Occupational Performance Coaching for stroke survivors (OPC-Stroke): A novel patient-centered intervention to improve participation in personally valued activities

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A thesis submitted to the
Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements
for the Doctorate in Philosophy degree in Rehabilitation Sciences

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Legend

ADL – Activities of daily living

ANOVA – Analysis of Variance

CBT - Cognitive Behavioral Therapy

CDSM - Chronic Disease Self-Management

CI - Confidence Interval

CMOP-E - Canadian Model of Occupational Performance and Engagement

CO-OP – Cognitive Orientation to Occupational Performance

COPM – Canadian Occupational Performance Measure

CPA - Collaborative Performance Analysis

df - degrees of freedom

FIM - Functional Independence Measure

GAS - Goal Attainment Scaling

GSAB-DFI – Goals Systems Assessment Battery – Directive Functions Indicators

HADS – Hospital Anxiety and Depression Scale

IADL - Instrumental activities of daily living

ICF – International Classification of Functioning Disability and Health

MAR – Missing at Random

MCAR – Missing Completely at Random

MI - Motivational Interviewing

MoCA – Montreal Cognitive Assessment

NFT - Neurofunctional treatment

OPC – Occupational Performance Coaching

OPC-Stroke – Occupational Performance Coaching for Stroke Survivors

PEO - Person Environment Occupation

PPA – Personal Projects Analysis

QOL – Quality of life

RA – Research Assistant

RCT – Randomized Controlled Trial

RNLI – Reintegration to Normal Living Index

SCT – Social Cognitive Theory

SF-36 – Medical Outcomes Study 36 Item Short Form Questionnaire

SIS – Stroke Impact Scale

SSM – Self-management program

SS-QOL - Stroke Specific Quality of Life

TBI – Traumatic brain injury

VMCI - Vascular Mild Cognitive Impairment

Abstract

Background: The majority of people living with the effects of stroke experience participation challenges. Occupational Performance Coaching for stroke survivors (OPC-Stroke) is designed to promote engagement in personally identified participation goals and develop the ability to address future participation goals.

Purpose: This thesis explored the potential efficacy of OPC-Stroke, its mechanisms of action, and the feasibility and acceptability of the randomized controlled trial methods to inform the planning of a larger trial.

Methods: A pilot randomized controlled trial with an embedded qualitative component. Twenty-one participants were randomly assigned to receive 10 sessions of OPC-Stroke or usual care. Participation, goal performance and satisfaction, goal self-efficacy, emotional well-being, and cognition were measured at pretest, posttest and six months follow-up. Qualitative interviews were conducted at posttest with individuals who were in the intervention group.

Results: No significant between group differences were noted for any outcomes, although scores for cognition approached significance ($p=0.065$) and also showed a large effect size (partial eta squared $=0.167$). Examination of effect sizes indicated a moderate clinically significant benefit of OPC-Stroke for goal performance and satisfaction scores (partial eta squared = 0.075 and 0.078 respectively). Participation scores improved for both groups but the overall trajectory of participation seemed to be different between groups. Goal self-efficacy remained stable across time and groups, and emotional well-being declined in both groups. Qualitative findings confirmed that all components - emotional support, individualized education and goal-focused problem-solving - made important contributions to promote achievement of

participant-selected participation goals. Recruitment, retention and outcome measure completion rates were satisfactory.

Conclusion: Based on the effect sizes of goal performance and satisfaction, and cognition, a larger trial to examine the efficacy of OPC-Stroke is warranted. Further work to select the most appropriate tools to measure participation and goal self-efficacy is recommended prior to the next trial.

Contexte: À la suite d'un AVC, la majorité des survivants qui vivent avec des séquelles éprouve des défis de participation. Le coaching pour le rendement occupationnel chez les gens qui ont vécu un accident vasculaire cérébral (CPRO-AVC) est un programme qui a été conçu pour promouvoir la participation, soit en encourageant les survivants à fixer et à atteindre des objectifs personnels de participation, et à développer des compétences qui leur serviront à atteindre leurs futurs objectifs de participation.

Objective: Cette thèse doctorale a exploré l'efficacité potentielle du programme CPRO-AVC et ses mécanismes d'action. De plus, la faisabilité et l'acceptabilité de la méthodologie de recherche ont été examinées afin d'informer la planification d'un essai clinique de plus grande envergure.

Méthode: Un essai clinique aléatoire pilote avec une composante qualitative intégrée a été complété. Vingt et un participants ont été répartis en deux groupes de façon aléatoire : le premier groupe a reçu les soins habituels, et le deuxième groupe a participé à 10 sessions du CPRO-AVC. La participation, le rendement et la satisfaction par rapport aux objectifs, l'auto efficacité dans l'atteinte des objectifs, le bien-être émotionnel, et la fonction cognitive, ont été mesurés lors d'un prétest, d'un post-test, et d'un suivi six mois après la dernière session de traitement. De plus, durant le post-test, le groupe d'intervention a participé à des entrevues qualitatives.

Résultats: Aucune différence significative entre les résultats des deux groupes n'a été notée, mais la différence entre les résultats des tests de cognition des deux groupes était presque significative (p=0,065), et la taille de l'effet observée était forte (êta-carré partiel = 0,167). L'examen des tailles d'effet pour les résultats des mesures de rendement et de satisfaction démontre un effet bénéfique clinique modéré pour le groupe ayant participé au CPRO-AVC (êta carré partiel = 0,075 et 0,078 respectivement). Les résultats des mesures de participation étaient meilleurs pour les deux groupes, mais la trajectoire globale de la participation dans le temps semblait différente. L'auto-efficacité dans l'atteinte des objectifs est restée stable dans le temps pour les deux groupes, et le bien-être émotionnel a diminué pour les deux groupes. Les données qualitatives ont confirmé que les composantes du programme, soit le soutien affectif, l'enseignement individualisé, et les techniques de résolution de problèmes axée sur les objectifs, ont contribué de façon importante à la promotion de la réalisation des objectifs de participation personnels des participants. Le recrutement, la rétention des participants, et les taux d'achèvement des mesures étaient satisfaisants.

Conclusion: Les résultats de cette étude, en particulier la taille de l'effet des mesures de rendement, de satisfaction, et de cognition, justifient un essai de plus grande envergure afin d'examiner l'efficacité du CPRO-AVC. Avant d'entreprendre le prochain essai, des études supplémentaires sont recommandées afin de sélectionner des outils de mesure plus appropriés pour la participation et pour l'auto-efficacité.

Acknowledgements

I would like to express appreciation to my Thesis Committee, my research team, research participants and my family and friends for their support with this project.

To my Thesis Supervisor, Dr. Mary Egan, I am somewhat saddened to complete this part of my journey. You have been my mentor and friend for many years. You have inspired me to learn and grow and have always been there when I needed advice, a squirrel or a push to do what I knew I should do but would have preferred not to.

To Dr. Claire Jehanne-Dubouloz, your wisdom, insightfulness and desire for depth of understanding have taught me to seek deeper theoretical understanding in my work.

To Dr. Fiona Graham, it was a pleasure to be able to build on your work. You have provided me with wonderful insights into the use of coaching in occupational therapy and have been critical in increasing my standards for attention to detail in my writing.

To Dr. Sara McEwen, your knowledge and insights into conducting clinical rehabilitation research have been invaluable.

I am honoured to be surrounded by a fantastic team: the stroke rehabilitation clinicians (occupational therapists and physiatrists) at Bruyère Continuing Care, Bruyère Research Institute staff, the research librarian at the University of Ottawa, and the research assistants and occupational therapist Coaches who worked on my project. I thank you for your persistence and commitment. I would also like to thank my research participants who gave their valuable time to take part in my study.

Throughout my program I received support in the form of several scholarships for which I am extremely thankful. I was thrilled and honoured to receive the Vanier Canada Scholarship but also to be supported by scholarships through the University of Ottawa, the Canadian Occupational Therapy Foundation, The Bruyère Research Institute and the Government of Ontario.

My thesis research was funded by the University of Ottawa Brain and Mind Research Institute. I would like to express my sincere gratitude to them for believing in this research project and in me as a researcher.

Last but not least, I would not be where I am today without my family and friends. Thank you for your support, advice, laughter, rides and lots of other stuff. I would particularly like to thank my husband Scott for his incredible support and belief in me.

Chapter 1: Introduction

1.1 Background

Approximately 300,000 Canadians live with the effects of stroke (Heart and Stroke Foundation of Canada, 2013). Following hospital discharge, people who have experienced stroke attempt to return to participation in valued activities but this can be quite challenging. When return to these activities is successful it occurs over several months and involves a process of acknowledging and accepting stroke-related problems, reappraisal of importance, values and meaning, and active decision making (Woodman, Riazi, Pereira, & Jones, 2014). In fact, the majority of people who have experienced stroke, across all disability levels, report problems occupying their time in meaningful ways (Desrosiers et al., 2006; Desrosiers et al., 2008; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002).

Participation is a concept that has been gaining recognition among health providers as a contributor to health and well-being since the introduction of the World Health Organization, International Classification of Functioning, Disability and Health framework (ICF;World Health Organization, 2002). In this framework, body functions and structures, activity and participation interact with and influence each other resulting in outcomes of health and well-being. Body functions refer to the physiological functions of body systems while body structures refer to the anatomical parts of the body and their components. Activity is defined as the execution of a task or action by an individual in a uniform and standard environment such as a rehabilitation unit. Participation is defined as involvement in life situations. The concepts of activity and participation share common domains of: learning and applying knowledge, general tasks and demands, communication, mobility, self-care,

domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life. Thus participation includes involvement in a broad spectrum of life situations. Personal and environmental factors are identified as contextual elements that can interact at any level (World Health Organization, 2002).

While the ICF brought recognition of the value of participation to health, the definition of participation provided by the ICF has been critiqued as lacking in conceptual clarity (Whiteneck & Dijkers, 2009). This is in part due to the fact that activity and participation share the same domains and are therefore not distinct. To provide more conceptual clarity some researchers have classified each domain as either activity or participation. Participation domains are those that clearly involve role performance at the societal level involving interaction with others (Stallinga, Dijkstra, Bos, Heerkens, & Roodbol, 2014; Whiteneck & Dijkers, 2009). This approach to defining participation allows easier operationalization of human actions from each domain; however, it does not allow for consideration of the relevance or meaning of these actions to the individual. The extent to which a particular item within a domain is personally valued may vary from individual to individual (Hemmingsson & Johnsson, 2005).

As well, participation may be considered to include solitary activities that do not involve interaction with others. From the perspective of those living with disability, participation has been be defined as a means and an end to the expression of personal and collective social values (Hammel et al., 2008). Similarly in occupational therapy literature, participation has been considered to be embedded within occupation, thereby incorporating concepts of individual, social and cultural meaning and value (Townsend & Polatajko, 2007). Thus, for this research, the ICF definition of participation is expanded to include involvement in life situations that have personal or societal value.

Despite the recognition of participation as an important outcome of stroke rehabilitation, the tendency is for health providers to continue to view stroke recovery in terms of changes in discreet aspects of disability (e.g., movement, cognition); there is little focus on participation with stroke rehabilitation (Korner-Bitensky, Desrosiers, & Rochette, 2008). People who have experienced stroke define recovery largely in terms of how well they have been able to return to engaging in their valued activities (Hafsteinsdottir & Grypdonck, 1997; Graven, Sansonetti, Moloczij, Cadilhac, & Joubert, 2013), i.e., participation. Many stroke survivors report participation challenges such as difficulty doing housework, leaving the house and pursuing leisure activities (Pound, 1998). Development of complex interventions to address participation has been identified as a priority for stroke rehabilitation and research (Bayley et al., 2007). Complex interventions are characterized by a multi-modal approach, are tailored to the person and involve multiple outcomes and time points (Medical Research Council, 2000).

Malleable factors that impact on participation in valued activities following stroke have been identified. These include self-efficacy (including similar concepts of perceived control, choice, confidence) (Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Asakawa, Usuda, Mizukami, & Imura, 2009; Reed, Wood, Harrison, & Paterson, 2012; Chau, Thompson, Twinn, Chang, & Woo, 2009; Woodman et al., 2014), functional ability (Kubina et al., 2013; Beckley, 2006; Chau et al., 2009; Mayo, Bronstein, Scott, Finch, & Miller, 2014), knowledge or information (Worrall et al., 2011; Hammel, Jones, Gossett, & Morgan, 2006), support (social contact, social resources, being listened to, guidance) (Kubina et al., 2013; Beckley, 2006; De Sepulveda & Chang, 1994; Reed et al., 2012; Mayo et al., 2014), affect (apathy or depression vs. positive affect) (Asakawa et al., 2009; Chau et al., 2009; Mayo, Fellows, Scott, Cameron, & Wood-Dauphinee, 2009; Rochette, Bravo, Desrosiers,

St.Cyr-Tribble, & Bourget, 2007), and having goals (Wood, Connelly, & Maly, 2010; Reed et al., 2012).

Current interventions to enhance participation in valued activities (described in Chapter 2) have been limited and studies of these have had mixed results. A few interventions have been found to be ineffective for enhancing participation (Bastien, Korner-Bitensky, Lalonde, LeBrun, & Matte, 1998; Logan, Gladman, Drummond, & Radford, 2003; Parker et al., 2001) or have been effective for increasing satisfaction but not performance (Egan, Kessler, Laporte, Metcalfe, & Carter, 2007). Others have led to positive changes which have not been maintained several months after treatment (Gilbertson, Langhorne, Walker, Allen, & Murray, 2000), or have not been examined for long-term effectivness (Desrosiers et al., 2007; Lund, Michelet, Sandvik, Wyller, & Sveen, 2012; Nour, Desrosiers, Gauthier, & Carbonneau, 2002). It is possible that success has been limited by lack of consideration of the above malleable factors in planning interventions or because there is not yet an efficient way to provide the kind of long term, individualized support that is required for successful return to valued activities. Effective and efficient interventions must be designed to build competence and provide people who have experienced stroke with the skills and the tools they need to allow them to plan and manage their own return to personally valued activities over the long term. Occupational Performance Coaching (OPC) is a new approach in occupational therapy whereby individuals are guided to solve problems critical to the achievement of self-identified goals related to participation (Graham, Rodger, & Ziviani, 2010) and thereby shows promise as an intervention for people who have experienced stroke.

OPC is a complex intervention that draws on concepts from personal coaching, solution-focused therapy, problem-solving interventions and emotional support. A positive,

strengths-based approach is used to promote patient self-efficacy and self-management (Graham, Rodger, & Ziviani, 2009). This individualized approach provides a time-limited intervention to address current participation goals, while allowing individuals to develop the skills to address future participation goals. OPC has been tested with families of children who face challenges participating in age appropriate activities (Graham et al., 2009; Graham et al., 2010) but has not been tested with adults who have experienced stroke. Following review of the literature, an adaptation of OPC for stroke survivors (OPC-Stroke) was developed that emphasizes individualized education and metacognitive strategies during both goal setting and problem-solving, and broadens how support is considered beyond the family.

1.2 Purpose of Research

The purpose of this research was to explore the efficacy of OPC-Stroke with adults who have experienced stroke and to examine the feasibility and acceptability of the research methods in preparation for a larger randomized controlled trial (RCT). This objective was attained through answering the following questions:

1. Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased participation compared with those receiving standard care?
2. Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased performance and satisfaction with individually identified participation goals, emotional wellbeing, and goal self-efficacy, and demonstrate better cognition compared with those receiving standard care?

3. What is the experience of research participants receiving OPC-Stroke?
4. Which components and processes of OPC-Stroke promote achievement of self-identified participation goals?
5. Are the research procedures feasible to implement and are they acceptable to participants and therefore appropriate for testing OPC-Stroke in a larger trial?

1.3 Relevance of this Research for Rehabilitation

Stroke is a common neurological condition that can affect movement, speech and language, mobility, perception, cognition and affect. Not surprisingly, "inability to occupy one's time in a manner appropriate to one's age, sex and background" (p. 827) is one of the most common difficulties one year after stroke, with 75% of people who have experienced stroke reporting this problem (Harwood, Gompertz, & Ebrahim, 1994). What is surprising, though, is that problems carrying out such activities are not completely predicted by level of impairment. Such problems, referred to by rehabilitation researchers as problems of participation, are common even among people with very mild disability following stroke (Rochette, Desrosiers, Bravo, St.Cyr-Tribble, & Bourget, 2007) and have been related to decreased quality of life and depression post stroke (Alguren, Fridlund, Cieza, Sunnerhagen, & Christensson, 2012; Kwok et al., 2006; Li, Wang, & Lin, 2003; Teoh, Sims, & Milgrom, 2009).

Occupational therapists have the potential to address issues related to participation among individuals post stroke, yet there tends to be minimal time spent attending to participation issues; instead, greater emphasis is placed on basic function and environmental adaptation to enhance safety (Richards et al., 2005; Moulton, 1997; Walker, Drummond,

Gatt, & Sackley, 2000). Efficient and effective interventions to promote participation in valued activities following stroke are needed. The need for research in this area of stroke rehabilitation is gaining recognition as more people are living with the effects of stroke and are struggling with re-engagement in valued activities (Hall et al., 2012). OPC-Stroke provides an innovative, time-limited and potentially cost-effective approach to improving participation in personally valued activities following stroke that this research begins to test. Through provision of emotional support and individualized education (needs specifically identified by people who have experienced stroke), self-efficacy for identified goals is developed through a collaborative goal-focused problem-solving process. In this way OPC-Stroke promotes a sense of control as well as knowledge and skills to take on future participation challenges.

The literature demonstrates an association between restricted participation and depression (D'Alisa, Baudo, Mauro, & Miscio, 2005). This relationship appears to be reciprocal; that is participation in meaningful activities promotes overall well-being and vice versa (Egan, Davis, Dubouloz, Kessler, & Kubina, 2014). In testing OPC-Stroke, the potential to diminish depression through promoting engagement in meaningful activities was explored.

Research has also established a relationship between exercise and improved or maintained cognitive abilities (Quaney et al., 2009; Kluding, Tseng, & Billinger, 2011; Cumming, Tyedin, Churilov, Morris, & Bernhardt, 2012). The stimulation, pleasure and physical activity inherent in being involved in activities that are personally meaningful may have a similar protective effect. This research examined the potential protective effect of participating in valued activities on cognition.

OPC-Stroke has a good fit with occupational therapy values and commitment to client-centered practice. Pentland (2012) highlights that coaching provides occupational therapists with tools to promote client awareness of meanings associated with occupations and to enable choices with regard to participation in valued activities. These types of tools are important for promoting client autonomy.

Patient autonomy, or responsibility for decision making in rehabilitation and involvement of clients in goal setting, is promoted in the literature but is often challenging in practice (Rosewilliam, Roskell, & Pandyan, 2011). This is due to differing views of recovery between clinicians and patients, differences in knowledge and expertise between patients and professionals and patient psychosocial factors (Rosewilliam et al., 2011). Even in occupational therapy, a profession committed to client-centered care, goals are more likely to reflect the expectations and constraints of the healthcare system as opposed to the client's true wishes (Rosewilliam et al., 2011). OPC-Stroke specifically provides a structure and processes for truly client-centered goal setting, along with planning and decision-making to achieve goals, and thereby may begin to address perceived barriers to autonomy and client directed goal setting.

It is also recognized that people who have experienced stroke require assistance and support when coping with and managing transitions in care (Ellis-Hill et al., 2009; Cott, Wiles, & Devitt, 2007). Providing OPC-Stroke immediately following discharge to the community helps ensure clients receive continuing support and contact with a health professional at a time when coping is particularly challenged (Ellis-Hill et al., 2009). Coaching techniques are tailored to meet individual needs and promote participation in valued activities. Being able to return to self-defining roles and valued activities contributes

to a successful transition to living in the community and to overall well-being (Cott et al., 2007; Hafsteinsdottir & Grypdonck, 1997).

As well as examining the potential efficacy of OPC-Stroke, this research was designed to examine and build on the current theoretical understanding of how OPC-Stroke works, and thereby provide greater insights into the structure, process and key ingredients needed to promote participation in valued activities following stroke.

Chapter 2: Literature Review

This chapter presents a review of the relevant literature including the background of OPC, a review of the stroke literature focusing on important characteristics and components of interventions to promote participation in valued activities following stroke, and a description of OPC-Stroke including its theoretical basis and how it is supported by the stroke research literature. To begin, the literature search strategy is presented.

2.1 Literature Search Strategy

A search of the literature up until Oct 31, 2014 was done to identify knowledge related to promoting return to participation following stroke for the purpose of informing the development of OPC for individuals who have experienced stroke. The definition of participation provided by the World Health Organization International Classification of Functioning Disability and Health (ICF; World Health Organization, 2002) was adopted to guide the literature search as it is a widely recognized framework for understanding links between health and well-being and disability. To reflect participation as involvement in life situations, research that captured a broad range of participation domains was sought. Research focusing on domains of mobility, self-care and communication were excluded unless combined with another domain, such as domestic life, as these domains can be considered to be primarily at the level of activity (Whiteneck & Dijkers, 2009; Chang & Coster, 2014). For example exercise interventions were excluded unless a domain such as leisure activities or instrumental activates of daily living were also specifically targeted by the intervention.

Key search terms were identified, with input from a research librarian, to capture the concept of participation broadly or specific domains of participation from the ICF such as leisure or domestic life (instrumental activities of daily living). These are presented in Table 1. Community reintegration was included as a search term as it refers to productive activity, independent living and social activity (Sander, Clark, & Pappadis, 2010), thus reflecting participation. Quality of life (QOL) is a frequent secondary outcome in stroke intervention research that often captures aspects of participation. Therefore QOL was also included as a search term.

