

Exploring Cognitive Health in Chronic Stroke

by

Kimberly Bennett

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The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, a thesis entitled:

Exploring Cognitive Health in Chronic Stroke

submitted by Kimberly Bennett in partial fulfillment of the requirements for

the degree of Master of Science

in Rehabilitation Sciences

Examining Committee:

Professor Teresa Liu-Ambrose, Department of Physical Therapy

Co-supervisor

Assistant Professor Jennifer C. Davis, Faculty of Management, UBC-O

Co-supervisor

Professor Janice J. Eng, Department of Physical Therapy

Supervisory Committee Member

Professor Todd C. Handy, Department of Psychology

Supervisory Committee Member

Professor Romeo Chua, School of Kinesiology

Additional Examiner

Abstract

Cognitive impairment is a common consequence of stroke that is largely overlooked in post-stroke care. To improve care for cognitive health in stroke, records of lived experience are needed to understand patient priorities. Post-stroke cognition is interrelated with other forms of post-stroke impairment. Specifically, executive performance is cross-sectionally related to mobility post-stroke but it is unknown if this relationship persists over time. This thesis examined: 1) the lived experience of cognitive changes post-stroke and 2) the relationship between executive performance and changes in mobility and balance over time in chronic stroke. Aim 1 was addressed through a qualitative study which captured the experience of post-stroke cognitive changes. This study showed that subjective post-stroke cognitive changes carried meaningful consequences for participants, and identified potential gaps in stroke care. Aim 2 was addressed in sub-analyses of data from a randomized control trial examining the effects of exercise and social and cognitive enrichment on cognition against a control (balance and tone exercises) in community-dwelling older adults (aged 55+ years) with chronic stroke (n=120). Four MANCOVA models were constructed wherein change in mobility was the dependent variable and executive performance and intraindividual variability at baseline were the independent variables; group allocation, age, sex, and education were included as covariates. Change in mobility was quantified through change scores calculated from baseline and 6-month performance on the Timed Up and Go test, the Short Physical Performance Battery and usual gait speed. Separate models were constructed for each independent variable: Digit Span test, Trail-Making Test Ratio, Stroop Colour Word test and intraindividual variability of the Stroop Colour Word test, using Pillai's Trace. If a significant multivariate test was identified for any

independent variable, the univariate F tests were examined. Given the known effect of two study groups: the control group and exercise training, on mobility, the 4 MANCOVA models were run within a sample of all 3 study groups (n=103/120), and a sample of the exercise and control groups (n=74/120). Future studies are needed to better understand whether executive performance or intraindividual variability predicts change in mobility and balance in chronic stroke.

Lay Summary

Cognitive health is often overlooked in post-stroke care. To improve care for cognitive health post-stroke, records of lived experiences are necessary to identify patient priorities in stroke care. Evidence suggests post-stroke cognitive impairment is associated with impaired mobility. Understanding the relationship between post-stroke cognition and mobility over-time will help identify appropriate screening measures post-stroke. My thesis examined post-stroke cognition in 2 ways: 1) the experience of post-stroke cognitive changes and 2) the relationship between cognition and changes in mobility over time post-stroke. The results of the first chapter identify themes across experiences of cognitive changes post-stroke. The results of the second chapter showed that there is no relationship between cognition and changes in mobility in analyses including all 3 study groups, however, the analyses including only exercise-related study groups showed a change in mobility by cognition. Further work is needed to understand the relationship between cognition and mobility in stroke.

Preface

This thesis was written by K. Bennett based on research conducted within the Aging, Mobility and Cognitive Neuroscience Laboratory. Professor Teresa Liu-Ambrose, Assistant Professor Jennifer C. Davis, Professor Janice Eng, Professor Todd C. Handy provided feedback that contributed to the final version of this document.

The study conducted in Chapter 1 is the original, unpublished work conducted by the author, K. Bennett under the mentorship of Jenny Leese, PhD candidate. Ethics approval for this study was approved by the University of British Columbia Clinical Research Ethics Board (H13-00715).

Chapter 2 is an unpublished sub-analysis of data from a randomized control trial conducted within the Aging, Mobility and Cognitive Neuroscience Laboratory. Ethics approval for this study was provided by the University of British Columbia Clinical Research Ethics Board (H13-00715). Professor Liu-Ambrose and I were responsible for the study concept and design. I conducted the statistical analyses with the help of Dr. Ryan Stanley Falck.

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List of Abbreviations

BAT: Balance and Tone Control Group

COG: Cog-Plus Intervention Group

FAS: Fit and Strong Intervention Group

Fugl-Meyer: Fugl Meyer Assessment of Motor Recovery after Stroke

IIV-RT: Intraindividual Reaction Time Variability

IIV: Intraindividual Variability

MMSE: Mini Mental State Exam

MoCA: Montreal Cognitive Assessment

PAR-Q: Physical Activity Readiness Questionnaire (PAR-Q)

RCT: Randomized Control Trial

RT: Reaction Time

SD: Standard Deviation

SPPB: Short Physical Performance Battery

TUG: Timed-up and Go Test

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Dedication

To my Dad - just trying to make you proud.

Chapter 1: The Lived Experience of Post-stroke Cognitive Changes

1.1 Introduction

1.1.1 Stroke Epidemiology

Stroke is the leading cause of neurological disability in Canada with over 50 000 Canadians sustaining sensory, motor, cognitive, and emotional impairment annually (1). These rates are expected to grow as the median age of the population rises along with the rates of obesity and diabetes – each a risk factor of stroke (2). Stroke survivorship is simultaneously increasing; as of 2013, 405 000 Canadians reported living with the lasting effects of stroke – a 97.56% increase from 1998 (1, 2). Recent advancements in thrombolytic agents and emergency service pathways have led to a 7-21% decrease in mortality rates in acute stroke, growing the number of stroke survivors returning to the community (3, 4).

1.1.2 Stroke Etiology

A stroke is commonly defined as an infarction of the central nervous system resulting in lasting cell death in the brain, spinal cord or retina (5). There are three main subtypes of stroke that carry different rates of prevalence: 87% of strokes are classified as an ischemic infarct, 10% are classified as primary hemorrhages and 3% are classified as a subarachnoid hemorrhage (6). Ischemic infarcts refer to the occlusion of a blood vessel supplying the brain, and are often linked to a vascular condition such as atherosclerosis or atrial fibrillation (7). Primary hemorrhages are the result of a rupture in a neural blood vessel, often related to uncontrolled hypertension, or abnormalities in blood vessel formation (7). A subarachnoid hemorrhage is a subtype of hemorrhagic stroke in which the subarachnoid cavity fills with blood (8). While a

stroke is often an acute event, subarachnoid hemorrhages may develop slowly in older adults with age, as shearing forces weaken the arachnoid trabeculae allowing the blood to fill the subarachnoid cavity (9). The classification and location of a stroke, in addition to timely access to medical care and rehabilitation services are key determinants of mortality and the resulting profile of impairments (10).

1.1.3 Stages of Stroke

The first month post-stroke is referred to as the acute stage of stroke, wherein individuals will often be admitted to a hospital in acute rehabilitation. Many experience pronounced recovery in physical function within the first weeks post-stroke which is often attributed to spontaneous mechanisms (11-15). Between 1-6 months post-stroke, stroke survivors are considered to be in the sub-acute phase (16). During this time, individuals may begin in-patient rehabilitation at a short-term care facility to prepare for reintegration into the community or transfer to a long-term care facility. While there is evidence for neuroplasticity throughout the lifespan, the effects of rehabilitation appear to be most substantial in the first 6 months post-stroke (15). McDonnell and colleagues (17) identified the point of fastest recovery at 5 weeks post-stroke; however, the permanence of rehabilitation progress is still debated (18). After 6 months, stroke survivors are considered to be in the chronic phase (19-21) and many have already returned to the community. Rehabilitation may continue through out-patient services however, such services must generally be sought privately after 12 months post-stroke (18) .

1.1.4 Post-stroke Cognitive Health

Post-stroke cognitive impairment refers to deficit across one or more domains of cognition including: attention, executive functions, memory, language and visuo-perceptual abilities. Over 65% of stroke survivors present with impairment to at least one cognitive domain (22). Notably, a stroke doubles the risk of dementia (23). As rates of stroke and survivorship rise, an increased number of stroke survivors have returned to the community with impaired cognition, denoting post-stroke cognitive impairment as a significant health concern (2, 4). Despite the prevalence of post-stroke cognitive impairment, clinical outcomes have traditionally been defined by measures of physical ability and focal cortical syndromes such as neglect or aphasia. Over 71% stroke survivors who made an excellent clinical recovery demonstrated impairment in one or more domains of cognition (24), suggesting cognitive health is overlooked within stroke care (25).

1.1.5 Growing Socio-cultural Traditions in Stroke Research

To better address cognitive health in stroke care, understanding the experiences of stroke survivors living with subjective cognitive changes is critical to identify patient priorities. These records of lived experience are necessary to ensure bioethical discussions, intervention planning, services, treatments and clinical management align with patient needs and goals (26). A growing sociocultural tradition within health research has helped foster patient-centered care and practices, which have improved outcomes (27), increased patient adherence to treatment (28), and bettered patient satisfaction with care (29).

The lived experience of cognitive changes among those with stroke is not well understood. This body of literature predominately relates the physical, emotional and social changes experienced

post-stroke to the changed physical body (30-34), while cognitive changes are not quantified or probed. Further, some studies exclude individuals with post-stroke cognitive impairment to examine a more homogenous sample (35). One study examined manifestations of mental slowing as reported by stroke survivors (36). While this study offered participant descriptions of different post-stroke cognitive changes, it did not explore their experience of changing cognitive function. Thus, the purpose of this study is to explore the experience of subjective cognitive changes who live with chronic stroke to offer an in-depth illustration of their lived experience.

1.2 Methods

1.2.1 Study Design

This was a qualitative study aiming to explore the lived experience of post-stroke cognitive changes. Semi-structured in-depth interviews were conducted among community-dwelling individuals with chronic stroke who reported subjective cognitive changes. Semi-structured interviews are a commonly accepted method within this paradigm as demonstrated by previous investigations of lived experience among individuals with chronic conditions (37, 38). This study design carries overtones of constructivism – a paradigm which asserts reality to be socially co-constructed by the participant and researcher.

1.2.2 Recruitment

Thirteen participants were purposefully sampled from the Vitality Study ($n=120$), a randomized control trial (RCT) which examined the effects of exercise and cognition training on cognition against a balance and tone control group (39). The Vitality study included community-dwelling adults in Metro Vancouver, Canada, over the age of 55 years, with history of a single

hemorrhagic or ischemic stroke at least one year prior to study enrolment as confirmed by a physician and imaging. Additional inclusion criteria included: the ability to comply with scheduled visits, treatment plan and trial procedures, using (or not expected to start) a stable fixed dose of cognitive medications during the 12-month study period, the ability to walk 6 meters (with or without rest and assistive devices), no current participation in regular therapy or progressive exercise and the provided personally signed and dated confirmed consent form. Those diagnosed with: dementia, any neurodegenerative or neurological condition, clinically important peripheral neuropathy, severe musculoskeletal or joint disease that impairs mobility (as determined by his/her family physician), aphasia (as judged by an inability to communicate by phone), medications that may negatively affect cognitive function or identified as high risk for cardiac complications during exercise class were excluded. Further study details are outlined in the study protocol (39). This qualitative study was approved by the University of British Columbia Clinical Research Ethics Board (H13-00715). All contacted participants provided informed, written consent before taking part in the study.

In-person recruitment was conducted for this study during the Vitality study taking place from February 2019-September 2019. KB visited each intervention group once to present the study premise to participants of the RCT and left her contact information for those interested in participating in this qualitative study. Participants were made aware that participation within this qualitative study would not affect their participation in the RCT. Interested participants were asked if they had experienced any cognitive changes post-stroke and those who answered ‘yes’ were considered during purposeful sampling. Purposeful sampling was conducted among the interested participants who experienced subjective cognitive changes to produce a sample with

maximum variation in age, sex, occupational status, cognitive ability and physical disability among those who self-reported cognitive changes post-stroke. Cognitive ability was measured by the Montreal Cognitive Assessment (MoCA) (40) and physical disability measured by Fugl-Meyer Assessment of Motor Recovery after Stroke (Fugl Meyer Assessment) (41). No participants refused to participate or dropped out from this study.

1.2.3 Data Generation

From May 2019 to February 2020, 13 semi-structured in-person interviews were conducted by a trained interviewer: KB, a female-identifying Master of Science student holding a BKIN with 2-years' experience working with individuals with chronic stroke. The interviewer was trained by a senior study team member: JL, a female-identifying Doctoral candidate holding a MA with 10 years of experience interviewing for qualitative research, through required readings and a practice interview with feedback. KB had led or assisted in classes for each study group of the Vitality Study: Exercise Training (FAS), Mental and Social Games (COG) and the Balance and Tone (BAT) control group which allowed her to establish a rapport with each participant prior to the interview. Because of her experience working with the study participants in relation to the intervention, they were aware of her status as a Masters student within the laboratory as well as her interest in healthcare experiences and personal bias that cognitive health may not be fully addressed within post-stroke care.

All interviews were audio-recorded and lasted approximately 60-150 minutes in duration (mean duration: 1.65 hours). Interviews were conducted at each participant's location of choice; 2 took place in the participant's home, 1 at a local community center, and 10 at the research center

where the Vitality study took place. No other individuals were present during the interview to ensure the participant privacy, given the sensitive nature of the discussed topics. After narrating the chronology of events related to their stroke incident, participants were asked about the changes they experienced in the acute and sub-acute stages of stroke, how such changes had evolved or if new changes had emerged in the chronic stage of stroke, and their view of their health in the future using a semi-structured interview guide.

The semi-structured interview guide (Appendix A) consisted of three primary sections: 1) the early impact of stroke on cognitive changes; 2) cognitive health since stroke; and 3) cognitive health in the future. While post-stroke cognitive changes were of primary interest, there was also interest in how cognitive changes may be experienced relative to changes in physical or spiritual health post-stroke; therefore, general questions were prepared with specific probes about cognitive changes. The interview guide was constructed by KB & JL and reviewed by a clinician (TLA) and tested during the training interview. Some adjustments were made to the interview guide after the interviews began to improve the researcher's connection with the participants. For example, after the first two interviews, it became clear that not all participants were familiar with the terms cognitive health and cognition. Terms such as mind-related, and changes to your mind or thinking as well as examples: memory loss, trouble concentrating, and mental fatigue, in were used in lieu or in conjunction with the terms cognition or cognitive health. The interview guide was present in all interviews but participants were encouraged to speak freely about their experiences in their own words. Field notes (Appendix B) were hand-written during and after the interview, and were used in triangulation with transcripts during analyses.

1.2.4 Data Analysis

Interviews were transcribed verbatim, and transcripts were checked for accuracy against the recordings and de-identified. Pseudonyms were chosen in collaboration with the participant. Reflexive thematic analysis was used to analyze the transcripts, informed by Braun and Clarke's [26] recursive six phase process: 1. data familiarization, 2. generating initial codes, 3. searching for themes, 4. reviewing themes, 5. defining and naming themes, 6. constructing the report, as outlined in the audit trail (Figure 1.1). Two study team members (KB, JL) read a sample of transcripts and created line-by-line codes independently with no predetermined coding structure. Early in this process, some participants described the important role their partner played in their recovery, prompting purposeful sampling for diversity in living status in addition to diversity in age, sex, physical ability and cognitive ability. Initial codes were identified, clarified and agreed upon through discussion and then sorted into potential themes. Themes were defined as an multi-faceted 'essence', to produce patterns at a broad level (42). Once a theme was identified, the data were re-analyzed to examine whether this theme was consistent between and within transcripts, and deviant cases sought to increase the trustworthiness of the analysis. The process of identifying themes was reflexive and recursive as interviews and analyses were conducted concurrently. This process was supported by reflective journaling (KB) (Appendix C), thematic mapping (43) (Appendix D) and frequent discussion between the first author (KB) and a senior study team member (JL). Using saturation to determine sample size is incompatible with reflexive thematic analysis, therefore, sample size was determined by the depth of the identified themes; sampling ceased after 13 interviews as the identified themes were thought to be multidimensional, and reflect both the breadth of the research question and the nuance of this sample (42). 'In-situ' sampling was conducted in alignment with reflexive thematic analysis

practices (42). High levels of *information power* (44) – wherein the more relevant data obtained, the less participants needed – may have contributed to the depth of the identified themes after 13 interviews. This was fostered by the strong relationships of trust built between the interviewer and the respondents during intervention classes. Field notes were included in the analysis. Paper based methods and NVivo 11 were used to manage data; data were handled confidentially and stored accordingly.

