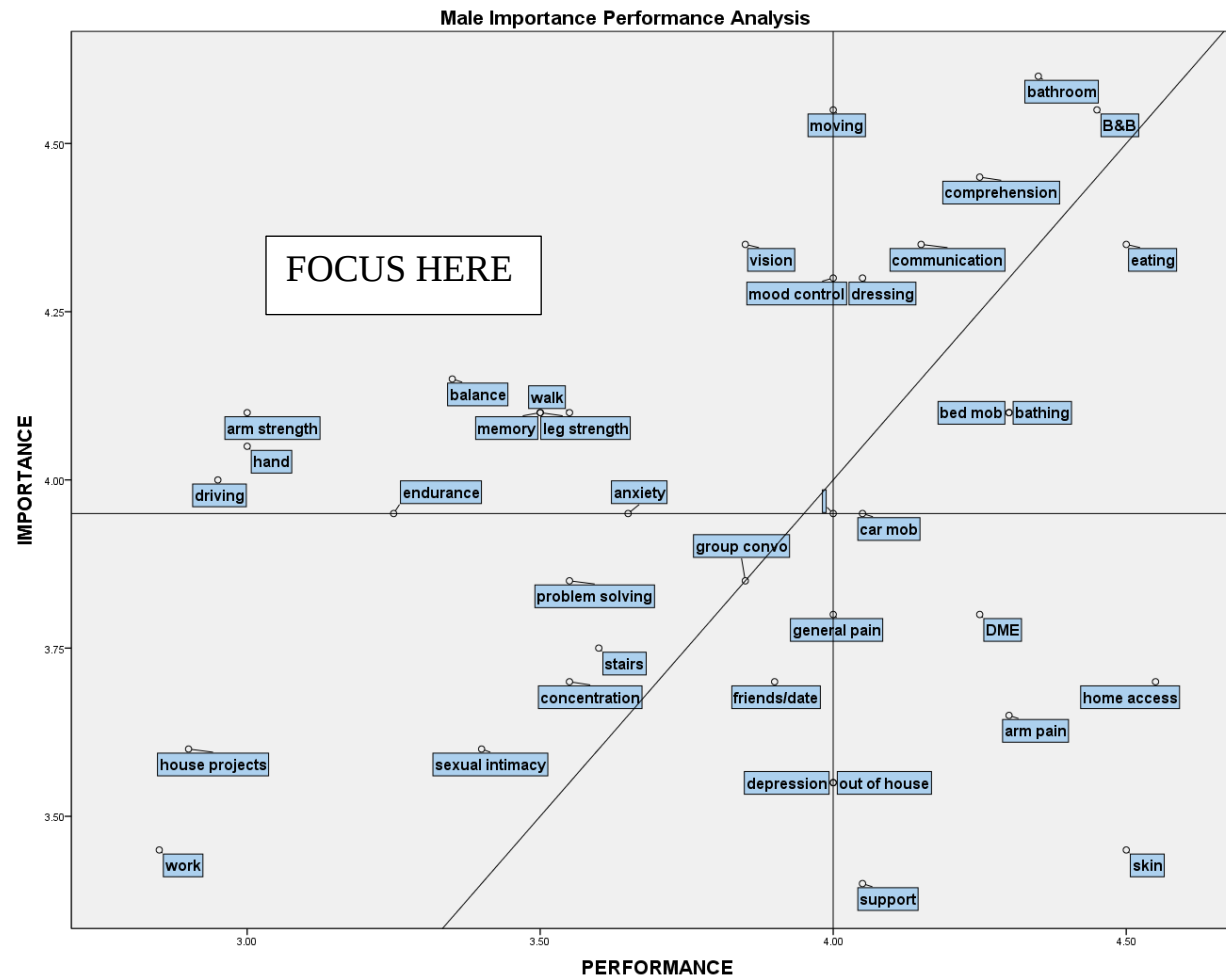


Figure 3.6: Female IPA

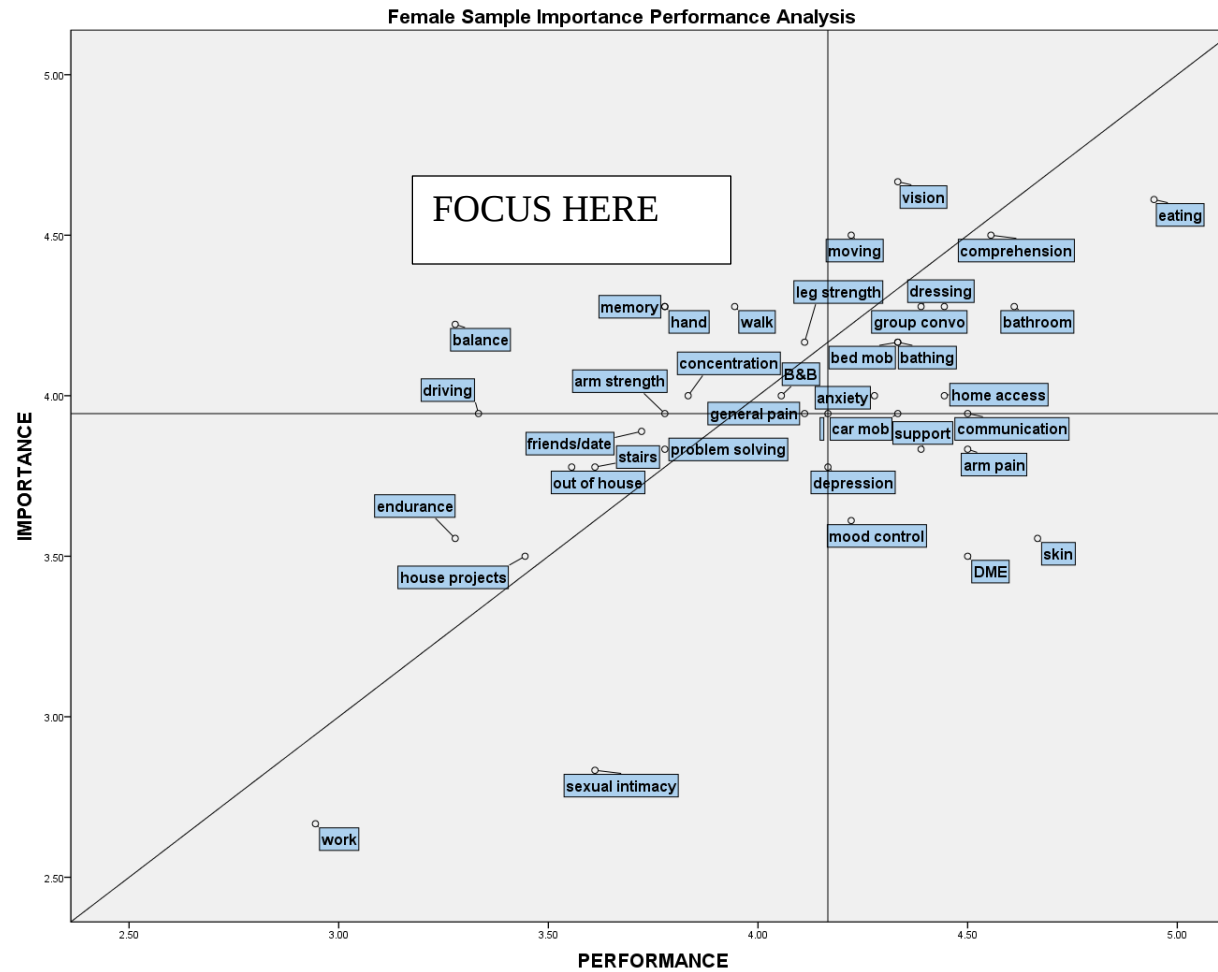


Figure 3.7: <65 IPA

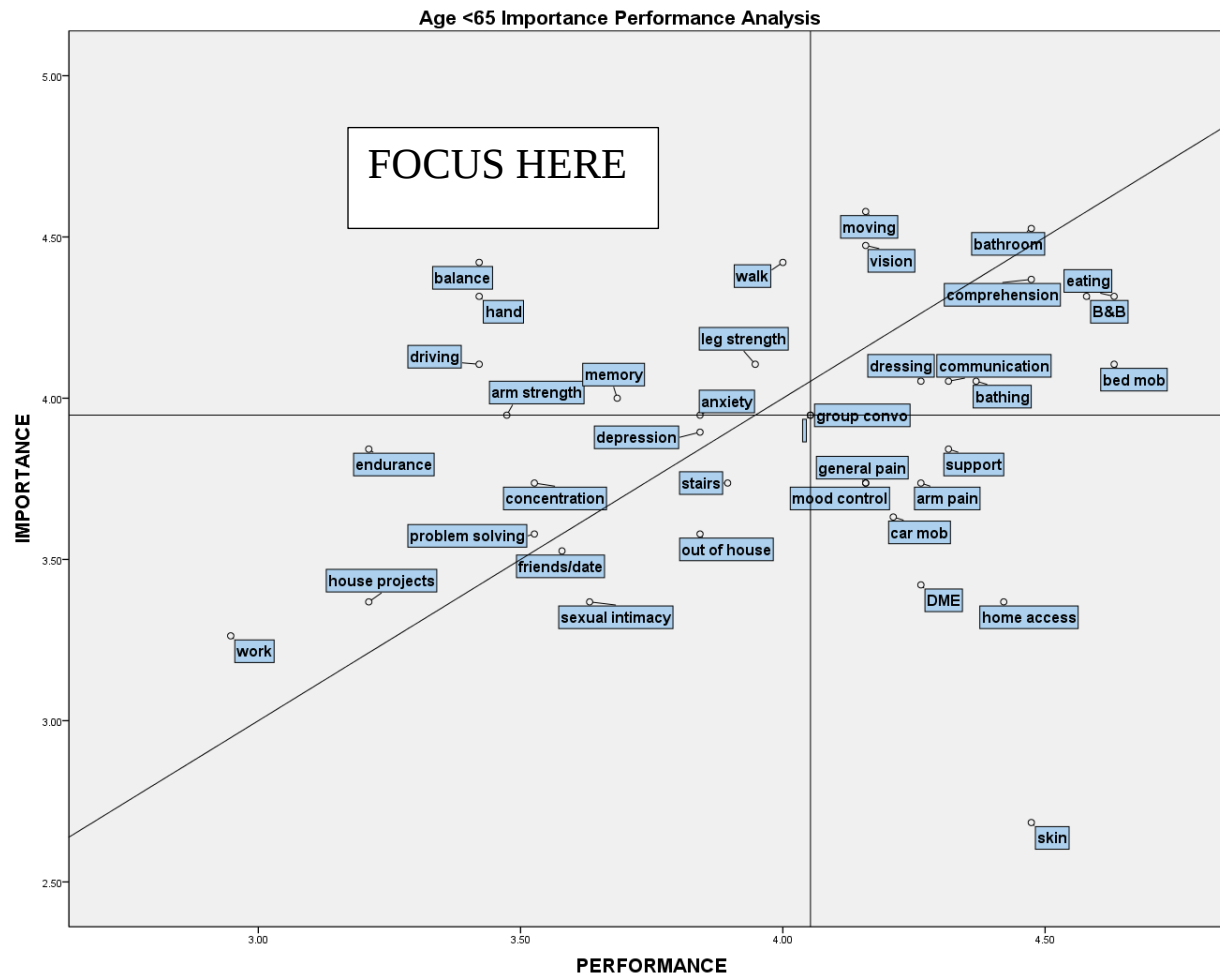


Figure 3.8: ≥ 65 IPA

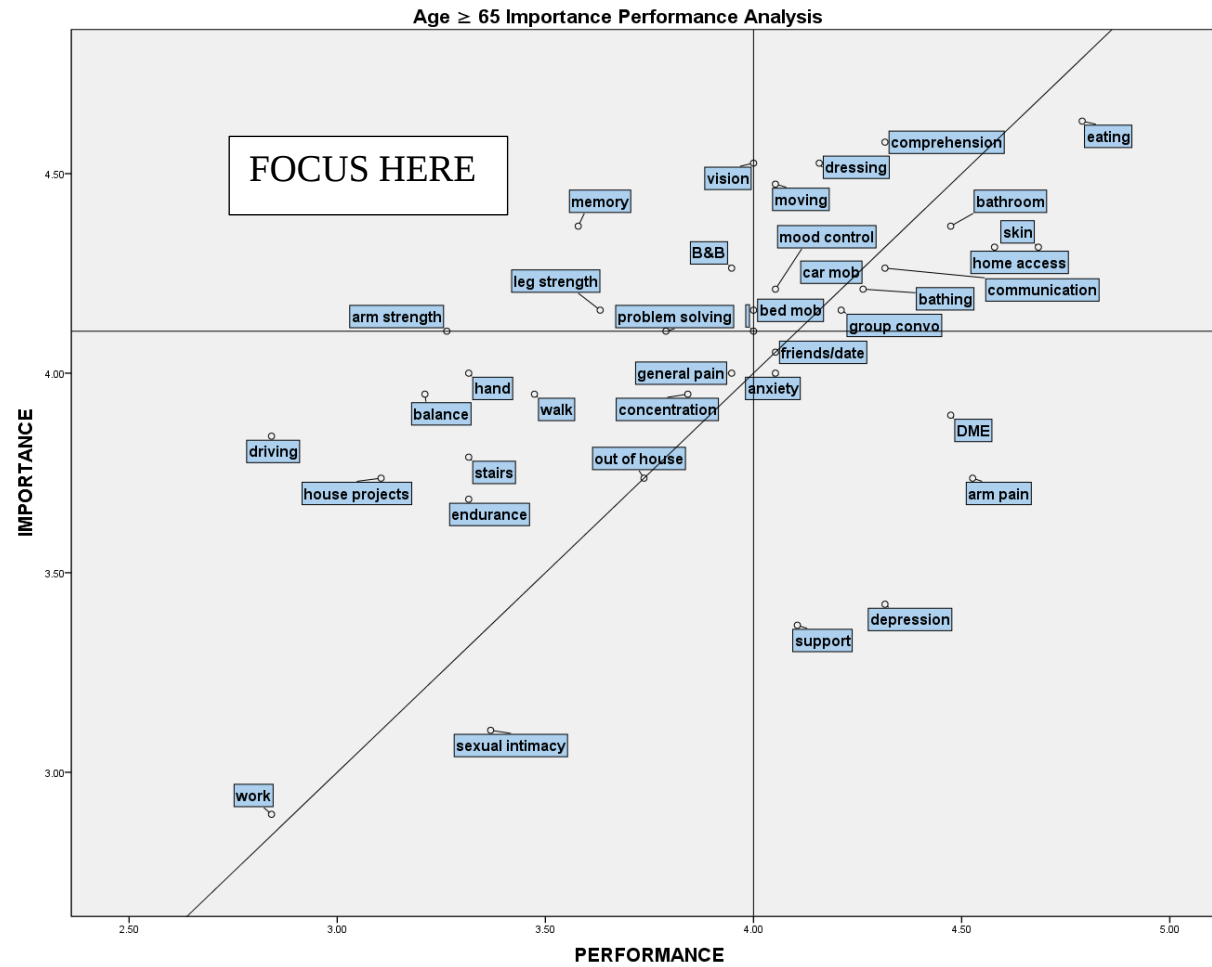


Figure 3.9 has a list of which goals are included in quadrant one for the total sample and each of the subgroups. There is also a description of the reasons why a goal did not end up in quadrant one (i.e., it was rated as important enough, but performance was better than the median).

Figure 3.9: Comparison of quadrant one goals for each group

COMPARISON OF IPA QUADRANT 1 GOALS BY SAMPLE GROUP					
GOAL	TOTAL	FEMALE	MALE	YOUNG	OLD
Balance	*	*	*	*	
Hand	*	*	*	*	
Memory	*	*	*	*	*
walk	*	*	*	*	
leg strength	*	*	*	*	*
anxiety	*		*	*	
driving	*	*	*	*	
vision	*		*		*
arm strength	*	*	*	*	*
endurance			*		
concentration		*			
bowel and bladder		*			*
problem solving					*
*= goal included in quadrant one					
not in quadrant one because has higher performance rating					
not in quadrant one because has lower importance rating					
has higher performance and lower importance					

DISCUSSION

In this investigation we described similarities and differences in the importance of goals after a stroke and considered how current performance may impact importance ratings. The agreement amongst the total group and each subgroup demonstrated a reliable

overall preference pattern. For this group of participants, the IPA analysis demonstrated similar focus areas for individuals with chronic stroke.

Similar to previous findings⁶⁰, walking, better use of arm and hand, and improved speech were listed in the top 5 goals for these participants, but unlike previous studies, return(ing) to work and driving was not. Unlike the previous survey of goal priorities,⁶⁰ driving and work were not ranked as highly important goals. While return to driving did score in the top half of goals for all groups and did have an overall average score of 3.66, it was not listed as a top 2 goal for any subgroup. However, when utilizing IPA to create a visual of the most important goals to an individual, men did include driving in the “focus here” quadrant, indicating that when performance and importance are considered together, different goal priorities are highlighted. Return(ing) to work scored towards the bottom of the goal list for the overall sample (37/40), for women (37/40), men (36/40), those <65 (29/40) and those ≥65 (39/40). Previous investigations indicate return to work goals often emerge 6-9 months after a stroke when an individual is living back in the community and has adjusted some to their residual deficits after a stroke.⁵⁷ The average time since stroke for our sample was over 8 years post stroke. It is possible goal priorities for these individuals changed in the years post stroke and return to work goals may have been more of a priority in the initial years after their stroke.

While our sample showed greater differences by age than gender, a comparison of rank of goals and the IPA found some differences by gender. In overall importance, men ranked continence and using the bathroom independently as top 10 goals whereas women had communication and concentration goals in their top 10. Studies on gender differences related to stroke have focused more on causes and outcomes and not on goal priorities.