Initially key words and databases (see Table 1) were used to identify relevant journal articles. Reference lists of these articles were reviewed to identify other relevant papers. Articles were selected if they included an objective of examining or improving participation as opposed to activity (as delineated above), reported results from qualitative or quantitative research on the experience of the people following a stroke either in hospital or in the community; and included a study population in which at least 50% were people who had experienced stroke.

Table 2.1. Search Strategy

Key words	Data bases
Participation	PsycINFO
Participation in valued activities	CINHAL
Social participation	Medline
Community reintegration	
Leisure participation/Leisure activities	
Instrumental activities of daily living	
Quality of life	
Stroke	
Cerebral vascular accident	

The background of OPC and related literature are presented next, followed by findings from the stroke literature.

2.2 OPC Background

OPC-Stroke is an adaptation of OPC as introduced by Graham and colleagues (2009) who defined OPC as a process whereby clients are guided in solving problems related to achieving self-identified, occupational performance goals. They described OPC as "a specialized form of health coaching that combines coaching processes with occupation-centred reasoning and specialist developmental and disability knowledge" (Graham et al., 2009, p. 5). The therapist, as Coach, utilizes active listening, questioning and reflection to guide clients to discover, implement and evaluate their own solutions within a problem-solving framework. The primary objective of OPC is improvement in participation in valued activities, while the secondary objective is the development of self-efficacy and problem-solving skills to manage future occupational performance challenges (Graham et al., 2009; Graham & Rodger, 2010).

Graham and colleagues situated OPC in an enabling framework, informed by occupation-centred practice, family-centered practice, and the cognate approach of coaching, solution-focused therapy and problem-solving interventions (Graham et al., 2009). They detailed three domains or components of OPC: emotional support, information exchange and a structured problem-solving process.

OPC was tested with parents who were experiencing occupational performance challenges related to their role as parents, or who had occupational performance goals for their children (Graham et al., 2010). Results from three case studies indicated that

participants had positive changes in goal outcome measures. As well, parents reported experiencing new learning, an improved family life and a sense of empowerment at overcoming challenges (Graham et al., 2010). OPC has not yet been tested with other populations.

The theoretical framework and domains of OPC described by Graham and colleagues appear to provide a promising approach to enable people who have experienced stroke to re-engage in their valued activities. The stroke research literature is presented next with attention to the fit between OPC-Stroke and what is known about promoting participation in valued activities.

2.3 Stroke Literature

The stroke literature was examined to identify important issues to be addressed and components of interventions to promote participation in valued activities. The ways in which OPC-Stroke addresses each issue and includes important identified intervention components are presented.

2.3.1 Literature highlighting important issues to be addressed.

As noted in the introduction, the following malleable factors have been identified as impacting on participation in valued activities following stroke: self-efficacy (Kubina et al., 2013; Asakawa et al., 2009; Reed et al., 2012; Chau et al., 2009; Woodman et al., 2014; Barclay-Goddard, Ripat, & Mayo, 2012), functional ability (Kubina et al., 2013; Beckley, 2006; Chau et al., 2009; Mayo et al., 2014; Barclay-Goddard et al., 2012), knowledge or information (Worrall et al., 2011; Hammel et al., 2006), support (Kubina et al., 2013;

Beckley, 2006; De Sepulveda & Chang, 1994; Reed et al., 2012; Mayo et al., 2014; Barclay-Goddard et al., 2012), apathy, depression or positive affect (Asakawa et al., 2009; Chau et al., 2009; Mayo et al., 2009; Rochette et al., 2007; Berges, Seale, & Ostir, 2012), and having goals (Wood et al., 2010; Reed et al., 2012).

Among the studies that identified malleable factors, five are described in more detail below as they present a process of return to participation, a model of participation or a meta-analysis of qualitative research related to return to participation following stroke.

Wood and colleagues (2010) examined the process of community re-integration over the first year post stroke. Qualitative interviews were conducted with 10 participants prior to discharge and then at two weeks, three months, six months and 12 months post stroke. Analysis revealed a process of community reintegration that involved transitioning between a series of goals that included gaining physical function, establishing independence and adjusting expectations to get back to real living. Transitions between goals were marked by some decreased confidence for facing new challenges and engaging in meaningful activity in the community. Appropriate support was noted to help improve confidence (Wood et al., 2010).

As part of longitudinal cohort study, Kubina and colleagues (2013) sought to develop a more in-depth understanding of the process of re-engagement in valued activities. Six people who had experienced stroke and were living in the community were interviewed at six, nine, 12, 18 and 24 months post stroke. A substantive grounded theory of re-engagement in personally valued activities emerged from the data with key concepts of “social connection” (belonging, reciprocity, doing one’s share and support for re-engagement) and “being in charge”. These key concepts led to activity engagement and risk-taking to test abilities, which in turn led to activity adaptation and hope with the outcome of adapted re-

engagement. However, activity challenges perceived as being related to aging led disengagement with valued activities (Kubina et al., 2013).

Barclay-Goddard and colleagues (2012) developed a model of participation post stroke using mixed methods. Using structured equation modeling with data collected from participants at 12 months post stroke, they developed an initial model that was then verified and refined using qualitative photo voice techniques. The resulting model includes three inter-connected latent variables of accomplishment, restricted roles and health efficacy that are impacted by the all-encompassing aspects of physical environment and social support. Accomplishment is related to self-selected activities in the domains of social function, recreational activities, work, driving and usual activities. Restricted roles refer to limitations in role performance related to cognitive, emotional and physical/health problems. Finally, health efficacy relates to perceptions of recovery and health (Barclay-Goddard et al., 2012).

A meta-synthesis of qualitative research was conducted by Reed and colleagues (2012) to identify the key factors that are necessary to account for when planning and developing rehabilitation and community services following stroke based on users' perspectives. The authors identified four key factors that should be considered when planning services to support people who have experienced stroke and assist them to maintain an active and positive presence in their unique social worlds. These are to: 1) identify personally relevant goals with people who have experienced stroke and their carers and promote personal control and independence; 2) provide appropriate levels of support; 3) provide guidance on how to overcome the physical, economic, and psychological barriers; and 4) enhance confidence by supporting positive social interaction (Reed et al., 2012).

A meta-ethnographic review of qualitative research on the experiences of social participation by people following stroke (Woodman et al., 2014) identified five main themes:

1) change and disruption, 2) perceived magnitude of individual barriers, 3) pursuing personal choices, 4) building confidence, and 5) evaluating personal meaning. Among these themes the authors noted that there seemed to be a continuous relationship between activities chosen by people who had experienced stroke, increased awareness of barriers and developing the confidence to overcome these barriers (Woodman et al., 2014).

These studies highlight the importance of support in setting and pursuing personally relevant goals, testing out abilities, building confidence for participation and management of recovery and health**,** and re-engaging in valued activities. OPC-Stroke addresses these needs by providing emotional support and promoting goal self-efficacy as people who have experienced stroke are guided to solve problems related to self-identified participation goals.

In the stroke literature, there appears to be growing interest in interventions to improve participation post stroke either as a primary or secondary outcome. To date, studies of such interventions have had limited or mixed results. These studies are grouped according to common intervention characteristics: a) interventions based on individual goals, b) psychosocial and cognitive behavioral interventions targeting mood or depression, c) interventions for leisure participation or instrumental activities of daily living, and d) community reintegration programs. They are presented below focusing on participation outcome results.

2.3.2 Interventions based on individual goals.

Four studies were identified that used participant identified goals as the focus of the intervention. Gilbertson and colleagues (2000) conducted a RCT with 138 people who had

experienced stroke comparing a six-week domiciliary occupational therapy program with routine service. Domiciliary occupational therapy consisted of approximately 10 visits of 30-45 minutes tailored to address recovery goals identified by the participant such as self-care, domestic or leisure activities. Therapists worked with participants to achieve goals and also linked them with agencies for advice, services and equipment. Participants in the intervention group scored significantly higher on the Nottingham Extended Activities of Daily Living scale post intervention, but these differences were no longer statistically significant at the six-month follow-up (Gilbertson et al., 2000).

The efficacy of Neurofunctional Treatment (NFT) with individualized occupational goal setting was tested in a pilot crossover design RCT with 23 community dwelling people who had been living with stroke for more than two years (Rotenberg-Shpigelman, Erez, Nahaloni, & Maeir, 2012). NFT is a compensatory approach designed for individuals with severe neurological disabilities. It focuses on achievement of individualized occupational goals through establishing a therapeutic alliance or relationship, task analysis, task-specific training and environmental supports and adaptations. Comparison of outcomes between groups following the initial intervention period and prior to crossover revealed a significant difference in Canadian Occupational Performance Measure (COPM) performance and satisfaction scores favoring the intervention group. No significant differences were noted between groups for participation as measured by the Stroke Impact Scale (SIS). Goal Attainment Scaling (GAS) results revealed that 75% of participants achieved at least one goal following the intervention and 26% attained all of their goals (Rotenberg-Shpigelman et al., 2012).

In a pilot RCT, Egan and colleagues (2007) evaluated a community-based occupational therapy intervention targeting participation in valued activities with 16

participants who were six months post discharge from stroke rehabilitation. The intervention included goal setting using the COPM, and collaborative partnership to address goals using approaches such as coaching, education, changes to the physical environment and use of resources. Intervention participants received weekly visits over two to four months whereas the control group received usual care. Outcome scores for the COPM revealed no difference between groups for goal performance but a significant difference favoring the intervention group for satisfaction with performance (Egan et al., 2007).

Cognitive Orientation to Occupational Performance (CO-OP) is a performance-based problem-solving approach that promotes skill acquisition through guided discovery of cognitive strategies to improve performance on selected goals (P& M REF). Participants are taught the global problem-solving strategy of Goal, Plan, Do, Check and are guided to develop plans to achieve self-identified performance goals and to evaluate their progress towards these goals. Participants are guided by the therapist to identify where breakdown in performance occurs and to develop specific strategies to improve performance (McEwen, Polatajko, Huijbregts, & Ryan, 2010; Polatajko & Mandich, 2004).

The CO-OP approach has been tested with participants with acute (Skidmore et al., 2011), sub-acute (McEwen et al., 2014) and chronic stroke (McEwen et al., 2010; Henshaw, Polatajko, McEwen, Ryan, & Baum, 2011; McEwen, Polatajko, Huijbregts, & Ryan, 2009; Polatajko, McEwen, Ryan, & Baum, 2012). Three series of single case experiments were used to explore the use of CO-OP with eight people who were at least six months post stroke. Results indicated that participants made significant performance improvements in self-selected functional goals but overall participation scores on the Stroke Impact Scale were mixed; scores improved for five participants, remained relatively the same for two participants and decreased for one participant (Henshaw et al., 2011; McEwen et al., 2009;

McEwen et al., 2010). Polatajko and colleageus (2012) then conducted a pilot RCT to compare the CO-OP approach to standard occupational therapy with eight community dwelling participants who were at least six months post stroke. Analysis of results indicated improvement in observed and self-rated performance but not in satisfaction. A subsequent exploratory RCT comparing CO-OP with usual occupational therapy was conducted with 26 people who had been referred to outpatient stroke rehabilitation and were less than three months post stroke (McEwen et al., 2014). Posttest and three-month follow-up results showed a medium to large effect of CO-OP for observation of trained and untrained goals using the Performance Quality Rating Scale. At the three-month follow-up, a small effect was noted for self-rated performance and satisfaction of untrained goals using the COPM and a medium effect on the participation domain of the Stroke Impact Scale**,** control over participation factor of the Community Participation Index and on the Self-Efficacy Gauge (McEwen et al., 2014).

CO-OP shares several similarities with OPC-Stroke. These are use of client-selected goals, a global problem-solving strategy, performance analysis and guiding participants to find solutions. However differences exist between the two approaches. OPC-Stroke includes two components not included in the CO-OP approach: emotional support and individualized education. Emotional support (Reed et al., 2012) and having relevant information or knowledge (Hammel et al., 2006; Worrall et al., 2011) have both been identified as important for promoting participation post stroke. CO-OP shows promise as an approach to address performance goals following stroke. The similarities between OPC-Stroke and CO-OP lend support to the design of OPC-Stroke.

In fact, outcomes from all four studies, albeit mixed, highlight the importance of facilitating goal setting and use of a process for problem-solving to promote participation following stroke. Provision of education, support and encouragement to progress towards goals may also be important. OPC-Stroke show promise as it provides all of these components.

The next section examining psychosocial and cognitive behavioral interventions provides more insight into components of interventions that may contribute to improved participation following stroke.

2.3.3 Psychosocial and cognitive behavioral interventions targeting mood or depression.

The following psychosocial or cognitive behavioral intervention studies sought to improve mood or depression but included participation as a secondary outcome.

Lincoln and Flannaghan (2003) conducted a randomized controlled trial of Cognitive Behavioral Therapy (CBT) with 123 stroke patients who were depressed. CBT was tailored to meeting individuals' needs. Techniques used included education, graded task assignment, activity scheduling, and identification and modification of unhelpful thoughts and beliefs. Ten, one-hour sessions of CBT were offered over three months. Outcomes of instrumental activities of daily living, the London Handicap Scale and satisfaction with care were administered at three and six months after recruitment. No significant differences were noted between groups for participation at three or six months (Lincoln & Flannaghan, 2003).

Watkins and colleagues (2011) examined the effect of four sessions of Motivational Interviewing (MI) on mood and activities of daily living (basic and instrumental) three and

12 months post stroke. The MI intervention consisted of patients talking about their adjustment to stroke and current concerns. Patients were then guided to identify personal, goals for recovery that were considered by the therapist to be realistic and perceived barriers to these goals. Patients were enabled to find their own solutions through supporting and reinforcing optimism and self-efficacy. The authors used a RCT design with 195 patients on an inpatient stroke rehabilitation unit to compare MI to usual care. Results indicated that the MI intervention had no effect on instrumental activities of daily living (Watkins et al., 2011).

A brief psychosocial-behavioral intervention with antidepressants was compared to usual care with antidepressant with 101 community dwelling post stroke patients with depression (Mitchell et al., 2009). The psychosocial-behavioral intervention consisted of nine sessions designed to increase the level of pleasant physical and social activity. Problem-solving strategies were taught and solutions to behavioral challenges were individualized. No significant effect of intervention was found for participation as measured using the Stroke Impact Scale immediately post treatment or at 12-month follow-up (Mitchell et al., 2009).

The results of these studies do not support the effectiveness psychosocial or cognitive behavioral approaches alone in addressing participation. This may be due to the lack of a focus on participation goals or actions towards these goals. While OPC-Stroke draws from cognitive behavioral theories in its approach to coaching, it does so in combination with goal-focused problem-solving. This combination may be more effective for improving participation following stroke.

2.3.4 Interventions for leisure participation/instrumental activities of daily living.

In a systematic review, Graven, Brock, Hill, and Joubert (2011) explored the effectiveness of community-based rehabilitation interventions delivered by allied health professionals or nursing staff in reducing depression, facilitating participation and improving health-related quality of life post inpatient stroke rehabilitation. Interventions were grouped into the following categories: 1) exercise programs, 2) gait and balance programs, 3) community interventions to enhance leisure pursuits, 4) care co-ordination, psycho-social and interdisciplinary management, 5) self-management programs, 6) information provision, 7) single discipline community-based rehabilitation, 8) comprehensive rehabilitation, and 9) continence programs. For the outcome of participation, interventions targeting facilitation of participation such as leisure rehabilitation and comprehensive rehabilitation showed limited to moderate effectiveness. This review did not examine key components of these interventions (Graven et al., 2011).

The following studies specifically focused on participation in leisure activities or instrumental activities of daily living. Walker and colleagues (2004) conducted a meta-analysis of RCT's of home-based occupational therapy for stroke patients. Results indicated that home-based occupational therapy is beneficial for instrumental activities of daily living (as measured by the Nottingham Extended Activities of Daily Living Scale) and leisure participation (as measured by the Nottingham Leisure Questionnaire) at end of intervention and at six- and 12-month follow-ups (Walker et al., 2004). Although this meta-analysis indicates positive results for some areas of home-based occupational therapy, components of the interventions are not identified. Other studies help to begin to examine potential important components.

Drummond and Walker (1995) conducted a RCT of leisure rehabilitation post discharge compared to conventional occupational therapy (ADL) group and a control group. The intervention group received 30 minutes of leisure therapy per week for three months. Examination of the therapy received by each group revealed that the ADL group received more mobility training, transfer training, cleaning, dressing, cooking and bathing training and the leisure group received more therapy utilizing sports, creative activities, games, hobbies, gardening, entertainment and shopping. The authors report that little is known about who chose the activities, and that the interventions were not well-defined in advance. Results showed significantly higher leisure scores in the intervention group at three and six months (Drummond & Walker, 1995). In a subsequent multicentre RCT (Logan et al., 2003; Parker et al., 2001) including 309 participants, no significant differences were found for instrumental ADL or leisure between the ADL and leisure groups at six- or 12-month follow-ups (Logan et al., 2003).

Corr, Phillips and Walker (2004) used a randomized cross-over design to evaluate a day service run by non-health or social care professionals for people aged 18-55 years who had had a stroke. The service was provided one day per week for six months and offered a range of activities including creative activities, social outings and some opportunity to learn new skills. Twenty-six participants were recruited to the study. Outcome measures for basic and instrumental ADL, leisure, quality of life, anxiety and depression, occupational performance, roles and self-concept were administered at the time of referral, at six months and at one year. The initial treatment group demonstrated significantly greater improvements in occupational performance and satisfaction with performance from pre to post intervention. The group receiving the intervention following crossover did show a similar improvement. However, this group had a significant increase in number of leisure activities carried out

from pre to post intervention. No significant differences were found between the groups (Corr et al., 2004).

Nour and colleagues (2002) conducted a RCT to examine the effectiveness of a home leisure education program for improving psychological adjustment post discharge from stroke rehabilitation. The leisure education program promoted self-management of leisure activities via 10 sessions where leisure goals were identified and the individual was guided to find solutions to promote autonomous participation. The program included leisure awareness, self-awareness and competency development related to using and integrating resources. A goal of promoting personal empowerment was incorporated in order to optimize leisure experiences. Thirteen stroke survivors were assigned to either the leisure educational group or a placebo "friendly visit" group. Outcome assessments for depression and quality of life were carried out pre and post intervention. However, leisure satisfaction and autonomous practice of leisure were only measured post intervention in the intervention group. While participants were satisfied with their leisure participation post intervention and reported relatively autonomous practice of leisure, due to the lack of measurement in the control group, we cannot attribute this outcome to the intervention (Nour et al., 2002).

In a follow-up study, Desrosiers and colleagues (2007) evaluated the effectiveness of the leisure education program described above, delivered at home once per week for eight to 12 weeks. A RCT design was used. Forty-two participants who were up to five years post stroke and living in community were randomly assigned to the treatment or control group. Results indicated that the treatment group had increased number and duration of active versus passive leisure activity compared to the control group (Desrosiers et al., 2007).

Ryan, Stiell, Gailey and Makinen (2008) evaluated a family centered approach to leisure and community reintegration. The eight week group therapy program for couples

consisted of couple therapy, recreation therapy/leisure education, speech therapy, recreation participation and informal peer contact. Results of this pretest posttest study revealed no change in caregivers' perception of partners' leisure competence, and no change in participants' other leisure outcomes. However participants reported trying new community based leisure and social activities following the program (Ryan et al., 2008).

Bastien, Korner-Bitensky, Lalonde, LeBrun, and Matte (1998) conducted a feasibility study of a group program designed to promote social, leisure and physical activities with 24 community-dwelling individuals post stroke. The program included components aimed at enhancing balance, coordination, flexibility, strength, and activity participation. Outcomes for balance, mobility, strength, community reintegration, and social and leisure activities practiced were collected pre and post intervention and at three-month follow-up. Findings for community reintegration and activities practiced did not change markedly (Bastien et al., 1998).

Specifically addressing community mobility, Logan and colleagues (2004) conducted a RCT to compare provision of leaflets plus a tailored occupational therapy intervention to enhance outdoor mobility with provision of leaflets alone among 168 community dwelling stroke survivors. The occupational therapy intervention consisted of an assessment session to identify barriers to outdoor mobility and negotiate mobility goals, followed by seven intervention sessions over three months at the participant's home to achieve the goals. Intervention sessions included information provision, use of simple aids or adaptations and strategies to overcome fear and apprehension. The intervention group was more likely to get out of the house as often as they wanted and reported more journeys outdoors at four and 10 months. There were no significant differences between groups on scores of IADL or leisure at either time point (Logan et al., 2004).

In summary, the findings of the above studies provide mixed support for participation interventions tested to date. An emphasis on support, individualization of the intervention, and competency development (Desrosiers et al., 2007; Nour et al., 2002; Ryan, et al., 2008) seem to increase potential effectiveness. Simply providing opportunity for social participation did appear to improve participation outcomes. The use of goal identification and problem-solving were not highlighted in these studies although Nour and colleagues (2002) promoted self-management of leisure and guided participants to find solutions to enable leisure participation. OPC-Stroke integrates the components that seem to increase effectiveness in that it provides emotional support and individualized education, and promotes competency development. These are integrated with a goal-focused problem-solving process to achieve participation goals.