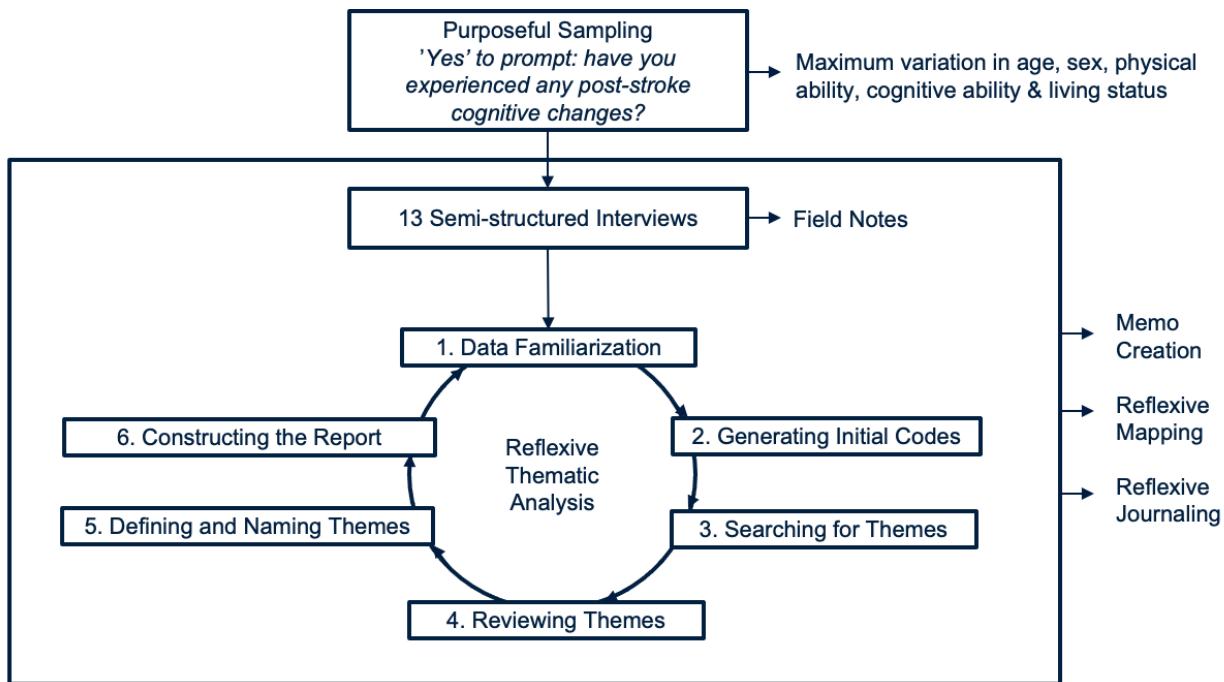


Figure 1.1 Audit Trail

Several strategies, as described by Shenton (45), were employed to ensure trustworthiness within this study. Credibility was addressed by utilizing a well-documented methodology previously used in projects with similar scope and aim that was accessible to the first author, a novice researcher with limited experience with qualitative methodology. The interviewer for this study also demonstrated “prolonged engagement” (46) with participants and established a relationship

of trust prior to interviews. Participants were encouraged to speak truthfully, informed that they may retract anything said during the interview or withdraw from the study at any time and ensured their participation in this study would not affect their position with the greater RCT. The first author (KB) debriefed with a senior study team member (JL) multiple times during the data generation and analyses process. Sufficient detail regarding study context and the role of the research have been provided to enable the reader to determine transferability. Dependability was averred through descriptions of the study design, data generation and reflexivity during data analysis.

1.3 Findings

This sample ($n=13$, age 58-83, 7 female) had an average MoCA score of 22.69 (range: 16-27) indicative of cognitive impairment (40) and a mean score of 74 (range: 8-100) on the Fugl Meyer Assessment indicative of moderate functional disability (47). Complete participant characteristics are reported in Table 1.1. This sample represented a self-selected group of individuals who were willing to participate in a cognitive training or exercise intervention. Four meta-themes were identified from the analysis: 1) a changed ability to maintain everyday activities; 2) experiencing emotional responses to living with post-stroke cognitive changes; 3) diminished social participation; and 4) seeking care for cognitive health post-stroke.

Table 1.1 Sample Characteristics (n=13) for Chapter 1

Pseudonym	Age	Sex	Fugl Meyer Assessment Score (max. 100)	MoCA Score (max. 30)	Self-reported living status
Doris	77	Female	33	23	Alone
Emily	70	Female	92	24	Alone
George	83	Male	82	22	Partner
Ivy	67	Female	100	24	Alone
Jared	64	Male	68	27	Partner
Leo	65	Male	46	23	Alone
Mallory	75	Female	98	19	Alone
Patrick	82	Male	96	18	Partner
Philip	71	Male	8	16	Partner
Tayla	71	Female	96	23	Roommate
Stephanie	58	Female	98	24	Roommate
Zac	62	Male	94	26	Partner
Zoey	77	Female	58	26	Alone

1.3.1 Theme 1: A Changed Ability to Maintain Everyday Activities

1.3.1.1 Disrupted Activities of Everyday Life

Participants described how they began to have trouble maintaining everyday activities such as self-care, personal accounting, and household work after their stroke. One participant (Tayla) described feeling stunned at her impaired ability to take part in personal grooming: “*I mean I know how to bath a person. But as far as my own personal care. That went out the, I just didn’t think anything like that was going to happen... So I was stunned and I didn’t really transform thoughts into actions very well*” (Tayla). Four participants (Leo, Emily, Tayla, Doris) experienced disruption moving around the community, both when walking and using other modes of transportation. One participant (Leo) conveyed the impact of changed perception on his ability to drive post-stroke: “*I had to get my license again after a couple years... and sometimes I would see something going by and I’m like wait a second that doesn’t make sense*” (Leo). Another participant (Emily) highlighted her concern when she forgot where she was going and the purpose of her trip while walking in the community: “*I’ll find myself on the street, walking down the street thinking, "Where am I going? What am I going to do?" ...I find it kind of concerning when I just left the house a few minutes ago*” (Emily).

Two participants (George, Patrick) recounted how their partners helped mitigate the difficulties they experienced maintaining everyday activities. For example, one participant (George) explained how his ability to complete household chores had been impeded by decreased energy levels post-stroke, with his wife now completing all household activities: “*before the stroke I used to do the house cleaning... and she has to do it all now... It's the energy that stops me*” (George). Another participant described a similar shift in regard to financial duties as his partner

had taken over the accounting tasks since his stroke: “*I just stay away from them... Well [my wife] is, she handles the finances and thank goodness. [She didn’t handle them] at the very beginning but she clearly has the discipline that I do not have. But she has a marvelous discipline in terms of when she tackles something it gets done. I may put it aside or forget about it*” (Patrick).

1.3.1.2 Disrupted Professional Role

The changed ability experienced through post-stroke cognitive changes extended to difficulties in maintaining previous professional roles. Changed cognitive abilities challenged eight (Leo, Tayla, Ivy, Stephanie, Mallory, Emily, Patrick, Jared) participants in their attempt to return to their previous professional role. One participant (Leo) experienced a heightened ability to think in a linear, logical manner post-stroke while his ability to conjure spontaneous and creative thought appeared to have diminished. He relied heavily on his ability to think creatively in his previous occupation of designer and coveted his pre-stroke mental processes: “*Like I can be a linear thinker... And that seems to be accentuated with my stroke that pushed that side of my sort of like plotting, one step after another figuring out something... But the sort of almost spontaneous kind of like revelations are like tangential thoughts and that I don’t have so much anymore... as a designer and an artist you rely on that kind of stuff to think outside the box or whatever you want to call it. I’m less able, much less able to do that nowadays. Which is that is what I miss... I don’t have so much sort of creative thinking abilities in a way that I used to*” (Leo).

Four participants (Jared, Ivy, Mallory, Stephanie) were able to navigate their changed abilities and return to their professions by adapting their workload or manner of work. One participant (Jared) continued to work post-stroke, but felt forced to accept a decrease in his pace and productivity. To contend with these changes, he reduced his workload and adopted new strategies: *“As far as work goes, I've uh got rid of one large client... and I downsized the second largest client... I'm trying to, trying to recognize that I can't do the same level of work and but at the same time continue to work [...] I also find... I was having difficulty with short term memory and ...I was finding I was forgetting the information; I'd look at it and then by the time I looked at the other screen, I would forget it... She suggested when I look at it over here, I verbalize it and amazingly it makes a huge difference by verbalizing it, by the time I get back here, it's still in the crazy brain, I'm able to work better but it's still slow, a lot slower”* (Jared).

Four others (Emily, Leo, Patrick, Tayla) described how their changed cognitive abilities prevented them from returning to their previous professions. One participant (Emily) attributed her decision to end her teaching career to the accumulation of fatigue, an overwhelming sense of change, and the resultant loss of confidence: *“I couldn't do the student teaching because I got too tired. I just couldn't do it ...so I tried to do it and I couldn't, it was just overwhelming... It was the fatigue. But also it was the fact that everything was different, right? But I think more than anything else is you lose your confidence a bit. Um, I felt like my students could smell blood. It's like they knew that I wasn't on top of my game... And, uh, I couldn't manage it. So in the end, I stopped teaching... I realized I just couldn't face another day, I couldn't face another class”* (Emily).

Table 1.2 Theme 1: A Changed Ability to Maintain Everyday Activities

A Changed Ability to Maintain Everyday Activities	
i. Disrupted Activities of Everyday Life	
	<p><i>"I mean I know how to bath a person. But as far as my own personal care. That went out the, I just didn't think anything like that was going to happen... So I was stunned and I didn't really transform thoughts into actions very well." (Tayla)</i></p>
	<p><i>"I had to get my license again after a couple years because I wanted to rent cars and stuff and sometimes I would see something going by and I'm like wait a second that doesn't make sense." (Leo)</i></p>
	<p><i>"I'll find myself on the street, walking down the street thinking, "Where am I going? What am I going to do?" ...I find it kind of concerning when I, when I, when I just left the house a few minutes ago... and I don't know where I'm going. I don't know what I was supposed to do. And within a minute, I'd say I can remember, but at the moment that I'm asking myself a question, I can't remember." (Emily)</i></p>
	<p><i>"I find that now, uh, I search for words. This, you know if, uh, I'm making a sentence, I'm ta-, saying something-And then there's that one pretty clear word-Uh, uh, uh, was could be a very simple word. You know, I think, I think, uh, as in w- one example, uh, I was talking, uh, uh, I go to do a lot, lot of, um, um, uh, t, community s- center- And v-, uh, there was one, one, one time I passed by, uh, I went to this program- She says, "Oh, um,", you know, I, I was early or late or something, and I said, "Well, you know, I'm really at the", and I, I n-, knew what I wanted to say, but I couldn't get the word. It was-Basically I'm really at the mercy of the- HandyDART. A simple, a simple thing like that and I just-It just didn't come out. Until later." (Doris)</i></p>
	<p><i>"You know, I use to do that, before the stroke I used to do the house cleaning I did cook, and she has to do it all now... I can't work now, so she has to do it all. So. The no energy. Peeling potatoes and uh, doing things it's difficult. It's the energy that stops me." (George)</i></p>
	<p><i>"I just don't tackle them, I just stay away from them... Well [my wife] is, she, she handles the finances and thank goodness. [She didn't handle them] at the very beginning but she, she clearly has the discipline that I do not have. But she, she has a marvelous discipline in terms of when she gets, tackles something it gets done. I may put it aside or forget about it" (Patrick)</i></p>
	<p><i>"I realize that another part of my life died when I can't manage in my daughter's house and I can't manage in the airport by myself so I really had to face that. Can I move out of that?" (Zoey)</i></p>
	<p><i>"You know I went to renew my medical card and the motor vehicle branch... I gave them another address. I don't even remember. It was [inaudible] because I had to go to the hospital and she said this is not your address. I went what." (Tayla)</i></p>
	<p><i>"So cleaning is kind of a bit of a bitch. The vacuum cleaner and the broom are odd. Vacuum cleaner because I get the noise-... but for the movement-... it really throws everything in my</i></p>

brain off. So like vacuuming. So it's you've, you've got your hand and the vacuum-... back to foot, right? And then it's, and it's this movement then you're changing corners. Then my brain gets really confused about that one." (Stephanie)

ii. Disrupted Professional Role

"Like I can be a linear thinker when there's a task that I have got to figure out... And that seems to be accentuated with my stroke that pushed that side of my sort of like plotting, one step after another figuring out something... But the sort of almost spontaneous kind of like revelations are like tangential thoughts and that I don't have so much anymore... as a designer and an artist you rely on that kind of stuff to think outside the box or whatever you want to call it. I'm less able, much less able to do that nowadays. Which is that is what I miss... I don't have so much sort of creative thinking abilities in a way that I used to." (Leo)

"Yeah, [my daily life], obviously it's changed since the stroke. As far as work goes, I'm, I've uh got rid of one large client ...and I downsized, that was the largest client and I downsized the second largest client. And so you know I'm trying to, trying to recognize that I can't do the same level of work and but at the same time continue to work [...] I also find that my short term memory, I was having difficulty with short term memory and ...I was finding I was forgetting the information; I'd look at it and then by the time I looked at the other screen, I would forget it ...What she suggested when I look at it over here, I verbalize it and amazingly it makes a huge difference by verbalizing it, by the time I get back here, it's still in the crazy brain, I'm able to work better but it's still slow, a lot slower." (Jared)

"I couldn't do the student teaching because I got too tired. I just couldn't do it. So they made some accommodations ...so I tried to do it and I couldn't it was just overwhelming. So even a year later, after the whole thing, I wasn't able to do it. It was the fatigue. But also it was the fact that everything was different, right? I've done this before... I went to do the same things. And the same thing happened when I went back to my job... I went back and I couldn't do it. So I don't know why I couldn't do it... I had all my curriculums, all my curricula and everything was already written. So I just had to go through some of the same things. But I think more than anything else is you lose your confidence a bit. Um, I felt like my students could smell blood. It's like they knew that I wasn't on top of my game... And, uh, I couldn't manage it. So in the end, I stopped teaching. I just thought, I can't do this anymore. And I just walked out, which I had never in my lifetime before... I realized I just couldn't face another day, I couldn't face another class, or anything" (Emily)

"I work at the airport still... on Friday's. And I'm finding that harder to do. I was working the - just when you first walk into the terminal. The door there, but everybody where am I going [inaudible] I had to last about three hours more my shifts are only four hours long but three hours is all I can do, the fourth hour I'm [inaudible] you know. And I find jeepers Mallory. I really feel that it's taking a toll on me and I never felt that before." (Mallory)

"And the, the difficult part was that I was working for my son. I decided to work with him. I had very good connections in the insurance industry. So I brought in a lot of business and he

still is doing that business but I felt very guilty [pause] very guilty leaving him alone... It would not have happened, the stroke, because I would not have stopped working and my job was, my job was always Canada wide so I had responsibility for all of Canada which meant I was always..." (Patrick)

"Anyway, after, up until the stroke I was a care aid doing home care... My friend replaced me. Cause I couldn't cut food. I said Gill I can't cut food for Elizabeth. Yeah, so he started doing things for me and Andre just yelled at me and says Tapioca cause I'm making my Tapioca filling and it was there and chocolate pudding. Needed one for the week. And then its breakfast and I forget how to do this. And so I had to read. My vision was almost blurry too. Cause I could read the ingredients, not the ingredients, the instructions without my glasses before. And now I couldn't it was blurry. So these are the things that I kept kind of quiet... to myself. And then you, and then. I thought this is it. I said now it's maybe two or three weeks after I have had this stroke." (Tayla)

"I start to go back to work. And of course, you know, um, for the first three weeks-... I was just had to, I just work for maybe a few hours a day. And, and I found that slowly, you know, my energy came back. And then, um, although, you know, at that point of time, one thing very noticeable is I have to ch- change my voicemail. And usually, the message on my voicemail is very fluent. But what I found was, because I came back to work so I have to change my voicemail and I had to record it for more than three times. And still, I was very unsatisfied with the way I speak." (Ivy)

"I went into the doctors and just had limited medication 'cause I can't afford it. This was the biggest one. When I'm down, I'm not working so I don't have any money, but I can't afford the medication to get myself back out again." (Stephanie)

1.3.2 Theme 2: Experiencing Emotional Responses to Living with Post-stroke Cognitive Changes

Six participants (Mallory, Tayla, Jared, Patrick, Doris, George) described how the disruptions they experienced during their everyday life prompted sadness, concern, frustration, fear and anxiety. For example, Jared conveyed his frustration when cognitive changes interfered with his ability to complete a work-related task: *"You know one day I got really upset because I was working on something and having difficulty ...it seemed like an endless loop where my perception of it was that the brain just wasn't working efficiently anymore and I got very upset"*

(Jared). Another participant (Tayla) felt afraid when experiencing difficulty in using public transport: “*You know the first time I rode it I went to a few bus stops past the Line 1 to get off it because I was scared to get off. I didn’t know how to get off the bus... I couldn’t visualize it*” (Tayla).