One small qualitative study from Sweden did report women's goals were related to a return to cooking and sewing whereas the men's goals were related more to driving and home maintenance. In our sample women and men rated return to driving similarly in overall average: men (3.70), women (3.61), and rank: men (18/40), women (21/40).

There were also differences in the ranking of sexual intimacy by men and women, with men and younger stroke survivors rating it as more important. In the IPA comparison by gender, men also ranked sexual intimacy with higher importance despite both men and women having similar performance levels. There are many possible reasons for a decrease in importance for sexual intimacy including the stroke lesion, medications, cognitive changes or depression.⁴⁶ While these results suggest a difference by gender, it is important for the clinician to consider all possible reasons and have discussions with the stroke survivor about their individual goals regarding sexual expression and intimacy.⁴⁵

We considered two suggested methods to interpret our IPA. First, we looked at the quadrants utilized in the original IPA analysis⁶¹. Second, we visualized the data with an additional delineation where performance=importance.⁶⁷ When the additional delineation diagonal line was utilized more goals shifted from the "low priority" to the "focus here" group. The next step to determine which method accurately interprets goal priorities of stroke survivors will be to use both methods in discussions with stroke survivors and get their feedback on the visual representations of their goals.

Similar to previous studies,^{18,19,57} our investigation found more differences in rank of goals by age, especially when comparing old and young women. The top ten goals for the younger group included items at the impairment level such as arm and leg strength as well as bowel and bladder control. The older group's goal differences included

information, communication, and concentration. Sharing information about what previous stroke survivors deemed most important by age and gender could facilitate goal discussions with individuals during acute rehabilitation. In the IPA young stroke survivors rated return to driving as more important. This is similar to previous findings that reported a return to driving as an important goal for young stroke survivors.¹⁹

Because the FIM™ is required documentation in IRFs, and is one area in which rehabilitation hospitals are compared, the content of the FIM™ tends to guide goal discussions in team conferences and during the development of the interdisciplinary treatment plan. All items on the FIM™, except stairs, were ranked high in the groups and subgroups, and the ratings on these areas were not influenced by current performance (i.e., they remained in the important range on the IPA whether the individual was performing well on the item or not).

However, there were also many items that were rated as more important by the participants that are not included on FIM™ documentation. These items include balance, arm strength, leg strength, and vision. These impairment level items are not measured by the FIM™.⁶⁸ Having required objective measures of these items in inpatient rehabilitation would provide more information to consumers about how IRFs are addressing these important areas.

Recent changes to Medicare outpatient documentation requirements now require more objective measures of progress during therapy services. A recent handout regarding the G Code requirements explains the change as follows: “The Middle Class Tax Relief and Jobs Creation Act (MCTRJCA) of 2012 amended the Social Security Act to require a claims-based data collection system for outpatient therapy services, including physical

therapy (PT), occupational therapy (OT), and speech-language pathology (SLP) services.” (G CODES) Having similar outcome measurement requirements in inpatient rehabilitation, with the same flexibility to choose measures that are important to the patient, could increase the spectrum of goals that are addressed during rehabilitation and improve patient centered care.

LIMITATIONS

While this investigation shares important information about goal priorities after a stroke, there are some limitations that should be considered. While the sample was large from a qualitative structured interview perspective, it was small from a survey perspective. A development of a survey that can be disseminated to a larger number of stroke survivors in all four groups (M/F <65 and M/F ≥65) would help validate the findings. The average time since stroke for this sample was over 8 years, which makes the findings more relevant to chronic stroke survivors than more acute stroke survivors. It is unclear at this time if the results of this study can be generalized to all stroke survivors because this sample had been living in the community for months to years post stroke. Conducting further investigation utilizing similar research methodology during other phases of stroke recovery would provide valuable information regarding acute stroke survivors goal priorities. Also, since the recipients were required to have a MOCA score indicating mild-no cognitive impairment, these results may not be indicative of the goal priorities of individuals with more significant cognitive impairment. Finally, this group of stroke survivors self-reported level of functioning was high, therefore the results could be more indicative of individuals at a higher functional level. While there are some limitations to the study, it still provides

important unique information about gender and age differences in goal priorities amongst community dwelling chronic stroke survivors.

CONCLUSIONS

In conclusion, this study reported goal priorities after a stroke and shared gender and age differences in goal rankings. The most important goals to individuals included balance, walking independently, feeding, and bathing. Women also prioritized communication and concentration whereas men prioritized bowel and bladder continence. IPA was used to visualize current goal priorities for an individual or group based on current performance and importance ratings. This analysis could be used in the future to frame goal discussions with clients to help guide patient centered goal discussions and make them more effective.

CHAPTER 4. GOAL ATTAINMENT

INTRODUCTION

Stroke is one of the leading causes of disability around the world.^{5,6} As more people survive their stroke, there has been increased interest in determining what factors may predict an individual's recovery trajectory after a stroke.

Studies have identified gender differences in the risk factors and acute management of stroke, which may impact an individual's recovery. Women tend to be older than men when they have their stroke, and have hypertension and atrial fibrillation more often than men.⁶⁹ Men have been found to be more likely to drink, smoke, have diabetes and hyperlipidemia prior to their stroke.⁶⁹ During acute care, women were less likely to receive standard of care treatment interventions for stroke management including DVT prophylaxis at 48 hours, and antithrombotic by 48 hours.⁷⁰ Women were also less likely than men to receive antiplatelets, statins, and tPA after an ischemic stroke.⁶⁹ These gender differences were noted in the care and management of stroke survivors despite no difference in baseline stroke severity.⁶⁹

The American Heart Association (AHA) has demonstrated an increased awareness and interest in gender differences in stroke occurrence and management, and recently included gender specific guidelines for prevention and management of stroke.⁷¹ A recent study summarized information about risk factors for stroke that are specific to women, including endogenous hormone levels, exogenous hormone therapy, pregnancy, parity, and timing of menarche and menopause.⁷²

When considering gender differences and what factors contribute to recovery, it is important to have an understanding of what outcome measures are utilized to measure

improvement after a stroke. Functional recovery and discharge disposition are common measures of rehabilitation effectiveness.^{73,74} Our study focused on functional recovery after stroke rehabilitation.

Common functional measures:

Two standard functional measures are the Barthel Index^{75,76} (BI) and the Functional Independence Measure (FIMTM).²⁸ The BI is a measure of independence in 10 areas of function: feeding, bathing, grooming, dressing, bowel, bladder, toileting, transfers, mobility and stairs. Scores range from 0-100, with a higher score indicating higher function. The FIMTM measures function in 18 areas. Along with the 10 items on the BI, it also includes toilet transfers, tub transfers, measures of expressive and receptive communication, social interaction, memory, problem solving, and separate measures for dressing upper body (UE) and lower body (LE). FIMTM score ranges from 18-126 and a higher score is indicative of higher function.

Many factors are associated with functional recovery after stroke. Inpatient rehabilitation admission scores are strong predictors of long term functional outcomes.⁷⁷ When individuals were grouped based on their admission FIMTM scores, it was found that with an admission FIMTM >80 almost all discharged to home, and with an admit FIMTM <40 almost all discharged to a nursing home.⁷⁸ An admission FIMTM of >60 indicated a higher probability of functional improvement during rehabilitation.⁷⁸

The results are mixed when other factors are considered in stroke rehabilitation outcomes. In young stroke survivors, female gender, age, and the presences of aphasia or neglect predicted a lower functional recovery.⁷⁹ Another study suggests that the variables most important to predicting recovery following a stroke are disability on admission,

urinary incontinence, degree of motor paresis, disorientation, and poor sitting balance, and the factors less relevant were gender, ethnicity, and location of the stroke.⁸⁰ Being female, living with family, having premorbid disability and neglect have been associated with decreased odds of discharging home after a stroke.⁸¹

Some observational studies have used a cut off score on the total FIM™ or Barthel score to measure progress, whereas others have looked at the individual items to see where recovery happens. When considering who reaches an independence level on the items on the Barthel, it was found the items individuals were most likely to reach independence included bowel and bladder, transfers, and walking, and the items least likely were bathing, dressing, grooming and stairs.⁸² The BI items that required the longest recovery time included dressing, stairs, and bathing.⁸³ Another study investigated stroke survivor's odds of reaching a score of 115 or higher at discharge from IRF and found admission FIM™, age, gender, aphasia and neglect all decreased ones odds of reaching that level.⁷⁹ Another study considered which individuals reached independence in eating, grooming, and UE dressing, and supervision level at transfers and continence. 26.1% of individuals reached this stage, and those who lived alone prior to their stroke had increased odds of reaching this stage.⁴⁹

Gender impact on stroke outcomes:

There are reported gender differences in occurrence of stroke,⁵ treatment after a stroke^{69,84} and outcomes after a stroke^{79,82,84,85}, but it is unclear why these differences occur. Gender differences in stroke outcomes are well documented in many observational studies.^{79,80,82,83} Most of the current observational studies report men tend to have a better recovery after a stroke than women. Some report female gender is a prognostic factor for

failure to reach independence with ADLs,⁷⁹ and men have been shown to have better odds of achieving independence in stair climbing and ADLs.⁸⁰ When considering FIM efficiency, female sex was associated with lower change in FIM score and lower discharge FIM.⁸⁶ Factors that decreased odds of discharging home included being female, living with family, having premorbid disability, or neglect.⁸¹

One recent study utilizing data from an observational study in the Texas valley was able to show that patient demographics and prestroke clinical factors explained 41% of the sex difference in stroke outcomes.⁸⁴

In contrast, other studies have found gender is not an important factor in recovery^{77,80,87} or beneficial towards reaching rehabilitation goals, and one recent investigation found being female made one more likely to reach rehabilitation goals.⁸⁸ When a group investigated whether individuals met their goals during inpatient rehabilitation they found that most of the time, the goals set by the clinicians were not met. Factors that were associated with not meeting goals included age, comorbidities, being African American, number of complications, and having a right brain stroke. Factors that made one more likely to reach or exceed goals were longer length of stay, admission FIM™ score, and being female.⁸⁸

Social Support:

Because women typically outlive their spouses and have strokes at a later age, one possible explanation for the gender difference in stroke outcomes could be the presence of a caregiver to offer support and assistance. After a stroke, women are more likely to be discharged to a chronic care facility and men are more likely to be discharged home.⁸⁴ Women report lower perceived caregiver availability than men.⁴⁹ However, other studies

that had as a requirement for inclusion the presence of a caregiver, still found women had worse outcomes than men, even when a caregiver was present.⁸² When considering factors that contribute to death, an MI or another stroke, gender or being married or living alone was not a predictor, but social isolation was a predictor for these negative outcomes,⁸⁹ where social isolation was defined as “knowing fewer than 3 people well enough visit within their home”.

There have been some findings that partially explain the gender difference in stroke outcomes. Women are typically older when they have their first stroke, and are more likely to have a lower pre-stroke functional status by the time they have a stroke.⁵ Women also are less likely to have a caregiver to assist with their needs when they go home.⁶⁹ However, none of these explanations have been able to fully explain the gender difference in stroke outcomes.

Gender has also been shown to influence the type of assistance Japanese individuals receive following a stroke.⁹⁰ Men tended to live with their spouses, whereas women tended to live with other family members. Also, men received more support from family members and had less active lifestyles than women.⁹⁰

METHODS

Population:

Participants were Medicare fee-for-service beneficiaries who were discharged from inpatient rehabilitation facilities in 2013 and 2014 after sustaining a stroke. The sample was drawn from the Medicare files for Inpatient Rehabilitation Patient Assessment Instrument (IRF-PAI) submissions, and then linked by beneficiary ID to the Beneficiary Summary Files, and Medicare Provider Analysis and Review (MedPAR) claims. The

sample included patients who were discharged from an IRF from January 1, 2013-December 31st 2014 after receiving rehabilitation for a stroke.

The MedPAR file contains (Part A) claims data for inpatient stays including acute care hospitals, inpatient rehabilitation facilities (IRF) and skilled nursing facilities (SNF). For this analysis only individuals admitted to IRFs was included. The MedPAR file was used to get information about the type of stroke, and whether the individual received tissue plasminogen activator (tPa) during their acute care stay. The Beneficiary Summary Files were utilized to gather information regarding the subject's race/ethnicity, previous level of disability and their socioeconomic status (Medicare/Medicaid eligibility). The IRFPAI files were utilized to gather rehabilitation specific information including FIM admission and discharge scores, IRF length of stay, as well as who the individuals were living with prior to their stroke.

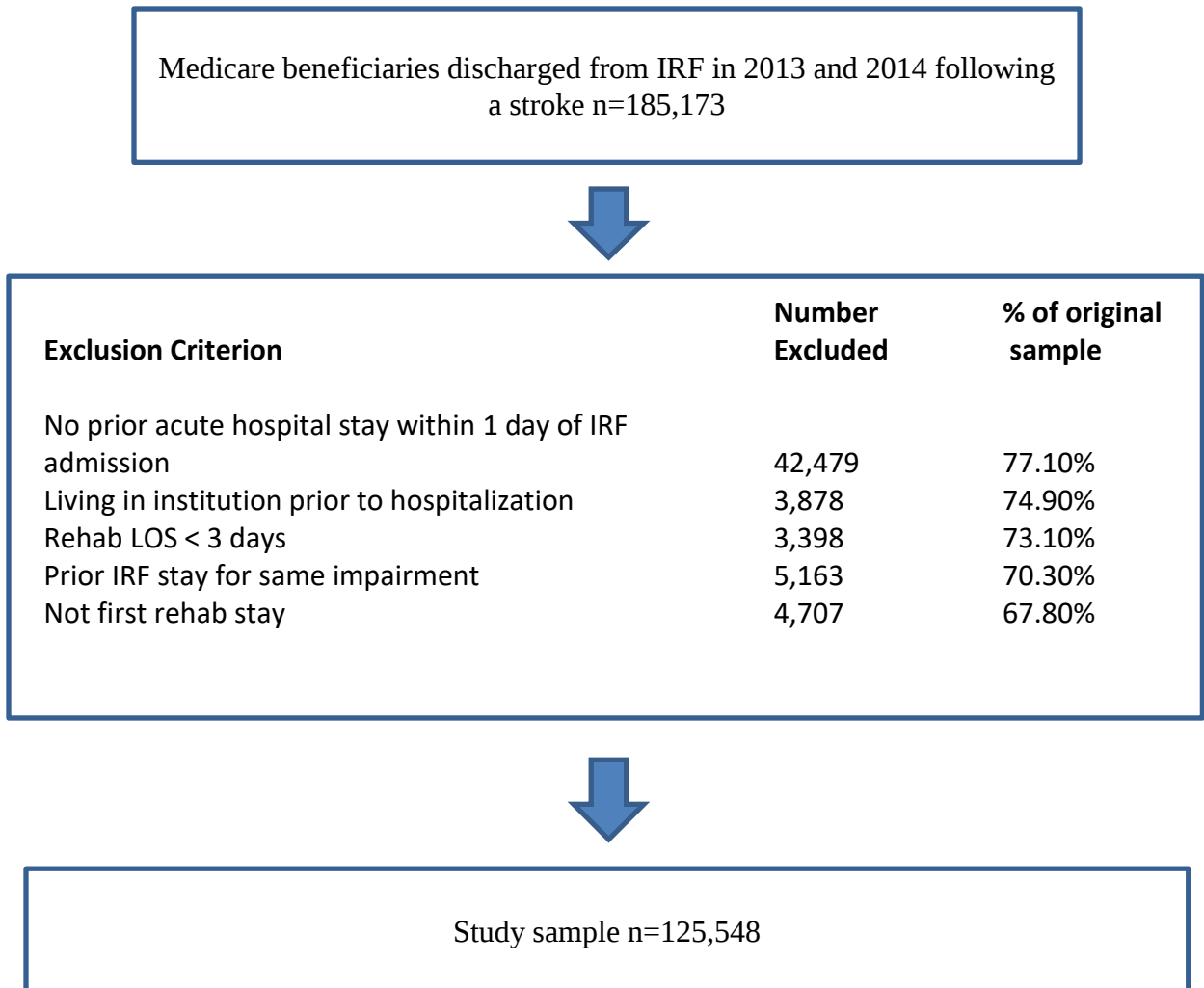
Inclusion/Exclusion:

Inclusion: Diagnosis of stroke with the following ICD-9 codes: Hemorrhagic stroke (430-432) Ischemic Stroke (433-434) Acute CVD-ischemic (436) and late effects of CVD (438) and received inpatient rehabilitation after discharge from acute care hospital.

Exclusion: Individuals without a prior acute hospital stay within 1 day of IRF admission, individuals who lived in an institution prior to their stroke, individuals who had an IRF length of stay less than 3 days, and individuals who had a prior IRF stay for the same diagnosis.

The following figure (4.1) provides a flow sheet of the total sample and the number removed for each exclusion.

Figure 4.1: Flow sheet inclusion criteria



Because the majority of the subjects available in the Medicare files are individuals 65 years or older, this analysis compared goal attainment by gender and not by age.

Intendent and Dependent Variable:

Independent variable: Gender

Dependent variable: FIM™ score at discharge and social support

FIM™ score at discharge for each individual FIM™ item, dichotomized as ≥ 5 or < 5 . A score of 5 represents a requirement of “supervision” assistance only for basic activities. This cutoff was selected based on clinical experience: with shortened length of stay in rehabilitation, individuals who discharge at a supervision level or above on the FIM™ items demonstrate good physical recovery from their stroke and have potential to recover to full independence in the months post discharge.