Next studies that evaluate community reintegration programs or approaches are presented

2.3.5 Studies evaluating community reintegration programs.

A number of community-based intervention studies have broadly targeted community reintegration. Bhogal, Teasell, Foley, and Speechley (2003) conducted a systematic review focused on highlighting the issues facing stroke survivors and their families upon reintegration into the community. Although only one RCT was identified, associations between social support and improved outcomes were found in multiple non-randomized studies, creating preliminary evidence in support of increasing social support to improve reintegration outcomes. In particular, two cohort studies found that emotional support correlated with better functional outcomes related to activities of daily living (Glass &

Maddox, 1992; Knapp & Hewison, 1998). This review also found that there is strong evidence based on five RCTs that an active educational-counselling approach has a positive impact on family functioning post stroke but no consensus regarding the benefit of leisure therapy (Bhogal et al., 2003).

The following studies were specifically examined for potential components that may be important for facilitating participation.

A community social support intervention was developed and tested using a RCT design by McColl and Friedland (1993). The program was designed to improve social support for stroke survivors with the goal of improved community reintegration. It included instrumental, informational and emotional support provided by an occupational therapist over six to 12 weeks. Outcomes for 48 stroke survivors who took part in the program were compared to 40 stroke survivors who did not. Results indicated no significant benefit of the program for social support or community integration; suggesting that support by itself does not promote participation. However, stroke survivors who were linked to a community group reported significantly more belonging support over time, and those who acquired more instrumental support as a result of the program reported significantly greater quantity and quality of social support. As well, those who strengthened associations with friends throughout the program reported more emotional support (McColl & Friedland, 1993).

Harrington and colleagues (2010) evaluated a community program using a RCT design. The community program was designed specifically for stroke survivors and their families with the goal of improving integration and well-being. The program was an eight week volunteer delivered program of exercise followed by an interactive educational sessions for stroke survivors and their families or carers. These sessions were interspersed with sessions for goal-setting, social activities and unstructured discussions. A directory of

local resources was provided to each participant. Two hundred and forty-three stroke survivors who were at least three months post stroke and felt able to participate in group activities took part in the RCT. Primary outcome measures were the Subjective Index of Physical and Social Outcomes, Frenchay Activities Index, Rivermead Mobility Index, National Health Systems social care and personal costs. There were no significant differences between groups on outcomes related to participation. Although subjective physical integration improved, there was no indication of improvement in overall participation (Harrington et al., 2010).

In a qualitative component of this study 12 stroke survivors were interviewed to examine if and how the program met their needs (Reed, Harrington, Duggan, & Wood, 2010). Three themes emerged from the interviews that reflected what stroke survivors needed to reconstruct their lives. These needs were the need for confidence and a sense of purpose to reconstruct their social self and the need for responsive services (accessible, individualized) and an informal support network (usually family) to provide responsive care, tailored encouragement and support within the context of their lives (Reed et al., 2010).

The Families in Recovery from Stroke Trial (FIRST) (Ertel, Glymour, Glass, & Berkman, 2007; Glass et al., 2004), evaluated a psychosocial intervention for stroke survivors and their families. The intervention consisted of 16 sessions over six months delivered to 241 participants by a mental health worker. The intervention was informed by family systems theory and cognitive behavioral therapy with goals of 1) increasing self-efficacy through stroke education, 2) optimizing social support through social network mobilization, 3) maximizing family system cohesion and stress reduction, and 4) enhancing problem-solving effectiveness through behavioral skills training related to identified goals. No significant differences were found between groups on outcomes including IADL and

social support (Glass et al., 2004). However, subgroup analysis identified a benefit for non-frail intervention participants in the area of IADL (Ertel et al., 2007). Goal achievement was not reported.

Hartman-Maeir and colleagues (2007) examined the functional status (ADL and IADL), leisure activity (Activity Card Sort) and life satisfaction in adults stroke survivors who were taking part in a long-term community rehabilitation program (n=27) compared to a convenience sample of stroke survivors not participating in any ongoing rehabilitation program (n=56). Outcomes were administered at one time point for the control group and pre post intervention for program participants. The objectives of the program were to maintain or improve functional status, provide opportunities to participate in meaningful activities, prevent social isolation and facilitate coping and reduce burden for family caregivers. Group treatments were provided by rehabilitation professionals. The program was designed to meet the long-term needs of severely disabled stroke survivors. Findings revealed that participants in the program were more disabled in basic ADLs than non-participants, yet life satisfaction as a whole and with leisure participation was higher in the participant group. Program participants showed significant improvements in leisure participation following the program (Hartman-Maeir et al., 2007).

Lund and colleagues (2012) compared the effectiveness of a lifestyle course plus a physical activity group to physical activity group only for improving aspects of wellbeing and social participation as captured by the Medical Outcomes Study 36 Item Short Form Questionnaire (SF-36) (n=99). The lifestyle program was an occupation-based, person-centred program that addressed themes relevant to participants through peer-exchange, self-reflection, discussions, lectures and outings. The physical activity program was led by volunteers at a seniors' center. Both programs consisted of 36 sessions offered once per

week. While both groups showed improvements on the SF-36 social functioning, role physical and role emotional scales, there were no significant differences between groups at the nine month follow-up (Lund et al., 2012).

Chronic Disease Self-Management (CDSM) is a community-based intervention that has been evaluated with stroke survivors. CDSM programs promote self-management of chronic illness in the community through increasing disease knowledge; shared goal setting, problem-solving and decision making; promoting healthy lifestyle choices; and management of the impact of illness on daily functioning (Lawn & Schoo, 2010). CDSM and OPC-Stroke have common elements of information exchange, shared decision making and encouraging the individual to take responsibility for actions towards goals.

In a systematic review to examine the evidence base underlying self-management programs specific to stroke survivors (Lennon, McKenna, & Jones, 2013), two studies noted improvements related to participation as measured using the Stroke Specific Quality of Life (SS-QOL) scale. Kendall and colleagues (2007) tested the seven week CDSM program with 100 participants and used outcome measures for SS-QOL (physical, psychological and social outcomes), and self-efficacy (CDSM Self-Efficacy Scale) at three, six, nine and12 months post stroke. Results indicated that self-efficacy did not change over time but was significantly related to the QOL variables. Outcomes between groups were similar at 12 months. However, differences were noted in trajectories; the control group experienced the declines in the QOL variables of family role, and work productivity between three and 12 months while the intervention group scores gradually improved over time (Kendall et al., 2007). Damush and colleagues (2011) compared a 12 week self-management program, consisting of six telephone sessions that targeted self-efficacy, using goal setting and behavioral contracting, to an attention control condition. Sixty-three male participants with

stroke were evaluated for SS-QOL, self-management behavior and depression at baseline, three and six months. Significant between group differences in favor of the intervention were found for SS-QOL Family Role, Social Role and Work scales (Damush et al., 2011).

A study published later by McKenna, Jones, Glenfield, and Lennon (2013) examined the feasibility of the Bridges self-management program (SSM) for people with stroke using a RCT. The Bridges SSM consist of six, one-to–one weekly sessions that promote strategies to enable people to take control of their daily lives by setting small targets, recording their progress and using problem-solving. Self-management strategies are facilitated by a specially designed workbook kept by the participants. Twenty-five people were recruited to the study. Findings on secondary outcomes of functional activity (ADL and IADL) and social participation were mixed post intervention and at follow-up with no significant differences between groups. Overall trends were noted that supported the Bridges SSM program for improved IADL and social integration at the three-month follow-up (McKenna et al., 2013).

The above studies describe a wide variety of approaches to improving participation as a primary or secondary outcome. Findings support inclusion of the following items when planning an intervention to enhance stroke survivors' participation and well-being: participant selected goals or engagement in activities that are personally relevant to the individual (Harrington et al., 2010; McKenna et al., 2013; Damush et al., 2011; Hartman-Maeir et al., 2007), active educational or problem-solving approaches (Bhogal et al., 2003; D'Alisa et al., 2005; Glass et al., 2004; McKenna et al., 2013), the provision of social support (particularly emotional support) (Kendall et al., 2007; Reed et al., 2010; Ertel et al., 2007; Glass et al., 2004; Hartman-Maeir et al., 2007), and self-efficacy or confidence as a contributing factor (Kendall et al., 2007; Reed et al., 2010; McKenna et al., 2013; Damush et al., 2011; Ertel et al., 2007; Glass et al., 2004). OPC-Stroke includes these items through

provision of support integrated into an individualized, goal-based approach for building skills and self-efficacy.

Overall the stroke literature suggests that OPC-Stroke contains important components for promoting participation in valued activities following stroke and therefore shows promise in addressing this. OPC-Stroke is a modification of OPC designed to improve the fit between the theoretical basis and explicit components of OPC and the needs of adults who have experienced stroke. The next section presents OPC-Stroke including theoretical understanding of OPC-Stroke and a detailed description of the OPC-Stroke components and processes.

2.4 Theoretical Understanding of OPC-Stroke

This section presents the theoretical underpinnings of OPC-Stroke followed by discussion of how OPC-Stroke works based on the theories presented.

2.4.1 Overview of the theoretical basis of OPC-Stroke.

OPC as developed by Graham and colleagues (2009) has been adapted for application with adults who have experienced stroke based on the specific needs of this population. As noted in the introduction, OPC involves guiding individuals using a positive, strength-based approach to solve problems related to achievement of self-identified participation goals (Graham et al., 2010). Theoretically, OPC draws from family-centered practice, occupation-centred practice and an enablement framework of disability as well as the cognate approaches of coaching, solution-focussed therapy and problem-solving interventions (Graham et al., 2009). OPC includes three domains of enabling: 1) emotional support, 2)

information exchange and 3) a structured process of problem-solving (Graham & Rodger, 2010).

In OPC-Stroke, minor changes have been made to the organization of the key underlying theories behind OPC to create a better alignment among these theories, the malleable factors impacting participation post stroke and the important components of interventions to promote participation following stroke identified in the stroke literature. The most significant change is the use of models of social support to replace family-centered practice as a key informing approach. This change broadens the way in which social roles, social systems and supports are considered. In practice, this may mean that the therapist includes social roles, supports and cultural expectations beyond those related specifically to the family. Following stroke, various types of support, beyond support provided by the family, have been shown to be important for return to participation (Kubina et al., 2013; Kessler, Dubouloz, Urbanowski, & Egan, 2009). This change is also made because in OPC-Stroke the focus of coaching is on the specific goals and needs of the stroke survivor instead of those of the family (which is a primary concern in OPC) (Graham & Rodger, 2010). However, OPC-Stroke does consider the person's role within the family as well as family customs, values and beliefs. Models of social support are described later in this chapter.

Another adaptation that differentiates OPC-Stroke from OPC relates to where change may occur when striving to achieve goals. While OPC focuses on adapting components of the activity and the environments to enable participation, OPC-Stroke also includes consideration of change within the person i.e. the potential for recovery (Kessler & Graham, 2015).

Theoretically, OPC-Stroke is situated within the International Classification of Disability, Functioning and Health framework (ICF) (World Health Organization, 2002) and

the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007). Within the context of the ICF and the CMOP-E, OPC-Stroke is informed by coaching, metacognitive theory and models of support. The contribution of each of these is discussed below.

2.4.2 International Classification of Disability, Functioning and Health (ICF).

OPC-Stroke is situated within the broad overarching framework of the International Classification of Disability, Functioning and Health (ICF) in which participation is an important contributor to health and well-being (World Health Organization, 2002). The ICF provides a broad holistic view of the person at different levels – body structures and functions, activity performance and participation - and gives consideration to personal and environmental factors that may affect the person at any one of these levels (World Health Organization, 2002). OPC-Stroke draws on this holistic view to promote health and well-being through enabling participation following stroke

However, the ICF framework offers little detail in terms of understanding factors that may promote participation. Therefore, OPC-Stroke draws on other theories and knowledge to understand these interactions. The Canadian Model of Occupational Performance and Engagement (CMOP-E) provides a framework and model to begin to understand these factors.

2.4.3 Canadian Model of Occupational Performance and Engagement (CMOP-E).

Occupational therapy is concerned with enabling clients to participate meaningfully in their occupations and OPC-Stroke is one approach within occupational therapy. The

CMOP-E (Townsend & Polatajko, 2007) defines occupation as "groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of a community (productivity)" (Townsend & Polatajko, 2007, p.17). It is believed that occupation gives meaning to life, is an important determinant of health, well-being and justice, organizes behavior, develops and changes over a lifetime, shapes and is shaped by environments, and has therapeutic potential (Townsend & Polatajko, 2007). Overall, occupations and their patterns express whom we are in the world, develop our self-identity, and determine how we organize our lives, and connect with, adapt to and maintain a sense of control over our environments (Townsend & Polatajko, 2007).

The CMOP-E promotes a broad vision within occupational therapy beyond performance to engagement in occupation. Where occupational performance refers to taking action and carrying out an occupation, occupational engagement more broadly encompasses all that one does to be involved in life or occupy one's time (Townsend & Polatajko, 2007). OPC-Stroke is concerned with participation, which, for the purposes of this research, is considered to encompass the continuum from occupational performance to engagement; the term participation is used interchangeably with participation in valued activities. Participation is the focus of OPC-Stroke because a strict focus on occupational performance would not provide opportunity to address all types of occupational goals that stroke survivors may wish to select.

OPC-Stroke starts with examining participation at the level of the occupation and in doing so considers factors that facilitate or impede participation. The CMOP-E provides a detailed model for examining occupational performance and engagement that considers

different aspects of the person and the environment. This model is comprehensive but potentially complex for a layperson to understand. The person occupation environment (PEO) model (Law et al., 1996) provides a similar yet simplified model of these interactions (see Figure 2.1; Law et al., 1996, p.18) that clients who have experienced stroke could understand without difficulty and potentially use as a framework for problem-solving both within the OPC-Stroke process and later on when facing other participation challenges.

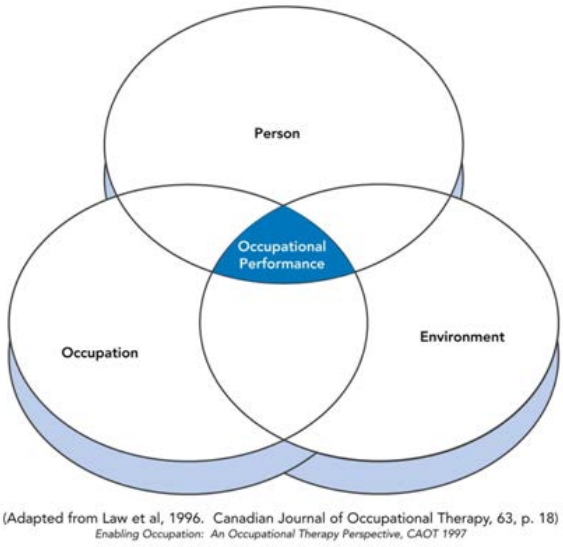

Figure 2.1. The Person Environment Occupation Model. From "The Person-Environment-Occupational Model: A transactive approach to occupational performance," by M. Law, B. Cooper, S. Strong, C. Stewart, P. Rigby and L. Letts, (1996). *Canadian Journal of Occupational Therapy, 63*, 1-15. Copyright 1996 by Canadian Association of Occupational Therapists. Reprinted with Permission.

The process of enabling occupation can draw on a number of skills including adapting, advocating, coaching, collaborating, consulting, coordinating, designing/building, educating, engaging and specializing (Townsend & Polatajko, 2007). OPC-Stroke draws primarily on the skill of coaching but also utilizes collaborating, educating and engaging. Coaching theory is discussed in the next section.

2.4.4 Coaching.

As stated above, coaching is the core enabling skill of OPC-Stroke. This section presents the definition of coaching and the theories that inform coaching, and highlights how these theories inform OPC-Stroke.

Several definitions of coaching can be found in the literature. For example, coaching is defined as "partnering with clients in a thought-provoking and creative process that inspires them to maximize their personal and professional potential" (International Coaching Federation, 2011), and as "a way of effectively empowering people to find their own answers, encouraging and supporting them on the path as they continue to make important choices" (Whitworth, Kimsey-House, Kimsey-House, & Sandahl, 2007, p. xx).

Within occupational therapy, coaching has been defined as:

> "an asset-based appreciative approach highly congruent with enabling lasting occupational change.... The emphasis is to coach people to take responsibility for self-direction in naming priorities and goals, which are most meaningful to them. Coaching involves collaboratively identifying challenges, setting goals and working towards the goals set." (Townsend & Polatajko, 2007, p. 119)

Coaching draws on a variety of theoretical approaches including: humanism, cognitive and behavioral sciences, positive psychology, adult development, and adult learning theory (Ives, 2008). Of these OPC-Stroke draws primarily from humanism, cognitive and behavioral sciences (Social Cognitive Theory, Goal Setting Theory and Solution-Focused Therapy), and adult learning theories. The contributions of these theories to OPC-Stroke are discussed below.

2.4.4.1 Humanism.

The humanistic approach arose as an alternative to behaviorism and psychoanalysis in the 1950s (Ashley, 2010). Humanism encourages a holistic approach to the person based on a collaborative therapeutic relationship where the client is valued and respected. In this approach, the client is viewed as having the knowledge and internal resources to resolve his or her own issues. The client is supported to develop an understanding of his or her thoughts, feelings and behaviors and then to shift back and forth between this subjective focus and action to achieve specific goals (Ashley, 2010).

OPC-Stroke has a strong basis in humanism with its commitment to a client-centered, empowering approach, provision of emotional support, development of the therapeutic relationship, and a focus on development of individual skills and competencies for achievement of personal participation goals. Emotional support, competency development and an approach that empowers stroke survivors to select and assume responsibility for achievement of their personal goals are components for enhancing participation in valued activities identified in the stroke literature section above.

2.4.4.2 Cognitive Behavioral Theories and Approaches.

Cognitive behavioral theories and approaches are combined here due to the prominence of the cognitive behavioral approach in coaching and other areas of psychology. Cognitive behavioral approaches bring a structured process and goal focus to coaching. Three cognitive behavioral theories that specifically inform OPC-Stroke are described below. These are Social Cognitive Theory, Goal Setting Theory and Solution Focused Therapy.

2.4.4.2.1 Social Cognitive Theory.

Social Cognitive Theory (SCT) (Bandura, 1977; Bandura & Cervone, 1983) posits that behavior is influenced by knowledge of performance, self-evaluation of how performance outcomes meet personal standards, and self-efficacy beliefs. Self-efficacy beliefs are the beliefs that a person has that he or she can successfully execute a behavior required to achieve a certain outcome. Self-efficacy is considered to be a major determinant of activity or goal choice, effort expenditure and sustainability of effort under stress (Bandura, 1977). Bandura describes four sources of information that contribute to self-efficacy: performance accomplishment or mastery, vicarious experience (similar others as role models), verbal persuasion and physiological state. These sources of information influence self-efficacy to varying degrees depending on the behavior and situation (Bandura, 1977). Of these sources, OPC-Stroke primarily utilizes performance accomplishment and verbal persuasion.

2.4.4.2.2 Goal setting theory.

Locke and Latham (2002) present a theory of goal setting. According to their theory, goals serve to direct of attention, enhance energy, promote persistence, and promote action. They posit that performance is moderated by goal commitment, feedback and task complexity. Goal commitment is in turn influenced by the importance assigned to goal attainment and self-efficacy for goal attainment. Feedback about goal progress allows a person to adjust his or her efforts and strategies. The amount of effort exerted depends upon one's success in discovering appropriate strategies in light of the complexity of the task.

Performance of complex tasks may be facilitated by use of short-term goals that lead to the longer-term goal (Locke & Latham, 2002).

Goal setting theory supports the focus in OPC-Stroke on a systematic approach to goal achievement. Goal commitment can be enhanced when a person assumes accountability for performance related to that goal. Success in dealing with the complexity and challenge presented by a goal will influence overall efforts and performance (Locke & Latham, 2002). Therefore the design of short-term goals to build on a person's knowledge, skills and resources is an important consideration.

2.4.4.2.3 Solution Focused Therapy.

Solution Focused Therapy is a cognate approach that is based in social constructionism. Social constructionists believe that reality is constructed within each of us based on our culture, perceptions and language (Berg & White, 2010). Solution Focused Therapy assumes that people are healthy, competent and capable of constructing solutions to improve their lives. It focuses on finding solutions for present and future goals as opposed to problems stemming from the past, and draws on a person's strengths and positive experiences to achieve these goals. OPC-Stroke shares the assumptions of Solution Focused Therapy and integrates principles of this approach in facilitating achievement of participation goals.

Overall, cognitive behavioral theories provide OPC-Stroke with an individualized systematic approach that aims to develop the client's self-efficacy and to promote assumption of responsibility for finding solutions and achieving selected goals. Chronic Disease Self-Management is another intervention approach used following stroke that is

based on the cognitive behavioral theories which shows promise for improving health behavior and aspects of participation (Damush et al., 2011; McKenna et al., 2013). As well, goal setting following stroke is considered to be an important part of the rehabilitation process and the literature promotes patient involvement in goal setting (Rosewilliam et al., 2011). Interventions that use goal setting, along with a process to facilitate goal achievement, also show promise for promoting participation in valued activities post stroke (Polatajko et al., 2012; Egan et al., 2007; Gilbertson et al., 2000; McEwen et al., 2014).

2.4.4.3 Adult Learning Theory.

There are a range of adult learning theories that inform the coaching process from the view of adults as goal-focused, self-directed learners, to the view of learning as transformation of meaning perspectives, where individuals change the assumptions used to interpret different aspects of life (Ives, 2008). Griffiths & Campbell (2009) describe learning during the coaching process as being a process of development where clients discover, apply and integrate new knowledge.