The distressing emotions evoked when experiencing symptoms of cognitive impairment persisted beyond the point of disruption. Mallory described how a lingering fear prevented her from visiting new places post-stroke: “*Now I feel, I don’t know if it’s because I’m not going out and doing things or whatever, but... I’m afraid to go places. Whereas now you know, I go to places that I know. I’m not one to - whereas before it didn’t bother me. Like even when I was driving I could go to a new place. Nothing ever bothered me*” (Mallory). Another participant (Tayla) reported anxiety after experiencing cognitive changes while in the community resulting in her feeling uncertain about her ability to complete errands: “*And I didn’t know where I was. I was losing my faculties. I get anxious. You know. Because now before I could run things off just... to heck with it...Just carry on. Now it’s I don’t know*” (Tayla).

One participant (Jared) conveyed the importance of social support to mitigate negative emotions and their lingering impact. During moments of frustration, Jared reflected on the importance of talking to his wife to help dissipate negative emotions: “*I can stand there for a few minutes and just don’t remember... And that’s frustrating and you know I think one of the biggest benefits that I have is you know [my wife] because when these things happen to me and I sit and I talk to her about it, just talking about it helps dissipate it*” (Jared).

Table 1.3 Theme 2: Experiencing Emotional Responses to Living with Post-stroke Cognitive Changes

Experiencing Emotional Responses to Living with Post-stroke Cognitive Changes
<i>"You know one day I got really upset because I was working on something and having difficulty. You know I was in this loop, it seemed like an endless loop where my perception of it was that the brain just wasn't working efficiently anymore and I got very upset" (Jared)</i>
<i>"And you know the first time I rode it I went to a few bus stops past the Line 1 to get off it because I was scared to get off. I didn't know how to get off the bus... I couldn't visualize it" (Tayla)</i>
<i>"And now I feel, I don't know if it's because I'm not going out and doing things or whatever, but... I'm afraid to go places. Whereas now you know, I go to places that I know. I'm not one to - whereas before it didn't bother me. Like even when I was driving I could go to a new place. Nothing ever bothered me." (Mallory)</i>
<i>"And I didn't know where I was. I was losing my faculties. I get anxious. You know. Because now before I could run things off just... to heck with it...Just carry on. Now it's I don't know. (Tayla)</i>
<i>"I can stand there for a few minutes and just don't remember, walk back downstairs and get into my office and I go hmm, walk back upstairs and get it. And that's frustrating and you know I think one of the biggest benefits that I have is you know [my wife] because when these things happen to me and I sit and I talk to her about it, just talking about it helps dissipate it" (Jared)</i>
<i>"Well, even now, but much less, after the stroke, if I, if, if I hear something or see something, well, I would, all of a sudden, just tears would come down. But after a couple of seconds-I stop. I said, "Look, that's enough now." And I think what happened is that it's part, although I don't feel unhappy, but I think that was, uh, a sadness. Some things, it just triggered, triggers- It and then I would just, like, a faucet-But then after a few minutes, I said, "That's enough." Before it would be, you know, initially, uh, I don't know, maybe about four or five times a day." (Doris)</i>
<i>"I do think I'm a little bit more emotional than I used to be. I'm probably sad a little bit more often than I used to be. So yes, I, I experience those a little bit more, particularly the sadness, particularly the, it's not depression but yes, not quite as flamboyant or positive or... I certainly cry more than I used to so I try not to let it bother me so until they sort of, people pointing at me, start laughing because I'm crying but that doesn't happen of course." (Patrick)</i>
<i>"I've always been an emotional person but I can cry very easily, as you've noticed... I mean I was always affected by it, but more so now that the stroke. It sort of amplified, you know." (George)</i>

1.3.3 Theme 3: Diminished Social Participation

Eight participants (Ivy, Jared, Leo, Mallory, Tayla, Stephanie, Philip, Patrick) described how post-stroke cognitive changes interfered with their participation in social activities. Participants described interference in their social connections as interactional (i.e. interference in their interactions with others) or relational (i.e. interference in their relationships with others). Participants related both the interactional and relational interference they experienced to their smaller social world.

1.3.3.1 Interactional Interference during Social Participation

Five participants (Tayla, Leo, Ivy, Stephanie, Mallory) described the difficulties that arose when they *interacted* with others, however these interruptions did not necessarily lead to altered relationships. For example, Tayla described how she struggled to communicate with others after her stroke: “*I had trouble communicating... like it was all there but...but I couldn’t get it out.*” Another participant described hearing words during conversations that, in reality, were not said by others: “*I was hearing things that people said and I’m sure I heard them. But that’s not what they said. And I found out afterward... I don’t know if it was an attention issue or what but my mind was making up things that people were saying*” (Leo).

1.3.3.2 Relational Interference during Social Participation

Four participants (Mallory, Stephanie, Patrick, Leo) described interruptions while *participating* in social activities with others. Stephanie experienced an increased sensitivity to noise post-stroke which caused noise in social spaces, such as restaurants, to become both distorted and painful to her. She described how the discomfort of distorted noise in public spaces prompted her

to seek out solitary activities rather than social events: “*Noise is the worst... I went out for dinner to a restaurant last night... they picked a quiet table but the noise was deafening for like everyone talking and for me it's now turning into this massive distortion and then it begins to hurt [...] I'm constantly looking for activities that are, are quiet and to loners*” (Stephanie).

Another participant, Leo, contended with changes to concentration and emotional regulation, which interrupted a social outing with others: “*I got into problems too with that I would in my social relationships that I would be sometimes frustrated let's say. I remember once I told my brother in law's new wife who I just met - and I was in a crowded restaurant and I was having a hard time concentrating because of all the background noise... But anyways, I told her to shut up. Which I shouldn't have done but it just came out of me right ... I just didn't have the filter kind of to be able to control myself at the time ... those are the kind of things that I had to reel in a bit ... so I'm getting back to like personality wise the way that I was before my stroke*” (Leo).

Participants further discussed how relational changes then occurred post-stroke. Philip described a noted decrease in his number of social connections post-stroke: “*And my friends before the stroke ... There are people that don't phone me because I am of no use to them anymore. Losers*” (Philip). Another participant (Patrick) related the interruptions they experienced during social interaction to diminished social participation: “*Well the memory issue sort of cuts your social interactions back... Because where a memory problem stands out is if you are in a social circle or in a circle, in a social environment and it becomes obvious to the others that hey, his memory's gone you know... you know you like to make a good presentation... so from that it is limiting so, I have probably turned more inwards*” (Patrick).

1.3.3.3 Relational Loss

Changes to social relationships and the subsequent diminished social participation were felt as a distinct loss among three participants (Stephanie, Jared, Patrick). One participant (Stephanie) alluded to feelings of loss when the cognitive changes she experienced prevented her from being able to help her daughter move into her new home: “*This week my daughter moved into her place and I couldn't help her at all. You know, because all of a sudden it's like, "No, I've woke up this morning and you know, and my brain's not functioning and I can't drive over to your place and I can't do anything. And... so what's the point?" So now... her mother-in-law is like over there repainting her place. And I mean... I would loved to have done that.*” (Stephanie) Another participant (Patrick) alluded to a sense of loss at his inability to take on a social persona. He described how his reduced social world impeded on his interest of fulfilling a social butterfly persona: “*Everything has become more around us. So, so our world has been reduced in size. [...] So the whole background has definitely has limiting effect on my interest at being a social butterfly. If I were to be a social butterfly, it would have been, had to be a long time ago but not, not anymore*” (Patrick). Jared equated the imagined loss of social connection with close others, such as his wife, to the loss of a meaningful life: “*My perception is that if you can't, if you know if [my wife] was sitting in front of me and I didn't recognize her as [my wife] ... I don't think that at that point I'm not what I consider alive. I'm, the body is functioning but you know the brain isn't working in any way, shape or form that I would consider being alive*” (Jared).

Table 1.4 Theme 3: Diminished Social Participation

Diminished Social Participation
i. Interactional Interference during Social Participation
<p><i>"I couldn't express myself very well... I had trouble communicating...Yea, like it was all there but...but I couldn't get it out." (Tayla)</i></p>
<p><i>"I was hearing things that people said and I'm sure I heard them. But that's not what they said. And I found out afterward and I made a lot of I don't know if it was an attention issue or what but my mind was making up things that people were saying..." (Leo)</i></p>
<p><i>"It... becomes really distorted and then I don't know what everybody is saying. My brain's working really hard to figure out what they're saying and I'm trying to tell my brain that such is not important. And so we're having a little bit of a fight, you know and that I'm going, it's not important we don't need to know what they're saying. Right? It's pretty automatic we're fighting with my, with my inner hearing." (Stephanie)</i></p>
<p><i>"So, sometimes, you know, I'll say, my husband will say, "I don't know what you're talking about." So that hurt him. (laughing) I go, "Huh? I just said it so clearly." (laughing) You don't know what I'm talking about. But then, then I realized that yes. There's something wrong. But I don't know where to turn for help though." (Ivy)</i></p>
<p><i>"Well for instance, even at my bible study I don't think people believe that I have a problem. What am I, mentally retarded or something? I don't think I am. I have a problem with what's the word I wanna use. I know it inside but I can't get it out... You know it's all up here but it's not coming out properly." (Mallory)</i></p>
ii. Relational Interference during Social Participation
<p><i>"I got into problems too with that I would in my social relationships that I would be sometimes frustrated let's say. I remember once I told my brother in law's new wife who I just met - and I was in a crowded restaurant and I was having a hard time concentrating because of all the background noise...But anyways, I told her to shut up. Which I shouldn't have done but it just came out of me right ... I just didn't have the filter kind of to be able to control myself at the time ...those are the kind of things that I had to reel in a bit ...so I'm getting back to like personality wise the way that I was before my stroke." (Leo)</i></p>
<p><i>"Well the memory issue sort of cuts your social interactions back... Because where a memory problem stands out is if you are in a social circle or in a circle, in a social environment and it becomes obvious to the others that hey, his memory's gone you know... you know you like to make a good presentation... so from that it is limiting so, I have probably turned more inwards." (Patrick)</i></p>
<p><i>"Well, I can't go anywhere. I mean, it's like I can't go to, I've got a friend who's, um, who plays the guitar. I mean we used to always go and listen to him like in open, open-mic nights, right? And I can't go there anymore. I can't go to the clubs, I can't do anything where there's mass amounts of people 'cause I can't have a conversation anyway. [...] Noise is the worst ...I</i></p>

went to, I went out for dinner to a restaurant last night ...they picked a quiet table but the noise was deafening for like everyone talking and for me it's now turning into this massive distortion and then it begins to hurt [...] I'm constantly looking for activities that are, are quiet and to loners." (Stephanie)

"And my friends before the stroke ... There are people that don't phone me because I am of no use to them anymore. Losers" (Philip)

iii. Relational Loss

"And my friends before the stroke ... There are people that don't phone me because I am of no use to them anymore. Losers." (Philip)

"Um, I'm not really with people that much now... It has, because you know somebody's always gotta pick me up you know blah, blah, blah. And I don't know I guess people get tired of doing that. I don't know... Oh if somebody offers, hey I'll pick you up, okay great I won't say no but. But they never offer" (Mallory)

"This week my daughter moved into her place and I couldn't help her at all, this week. You know, because all of a sudden it's like, "No, I've woke up this morning and you know, and my brain's not functioning and I can't drive over to your place and I can't do anything. And-... so what's the point?" So now-... her mother-in-law is like over there repainting her place. And I mean... I would loved to have done that." (Stephanie)

"Everything has become more around us. So, so our world has been reduced in size. [...] So the whole background has definitely has limiting effect on my interest at being a social butterfly. If I were to be a social butterfly, it would have been, had to be a long time ago but not, not anymore." (Patrick)

"My perception is that if you can't, if you know if [my wife] was sitting in front of me and I didn't recognize her as [my wife], I mean that would be pretty, that I would find, I, I don't think that at that point I'm not what I consider alive. I'm, the body is functioning but you know the brain isn't working in any way, shape or form that I would consider being alive." (Jared)

1.3.4 Theme 4: Seeking Care for Cognitive Health Post-stroke

Four participants (*Tayla, Mallory, Patrick, Stephanie*) described how their ability to seek care for health needs diminished, with varying consequences. For example, one participant (Mallory) related a forgotten doctors' appointment to the loss of sight in one eye: *"And um, course I don't drive anymore, I can't but cause I'm also blind in this eye. I had a, I forget what I had but I didn't make it back to the doctors... you know you have to go every year and I didn't make it one year, and forgot about it and that's when I lost the eyesight in this eye." (Mallory)*

1.3.4.1 Feeling Overlooked

Participants went on to describe the challenges they faced within mainstream systems of care.

Five participants (Jared, Ivy, Mallory, Patrick, Zoey) described experiences in which their perspective had been overlooked during clinical encounters, leading some to seek out other avenues of support to improve their cognitive health. For example, Jared described how he felt his physical recovery had been prioritized over his cognitive health during stroke rehabilitation:

“With stroke, all the things that I've been involved with stroke recovery, it's all been more physical. Some of healthcare professionals suggest it's all in your mind, but they don't sort of focus on how to fix the mind kind of thing” (Jared). Another participant (Mallory) described feeling overlooked during communication with her doctor in an appointment: *“I think the medical field puts us down a little bit... Just the attitude of people. [...] Like even one time I took my best friend to my doctor. And my doctor talked to her like I was not in the room” (Mallory).*

The same participant conveyed previous distress when she felt overlooked while admitted in hospital: *“I was left in a hospital room [over the weekend], Monday morning still nobody had come... And with me I didn't really know what was happening right. Nobody came and nobody anything. And I went, I just went ballistic. And I walked out. Okay. They're not doing anything; I'm getting the hell out” (Mallory).*

Two participants (Zoey, Ivy) described their emotional response (e.g., uncertainty, anger) to feeling their perspectives were overlooked in disagreements with healthcare professionals about their care. For example, one participant (Ivy) recalled how she felt uncertain after disagreeing with healthcare professionals about her care: *“I was, I wary- I thought they should, you know, at least give me a test. See to what extent, say like, my speech is, you know, say like, damaged....*

But I never got a chance... But then the answer was, "No. You don't need it." I thought, I, I think I need it" (Ivy). Zoey also recalled her anger from disagreements with clinicians about her care: "*They want to give me antibiotics for the rest of my life... I took them twice and yeah, they do help but I'm not gonna live like that... they're just focused on pharmaceuticals. They just write a prescription and they tell me that this will help this and this will help that... They're bought by the pharmaceutical companies. They're not doctors anymore. [...] I don't have the money to go to a functional medicine doctor either. So I'm stuck with the system and but I'm getting so that I'm gonna walk away from the system because it's more stressful*" (Zoey).