A score of 5 for self-care and transfer items indicates the individual can physically complete the task and only requires supervision, or set up of the item. Reasons for supervision could include the need for verbal cues on technique or cues for safety awareness. Set up includes clothes retrieval and the donning of orthotics, but once the patient has the clothes/supplies they are able to complete the task without further physical assistance.

For the mobility and stairs FIM™ items, a score of 5 indicates the following: A score of 5 for mobility indicates the individual can walk or propel their wheelchair at least 50 feet without any assistance, or 150 feet with supervision. A score of 5 for stairs indicates the individual can go up and down at least 4-6 steps without any assistance, or 12-14 steps with supervision.

For comprehension and expression a score of 5 indicates the individual can comprehend and express statements about daily needs 90% of the time and only rarely

(<10% of the time) requires assistance. For social interaction, the individual can participate in activities with others and interact appropriately most of the time (>90%), and only requires assistance during stressful or unfamiliar situations.

For problem solving an individual who scores a 5 only requires assistance solving routine problems under stressful or unfamiliar situations, which can only occur up to 10% of the time. Similarly a score of 5 for memory indicates the individual remembers people routines and tasks >90% of the time, and only requires assistance during stressful or unfamiliar situations.

Social Support: Based on who was living with the individual prior to their stroke. 3 categories: 1: Lived Alone, 2: Lived with family or spouse, 3: Lived with a hired caregiver. Table 4.1 provides a summary of the variables included in the analysis.

Clinical Covariates:

Admit FIM™: Admission FIM™ score for each individual FIM™ item, score of 1-7. Individuals who scored 0 “did not occur” on admission had scores changed to a 1.

LOS: Rehabilitation length of stay. 4 categories determined based on average length of stay: (15.42 days, SD 7.4), and clinical judgement 1: ≤10 days, 2: 11-22 days, 3: 23-35 days, and 4: 35+days

Elixhauser comorbidity: This comorbidity index was chosen as it has an extensive list of comorbidities that might interfere with an individual’s progress during rehabilitation and

has been used extensively with claims data.⁹¹ There is another more stroke specific comorbidity index,⁹² but it was not used because it requires a grade of the level of functional impairment based on the comorbidity and that information was not available in our claims data.

(The 30 comorbidity areas for the elixhauser comorbidity index are:

- | | |
|--|-------------------------------------|
| 1. congestive heart failure | 17. lymphoma |
| 2. cardiac arrhythmias | 18. metastatic cancer |
| 3. valvular disease | 19. solid tumor with metastasis |
| 4. pulmonary circulation disorders | 20. rheumatoid arthritis |
| 5. peripheral vascular disorders | 21. coagulopathy |
| 6. hypertension | 22. obesity |
| 7. paralysis | 23. weight loss |
| 8. other neurological disorders | 24. fluid and electrolyte disorders |
| 9. chronic pulmonary disease | 25. blood loss anemia |
| 10. diabetes uncomplicated | 26. deficiency anemias |
| 11. diabetes complicated | 27. alcohol abuse |
| 12. hypothyroidism | 28. drug abuse |
| 13. renal failure | 29. psychoses |
| 14. liver disease | 30. depression |
| 15. peptic ulcer disease, excluding bleeding | |
| 16. AIDS | |

Elixhauser: 3 categories 1: no comorbidities, 2: 1-2 comorbidities, and 3: 3+ comorbidities.

Type of stroke: 3 categories 1: Hemorrhagic Stroke, 2: Ischemic Stroke, and 3: Unknown

tPA received: Whether the individual received tPA during their acute care admission for their stroke. Dichotomized as yes/no

Disability prior to stroke: Yes/no if subject was on disability prior to their stroke

Sociodemographic and Economic Status Variables

Age: 5 categories: <70, 70-74, 75-79, 80-84, 85+

Race/Ethnicity: Four categories: 1:White/NonHispanic, 2: African American, 3: Hispanic, 4: Other

Dual Eligibility: Yes/No if individuals were receiving coverage from Medicaid and Medicare.

Table 4.1: Variables in analysis

Variable	Variable Description	Variable Type	Category Description	Data Source
Dependent Variable	FIM at discharge	Categorical	Score on each FIM item 2: ≥ 5 or < 5	IRF-PAI
Independent Variable	Gender	Categorical	2: M/F	MedPar
Independent Variable	Social Support	Categorical	3: no (lived alone), yes (lived with family or spouse) , hired caregiver	IRF-PAI
Covariate	Age	Categorical	5: < 70 , 70-74, 75-79, 80-84, 85+	MedPar
Covariate	Race/Ethnicity	Categorical	4: white, black, Hispanic, other	Beneficiary Summary File
Covariate	Medicare+Medicaid	Categorical	2: yes/no	Beneficiary Summary File
Covariate	Disability	Categorical	2: yes/no	Beneficiary Summary File
Covariate	Elixhauser Comorbidity Index	Categorical	3: no comorbidities, 1-2 comorbidities, 3+	IRF-PAI
Covariate	FIM score on each item at admission	Continuous	Range from 1-7	IFR-PAI
Covariate	Days in rehab	Categorical	4: ≤ 10 days, 11-22 days, 23-35 days, and 35+ days	IRF-PAI
Covariate	TPA received	Categorical	2: Yes/No	MedPar
Covariate	Type of Stroke	Categorical	3: Hem/Ischem/Other	MedPar

Analysis:

First we calculated descriptive summaries to describe the sample, means and standard deviations for continuous variables (e.g. age, LOS) and frequencies and percentages for each of the categorical variables: (e.g. gender, race, Medicare+Medicaid, caregiver presence, disability, elixhauser comorbidity score, admit FIM™, days in rehab, tPA received).

Next, we stratified the sample by gender and compared the two groups on all covariates. To compare the two groups, a Chi Square test was used for categorical variables and a two-sided independent t-test was used for continuous variables.

To determine if social support mediates the effect of gender on goal attainment, we performed logistic regression models using the GLIMMIX procedure. The generalized linear mixed model was used to take into account the random effects of individual hospitals or geographic regions. The outcome was goal attainment (target= FIM $\geq$ 5) FIM.

First model- association of gender with goal attainment while adjusting for age, sociodemographic and economic status variables (race/ethnicity and Medicare+Medicaid) and clinical covariates (admit FIM™, days in rehab, elixhauser comorbidity, type of stroke, tPA received and disability prior to stroke).

Second model- association of gender on goal attainment while adjusting for all of the above + social support variable.

Statistical analysis was completed in both SPSS and SAS, version 9.4, and tested for significance at a 0.05 alpha level ($p < .05$).

RESULTS

Participants:

Table one presents demographic information about the total sample and comparison of the sample by gender. The final sample size was 125,548 with 58,715 men and 66,833 women. The two groups were statistically different in all categories except whether they received tPA or not. The male group was more likely to be white, and the female group had a higher black population. Men were more likely to be living with a spouse or friends prior to their stroke (80.4% vs 64.1%), and women were more likely to be living alone (34.9% vs 19.1%). More women were dual eligible for both Medicare and Medicaid (23.0% vs 16.0%) and more men were on disability prior to their stroke (23.0% vs 19.0%). Stroke type, while statistically different between the two groups was closer with 86.8% of men having an ischemic stroke vs 88.3% of women. Women were older (76.7 years vs 74.8 years) and had more comorbidities (4.0 vs 3.8). Women had slightly shorter LOS (15.4 days vs 15.5 days). Total admission and discharge FIM scores between the two groups were similar between the two groups (Admit FIM Women 54.0 admit FIM men 54.0) and (Discharge FIM women 81.2 and discharge FIM men 81.6). However, men tended to have higher motor scores at admission and discharge than the women.

As Table 4.3 shows, when each individual FIM™ item was considered, there were some differences by gender on who was admitted or discharged at a FIM™ level of 5 or better for each individual FIM™ item. Statistically more men were admitted with a FIM score of 5 or better for most of the motor FIM™ items including: bathing, UE dressing, toileting, bowel control, all transfers, walking and stairs. Women were more likely to be admitted with a FIM™ score of 5 or better in expression and social interaction. At

discharge, more men discharged at a FIM™ score of 5 or better in UE dressing, tub transfers, walking, and stairs. More women discharged with a score of 5 or better in expression and social interaction, eating, and bladder control.

Table 4.2: Sample Characteristics

	Total	Male	Female	p-value
N	125,548	58,715	66,833	
Race/ethnicity				<.0001
White	75.4%	76.1%	74.9%	
Black	15.0%	13.7%	16.1%	
Hispanic	6.0%	6.2%	5.7%	
Other	3.4%	3.6%	3.1%	
Unknown	0.3%	0.5%	0.2%	
Social support				<.0001
Family/friends	71.8%	80.4%	64.1%	
Paid/other	0.7%	0.5%	1.0%	
None	27.5%	19.1%	34.9%	
Dual eligible	19.7%	16.0%	23.0%	<.0001
Disability	20.8%	23.0%	19.0%	<.0001
Stroke type				<.0001
Ischemic	88.3%	87.6%	89.0	
Hemorrhagic	9.43%	9.9%	9.0%	
Other	2.2%	2.5%	2.0%	
tPA Received	6.9%	6.9%	6.9%	0.83
Variable: Mean (SD)	Total	Male	Female	p-value
Age	75.79(10)	74.8(9.8)	76.7(10.1)	<.0001
Elixhauser Sum	3.9(1.8)	3.8(1.8)	4.0(1.8)	<.0001
LOS	15.4(7.4)	15.5(7.7)	15.4(7.2)	0.0098
Admit total	54.1(18.2)	54.2(18.3)	54.0(18.1)	0.04
Admit cognitive	19.0(7.0)	18.9(7.1)	19.1(7.1)	<.0001
Admit motor	35.1(13.5)	35.3(13.5)	34.9(13.5)	<.0001
DC total	81.4(23.3)	81.6(23.3)	81.2(23.4)	.004
DC cognitive	24.3(6.9)	24.3(6.9)	24.4(6.9)	0.03
DC motor	57.0(18.6)	57.3(18.5)	56.8(18.6)	<.0001

Table 4.3: FIM SCORE COMPARSION BY GENDER- UNADJUSTED

FIM item	FIM rating ≥ 5			p-value	FIM item	FIM rating ≥ 5			p-value
	Total	Male	Female			Total	Male	Female	
Admit eat	61.4%	61.3%	61.4%	0.55	DC eat	87.6%	87.1%	88.0%	<.001
Admit groom	32.3%	32.5%	32.2%	.213	DC groom	78.7%	78.8%	78.6%	.310
Admit bath	7.9%	8.2%	7.6%	<.001	DC bath	53.8%	54.1%	53.5%	.031
Admit dressup	18.9%	21.0%	17.0%	<.001	DC dressup	66.3%	69.4%	63.5%	<.001
Admit dresslo	4.5%	4.5%	4.4%	.346	DC dresslo	50.0%	49.7%	50.2%	0.04
Admit toilet	5.8%	6.5%	5.2%	<.001	DC toilet	52.8%	52.9%	52.8%	.690
Admit bladder	31.4%	31.0%	31.8%	.005	DC bladder	61.2%	60.3%	62.0%	<.001
Admit bowel	50.1%	52.1%	50.0%	<.001	DC bowel	74.4%	74.7%	74.2%	.064
Admit tranbcw	2.3%	2.6%	2.1%	<.001	DC tranbcw	53.7%	54.2%	53.3%	.003
Admit trantlt	3.3%	3.8%	3.0%	<.001	DC trantlt	53.2%	53.5%	53.0%	.022
Admit trantub	4.1%	4.3%	3.9%	<.001	DC trantub	46.5%	47.1%	46.0%	<.001
Admit walkwc	2.5%	2.9%	2.2%	<.001	DC walkwc	57.0%	58.4%	55.9%	<.001
Admit stairs	1.6%	1.9%	1.3%	<.001	DC stairs	35.3%	37.7%	33.2%	<.001
Admit comp.	42.4%	42.2%	42.6%	0.14	DC comp.	72.0%	71.9%	72.1%	.380
Admit express	40.3%	39.4%	41.0%	<.001	DC express	68.8%	68.1%	69.5%	<.001
Admit interact	52.8%	52.2%	53.5%	<.001	DC interact	79.2%	78.8%	79.5%	0.0015
Admit probsol	22.3%	22.1%	22.5%	0.052	DC probsol	50.9%	50.8%	51.0%	.635
Admit memory	25.1%	24.8%	25.4%	0.011	DC memory	52.5%	52.4%	52.7%	.270

Table 4.4: Model Examining effect of gender and social support on D/C FIM score

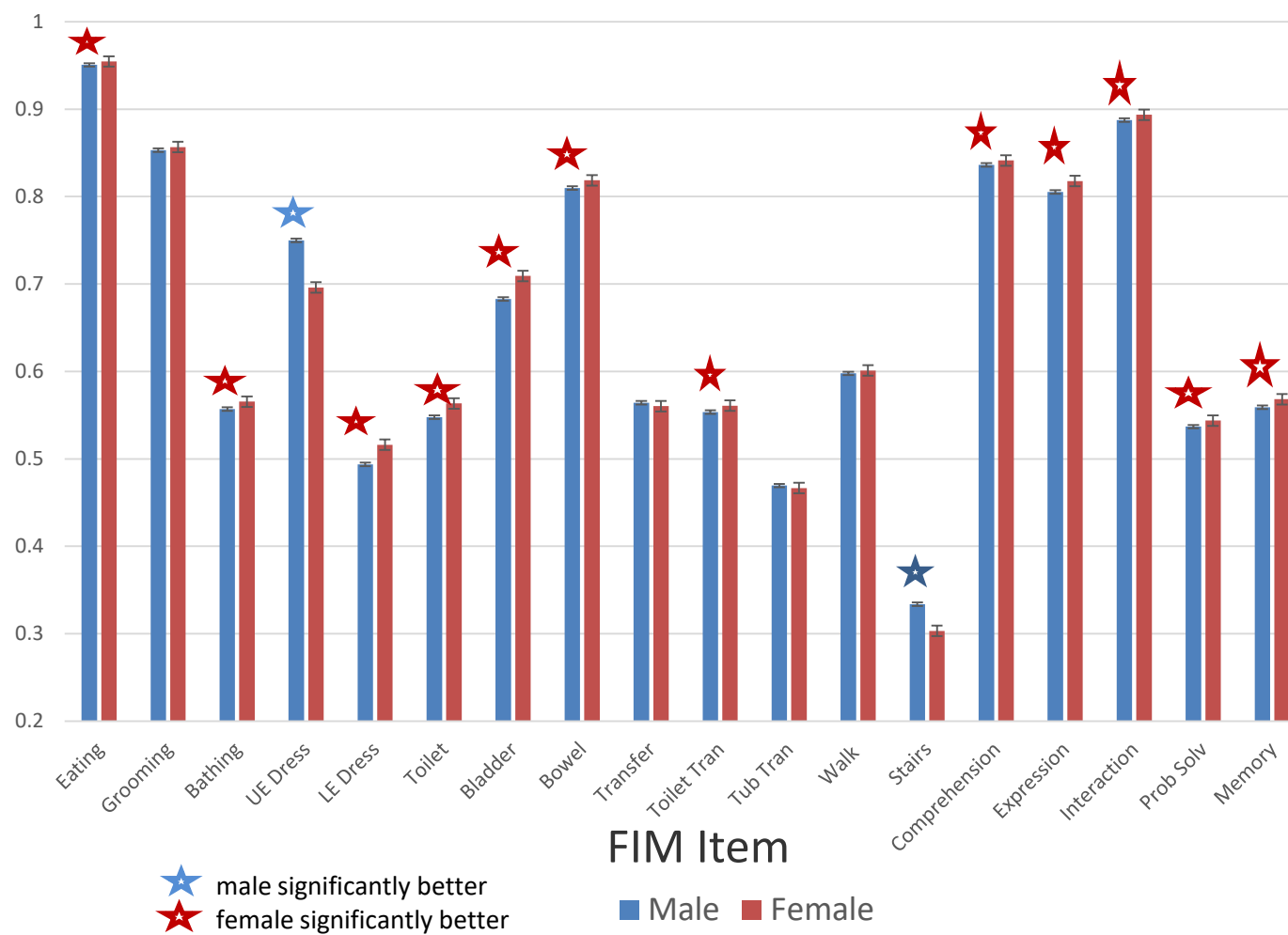
Model Examining the Effect of Gender and Social support on D/C FIM Score					
		Eating	Grooming	Bathing	Dressing Upper
Step One	Female	1.10 (1.05,1.14)	1.04 (1,1.07)	1.05 (1.03,1.08)	0.79 (0.77, 0.81)
Step Two	Female	1.08 (1.03, 1.13)	1.03(0.99,1.06)	1.03(1.01,1.06)	0.78(0.75,0.8)
	Support (family/Friends)	1.00	1.00	1.00	1.00
	Paid/Other	0.74 (0.6, 0.91)	0.65(0.56,0.77)	0.62(0.53,0.72)	0.61(0.52,0.72)
	None	1.14 (1.08, 1.2)	1.09(1.05,1.13)	1.17(1.13,1.2)	1.12(1.09,1.16)
		Bladder	Bowel	Transfers	Toilet Transfers
Step One	Female	1.13 (1.1, 1.17)	1.08 (1.05, 1.11)	1.01 (0.98, 1.03)	1.05 (1.02, 1.08)
Step Two	Female	1.12(1.09,1.15)	1.07(1.03,1.1)	0.98(0.96,1.01)	1.03(1,1.06)
	Support (family/Friends)	1.00	1.00	1.00	1.00
	Paid/Other	0.68(0.58,0.8)	0.65(0.56,0.76)	0.64(0.55,0.75)	0.63(0.54,0.74)
	None	1.11(1.07,1.15)	1.11(1.07,1.15)	1.18(1.14,1.22)	1.17(1.14,1.21)
		Stairs	Comprehension	Expression	Problem Solving
Step One	Female	0.9 (0.88, 0.92)	1.05 (1.02, 1.09)	1.09 (1.06, 1.13)	1.04 (1.01, 1.07)
Step Two	Female	0.88(0.85,0.9)	1.04(1.01,1.08)	1.09(1.05,1.12)	1.03(1,1.06)
	Support (family/Friends)	1.00	1.00	1.00	1.00
	Paid/Other	0.51(0.43,0.62)	0.67(0.56,0.8)	0.73(0.61,0.88)	0.62(0.52,0.74)
	None	1.23(1.19,1.26)	1.09(1.05,1.13)	1.06(1.02,1.1)	1.06(1.02,1.1)
		Dressing Lower	Toileting	Tub Transfers	Walking
Step One	Female	1.12 (1.09, 1.15)	1.09 (1.06, 1.12)	1.02 (0.99, 1.04)	1.03 (1.01, 1.06)
Step Two	Female	1.09(1.06,1.12)	1.07(1.04,1.1)	0.99(0.96,1.01)	1.01(0.99,1.04)
	Support (family/Friends)	1.00	1.00	1.00	1.00
	Paid/Other	0.61(0.52,0.72)	0.59(0.5,0.7)	0.64(0.55,0.75)	0.59(0.51,0.69)
	None	1.19(1.15,1.22)	1.17(1.14,1.21)	1.24(1.2,1.27)	1.17(1.14,1.21)
		Memory	Social Interaction		
Step One	Female	1.05 (1.02, 1.08)	1.07 (1.04, 1.11)		
Step Two	Female	1.04(1.01,1.07)	1.07(1.03,1.11)		
	Support (family/Friends)	1.00	1.00		
	Paid/Other	0.65(0.54,0.78)	0.59(0.5,0.71)		
	None	1.07(1.03,1.1)	1.05(1.01,1.1)		

ADJUSTED MODEL WITHOUT SOCIAL SUPPORT: Table 4.4 has the results for each FIM™ item with the two models (with and without social support). Women had higher odds of reaching the cutoff FIM™ score in 14/18 FIM™ items including eating, grooming, bathing, LE dressing, toileting, bladder control, bowel control, toilet transfers, comprehension, expression, interaction, problem solving, and memory. Men had higher odds in 2/18 FIM™ items: UE dressing and stairs. There was no difference between the two groups in 2/18 FIM™ items: W/C transfers and tub transfers.