The stroke literature that focuses on effective education and provision of information recommends use of methods consistent with adult learning theory. This research indicates that individualization (Maasland, Koudstaal, Habbema, & Dippel, 2007; Wiles, Pain, Buckland, & McLellan, 1998), an action-oriented approach that engages stroke clients and their carers (Forster et al., 2001; Allison, Evans, Kiolbride, & Campbell, 2008), and planned follow-up for clarification and reinforcement (Allison et al., 2008) are important aspects of effective programs for stroke survivors. OPC-Stroke uses an action-oriented approach to facilitate participation. This approach includes promotion of self-direction or responsibility

for actions and choices, building upon knowledge, skills and life experiences, individualizing the approach to promote meaning, and being goal-oriented (Collins, 2004).

In summary, OPC-Stroke draws on and integrates ideas from the above theories, utilized in coaching, to provide an approach to enabling participation that utilizes a strong client-centered, therapeutic relationship, a positive, goal-focused problem-solving approach, and recognizes the knowledge, skills and personal characteristics contributed by the individual. The goal-focused problem-solving approach of OPC-Stroke is further informed by metacognition theory as described next.

2.4.5 Metacognitive theory.

Metacognition refers to cognition about thoughts, knowledge and reflections on actions (Papaleontiou-Louca, 2008). These cognitions includes knowledge people have about the nature of cognitive tasks, potential problem-solving strategies for tasks, and executive skills for monitoring and regulating their cognitive activities (Flavell, 2000). Metacognitive skills or strategies refer to consciously planning, monitoring progress, allocating effort, using specific strategies and regulation of cognition (Papaleontiou-Louca, 2008).

Following stroke, training in metacognitive strategy use has demonstrated effectiveness in improving executive function and behavior (Goal Management Training; Schweizer et al., 2008), memory test performance (Aben et al., 2009); knowledge gained from a stroke information package (Lorenc, Sturmey, & Brittain, 1992); and performance of tasks and activities (Cognitive Orientation to Occupational Performance approach; McEwen et al., 2009; Polatajko et al., 2012; Skidmore et al., 2011; McEwen et al., 2014).

In OPC-Stroke patients are taught metacognitive strategies to improve their performance of higher-level participation goals which are considered within their social context. Thus, OPC-Stroke also draws from models of social support.

2.4.6 Models of social support.

There are two types of models of social support in the literature: direct effect models, and the buffering model of support (Uchino, 2004). Direct effect models consider social support as operating across a wide range of situations and to be beneficial irrespective of the individual's stress level. These models emphasize the benefit to health of being embedded in a social network. In contrast the second type of model, the buffering model of support, posits that social support is beneficial because it alters a person's perception or appraisal of the stressfulness of an event. This process is believed to be most effective when the type of support received matches the challenges posed by the event. For example, emotional and belonging support may be more effective during uncontrollable events (Uchino, 2004) such as stroke. A study by Beckley supports this. Beckley (2006) interviewed 95 stroke survivors 3-6 months post discharge from hospital to examine the interaction between social support and functional limitations on community participation. In this research, social support was defined as "the availability or provision of a relationship, information or assistance that empowers a person to manage their day to day life effectively in the presence or absence of crisis" (Newsham, 1998 as cited in Beckley, 2006, p.129). She found that subjective social support (sense of being listened to) moderated the relationship between reported functional limitations and community participation. The other aspects of social support (quality, quantity and instrumental –physical or financial assistance - social support) did not show an

effect on community participation. Other stroke literature has identified the importance of support for return to participation in valued activities. In particular, the family reaction to stroke and the type of support they are able to provide impacts on the adjustment and functioning of the stroke survivor (Cox, Dooley, Liston, & Miller, 1998; Klinedinst et al., 2009; Nilsson, Axelsson, Gustafson, Lundman, & Norberg, 2001; Pilkington, 1999).

The direct and buffering models may be considered to be complementary. In combination, they offer a way to consider both the structure and process of social support (Uchino, 2004). OPC-Stroke draws on both models by considering social roles and social resources (the nature and type of support available from family and other sources) while providing emotional support.

To summarize the theoretical underpinnings of OPC-Stroke, the ICF provides a broad overarching framework where participation is recognized as a contributor to health, the CMOP-E provides an understanding of participation and the various roles it serves, and coaching and metacognition theory form the key enabling components of OPC-Stroke. The application of the enabling components of OPC-Stroke is further informed by social support models. An understanding of the OPC-Stroke process is presented next.

2.5 OPC-Stroke Structure and Processes

This section presents the processes of OPC-Stroke including a description of the domains of OPC-Stroke, and an understanding of the mechanisms of action of OPC-Stroke based on its theoretical underpinnings. Support from the stroke literature for these domains and assumptions with regards to mechanisms of action are also discussed.

2.5.1 Domains of OPC-Stroke.

The OPC-Stroke Process involves development of a therapeutic coaching relationship that provides the milieu for individualized education, selection of participation goals, and progressing through the problem-solving process. These components are defined as the domains of OPC-Stroke: emotional support, individualized education and a goal-focused problem-solving process (see Table 2.2).

Table 2.2. Domains of Enabling

Emotional Support	Individualized Education	Goal-Focused Problem-Solving
Listen	Health Conditions and Impairments	Set goal
Empathize	Specialized strategies	Explore options
Reframe	Community Resources and Entitlements	Plan action
Guide	Typical development	Carry out plan
Encourage	Teaching and learning strategies	Check performance
		Generalize

From Graham, F. & Rodger, S. Occupational Performance Coaching: Enabling children's and parents' occupational performance. In *Occupation-centred practice with children* (p. 205*)* by S. Rodger (Editor), 2010, Oxford: Wiley-Blackwell. Copyright by John Wiley & Sons Inc. Adapted with permission.

2.5.1.1 Emotional support.

Support following stroke, particularly emotional support, has been identified as essential for facilitating participation (Beckley, 2006; Kessler et al., 2009; Reed et al., 2012). While studies that explore different aspects of adaptation following stroke report the influence of social support on well-being, quality of life (Clarke & Black, 2005; Wyller &

Kirkevold, 1999) and continuity of self (Secrest & Thomas, 1999), specific forms of social support have been particularly associated with enhanced participation in valued activities. These are a) support in the form of being listened to (Beckley, 2006) b) support that provides a sense of shared experience, continuity, being valued, c) support that builds feelings of competence (Kessler et al., 2009), and d) support that allows risk-taking (Kubina et al., 2013). With the exception of promoting a sense of shared experience, OPC-Stroke incorporates these specific forms of social support under the domain of emotional support.

Emotional support is critical for establishing a therapeutic coaching relationship. This relationship provides a "safe" environment of trust, collaboration and mutual respect for sharing information, exploring options and taking the steps necessary to work towards goals (Hubble, Duncan, & Miller, 1999). Emotional support is conveyed to the client through use of active listening, empathizing, reframing, guiding and encouraging (Graham & Rodger, 2010).

Through active listening, information about the client's perceptions regarding goal performance and factors influencing this performance is gathered and an in-depth understanding of the client's beliefs, values, feelings and knowledge is developed. Empathy is used to promote trust, which, in turn, facilitates engagement in the problem-solving process. Reframing, through paraphrasing or offering alternate interpretations of a situation, facilitates the problem-solving process through promoting consideration of alternate approaches or techniques. In the coaching process, direct provision of advice is discouraged. Instead the Coach provides guidance, emphasizing the client's capabilities and encouraging the client to make choices and take action. Encouragement is provided through commenting on progress, complimenting decisions to take action, insights and new learning, and offering hope based on the past experience of the person or similar others (Graham & Rodger, 2010).

In summary, emotional support is essential for establishing the therapeutic coaching relationship and creating a milieu that promotes client readiness to engage in the goal-focused problem-solving process and to actively explore solutions.

2.5.1.2 Individualized education.

Knowledge is an important ingredient in the process of recovery from stroke and return to participation in valued activities. Yet knowledge of the effects of stroke, risk factors, and resources for recovery and return to activities following stroke continues to be identified as an unmet need (Forster et al., 2001). As noted earlier, research to date does indicate that individualization, or tailoring information to address individual needs, is one important aspect of effective education intervention programs (Maasland et al., 2007; Wiles et al., 1998). Other critical factors are inclusion of planned follow-up for clarification and reinforcement (Allison et al., 2008), use of an action-oriented approach that engages stroke clients and their carers (Forster et al., 2001; Allison et al., 2008) and provision of support (Allison et al., 2008; Hare, Rogers, Lester, McManus, & Mant, 2006). OPC-Stroke is designed to encompass all of these crucial elements.

In OPC-Stroke, individualized education occurs through a reciprocal exchange of information between Coach and client that is grounded in adult learning principles (Collins, 2004). The knowledge and skills that the client brings to the situation are recognized and validated as being important for achieving current goals. The Coach highlights the client's existing knowledge, guides the client to seek out new knowledge where gaps exist and, as indicated, shares information that contributes directly to planning and carrying out goal-related actions. The individualized education includes exchange of information related to

health conditions and impairments, specialized strategies, provision of information about community resources and entitlements, typical development related to the person's stage of life, and teaching and learning strategies (Graham & Rodger, 2010) according to the individual needs of the stroke survivor. These are described below.

An exchange of information about specific health conditions and impairments is useful for enabling participation with individuals who have experienced stroke. During this education, the Coach explores the client's knowledge of their health condition and related impairments as they relate to the selected goals. Where a knowledge gap is identified, the Coach can facilitate acquisition of this knowledge through available resources (e.g., brochures, internet) as well as share information. In particular the Coach can assist in interpreting and applying the information to the client's context (Graham & Rodger, 2010). As recovery of stroke-related impairments can continue for several months post stroke, the Coach may explore the client's knowledge related to promoting recovery of impairment as it relates to specific goals. The preferred situation is to enable the client to find and apply the needed information and thereby build skills and competence in this area for the future.

Specialized strategies are specific procedures or techniques that can be used to enable participation in specific situations. Examples of specialized strategies are use of memory aids, adaptive equipment, and one-handed techniques. Specialized strategies may be proposed by the Coach, but may also be presented by the client based on past experience or other resources. The Coach encourages use of strategies based on the client's perceptions regarding how practical, acceptable and effective they may be (Graham & Rodger, 2010).

Exchange of information related to community resources and services that the client may be entitled to receive can contribute to attaining participation goals. Information about community resources and services such as peer group associations, regular and specialized

fitness programs, subsidized recreational or therapy programs or income support programs may contribute to goal achievement. Equally important as knowledge of services and resources that may support goal attainment is the sharing of information related to how to access these services (Graham & Rodger, 2010).

Exchange of information related to typical development or stage of life with related expectations may be important in the process of setting and achieving goals (Graham & Rodger, 2010). For example, motivation or persistence may be influenced by the congruence of goals with underlying beliefs related to a person's stage of life.

Finally, teaching and learning strategies are individualized to suit the individual's strengths, learning styles, life experiences, and cognitive and communicative abilities following stroke. Strategies are explored collaboratively with the client with the goal of promoting mastery and facilitating participation (Bandura, 1977; Collins, 2004; Graham & Rodger, 2010).

In summary, the process of individualized education used in OPC-Stroke both reinforces the person's current knowledge and skills and provides information in a manner that is timely and relevant. The process is interactive and provided in the context of identified goals. The opportunity for clients to demonstrate knowledge, skills and resourcefulness, acquire new knowledge, and to master new techniques, facilitates goal attainment and builds competence in problem-solving (Graham & Rodger, 2010; Locke & Latham, 2002). Information exchange also provides the Coach with important information about client's knowledge, strengths and approaches to learning that will aid in guiding the OPC-Stroke process.

Closely linked with individualized education are metacognitive strategies inherent in the goal-focused problem-solving process; these are described next.

2.5.1.3 Goal-focused problem-solving process.

The use of a process to facilitate goal setting and problem-solving to promote goal achievement are important components of interventions designed to promote participation following stroke (Wood et al., 2010; Brock et al., 2009). Metacognitive strategies for goal setting and problem-solving show promise in facilitating participation (McEwen et al., 2014; Polatajko et al., 2012).

2.5.1.3.1 Facilitated goal setting.

In OPC-Stroke, identification of participation goals is facilitated through use of Personal Projects Analysis (PPA; Little, 1998). Personal projects are activities carried out over time within a particular social context to achieve an end named and given meaning by the doer (Little, 1998). Personal projects are described to participants as "activities and concerns that occupy our life" and "things we think about doing, plan for, carry out, and sometimes, though not always complete". These can include activities that are ongoing (for example, working, favorite pastimes), or single events (for example planning a party or going on vacation), relational concerns (for example, trying to improve a relationship with a family member) or health concerns (for example, attending therapy sessions). In this way, personal projects reflect everyday activities that are individually defined and personally valued. PPA provides an effective and efficient method to prime individuals to identify participation goals of high relevance (Maes & Karoly, 2005). During the process of PPA, participants are facilitated to identify personally valued project and reflect on specific aspects of these activities such as their value, importance, and degree of challenge.

2.5.1.3.2 Problem-solving process.

Once goals have been identified, a structured problem-solving process of 1) set goal, 2) explore options, 3) plan action, 4) check performance, 5) carry out plan, and 6) generalize is presented (Graham & Rodger, 2010). The Coach guides the participant through this process as he or she strives to achieve set goals. During the explore options step of a particular goal, Collaborative Performance Analysis (CPA) is used. In CPA, the client is guided to analyze different aspects that contribute to his or her performance using the Person-Environment-Occupation (PEO) model (Law et al., 1996). The PEO model facilitates the examination of the interaction between the person, the environment (including social support) and the demands of the occupation that promote or inhibit participation. In conjunction with the use of the PEO model, CPA involves the following four steps: 1) identify what currently happens, 2) identify what the client would like to happen, 3) explore barriers and bridges to enabling performance, and 4) identify client needs in planning and taking actions to achieve goals. Throughout these steps the focus is on finding solutions as opposed to focusing on problems (Berg & White, 2010; Graham & Rodger, 2010).

To promote persistence and effort in working towards goals, the Coach guides the client during exploration of options and planning to select action steps that present challenge yet are achievable (Bandura, 1977). This may include consideration of the situation or environment in which the action takes place.

Although the problem-solving process is set out in a linear progression (See Figure 2.2), a step may be revisited at any time.

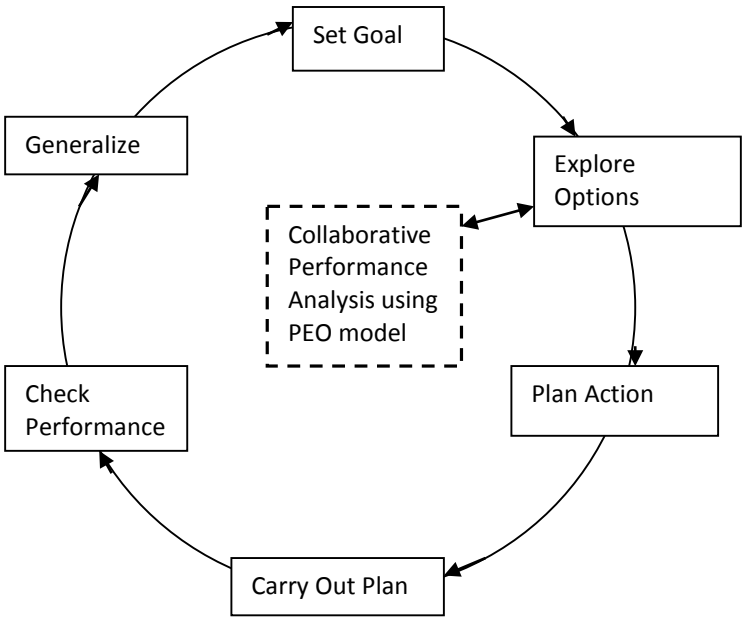

Figure 2.2. OPC-Stroke Structured Problem-Solving Process. “Occupational Performance Coaching for stroke survivors: A pilot randomized controlled trial protocol,” by D. E. Kessler, M. Y. Egan, C. J. Dubouloz, F. P. Graham and S. E. McEwen, 2014, *Canadian Journal of Occupational Therapy, 18.,* p. 282. Copyright by Sage Publications. Reprinted with persmission.

The domains of OPC-Stroke address important needs, facilitators and barriers for enabling participation following stroke. When provided together the provision of emotional support, individualized education and use of goal-focused problem-solving form a comprehensive package that utilizes many of the components identified as important to promoting participation post stroke. The ways in which these domains may interact to facilitate participation are described below.

2.5.2 Mechanisms of action of OPC-Stroke.

The mechanisms of action of OPC-Stroke or how OPC-Stroke works is described in this section. These mechanisms stem from the theoretical basis of OPC-Stroke. The theoretical background to support each component is detailed in Appendix A.

Figure 2.3. How OPC-Stroke Works (versions1) illustrates the hypothesized interaction between the domains of OPC-Stroke (emotional support, individualized education, and goal-focused problem-solving) and goal self-efficacy to promote achievement of participation goals. This interaction is dynamic and evolving as the person goes through the problem-solving process and experiences success in progressing towards his or her participation goal.

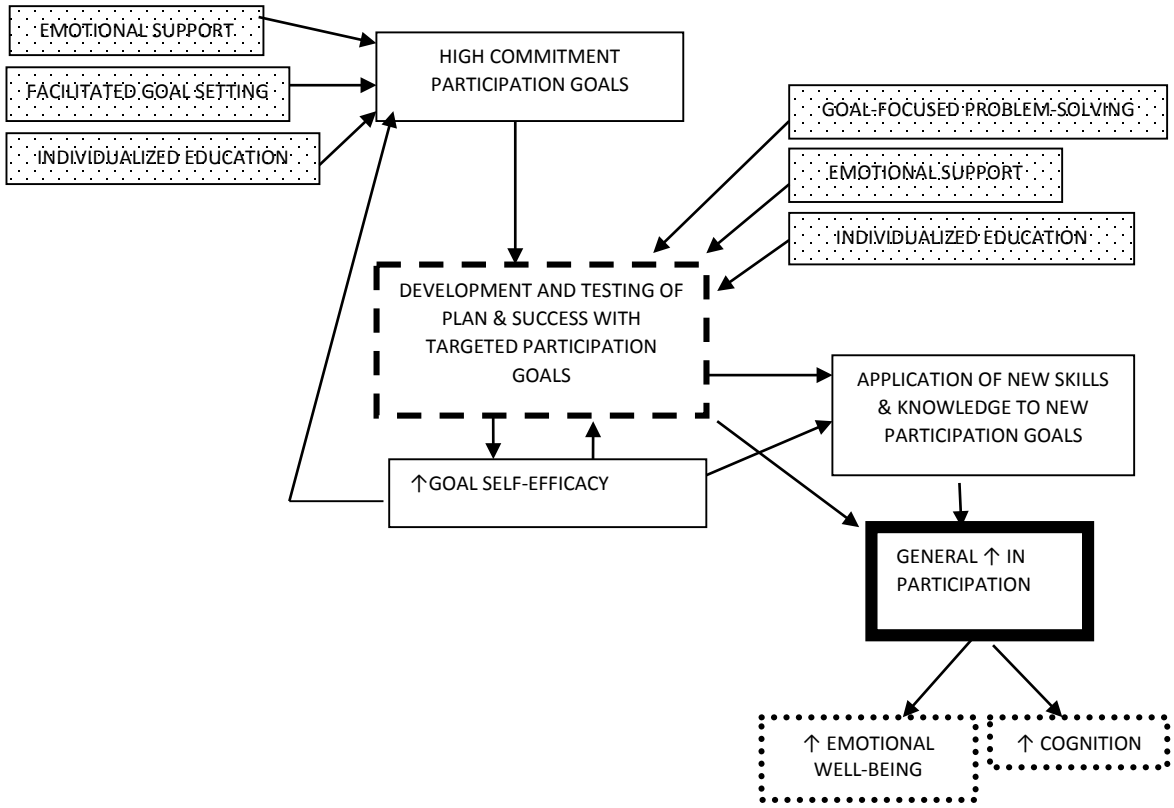

Figure 2.3. How OPC-Stroke Works (version1)

Through provision of emotional support, a therapeutic coaching relationship is established that results in creation of a milieu of trust, respect and collaboration (Hubble et al., 1999). This milieu facilitates information exchange during individualized education; selection of highly valued goals using PPA; readiness to engage in the goal-focused problem solving process and to assume responsibility for actively exploring solutions; and action steps to achieve goals (Graham & Rodger, 2010; Hubble et al., 1999).

Individualized education promotes learning and integration of new knowledge and information (Collins, 2004), which in turn facilitates goal achievement. This new knowledge along with reinforcement of current knowledge and skills and the opportunity to make choices is believed to be a source of self-efficacy following stroke (Kessler et al., 2009; Easton, 1999; Hare et al., 2006) which promotes action or goal pursuit (Kessler et al., 2009; Locke & Latham, 2002). Maintenance of self-efficacy post stroke has also been linked to sustained participation in meaningful occupations (White, MacKenzie, Magin, & Pollack, 2008).

Self-efficacy refers to an individual's beliefs about their capability to utilize strategies and accomplish behaviors that will lead to specific goal achievement. Internal positive feedback gained as a person progresses towards goals builds competence for problem solving and promotes goal self-efficacy (Bandura, 1977).