1.3.4.2 Seeking Additional Avenues of Support

Seven participants (Stephanie, Ivy, Zoey, Jared, Mallory, Patrick, Tayla) described a persistent motivation to support their cognitive health. Patrick actively sought resources to support his cognitive health: "*Yeah, if [the memory issues] got worse and they probably will. I deal with the memory in the writings here, just, I just rely more on writing notes [...] There are techniques that I'm missing out on but I could benefit from them. Well, even if you can tell me where I might be able to read on it or if there's any literature for anything*" (Patrick). Tayla described a similar motivation to improve her cognitive health and took action to improve in areas she felt were her weakness: "*I would like to improve [...] I was very feeble and I'm still working on doing geometrics... I'm like look it oh rectangles, and 3-D and circles. I just can't get the grasp of those things. But now you know what, since the last assessment here last week. I went to the library and I got a book on it. And I'm tracing over them so I can get them down*" (Tayla).

Five participants (Stephanie, Ivy, Zoey, Jared, Mallory) pursued forms of care outside of mainstream healthcare from various practitioners of acupuncture, functional medicine, naturopathic medicine, reiki and energy healing. One participant (Ivy) described how she pursued acupuncture when she was uncertain of how to improve her symptoms of cognitive impairment: *"And then, I thought, "What should I do?" I, I don't want to be like this for the rest of my life... and I thought, maybe acupuncture could help me. So I went to an acupuncturist who is actually in this area... And I think that helped me, too"* (Ivy). Despite a desire to pursue non-mainstream therapies post-stroke, financial strain was a barrier to access for some participants. Mallory described being unable to afford appointments with her naturopathic doctor: *"She's... A naturopathic, she's more than that I forget what she calls herself. But I just can't afford her right now... it's not covered. So I haven't been back to her. Yeah, so maybe that's why I've been getting a little more off..."* (Mallory).

Table 1.5 Theme 4: Seeking Care for Cognitive Health

Seeking Care for Cognitive Health Post-stroke
<i>"And um, course I don't drive anymore, I can't but cause I'm also blind in this eye. I had a, I forget what I had but I didn't make it back to the doctors... you know you have to go every year and I didn't make it one year, and forgot about it and that's when I lost the eyesight in this eye."</i> (Mallory)
<i>"I wish I had gotten physio. I got no physio until after this [fall]. And even my health the public health nurse came in from Marpole and said this girl needs physio, she's slipped through the cracks."</i> (Tayla)
<i>"Well my wife had noticed them before I did, in fact she drew to my attention, mixing up words and [pause] forgetting names. Forgetting commitments"</i> (Patrick)
<i>"Everything is, everything is a lot of work. And I'm on my own. I mean, I don't have a, I don't have a partner. Um, my daughter lives in town, but my daughter's not my personal assistant... It's, makes my brain too tired but it's a lot of work. I mean I've looked at what I needed, all the, all the information needed to get in. It was a full time job. To get all my applications in and to get my disability status."</i> (Stephanie)

i. Feeling Overlooked

"With stroke, all the things that I've been involved with stroke recovery, it's all been more physical. Some of them suggest it's all in your mind, but they don't sort of focus on how to fix the mind kind of thing." (Jared)

"I think the medical field puts us down a little bit... Just the attitude. Just the attitude of people. [...] Like even one time I took my best friend to my doctor. And my doctor talked to her like I was not in the room." (Mallory)

"I was, I wary- I thought they should, you know, at least give me a test. See to what extent, say like, my speech is, you know, say like, damaged. Or, you know, the, some of the cog- you know, say like, uh, uh, uh, function of whatever, you know- is, is, is, to what extent, you know. Um, whether or not I could be better. But I never got a chance... But then the answer was, "No. You don't need it." I thought, I, I thought, I, I, I think I need it." (Ivy)

"I was left in a hospital room [over the weekend], Monday morning still nobody had come... And with me I didn't really know what was happening right. Nobody came and nobody anything. And I went, I just went ballistic. And I walked out. Okay. They're not doing anything; I'm getting the hell out." (Mallory)

"They want to give me antibiotics for the rest of my life... I took them twice and yeah, they do help but I'm not gonna live like that ...they're just focused on pharmaceuticals. They just write a prescription and they tell me that this will help this and this will help that... They're bought by the pharmaceutical companies. They're not doctors anymore. [...] I don't have the money to go to a functional medicine doctor either. So I'm stuck with the system and but I'm getting so that I'm gonna walk away from the system because it's more stressful..." (Zoey)

"With the cognitive... Our doctor, we think the world of him and we do continue to, but just a long comment that he made you know of just a rare slip in his professionalism but clearly as far as this is concerned, he is concerned, it's not gonna be that, all that much help so yeah." (Patrick)

ii. Seeking Additional Avenues of Support

"I would like to improve [...] I was very feeble and I'm still working on doing geometrics ...I'm like look it oh rectangles, and 3-D and circles. I just can't get the grasp of those things. But now you know what, since the last assessment here last week. I went to the library and I got a book on it. And I'm tracing over them so I can get them down." (Tayla)

"And then, I thought, "What should I do?" I, I don't want to be like this for the rest of my life... and I thought, maybe acupuncture could help me. So I went to an acupuncturist who is actually in this area... I went to him say like, um, every two days. For I think close to two months. And I think that helped me, too." (Ivy)

"She's... A naturopathic she's more than that I forget what she calls herself. But I just can't afford her right now... it's not covered. So I haven't been back to her. Yeah, so maybe that's why I've been getting a little more off is not the right word to use, but I don't know what else

to say. You know, when I mean when I was taking this stuff from her it was just absolutely amazing. Absolutely amazing. But as I say I can't afford it... ” (Mallory)

“Yeah, if [the memory issues] got worse and they probably will. I deal with the memory in the writings here, just, I just rely more on writing notes [...] There are techniques that I'm missing out on but I could benefit from them. Well, even if you can tell me where I might be able to read on it or if there's any literature for anything.” (Patrick)

“I think this cost me about \$200 and you supposedly clip them on your shoes and on, by your, your neck and now get ready for this, they cause a quantum disruption in the energy that you feel in the body, nice big words, and so I bought it, I tried it. It hasn't worked yet but you know I'm willing to try anything, right? As far out as it may seem I'm willing to try it and I've done, like I've done acupuncture, I've done all kinds of weird things” (Jared)

“If I had the money right now, if I had the money right now, I would probably go to China and go to a functional hospital or a Qi Gong hospital but I don't and I don't have the money to go to a functional medicine doctor either.” (Zoey)

“And I'm like, my brain won't work anymore, I can't move any parts of my body. And all I can do is I have to lie down... And then, and I get in and then getting new drugs done. Um, and um, yeah, just it's, and then I've been, yeah, in this last year I mean, trigger points I'm getting... and, and my nerve endings are coming alive” (Stephanie)

1.4 Discussion

This is the first in-depth examination of the lived experience of cognitive changes among individuals with chronic stroke who had both cognitive impairment and challenging physical impairments – a unique population not yet studied. This study identified 4 meta-themes: 1) a changed ability to maintain everyday activities, 2) experiencing emotional responses to living with post-stroke cognitive changes, 3) diminished social participation and, 4) seeking care for cognitive health post-stroke. These four meta-themes showed that subjective post-stroke cognitive changes carry meaningful consequences for participants, and are perceived to be largely constraining in everyday activities, emotional health, social participation and seeking care. As participants described their experiences within mainstream and non-mainstream healthcare, this study identified three potential gaps in current stroke care.

Participants described the perceived consequences of cognitive changes within their lives, emphasizing the role of changed cognitive status in their ability to complete everyday activities, emotional reactions, social participation and seek care. The consequences described by participants mirrored those recorded in previous studies of lived experience in stroke (30, 33, 48). This study, however, is the first wherein participants attached such consequences to *self-perceived cognitive changes* post-stroke. In contrast, previous studies of lived experience in stroke have largely discussed such consequences in terms of *physical ability* and the changed *physical body post-stroke*. For example, lived understandings of stroke have described negative emotions as result of the “body as locus of uncertainty and disappointment” (34) and diminished social participation as: “discomfort with current [self], in terms of physical ability and appearance, and [becoming] withdrawn to avoid becoming a burden” (32, 49), each rationale hinging on the loss of control over the body. This study thereby demonstrates that subjective post-stroke cognitive changes carry meaningful consequences for participants and are largely perceived as constraints to participation in desired activities and experiences.

Overall, participants did not appear to be concerned with the connotations of cognitive impairment and did not allude to the social stigma attached to Alzheimer’s dementia (50, 51). This stands in stark contrast to literature examining the lived experience of mild cognitive impairment (MCI), a difference that may be driven by exposure to clinical labels. Within studies of the lived experience of MCI, participants have often been driven to seek clinical care for subjective cognitive changes and have received the clinical label of MCI from a healthcare provider. This clinical label of MCI, is then interpreted by the participant as ‘normal’ aging or perceived as an early or mild form of dementia, and thereby a “death sentence... [meaning] the

loss of function as a human being” (26). The interpretation of MCI as normal aging carries two meanings (52): normative - ‘just a part of getting older’ or non-pathological, in which participants feel they have precluded dementia and thereby subvert the social stigma of Alzheimer’s dementia. The interpretation of MCI as a ‘death sentence’ instead engages with this stigma, affirming MCI as part of the inevitable decline toward a ‘vegetative state’ (53). None of the participants within this study described receiving a formal diagnosis of MCI from a healthcare provider despite subjective complaints of cognitive changes, and further described cognitive health as overlooked by clinicians within mainstream systems of care. As the significance of cognitive changes for individuals with MCI appears to be, in part, constructed through clinical interactions and clinical labels, the absence of this concern within the sample may reflect the absence of this factor: limited clinical interactions regarding cognitive health. Further studies may seek to explore the impact of the clinical label of MCI from the perspective of those with chronic stroke.

This study identified three potential gaps in stroke care: 1) limited accessibility to care, 2) incomplete clinical encounters and 3) a lack of affordable, community resources for cognitive health post-stroke. Living with post-stroke cognitive changes presented intrinsic challenges for participants coordinating their own healthcare, limiting their access to care. For example, participants described forgetting appointments, which led to consequences such as blindness or falls. Other participants highlighted their reliance on close others to coordinate their care post-stroke. This aligns with previous work addressing the burden on caregivers to manage complex care for the stroke survivor physical, cognitive and emotional difficulties (54-57). This contrast in experiences suggests a difference in accessibility to care between stroke survivors who

coordinate their own care and those who can rely on caregivers to coordinate their care. As a result, stroke survivors coordinating their own care may experience heightened vulnerability to comorbidities. Future research may seek to quantify the consequences, such as the rate of comorbidities, of coordinating one's own care while experiencing subjective cognitive changes post-stroke.

As participants entered mainstream systems of care they faced extrinsic challenges to receiving care. Participants' descriptions of their clinical encounters highlighted the perceived shortcomings in clinical management of both their general and cognitive health. Clinical encounters wherein patients described feeling unheard or ignored 'as if not in the room' are consistent with other accounts of healthcare encounters among individuals with chronic conditions (58, 59). Other experiences spoke directly to the lack of attention to cognitive health in stroke. Participants described a bias in care for their symptoms of physical impairment over their cognitive impairment, which parallels a previous report that identified cognitive impairment even among those considered to have an excellent clinical recovery (24). Emotions of uncertainty and frustration enveloped clinical interactions regarding subjective cognitive changes, echoing the experiences of those living with MCI (52). These findings warrant further investigation of clinical encounters in stroke care to elucidate issues such as patient satisfaction in clinical encounters and information sharing in regard to post-stroke cognitive changes.

Despite limited support for cognitive health through mainstream systems of care, participants positioned themselves as active seekers of care, taking action to improve or avoid further decline of their perceived cognitive changes. Their high motivation to intervene on their perceived

cognitive status was evident in their pursuit of therapies, both makeshift and outside of mainstream systems of health. Despite largely positive experiences in non-mainstream care, the associated financial burden limited some participants from continuing their treatment with non-mainstream practitioners. A previous study of lived experience among high-functioning stroke survivors (MoCA score >26) reported a similar lack of affordable and accessible resources for cognitive rehabilitation, wherein a participant similarly described their “do-it-yourself” cognitive training program (60). Together, this patient-driven motivation to improve post-stroke cognitive changes, that appears to be unmet by mainstream systems of healthcare, highlights a potential need for accessible and affordable community resources for cognitive health.

1.4.1 Limitations

While semi-structured interviews are an accepted method of data generation within a constructivist paradigm, this method limits the ability to capture strong emotional reactions from participants. There were many instances wherein participants displayed non-verbal emotional reactions, such as crying, to certain topics. While emotional responses were recorded in field notes, transcribed interviews often did not reflect a similar emotional weight in regard to such topics. As a result, this analysis may not fully convey the depth of emotions experienced by participants.

This study is limited, in part, by sampling methods. Purposeful sampling was conducted among participants enrolled in a RCT. This sample thereby consists of a self-selected group of individuals that were willing take part in a 6-month exercise or cognitive training intervention.

Such individuals may differ from the average stroke survivor which may limit the transferability of these results.

This study does not assert any interrelation or directionality between the identified themes. As the data were analyzed using reflexive thematic analysis, this analysis only describes the identified themes in alignment with this approach. Some previous studies of the lived experience of stroke have drawn relationships between identified themes (61, 62), but the methods of this study do not afford similar hypothesis generation or theory construction. Future studies may consider using a grounded theory approach to generate theory of the experience of chronic stroke.

1.5 Conclusion

This study demonstrates the meaningful impact of subjective cognitive changes for individuals with chronic stroke, which enabled and constrained their ability to complete everyday activities, their emotional reactions, and social participation. This study further identified potential gaps in stroke care: 1) limited accessibility to care, 2) incomplete clinical management, and 3) a lack of affordable community resources for cognitive health. Further work is needed to elucidate these gaps within stroke care and investigate how they can be best addressed.

1.6 Interplay between Cognition and Mobility and Balance

In this previous chapter, participants' experiences described the interplay between cognition and mobility in everyday life. For example, participants described having trouble with activities that required both physical and cognitive contributions such as walking around the community and

self-care. While the lasting consequences of stroke are evident both physically and cognitively, how these lasting impairments of stroke may be interrelated is less understood. In healthy older adults, there is evidence of a relationship between cognition and mobility and balance, but it is unclear how this relationship translates within a chronic stroke population. The relationship between cognition and mobility and balance in chronic stroke will be the subject of further investigation in Chapter 2 of this thesis.

Chapter 2: The Relationship between Executive Performance and Changes in Mobility and Balance over Time in Chronic Stroke

2.1 Introduction

2.1.1 Mobility Impairment Post-stroke

Stroke leaves a majority of survivors with varying degrees of mobility impairments known to contribute to activity limitation (63, 64). A number of measures are commonly used to index mobility post stroke. They include: the Timed Up and Go (TUG) test (65), Short Physical Performance Battery (66) and usual gait speed (67).