MODEL WITH SOCIAL SUPPORT: When social support was added to the model, women continued to have higher odds of reaching the FIM™ cutoff for all but one of the FIM™ items, but the odds of women doing better decreased slightly. Walking was the one FIM™ where the odds ratio changed from favoring women (OR 1.034 CI 1.008-1.061) to not significant (OR 1.013 CI 0.987-1.039) when social support was added to the model. When social support was included in the model, individuals who lived alone prior to their stroke had higher odds of reaching the cutoff FIM™ score than individuals who lived with a caregiver or lived with family or friends for all FIM™ items.

Table 4.5 includes the fully adjusted probabilities with confidence intervals for men and women discharging at a supervision level for each FIM™ item. For most items, there were not large differences in probabilities by gender. The items that were significantly different included 2 areas where men performed better (stairs and UE dressing) and three areas where women performed better (LE dressing, toileting and bladder co

Figure 4.2: Probability of Supervision Level at Discharge By Gender-Fully Adjusted Model



DISCUSSION

In this investigation we found that while men had better odds of reaching the cutoff FIM™ score in the unadjusted model, women did better when the clinical, demographic and socioeconomic covariates were included in the model. This was similar to recent findings on goal achievement after rehabilitation that found women were more likely to reach a FIM™ level goal established by the clinicians than men were.⁸⁸

For the two FIM™ items where men continued to do better than women after adjusting for all the covariates, there are plausible clinical explanations. The UE dressing FIM™ item is a harder task for women than for men because women typically must don a bra as well as a shirt. Donning a bra is one of the most challenging dressing tasks, as it requires fine motor dexterity as well as strength in both hands. Even when a bra is used that doesn't require fasteners, the material is typically elastic and requires strength from both arms to don and adjust the bra appropriately. Stairs is the most challenging item on the FIM™ scale as it requires good trunk stability and at least some strength in the affected LE. Previous research has indicated men may do better than women after a stroke secondary to premorbid strength differences.⁸⁵ Being physically stronger prior to the stroke could explain why men tend to do better on stairs, and equally well to women on transfers and walking.

Our results, that women do better after stroke rehabilitation is different from many previous studies that reported men had better functional outcomes^{86,93-95} and discharge disposition^{81,84} than women. A recent systematic review reported that while most studies do report men do better than women many did not adjust for typical covariates such as age

and stroke severity.²⁰ Similar to previous research, we found that the older and individual was when they had their stroke, the less likely they were to reach a supervision level on each FIM™ item. Also, hospital based studies tended to find significant gender differences more often than population based studies.²⁰ Women do tend to have more severe strokes, and be older when they have their strokes, which could explain why acute hospital based studies may find poorer outcomes for women. Because our study involved subjects eligible for inpatient rehabilitation, the group overall would be a higher functioning group of stroke survivors than those who ended up going to a SNF.

In our study, women consistently did better on the cognition and communication FIM™ items. Because a higher percentage of the women were living alone prior to their stroke this could indicate a premorbid higher level of cognition. We were not able to control for which hemisphere the lesion occurred which can impact communication and expression deficits.

Some previous investigations have suggested that the reason for a gender difference in stroke outcomes is secondary to gender differences in the acute care management of stroke^{84,96} including less usage of intravenous thrombolysis(IVT).⁹⁷ The women and men included in our study were not different on the usage of IVT therapy. Our study involved only those individuals who received inpatient rehabilitation after their stroke which could explain why there were not gender differences found in this group.

Social support is an important component of stroke recovery, and appears to partially mediate the gender difference in FIM™ outcomes. When social support was added to the model, there was less of a difference between genders on each outcome, and some items (walking, grooming) went from being statistically different to not.

When social support was included in the model, we also found that individuals who lived alone prior to their stroke did better than those who lived with family/friends or a caregiver. The fact that individuals who lived alone prior to their stroke do better indicates this measure for this sample is more of a measure of premorbid function than it is of the support one receives from family and friends. A similar investigation into the impact of social isolation on stroke recovery found individuals who lived alone had less severe strokes at admission and better recovery at 3 months than those who lived with a spouse, family or caregiver ⁹⁸ This indicates those who live alone prior to their stroke could be healthier and prone to less severe strokes which could explain why individuals who live alone did better.

LIMITATIONS

There are a few limitations to this study that should be considered. Our results are limited to stroke survivors who received inpatient rehabilitation after their stroke which could limit the generalizability of our findings to individuals with less severe stroke who were able to go home from the acute care hospital and more severe stroke survivors who were not able to tolerate the required 3 hours of therapy in an IRF. Also, the amount of individuals who received tPA could be underreported because this medication is typically given while the patient is still in the emergency room and the Medicare claims data we utilized does not include ER data. However, this study does provide valuable information regarding FIM™ outcome of participants who do receive rehabilitation in an IRF. Also, while our measure of social support does provide information about the presence or absence of family, it does not provide information about the level of involvement of the potential caregivers. There were also a couple of factors related to the stroke that we were

not able to include in our investigation. While initial stroke severity was not included, we did have admission FIM™ scores which provides information about the level of assistance required for that individual.

CONCLUSIONS

For most FIM™ items, when socio-demographic and clinical factors are controlled, women are more likely to discharge from inpatient rehabilitation at a supervision level or better. The items where men do better could be explained by premorbid genetic strength differences, or task difficulty differences. Individuals who live alone prior to their stroke are more likely to discharge from rehab at a supervision level on each FIM™ item.

CHAPTER 5. CONCLUSION AND NEXT STEPS

This study utilized a mixed methods approach to investigate patient centered outcomes after a stroke, with a specific focus on comparing outcomes and priorities by gender and age. First, we asked subjects to complete a card sorting task to determine how stroke survivors categorize goals. The information gathered from the card sorting task can be used in the development of a survey. Next, we asked stroke survivors to rate the importance of 40 stroke goals to overall stroke recovery and compared these ratings by gender and age. We also asked the stroke survivors to rate their current importance and their current performance on each of the goals and used this information to create a visual representation of their goal priorities. This visualization can be utilized to frame goal discussions with rehabilitation participants and possibly make the goal discussions more effective and beneficial. Finally, we utilized claims data to compare stroke outcomes after rehabilitation for older stroke survivors. We compared men and women on the probability of reaching a supervision level on each FIM™ item, and also investigated what impact pre-stroke social support would have on these outcomes. Each of the study aims and our findings will be summarized in the following paragraphs.

The first aim of the study was: Describe how stroke patients classify and organize stroke recovery goals and compare classification by age and gender. We found that stroke survivors grouped items into the following categories: 1) Information, 2) Communication and Social Participation, 3) Physical Impairments, 4) Daily Tasks, 5) Mobility, and 6) Mood. While the physical impairments related to movement (i.e., weak arm, weak leg) were all grouped together in a separate category, impairments related to speech and cognition (i.e., memory, expressive communication) were grouped together with the

activity and participation tasks (i.e., seeing friends, support groups) that they encompassed. Similarly, the mobility group included items at the activity level (i.e., stairs, walking) together with participation items that participants saw as similar (i.e., working, driving, getting out of the house).

Overall, the groupings by men and women and old and young were similar and followed a pattern similar to the group as a whole. While all groups followed some of the groupings of the FIM™ scale and the ICF model, none directly followed either scale. The next step will be to develop a survey utilizing the groupings suggested here and assess the survey with a larger group of stroke survivors.

The second aim of this investigation was: Examine the effects of age (<65, 65+years) and gender on stroke patients' perceived importance rating of patient centered outcomes. The most important goals for the overall group included balance, information to prevent a second stroke, walking independently, feeding and bathing. When we compared the ratings by gender, we found both sexes rated the above goals as important, and females also prioritized communication, concentration and memory whereas men also prioritized bowel and bladder continence. Older stroke survivors did not rate sexual intimacy and return to work as important as younger stroke survivors.

There were many items rated as very important to stroke survivors that are not currently captured on required rehabilitation outcome measures. Having a required way to track and monitor progress on these goals (i.e., balance, upper extremity use) could improve our understanding of rehabilitation effectiveness and patient centered care.

Next steps for this investigation would be to include a sample of a larger group of stroke survivors to determine if the trends observed here during the structured interviews with this small sample continue with a larger sample of stroke survivors.

The next aim of the study was: Determine the relationship between perceived importance and current performance on specific goals among stroke patients. To answer this we utilized IPA analysis as a way to visualize the relationship between importance and performance in chronic stroke survivors. Responses for all groups indicated the goals to focus efforts on with this group of chronic stroke survivors were: balance, hand function, memory, leg and arm strength. The older stroke survivors had similar (memory, leg strength, arm strength) and different (bowel and bladder and problem solving) focus areas when compared to the other groups.

The next step for this investigation will be to utilize IPA to facilitate goal discussions with stroke survivors and determine the effectiveness of IPA in improving goal discussions amongst rehabilitation clients, both in the acute and chronic stages of recovery. It will also be of interest to follow the same stroke survivors during and after acute rehabilitation to measure the change in importance and performance of these goals over time, and visualize how the priority goals change as the stroke survivor recovers.

The final aim of this study was: Evaluate goal achievement following inpatient rehabilitation by gender in a large population based sample of older stroke patients. Goal achievement was defined as discharging from the hospital at a supervision level on each FIM™ item. We found that for most FIM™ items women had slightly higher odds of discharging at a supervision level or better. Men had better odds of discharging at a supervision level in two items: UE dressing and stairs. When social support was included

in the model, individuals who lived alone prior to their stroke had significantly better odds of discharging at a supervision level.

Future steps for this investigation will be to examine further the differences in goal outcomes by race, and consider further the role social support in outcomes and rehabilitation length of stay, with a particular focus on the individuals who live alone prior to their stroke. Individuals who live alone prior to their stroke tend to be healthier, but also run the risk of being socially isolated^{89,98}. Having a better understanding of the relationship between rehabilitation effectiveness and the roles of race, gender, social support and social isolation can lead to improved patient centered care and outcomes. Further research should consider the interaction between these characteristics and promote aging in place policies that also combat social isolation.

The results from this investigation can guide clinical practice by providing clinicians with information about what goals are important to stroke survivors during stroke recovery. We found that stroke survivors group goal items at the impairment, activity and participation level, so clinicians should approach goal discussions and interventions in this manner. We also found that stroke survivors group sexual intimacy with the other mood goals rather than the physical functioning or other activity goals. Therapists can use this information to guide goal discussions and increase discussions around goals that aren't always discussed or measured, such as sexual intimacy. Having policy in place that supports psychological intervention as well as community re-integration activities would address more of the stroke survivor's current and long term goals.

In conclusion, this investigation considered the role of gender and age on goal categorization and prioritization and the impact of gender and social support on goal

attainment. At the center of providing patient centered care is to have a good understanding of the individual, their roles, and the context in which they live. This investigation provided further understanding of stroke survivor's goal priorities and goal attainment and assessed whether there were differences by gender. Also, new tools to facilitate communication between stroke survivors and the rehabilitation providers were introduced. Utilizing this information when providing stroke rehabilitation services and during future research can further out understanding of what is most important to stroke survivors at different stages of recovery and facilitate goal conversations.

Appendix A Stroke Goals

*The highlighted questions are included in the final list of goals

LIST OF REHAB GOALS AFTER STROKE	WHERE ITEM WAS DEVELOPED	WHY NOT INCLUDED IN QUESTIONNAIRE
I want to be able to walk on my own without a cane or a walker	INTERVIEW/FIM/SIS	
I want to be able to talk again- to communicate what I want or need	INTERVIEW/SIS/FIM	
I want to be able to go to the bathroom by myself	INTERVIEW/SIS/FIM	
I want my hand to work better	INTERVIEW/SIS	
I want to get my strength back-	INTERVIEW/SIS	have separate items for endurance and arm and leg strength
I want help with my depression	INTERVIEW/SIS	
I want to drive again	INTERVIEW	
I want more rehabilitation- more therapy	INTERVIEW	individuals will be receiving therapy at time of interview
I want to be a part of a support group	INTERVIEW	
I want my balance to be better	INTERVIEW	
I want to get back home again	INTERVIEW	1/2 participants will be at home and receiving outpatient therapy
I want to be able to get in and out of bed by myself	INTERVIEW	
I want to know how to prevent another stroke	INTERVIEW	
I want to be able to do projects around the house	INTERVIEW	more general questions included
I want to have better stamina/endurance, to not get tired so easily	INTERVIEW	
I want to be able to take care of myself	INTERVIEW	
I want to get back to normal again- to be able to do all the things I used to do	INTERVIEW	
I want my vision to be better	INTERVIEW	
I want more information about my stroke- to sit down with the doctor and have them explain things to me	INTERVIEW	

I want more information about what equipment is available and best for me	INTERVIEW	equipment question included about wanting equipment
I want to be independent- to not have to rely on others for things	INTERVIEW	other questions tied to independence and function
I want to be able to move around by myself more	INTERVIEW	
I want to get back to work	INTERVIEW	
I want to be social, to date again	INTERVIEW	
I want to do more activities- to get out of the house more	INTERVIEW	
I want a new brace or equipment to make things easier for me	INTERVIEW	
I want to be able to put on my pants and socks	INTERVIEW	added a general question about getting dressed on own
I want clear communication from by doctors	INTERVIEW	only mentioned by one participant other questions related to information
I want a neurologist to follow up with me right after discharge from the hospital	INTERVIEW	only mentioned by one participant other questions related to information
I want the pain and hypersensitivity in my arm to go away	INTERVIEW	
I want less intensive rehabilitation to start out	INTERVIEW	from interview reflecting back on rehab-
I want to be able to swallow my food	INTERVIEW	other questions on eating
I want more education and training from the therapists	INTERVIEW	other questions on specific education and training needs
I want my home set up so it is easy and safe to get around	INTERVIEW	
I want my doctor to consider the cost of medications when deciding what I should take	INTERVIEW	only mentioned by one participant- may still be important...
I want my skin to stay healthy	INTERVIEW	only mentioned by one participant - not part of SIS or FIM

I want help stretching my muscles	INTERVIEW	only mentioned by one participant not part of SIS or FIM
I want to be able to get in and out of the car	INTERVIEW	
I want my arm to work better	INTERVIEW	
I want information about resources available to stroke patients- free clinics, support groups, etc.	INTERVIEW	
I want to be able to climb one flight of stairs by myself	FIM/SIS	
I want to go through my day without having a bowel accident	FIM/SIS	
I want to go through my day without having a bladder accident	FIM/SIS	
I want to be able to feed myself	FIM	
I want to be able to cut my food with a knife and fork	SIS/FIM	statement included on feeding self
I want to be able to bathe myself	FIM/SIS	
I want to be able to control my mood and not yell at my family when I am frustrated or angry	INTERVIEW	
I want to remember to do things (examples: keep appointments, or take medication)	SIS/FIM	
I want to be able to concentrate	SIS	
I want to be able to solve everyday problems without help	SIS/FIM	
I want to be able to communicate what I need and want	SIS/FIM	
I want to be able to understand what is being said to me in a conversation	SIS/FIM	
I want to participate in a conversation with a group of people	SIS	
I want my leg to be stronger	SIS	
I want my arm to be stronger	SIS	statement included on arm working better
I want to be able to pick up small objects with my weaker hand	SIS	statement included on hand working better

Appendix B: SADI

Self-Awareness Deficit Interview (SADI)

Overview

The SADI is an interviewer rated structured interview based on a model of self-awareness proposed by Fleming and Strong (1995). The SADI consists of three sections that allow collection of qualitative and quantitative data in relation to (a) clients' self-awareness of deficits, (b) clients' self-awareness of functional consequences of deficits, and, (c) clients' ability to set realistic goals for the future.