Achievement of selected participation goals leads to increased participation (that is, engagement in other valued activities) through changes to the person, the demands of the goal or the environment (including social support). In addition, increased goal self-efficacy along with new knowledge and skills promotes pursuit of future participation goals, which further increases participation. Secondary benefits of improved participation in valued

activities may include better emotional well-being (Egan et al., 2014) and improved cognition due to the stimulation offered by this participation.

OPC-Stroke is a new approach to promote participation in valued activities following stroke which addresses many needs highlighted in the stroke literature and encompasses most of the important intervention components identified. An initial pilot of the intervention was carried out with four stroke survivors (Kessler, Ineza, Patel, Phillips, & Dubouloz, 2014). The results and lessons learned from this pilot are presented next.

2.5.3 Results from pilot evaluation of OPC-Stroke.

A pilot of OPC-Stroke with four participants (three men and one woman) was carried out to evaluate the feasibility and acceptability of the intervention and outcome measures (Kessler et al., 2014). The intervention consisted of eight weekly sessions of approximately one hour each. Goals were identified and set on the first visit using Personal Projects Analysis (PPA; Little, 1998) as described earlier. Following the goal setting session, the Coach introduced the Person-Environment-Occupation model as a problem solving tool and the problem solving process was initiated. Subsequent sessions involved continued guidance through the problem solving process.

Two participants completed the coaching sessions while two others withdrew after the first session. While the reasons that these participants withdrew are not known, these participants were noted to have difficulty with the process of goal setting. As well, they did not seem to understand the coaching approach as one of guiding rather than a more directive therapy approach. Additionally, the Coaches (occupational therapy students) may not have possessed the skills necessary to effectively communicate the potential usefulness of the

guiding approach to these participants, who may have expected a more directive approach. These participants also reported having decreased memory and may have had other cognitive deficits which may have affected their expectations and understanding of the intervention (Kessler et al., 2014).

The two participants who completed the intervention achieved, for the most part, the goals that were addressed during the OPC-Stroke. Both showed clinically important improvements in performance and satisfaction in two out of three of their selected goals as measured by the Canadian Occupational Performance Measure (Law, Carswell, McColl, Polatajko, & Pollock, 1998). As well, scores on the Reintegration to Normal Living Index scale (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988) increased for both participants, indicating increased overall participation (Kessler et al., 2014).

The two participants who completed the OPC-Stroke sessions were interviewed to gather their feedback on the intervention. During these interviews participants noted the importance of setting goals and of having regular follow-up for encouragement and monitoring of progress. One participant noted that this follow-up provided motivation, as he felt more accountable for goal progress. This participant would have liked the OPC-Stroke sessions to continue for longer with potentially more time between sessions. Both participants commented that they found it helpful to be able to talk to someone, who was not a friend or family member, about their stroke and their participation goals following stroke. Overall they found OPC-Stroke to be helpful and liked the convenience of the Coach coming to their home for the intervention (Kessler et al., 2014).

Several lessons were learned from this pilot evaluation that informed the pilot RCT described below. First, the coaching process needs to be clearly explained to participants with emphasis on the roles of both the Coach and the participant. As well, efforts to establish

a therapeutic coaching relationship through active listening and empathy are important very early on (Kessler et al., 2014). Simplification of the PPA tool that was used to promote reflection on goals was needed as the meanings of a couple of project characteristic ratings in the PPA were not clear to all participants (Ineza, Patel, & Phillips, 2012).

Although participants were screened to ensure an adequate level of cognition and communication to take part in OPC-Stroke, cognitive impairment among participants may have been present, and making it challenging for them to participate in the intervention. Therefore a cognitive assessment tool was used in the pilot RCT to give insights into the possible impact of cognition on ability to actively engage in OPC-Stroke and on study outcomes.

Finally, for the pilot RCT, the number of coaching sessions was extended from eight to ten and these were delivered over a period of 16 weeks to provide time for participants of differing abilities to achieve goals.

Chapter 3: Methods

As stated in the Introduction, the following research questions were addressed to explore the efficacy of OPC-Stroke with adults who have experienced stroke and to examine the feasibility and acceptability of the research methods in preparation for a larger randomized controlled trial (RCT).

1. Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased participation compared with those receiving standard care?
2. Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased performance and satisfaction with individually identified participation goals, emotional wellbeing, and goal self-efficacy and demonstrate better cognition compared with those receiving standard care?
3. What is the experience of research participants receiving OPC-Stroke?
4. Which components and processes of OPC-Stroke promote achievement of self-identified participation goals?
5. Are the research procedures feasible to implement and are they acceptable to participants and therefore appropriate for testing OPC-Stroke in a larger trial?

3.1 Design

This study used a concurrent mixed method design of a pilot RCT with an embedded qualitative study (Creswell, 2009). To answer questions 1), 2), 4) and 5) a pilot RCT was conducted. The pilot RCT was a single blinded design to test the efficacy of OPC-Stroke**.** RCTs are considered to be the most rigorous type of research design for testing the efficacy

or effectiveness of an intervention in a single study (Torgerson & Torgerson, 2008; Higgins & Green, 2011). A pilot RCT may be undertaken to provide preliminary evidence of the efficacy of the intervention and test out the feasibility of conducting a full scale RCT (Torgerson & Torgerson, 2008). This testing of the overall design and implementation of a study can be a useful step in the process of planning for a larger study (Arnold et al., 2009; Feeley et al., 2009).

To explore the experience of participants who received OPC-Stroke, and examine the components and processes of OPC-Stroke that seem to contribute to goal achievement (questions 3 and 4), a qualitative approach was used. Inclusion of such a process evaluation is considered to be highly valuable during the development and evaluation of complex interventions (Medical Research Council, 2008). Combining quantitative and qualitative methods promotes increased insight into and a deeper understanding of the key ingredients and potential effectiveness of the intervention (Creswell, 2009).

3.2 Study Population

Stroke survivors being discharged home from the acute stroke unit at The Ottawa Hospital, the Bruyère Continuing Care in-patient stroke rehabilitation unit or the Bruyère Continuing Care outpatient stroke service were recruited to the study between March 2012 and May 2014. Services offered by hospital programs are time-limited and are structured to address specific short-term goals such as basic activities of daily living, upper extremity function and very limited participation goals. Since return to participation in valued activities tends to occur over a longer time period (Davis, Egan, Dubouloz, Kubina, & Kessler, 2013)

stroke survivors discharged from all of these settings were expected to have unmet participation goals. The target sample size was 24 participants.

Although this was a pilot evaluation, a group size of 11 participants **was estimated to** provide a power of 80% with an α of .05 to detect as statistically significant 12 point difference on the primary outcome measure, the RNLI (scale range 11-110 points), given a standard deviation of 10. A 12 point difference on the RNLI is half the difference we observed on uncontrolled testing (Kessler et al., 2014). As noted previously, the aim was to recruit 24 participants, 12 per group. To decrease the likelihood of attrition, the control group was offered the OPC-Stroke following completion of the study as an incentive to remain in the study.

Based on data available from the two hospital sites, it was anticipated that four participants could be recruited into the study per month. At Bruyère Continuing Care, 247 patients were admitted onto the stroke rehabilitation service in 2011-12. From all rehab services, 61.6% of patients were discharged to home. In other words, approximately 12-13 people were discharged home per month. Of these, three to six were referred to outpatient occupational therapy leaving six to ten people/month who could be eligible for the study from this site pending meeting of other inclusion and exclusion criteria.

The specific number of admissions and discharges to home was not available for the Ottawa Hospital. However, within the Champlain region, 581 patients were admitted with stroke in 2010-11 to a regional stroke center, of which the Ottawa Hospital is one. As well within the Champlain region approximately 53% of patients were discharged home with or without support (Hall et al., 2012). Based on these numbers, a conservative estimate is that

150 patients are discharged home following stroke from the Ottawa Hospital per year (approximately 12 per month).

Therefore, assuming 18 eligible participants per month, with 25% agreeing to participate (four per month), in planning the study, a year was determined to be conservative estimate of time needed for recruitment.

Participants were included in the study if they met the following criteria:

1) first hospitalization with a diagnosis of stroke as previous experience of adjustment to stroke may influence outcomes,

2) discharged from acute care hospital or inpatient rehabilitation to a non-institutionalized setting,

3) FIM™ scores at rehabilitation discharge of at least three for expression, comprehension, memory and problem-solving to ensure potential participants' ability to participate in coaching process and

4) lived within the City of Ottawa.

Participants were excluded from the study if they:

1) were currently receiving hospital-based occupational therapy services, due to potential overlap of client goals.

2) had other degenerative neurological diagnoses, such as Parkinson's, Multiple Sclerosis, or

3) had a current major depressive or psychotic disorder.

Inclusion and exclusion criteria were selected to promote feasibility of the study and to assist with controlling for potential confounders. The above diagnoses were exclusion criteria as these diagnoses could impact on the research outcomes.

Participants were recruited at the time of discharge from hospital or outpatient stroke occupational therapy, or during an outpatient stroke clinic follow-up visit. The occupational therapists or physicians at the hospitals screened potential participants and referred potentially interested patients to the Research Assistant who sought informed consent.

3.3 Randomization

Following consent to participate in the research study and completion of the initial outcome measures, participants were allocated to the treatment (OPC-Stroke plus usual care) or control (usual care) group using block randomization (block size of four) stratified by source of recruitment i.e. post inpatient hospital stay or post outpatient rehabilitation services. The randomization sequence was computer generated by the statistician on contract with the Bruyère Research Institute and then concealed prior to allocation using opaque sealed and numbered envelopes. The envelopes were kept by research staff not associated with the study who opened the envelopes and revealed the allocation to the primary investigator and occupational therapist providing the intervention following completion of the initial outcome measures.

Initially the plan was to recruit only following discharge from inpatient rehabilitation or acute care and to stratify based on gender. However, following changes to the stroke rehabilitation service resulting in a reduction in inpatient stroke rehabilitation beds and an increase in outpatient services, including outpatient occupational therapy, the decision was made to recruit participants following outpatient occupational therapy. Due to the small sample size it was not feasible to stratify by both gender and recruitment source and ensure equal group sizes. At the time it was felt that controlling for source of recruitment (post

inpatient vs post outpatient) through stratification was more important than stratifying for gender. New blocks were developed by recruitment source (in-patient versus out-patient). However, no further patients were recruited directly post inpatient care after this time due to a lack of eligible participants.

After several more participants had been recruited and randomized, it was discovered that the staff member assigning participants was continuing to stratify by gender as well as recruitment source. At this point, group sizes were relatively balanced. Given that the primary investigator could predict the allocation for both blocks that had been started, a new block was started to maintain concealment and avoid selection bias.

3.4 OPC-Stroke Intervention

The design of the OPC-Stroke intervention to be tested was based on the theoretical understanding of OPC-Stroke, relevant stroke literature as presented above, preliminary testing and consultation with stroke service providers and managers who provided input into the timing, content, process and feasibility of implementation. Generally, the stroke service providers and managers viewed the intervention favourably as an approach that fit with their values and perceived needs of stroke survivors. Intervention manuals are recommended to promote consistency of application of interventions (Blanche, I, Fogelberg, Diaz, Carlson, & Clark, 2011). A manual for OPC-Stroke was developed that included the structure of the intervention as described below. A general outline for each session (Appendix B) was also included in the manual.

3.4.1 OPC-Stroke intervention structure.

The OPC-Stroke intervention consisted of 10 face to face visits with an occupational therapist trained in OPC-Stroke over a 16 week period. Visits lasted approximately one hour. The 16 week period was designed to allow for disruptions in scheduling related to medical appointments, vacation or other factors, and to allow time for participants to follow-up on action steps between sessions.

Since one of the secondary outcomes was change in performance and satisfaction with individually-identified participation goals, all participants received the first visit to set goals prior to randomization. During this visit the Coach used Personal Project Analysis (Little, 1998) combined with the Canadian Occupational Performance Measure (COPM; Law et al., 1998) to facilitate discussion of and reflection on current participation in valued activities or projects. Three personal projects were identified by each participant as intervention goals, and later OPC-Stroke sessions were focused on these projects. Finally, during this first session participants scored their current performance and satisfaction in these projects using the COPM; as well, goal self-efficacy for each goal was rated using the Goals Systems Assessment Battery-Directive Functions Indicators (GSAB-DFI; Karoly & Ruehlman, 1995).

Intervention participants proceeded directly to receive the OPC-Stroke intervention. As noted in the introduction, OPC-Stroke is a process of goal-focused problem solving and collaborative performance analysis examining the interaction between the person, the environment and the task demands of the project or goal. Throughout the process, the Coach provided emotional support and promoted exchange of information. During the final intervention visit, goal progress and the problem solving process was reviewed.

3.4.2 Treatment fidelity.

To promote treatment fidelity, structured training was provided to the Coaches and a process was implemented to monitor the intervention and ensure it was delivered as planned (Bellg et al., 2004). Intervention participants received the OPC-Stroke intervention from one of two Coaches. Both Coaches were female occupational therapists with seven to 17 years of experience, including work with people who had experienced stroke. Training for the therapists included readings and instruction from the primary investigator on coaching theory, principles, and techniques, as well as specific review of the OPC-Stroke intervention manual. To ensure adherence to coaching principles and the components and processes of OPC-Stroke, the primary investigator listened to recordings of the initial sessions delivered by the therapists and provided feedback. The primary investigator reviewed audiotaped sessions until she determined that the therapists were able to deliver the intervention as planned. Ongoing feedback was provided, as needed, following planned fidelity checks (as described in section 3.7.4) or as requested by the therapist.

3.5 Control Group

The purpose of the control group in this study was to enhance internal validity including controlling for change that may have occurred due to the passage of time (Freedland, Mohr, Davidson, & Schwartz, 2011; Torgerson & Torgerson, 2008). This is particularly relevant following stroke as the course of natural recovery and adjustment may lead to changes in participation. A usual care option for the control group was selected. Usual care may consist of limited outpatient therapy (excluding occupational therapy) or personal support services for activities of daily living. Ideally, the randomization process

would control for differences in services received between groups. Information on services received was gathered from both groups to allow for analysis of equivalency.

The choice of a usual care control group is considered to be appropriate for early stages of testing where the goal is to determine preliminary efficacy. Establishing that a therapy is efficacious is an important first step before determining if it is more effective than other therapies (Freedland et al., 2011).

3.6 Data Collection

3.6.1 Quantitative data.

At baseline, the Research Assistant (RA1) obtained consent and completed the following pretest outcome measures: Reintegration to Normal Living Index (RNLI), Hospital Anxiety and Depression Scale (HADS), and Montreal Cognitive Assessment (MoCA).

As well, as noted previously, at baseline the Coach administered the COPM and the Goals Systems Assessment Battery-Directive Function Indicators (GSAB-DFI) to participants in both groups as the COPM is an integral part of the goal setting process used in the OPC-Stroke process and the GSAB-DFI is scored for each goal identified. The goal setting process is an important time to provide emotional support and begin to build rapport supportive of the problem solving process. The COPM and GSAB-DFI were administered to participants in both groups by the Coach (instead of the Research Assistant) to allow for rapport building with the intervention group, promote consistency of application, and maintain masking of the Research Assistant.

Following intervention or 14 weeks following enrolment into the study (T2) and at six months follow-up (T3), to minimize bias RA1 completed all post evaluations: RNLI, HADS, COPM, GSAB-DFI and MoCA (See Figure 3.1).

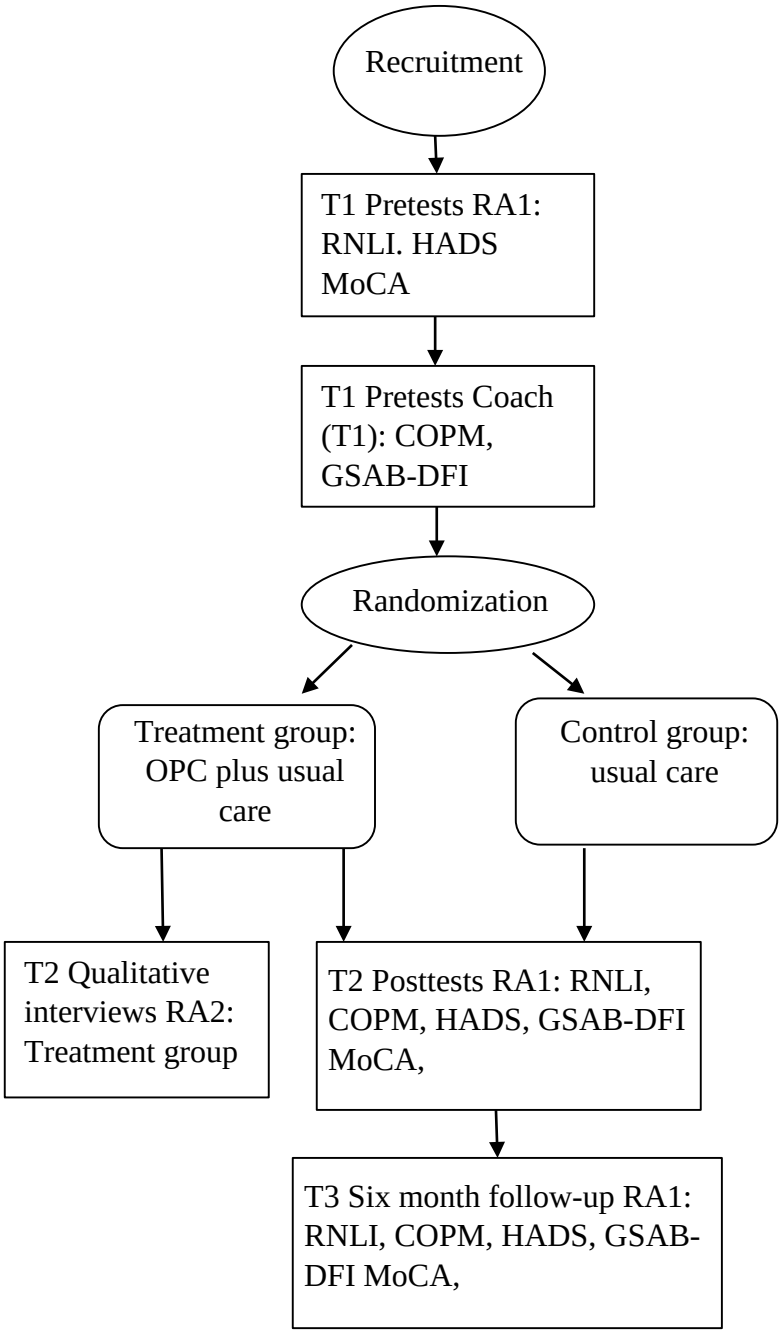

Figure 3.1. Data Collection

The primary outcome measure was overall participation measured using the RNLI. Secondary outcome measures for performance of and satisfaction with personally valued activity goals (COPM), emotional well-being (HADS), goal self-efficacy (GSAB-DFI), and cognition (MoCA) were also gathered at all three time points (pretest, post intervention and six month follow-up).

The Reintegration to Normal Living Index (RNLI; Appendix C; Wood-Dauphinee et al., 1988) was used to measure overall participation. The RNLI is an 11-item scale with proven reliability and validity. Internal consistency was found to be excellent when the RNLI was tested with patients, significant others and health professionals (Cronbach's alpha = .90-.95; Wood-Dauphinee et al., 1988) and with community-dwelling people between the ages of 18 and 80 years (including stroke survivors) who had mobility limitations and had been discharged from rehabilitation for at least one year (Cronbach's alpha = 0.91) (Stark, Edwards, Hollingsworth, & Gray, 2005). Test retest reliability was established among community-dwelling persons aged 75 and older with r=0.83 (Steiner et al., 1996). A strong correlation was found between the Participation Survey/Mobility and the RNLI (canonical correlation =0.71, $p < .001$) among people with mobility limitations due to a diagnosis of spinal cord injury, multiple sclerosis, cerebral palsy, stroke or post poliomyelitis (Gray, Hollingsworth, Stark, & Morgan, 2006). The RNLI has also been found to be sensitive to change (Wood-Dauphinee et al., 1988).

The RNLI includes questions regarding daily functioning items i.e. mobility in the home, mobility in the community, taking trips, self-care, work activities which include volunteering, housework and studying, recreational activities, social activities, and family role; and perception of self items (i.e., comfort with others, comfort with self, ability to deal with life events). All questions are worded to take into consideration the satisfactoriness of

the present situation to the individual. A 10-point Likert scale was used in lieu of the original visual analogue scale, as this was found to be more appropriate post stroke (Price, Curless, & Rodgers, 2012).

The Canadian Occupational Performance Measure (COPM; Law et al., 1998) is a reliable, valid and responsive tool (Carswell et al., 2004) for measuring performance and satisfaction with personally identified participation goals. Cup, op Reimer, Thijssen, and van Kuyk-Minis (2003) examined the reliability and validity of the COPM with 26 stroke patients. They found that the test retest reliability was good for both performance (Spearman's rho = 0.89) and satisfaction (Spearman's rho = 0.88). Discriminant validity was demonstrated by a low correlation between the COPM and five standardized function measures (Cup et al., 2003). Concurrent validity testing may be problematic as the COPM measures performance and satisfaction on a small number of individualized activity goals, rather than more generically defined activities. However, McColl (2000) argued for the concurrent validity of the COPM by identifying fair to good correlation with three tests that have theoretically related constructs: satisfaction with performance (Satisfaction and Performance Scaled Questionnaire, .394, $p<.05$), reintegration to normal living (RNLI, .375, $p<.01$) and life satisfaction (Life Satisfaction Scale, .463, $p<.01$) when tested with 61 community dwelling individuals with various disabilities.