The TUG test is a task of functional mobility in which participants are timed as they complete a chair stand, walk 3 meters ahead, turn around and walk 3 meters back and return to a seat (65). Community dwelling older adults (70-79 years) display a normative time of 9 seconds (68) as compared with those who have been discharged from geriatric rehabilitation, displaying a normative time of 21.2 seconds (69). A TUG test completion time of >15 seconds is associated with a higher propensity for falls 1-year post-stroke (70).

The Short Physical Performance Battery (SPPB), first established as a measure of disability in older adults, also holds applications to stroke rehabilitation (66). The SPPB directly measures standing balance in addition to two other measures of mobility: usual gait speed and sit-to-stand. Balance is measured through timed evaluations of participants' ability to stand unassisted with feet side-by-side, in a semi-tandem stance and tandem stance. In the walking component,

participants are timed as they walk 3 or 4 meters at their preferred gait speed. In the sit-to stand component, participants are timed as they complete 5 chair stands. Vanzzana and colleagues (71) defined impaired mobility as a score <10. Community-dwelling older adults (>68 years) display normative values of 7.5-8.4 (72) while investigations using the SPPB within a stroke population report mean scores of 5.8-7.4 (73-75).

Gait improvement in stroke rehabilitation is commonly quantified by usual gait speed, which can be assessed by asking an individual to walk 4 meters at their preferred speed while being timed by an assessor (67). Community dwelling older adults (aged 70+ years) display normative walking speeds of 0.917-0.954 meters per second (76) while those who are ambulatory after geriatric care display a slower normative speed of 0.739 meters per second (77). Usual gait speed is a commonly used measure of post-stroke ambulation as over 75% of stroke survivors lose the ability to walk independently (78), and individuals with stroke commonly identify gait improvement as one of their primary goals during rehabilitation (79).

Impaired mobility contributes to fall risk (80-82). Falls are one of the leading medical complications post-stroke and often lead to devastating consequences on the individual and society (83, 84). Post-fall, stroke survivors often suffer physically and psychologically (85). Physically, over one third of those who fall sustain a serious injury such as hip fracture or hematoma (86). Psychologically, individuals commonly develop a fear of falling post-fall that inhibits participation in regular activities and infringes on their quality of life (87-89).

2.1.2 Executive Dysfunction Post-stroke

Executive functions can be defined as the cognitive abilities that enable the execution of goal-directed behaviours and integration of novel stimuli from the environment (90). The prevalence of executive dysfunction among stroke survivors ranges between 18-60%, highlighting the predominate impact of stroke on executive function as compared to other cognitive domains (91-94). The prominence of executive dysfunction among stroke survivors does not appear to resolve over time. At one year post-stroke, deficits in executive function persisted, while deficits in visual memory, verbal memory and language were more likely to have resolved (95). In a five year follow-up, this pattern was reproduced highlighting the persistence of executive dysfunction post-stroke (95).

Three central executive functions have been identified by Miyake and colleagues (90): 1) selective attention and conflict resolution; 2) set shifting; and 3) working memory. Miyake (96) demonstrated that while these three executive functions are moderately correlated with one another, they are distinct and as a result, can be precisely defined. Response inhibition refers to the ability to interrupt automatic responses (90). Set-shifting refers to the ability to alternate between multiple tasks or mental sets. Working memory involves the temporary storage and manipulation of information (97, 98). In the context of cognitive tasks, working memory is responsible for surveillance for information relevant to the task and effectively integrating the new information (97, 98). While all require goal-oriented cognitive processes, each aspect of executive function is evaluated individually. These functions are often hypothesized to contribute to the planning and performance of complex tasks and mobility (99).

Executive dysfunction is shown to have a deleterious effect on the ability to complete complex activities of daily life, resulting in decreased quality of life (92) and independence (94) post-stroke. Executive dysfunction is further shown to impede the rehabilitation process resulting in decreased participation in rehabilitation activities and poor adherence to treatment guidelines (100). Participation in complex activities of daily life or rehabilitation does not appear to increase over time, further reflecting the persistence of executive dysfunction (101). While cognition and mobility appear to be related in chronic stroke, current stroke rehabilitation practices do not effectively address the cognitive consequences of stroke (102).

The executive functions appears to be the domain of cognition most commonly associated with mobility and balance performance and are further related to the increased rate of falls observed among stroke populations (91, 103). Among acute and subacute stroke survivors, Hayes and colleagues (104) found the executive functions to be associated with balance. This relationship was replicated in a chronic stroke population by Liu-Ambrose and colleagues (105). Liu-Ambrose et al. (105) reported cognitive flexibility, as measured by the Stroop Colour Word test, to be independently associated with performances of balance and mobility among older adults with chronic stroke. Executive dysfunction was further related to fall rate post-stroke: Rapport et al. (103) found working memory, as measured by Backwards Digit Span, to be associated with falls. Research exploring the relationship between executive function and balance and mobility in stroke is limited to cross-sectional or retrospective studies to date. To our knowledge, no study has examined whether this relationship persists over time. Longitudinal studies examining the relationship between post-stroke executive function and balance and mobility would advance our

understanding of the importance of baseline executive function for changes in measures of balance and mobility over time.

2.1.2.1 Intraindividual Variability: Potential Applications to Stroke

Studies of cognition have largely focused on traditional summary scores (e.g., overall accuracy, average response time) to quantify cognitive performance. However, over the past decade, intraindividual variability (IIV) in cognitive performance has emerged as a critical and more sensitive measure (106-108). There are two conceptualizations of IIV: 1. within-person variability across multiple domains at a single timepoint (dispersion) and 2. within-person variability in reaction time across multiple trials within a single task and timepoint (intraindividual reaction time variability) (109). Intraindividual reaction time variability (IIV-RT) is indexed through the standard deviation (SD) of trial reaction times (RT) to convey the variability around an individual's average response time within a given cognitive task (110-113).

IIV increases with age (108, 114), can distinguish older adults with cognitive impairment from those without (114), and is a risk factor for future cognitive impairment and dementia (115, 116). MacDonald, Li, and Bäckman (117) summarized the evidence linking IIV to brain health and report that increased IIV can reflect frontal lobe impairment, reduced white matter integrity, and increased white matter lesions. Moreover, IIV is responsive to interventions, including physical activity (118) and mindfulness (119). Specifically, Brydges, Liu-Ambrose and colleagues (120) reported a decrease in IIV-RT on a task-switching measure in relation to a 6-month exercise training intervention among healthy older women.

Growing evidence has identified the IIV-RT in cognitive tasks as a marker of cognitive function and status (112, 121-125). Increases in IIV-RT are observed in parallel with increased age and neurodegenerative disease including: mild cognitive impairment (123, 126), dementia (124, 125), epilepsy (127), traumatic brain injury (112, 121), and Parkinson's disease (122, 128, 129). Thereby, this measure of cognition is thought to reflect both age-related decline in neuronal structure and function and neurobiological disturbance (111, 130).

Of relevance to this thesis, IIV-RT is associated with mobility and falls. Holtzer and colleagues (131) found IIV-RT in the Flanker test of response inhibition was associated with gait speed among older adults. Bauermeister et al. (132) found the IIV-RT in 2-Choice RT tasks, the Flanker task and the Stroop Colour Word test significantly predicted falls after accounting for executive function among healthy older adults.

IIV has not yet been examined in a chronic stroke population. As a neurobiologically impaired population, chronic stroke populations are expected to demonstrate increased IIV in alignment with other clinical populations such as mild cognitive impairment (123, 126), dementia (124, 125), Parkinson's disease (122, 128, 129) and traumatic brain injury (112, 121). However, it is unknown if the relationship between IIV and functional measures extends to individuals with chronic stroke. In turn, IIV may be of interest to explore in relation to measures of mobility and balance in this population.

2.2 Purpose

To explore the role of executive performance and IIV-RT, on changes in mobility and balance in community-dwelling older adults with chronic stroke. Specifically, three executive processes: response inhibition, working memory, and set shifting, as well as IIV-RT in a response inhibition task, were evaluated separately on changes in mobility and balance as measured by the Timed Up and Go test (TUG), Short Physical Performance Battery (SPPB), and usual gait speed over 6 months.

2.3 Methods

2.3.1 Study Design

A secondary analysis of a RCT dataset (39). The Vitality Study was a CIHR-funded 6-month RCT which evaluated the effect of exercise training and cognitive training on cognition against a balance and tone exercise control group in individuals with chronic stroke.

2.3.2 Measures

2.3.2.1 Measures of Executive Performance

Response inhibition, set-shifting, and working memory were examined using the Stroop Colour Word Test, the Trail-Making Test Ratio (B/A), and the Digit Span Difference, respectively. Participants with a missing value for the Trail-Making Test Ratio (B/A), the Digit Span test or the Stroop Colour Word test were listwise excluded from the analyses.

2.3.2.1.1 The Stroop Colour Word Test

Response inhibition was evaluated using the Stroop Colour Word test (133). A computerized version of the test was utilized in this study as described in the Vitality Study protocol (39). The task was completed using an E-prime program run on a computer with a Windows operating system and a response pad (Cedrus RB-540). Colour and non-colour words printed in blue, yellow or green was displayed on the screen for 2000 milliseconds. The task began with 18 practice trials in which only non-colour words are shown. After completion of the practice trials, 42 congruent trials, 42 neutral and 42 incongruent trials were be presented in random order. When each word was shown, participants were asked to press the button on the response pad that matches the print colour of the word as quickly and as accurately as possible. The difference between the median response time (RT) for the incongruent trials and the median response time (RT) for the congruent trials, using only trials with correct responses, is used in analyses. A greater difference is thought to be reflective of a stronger Stroop effect and thereby, decreased inhibition. The Stroop Colour Word test evaluates response inhibition as selective attention and conflict resolution are directly involved in inhibiting the automatic response to read the word rather than the print colour. The computerized Stroop Colour Word test has emerged as an adaptation of the paper Stroop Colour Word test within the past decade, offering increased accuracy, control and consistency over the stimuli presented each trial as compared to the pen and paper version (134). Despite the novelty of this adapted measure, there is evidence of validity and reliability (134, 135).

2.3.2.1.2 Trail-making Test Ratio (B/A)

Set-shifting was assessed using the Trail-Making Test Ratio of Part B to A (136, 137). The Trail-Making Test consists of 2 parts: Part A and Part B. Part A instructs participants to connect numbers in ascending order while Part B requires participants to connect numbers and letters in alternating and ascending fashion. The time to complete each part is recorded and the ratio of Part B to Part A is taken with a smaller quotient reflective of better set-shifting. The Trail-Making Test Ratio is shown to have superior sensitivity than the Trail-Making Test Difference (B-A) among individuals with brain damage and higher resistance to malingering (138-140).

2.3.2.1.3 Working Memory

Working memory was assessed using the Digit Span test (136, 137). The Digit Span test consists of two parts: Forwards and Backwards. The Digit Span Forwards requires participants to recite random number sequences in forward order while the Digit Span Backwards requires participants to recite different random number sequences in backwards order. Seven pairs of number sequences are presented, with each pair increasing by 1 digit. Participants repeat the digit sequence as read by the assessor in the indicated order. The test continues until the participant is unable to correctly recite both sequences within a set pair. The participants score on the Digit Span Backwards is then subtracted from their score on the Digit Span Forwards; a smaller difference is thought to be reflective of better working memory. These tests of executive function have been previously used in stroke populations (105, 141, 142).

2.3.2.1.4 Intraindividual Variability in Reaction Time

The Stroop Colour Word test was used to assess IIV-RT. To calculate IIV-RT, the standard deviation of mean RT on congruent trials in the Stroop Colour Word test was subtracted from the standard deviation of mean RT on incongruent trials. As the mean RT on incongruent and congruent trials is calculated using only accurate trials, the IIV-RT similarly reflects the IIV on accurate trials only. IIV-RT was only be evaluated in response inhibition as it is the only computerized task within the neuropsychological battery used in the Vitality study. Many investigations of IIV-RT in older adults with neurological disturbances, including mild cognitive impairment, have used the SD of RT as a measure of IIV-RT in executive function (112, 113, 121-129, 143, 144). Further evidence has shown that IIV-RT is sensitive to change over time as Brydges and colleagues (120) reported a decrease in IIV-RT in a task-switching measure in older adults over the course of an aerobic exercise training intervention.

2.3.2.2 Measures of Mobility

The general measures of balance and mobility that were examined in relation to cognition included: the TUG test (65), the SPPB (66) and usual gait speed (67). Participants with a missing value for the TUG test, the SPPB, or any subsection of the SPPB were listwise removed from analyses.

2.3.2.2.1 The Timed Up and Go Test

The TUG test is used to evaluate functional mobility and carries implications for fall risk as a TUG time >15 seconds is associated with an increased risk of falling (65, 145). To complete this test, participants are instructed to begin seated in a standard chair with arm rests (seat height: 45

cm, arm height 62 cm), walk forward distance of 3 m, walk back to the chair, and sit down (65). Two trials are timed with the average time of both trials used the analyses. This test was shown to have a strong inter-rater and intra-rater reliability among older adults, including those with stroke (146). Within a stroke population, the TUG test has a test-retest reliability of ICC=0.96 (0.93-0.98) (147).

2.3.2.2.2 The Short Physical Performance Battery

The SPPB evaluates overall balance, gait, and strength through 3 tasks scored out of a total of 12 points (66). Performance on each measure is correlated with a score of 0-4; 0 signifies the inability to complete task or need of maximal assistance to complete task safely while a 4 indicates the ability to complete the task safely and independently. The SPPB is a validated measure of lower extremity function in stroke populations (148). It has strong test-retest reliability (ICC=0.98) and inter-rater reliability ([ICCs]=0.95-0.98). Convergent construct validity has also been established in stroke as the SPPB total score was found to have moderate to high correlations with the Barthel Index ($r=0.80-0.94$) (149), the Fugl-Meyer Assessment ($r=0.62-0.94$) (41), gait speed ($r=0.60$) (150) and postural sway ($r=0.55$) (151).

2.3.2.2.3 Usual Gait Speed

Usual gait speed is a measure of walking ability and is highly correlated community ambulation (152). Usual gait speed is calculated from the gait speed subsection of the SPPB. Participants begin behind the start line and are instructed to walk at their usual walking speed beyond the end line. The assessor begins the stopwatch when the participant crosses the start line and crosses the end line. Two trials are completed and the average time of both trials was used in the analyses.

The 4-meter distance walked by participants during the gait speed subsection is divided by their time to complete the walk in seconds to produce their usual gait speed in the unit meters per second used in analyses. Usual gait speed is established as a reliable measure of walking ability within a stroke population with an intra-rater reliability of 0.87 and inter-rater reliability of 0.97 (153, 154). Among individuals with chronic stroke, gait speed has a test-rest reliability of ICC=0.94 (0.90=0.97) (147).

2.3.3 The Vitality Study

The Vitality study is a 6 month, single-blinded, RCT that compared the effect of a resistance training program (FAS) and a mental and social activities program (COG) on cognition in older adults with chronic stroke against a sham exercise training program consisting of stretch and relaxation exercises (BAT) which served as a control group. This study ran from May 2013 to February 2020. Participants of this study were randomized and allocated to one of 3 groups: FAS, COG or BAT. Each treatment program was 26 weeks in length, with intervention classes taking place at the Centre for Hip Health and Mobility in Vancouver, British Columbia, 2 times a week for 1 hour per session. Physical and cognitive assessments took place at 3 months, 6 months, and 12 months. Participants were fully informed that they may drop-out of the study at any point in their participation.

2.3.3.1 Exercise Intervention

The Fit and Strong exercise program (FAS) was adapted from the FAME program established by Pang and colleagues (155). Each FAS class carried a standard protocol: 10 minute warm-up, 20 minutes of resistance training exercises, 20 minutes of aerobic training and 10 minute cool-

down. The 10 minute warm-up and 10 minute cooldown remained consistent throughout the 26 week program, however, the exercises within the resistance training and aerobic training components of the program progressed in difficulty over time if afforded by participant ability. The rate of perceived exertion scale (156-158) (RPE; 6-20 scale) was recorded at 15 minute intervals during each class and at the end of class to establish overall RPE. At the start of the program, participants were encouraged to work between an 11 to 13 on the RPE scale (fairly light to somewhat hard) with progression to a moderate intensity over time.