Background knowledge of the client's current level of functioning, which may require collection of collateral information from significant others, is required for the interviewer to rate the responses on a 4 - point scale. Each section is given a score ranging from 0 (no disorder of self-awareness) to 3 (severe disorder of self-awareness). The three sections can be summed to give a maximum possible score of 9, with higher scores indicating more severe impairment of self-awareness.

Reliability of the Self-Awareness of Deficits Interview:

Source

School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia.

Abstract

PRIMARY OBJECTIVE:

This paper investigates the test-re-test reliability of the Self-Awareness of Deficits Interview (SADI) for assessing level of self-awareness in clients with traumatic brain injury (TBI).

RESEARCH DESIGN:

Twenty rehabilitation clients with TBI were interviewed using the SADI and re-test interviews were conducted 2-4 weeks later.

METHODS AND PROCEDURES:

Two checklists were used to collect collateral information on the client from significant others and rehabilitation staff. This information was used to assist in assigning SADI scores.

MAIN OUTCOMES AND RESULTS:

High test-re-test reliability was demonstrated for both total (ICC = 0.94) and sub-section scores (ICC = 0.85, 0.86 and 0.86). The results, combined with previous research indicating the high inter-rater reliability of the SADI, suggest the SADI is a reliable means of evaluating level of self-awareness. Further research is required to investigate other psychometric properties of the SADI and the two checklists.

THERAPIST Conducts
Self-Awareness Deficit Interview and Scoring

Part 1: S-A Deficits

Q: Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you or your abilities has changed?

Alt: *Do people who know you well notice that anything is different about you since the accident? What might they notice?*

Alt: *What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on/would like to get better?*

Prompts:

Physical abilities (e.g., move arms/legs, balance, vision, endurance)?

Memory/confusion?

Concentration?

Problem-solving, decision-making, organizing and planning things?

Controlling behavior?

Communication?

Getting along with other people?

Has your personality changed?

Are there any other problems that I haven't mentioned?

Score: **CIRCLE 1**

0	Cognitive/psychological problems where relevant are reported by patient/client in response to general questioning, or readily acknowledged in response to specific questioning.
1	Some cognitive/psychological problems reported, but others denied or minimized. Patient/client may have a tendency to focus on relatively minor physical changes (e.g., scars) and acknowledge cognitive/psychological problems only on specific questioning about deficits.
2	Physical deficits only acknowledged; denies, minimizes, or is unsure of cognitive/psychological changes. Patient/client may recognize problems that occurred at an earlier stage, but denies existence of persisting deficits, or may state that other people think there are deficits, but s/he does not think so.
3	No acknowledgement of deficits can be obtained (other than for obvious physical deficits). Or – patient/client will only acknowledge problems that have been imposed on him/her (e.g., not allowed to drive, not allowed to drink alcohol).

Subject Statements (and cues):

Part 2: S-A Functional Impact

Q: Does your head injury have any affect on your everyday life? In what way?

Prompts:

Ability to live independently?

Managing finances?

Look after family/manage home?

*Driving? *Do you see anything in your current function that would make your driving less safe?*

Work/study?

Leisure/social life?

Are there any other areas of life which you feel have changed/may change?

Score: **CIRCLE 1**

0	Patient/client accurately describes current functional status in independent living, work/study, leisure, home management, driving) and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems
1	Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g., is unable to say because s/he has not tried an activity yet.
2	Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
3	Little acknowledgement of functional consequences can be obtained. The patient/client will not acknowledge problems: except that s/he is not allowed to perform certain tasks. S/he may actively ignore medical advice and may engage in risk-taking behaviors (drinking, driving).

Subject Statements (and cues):

Part 3: Ability to set realistic goals

Q: What do you hope to achieve in the next 6 months? Do you have any goals? What are they?

Alt: In 6 months time, what do you think you will be doing? Where do you think you will be?

Alt: Do you think your head injury will still be having an affect on your life in 6 months time? If *yes* – how? If *no* – are you sure?

Score: **CIRCLE 1**

0	Patient/client accurately describes current functional status in independent living, work/study, leisure, home management, driving) and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems
1	Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g., is unable to say because s/he has not tried an activity yet.
2	Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
3	Little acknowledgement of functional consequences can be obtained. The patient/client will not acknowledge problems: except that s/he is not allowed to perform certain tasks. S/he may actively ignore medical advice and may engage in risk-taking behaviors (drinking, driving).

Subject Statements (and cues):

____ TOTAL SCORE for 3 parts

SADI section three corrected scoring criteria:

SECTION 3: Ability to set realistic goals:

- 0 Patient/client sets reasonably realistic goals, and (when relevant) identifies that the head injury will probably continue to have an impact on some areas of functioning, i.e. goals for the future have been modified in some way since the injury.
- 1 Patient/client sets goals, which are somewhat unrealistic, or is unable to specify a goal, but recognizes that he/she may still have problems in some areas of function in the future, i.e. sees that goals for the future may need some modification, even if he/she has not yet done so.
- 2 Patient/client sets unrealistic goals, or is unable to specify a goal, and does not know how he/she will be functioning in 6 months' time, but hopes he/she will return to pre-trauma, i.e. no modification of goals has occurred.
- 3 Patient/client expects without uncertainty that in 6 months' time he/she will be functioning at pre-trauma level (or at a higher level).

Appendix C: MOCA

MONTREAL COGNITIVE ASSESSMENT (MOCA) Version 7.1 Original Version						NAME : Education : Sex :		Date of birth : DATE :		
VISUOSPATIAL / EXECUTIVE						Copy cube		Draw CLOCK (Ten past eleven) (3 points)		POINTS
[]						[]		[] [] [] Contour Numbers Hands		___/5
NAMING										
[]						[]		[]		___/3
MEMORY										
Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.										
						FACE		VELVET		CHURCH
1st trial										DAISY
2nd trial										RED
										No points
ATTENTION										
Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order						[] 2 1 8 5 4				
Subject has to repeat them in the backward order						[] 7 4 2				___/2
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors						[] FBACMNAAJKLBAFAKDEAAAJAMOFAB				___/1
Serial 7 subtraction starting at 100						[] 93		[] 86		[] 79
								[] 72		[] 65
4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt										___/3
LANGUAGE										
Repeat: I only know that John is the one to help today. []										
The cat always hid under the couch when dogs were in the room. []										___/2
Fluency / Name maximum number of words in one minute that begin with the letter F						[] _____ (N ≥ 11 words)				___/1
ABSTRACTION										
Similarity between e.g. banana - orange = fruit						[] train - bicycle		[] watch - ruler		___/2
DELAYED RECALL										
Has to recall words WITH NO CUE						FACE		VELVET		CHURCH
						[]		[]		DAISY
						[]		[]		RED
										Points for UNCUE recall only
Optional										
Category cue										
Multiple choice cue										
ORIENTATION										
[] Date						[] Month		[] Year		[] Day
								[] Place		[] City
										___/6
© Z.Nasreddine MD						www.mocatest.org		Normal ≥ 26 / 30		
Administered by: _____								TOTAL		___/30
								Add 1 point if ≤ 12 yr edu		

Appendix D IPA Form

SUBJECT # _____ **DATE:** _____

PERFORMANCE AND IMPORTANCE RATING FORM:

GOAL	PERFORMANCE RATING	IMPORTANCE RATING
I want to be able to walk on my own without a cane or a walker		
I want to be able to go to the bathroom by myself		
I want my hand to work better		
I want help with my depression/depression affects my performance on daily tasks		
I want to drive again		
I want to be a part of a support group		
I want my balance to be better		
I want to be able to get in and out of bed by myself		
I want to know how to prevent another stroke		
I want to be able to do projects around the house again		
I want to have better stamina/endurance to not get tired so easily/Poor endurance affects my performance on daily tasks		
I want my vision to be better/Poor vision affects my performance on daily tasks		
I want more information about my stroke- to sit down with the doctor and have them explain things to me		
I want to be able to move around by myself more		
I want to get back to work		
I want to be social, to see my friends/date again		

I want to do more activities- to get out of the house more		
I want a new brace or equipment to make things easier for me/a lack of equipment affects my performance on daily tasks		
I want my home set up so it is easy and safe to get around/how my home is set up affects my performance on daily tasks		
I want my skin to be healthy/poor skin affects my performance on daily tasks		
I want to be able to get in and out of the car		
I want the pain in my arm to go away. The pain in my arm affects my ability to participate in daily tasks		
I want information about resources available to stroke patients- free clinics, support groups, etc.		
I want to be able to climb one flight of stairs by myself		
I want to go through my day without having a bowel or bladder accident		
I want to be able to feed myself		
I want to be able to bathe myself		
I want to be able to control my mood and not yell at my family when I am frustrated or angry/mood control affects my performance on daily tasks		
I want to remember to do things (examples: keep appointments, or take my medications)		
I want to be able to concentrate		
I want to be able to solve everyday problems without help		
I want to be able to communicate what I need and want		
I want to be able to understand what is being said to me in a conversation		
I want to participate in a conversation with a group of people		

I want my leg to be stronger		
I want help with my anxiety/my anxiety affects my performance in daily tasks		
I want to be sexually intimate with someone		
I want to be able to get dressed by myself		
I want help with my pain/pain affects my ability to participate in daily tasks		
I want my arm to be stronger/arm strength affects my ability to participate in daily tasks.		

Appendix E Demographic Questionnaire

SUBJECT NUMBER:

DATE:

Demographic Questionnaire:

Subject # _____

Age: _____

Gender: _____

Race/Ethnicity: _____

Date of Stroke: _____

Type of Stroke: Ischemic Hemorrhagic Unknown

Post-Acute Rehab: NONE IRF SNF HH LTAC OUTPATIENT
UNKNOWN

Support System:

Is there someone who currently helps you with day to day activities? YES NO

WIFE HUSBAND PARTNER CHILDREN FRIENDS
OTHER _____

When you first had your stroke, did you have someone to help you with day to day activities? YES NO

WIFE HUSBAND PARTNER CHILDREN FRIENDS
OTHER _____

Appendix F Odds Ratios Self-Care Items

SELF CARE FIM GOAL ODDS RATIO WITH AND WITHOUT SOCIAL SUPORT IN MODEL

	Eating OR(95%CI)		Grooming OR(95%CI)		Bathing OR(95%CI)	
Age, ref <70	1.00	1.00	1.00	1.00	1.00	1.00
70-74	0.82 (0.76, 0.88)	0.82 (0.76, 0.88)	0.83 (0.78, 0.87)	0.83(0.78,0.87)	0.83 (0.79, 0.86)	0.83(0.79,0.86)
75-79	0.69 (0.64, 0.74)	0.69 (0.64, 0.74)	0.73 (0.69, 0.77)	0.73(0.69,0.77)	0.75 (0.72, 0.78)	0.75(0.72,0.78)
80-84	0.67 (0.62, 0.72)	0.67 (0.62, 0.72)	0.68 (0.64, 0.72)	0.68(0.64,0.72)	0.63 (0.6, 0.66)	0.63(0.6,0.66)
85+	0.54 (0.51, 0.58)	0.54 (0.5, 0.58)	0.56 (0.53, 0.59)	0.56(0.53,0.59)	0.47 (0.45, 0.5)	0.47(0.45,0.49)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00	1.00	1.00
Black	0.85 (0.79, 0.90)	0.85 (0.79, 0.9)	0.82 (0.78, 0.86)	0.82(0.78,0.86)	0.88 (0.84, 0.92)	0.88(0.85,0.92)
Hispanic	0.91 (0.83, 1.00)	0.92 (0.84, 1.01)	0.95 (0.88, 1.02)	0.95(0.88,1.02)	0.91 (0.86, 0.97)	0.92(0.87,0.99)
Other	0.90 (0.80, 1.01)	0.91 (0.81, 1.02)	0.92 (0.84, 1.01)	0.93(0.85,1.01)	0.9 (0.83, 0.97)	0.91(0.84,0.99)
Unknown	1.10 (0.74, 1.63)	1.1 (0.74, 1.63)	0.96 (0.71, 1.28)	0.96(0.71,1.29)	0.77 (0.6, 0.98)	0.77(0.61,0.98)
Dual eligible	0.85 (0.80, 0.90)	0.84 (0.8, 0.89)	0.79 (0.76, 0.82)	0.78(0.75,0.82)	0.79 (0.76, 0.82)	0.78(0.75,0.81)
Disability entitlement	1.00 (0.94, 1.06)	1 (0.94, 1.06)	0.99 (0.94, 1.03)	0.99(0.94,1.04)	0.95 (0.91, 0.99)	0.95(0.91,0.99)
Elixhauser, ref = none	1.00	1.00	1.00	1.00	1.00	1.00
1 or 2	0.85 (0.63, 1.14)	0.85 (0.63, 1.15)	0.8 (0.64, 1)	0.8(0.64,1)	1.03 (0.88, 1.21)	1.03(0.88,1.21)
≥3	0.65 (0.48, 0.87)	0.65 (0.49, 0.88)	0.57 (0.46, 0.71)	0.57(0.46,0.72)	0.75 (0.64, 0.88)	0.76(0.65,0.89)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00	1.00	1.00
Hemorrhagic	0.95 (0.88, 1.01)	0.95 (0.89, 1.02)	0.96 (0.91, 1.01)	0.96(0.91,1.01)	1.05 (1, 1.1)	1.05(1,1.1)
Other	0.85 (0.74, 0.97)	0.85 (0.75, 0.98)	0.77 (0.7, 0.86)	0.78(0.71,0.86)	0.56 (0.51, 0.61)	0.56(0.52,0.62)
Tpa received	1.00 (0.93, 1.08)	1.01 (0.94, 1.09)	0.91 (0.85, 0.96)	0.91(0.86,0.97)	0.98 (0.93, 1.04)	1(0.94,1.05)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00	1.00	1.00
10-22 days	2.11 (2.00, 2.22)	2.11 (2, 2.22)	1.53 (1.47, 1.59)	1.52(1.46,1.58)	0.96 (0.93, 0.99)	0.96(0.93,0.99)
23-35 days	2.86 (2.67, 3.05)	2.85 (2.67, 3.04)	1.33 (1.26, 1.4)	1.32(1.26,1.39)	0.44 (0.42, 0.46)	0.44(0.42,0.46)
> 35 days	4.38 (3.71, 5.18)	4.38 (3.7, 5.18)	1.6 (1.4, 1.82)	1.59(1.4,1.82)	0.36 (0.31, 0.41)	0.36(0.31,0.41)
Admit FIM	2.74 (2.71, 2.78)	2.74 (2.7, 2.78)	2.41 (2.38, 2.44)	2.4(2.37,2.43)	2.44 (2.41, 2.47)	2.43(2.4,2.46)
Female	1.10 (1.05, 1.14)	1.08 (1.03, 1.13)	1.04 (1, 1.07)	1.03(0.99,1.06)	1.05 (1.03, 1.08)	1.03(1.01,1.06)
Social support, ref = spouse/Family		1.00		1.00		1.00
Paid Caregiver		0.74 (0.6, 0.91)		0.65(0.56,0.77)		0.62(0.53,0.72)
Alone		1.14 (1.08, 1.2)		1.09(1.05,1.13)		1.17(1.13,1.2)