On the COPM, participants are asked to identify goals in self-care, productivity or leisure activities, and then rate their performance and satisfaction with current status on a scale of 1-10, where 10 indicates optimal performance or satisfaction. Numbers are summed and divided by the number of goals. This tool has been widely used as an outcome measure in stroke rehabilitation research (Cup et al., 2003; Jansa, Sicherl, Angleitner, & Law, 2004; Jenkinson, Ownsworth, & Shum, 2007).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure emotional well-being. The HADS is a brief psychometrically sound measure for depression and anxiety. Internal consistency has been tested with participants with a diagnosis of stoke and found to be adequate to excellent (Cronbach's alpha = 0.76-0.89 (Aben, Verhey, Lousberg, Lodder, & Honig, 2002; Johnston, Pollard, & Hennessey, 2000). Bjelland and colleagues (2002) conducted a review to examine the concurrent validity of the HADs. Adequate to excellent validity was found between the HADS and the Beck Depression Inventory, the Clinical Anxiety Scale, Spielberger's State-Trait Anxiety Inventory, the Symptom Checklist 90 Scale, the Montgomery Asberg Depression Rating Scale and the Hamilton Anxiety Rating Scale (r= 0.34 - 0.83). The HADS has been reported to be sensitive to change when used with people with a variety of chronic conditions (Herrmann, 1997). The HADS consists of 14 items that reflect the client's mood in the past week.

The Goals Systems Assessment Battery - Directive Function Indicators (GSAB-DFI; Karoly & Ruehlman, 1995) was used to measure goal-self-efficacy. The Goals System Assessment Battery is based on the Multiple Function Model of behavior and personality (Ford, 1987). It consists of four subscales – Directive Function, Regulatory Function, Control Function and Arousal Function indicators. The Directive Function Indicators subscale provides a valid and reliable measure of goal value and self-efficacy (Karoly & Ruehlman, 1995). Confirmatory factor analysis using goal ratings from 291 undergraduate students supported the structure of the GSAB with four questionnaires with subscales. Test-retest reliability was examined with a group of 99 undergraduate students and found to be .75 for goal value ($p<.001$) and .83 for goal self-efficacy ($p<.001$; Karoly & Ruehlman, 1995). The goal value and self-efficacy subscales have been found to correlate with the positive

health habits items of the Multi-Dimensional Health Profile - Health Functioning Index with coefficients of .32 and .26 ($p<.001$) respectively (Karoly & Ruehlman, 1995).

Although not previously used with stroke survivors, GSAB-DFI items have been used to examine goal attainment and the relationship between goal self-efficacy and health-related quality of life following myocardial infarct (Boersma, Maes, Joekes, & Dusseldorp, 2006).

Each goal is rated on four questions related to goal value (e.g., “This goal is worthwhile”) and four questions related to self-efficacy (e.g., “I possess the necessary skills to attain this goal”) for that specific goal. Each of the goals identified using the COPM was rated individually using this measure.

The GSAB-DFI measure was not available in French and therefore was translated using a process adapted from the guidelines of Beaton, Bombardier, Guillemin and Ferraz (2000) for cross-cultural adaptation of self-report measures. The GSAB-DFI was translated into French by a translator with knowledge of the concepts. The measure was then translated back into English and the French version revised as needed. The French version (Appendix D) was then reviewed by four older adults (two male healthy adults and two stroke survivors; one male and one female) whose first language was French. These individuals judged that the translated items were clear and were not ambiguous.

The Montreal Cognitive Assessment (MoCA; Appendix E; Nasreddine et al., 2005) is a quick screening tool designed to detect mild cognitive impairment that has been tested with people who have experienced stroke (Toglia, Fitzgerald, O'Dell, Mastrogiovanni, & Lin, 2011; Cumming, Bernhardt, & Linden, 2011). Nasreddine et al. (2005) examined the internal consistency, test retest reliability and validity of the MoCA. They reported excellent internal consistency (alpha = 0.83), excellent test-retest reliability

(r = 0.92) and a strong correlation between the MoCA and the Mini Mental Status Exam (r=0.87). The MoCA includes assessment of a broad range of cognitive skills including attention and concentration, executive functions, memory, language, visuo-constructional skills, conceptual thinking, calculations, and orientation.

In addition to the above scales, descriptive data including date of stroke, type and location of stroke, stroke severity as indicated by the discharge Functional Independence Measure (FIM)^{TM} score (Keith, Granger, Hamilton, & Sherwin, 1987), age, gender, living situation, services received post discharge and co-morbidities were collected.

To examine feasibility and acceptability of the research procedures, recruitment and drop-out rates, and data missing from outcome measures were tracked. As well, the Research Assistant was asked to guess group assignment following the final evaluation to evaluate maintenance of blinding.

3.6.2 Qualitative data.

For the qualitative component of the study, semi structured interviews (Appendix F) were conducted with the intervention group at T2 in order to gain insight into the participants' experiences of OPC-Stroke, the "active ingredients" of the intervention, and the participants' expressed met and unmet needs as a result of the intervention**.** A second Research Assistant (RA2) completed the interviews with the intervention group post intervention (T2; See Figure 4) to maintain masking of RA1 at the six month follow-up**.** Interviews were digitally audio recorded and transcribed verbatim for analysis.

3.6.3 Treatment fidelity.

The Coach kept notes and digitally audio recorded each session in order to document the process, frequency, duration and content of the coaching intervention. The above data were used to examine for the treatment fidelity of the OPC-Stroke intervention.

3.7 Analysis

3.7.1 Quantitative data analysis.

The data were checked for missing values and verified for accuracy. Descriptive data were used to describe the sample groups and to examine for potential differences between groups at admission into the study.

To answer the first question, that following receipt of OPC-Stroke the participants in the intervention group would have increased participation compared to the control group, RNLI scores over the three time points were compared using repeated measures analysis of variance (ANOVA; Park, Cho, & Ki, 2009).

To answer the second question, that participants in the intervention group would show improved performance and satisfaction with identified goals, emotional well-being, goal self-efficacy, mobility and cognition compared to the control group, COPM, HADS, GSAB-DFI, and MoCA scores over the three time points were compared using repeated measures ANOVA.

The assumptions for repeated measures ANOVA were addressed as follows. Repeated measures ANOVA requires interval or ratio variables. Although strictly speaking the RNLI, COPM, HADS, MoCA and GSAB-DFI scales are ordinal in nature, current practice in the social sciences is to treat these types of scales that have multiple items as

interval data for analysis with inferential statistics. The amount of error in this approach has been found to be minimal compared to the advantage gained by being able to use more powerful and easy to interpret statistical techniques (Bryman & Cramer, 2011; Armstrong, 1981). Normality was evaluated through visual inspection of Q-Q plots and sphericity was tested during analysis using Mauchly's Test of Sphericity. Where the condition for sphericity was not met, adjustments were made to correct for inflation of type I error using the Greenhouse-Geisser method.

For each outcome, mean scores and mean change scores with 95% confidence intervals across the three evaluation time points were calculated to assist with understanding findings from the repeated measures ANOVAs and to identify potential trends.

Given the small sample size of this study, it was not possible to impute missing outcome scores resulting from loss to follow-up without adding bias. Therefore, a compete case analysis approach was used. This approach is appropriate when data are deemed to be missing completely at random (Wood, White, & Thompson, 2004).

For missed individual items on outcome measures, the missing scores were imputed by taking an average of scored items in the complete measure at that time point or the relevant scale of the measure (Bryman & Cramer, 2011). For example, to impute a missing self-efficacy item on the GSAB-DFI an average of scored self-efficacy items was used. The software SSPS (SPSS Statistics, 2014) was used to conduct the analysis**.**

The feasibility and acceptability of the research design (Objective 5) was determined based on examination of recruitment rates, drop-out rates, consistency of completion and performance of the outcome measures and evaluation of the maintenance of blinding.

3.7.2 Qualitative data analysis.

Qualitative content analysis (Hsieh & Shannon, 2005) was used to answer the third question, what is the experience of research participants receiving OPC-Stroke, and to begin to answer the fourth question, which components and processes of OPC-Stroke promote achievement of self-identified participation goals.

A conventional approach to content analysis was used to explore the experience of research participants as this approach is appropriate when the purpose is to describe a phenomenon. In conventional content analysis, key thoughts or concepts are allowed to emerge from the data and are labeled as codes. These codes are then sorted into broad categories based on relationships and linkages between the codes (Hsieh & Shannon, 2005).

In contrast, directed content analysis was used for the fourth question. This approach is appropriate for validating or extending a theoretical framework. In this case, directed content analysis was used to examine the proposed theoretical framework of OPC-Stroke. In directed content analysis the content of text is interpreted through a systematic, deductive process of coding and identifying themes or patterns in order to examine credibility of a theoretical framework and inform its development (Hsieh & Shannon, 2005).

This analytic process begins with development of a coding structure based on the theoretical framework. In this case, components and processes from the theoretical understanding of OPC-Stroke were used to define codes and relationships between codes (Figure 3). Operational definitions of codes were developed and reviewed by an auditor familiar with the research but not involved in the qualitative analysis (Hsieh & Shannon, 2005). This coding structure (Appendix G) was used to increase the accuracy of the predetermined codes and consistency of coding (Potter & Levine-Donnerstein, 1999). Data that could not be coded within the initial coding structure were identified and analyzed to

determine if they represented a new code or a subcategory of an existing code (Hsieh & Shannon, 2005). Emerging codes that captured the experience of OPC-Stroke were also identified and grouped into categories and dimensions of categories.

All interviews were transcribed and transcriptions were checked for accuracy. Analysis began with coding after all interviews were completed. The first three interviews were coded separately by two coders. Formative checks for consistency of coding (Potter & Levine-Donnerstein, 1999) were conducted following each of these interviews. These checks involved discussion of any discrepancies between coders and revision of the coding structure, as needed, to increase clarity of codes. As well emerging codes related to the experience of OPC-Stroke were reviewed. Memos of discussions, decisions and changes made were kept throughout coding to provide an audit trail (Hsieh & Shannon, 2005). Following coding of all interviews, the coders met to examine consistency of coding for the final interviews and to discuss emerging categories and dimensions of categories. Final categories, sub-categories and dimensions were determined through an iterative process of review and discussion between the author and the member of the team involved in establishing the initial theoretical framework. The software Atlas.ti 7.5.2 (Scientific Software Development GmbH., 2014) was used to facilitate coding.

During the analysis of the interviews, findings emerged that sparked a desire for a deeper understanding of the specific participants' experiences and the OPC-Stroke process for these participants. When this occurred, relevant taped intervention sessions were reviewed to get a sense of the tone of the conversation and sequence of events during individual sessions and as the intervention progressed. This need for a deeper understanding was not anticipated when planning the data analysis. Therefore, this approach to exploring these situations deeper was determined post hoc.

Categories and dimensions are presented in Chapter 4 with quotes (Hsieh & Shannon, 2005) selected to offer support for or against the theoretical framework of OPC-Stroke.

3.7.2.1 Rigor.

Bias is recognized as being inherent in directed content analysis as the data are approached using a predetermined theoretical framework. However measures can be taken to promote validity of the coding structure and consistency of coding and thereby diminish some sources of bias (Hsieh & Shannon, 2005). Three processes were used to promote scientific rigor during the qualitative analysis (Potter & Levine-Donnerstein, 1999).

First, to promote validity, a coding structure was established that was closely tied to the underlying theoretical framework (Potter & Levine-Donnerstein, 1999). To ensure the coding structure was representative of the theoretical framework of OPC-Stroke, the coding structure was reviewed by an auditor who was familiar with the theoretical framework of OPC-Stroke. The auditor ensured that the coding structure was clear and that the operational definitions were theoretically based. Data not fitting into this coding structure were assigned new codes.

Second, to promote consistency of coding, two coders were used for the analysis of all interviews and formative checks were conducted following coding of the first three interviews and at the completion of the seventh interview (Potter & Levine-Donnerstein, 1999). During the formative checks, consistency of coding between the two coders was examined and the coding structure was revised as needed based on consensus between the coders. It was planned that if the coders could not reach consensus, the auditor would be consulted to resolve the discrepancy. However, this step was not required as the coders were able to reach consensus.

Finally, an audit trail of decisions made during the formative checks was kept using memos. An audit trail describes the thinking and action used in analysis. This allows others to understand and follow the logic of how knowledge was developed (DePoy & Gitlin, 1998).

3.7.3 Integration of quantitative and qualitative data.

Qualitative methods were embedded within this research design to provide a more in-depth evaluation of the process and outcomes of OPC-Stroke (Creswell, 2009). To further address the fourth objective, qualitative and quantitative data were integrated using a matrix display for analysis (Bazeley, 2009). Using the theoretical understanding of how OPC-Stroke works, qualitative and quantitative findings were aligned to indicate support or lack of support for this understanding. Table 3 provides a matrix for the analysis.

Table 3.1. Matrix for Integrated Analysis

Components of theoretical understanding	Qualitative findings	Quantitative findings
• E.g. Therapeutic relationship established through provision of emotional support		

The integration of qualitative and quantitative data provided greater insight into the efficacy of OPC-Stroke and understanding of the OPC-Stroke process.

3.7.4 Treatment fidelity.

Digital audio recordings of coaching sessions were used to monitor treatment fidelity. Five sessions for the first five participants were selected for monitoring. For the remaining

participants receiving OPC-Stroke, three sessions were chosen randomly for monitoring (e.g. sessions 2, 5 and 7). RA2 and the primary investigator reviewed the recordings of these sessions and scored them using a treatment fidelity checklist (Appendix H). This checklist was developed based on the OPC-Stroke manual and was geared towards assuring that the intervention followed the essential aspects of OPC-Stroke i.e., emotional support, information exchange and goal-focussed problem solving. Cut off scores for reaching fidelity were established a priori based on the minimal acceptable score for each item that was expected to be addressed at each session. Cut-off scores varied between sessions because not all activities were expected to be present at each session. For example, session one was focused on goal setting. During this session the problem solving process was not yet expected to be initiated, so this activity was not included in the cut-off score for this session. Treatment fidelity was considered present when both raters rated the session at or above the minimal cut-off score.

3.8 Ethical Considerations

Ethics approval for this research was obtained from the Bruyère Continuing Care, the Ottawa Health Science Network and the University of Ottawa Research Ethics Boards (See Appendix I).

There were two main ethical considerations specific to this research. These were the potential risks to participants associated with involvement in OPC-Stroke and the issue of not offering a potentially beneficial intervention to the control group.

While no serious risks related to participation in this project were anticipated, there was risk of a participant experiencing emotional distress or anxiety related to the

intervention. If this were to occur, the Coach, an experienced occupational therapist trained in OPC-Stroke, had the knowledge and skills to decrease distress or involve others, such as a family member, with the permission of the participant.

Another potential risk was the risk of injury associated with goal pursuit where very challenging goals were selected in the context of specific impairments. While participants were not discouraged from setting challenging goals, they were guided during the problem solving process to select steps or sub-goals that were deemed by the Coach to be safe and achievable during the timeframe of the intervention. This sub-goal selection promoted the experience of success while providing opportunity to test abilities.

To address the issue of not offering a potentially beneficial intervention to the control group, the intervention was offered to the control group at the end of the study.

Chapter 4: Findings

4.1 Quantitative Results

This section presents the quantitative findings in response to the research questions 1) Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased participation compared with those receiving standard care? 2) Do people who have experienced stroke receiving OPC-Stroke following discharge to the community report increased performance and satisfaction with individually identified participation goals, emotional wellbeing, and goal self-efficacy, and demonstrate better cognition compared with those receiving standard care? and 5) Are the research procedures feasible to implement and are they acceptable to participants and therefore appropriate for testing OPC-Stroke in a larger trial? Data related to participant recruitment and characteristics are presented first followed by findings from data analysis to address the above questions.

4.1.1 Participants.

Clinicians reported assessing 32 people as eligible for the study. The CONSORT diagram (Moher et al., 2010) depicts the flow of these people through the study (see Figure 4.1).

When approached for consent to participate, one person described herself as being too busy and not having the energy to take part in a study and therefore declined participation. Five people did not provide reasons for declining to participate. Four people declined to participate or withdrew at the goal setting session as they were unable to identify participation goals that they had not yet achieved. These people described themselves as

having fully recovered from their strokes. Two of these participants were recruited through the outpatient clinic. The two others were recruited following acute hospital discharge. One additional person could not be contacted by the research team.

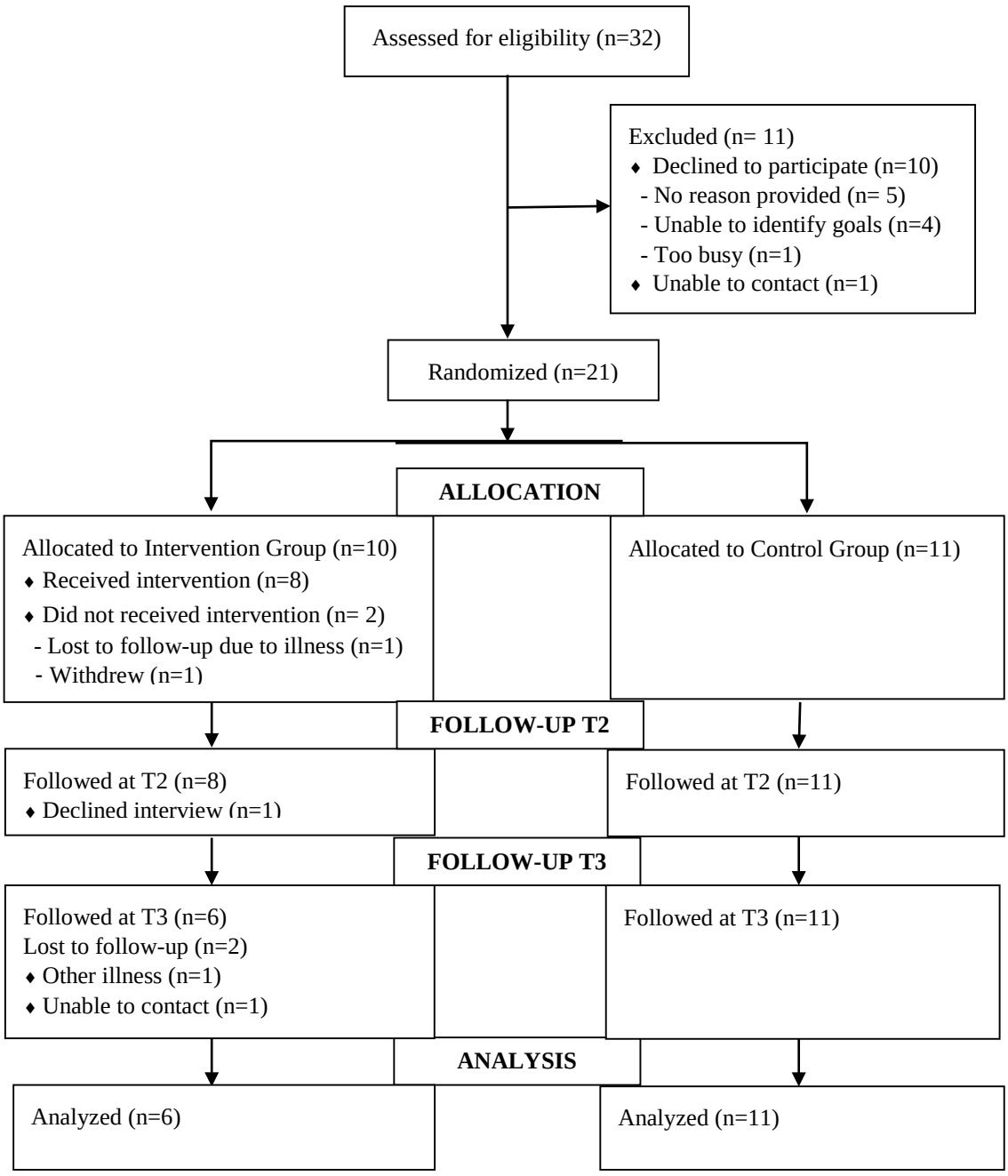

Figure 4.1. CONSORT Flow Sheet Diagram

The remaining 21 (66%) people agreed to participate and were randomized. Ten participants were allocated to receive OPC-Stroke and 11 were allocated to the control group. All participants in the control group were followed at T2 and T3. However, in the intervention group, only eight participants were followed at T2 and six at T3. One participant withdrew following four intervention sessions, stating that the intervention was not what she had expected. She agreed that data collected to date could be used in analysis but did not want to take part in further evaluations. One participant was lost to follow-up after two sessions due to exacerbation of other illnesses. One participant could not be contacted at T3 and one declined T3 evaluation as he was undergoing treatment for another unrelated illness.

Outcome measure scores for participants who were lost to follow-up were determined to be missing completely at random (MCAR); that is, the reason for missing data was judged as not being related to the outcome of interest. For the participant who withdrew from the study, the data were determined to be potentially missing at random (MAR) as the reason for missing data may be explained by observed data (Wood et al., 2004). In this case, the participant's HADS score at T1 was relatively high indicating high anxiety, which may have contributed to her withdrawal from the study. However data was only collected at one time point for this participant. For the above scenarios of missing data, complete case analysis is considered to be acceptable (Wood et al., 2004).