2.3.3.2 Cog-Plus Intervention

The complex social and mental activity program (COG) was adapted from the pilot study and current literature (142, 159). Each class carried a standard protocol beginning with the presentation of a word list (5 minutes), 25 minutes of online cognitive games using the Lumosity brain training app on iPads and 25 minute of various social games, followed by delayed recall of the word list presented at the beginning of class (5 minutes). The Lumosity brain training recorded the progress of each individual and offered progressions based on the individual's performance.

2.3.3.3 Balance and Tone Control Group

The balance and tone program (BAT) was adapted from protocols used in previous RCTs led by Professor Liu-Ambrose (160). Each stretch and relaxation intervention class consisted of a 10 minute warmup, 40 minute stretch and relaxation exercises including deep stretching, breathing and relaxation techniques, postural control and core activation exercises, and a 10 minute cool-down. There were no aerobic or resistance exercises within the balance and relaxation protocol.

The RPE scale was recorded at 15-minute intervals and at the end of class to ensure participant safety and appropriate exertion levels among participants. This group served as the control group to control for the increase in exercise participants may have experienced travelling to the Centre for Hip Health 2 times weekly for 26 weeks.

2.3.3.4 Inclusion Criteria

This study sampled community-dwelling individuals who experienced a single ischemic or hemorrhagic stroke a minimum of 12-months prior to entering the study as confirmed by previous MRI or CT. A time frame of 12 months was enforced for study participation due to the high prevalence of secondary strokes occurring in the year following an initial stroke (161). Due to patterns of age-related cognitive decline, participants were required to be 55 years or older to ensure homogeneity within the sample. To ensure all participants were able to actively take part in study intervention classes, participants were required to score 22 or higher on the Mini Mental State Examination (MMSE) at screening, including a perfect score on the 3-step command indicative of intact comprehension and ability follow instructions. For similar reasons, participants were required to have the ability to read, write and speak English with acceptable visual and auditory acuity and have the ability to walk 6 meters with or without rest intervals. Participants were also community-dwelling individuals in Greater Vancouver to ensure they were able to attend regular classes at the Centre for Hip Health. Individuals were not currently participating in any regular therapy or progressive exercise at the time of the study to prevent effects unrelated to the intervention. All participants provided informed consent to participate in the study.

2.3.3.5 Exclusion Criteria

Individuals were excluded from the study if they had been diagnosed with any type of dementia or any other type of neurodegenerative or neurological condition known to affect mobility and cognition. To minimize adverse events and ensure safety for all participants, those at high risk for cardiac complications during exercise or those unable to self-regulate activity and understand the recommended activity level were excluded. Individuals with significant peripheral neuropathy or severe musculoskeletal or joint disease that impaired mobility as determined by physician, raised safety concerns and therefore were excluded from the study. Individuals were also excluded from the Vitality study if they were regularly taking medication that negatively affected cognitive function such as anticholinergics, including agents with anticholinergic effects, and anticonvulsants such as gabapentin. Individuals with aphasia, as judged by an inability to communicate by phone, were excluded as communication continued by phone in the 6 months following the intervention.

2.3.3.6 Recruitment

The recruitment process for the Vitality study occurred from 2013-2019 with staggered enrolment of cohorts. Individuals with chronic stroke were recruited through advertisements in local community centres, stroke support groups and newspapers across Greater Vancouver. Individuals who expressed interest were mailed an information package. This information package outlined a participant's involvement, their rights throughout the study, the potential risks and benefits of each study arm and how information will be gathered, securely stored and for how long. If the individual continued to express interest, they were screened by phone or on-site

using the inclusion criteria and the Physical Activity Readiness Questionnaire (PAR-Q), which indicates readiness to participate in physical activity.

2.4 Data Analysis

Participants with complete data at baseline and 6-months were included in this analyses (n=103/120). Changes in mobility and balance were quantified through change scores (baseline and 6-months) calculated from performance on the TUG, the SPPB, and usual gait speed. Four MANCOVA models were constructed wherein change in mobility and balance was the dependent variable; group allocation, age, sex, education were included as covariates. Four models were conducted to evaluate each measure of executive performance and IIV-RT: 1) the Digit Span test, 2) the Trail-Making Test Ratio (B/A), 3) the Stroop Colour Word test and 4) IIV-RT of the Stroop Colour Word test, separately, using Pillai's trace. If a significant multivariate test was identified for any variable of interest: 1) the Digit Span test, 2) the Trail-Making Test Ratio, 3) the Stroop Colour Word test and 4) IIV-RT of the Stroop Colour Word test, the univariate F tests were examined.

Both the FAS and BAT groups involved exercises known to impact mobility (162, 163). The effect of FAS and BAT may not be adequately controlled by statistics (i.e., accounting for group in the MANOVA). Thus, we conducted further analyses with only the FAS and BAT groups producing a sub-sample of 74 participants. The four MANCOVA models were replicated within this sub-sample (n=74/120), maintaining mobility and balance as the dependent variable and group allocation, age, sex and education. Each measure of executive performance was evaluated separately using Pillai's Trace. The univariate F tests were evaluated if a significant multivariate

test was identified for any variable of executive performance: 1) 1) the Digit Span test, 2) the Trail-Making Test Ratio, 3) the Stroop Colour Word test and 4) IIV-RT of the Stroop Colour Word test.

Assumptions of linearity, normality, multi-collinearity and homoscedascity of population covariance matrices in each model were assessed. Overall alpha was set at $p < .05$. All analyses were conducted in R (www.r-project.org) (164).

2.5 Results

2.5.1 Characteristics of Participants

Complete descriptive statistics for the participants within this sub-analysis (n=103/120) are reported in Table 2.1. Based on average scores on the MoCA (sample mean=22) and MMSE (sample mean=27), this sample is cognitively impaired. The lower average score on the MoCA is likely reflective of the superior sensitivity of the measure to detect early changes in cognitive ability (149). The average Fugl-Meyer Total Score within this sample (sample mean=81) is indicative of mild physical impairment (47).

Table 2.1 Sample Characteristics (n=103/120) for Chapter 2

Variable	Mean (SD)	Range
Age (years)	69.91 (8.61)	55-88
BMI	27.73 (4.54)	16.34-47.73
Female (number)	41(39.80%)	
Education		
Less than grade 9	1 (0.97%)	
Grades 9-12 (without certificate or diploma)	6 (5.83%)	
High school certificate or diploma	15 (14.56%)	
Trades or professional certificate or diploma	10 (9.70%)	
Some university or diploma	21 (20.38%)	
University degree	50 (48.54%)	
CESD (maximum)	9.47 (8.18)	0-43
MMSE (maximum 30)	27.43 (2.42)	19-30
MoCA (maximum 30)	22.09 (3.99)	10-30
Fugl-Meyer total score	81.43 (23.43)	6-100
Baseline TUG performance (seconds)	19.41 (18.63)	6.10-39.42
Baseline SPPB performance (maximum 12)	8.37 (2.61)	1-12
Baseline usual gait speed (m/s)	0.87 (0.33)	0.048-1.61
6-month TUG performance (seconds)	16.17 (10.44)	5.93-63.93
6-month SPPB performance (maximum 12)	8.91 (2.23)	3-12
6-month usual gait speed (m/s)	1.64 (3.30)	0.54-3.67
Baseline Stroop Colour Word test (Median RT Incongruent Trials-Congruent Trials)	140.26 (100.56)	-50.50-475.50
Baseline Verbal Digit Span (Forwards-Backwards)	1.56 (1.70)	-2-6
Baseline Trail-Making Test Ratio (seconds)	110.15 (125.96)	6.47-798.91
Baseline Stroop Colour Word Test Intraindividual Variability (SD Incongruent Trials-Congruent Trials)	43.36 (60.07)	-225.69-204.63

2.5.2 MANCOVA Models – All groups

Four MANCOVA models examined change in mobility and balance by executive performance

and the IIV-RT of the Stroop Colour Word test; main effects are reported in Tables 2.2-2.5.

There were no statistically significant differences in changes in mobility and balance based on any of variables of interest: Stroop Colour Word test, the Digit Span test, Trail-Making Test

Ratio (B/A), or IIV-RT of the Colour-Word Stroop test. Significant changes in mobility and balance based on group allocation, a covariate, were demonstrated in Table 2.2 ($F(3,89)=4.272$, $p=0.007$), Table 2.3 ($F(3, 89)=4.241$, $p=0.008$), Table 2.4 ($F(3, 89)=4.263$, $p=0.007$) and Table 2.5 ($F(3, 89)=4.003$, $p=0.010$). Univariate testing was not pursued because the omnibus test was not significant for any variables of interest. Complete R output is provided in Appendix E.

Table 2.2 MANCOVA Omnibus test including Factors: Age, Sex, Education and Baseline Digit Span in all Study Groups (n=103/120)

Variable	Pillai's Trace	F Value	df	Error df	Sig.
Age (years)	0.018966	0.5735	3	89	0.633899
Sex	0.001176	0.0349	3	89	0.991187
Education	0.107736	0.5650	18	273	0.922586
Group	0.125895	4.2728	3	89	0.007242 **
Baseline Digit Span (Forwards- Backwards)	0.013844	0.4165	3	89	0.741607

** $p < .01$

Table 2.3 MANCOVA Omnibus test including Factors: Age, Sex, Education and Baseline Trail-Making Test Ratio in all Study Groups (n=103/120)

Variable	Pillai's Trace	F Value	df	Error df	Sig.
Age (years)	0.018969	0.5736	3	89	0.633823
Sex	0.001172	0.0348	3	89	0.991236
Education	0.109327	0.5736	18	273	0.917006
Group	0.125061	4.2405	3	89	0.007534 **
Baseline Trail-Making Test Ratio (B/A)	0.036853	1.1351	3	89	0.339312

** $p < .01$

Table 2.4 MANCOVA Omnibus test including Factors: Age, Sex, Education and Baseline Stroop Median RT in all Study Groups (n=103/120)

Variable	Pillai's	F Value	df	Error	Sig.
	Trace			df	
Age (years)	0.019148	0.5792	3	89	0.630214
Sex	0.001170	0.0348	3	89	0.991255
Education	0.108185	0.5674	18	273	0.921033
Group	0.125648	4.2632	3	89	0.007327 **
Baseline Stroop Median RT	0.018634	0.5633	3	89	0.640623

** $p < .01$

Table 2.5 MANCOVA Omnibus test including Factors: Age, Sex, Education and Baseline IIV-RT in all Study Groups (n=103/120)

Variable	Pillai's	F Value	df	Error	Sig.
	Trace			df	
Age (years)	0.016962	0.5061	3	88	0.67905
Sex	0.002202	0.0647	3	88	0.97838
Education	0.100821	0.5216	18	270	0.94699
Group	0.120080	4.0030	3	88	0.01011 *
Baseline IIV-RT	0.010560	0.3131	3	88	0.81589

* $p < .05$

2.5.3 MANOVA – FAS AND BAT Groups Only

The four MANCOVA models were replicated and evaluated changes in mobility and balance by measures of executive performance within the sub-sample of exercise-related study groups. Age, sex and education were included as covariates. The main effects (Tables 2.6-2.9), revealed a statistically significant change in mobility and balance by the Trail-Making Test Ratio (B/A). This prompted univariate testing, reported in Tables 2.7.1-2.7.3, which identified Trail-Making Test Ratio as a significant predictor of changes in gait-speed over time ($F(1,63)=4.32, p=0.048$). Complete R output is provided in Appendix F. Figure 2.1 depicts changes in Gait Speed by Timepoint, showing larger changes in Gait Speed between Baseline and 6-Month Assessments in

the Fit and Strong Exercise Group and Balance and Tone Control Group as compared to the Masterminds Cognitive Training Group. Figures G1 and H1, depicting changes in SPPB Total Score and TUG by Timepoint, are shown in Appendices G and H respectively.

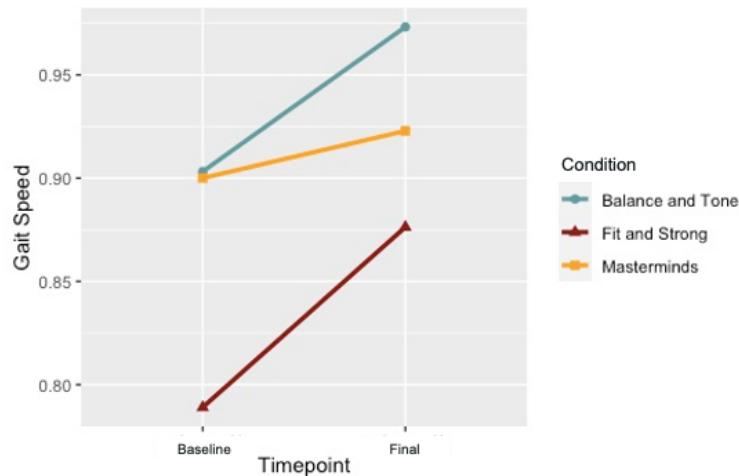


Figure 2.1 Usual Gait Speed by Timepoint (n=103/120)

Table 2.6 MANCOVA Omnibus Test with Factors: Age, Sex, Education & Digit Span in BAT and FAS Groups (n=74/120)

Factor	Pillai's Trace	F Value	df	Error df	Sig.
Age	0.020898	0.44822	3	63	0.7194
Sex	0.001058	0.02224	3	63	0.9955
Education	0.118753	0.53581	15	195	0.9182
Baseline	0.014263	0.30385	3	63	0.8225
Digit Span					

Table 2.7 MANCOVA Omnibus Test with Factors: Age, Sex, Education & Trail-Making Test Ratio in BAT and FAS Groups (n=74/120)

Factor	Pillai's	F Value	df	Error	Sig.
	Trace			df	
Age	0.020942	0.44918	3	63	0.71875
Sex	0.001064	0.02236	3	63	0.99543
Education	0.122305	0.55252	15	195	0.90746
Baseline Trail-making Test Ratio (B/A)	0.116587	2.77144	3	63	0.04876 *

* $p < .05$

Table 2.8 MANOVA Omnibus Test with Factors: Age, Sex, Education & Stroop Median RT in BAT and FAS Groups (n=74/120)

Factor	Pillai's	F Value	df	Error	Sig.
	Trace			df	
Age	0.021046	0.45147	3	63	0.7172
Sex	0.001053	0.02214	3	63	0.9955
Education	0.119190	0.53786	15	195	0.9169
Baseline Stroop Median RT	0.018028	0.38554	3	63	0.7638

Table 2.9 MANOVA Omnibus Test with Factors: Age, Sex, Education & IIV-RT of the Stroop Colour Word Test in BAT and FAS Groups (n=74/120)

Factor	Pillai's	F Value	df	Error	Sig.
	Trace			df	
Age	0.018838	0.39680	3	62	0.7558
Sex	0.002901	0.06013	3	62	0.9805
Education	0.104098	0.46012	15	192	0.9574
Baseline IIV-RT	0.003022	0.06264	3	62	0.9793

Table 2.10 Univariate Effects Examining Significant Predictors of Change in TUG Performance in BAT and FAS Groups (n=74/120)

Predictor	df	Sum of Squares	Mean Square	F value	Probability
Age	1	0.1	0.130	0.0022	0.9629
Sex	1	2.0	1.976	0.0332	0.8561
Education	5	96.7	19.339	0.3246	0.8964
Baseline Trail-Making Test Ratio	1	69.5	69.525	1.1670	0.2840

Table 2.11 Univariate Effects Examining Significant Predictors of Change in SPPB Performance in BAT and FAS Groups (n=74/120)

Predictor	df	Sum of Squares	Mean Square	F value	Probability
Age	1	2.549	2.5486	0.9966	0.3218
Sex	1	0.014	0.0138	0.0054	0.9417
Education	5	11.517	2.3034	0.9008	0.4861
Baseline Trail-Making Test Ratio	1	3.337	3.3369	1.3049	0.2575

Table 2.12 Univariate Effects Examining Significant Predictors of Change in Usual Gait Speed in BAT and FAS Groups (n=74/120)

Predictor	df	Sum of Squares	Mean Square	F value	Probability
Age	1	0.03321	0.033206	0.8294	0.3658
Sex	1	0.00026	0.000262	0.0065	0.9358
Education	5	0.11273	0.022546	0.5632	0.7278
Baseline Trail-Making Test Ratio	1	0.17316	0.173156	4.3250	0.0415 *

2.6 Discussion

This study aimed to study the relationship between executive performance and IIV-RT and change in mobility and balance over 6-months in chronic stroke. Analyses with all three study groups (n=103/120) did not identify changes in mobility by executive performance or IIV-RT while analyses using only exercise related study groups (i.e., BAT and FAS; n=74/120) found set-shifting ability predicted changes in usual gait speed. Thus, we cannot determine if a relationship between executive performance or IIV-RT and changes in mobility and balance exists among individuals with chronic stroke.