	UE Dressing OR(95%CI)		LE Dressing OR(95%CI)		Toileting OR(95%CI)	
Age, ref <70	1.00	1.00	1.00	1.00	1.00	1.00
70-74	0.84 (0.8, 0.88)	0.84(0.8,0.88)	0.86 (0.82, 0.9)	0.85(0.82,0.89)	0.83 (0.8, 0.87)	0.83(0.8,0.87)
75-79	0.75 (0.72, 0.79)	0.75(0.72,0.79)	0.75 (0.71, 0.78)	0.74(0.71,0.78)	0.74 (0.71, 0.77)	0.74(0.7,0.77)
80-84	0.68 (0.64, 0.71)	0.67(0.64,0.71)	0.62 (0.59, 0.65)	0.62(0.59,0.65)	0.63 (0.6, 0.66)	0.63(0.6,0.66)
85+	0.52 (0.5, 0.55)	0.52(0.49,0.54)	0.47 (0.44, 0.49)	0.46(0.44,0.48)	0.48 (0.46, 0.51)	0.48(0.46,0.5)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00	1.00	1.00
Black	0.87 (0.84, 0.91)	0.87(0.84,0.91)	0.83 (0.8, 0.87)	0.83(0.8,0.87)	0.86 (0.83, 0.9)	0.86(0.83,0.9)
Hispanic	0.88 (0.82, 0.94)	0.89(0.83,0.95)	0.87 (0.82, 0.93)	0.88(0.83,0.95)	0.91 (0.85, 0.97)	0.92(0.86,0.98)
Other	0.95 (0.87, 1.03)	0.96(0.88,1.04)	0.85 (0.78, 0.92)	0.86(0.79,0.94)	0.92 (0.85, 1)	0.93(0.86,1.01)
Unknown	0.86 (0.66, 1.12)	0.86(0.66,1.12)	0.81 (0.63, 1.04)	0.81(0.63,1.05)	0.92 (0.72, 1.18)	0.92(0.72,1.19)
Dual eligible	0.86 (0.82, 0.89)	0.85(0.82,0.88)	0.81 (0.78, 0.84)	0.8(0.77,0.83)	0.81 (0.78, 0.84)	0.8(0.77,0.83)
Disability entitlement	1.01 (0.97, 1.05)	1.01(0.97,1.06)	0.94 (0.9, 0.98)	0.94(0.9,0.98)	0.96 (0.92, 1)	0.96(0.92,1)
Elixhauser, ref = none	1.00	1.00	1.00	1.00	1.00	1.00
1 or 2	1.16 (0.97, 1.38)	1.16(0.97,1.39)	1.06 (0.9, 1.25)	1.06(0.9,1.25)	1.06 (0.9, 1.25)	1.07(0.91,1.26)
≥3	0.82 (0.69, 0.98)	0.83(0.69,0.99)	0.77 (0.66, 0.91)	0.78(0.66,0.91)	0.79 (0.67, 0.93)	0.79(0.67,0.93)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00	1.00	1.00
Hemorrhagic	1.07 (1.02, 1.12)	1.07(1.02,1.12)	1.03 (0.98, 1.08)	1.04(0.99,1.09)	0.96 (0.92, 1.01)	0.96(0.92,1.01)
Other	0.63 (0.58, 0.69)	0.64(0.58,0.7)	0.52 (0.47, 0.57)	0.53(0.48,0.58)	0.61 (0.55, 0.66)	0.61(0.56,0.67)
Tpa received	0.94 (0.89, 1)	0.95(0.9,1.01)	1.04 (0.98, 1.09)	1.05(0.99,1.11)	1 (0.95, 1.06)	1.02(0.96,1.07)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00	1.00	1.00
10-22 days	1.38 (1.33, 1.43)	1.37(1.32,1.42)	1.09 (1.06, 1.13)	1.09(1.05,1.12)	1.13 (1.09, 1.17)	1.12(1.09,1.16)
23-35 days	0.94 (0.9, 0.99)	0.94(0.89,0.98)	0.47 (0.45, 0.49)	0.46(0.44,0.49)	0.49 (0.47, 0.52)	0.49(0.46,0.51)
> 35 days	0.96 (0.85, 1.09)	0.96(0.85,1.08)	0.33 (0.28, 0.39)	0.33(0.28,0.38)	0.38 (0.33, 0.44)	0.38(0.33,0.43)
Admit FIM	2.64 (2.61, 2.68)	2.64(2.6,2.67)	2.84 (2.79, 2.88)	2.83(2.79,2.87)	2.6 (2.56, 2.63)	2.59(2.55,2.62)
Female	0.79 (0.77, 0.81)	0.78(0.75,0.8)	1.12 (1.09, 1.15)	1.09(1.06,1.12)	1.09 (1.06, 1.12)	1.07(1.04,1.1)
Social support, ref = spouse/Family		1.00		1.00		1.00
Paid Caregiver		0.61(0.52,0.72)		0.61(0.52,0.72)		0.59(0.5,0.7)
Alone		1.12(1.09,1.16)		1.19(1.15,1.22)		1.17(1.14,1.21)

	Bladder OR(95%CI)		Bowel OR(95%CI)	
Age, ref <70	1.00	1.00	1.00	1.00
70-74	0.82 (0.79, 0.86)	0.82(0.79,0.86)	0.87 (0.83, 0.91)	0.87(0.83,0.91)
75-79	0.73 (0.7, 0.77)	0.73(0.7,0.76)	0.75 (0.72, 0.79)	0.75(0.71,0.79)
80-84	0.62 (0.59, 0.65)	0.62(0.59,0.65)	0.69 (0.66, 0.73)	0.69(0.66,0.73)
85+	0.51 (0.48, 0.53)	0.5(0.48,0.53)	0.56 (0.53, 0.58)	0.55(0.52,0.58)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00
Black	0.8 (0.77, 0.84)	0.8(0.77,0.84)	0.84 (0.8, 0.88)	0.84(0.8,0.88)
Hispanic	0.97 (0.9, 1.03)	0.97(0.91,1.04)	0.93 (0.87, 1)	0.94(0.88,1.01)
Other	1.04 (0.96, 1.13)	1.05(0.97,1.14)	1.03 (0.94, 1.12)	1.04(0.95,1.13)
Unknown	1.08 (0.83, 1.4)	1.08(0.83,1.4)	1.08 (0.82, 1.43)	1.08(0.82,1.43)
Dual eligible	0.82 (0.79, 0.85)	0.82(0.79,0.85)	0.83 (0.8, 0.86)	0.82(0.79,0.86)
Disability entitlement	1.03 (0.99, 1.08)	1.03(0.99,1.08)	1 (0.96, 1.05)	1(0.96,1.05)
Elixhauser, ref = none	1.00	1.00	1.00	1.00
1 or 2	0.9 (0.76, 1.08)	0.9(0.76,1.08)	0.74 (0.6, 0.91)	0.74(0.6,0.91)
≥3	0.66 (0.56, 0.79)	0.67(0.56,0.79)	0.52 (0.42, 0.63)	0.52(0.42,0.64)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00
Hemorrhagic	0.97 (0.93, 1.02)	0.97(0.93,1.02)	0.93 (0.89, 0.98)	0.93(0.89,0.98)
Other	0.65 (0.59, 0.71)	0.65(0.59,0.71)	0.74 (0.67, 0.81)	0.74(0.68,0.82)
Tpa received	1.01 (0.96, 1.07)	1.02(0.97,1.08)	0.95 (0.9, 1.01)	0.96(0.9,1.01)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00
10-22 days	1.1 (1.06, 1.14)	1.1(1.06,1.14)	1.08 (1.04, 1.12)	1.08(1.04,1.12)
23-35 days	0.7 (0.67, 0.74)	0.7(0.67,0.74)	0.72 (0.69, 0.76)	0.72(0.69,0.76)
> 35 days	0.73 (0.64, 0.82)	0.73(0.64,0.82)	0.85 (0.75, 0.96)	0.85(0.75,0.96)
Admit FIM	2.03 (2.01, 2.05)	2.03(2.01,2.05)	1.65 (1.64, 1.66)	1.65(1.63,1.66)
Female	1.13 (1.1, 1.17)	1.12(1.09,1.15)	1.08 (1.05, 1.11)	1.07(1.03,1.1)
Social support, ref = spouse/Family		1.00		1.00
Paid Caregiver		0.68(0.58,0.8)		0.65(0.56,0.76)
Alone		1.11(1.07,1.15)		1.11(1.07,1.15)

Appendix G Odds Ratios Mobility Items

MOBILITY ODDS RATION WITH AND WITHOUT SOCIAL SUPPORT						
	Transfers OR (95% CI)		Toilet Transfers OR (95% CI)		Tub Transfers OR (95% CI)	
Age, ref <70	1.00	1.00	1.00	1.00	1.00	1.00
70-74	0.82 (0.78, 0.86)	0.82(0.78,0.85)	0.82 (0.78, 0.85)	0.82(0.78,0.85)	0.8 (0.77, 0.84)	0.8(0.77,0.83)
75-79	0.72 (0.69, 0.75)	0.72(0.69,0.75)	0.71 (0.68, 0.75)	0.71(0.68,0.74)	0.72 (0.69, 0.75)	0.72(0.69,0.75)
80-84	0.61 (0.58, 0.64)	0.61(0.58,0.63)	0.61 (0.58, 0.64)	0.6(0.58,0.63)	0.61 (0.58, 0.64)	0.6(0.58,0.63)
85+	0.47 (0.45, 0.49)	0.46(0.44,0.48)	0.46 (0.44, 0.48)	0.45(0.43,0.48)	0.45 (0.43, 0.47)	0.44(0.42,0.46)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00	1.00	1.00
Black	0.88 (0.84, 0.92)	0.88(0.84,0.92)	0.86 (0.82, 0.9)	0.86(0.83,0.9)	0.87 (0.84, 0.91)	0.87(0.84,0.91)
Hispanic	0.9 (0.84, 0.96)	0.91(0.85,0.97)	0.86 (0.8, 0.92)	0.87(0.81,0.93)	0.87 (0.81, 0.92)	0.88(0.83,0.94)
Other	0.81 (0.75, 0.88)	0.82(0.76,0.89)	0.83 (0.77, 0.9)	0.85(0.78,0.92)	0.86 (0.79, 0.93)	0.88(0.81,0.95)
Unknown	1.1 (0.85, 1.41)	1.1(0.85,1.42)	0.9 (0.71, 1.16)	0.91(0.71,1.16)	0.89 (0.71, 1.13)	0.9(0.71,1.13)
Dual eligible	0.81 (0.78, 0.84)	0.8(0.77,0.83)	0.8 (0.77, 0.83)	0.79(0.76,0.82)	0.8 (0.77, 0.83)	0.79(0.76,0.82)
Disability entitlement	0.96 (0.92, 1)	0.96(0.92,1)	0.95 (0.91, 0.99)	0.95(0.91,0.99)	0.92 (0.89, 0.96)	0.92(0.89,0.96)
Elixhauser, ref = none	1.00	1.00	1.00	1.00	1.00	1.00
1 or 2	0.99 (0.84, 1.17)	0.99(0.84,1.17)	1.04 (0.89, 1.22)	1.04(0.89,1.23)	1.02 (0.88, 1.18)	1.02(0.88,1.19)
≥3	0.74 (0.63, 0.87)	0.75(0.64,0.88)	0.77 (0.65, 0.9)	0.77(0.66,0.9)	0.74 (0.64, 0.86)	0.75(0.65,0.87)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00	1.00	1.00
Hemorrhagic	0.97 (0.92, 1.01)	0.97(0.93,1.02)	0.93 (0.89, 0.98)	0.94(0.89,0.98)	0.91 (0.87, 0.95)	0.91(0.87,0.96)
Other	0.62 (0.57, 0.68)	0.63(0.57,0.69)	0.67 (0.61, 0.73)	0.67(0.62,0.74)	0.58 (0.53, 0.64)	0.59(0.54,0.65)
Tpa received	1.05 (0.99, 1.11)	1.06(1,1.12)	0.99 (0.94, 1.05)	1.01(0.95,1.06)	1.02 (0.97, 1.08)	1.04(0.99,1.1)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00	1.00	1.00
10-22 days	1.12 (1.08, 1.16)	1.12(1.08,1.15)	1.04 (1.01, 1.08)	1.04(1.01,1.07)	0.8 (0.78, 0.83)	0.8(0.78,0.82)
23-35 days	0.63 (0.6, 0.67)	0.63(0.6,0.66)	0.57 (0.54, 0.6)	0.57(0.54,0.6)	0.3 (0.29, 0.32)	0.3(0.29,0.32)
> 35 days	0.51 (0.44, 0.58)	0.5(0.44,0.58)	0.43 (0.37, 0.5)	0.43(0.37,0.5)	0.23 (0.19, 0.26)	0.22(0.19,0.26)
Admit FIM	2.82 (2.78, 2.86)	2.81(2.78,2.85)	2.68 (2.64, 2.72)	2.67(2.64,2.71)	1.87 (1.85, 1.89)	1.87(1.85,1.89)
Female	1.01 (0.98, 1.03)	0.98(0.96,1.01)	1.05 (1.02, 1.08)	1.03(1,1.06)	1.02 (0.99, 1.04)	0.99(0.96,1.01)
Social support, ref = spouse/Family		1.00		1.00		1.00
Paid Caregiver		0.64(0.55,0.75)		0.63(0.54,0.74)		0.64(0.55,0.75)
Alone		1.18(1.14,1.22)		1.17(1.14,1.21)		1.24(1.2,1.27)

	Walking OR (95% CI)		STAIRS OR (95% CI)	
Age, ref <70	1.00	1.00	1.00	1.00
70-74	0.85 (0.81, 0.88)	0.85(0.81,0.88)	0.83 (0.8, 0.87)	0.83(0.8,0.87)
75-79	0.76 (0.73, 0.79)	0.76(0.73,0.79)	0.73 (0.7, 0.76)	0.73(0.7,0.76)
80-84	0.66 (0.63, 0.69)	0.66(0.63,0.69)	0.6 (0.57, 0.63)	0.59(0.57,0.62)
85+	0.53 (0.5, 0.55)	0.52(0.5,0.54)	0.43 (0.41, 0.45)	0.42(0.4,0.44)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00
Black	0.87 (0.84, 0.91)	0.87(0.84,0.91)	0.9 (0.87, 0.94)	0.91(0.87,0.95)
Hispanic	0.92 (0.86, 0.97)	0.93(0.87,0.99)	0.93 (0.87, 1)	0.95(0.89,1.02)
Other	0.8 (0.74, 0.86)	0.81(0.75,0.87)	0.88 (0.81, 0.96)	0.9(0.83,0.98)
Unknown	0.91 (0.72, 1.14)	0.91(0.72,1.14)	0.95 (0.75, 1.21)	0.96(0.75,1.21)
Dual eligible	0.78 (0.76, 0.81)	0.78(0.75,0.8)	0.79 (0.76, 0.82)	0.78(0.75,0.81)
Disability entitlement	1.02 (0.98, 1.06)	1.02(0.98,1.06)	0.88 (0.84, 0.91)	0.87(0.84,0.91)
Elixhauser, ref = none	1.00	1.00	1.00	1.00
1 or 2	0.92 (0.79, 1.07)	0.92(0.79,1.07)	0.8 (0.69, 0.93)	0.8(0.69,0.93)
≥3	0.68 (0.58, 0.79)	0.68(0.59,0.8)	0.56 (0.48, 0.64)	0.56(0.48,0.65)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00
Hemorrhagic	0.87 (0.83, 0.91)	0.87(0.84,0.91)	0.99 (0.94, 1.04)	1(0.95,1.04)
Other	0.75 (0.69, 0.82)	0.76(0.7,0.83)	0.53 (0.48, 0.58)	0.53(0.48,0.59)
Tpa received	0.99 (0.95, 1.05)	1.01(0.96,1.06)	1.11 (1.06, 1.18)	1.13(1.07,1.19)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00
10-22 days	1.06 (1.03, 1.09)	1.05(1.02,1.09)	0.73 (0.71, 0.75)	0.73(0.71,0.75)
23-35 days	0.51 (0.49, 0.53)	0.51(0.49,0.53)	0.2 (0.19, 0.22)	0.2(0.19,0.21)
> 35 days	0.54 (0.48, 0.61)	0.54(0.48,0.61)	0.14 (0.12, 0.17)	0.14(0.12,0.17)
Admit FIM	2.37 (2.33, 2.41)	2.36(2.33,2.4)	2.88 (2.81, 2.95)	2.87(2.8,2.94)
Female	1.03 (1.01, 1.06)	1.01(0.99,1.04)	0.9 (0.88, 0.92)	0.88(0.85,0.9)
Social support, ref = spouse/Family		1.00		1.00
Paid Caregiver		0.59(0.51,0.69)		0.51(0.43,0.62)
Alone		1.17(1.14,1.21)		1.23(1.19,1.26)

Appendix H Odds Ratios Communication/Cognition Items

COGNITION AND COMMUNICATION ODDS RATIO WITH AND WITHOUT SOCIAL SUPPORT

	EXPRESSIONOR (95% CI)		INTERACTION OR (95% CI)		COMPREHENSION OR (95% CI)	
Age, ref <70	1.00	1.00	1.00	1.00	1.00	1.00
70-74	0.87 (0.82, 0.92)	0.87(0.82,0.92)	0.89 (0.84, 0.94)	0.89(0.84,0.94)	0.89 (0.84, 0.94)	0.89(0.84,0.94)
75-79	0.8 (0.76, 0.85)	0.8(0.76,0.85)	0.81 (0.76, 0.85)	0.81(0.76,0.85)	0.76 (0.72, 0.81)	0.76(0.72,0.8)
80-84	0.77 (0.73, 0.81)	0.77(0.72,0.81)	0.73 (0.69, 0.77)	0.73(0.68,0.77)	0.7 (0.66, 0.74)	0.69(0.66,0.73)
85+	0.7 (0.66, 0.74)	0.7(0.66,0.74)	0.65 (0.62, 0.69)	0.65(0.62,0.69)	0.62 (0.59, 0.66)	0.62(0.59,0.66)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00	1.00	1.00
Black	0.81 (0.77, 0.85)	0.81(0.77,0.85)	0.79 (0.75, 0.84)	0.79(0.75,0.84)	0.81 (0.77, 0.85)	0.81(0.77,0.85)
Hispanic	1.01 (0.93, 1.09)	1.01(0.94,1.1)	0.98 (0.91, 1.07)	0.98(0.91,1.07)	0.88 (0.82, 0.95)	0.89(0.82,0.96)
Other	0.91 (0.83, 1)	0.91(0.83,1)	0.81 (0.73, 0.89)	0.81(0.73,0.89)	0.78 (0.71, 0.85)	0.78(0.71,0.86)
Unknown	0.97 (0.72, 1.32)	0.97(0.72,1.32)	0.94 (0.7, 1.28)	0.94(0.7,1.28)	0.98 (0.72, 1.33)	0.98(0.72,1.33)
Dual eligible	0.86 (0.82, 0.9)	0.86(0.82,0.89)	0.88 (0.84, 0.92)	0.88(0.84,0.92)	0.88 (0.85, 0.92)	0.88(0.84,0.92)
Disability entitlement	1.02 (0.97, 1.07)	1.02(0.97,1.07)	0.97 (0.92, 1.02)	0.97(0.92,1.02)	1.02 (0.98, 1.08)	1.03(0.98,1.08)
Elixhauser, ref = none	1.00	1.00	1.00	1.00	1.00	1.00
1 or 2	1.02 (0.83, 1.26)	1.02(0.83,1.26)	0.92 (0.74, 1.15)	0.92(0.74,1.15)	1.04 (0.85, 1.27)	1.04(0.85,1.27)
≥3	0.82 (0.67, 1.01)	0.83(0.67,1.02)	0.74 (0.59, 0.92)	0.74(0.6,0.93)	0.86 (0.71, 1.05)	0.86(0.71,1.05)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00	1.00	1.00
Hemorrhagic	0.99 (0.94, 1.05)	1(0.94,1.05)	0.94 (0.89, 0.99)	0.94(0.89,0.99)	0.92 (0.87, 0.97)	0.92(0.87,0.97)
Other	0.77 (0.69, 0.86)	0.77(0.69,0.86)	0.8 (0.72, 0.89)	0.81(0.72,0.9)	0.87 (0.78, 0.97)	0.87(0.78,0.97)
Tpa received	0.85 (0.8, 0.91)	0.86(0.8,0.91)	0.95 (0.89, 1.02)	0.96(0.9,1.02)	0.9 (0.85, 0.96)	0.91(0.85,0.97)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00	1.00	1.00
10-22 days	1.57 (1.51, 1.64)	1.57(1.51,1.63)	1.5 (1.44, 1.56)	1.5(1.44,1.56)	1.45 (1.39, 1.51)	1.45(1.39,1.5)
23-35 days	2.14 (2.03, 2.26)	2.14(2.03,2.26)	1.81 (1.71, 1.91)	1.8(1.71,1.91)	1.9 (1.8, 2)	1.9(1.8,2)
> 35 days	3.37 (2.9, 3.91)	3.37(2.9,3.91)	2.54 (2.18, 2.96)	2.54(2.18,2.96)	3.07 (2.65, 3.56)	3.07(2.65,3.56)
Admit FIM	3.95 (3.89, 4.02)	3.95(3.89,4.01)	2.84 (2.8, 2.88)	2.84(2.8,2.88)	3.63 (3.57, 3.68)	3.62(3.57,3.68)
Female	1.09 (1.06, 1.13)	1.09(1.05,1.12)	1.07 (1.04, 1.11)	1.07(1.03,1.11)	1.05 (1.02, 1.09)	1.04(1.01,1.08)
Social support, ref = spouse/Family		0(0,0)		0(0,0)		0(0,0)
Paid Caregiver		0.73(0.61,0.88)		0.59(0.5,0.71)		0.67(0.56,0.8)
Alone		1.06(1.02,1.1)		1.05(1.01,1.1)		1.09(1.05,1.13)