Table 4.1 provides summary scores for participants' demographics by group. No significant between group differences were noted at baseline for demographic variables or outcome variables. While not statistically significant, the weeks post stroke were longer and more variable in the control group compared to the intervention group. On average, all participants were at least six months post stroke. As well, the intervention group scored higher on the HADS at baseline indicating poorer overall emotional well-being. This

difference is not likely to be clinically significant as the control group average score was just below the mild impairment range (score of 8-10) and the intervention group average score was in the mild range.

Table 4.1. Participants' Demographics at Baseline

Variable	Control Group $\bar{x}$ (SD) (n)	Intervention Group $\bar{x}$ (SD) (n)	p value
Age	64.9 (16.3) (11)	71.0 (13.2) (10)	.361
Discharge FIM	109.1 (7.1) (8)	105.6 (13.2) (8)	.522
Weeks post stroke	60.6 (87.6) (11)	29.2 (18.2) (10)	.271
Number of comorbidities	4.1 (1.6) (11)	4.1 (2.3) (10)	.992
RNLI	79.1 (17.6) (11)	80.0 (25.9) (10)	.925
COPM-P	5.0 (2.3) (11)	4.1 (1.9) (10)	.356
COPM-S	4.1 (2.3) (11)	3.3 (2.1) (10)	.389
HADS	7.4 (3.1) (11)	10.1 (6.5) (10)	.226
GSAB-DFI	25.0 (4.2) (11)	23.8 (2.7) (10)	.468
MoCA	25.7 (2.6) (11)	26.0 (2.6) (10)	.814
	n (%) (n=11)	n (%) (n=10)	Fisher's exact
Male	6 (55)	5 (50)	.670
Side of stroke:			-
Left	4 (36)	2 (20)	
Right	5 (46)	7 (70)	
Bilateral	2 (18)	1(10)	
Stroke type:			.476
clot	9 (82)	10 (100)	
hemorrhage	2 (18)	0 (0)	
Living situation:			1.000
Alone	4 (36)	4 (44)	
Spouse/Family	7 (64)	6 (60)	
Support:			
Personal	3 (28)	3 (30)	1.000
Therapy	7 (64)	5 (50)	.670
Other	9 (82)	7 (70)	.635
Occupational status:			-
Working full-time	1 (9)	1(10)	
Retired post stroke	2 (18)	1 (10)	
Retired prestroke	4 (37)	8 (80)	
Long-term disability	2 (18)	0 (0)	
Sick leave	2 (18)	0 (0)	
Language			1.000
English	10 (91)	9 (90)	
French	1 (1)	1 (10)	

FIM™= Functional Independence Measure, RNLI = Reintegration to Normal Living Index, COPM-P = Canadian Occupational Performance Measure performance rating, COPM-S = Canadian Occupational Performance Measure satisfaction rating, HADS = Hospital Anxiety and Depression Scale, GSAB-DFI = Goals Systems Assessment Battery-Directive Functions Indicators, MoCA = Montreal Cognitive Assessment

4.1.2 Outcome analysis.

Repeated measures ANOVAs were carried out to examine whether participants who received OPC-Stroke had increased participation (RNLI), goals performance and satisfaction (COPM), emotional well-being (HADS), goal self-efficacy (GASB-DFI) and cognition (MoCA) compared with those receiving standard care.

All outcomes were approximately normally distributed. Repeated measures ANOVA is robust in that the assumption of normality can be a violated a little and still provide valid results (Norman, 2010). The assumption for sphericity was met in all outcomes except the RNLI and HADS. Therefore the Greenhouse Geisser adjustment was used for RNLI and HADS outcomes in the repeated measures ANOVA (Keselman, 1998).

4.1.2..1 Participation.

While it was hoped that this pilot study would be powered to detect a statistically significant difference in RNLI scores and thereby provide more definitive findings to guide future studies, there was insufficient power ($1-\beta < .80$) to detect a between group difference at $\alpha = .05$. Therefore effect sizes were also examined to inform the clinical significance of differences between intervention and control groups. Partial eta squared of 0.01 is considered be a small effect, while 0.06 is considered to be medium and 0.14 to be a large effect (Lakens, 2013; Norman & Streiner, 2008). Table 4.2 reports the results of the repeated measures ANOVA for the RNLI. The effect size for the RNLI suggests a medium to large time by group effect.

Table 4.2. RNLI Repeated Measures ANOVA Results

	Correction for sphericity	df	F	p value	Partial Eta Squared	Observed Power
Time	Greenhouse-Geisser	1.446	1.566	.231	.095	.258
Time*group	Greenhouse-Geisser	1.446	1.680	.212	.101	.274

RNLI = Reintegration to Normal Living Index, df = degrees of freedom

On examining mean changes in RNLI over time (See Table 4.3), it was noted that both groups tended to improve over time but the overall trajectory of participation seemed to be different between the groups. The mean scores for the control group indicate a gradual improvement over time while the mean scores for the intervention group showed a high RNLI score at T1 with a drop in score at T2, and a return to slightly above baseline at T3.

Table 4.3. Mean RNLI Scores and Change in Scores over Time

Group	RNLI T1 $\bar{x}$ (95% CI)	RNLI T2 $\bar{x}$ (95% CI)	RNLI T3 $\bar{x}$ (95% CI)	RNLI change T1-T2 $\bar{x}$ (95% CI)	RNLI change T2-T3 $\bar{x}$ (95% CI)	RNLI change T1-T3 $\bar{x}$ (95% CI)
Control (n=11)	79.0 (67.3, 90.9)	86.7 (74.3, 99.1)	88.7 (80.7, 96.6)	7.6 (-8.2, 23.6)	1.9 (-6.9, 10.7)	9.5 (-1.3, 20.4)
Intervention (n=6)	92.0 (74.9, 109.1)	84.7 (62.9, 106.5)	95.2 (80.2, 110.2)	-7.3 (-19.7, 5.1)	10.5 (-2.2, 23.2)	3.2 (-5.8, 12.2)

RNLI = Reintegration to Normal Living Index, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

4.1.2.2 Secondary Outcomes.

Results for the repeated measure ANOVA for the secondary outcomes are reported in Table 4.4. These results are described for each outcome below.

Table 4.4. Secondary Outcomes Repeated Measures ANOVA Results

	Correction for sphericity	df	F	p value	Partial Eta Squared	Observed Power
COPM Performance						
time	Not required	2	10.537	<.001	.413	.981
time*Group	Not required	2	1.219	.310	.075	.245
COPM Satisfaction						
time	Not required	2	15.734	<.001	.512	.999
time*Group	Not required	2	1.268	.296	.078	.254
HADS						
time	Greenhouse-Geisser	1.353	2.553	.117	.145	.378
time*Group	Greenhouse-Geisser	1.353	.067	.868	.004	.058
GSAB-DFI						
time	Not required	2	.317	.731	.021	.096
time*Group	Not required	2	.115	.819	.008	.066
MoCA						
time	Not required	2	2.914	.070	.163	.526
time*Group	Not required	2	3.005	.065	.167	.540

COPM = Canadian Occupational Performance Measure, df = degrees of freedom, HADS = Hospital Anxiety and Depression Scale, GSAB-DFI = Goals Systems Assessment Battery- Directive Functions Indicators, MoCA = Montreal Cognitive Assessment

4.1.2.2.1 Goal performance and satisfaction.

COPM performance and satisfaction increased over time significantly in both groups but there were no significant between group differences. However, a moderate time by group effect is noted. Examination of mean changes in COPM performance and satisfaction scores indicate a clinically important improvement in the COPM performance rating for the intervention group post intervention and at the six month follow-up. While improvement was noted for the control group, this group did not reach a clinically important change (See Table 4.5). As noted in the Methods chapter, a change of two on the COPM is considered to be clinically important. For the COPM satisfaction rating, both groups achieved a clinically important improvement at posttest but only the intervention group retained this level of improvement at six months (See Table 4.6). However the difference in change scores between groups was not clinically important.

Table 4.5. Mean COPM Performance Scores and Change in Scores over Time

Group	COPM-P T1 $\bar{x}$ (95% CI)	COPM-P T2 $\bar{x}$ (95% CI)	COPM-P T3 $\bar{x}$ (95% CI)	COPM-P change T1-T2 $\bar{x}$ (95% CI)	COPM-P change T2-T3 $\bar{x}$ (95% CI)	COPM-P change T1-T3 $\bar{x}$ (95% CI)
Control	5.0	6.3	6.1	1.4	-0.3	1.1
(n=11)	(3.4, 6.5)	(5.0, 7.7)	(4.2, 8.0)	(0.3, 2.5)	(-1.5, 0.9)	(-0.7, 3.0)
Intervention	3.7	6.3	6.1	2.7	-0.3	2.4
(n=6)	(2.1, 5.3)	(3.9, 8.8)	(4.1, 8.0)	(0.9, 4.4)	(-1.3, 0.7)	(1.0, 3.8)

COPM = Canadian Occupational Performance Measure, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

Table 4.6. Mean COPM Satisfaction Scores and Change in Scores over Time

Group	COPM-S T1 $\bar{x}$ (95% CI)	COPM-S T2 $\bar{x}$ (95% CI)	COPM-S T3 $\bar{x}$ (95% CI)	COPM-S change T1-T2 $\bar{x}$ (95% CI)	COPM-S change T2-T3 $\bar{x}$ (95% CI)	COPM-S change T1-T3 $\bar{x}$ (95% CI)
Control	4.1	6.2	5.7	2.0	-0.5	1.5
(n=11)	(2.6, 5.6)	(4.8, 7.5)	(3.7, 7.6)	(0.7, 3.4)	(-2.0, 1.0)	(-0.3, 3.4)
Intervention	2.7	6.2	5.6	3.6	-0.6	2.9
(n=6)	(1.4, 4.0)	(4.0, 8.5)	(3.7, 7.5)	(1.6, 5.5)	(-2.3, 1.1)	(1.7, 4.2)

COPM = Canadian Occupational Performance Measure, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

To gain more insight into potential differences between groups, the types of goals selected by each group were noted (See Table 4.7). There is some overlap of goals between individuals (e.g., walking) and groups (e.g., driving) but the majority of goals are unique to each individual. There were no marked between group differences in the types of goals selected. Both groups selected a variety of participation goals related to social participation, leisure participation, home management and personal development. A few participants selected goals that were not specifically at the level of participation e.g., improving hand use for functional tasks, and improving balance.

Table 4.7. Participation Goals Selected

OPC-Stroke Group	Control Group
Driving/ be able to go where I want when I want (3)	Driving/getting places on my own (4)
Improve fitness	Improve health and fitness level (5)
Walking on uneven ground, further, without mobility aid (4)	Exercise: Swimming lengths; Running (2)
Travel (2)	Be able to put on bra independently
Get dressed on own	Be able to put on and take off bathing suit independently
Get back to doing own hair	Stop falling
Do outdoor maintenance at the cottage	Improve balance
Go fishing in the boat	Enjoy life: doing things I enjoy
Organize computer pictures of life	Put my affairs in order
Learn Spanish	Return to curling
Recover the ability to write	To get back to work
Manage quick escalation of anger	To get back spontaneity
Share positive feelings with my family	Getting back to taking care of the home/family
Manage money appropriately	Getting back to community activities (volunteering, church) (2)
Get back to sewing and quilting	Increase fine motor skills eg for soldering
Get back to cooking and baking	Get back to "full" golfing
Start working on downsizing	Housekeeping/Do more around the house (2)
Go to a baseball game with friends in Toronto	Be able to read regular books
Regain use of my left hand and be able to open jars and carry groceries	Baking for pleasure
Go to Montreal to work in soup kitchen with brother	Increase social activities with friends (2)
	Helping own children with homework
	Improving piano playing
	Feel like voice is "my own"
	Be able to use a regular bus

4.1.2.2.2 Emotional well-being.

No significant differences were noted for emotional well-being as measured by the HADS between groups or over time. HADS scores tended to increase slightly over time in both groups indicating poorer overall emotional well-being (see Table 4.8). The experience of significant life changes by some participants over the course of the study e.g., death or illness of a spouse, may have contributed to the variability of these scores.

Table 4.8. Mean HADS Scores and Change in Scores over Time

Group	HADS T1 $\bar{x}$ (95% CI)	HADS T2 $\bar{x}$ (95% CI)	HADS T3 $\bar{x}$ (95% CI)	HADS change T1-T2 $\bar{x}$ (95% CI)	HADS change T2-T3 $\bar{x}$ (95% CI)	HADS change T1-T3 $\bar{x}$ (95% CI)
Control (n=11)	7.4 (5.3, 9.5)	10.0 (5.4, 14.6)	9.6 (6.1, 13.2)	2.6 (-1.8, 7.0)	-0.4 (-2.0, 1.3)	2.3 (-1.0, 5.6)
Intervention (n=6)	5.8 (1.5, 10.2)	7.7 (2.2, 13.1)	7.8 (1.6, 14.1)	1.8 (-1.1, 4.8)	0.2 (-3.6,3.9)	2.0 (-0.9, 4.9)

HADS = Hospital Anxiety and Depression Scale, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

4.1.2.2.3 Goal self-efficacy.

Goal self-efficacy did not change for either group over time as measured by the GSAB-DFI. Scores for both groups were comparable at baseline and remained stable at a moderate level of self-efficacy (see Table 4.9).

Table 4.9. Mean GSAB-DFI Scores and Change in Scores over Time

Group	GSAB-DFI T1 $\bar{x}$ (95% CI)	GSAB-DFI T2 $\bar{x}$ (95% CI)	GSAB-DFI T3 $\bar{x}$ (95% CI)	GSAB-DFI change T1-T2 $\bar{x}$ (95% CI)	GSAB-DFI change T2-T3 $\bar{x}$ (95% CI)	GSAB-DFI change T1-T3 $\bar{x}$ (95% CI)
Control (n=11)	25.0 (22.1, 27.8)	24.4 (22.4, 26.5)	24.0 (21.7, 26.2)	-0.5 (-3.0, 2.0)	-0.5 (-2.5. 1.5)	-1.0 (-4.0, 2.0)
Intervention (n=6)	23.4 (20.1, 26.7)	23.8 (20.8, 26.9)	23.0 (17.3, 28.6)	0.4 (-3.8, 4.7)	-0.9 (-5.6, 3.8)	-0.4 (-5.5, 4.6)

GSAB-DFI = Goals Systems Assessment Battery-Directive Functions Indicators, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

4.1.2.2.4 Cognition.

A between groups differences over time that approached the conventional level of significance (p = 0.05) was noted for the MoCA (p=.065). The effect size for time by group was large at .167. Findings favored the intervention group (see Table 4.10) who had an average improvement of two points from baseline to the six month follow-up while the control group had an average improvement of 0.2 points.

Table 4.10. Mean MoCA Scores and Change in Scores over Time

Group	MoCA T1 $\bar{x}$ (95% CI)	MoCA T2 $\bar{x}$ (95% CI)	MoCA T3 $\bar{x}$ (95% CI)	MoCA change T1-T2 $\bar{x}$ (95% CI)	MoCA change T2-T3 $\bar{x}$ (95% CI)	MoCA change T1-T3 $\bar{x}$ (95% CI)
Control (n=11)	25.7 (24.0, 27.5)	26.7 (25.4, 28.0)	25.9 (24.1, 27.7)	1.0 (-0.3, 2.3)	-0.8 (-2.2, 0.6)	0.2 (-1.4, 1.8)
Intervention (n=6)	26.2 (23.7, 28.6)	26.8 (24.7, 29.0)	28.2 (26.2, 30.1)	0.7 (-0.8, 2.1)	1.3 (0.5, 2.2)	2.0 (0.7, 3.3)

MoCA = Montreal Cognitive Assessment, CI = confidence interval, T1 = pretest, T2 = posttest, T3 = follow-up

4.1.3 Summary.

Overall, both groups showed improved participation, goal performance and satisfaction over time. The trajectory of participation appeared to differ between groups with the control group showing more overall improvement. However, intervention group participants experienced clinically important improvements in both goal performance and satisfaction at posttest and six months later while the control group showed clinically important improvement in goal satisfaction only at posttest. Surprisingly, there was no change in goal self-efficacy and emotional well-being decreased for both groups. For cognition, there was a large effect size and the difference between groups approached significance in favor of the intervention group.

4.2 Qualitative Findings

This section consists of two parts that present findings from the qualitative analysis to address the research questions "What is the experience of research participants receiving OPC-Stroke?" and "Which components and processes of OPC-Stroke promote achievement of self-identified participation goals?" In the first section, findings from analysis of qualitative interviews that elucidate participants' overall experience of OPC-Stroke are presented. The second section presents findings that inform the contributions of the components and processes of OPC-Stroke to achievement of self-identified participation goals.

Of the eight participants who completed the intervention, seven agreed to be interviewed. One participant was not available due to family circumstances. For two participants, spouses were present at the time of the interview and provided some feedback at the invitation of the participants.

In the descriptions below participants have been given pseudonyms. Participants' demographics are presented in Table 4.11. One participant was interviewed in French. Quotes from this participant are presented in French with free translation in parentheses following the quote.

Table 4.11 Qualitative Participants' Demographics

Pseudonym	Age	Side of Stroke	Living Situation
Alex	59	Left CVA	Spouse
Christine	69	Left CVA	Alone
Bev	65	Right CVA	Alone
Doug	51	Right CVA	Family
Lynn	85	Right CVA	Alone
John	64	Right CVA	Alone
Ken	64	Right CVA	Spouse

4.2.1 Participant experience of OPC-Stroke.

As the experience of OPC-Stroke was expected to be unique for each individual, conventional content analysis was used to capture these experiences. During this analysis, three categories were identified: (1) *OPC-Stroke was helpful*, (2) *OPC-Stroke provided opportunity for insightful reflection*, and (3) *desire for a different approach*. The dimensions of these categories that represent participant experiences are presented below and are summarized in Table 4.11.

Table 4.12. Participant Experience of OPC-Stroke

Category	Dimensions
OPC-Stroke was helpful	Pleasant Personal time Hope Motivation Focus for goal achievement Different perspective
OPC-Stroke provided opportunity for insightful reflection	Discovery of confidence in ability to achieve goals
Desire for a different approach	Preference for remediation of motor impairments

4.2.1.1 OPC-Stroke was helpful.

Most participants reported that they found the intervention helpful in some way. They looked forward to the Coach's visits and found them to be pleasant. For example, Alex said, "It was enjoyable sessions." Sessions were also viewed as a special time, as noted by Christine, "C'était un temps […] que j'attendais, pour moi." (It was a time I looked forward to, for me.)

Christine also commented that the weekly visits from the Coach provided reassurance for herself and for her family. In her words, "Et puis d'avoir quelqu'un qui vient toutes les semaines c'était rassurant pour moi aussi. Et c'était rassurant pour eux [famille] autant." (So

to have someone come every week was reassuring for me. And it was reassuring for my family as well.) Similarly the regular social contact was helpful for some participants who were lonely. As Lynn said, "I liked her […], I'm alone and that's why I like to talk."

Some participants indicated that taking part in the intervention provided hope and motivation. Bev spoke about her hope for return to normalcy in stating, "Hopeful about being able to […] do these things naturally, without having to think about what I'm going to do all the time." She also commented that the sessions sustained her drive to keep working on her recovery: "You know, it kept me motivated to keep going." Similarly John spoke about feeling more motivated to try new things. As he said, "I thought it really helped because I would try to do different things just to see that I could do it, you know? And it got you back into the mood of doing things." This stimulation of motivation helped participants to keep focused on their goals. When asked if he might have achieved his goals without the intervention, Ken responded, "I probably would have, but longer. It would have taken me longer to do that."

For some participants, the Coach was able to provide a different way to think about achieving goals. Alex commented, "Well, she [Coach] tried to help me […] look at a different perspective, […] Okay I don't have to do it all at once."

The above findings illustrate the different dimensions of OPC-Stroke being helpful; being pleasant, being a private time, and facilitating hope, motivation and a different perspective. The category of *OPC-Stroke provided opportunity for insightful reflection* is presented next.

4.2.1.2 OPC-Stroke provided opportunity for insightful reflection.

A few participants, when reflecting back on the intervention, conveyed confidence that they could have achieved their goals on their own. Lynn reported "I would have done the same, what I did." Christine also said, "C'était quelque chose que j'aurais peut-être pu faire moi-même." (It is something I might have been able to do myself.). Alex provided mixed messages. While stating that he likely would have achieved his goals without the coaching, he also commented on how the opportunity to reflect on his goals with the Coach provided a different perspective. These messages of self-confidence seemed to have emerged as a result of reflecting on the intervention and on progress made towards achieving goals.

These statements from participants led to reflection as to whether the intervention had influenced goal achievement, or whether these participants would have achieved their goals without the intervention. Therefore, tapes of the coaching sessions were reviewed looking for instances of communications that may have facilitated the identification of goals or development of plans. These data revealed that during conversations around goals and plans, ideas and strategies that came from the Coach were reframed by participants. This reframing entailed participants to take ownership of these strategies and build on them.

For example, setting goals and then feeling accountable for actions to achieve these goals appeared to create stress for Lynn initially. She required gentle encouragement to take on small steps. As she progressed, she appeared to become more comfortable with integrating suggestions presented by the Coach, such as enlisting the help of a friend to help with organizing her home (Session 3).

Although Christine had started to work on her goals prior to the intervention, she seemed to lack commitment to carrying out actions to achieve these goals. During the intervention, the process of setting small goals, along with encouragement from the Coach

and feeling accountable for her actions, promoted ongoing action by Christine to achieve her goals.