The differential effects of the three experimental groups on mobility may explain the equivocal results. Aerobic and resistance training programs, akin to the FAS group, have been shown to significantly improve mobility among individuals with stroke (163). Similarly, stretching and toning exercises, akin to the BAT group, increase both balance and mobility within the same population (162, 163). While there are theoretical models that support the notion of cognitive training may impact mobility (165), the effect of cognitive training on mobility and balance has not yet been examined chronic stroke. A RCT examining the effects of cognitive training, akin to the COG group, on Instrumental Activities of Daily Living in healthy older adults did not report any significant effect suggesting transfer to mobility may be limited (166). While group allocation was included in each model in the primary analyses, the effect of a statistical control is limited.

The results of the analyses examining only the exercise-based study groups (BAT and FAS; n=74/120) aligned with prior investigations of executive function and mobility in healthy older

adults. In aging literature, physical and cognitive decline co-occur and appear interconnected. While multiple domains of cognition including attention and memory have been related to mobility in aging, the relationship between the executive functions and mobility, specifically gait-related measures, appears to be most robust (167-169). Several studies have identified executive performance specifically, to be associated with mobility and balance as measured by the TUG test (170, 171), the SPPB (172), and usual gait speed (170). While executive performance and mobility are correlated, directionality within this relationship has not been determined. Evidence of this relationship is bidirectional; executive performance predicts mobility at 12 months (173) and annual decline in gait speed (168) and alternately, gait speed predicts executive performance in 5 years (174) and declines in gait speed predict declines in executive performance (175). The consistency of this relationship is suggestive of a common mechanism.

The relationship between set-shifting and changes in usual gait speed over 6-months observed in the subsequent analyses is notable given the growing body of literature observing the co-occurrence of slowed gait and executive dysfunction, suggestive of shared neural underpinnings (176). Different perspectives from epidemiological, neuropsychological, and imaging literature converge to suggest gait lies under executive control (177-179). While components of gait are automatic, operating at a spinal and sub-cortical level, locomotion appears to become less automatic in aging, with imaging studies implicating the front and temporal lobe networks in gait control (5-7). Gait modifications, such as post-stroke gait asymmetry, are thought to require further cognitive resources, and thereby rely more heavily on executive control and related networks (6). There is some evidence the effects of executive dysfunction may extend beyond

gait control to fall rate as healthy older adults displaying only poor executive performance demonstrated a 1.45 fold increase in fall rate (180). This emerging theory carries clinical implications. Executive dysfunction appears to be entwined with slower gait, and in turn falls, thus, clinicians should consider addressing cognitive and mobility dysfunction in tandem rather than as separate complications (176).

The results of this analysis should be interpreted with caution. As discussed, the significant effect of group allocation within these models suggests the intervention groups differentially impacted participants' mobility over time. Further, the Trail-Making Test is a pen-and-paper task which relies on upper-motor function. While this sample and sub-sample displayed mild physical impairment (47) (Sample Average Fugl-Meyer Total score: 81.43; Sub-sample Average Fugl-Meyer Total Score: 81.14), upper limb impairment is common post-stroke and may impact one's ability to complete this task of executive performance. Further limitations include a lack of information regarding the participants' stroke lesion type and location. The heterogeneity of this sample may have contributed to an underestimation of the relationship between executive performance and mobility.

2.7 Conclusion

In summation, the relationship between executive performance and IIV-RT, and changes in mobility and balance in chronic stroke cannot be determined from this study. While the multivariate analyses including all three study groups did not reveal any changes in mobility and balance by executive performance or IIV-RT, the multivariate analyses including only exercise-related study groups did reveal a significant change in mobility and balance by executive

performance. Subsequent univariate analyses revealed set-shifting ability to be a significant predictor of changes in gait speed over 6-months. Further investigation of this research question using an observational design is warranted.

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Appendices

Appendix A - Semi-Structured Interview Guide

This is not a verbatim interview.

The prompts/probes are to be used as reminders during active listening.

The interviewee will be telling his/her story and details may be asked about further.

General probes: Can you say a bit more about that/give me an example?

Introduction:

- Thank participant for their interest
- Review purpose of the study with participant
- Review completed consent form with participant
- Review participant's right to anonymity and ensure them that all identifiers including names and locations will be erased from audio recordings
- Address voice recorder and review participant's right to refuse audio recording at anytime
- Let participant know that they should feel free to add anything they would like throughout the interview

PART 1: EARLY IMPACT OF STROKE ON YOUR COGNITIVE HEALTH

1. Thinking back, would you be willing to tell me about your stroke?

Probes to be used if appropriate:

- What was happening in your life when your stroke occurred?
- Did you experience your stroke in a familiar place?
- Were you able to receive medical attention quickly?
- What kinds of changes did you experience?

PART 2: COGNITIVE HEALTH SINCE YOUR STROKE

1. Since your stroke, have you noticed any changes in your health? (ask to elaborate on any that are relevant to cognitive health/give examples)

Probes:

- Can you talk me through a typical day/week since your stroke?
- Can you tell me about any changes in memory, fatigue, emotions etc.?
- Have you noticed any changes in your daily life since your stroke?

- Some people say they see themselves differently after a stroke. What has your experience been?

2. What helped/could have made things better?

Probes:

- When you were in hospital / at home?
- What about any health professionals you saw? How helpful/unhelpful?
- Has any information you received during this study changed the way you think about these aspects of your health? How helpful/unhelpful?

PART 3: YOUR COGNITIVE HEALTH IN THE FUTURE

1. Have you thought about what might be helpful for these aspects of your health (e.g., memory/fatigue/emotions) in the future?

Probes:

- How do you feel about that? (e.g., worry/optimistic)
- Can you talk me through any changes you're anticipating to these aspects of your health?
- How important is attitude; spiritual beliefs; your physical health?

Thank you:

- Ask participant: Any questions you thought I would ask I didn't?
- Thank the participant for their participation
- Let participant know that they have the right to retract anything they have said and it will be erased from the recording

Appendix B - Field Notes

DESCRIPTIVE INFORMATION	REFLECTIVE INFORMATION
<ul style="list-style-type: none"> - interview took place @ RP, room # ↳ px recognized room as one where assessments had taken place - participant enrolled in study @ time of interview - BAT group, incorrectly named instructors, spoke highly of program "so good" "very thankful" ↳ indication of cog. impairment - px entered using walker - used as aid to sit down/get up "I wouldn't go anywhere w/o my thing" → not much room for movement - px and myself (interviewer sat side) [walker, find more by side - sitting across too far to /may appear too formal to each other but we turned our chairs to face each other] - px appeared frazzled and nervous upon arrival, very quiet pace in speaking → related to nerves? ↳ quick pace in speaking maintained throughout interview, eyes darted around room while speaking - appeared uncomfortable w/ eye contact? ↳ despite attempts to calm down px during intro/ consent ↳ px admitted to never, feeling as if she might "say the wrong thing" and I shared I was nervous too to connect w/px - px spoke in short fragmented sentences - often grammatically incorrect jumping from topic to topic in ways that were not logical and hard to follow ↳ few extended pauses, px continued to speak at quick pace (passionate tone) making it difficult to interject and clarify or ask questions. ↳ px reported age that did not match age on file px reported appointments that contradicted, timeline of events does not make sense 	<ul style="list-style-type: none"> - many indications of cognitive impairment <ul style="list-style-type: none"> ↳ logic jumps while speaking - incoherent at many times ↳ fragmented sentences ↳ appeared to lose train of thought in middle of sentences many times ↳ quick pace of tone, non-stop speaking in bubbly manner → potential defense mechanism to hide loss of px's train of thought? - level of awareness regarding cognitive impairment unknown <ul style="list-style-type: none"> ↳ participant did not speak to any cognitive ax. any healthcare professionals mentioning cognitive impairment, no cognitive ax ↳ reflecting what she has been told by healthcare professionals? do healthcare professionals ward inform how the px experiences the symptoms of their stroke? ↳ appears to be bias towards physical funct as majority of stroke-related informed ↳ ethical to interview her - can consent be obtained if she has unknowingly ↓ in cog funct to dementia state since stroke? - "Slipped through the cracks" ↳ px appeared vulnerable in many ways <ul style="list-style-type: none"> - unable to relate correct / chronological healthcare history = implications for level of care received from healthcare professionals

An example of field notes written after an interview on June 12, 2019 at the Research Pavilion. Some sections of this entry are not pictured to preserve participant anonymity.

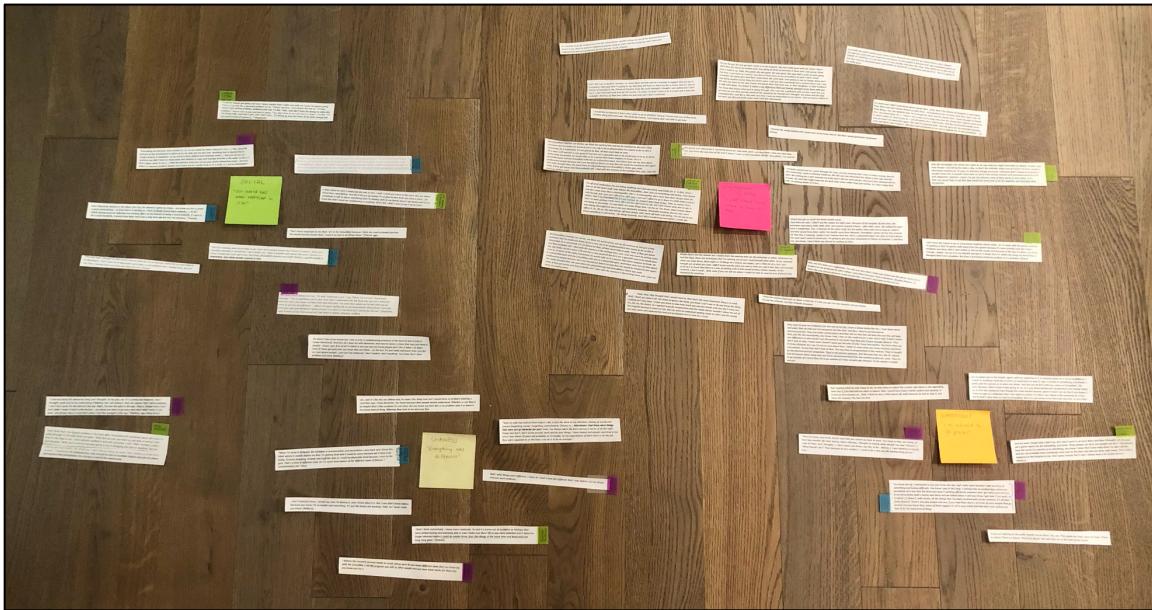
Appendix C - Reflexive Journal Entry

'heightened vulnerability' - some evidence of this in early interviews but this does not seem to be in more recent interviews. In earlier interview Tayla seems to reflect this: inability to recall medical history, keep track of appointments, advocate for self → didn't get out-patient physio or walker leading to falls, referred to as "slipping through the cracks" by public health nurse. Malvony also showed 'heightened vulnerability' when she forgot about appl. → resulted in blindness. Both participants seem to coordinate own care (Malvony - lives alone, divorced, 1 son in care home) (Tayla - lives with roommate/potential partner) but does not describe him as involved in her care. Does living status potentially "mediate" the vulnerability of cog. impairment post-stroke? Patrick also reported forgetting appointments but stated his partner now coordinates his care post-stroke. Also questioning, is heightened vulnerability really in the data - participants do not seem to refer to themselves as vulnerable if anything it seems to be others that label them as such like the public health nurse that identified Tayla as "slipping through the cracks". Do participants feel more vulnerable b/c of cog. changes post-stroke? → Also relates to the question of the awareness of cog. changes as any more than changes, rather than impairment?
⇒ Ask Jenny how to probe about their vulnerability among participants.

- Social meta-theme - general trend of socializing decreasing post-stroke but many differences in such descriptions. Eg. Patrick describes memory issues stand out in social situations → he feels embarrassed and takes a step back from social situations as a result → he is making own decision to ↓ his social interactions. Some descriptions of cog. impairment affecting communication w/ others: like hearing things that weren't said, Ivy said one word but thought she was saying another → but these descriptions are not necessarily related to decrease in social connections. Other descriptions were - Stephanie described how her heightened sensitivity to light, sound keeps her from attending social events (again self-imposed restriction on social activities). How to reconcile these nuances in experience? Self-imposed restriction in social activities versus others restricting activity w/ them? Changes affecting social life/^{activities} vs. changes affecting communication?
⇒ Ask Jenny for her opinion on how to capture these nuances in social changes

An example of a reflexive journal entry written on February 12, 2020.

Appendix D - Reflexive Mapping



An example of the reflexive mapping process used during the reflexive thematic analysis.