	PROBLEM SOLVING OR (95% CI)		MEMORY OR (95% CI)	
Age, ref <70	1.00	1.00	1.00	1.00
70-74	0.83 (0.79, 0.87)	0.83(0.79,0.87)	0.79 (0.75, 0.82)	0.78(0.75,0.82)
75-79	0.75 (0.72, 0.79)	0.75(0.72,0.79)	0.7 (0.67, 0.74)	0.7(0.67,0.74)
80-84	0.65 (0.62, 0.68)	0.65(0.62,0.68)	0.58 (0.55, 0.61)	0.58(0.55,0.61)
85+	0.56 (0.53, 0.59)	0.56(0.53,0.59)	0.5 (0.48, 0.53)	0.5(0.48,0.53)
Race/ethnicity, ref = White	1.00	1.00	1.00	1.00
Black	0.82 (0.78, 0.86)	0.82(0.78,0.86)	0.81 (0.77, 0.84)	0.8(0.77,0.84)
Hispanic	0.93 (0.86, 0.99)	0.93(0.86,1)	0.88 (0.82, 0.94)	0.88(0.82,0.94)
Other	0.91 (0.84, 0.99)	0.92(0.84,1)	0.9 (0.83, 0.99)	0.91(0.83,0.99)
Unknown	1.04 (0.8, 1.36)	1.04(0.8,1.36)	1.02 (0.78, 1.33)	1.02(0.78,1.33)
Dual eligible	0.84 (0.8, 0.87)	0.83(0.8,0.87)	0.87 (0.84, 0.91)	0.87(0.83,0.9)
Disability entitlement	0.97 (0.93, 1.01)	0.97(0.93,1.01)	0.95 (0.91, 0.99)	0.95(0.91,0.99)
Elixhauser, ref = none	1.00	1.00	1.00	1.00
1 or 2	1.08 (0.91, 1.28)	1.08(0.91,1.28)	0.92 (0.77, 1.09)	0.92(0.77,1.09)
≥3	0.86 (0.73, 1.02)	0.87(0.74,1.03)	0.76 (0.65, 0.91)	0.77(0.65,0.91)
Stroke type, ref = ischemic	1.00	1.00	1.00	1.00
Hemorrhagic	0.83 (0.79, 0.87)	0.83(0.79,0.87)	0.82 (0.78, 0.86)	0.82(0.78,0.86)
Other	0.82 (0.74, 0.9)	0.82(0.75,0.91)	0.86 (0.78, 0.94)	0.86(0.78,0.95)
Tpa received	0.98 (0.92, 1.03)	0.98(0.92,1.04)	1 (0.95, 1.06)	1.01(0.95,1.07)
Length of stay, ref ≤ 10 days	1.00	1.00	1.00	1.00
10-22 days	1.07 (1.03, 1.11)	1.07(1.03,1.1)	1.09 (1.06, 1.13)	1.09(1.05,1.13)
23-35 days	1.15 (1.1, 1.21)	1.15(1.1,1.21)	1.3 (1.24, 1.36)	1.29(1.23,1.36)
> 35 days	1.56 (1.37, 1.79)	1.56(1.37,1.79)	2.06 (1.8, 2.35)	2.06(1.8,2.36)
Admit FIM	3.22 (3.18, 3.26)	3.22(3.17,3.26)	3.22 (3.18, 3.27)	3.22(3.18,3.26)
Female	1.04 (1.01, 1.07)	1.03(1,1.06)	1.05 (1.02, 1.08)	1.04(1.01,1.07)
Social support, ref = spouse/Family		1.00		1.00
Paid Caregiver		0.62(0.52,0.74)		0.65(0.54,0.78)
Alone		1.06(1.02,1.1)		1.07(1.03,1.1)

References

1. Prevalence and most common causes of disability among adults--United States, 2005. *MMWR Morb Mortal Wkly Rep*. 2009;58(16):421-426.
2. Mozaffarian D, Benjamin EJ, Go AS, et al. Heart Disease and Stroke Statistics—2015 Update: A Report From the American Heart Association. *Circulation*. 2015;131(4):e29-e322.
3. Reeves MJ, Bushnell CD, Howard G, et al. Sex differences in stroke: epidemiology, clinical presentation, medical care, and outcomes. *Lancet Neurol*. 2008;7(10):915-926.
4. Ovbiagele B, Goldstein LB, Higashida RT, et al. Forecasting the future of stroke in the United States: a policy statement from the American Heart Association and American Stroke Association. *Stroke*. 2013;44(8):2361-2375.
5. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics-2017 Update: A Report From the American Heart Association. *Circulation*. 2017;135(10):e146-e603.
6. Feigin VL, Krishnamurthi RV, Parmar P, et al. Update on the Global Burden of Ischemic and Hemorrhagic Stroke in 1990-2013: The GBD 2013 Study. *Neuroepidemiology*. 2015;45(3):161-176.
7. Seshadri S, Beiser A, Kelly-Hayes M, et al. The lifetime risk of stroke: estimates from the Framingham Study. *Stroke*. 2006;37(2):345-350.
8. Kleindorfer DO, Khoury J, Moomaw CJ, et al. Stroke incidence is decreasing in whites but not in blacks: a population-based estimate of temporal trends in stroke incidence from the Greater Cincinnati/Northern Kentucky Stroke Study. *Stroke*. 2010;41(7):1326-1331.
9. Nedeltchev K, der Maur TA, Georgiadis D, et al. Ischaemic stroke in young adults: predictors of outcome and recurrence. *J Neurol Neurosurg Psychiatry*. 2005;76(2):191-195.
10. Kissela BM, Khoury JC, Alwell K, et al. Age at stroke: temporal trends in stroke incidence in a large, biracial population. *Neurology*. 2012;79(17):1781-1787.
11. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet*. 2014;383(9913):245-254.

12. PCORI National Priorities and Research Agenda, 2013. *PCORI National Priorities and Research Agenda* 2013. Accessed June 9, 2016.
13. Services CfMaM. Federal Register Proposed Rules Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies. In. Vol 802015.
14. WHO *International Classification of Functioning, Disability, and Health (ICF)* 2001. Accessed June 8, 2016.
15. Winstein CJ, Stein J, Arena R, et al. Guidelines for Adult Stroke Rehabilitation and Recovery: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke*. 2016;47(6):e98-e169.
16. Laver K, Halbert J, Stewart M, Crotty M. Patient readiness and ability to set recovery goals during the first 6 months after stroke. *J Allied Health*. 2010;39(4):e149-154.
17. Gallacher K, Morrison D, Jani B, et al. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Med*. 2013;10(6):e1001473.
18. Medin J, Barajas J, Ekberg K. Stroke patients' experiences of return to work. *Disabil Rehabil*. 2006;28(17):1051-1060.
19. Low JT, Kersten P, Ashburn A, George S, McLellan DL. A study to evaluate the met and unmet needs of members belonging to Young Stroke groups affiliated with the Stroke Association. *Disabil Rehabil*. 2003;25(18):1052-1056.
20. Gall SL, Tran PL, Martin K, Blizzard L, Srikanth V. Sex differences in long-term outcomes after stroke: functional outcomes, handicap, and quality of life. *Stroke*. 2012;43(7):1982-1987.
21. Whitson HE, Landerman LR, Newman AB, Fried LP, Pieper CF, Cohen HJ. Chronic medical conditions and the sex-based disparity in disability: the Cardiovascular Health Study. *J Gerontol A Biol Sci Med Sci*. 2010;65(12):1325-1331.
22. Synhaeve NE, Arntz RM, van Alebeek ME, et al. Women have a poorer very long-term functional outcome after stroke among adults aged 18-50 years: the FUTURE study. *J Neurol*. 2016;263(6):1099-1105.
23. Nathenson PA, Nathenson SL, Divito KS. Implementing the new CARF wellness standards. *J Stroke Cerebrovasc Dis*. 2014;23(5):1118-1130.

24. Leach E, Cornwell P, Fleming J, Haines T. Patient centered goal-setting in a subacute rehabilitation setting. *Disabil Rehabil.* 2010;32(2):159-172.
25. Playford ED, Dawson L, Limbert V, Smith M, Ward CD, Wells R. Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. *Clin Rehabil.* 2000;14(5):491-496.
26. Plant SE, Tyson SF, Kirk S, Parsons J. What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-synthesis. *Clin Rehabil.* 2016;30(9):921-930.
27. Dodds TA, Martin DP, Stolov WC, Deyo RA. A validation of the functional independence measurement and its performance among rehabilitation inpatients. *Arch Phys Med Rehabil.* 1993;74(5):531-536.
28. Keith RA, Granger CV, Hamilton BB, Sherwin FS. The functional independence measure: a new tool for rehabilitation. *Adv Clin Rehabil.* 1987;1:6-18.
29. *Future of Disability in America, The: Committee on Disability in America Board on Health Sciences Policy.* National Academies Press; 2007.
30. Bernard HR, Ryan GW. *Analyzing qualitative data : systematic approaches.* Los Angeles Calif.: SAGE; 2010.
31. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005;53(4):695-699.
32. Toggia J, Fitzgerald KA, O'Dell MW, Mastrogiovanni AR, Lin CD. The Mini-Mental State Examination and Montreal Cognitive Assessment in persons with mild subacute stroke: relationship to functional outcome. *Arch Phys Med Rehabil.* 2011;92(5):792-798.
33. Pendlebury ST, Mariz J, Bull L, Mehta Z, Rothwell PM. Impact of different operational definitions on mild cognitive impairment rate and MMSE and MoCA performance in transient ischaemic attack and stroke. *Cerebrovasc Dis.* 2013;36(5-6):355-362.
34. Godefroy O, Fickl A, Roussel M, et al. Is the Montreal Cognitive Assessment superior to the Mini-Mental State Examination to detect poststroke cognitive impairment? A study with neuropsychological evaluation. *Stroke.* 2011;42(6):1712-1716.
35. Dong Y, Sharma VK, Chan BP, et al. The Montreal Cognitive Assessment (MoCA) is superior to the Mini-Mental State Examination (MMSE) for the

- detection of vascular cognitive impairment after acute stroke. *J Neurol Sci.* 2010;299(1-2):15-18.
36. J. M. Fleming JSRA. Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Injury.* 1996;10(1):1-16.
 37. Krishnan S, Pappadis MR, Weller SC, Fisher SR, Hay CC, Reistetter TA. Patient-centered mobility outcome preferences according to individuals with stroke and caregivers: a qualitative analysis. *Disabil Rehabil.* 2017:1-9.
 38. Duncan PW, Wallace D, Studenski S, Lai SM, Johnson D. Conceptualization of a new stroke-specific outcome measure: the stroke impact scale. *Top Stroke Rehabil.* 2001;8(2):19-33.
 39. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. *Stroke.* 1999;30(10):2131-2140.
 40. Grenier-Genest A, Gerard M, Courtois F. Stroke and sexual functioning: A literature review. *NeuroRehabilitation.* 2017;41(2):293-315.
 41. Calabro RS, Bramanti P. Post-stroke sexual dysfunction: an overlooked and under-addressed problem. *Disabil Rehabil.* 2014;36(3):263-264.
 42. Yeh HW, Gajewski BJ, Perdue DG, et al. Sorting it Out: Pile Sorting as a Mixed Methodology for Exploring Barriers to Cancer Screening. *Qual Quant.* 2014;48(5):2569-2587.
 43. Harrison RA, Field TS. Post stroke pain: identification, assessment, and therapy. *Cerebrovasc Dis.* 2015;39(3-4):190-201.
 44. Paolucci S, Iosa M, Toni D, et al. Prevalence and Time Course of Post-Stroke Pain: A Multicenter Prospective Hospital-Based Study. *Pain Med.* 2016;17(5):924-930.
 45. Steinke EE, Jaarsma T, Barnason SA, et al. Sexual counselling for individuals with cardiovascular disease and their partners: a consensus document from the American Heart Association and the ESC Council on Cardiovascular Nursing and Allied Professions (CCNAP). *Eur Heart J.* 2013;34(41):3217-3235.
 46. Kautz DD, Van Horn ER. Sex and Intimacy after Stroke. *Rehabil Nurs.* 2016.
 47. Song H, Oh H, Kim H, Seo W. Effects of a sexual rehabilitation intervention program on stroke patients and their spouses. *NeuroRehabilitation.* 2011;28(2):143-150.

48. Sugavanam T, Mead G, Bulley C, Donaghy M, van Wijck F. The effects and experiences of goal setting in stroke rehabilitation - a systematic review. *Disabil Rehabil.* 2013;35(3):177-190.
49. Stineman MG, Rist PM, Kurichi JE, Maislin G. Disability meanings according to patients and clinicians: imagined recovery choice pathways. *Qual Life Res.* 2009;18(3):389-398.
50. Brown M, Levack W, McPherson KM, et al. Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. *Disabil Rehabil.* 2014;36(12):1020-1026.
51. Levack WM, Dean SG, Siegert RJ, McPherson KM. Navigating patient-centered goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities. *Patient Educ Couns.* 2011;85(2):206-213.
52. Dalton C, Farrell R, De Souza A, et al. Patient inclusion in goal setting during early inpatient rehabilitation after acquired brain injury. *Clin Rehabil.* 2012;26(2):165-173.
53. Wain HR, Kneebone, II, Billings J. Patient experience of neurologic rehabilitation: a qualitative investigation. *Arch Phys Med Rehabil.* 2008;89(7):1366-1371.
54. Lawrence M. Young adults' experience of stroke: a qualitative review of the literature. *Br J Nurs.* 2010;19(4):241-248.
55. Morris R. The psychology of stroke in young adults: the roles of service provision and return to work. *Stroke Res Treat.* 2011;2011:534812.
56. Kempers E. Preparing the young stroke survivor for return to work. *Top Stroke Rehabil.* 1994;1(1):65-73.
57. Hartke RJ, Trierweiler R. Survey of survivors' perspective on return to work after stroke. *Top Stroke Rehabil.* 2015;22(5):326-334.
58. Teasell RW, McRae MP, Finestone HM. Social issues in the rehabilitation of younger stroke patients. *Arch Phys Med Rehabil.* 2000;81(2):205-209.
59. Daniel K, Wolfe CD, Busch MA, McKeivitt C. What are the social consequences of stroke for working-aged adults? A systematic review. *Stroke.* 2009;40(6):e431-440.
60. Association NS. National Stroke Association Stroke Perceptions Study. 2006. Accessed 12/1/2017, 2017.