Appendix E - R Output for Table 2.2-2.5

R Output for Table 2.2

```
model1<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~  
                  age+sex+education+digit.diff1, data=vit.complete)  
  
summary(model1)  
  
##  
##          Df    Pillai approx F num Df den Df Pr(>F)  
## age      1 0.018961  0.57982      3     90 0.6298  
## sex      1 0.001050  0.03152      3     90 0.9924  
## education 6 0.105774  0.56038     18    276 0.9255  
## digit.diff1 1 0.017769  0.54270      3     90 0.6543  
## Residuals 92  
  
summary.aov(model1)  
  
## Response tug.ch :  
  
##          Df Sum Sq Mean Sq F value Pr(>F)  
## age      1    0.2   0.215  0.0046 0.9460  
## sex      1    1.5   1.455  0.0312 0.8602  
## education 6   62.5  10.412  0.2232 0.9684  
## digit.diff1 1   14.5  14.495  0.3107 0.5786  
## Residuals 92 4291.5  46.647  
##  
## Response gaitspeed.ch :  
  
##          Df Sum Sq Mean Sq F value Pr(>F)  
## age      1 0.0284  0.028377  0.7357 0.3933
```

```

## sex          1 0.0006 0.000586 0.0152 0.9022
## education    6 0.0783 0.013054 0.3384 0.9149
## digit.diff1  1 0.0484 0.048390 1.2545 0.2656
## Residuals    92 3.5487 0.038573
##
## Response sppb.tot.ch :
##              Df  Sum Sq Mean Sq F value Pr(>F)
## age           1   3.167  3.1670 1.4567 0.2306
## sex           1   0.034  0.0342 0.0157 0.9005
## education     6  15.955  2.6592 1.2231 0.3017
## digit.diff1   1   0.079  0.0789 0.0363 0.8493
## Residuals    92 200.020  2.1741
##
## 1 observation deleted due to missingness

```

R Output for Table 2.3

```

model3<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~age+sex+education+tmt
ba.ratio1, data=vit.complete)

summary(model3)

##              Df Pillai approx F num Df den Df Pr(>F)
## age           1 0.018968  0.58004      3     90 0.6296
## sex           1 0.001047  0.03144      3     90 0.9925
## education     6 0.107442  0.56955     18    276 0.9197
## tmtba.ratio1  1 0.037275  1.16156      3     90 0.3289
## Residuals    92

```

```

summary.aov(model3)

## Response tug.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age         1   0.2   0.215  0.0046 0.9459
## sex         1   1.5   1.455  0.0314 0.8598
## education    6  62.5  10.412  0.2244 0.9679
## tmtba.ratio1 1  36.6  36.602  0.7887 0.3768
## Residuals   92 4269.4  46.407

## 

## Response gaitspeed.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age         1 0.0284 0.028377  0.7318 0.3945
## sex         1 0.0006 0.000586  0.0151 0.9025
## education    6 0.0783 0.013054  0.3367 0.9159
## tmtba.ratio1 1 0.0298 0.029782  0.7681 0.3831
## Residuals   92 3.5673 0.038775

## 

## Response sppb.tot.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age         1   3.167   3.1670  1.4808 0.2268
## sex         1   0.034   0.0342  0.0160 0.8997
## education    6  15.955   2.6592  1.2433 0.2917
## tmtba.ratio1 1   3.332   3.3319  1.5579 0.2151
## Residuals   92 196.767   2.1388

```

```

##  

## 1 observation deleted due to missingness

```

R Output for Table 2.4

```

model5<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~  

                  age+sex+education+stroop.med.diff1, data=vit.complete)  

summary(model5)  

##  

##          Df Pillai approx F num Df den Df Pr(>F)  

## age       1 0.019147  0.58563      3     90 0.6260  

## sex       1 0.001039  0.03121      3     90 0.9925  

## education 6 0.106136  0.56237     18    276 0.9242  

## stroop.med.diff1 1 0.016362  0.49902      3     90 0.6839  

## Residuals 92  

summary.aov(model5)  

## Response tug.ch :  

##  

##          Df Sum Sq Mean Sq F value Pr(>F)  

## age       1    0.2   0.215  0.0046 0.9460  

## sex       1    1.5   1.455  0.0312 0.8602  

## education 6   62.5  10.412  0.2232 0.9683  

## stroop.med.diff1 1   15.2  15.153  0.3249 0.5701  

## Residuals 92 4290.9  46.640  

##  

## Response gaitspeed.ch :  

##  

##          Df Sum Sq Mean Sq F value Pr(>F)

```

```

## age              1 0.0284 0.028377 0.7319 0.3945
## sex              1 0.0006 0.000586 0.0151 0.9025
## education        6 0.0783 0.013054 0.3367 0.9159
## stroop.med.diff1 1 0.0300 0.030000 0.7737 0.3814
## Residuals       92 3.5671 0.038772
##
## Response sppb.tot.ch :
##                               Df  Sum Sq Mean Sq F value Pr(>F)
## age                  1   3.167  3.1670  1.4719 0.2282
## sex                  1   0.034  0.0342  0.0159 0.9000
## education           6  15.955  2.6592  1.2359 0.2953
## stroop.med.diff1   1   2.142  2.1423  0.9956 0.3210
## Residuals          92 197.956  2.1517
##
## 1 observation deleted due to missingness

```

R Output for Table 2.5

```

model6<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~
                  age+sex+education+iiv1, data=vit.complete)

summary(model6)

##                               Df Pillai approx F num Df den Df Pr(>F)
## age                  1 0.016831  0.50786      3     89 0.6779
## sex                  1 0.001937  0.05759      3     89 0.9817
## education           6 0.099355  0.51950     18    273 0.9481

```

```

## iiv1      1 0.009363  0.28040      3     89 0.8394

## Residuals 91

summary.aov(model6)

## Response tug.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age        1   2.8   2.843  0.0617 0.8044
## sex        1   5.6   5.615  0.1219 0.7278
## education  6  37.2   6.198  0.1345 0.9915
## iiv1       1   3.5   3.528  0.0766 0.7826
## Residuals  91 4193.0  46.077
## 

## Response gaitspeed.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age        1 0.0246  0.024600  0.6259 0.4309
## sex        1 0.0008  0.000840  0.0214 0.8841
## education  6 0.0779  0.012984  0.3303 0.9194
## iiv1       1 0.0183  0.018262  0.4646 0.4972
## Residuals  91 3.5768  0.039306
## 

## Response sppb.tot.ch :

##           Df Sum Sq Mean Sq F value Pr(>F)
## age        1   2.295  2.29451  1.0493 0.3084
## sex        1   0.004  0.00358  0.0016 0.9678
## education  6  14.634  2.43903  1.1154 0.3597

```

```
## iiv1      1  0.910 0.90991  0.4161 0.5205
## Residuals  91 198.990 2.18670
##
## 2 observations deleted due to missingness
```

Appendix F - R Output for Tables 2.6-2.9

R Output for Table 2.6

```
model1<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~  
                  age+sex+education+digit.diff1, data=vit.complete)  
  
summary(model1)  
  
##  
##          Df    Pillai approx F num Df den Df Pr(>F)  
## age      1 0.020898  0.44822      3     63 0.7194  
## sex      1 0.001058  0.02224      3     63 0.9955  
## education 5 0.118753  0.53581     15    195 0.9182  
## digit.diff1 1 0.014263  0.30385      3     63 0.8225  
## Residuals 65  
  
summary.aov(model1)  
  
## Response tug.ch :  
  
##          Df Sum Sq Mean Sq F value Pr(>F)  
## age      1   0.1   0.130  0.0021 0.9632  
## sex      1   2.0   1.976  0.0326 0.8572  
## education 5  96.7  19.339  0.3193 0.8997  
## digit.diff1 1   4.7   4.663  0.0770 0.7823  
## Residuals 65 3937.4  60.575  
##  
## Response gaitspeed.ch :  
  
##          Df Sum Sq Mean Sq F value Pr(>F)  
## age      1 0.03321 0.033206  0.7799 0.3804
```

```

## sex           1 0.00026 0.000262  0.0062 0.9377
## education     5 0.11273 0.022546  0.5296 0.7531
## digit.diff1   1 0.00812 0.008119  0.1907 0.6638
## Residuals    65 2.76736 0.042575
##
## Response sppb.tot.ch :
##              Df Sum Sq Mean Sq F value Pr(>F)
## age          1  2.549  2.54859  0.9809 0.3257
## sex          1  0.014  0.01378  0.0053 0.9422
## education     5 11.517  2.30344  0.8865 0.4953
## digit.diff1   1  0.668  0.66816  0.2572 0.6138
## Residuals    65 168.887 2.59827

```

R Output for Table 2.7

```

model3<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~age+sex+education+tmt
ba.ratio1, data=vit.complete)

summary(model3)

##              Df Pillai approx F num Df den Df Pr(>F)
## age          1 0.020942  0.44918      3     63 0.71875
## sex          1 0.001064  0.02236      3     63 0.99542
## education     5 0.122305  0.55252     15    195 0.90746
## tmtba.ratio1 1 0.116587  2.77144      3     63 0.04876 *
## Residuals    65
##
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1

```

```
summary.aov(model3)
```

R Output for Table 2.8

```
model5<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~  
                  age+sex+education+stroop.med.diff1, data=vit.complete)  
  
summary(model5)  
  
##  
## Df Pillai approx F num Df den Df Pr(>F)  
## age 1 0.021046 0.45147 3 63 0.7172  
## sex 1 0.001053 0.02214 3 63 0.9955  
## education 5 0.119190 0.53786 15 195 0.9169  
## stroop.med.diff1 1 0.018028 0.38554 3 63 0.7638  
## Residuals 65  
  
summary.aov(model5)  
  
## Response tug.ch :  
##  
## Df Sum Sq Mean Sq F value Pr(>F)  
## age 1 0.1 0.130 0.0022 0.9631  
## sex 1 2.0 1.976 0.0328 0.8568  
## education 5 96.7 19.339 0.3210 0.8986  
## stroop.med.diff1 1 26.4 26.425 0.4387 0.5101  
## Residuals 65 3915.6 60.240
```

```

## Response gaitspeed.ch :

##                               Df  Sum Sq  Mean Sq F value Pr(>F)
## age                      1 0.03321 0.033206  0.7851 0.3789
## sex                      1 0.00026 0.000262  0.0062 0.9375
## education                 5 0.11273 0.022546  0.5331 0.7504
## stroop.med.diff1      1 0.02629 0.026293  0.6217 0.4333
## Residuals                65 2.74919 0.042295

## Response sppb.tot.ch :

##                               Df  Sum Sq  Mean Sq F value Pr(>F)
## age                      1   2.549  2.54859  0.9822 0.3253
## sex                      1   0.014  0.01378  0.0053 0.9421
## education                 5 11.517  2.30344  0.8877 0.4946
## stroop.med.diff1      1   0.890  0.88979  0.3429 0.5602
## Residuals                65 168.666 2.59486

```

R Output for Table 2.9

```

model6<-manova(cbind(tug.ch, gaitspeed.ch, sppb.tot.ch)~
                  age+sex+education+iiv1, data=vit.complete)

summary(model6)

##                               Df Pillai approx F num Df den Df Pr(>F)
## age                      1 0.018838  0.39680       3     62 0.7558
## sex                      1 0.002901  0.06013       3     62 0.9805
## education                 5 0.104098  0.46012      15    192 0.9574

```

```

## iiv1      1 0.003022  0.06264      3     62 0.9793

## Residuals 64

summary.aov(model6)

## Response tug.ch :

##                               Df Sum Sq Mean Sq F value Pr(>F)
## age                  1   9.8   9.765  0.1635 0.6873
## sex                  1   9.0   8.952  0.1499 0.6999
## education           5  46.3   9.257  0.1550 0.9778
## iiv1                 1   6.5   6.496  0.1088 0.7426
## Residuals       64 3821.6  59.712
## 

## Response gaitspeed.ch :

##                               Df Sum Sq Mean Sq F value Pr(>F)
## age                  1 0.02745 0.027453  0.6346 0.4286
## sex                  1 0.00054 0.000536  0.0124 0.9118
## education           5 0.11262 0.022524  0.5206 0.7597
## iiv1                 1 0.00364 0.003638  0.0841 0.7728
## Residuals       64 2.76872 0.043261
## 

## Response sppb.tot.ch :

##                               Df Sum Sq Mean Sq F value Pr(>F)
## age                  1   1.613   1.6129  0.6097 0.4378
## sex                  1   0.002   0.0020  0.0008 0.9782
## education           5 10.052   2.0105  0.7600 0.5820

```

```

## iiv1      1  0.036  0.0362  0.0137 0.9072

## Residuals 64 169.310  2.6455

## 

## 1 observation deleted due to missingness

```

R Output for Table 2.10

```

## Response tug.ch :

##              Df Sum Sq Mean Sq F value Pr(>F)
## age          1   0.1   0.130  0.0022 0.9629
## sex          1   2.0   1.976  0.0332 0.8561
## education    5  96.7  19.339  0.3246 0.8964
## tmtba.ratio1 1  69.5  69.525  1.1670 0.2840
## Residuals    65 3872.5  59.577

```

R Output for Table 2.11

```

## Response sppb.tot.ch :

##              Df Sum Sq Mean Sq F value Pr(>F)
## age          1  2.549  2.5486  0.9966 0.3218
## sex          1  0.014  0.0138  0.0054 0.9417
## education    5 11.517  2.3034  0.9008 0.4861
## tmtba.ratio1 1  3.337  3.3369  1.3049 0.2575
## Residuals    65 166.219  2.5572

```

R Output for Table 2.12

```
## Response gaitspeed.ch :  
  
##           Df  Sum Sq  Mean Sq F value Pr(>F)  
## age          1 0.03321 0.033206  0.8294 0.3658  
## sex          1 0.00026 0.000262  0.0065 0.9358  
## education    5 0.11273 0.022546  0.5632 0.7278  
## tmtba.ratio1  1 0.17316 0.173156  4.3250 0.0415 *  
## Residuals    65 2.60233 0.040036  
## ---  
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
```

Appendix G - Figure G1 SPPB Performance by Timepoint (n=103/120)

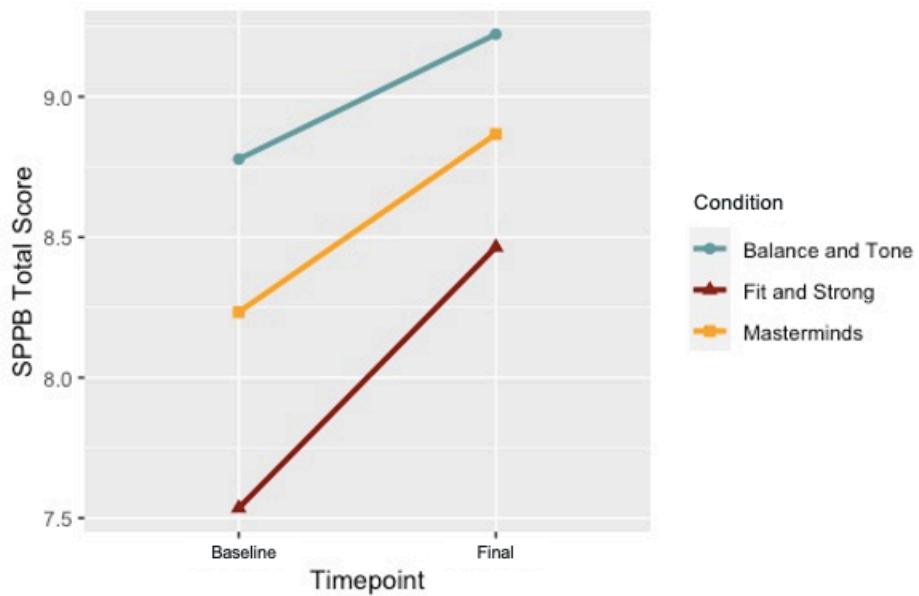


Figure G1. Graph of SPPB Total Score by Timepoint (n=103/120)

Appendix H - Figure H1 TUG Performance by Timepoint (n=103/120)

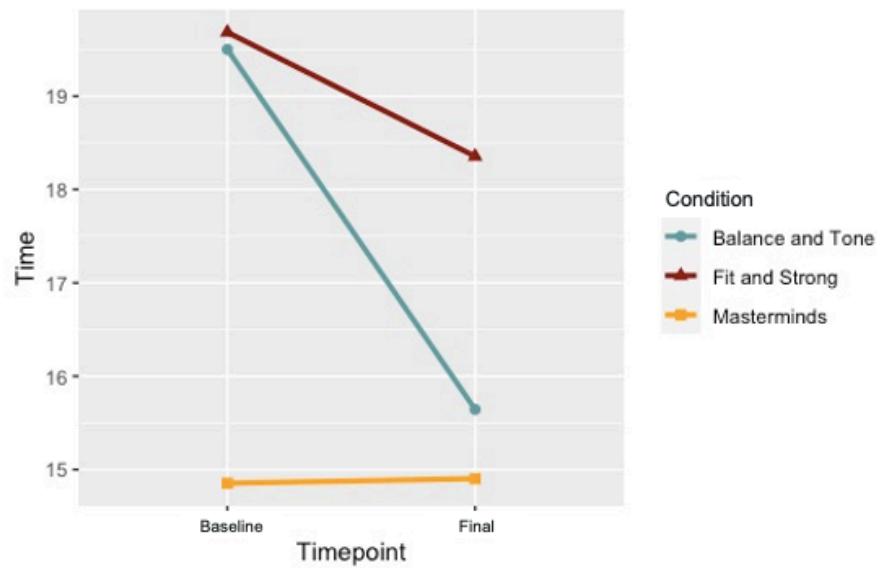


Figure H1. Graph of TUG Time by Timepoint (n=103/120)