61. Martilla J. Importance-performance analysis. *Journal of Marketing*. 1977;41:77-79.
62. Cunningham MA, Gaeth GJ. Using importance-performance analysis to assess patients' decisions to seek care in a dental school clinic. *J Dent Educ*. 1989;53(10):584-586.
63. Cohen JF, Coleman E, Kangethe MJ. An importance-performance analysis of hospital information system attributes: A nurses' perspective. *Int J Med Inform*. 2016;86:82-90.
64. Hocine MN, Ait Bouziad K, Legeron P, Dab W, Saporta G. How to Identify and Prioritize Psychosocial Factors Impacting Stress Level. *PLoS One*. 2016;11(6):e0157078.
65. Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian occupational performance measure: an outcome measure for occupational therapy. *Can J Occup Ther*. 1990;57(2):82-87.
66. Cup EH, Scholte op Reimer WJ, Thijssen MC, van Kuyk-Minis MA. Reliability and validity of the Canadian Occupational Performance Measure in stroke patients. *Clin Rehabil*. 2003;17(4):402-409.
67. Abalo J, Varela J, Manzano V. Importance values for Importance=Performance Analysis: A formula for spreading out values derived from preference rankings. *Journal of Business Research*. 2007;60:115-121.
68. Roth EJ, Heinemann AW, Lovell LL, Harvey RL, McGuire JR, Diaz S. Impairment and disability: their relation during stroke rehabilitation. *Arch Phys Med Rehabil*. 1998;79(3):329-335.
69. Giralt D, Domingues-Montanari S, Mendioroz M, et al. The gender gap in stroke: a meta-analysis. *Acta Neurol Scand*. 2012;125(2):83-90.
70. McDermott M, Lisabeth LD, Baek J, et al. Sex Disparity in Stroke Quality of Care in a Community-Based Study. *J Stroke Cerebrovasc Dis*. 2017;26(8):1781-1786.
71. Bushnell C, McCullough LD, Awad IA, et al. Guidelines for the prevention of stroke in women: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2014;45(5):1545-1588.
72. Demel SL, Kittner S, Ley SH, McDermott M, Rexrode KM. Stroke Risk Factors Unique to Women. *Stroke*. 2018;49(3):518-523.

73. Ottenbacher KJ, Smith PM, Illig SB, Fiedler RC, Gonzales V, Granger CV. Characteristics of persons rehospitalized after stroke rehabilitation. *Arch Phys Med Rehabil.* 2001;82(10):1367-1374.
74. Ottenbacher KJ, Graham JE, Ottenbacher AJ, et al. Hospital readmission in persons with stroke following postacute inpatient rehabilitation. *J Gerontol A Biol Sci Med Sci.* 2012;67(8):875-881.
75. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61-63.
76. Granger CV, Albrecht GL, Hamilton BB. Outcome of comprehensive medical rehabilitation: measurement by PULSES profile and the Barthel Index. *Arch Phys Med Rehabil.* 1979;60(4):145-154.
77. Lin JH, Hsieh CL, Lo SK, Hsiao SF, Huang MH. Prediction of functional outcomes in stroke inpatients receiving rehabilitation. *J Formos Med Assoc.* 2003;102(10):695-700.
78. Ween JE, Alexander MP, D'Esposito M, Roberts M. Factors predictive of stroke outcome in a rehabilitation setting. *Neurology.* 1996;47(2):388-392.
79. Haselbach D, Renggli A, Carda S, Croquelois A. Determinants of neurological functional recovery potential after stroke in young adults. *Cerebrovasc Dis Extra.* 2014;4(1):77-83.
80. Kwakkel G, Wagenaar RC, Kollen BJ, Lankhorst GJ. Predicting disability in stroke--a critical review of the literature. *Age Ageing.* 1996;25(6):479-489.
81. Mutai H, Furukawa T, Araki K, Misawa K, Hanihara T. Factors associated with functional recovery and home discharge in stroke patients admitted to a convalescent rehabilitation ward. *Geriatr Gerontol Int.* 2012;12(2):215-222.
82. Morone G, Paolucci S, Iosa M. In What Daily Activities Do Patients Achieve Independence after Stroke? *J Stroke Cerebrovasc Dis.* 2015;24(8):1931-1937.
83. Kong KH, Lee J. Temporal recovery of activities of daily living in the first year after ischemic stroke: a prospective study of patients admitted to a rehabilitation unit. *NeuroRehabilitation.* 2014;35(2):221-226.
84. Holroyd-Leduc JM, Kapral MK, Austin PC, Tu JV. Sex differences and similarities in the management and outcome of stroke patients. *Stroke.* 2000;31(8):1833-1837.
85. Paolucci S, Bragoni M, Coiro P, et al. Is sex a prognostic factor in stroke rehabilitation? A matched comparison. *Stroke.* 2006;37(12):2989-2994.

86. Ng YS, Stein J, Salles SS, Black-Schaffer RM. Clinical characteristics and rehabilitation outcomes of patients with posterior cerebral artery stroke. *Arch Phys Med Rehabil*. 2005;86(11):2138-2143.
87. Chiou-Tan FY, Keng MJ, Jr., Graves DE, Chan KT, Rintala DH. Racial/ethnic differences in FIM scores and length of stay for underinsured patients undergoing stroke inpatient rehabilitation. In: *Am J Phys Med Rehabil*. Vol 85. United States 2006:415-423.
88. O'Brien SR, Xue Y. Predicting goal achievement during stroke rehabilitation for Medicare beneficiaries. *Disabil Rehabil*. 2014;36(15):1273-1278.
89. Boden-Albala B, Litwak E, Elkind MS, Rundek T, Sacco RL. Social isolation and outcomes post stroke. *Neurology*. 2005;64(11):1888-1892.
90. Hachisuka K, Tsutsui Y, Furusawa K, Ogata H. Gender differences in disability and lifestyle among community-dwelling elderly stroke patients in Kitakyushu, Japan. *Arch Phys Med Rehabil*. 1998;79(8):998-1002.
91. Elixhauser A, Steiner C, Harris DR, Coffey RM. Comorbidity measures for use with administrative data. *Med Care*. 1998;36(1):8-27.
92. Liu M, Tsuji T, Tsujiuchi K, Chino N. Comorbidities in stroke patients as assessed with a newly developed comorbidity scale. *Am J Phys Med Rehabil*. 1999;78(5):416-424.
93. Lisabeth LD, Reeves MJ, Baek J, et al. Factors influencing sex differences in poststroke functional outcome. *Stroke*. 2015;46(3):860-863.
94. Kim JS, Lee KB, Roh H, Ahn MY, Hwang HW. Gender differences in the functional recovery after acute stroke. *J Clin Neurol*. 2010;6(4):183-188.
95. Roth DL, Haley WE, Clay OJ, et al. Race and gender differences in 1-year outcomes for community-dwelling stroke survivors with family caregivers. *Stroke*. 2011;42(3):626-631.
96. Jamieson DG, Skliut M. Gender considerations in stroke management. *Neurologist*. 2009;15(3):132-141.
97. Faigle R, Urrutia VC, Cooper LA, Gottesman RF. Individual and System Contributions to Race and Sex Disparities in Thrombolysis Use for Stroke Patients in the United States. *Stroke*. 2017;48(4):990-997.
98. Aron AW, Staff I, Fortunato G, McCullough LD. Prestroke living situation and depression contribute to initial stroke severity and stroke recovery. *J Stroke Cerebrovasc Dis*. 2015;24(2):492-499.

Vita

CURRICULUM VITAE

BIOGRAPHICAL

Citizenship: U.S.A.
Home: Houston, Texas 77009
Born: Cincinnati, Ohio
Parents: Ann and Don Cooper

EDUCATION

1994 B.S. Biopsychology, University of California at Santa Barbara, Santa Barbara, California
1996 M.S. Occupational Therapy, Tufts University, Boston, Massachusetts

PROFESSIONAL AND TEACHING EXPERIENCE

University of Texas Medical Branch, Galveston, Texas

2014 – Present Graduate Assistant, Division of Rehabilitation Sciences
05/2017 – 09/2017 Adjunct Faculty, Department of Occupational Therapy

Mt. Sinai/Brain Injury Association of America

2016 – Present Systematic Review Consultant

TIRR Memorial Hermann Hospital, Houston, Texas

2014 – Present Supplemental Occupational Therapist
2008 – 2014 Occupational Therapy (OT) Field Coordinator and OT Research Coordinator
2006 – 2008 Supplemental Occupational Therapist
2001 – 2005 Senior Occupational Therapist, Brain Injury Team

Texas Women's University, Houston, Texas

2013 - Present Supplemental Lab Assistant, Department of Occupational Therapy

Houston Community College, Houston, Texas

2008 – 2009 Adjunct Faculty

Sharp Healthcare, San Diego, California

2005 – 2006 Supplemental Occupational Therapist (Acute care and ICU)

Memorial Hermann Southeast Hospital, Houston, Texas

2000 – 2001 Occupational Therapy Manager (Acute care, Rehabilitation, and Outpatient)

St. David's Rehabilitation Center, Austin, Texas

1996 – 2000 Senior Occupational Therapist (Traumatic Brain Injury Team)

LICENSURE AND CERTIFICATIONS

1996 – Present Texas Occupational Therapy License #107279 (valid through 6/30/2018)
1996 – Present NBCOT National Board Certification in Occupational Therapy
Certification #1010610 (valid through 3/31/2018)
2014 – Present Certified Stroke Rehabilitation Specialist
2009 – 2013 Certified Brain Injury Specialist

RESEARCH ACTIVITIES

Area of Research

Patient Centered Outcomes Research, Rehabilitation, Stroke, Brain Injury, Health Disparities, Occupational therapy interventions.

Grant support

Current

Dissertation title: "The Impact of Gender, Age, and Performance on Stroke Survivors' Goal Conceptualization, Prioritization, and Attainment"
Health of Older Minorities (T32 AG00270)
Granting Agency: National Institute on Aging
Period: 5/1/17-4/30/2022
Role: T32 Scholar (PI – R. Wong)

Past

Patient Centered Outcomes Research in the Elderly (R24 HSO22134)
Granting Agency: Agency for Healthcare Research and Quality (AHRQ)
Period: 5/1/13-4/30/18
Role: Research Assistant (Project 2 PI – T. Reistetter)

The use of the iPad during occupational therapy brain injury rehabilitation
Granting Agency: TIRR Rehabilitation Innovations, TIRR Memorial Hermann
Period: 10/2011 – 2012
Role: Principal Investigator
Total Direct Costs: \$5,000

Unfunded

Title: The Impact of Gender and Performance on Stroke Survivors' Goal Prioritization and Attainment
Granting Agency: American Heart Association (AHA)
Role: Principal Investigator

Total Direct Costs: \$25,000

Title: The Impact of Gender, Age, and Performance on Stroke Survivors' Goal
Conceptualization and Prioritization

Granting Agency: FAHS-BECK Fund for Research and Experimentation (The New York
Trust)

Role: Principal Investigator

Total Direct Costs: \$5,000

COMMITTEE RESPONSIBILITIES

- 2009 – Present Volunteer and Leadership Council member, The Rehabilitation Services
Volunteer Project (RSVP)
RSVP is an all-volunteer, nonprofit organization that provides
physical rehabilitation services and equipment to uninsured
individuals with disabilities.
- 05/2011 – 05/2013 Secretary, The Travis Foundation. A non-profit organization
formed to support the education of students at Travis Elementary.
- 07/2001 – 3/2005 Education Committee Chair, TIRR Memorial Hermann.
Responsible for bringing educational opportunities to the staff
during weekend and evening courses.

TEACHING RESPONSIBILITIES

University of Texas Medical Branch

- 05/2017 – 09/2017 **Adjunct Faculty**, Occupational Therapy
- OCCT 6221: Interventions for Neurological Practice
- 2016 **Guest Lecturer**, Department of Physical Therapy
- “Upper Extremity Dysfunction Following Brain Injury”
[Summer 2016 – June 20 & 22, 2016].
- 2011 – 2012 **Guest Lecturer**, Department of Occupational Therapy
- “Occupational Therapy and Evidence Based Practice” [Fall
2011 & 2012].

Texas Women’s University, Houston, Texas

- 2013 – Present **Supplemental Lab Assistant**, Department of Occupational Therapy
- 2010 – 2012 **Guest Lecturer**, Department of Occupational Therapy
- “Spasticity Management in Occupational Therapy” [Spring
2010, 2011 & 2012].

Houston Community College, Houston, Texas

2008 – 2009

Adjunct Faculty

- OTA Course on Human Development

MEMBERSHIP IN SCIENTIFIC SOCIETIES/PROFESSIONAL ORGANIZATIONS

American Occupational Therapy Association (AOTA)

Texas Occupational Therapy Association (TOTA)

American Congress of Rehabilitation Medicine (ACRM)

HONORS

2017	Samuel N.Kolmen,PhD & Barbara Kass Kolmen, MD Travel Scholarship
2017	Peyton and Lydia Schapper Endowed Scholarship
2017	Micks Scholarship in Preventive Medicine and Community Health
2017	Forum on Aging Student Poster Winner (Comparative Effectiveness/ Patient-Centered Outcomes Research)
2016	Peyton and Lydia Schapper Endowed Scholarship
2016	Emily E. Dupree Award for Excellence in Rehabilitation Science

ADDITIONAL INFORMATION

Grant Reviewer

2016-2017	Reviewer, Center for Large Data Research & Data Sharing in Rehabilitation (CLDR) Pilot Program
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PUBLICATIONS

Peer-Reviewed Journal Articles

Hong, I., Lim, Y., Han, H., Hay, C.C., & Woo, H. (2017). Application of the Korean version of the modified barthel index: Development of a keyform for use in clinical practice. *Hong Kong Journal of Occupational Therapy*, 29: 39-46.

Krishnan, S., Pappadis, M. R., Weller, S. C., Fisher, S. R., Hay, C. C., & Reistetter, T. A. (2017). Patient-centered mobility outcome preferences according to individuals with stroke and caregivers: a qualitative analysis. *Disabil Rehabil*, 1-9. doi:10.1080/09638288.2017.1297855

Lewis, Z. H., Hay, C. C., Graham, J. E., Lin, Y. L., Karmarkar, A. M., & Ottenbacher, K. J. (2016). Social support and actual versus expected length of stay in inpatient rehabilitation facilities. *Arch Phys Med Rehabil*. doi:10.1016/j.apmr.2016.06.005

Pappadis, M.R., Davis, L.C., Hay, C.C., & Lockhart, A. (2016). “Rehabilitación vocacional en personas con traumatismo craneoencefálico (TCE).” *Revista Neuropsicología, Neuropsiquiatría y Neurociencias*, 16(1), 51-68. In: *Rehabilitación Integral del Paciente con Daño Cerebral*.
<https://revistannn.files.wordpress.com/2016/08/rnnn-vo-1612016.pdf>

Yozbatiran N., Keser Z., Davis M., et al. (2016). Transcranial direct current stimulation (tDCS) of the primary motor cortex and robot-assisted arm training in chronic

incomplete cervical spinal cord injury: A proof of concept sham-randomized clinical study. *NeuroRehabilitation*, 39 (3): 401-411.

Brauer, J., Cooper Hay, C., Francisco, G. (2011) A retrospective investigation of occupational therapy services received following a traumatic brain injury. *Occupational Therapy in Health Care*, 25(2-3):119-130.

Published Abstracts

Hay, C. C., Pappadis, M.R., Graham, J., & Reistetter, T. A. (2017). The influence of gender and performance on stroke survivors' goal prioritization. *Archives of Physical Medicine and Rehabilitation*, 98(10), e118-e119. doi: 10.1016/j.apmr.2017.08.383

Hay, C. C., Graham, J., Pappadis, M.R., Ottenbacher, K., & Reistetter, T. A. (2017). The impact of gender and social support on goal attainment after stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation*, 98(10), e118. doi: 10.1016/j.apmr.2017.08.381

Pappadis, M.R., Krishnan, S., Hay, C. C., & Reistetter, T. A. (2016). Long-term cognitive impairment and decreased mood among community-dwelling adults again with stroke. *Archives of Physical Medicine and Rehabilitation*, 97(10), e115. doi: 10.1016/j.apmr.2016.08.358

PRESENTATIONS

National

Hay, C. C., Pappadis, M.R., Graham, J., & Reistetter, T. A. (2017, October). *The influence of gender and performance on stroke survivors' goal prioritization*. Abstract accepted for poster presentation at the 2017 American Congress of Rehabilitation Medicine (ACRM) Conference, October 23 – October 28, Atlanta, GA.

Hay, C. C., Graham, J., Pappadis, M.R., Ottenbacher, K., & Reistetter, T. A. (2017, October). *The impact of gender and social support on goal attainment after stroke rehabilitation*. Abstract accepted for poster presentation at the 2017 American Congress of Rehabilitation Medicine (ACRM) Conference, October 23 – October 28, Atlanta, GA.

Pappadis, M.R., Krishnan, S., Hay, C. C., & Reistetter, T. A. (2016, October). *Long-term cognitive impairment and decreased mood among community-dwelling adults again with stroke*. Abstract presented as a poster presentation at the 2016 American Congress of Rehabilitation Medicine (ACRM) Conference, October 30 – November 4, Dallas, TX.

Hay, C. C., Scully, T., Seiber, R. (2014, April). *The Use of the iPad in Brain Injury Rehabilitation*. Presented at the AOTA Annual Conference, April 2014, Baltimore, Maryland.

Local/Regional

Hay, C. C. (2016, November). *Outcome Preferences Among Individuals With Stroke and Their Caregivers*. Presented at the TOTA annual conference, November 2016, Houston, Texas.

Hay, C. C., Lewis, Z.H., Graham, J., (2015, October). *Not as expected! Length of Stay in Inpatient Rehabilitation Facilities*. Abstract presented as a poster presentation at the 2015 American Congress of Rehabilitation Medicine (ACRM) Conference, October 25-30, Dallas, TX.

Hay, C. C., Scully, T. Seiber, R., Vanlandingham, C.(2013, November). *The Use of the iPad in Brain Injury Rehabilitation*. Presented at the TOTA Mountain Central Conference, November 2013, Sugarland, Texas.

Hay, C. C., (2011, April). *Using Mirror Therapy to Improve Upper Extremity Function after Stroke*. Presented at the AOTA annual conference, April 2011, Philadelphia, Pennsylvania.

Hay, C. C., Phillips, D., Scully, T. (2012, November). *Beyond the Journal Pages*. Presented at the TOTA annual conference, November 2012, Austin, Texas.

Permanent address: 517 Byrne Street Houston, Texas 77009

This dissertation was typed by Catherine Cooper Hay.