Prior to the goal setting visit from the Coach, Alex appeared to be struggling with day to day tasks and did not seem to have conceived of the possibility of returning to fishing or outdoor maintenance activities due to his impaired balance. He tested strategies suggested by the Coach and when they were successful applied these strategies to new situations. For example, during session four the Coach suggested that Alex sit on his walker on the dock to fish. When this was successful, Alex and his wife came up with the idea of putting a lawn chair in the boat to decrease demands for balance.

Participants' comments that they could have achieved their goals without the intervention suggests that reframing by participants occurred that led to discovery of self-confidence for goal achievement.

The category of *desire for a different approach* is presented next.

4.2.1.3 Desire for a different approach.

Two participants appeared to be looking for an approach that was more focused on remediation of specific motor impairments as opposed to focusing on achievement of participation-related goals. As Lynn stated, "And I thought, 'Oh God, I'd rather have you work on my arm than to talk about this.' But that's all right."

While Lynn remained in the study and worked towards some of her participation goals, the other participant withdrew after four sessions. In her exit interview she indicated that she was hoping to have more direction with regards to specific exercises she could do to improve her strength and balance. To gain more insight into the potential reasons for

withdrawal, the taped intervention sessions of this participant were reviewed. This was the first participant for the Coach and she seemed to be focusing on delivering the intervention according to guidelines as opposed to focusing on establishing a therapeutic relationship with the participant. Listening to these sessions revealed that the Coach missed instances for providing emotional support through providing positive encouragement for small steps taken. For example, in Session 2, the participant reported that she had done exercises to build her strength for walking and driving once that week and had walked in the mall with a friend. While the Coach listened and sought details around this, she did not applaud Lynn's efforts, nor specifically highlight this as a step in the right direction. The participant later asked the Coach what she should be doing to improve her strength and balance.

While not all participants expressed this desire for a more impairment-focused approach, it was clearly expressed by two participants.

4.2.1.4 Summary of participants' experiences of OPC-Stroke.

The categories and dimensions that represent participants' experiences of OPC-Stroke are presented in Table 4.12. In summary, participants found OPC-Stroke to be helpful in that is was pleasant, was a personal time, provided social contact that was reassuring and decreased loneliness, provided hope, motivation and a focus for goal achievement, and provided a different perspective or way to think about achieving goals. On reflecting back on the intervention, a few participants expressed confidence in their abilities to potentially have achieved their goals without the intervention, but this confidence did not seem apparent early in the intervention process. As well, a couple of participants experienced OPC-Stroke as not meeting their desire for a more expert-driven approach to remediation of impairment.

While these categories specifically reflect participants' experiences of OPC-Stroke, the next section, which presents findings related to components and processes of OPC-Stroke, provides further insight into their experiences.

4.2.2 Components and processes of OPC-Stroke.

This section begins to address the research question "Which components and processes of OPC-Stroke promote goal achievement?' Content analysis for this section utilized the established coding framework (Appendix G) based on the conceptual model of how OPC-Stroke works, which included the broad categories of *support, education, goals, goal-focused problem-solving* and *application to new goals*. Findings related to each of these categories are presented below.

4.2.2.1 Support.

As per the coding framework, the category of *support* included the subcategories of *therapeutic relationship*, *emotional support* and *social support*. Findings related to these dimensions are presented below and are summarized in Table 4.12.

4.2.2.1.1 Therapeutic relationship.

In the coding framework, the therapeutic relationship was defined as being one of trust, mutual respect, and collaboration that promoted readiness to work towards goals. The qualitative data revealed these dimensions of a therapeutic relationship in that participants felt connected to and trusting of the Coach. As Lynn commented, "But you know, sometimes you gravitate and she was just a young woman that was very, very personable." When asked

about how she felt with the Coach, Christine expressed trust when she responded, “Très à l’aise. […] et je crois qu’elle aussi.” (Very comfortable […] and I believe she was comfortable also.)

The respect and collaboration shown by the Coach were integral to developing this relationship. The Coach used active listening and reflecting to convey respect and collaboration. As Bev commented, “She would say good things, you know. And she had wonderful suggestions and she was willing to listen to my suggestions too.” Ken referred to the Coach using reflective questions that prompted critical thinking. These questions could be asked due to the trust established. In his words, “She’s like a mirror. She’s reflecting what you’re saying, but yet she’s not afraid to say, ‘Well, what did you think about that? You’ve done that, but was that what you really wanted to do?’”

Using a collaborative approach the Coach maintained a focus on participant’s goals. Doug’s comment illustrates this focus:

> Her approach was one of, you know, I see your side. […] Let’s see what we can do and work together. So I think she was very careful to do that and let’s stick to some of these goals.

The therapeutic relationship was nurtured through the Coach not just focusing on goal achievement but by taking time before and after discussion of goals to listen to and be with participants. This form of respect was defined by sharing of ideas, having fun and discussing the participant’s current reality. Christine referred to sharing ideas when she said, “Et, ce que j’ai aimé […] on se rencontrait, on établissait, on faisait le travail et puis après ça, bon on parlait un petit peu. (And that was what I liked […] we met, we planned, we did the work and then after that, we talked a bit.) Ken indicated having fun, “We could laugh.” while

John spoke about discussing his reality, “We just talked about ordinary things and about how bad I was, how sick I was.”

The Coach’s characteristics and interactions promoted personal information sharing on the side of the participant indicating trust in the Coach.

The therapeutic relationship created by the Coach appeared to be a source of motivation and promoted readiness to take action to pursue goals. This readiness to act was encouraged through use of a positive approach. As Bev said, “She was inspirational. She had a very positive approach.” The communication skills of the Coach also contributed to this readiness to act. John indicated, “She just would […] get you going by just asking one question. […] She made you do all the work even though it didn’t seem like it.”

Motivation to work towards goals was also created through a feeling of being accountable and being able to share success experiences. Christine expressed feelings of being accountable when she said, “Je me disais, ‘Elle [Coach] va venir demain, faut que j’ai quelque chose à lui montrer.’“ (I said to myself, “She is coming tomorrow, I have to have something to show her.”) When asked what she thought about when she knew the Coach was coming, Bev responded, “Well, I’d like to be able to show that I can do this now.”

The above characteristics and skills match the designed approach of coaching where the Coach is positive and respectful, collaborative, instills trust and is focused on attaining goals. These characteristics and skills appear to be imperative for the establishment of a therapeutic relationship. However, taking time to be with and listen to participants also emerged as an important dimension contributing to the therapeutic relationship. As well the relationship appeared to contribute to motivation to take action towards achieving goals.

Provision of emotional support is identified in OPC-Stroke as also being integral to developing and maintaining the therapeutic relationship. Findings related to *emotional support* provided by the Coach are presented next.

4.2.2.1.2 Emotional support.

Emotional support was defined in the coding framework as (1) the Coach providing encouragement, (2) participants feeling listened to, and (3) the Coach being non-critical.

The Coach listened actively to participants. Ken commented on the importance of this listening, “But she listens a lot so she – the fact that she’s listening is very important.” Active listening was conveyed through showing interest, and being receptive to participants’ ideas. As Bev noted, “She was interested in my progress,” and “She was receptive to how I felt about doing the various exercises, and my suggestions on different exercises that I could do.”

The guidance and encouragement provided by the Coach was non-critical and non-directive. In describing interactions with the Coach, Alex noted that there was “no pressure at all.” The non-critical approach was conveyed through being non-judgmental of participants as illustrated by the following quotes:

> It was a non-threatening environment to me and very non-judgmental. (Doug)
>
> She [the Coach] never made me feel like I was a failure because I couldn’t do it, which was nice. (Bev)
>
> Mais, y avait jamais ‘Oh, tu as pas fait ça, tu as pas fait ça [les actions prévues].’ (But there was never 'Oh, you have not done that, you have not done that [planned action

steps].; Christine)

At the same time, the Coach was able to encourage participants to progress, and to provide feedback to validate their struggles and their achievements. As John noted, “She pushed you. Yeah. She got you out of your comfort zone.” Similarly, Bev commented:

> So then I would try that [exercises] for the week and see how it worked. And there were ones that I couldn’t do, that I couldn’t seem to get. And she [Coach] said, “Well, don’t get discouraged with it. That’s very difficult to do, it’s hard to do.”

Participants’ descriptions illustrate that emotional support received from the Coach was conveyed through listening, and providing encouragement and feedback in a supportive, non-directive manner. Support for goals was also received from other sources. Findings related to *social support* are presented next.

4.2.2.1.3 Social support.

Social support was defined as support from family and other sources that was directly related to goal achievement. Along with emotional support from the Coach, participants also spoke of support from family, friends and health professionals that was directly targeted at supporting them to achieve their goals. For example, Bev spoke of how a formal caregiver supported her goal of doing her hair by helping her to use her arm and hand during washing of her hair. Lynn spoke of a friend who helped her with her goal of tidying up and organizing papers.

Table 4.13. Category of Support

Subcategory	Dimensions
Therapeutic relationship	Feeling connected
	Trust
	Collaboration
	Respect: active listening, sharing ideas, having fun, discussing current reality
	Source of motivation: positive approach, feeling accountable
Emotional Support	Active listening: showing interest, being receptive to ideas
	Encouragement: non-directive, non-judgmental, validating struggles and achievements
Social Support	Support for goals

Establishment of a therapeutic relationship through provision of emotional support, and availability of social support for goals appeared to be important ingredients to promote goal achievement. Education is another component of OPC-Stroke. Findings related to *education* are presented next.

4.2.2.2 Education.

Education was identified as a broad category for coding in the framework with dimensions of being individualized and relevant to participants' needs and goals and occurring through an exchange of information where participants felt comfortable sharing their ideas. Findings revealed that education was individualized and relevant to participants' goals as it primarily included suggestions of strategies for goal achievement.

These strategies included suggestions to adapt approaches to activities and to explore new ways of doing to achieve goals. For example, Bev described changing her approach to walking:

> I used to tend to take just little steps […] Then she [Coach] said to try and make my steps longer […] I was afraid I would trip, but actually, lengthening the stride [...]

works well for me.

Ken and his wife described a strategy for energy conservation introduced by the Coach. For this strategy, a visual tool was used to assist with planning energy use for goals and other activities. This strategy introduced a new way of thinking about fatigue following stroke and of planning activities to respect this fatigue.

In some instances participants were introduced to new ideas that contradicted what they had been told during rehabilitation and had never questioned. This gave them permission to question further and come up with their own strategies when faced with other challenges. Bev spoke about the Coach suggesting a different approach to dressing from the way she was taught in the hospital:

> And in the hospital that's what they said, I should always put the left leg on first. […] She (Coach) said, "[…] mostly, that's the best way to do it. But depending on what clothes you're putting on, sometimes it's not always the easiest way. So I'd never thought about that. (Bev)

Relevancy of information was indicated by participants integrating suggestions during the intervention (as above), or retaining them for future consideration. For example, Lynn spoke about the Coach's suggestion to hire someone to help her clear out stuff from her house. She stated, "I might end up doing that, but at the moment, not."

Education occurred through discussions of goals where strategies from both the Coach and participant were shared. As Bev reported, "I would ask for her ideas and she was open to ideas, ways of trying things."

Findings from participant interviews indicate that education was focused on strategies that were individualized and relevant to participants' needs and goals and occurred through

collaborative discussion. Because of the limited scope of education that was revealed during data analysis, data from treatment fidelity checks were reviewed to determine if other areas of education occurred and relevant intervention sessions were reviewed to learn details of the content of different types of education. These data revealed that education had also occurred related to health conditions and impairments and community resources. For example, the Coach provided information to Lynn related to recovery of her arm when they discussed the importance of providing stimulation and using her affected arm to promote recovery (Session 2). Similarly, the Coach discussed motor re-learning principles with Christine related to her goal of relearning to write (Session 4). With Ken, the Coach conveyed information related to community resources when she provided guidance on the roles of different healthcare providers (Session 7).

The next section presents findings related to the category of *goals*.

4.2.2.3 Goals.

In the coding framework the category of *goals* was defined as including the following dimensions: (1) goals are chosen by participants, (2) having goals is important, (3) goals are valued and important to participants and (4) goals promoted action through directing attention, triggering action and promoting persistence. Dimensions identified during analysis reflect those identified in the framework. These are summarized in Table 4.13 and described below.

Findings indicated that the intervention goals were chosen by participants and reflected highly valued activities that were given meaning for personal reasons, social reasons or because the activity was related to their identities. Examples of personal goals

were going fishing, being able to do hair, clearing up clutter, and improving fitness. When asked about goals, Alex said, “My biggest one was going fishing in my boat.” Bev indicated, “The first one was to be able to do my own hair […] washing and being able to fix it myself.”

Goals chosen that had social value related to being able to do activities with friends and to being a resource for friends. John wanted to be able to go to a ball game in another city with his friends. As he said, “Because the year before that everybody got fed up because I was so slow in moving and they’d have to wait for me all the time and, you know.” Christine was planning to travel to Mexico with friends. One of her goals was to review and practice Spanish for her trip. She stated, “J’étais partie avec des amis qui étaient rassurés de savoir que je parlais espagnol parce qu’eux ne le parlaient pas.” (I was going with my friends who were reassured to know that I could speak Spanish because they could not speak it.)

Goals that supported identity related to independence and being part of a community. For example, John wanted to have the independence offered by getting his driver’s license back. In his words, “I didn’t like being sick and I didn’t like having to depend on everybody […] I didn’t like that because you knew you were putting people out.” Christine wanted to be able to resume volunteer activities that gave her a role in her community. She commented, “Avant j’écrivais des articles etc., et je fais partie d’une communauté.” (Before I wrote articles, etc. and I was part of a community.)

Having goals seemed to be important for participants. When discussing their goals, several participants used language that indicated feelings of ownership for their goals and responsibility for actions to achieve them. For example Ken stated, “The goal came from me, obviously.” Similarly, Bev noted, “We talked about trying to achieve the three goals that I had set out to do.” For some participants formally setting goals was new. Their comments

reflect that previously they used a less formal, more implicit approach to determining goals. As Ken said, “I did have an intuitive way of doing things. So when [Coach] came and I had to set up a goal – I think I had three goals.” Christine also commented, “Parce que avant je me mettais pas de but, si j’arrivais, j’arrivais, mais y avait rien d’écrit ou quoi que ce soit.” (Because before I never set goals. If I did something, I did it, but there was nothing written or anything.) Bev noted that during her rehabilitation, no one had asked her what her goals were. She found the opportunity to set her own goals to be “refreshing”.

Despite being new for some participants, setting goals seemed to assist in directing attention. Identifying goals provided a focus for action. As John said, “We would have goals. […] So we would work on these goals.” Doug also saw his goals as things to be worked on. He said, “No they came from me. […] These are things that I could definitely work on and so here’s an opportunity […]. Perfect, let’s do that.”

As well as directing attention, goals seemed to trigger action from participants. For John, having goals seemed to prompt a turning point where he made a decision to act.

> And like the goal thing and all that. I would never think of that. And then getting to do it, you know? So that was good, I guess. I thought it was stupid […]. And then I realized, “No, no. Let’s go with this.”

When asked to elaborate on how she worked towards achieving her goal of getting rid of clutter, Lynn simply stated, “Well, I got rid of stuff.”

Persistence was reflected in participants talking about the need to keep working, take small steps and expend effort to achieve their goals. As John stated:

> Somehow the light goes on and you say, "You got to quit saying I can't do this." And you got to try and once you try you get better at it and you keep working on it. That's all it was for me.

Doug spoke about making small steps towards his goal that seemed unimportant but kept him moving towards his goal:

> Some of them [steps towards goal] were somewhat inconsequential but they were things that you could kind of step towards and […] the whole point was to carry us forward and continue to do it.

Christine spoke about the effort required to work on her goal of relearning to write. As she said, "Je lui ai écrit une carte après son départ [Coach], […] et elle m'a dit, 'C'est très bien comparé à ce que c'était.' Ben, j'ai dit, 'J'ai fait un effort.'" (I wrote the Coach a card before she left and she said to me, "It is very good compared to what it was." And I said, "I made an effort.")

Table 4.14. Category of Goals

Category	Dimensions
Goals	Chosen by participants: refreshing
	Valued and given meaning for personal, social and identity-related reasons
	Feeling of ownership
	Formally setting goals was new
	Directed attention
	Promoted persistence and action

Overall, findings present participant-selected goals as being highly valued, new to some participants yet important, serving to direct attention and promote action and persistence. Findings related to the goal-focused problem-solving process are presented next.

4.2.2.4 Goal-focused problem-solving process.

The goal-focused problem-solving process included the predefined subcategories of (1) developing plans, (2) testing plans and (3) success with participation goals. New subcategories and dimensions emerged during coding. Within the subcategory of testing plans, dimensions that emerged were *challenges in achieving goals* related to the experience of stroke and the demands of the goal, and *plans are not easy*. Within the subcategory of success with participation goals, dimensions that emerged were *new ways of doing*, and *lack of success for some goals*. One new subcategory emerged that influenced goal-focused problem-solving. This was *personal characteristics*.

Findings related to each subcategory are presented below and summarized in Table 4.15.

4.2.2.4.1 Developing and testing plans.

In the coding framework, developing plans was defined as drawing on strengths, resources and positive experiences and breaking down goals into steps. Testing plans included participants feeling responsible for action and choices, checking on goal progress, the Coach providing guidance, and the Coach being non-directive. As noted above, the definition of testing plans was expanded to include the challenges faced by participants and participants' experiences of plans not being easy.

When participants spoke of developing and testing plans to achieve goals, the two ideas were intertwined; reflecting the cyclical nature of the problem-solving process. Participants spoke about setting small goals from week to week, checking in on their progress, re-evaluating and making new plans. These small goals were quantifiable. As noted

by Doug, “So with [Coach] we set goals each week. […] try to make them quantifiable goals and report it back […] what worked and what didn’t work.”

Participants reported learning through testing plans. For example Ken reported, “But I made a mistake because I didn’t realize at the time how much effort was involved in driving.” Having guidance from the Coach that provided a different perspective when testing plans was helpful. As Alex noted, “Look at a different perspective, I mean, figuring out, okay, I don’t have to do it all at once.”

When providing guidance, the Coach took a non-directive approach (as presented under the subcategory of *emotional supp*ort) and facilitated participants to make their own choices. As Bev noted, “But, you know, she [Coach] said you can always try something different, you know, you don’t always have to do it a certain way.” Ken spoke about his decisions to make changes when working on his goals. As he said, “And you could see that in a lot of my decisions I’m doing something […] and then all of a sudden I’m changing because I have to cope.”

In the above findings related to developing and testing plans, use of the active voice, I, indicates that participants felt a sense of agency or responsibility for taking actions and carrying out their plans.

When working towards their goals, there were challenges presented by stroke related deficits, other health conditions and the environment that participants had to negotiate. Participants spoke of physical, cognitive and emotional challenges resulting from their stroke. For example Alex said, “Left to right my balance that way is fine. Forward and backwards is no good.” Bev made reference to hemiparesis in her arm and hand, “It wasn’t because I didn’t try. Maybe I still haven’t got enough mobility yet in my hand and my arm.” Doug’s wife spoke about mild cognitive changes she had noticed that affected the

accomplishment of Doug's goals related to family interactions. She referred to his challenge of not filtering what he says when commenting, "Because the filter, again, had changed [...] as opposed to usually if something happens you think, 'Well, I may think that but I better not say it.'" Doug, himself, spoke about challenges related to emotions. In his words, "Well, it's interpersonal but I also have to suppress my feelings of inferiority or my inability to do things. To simple say, 'Alright, I'm not taking it personally.'"

For some participants, other health conditions interfered with goal achievement. For example, Bev pointed out, "I have osteoarthritis in my back. And I have a sciatic nerve on my left side, causes me a lot of problems. So painful to bend over [for dressing]."

A few participants identified the outdoor environment, particularly related to winter, as a challenge that posed safety risks. For example, John spoke of his fear of the ice in winter. He said, "I was petrified of the ice. I had never been like that before where if I slipped and fell I would be in so much trouble." Lynn referred to the need for railings on her steps. She stated, "I can't even go outside and go down the steps because I can't go alone. I'm going to get metal railings put in the front and one in the back."

Several participants spoke about the fact that carrying out plans was not easy. As Christine said, "Réapprendre à écrire, ben c'était difficile." (Relearning to write, well it was difficult.) Alex spoke about his struggle to get in and out of his boat. As he said, "The first time I went in the boat it was terrible because I had to crawl in, crawl out and it was worse getting out. Because the boat doesn't […] stay stable."

During interviews participants did not directly speak about drawing on strengths, resources and positive experiences, yet they were able to keep a positive approach as indicated by their comments related to the need to persevere, have patience, and build

confidence. Alex referred to persevering when he said, “I set a goal, and like [if] I couldn’t achieve [it] over the week that it was there, we tried harder for the next week.” Christine indicated the need to have patience when she said, “Je me frustre pas facilement dans le sens que c’est pas une question de vie ou de mort encore là. Alors, je croyais que ça [progression avec d'écriture] serait plus rapide que ça.” (I don’t get frustrated easily. It is not question of life or death. But I believed that it [progress writing] would be faster than that.). Bev made reference to the need to build confidence when stating, “So I can do that, maybe I can walk without using a mobility aid smoothly. I’m not too comfortable about doing it by myself yet.”

In summary, developing and testing plans involved a cyclical process of taking steps and evaluating progress made through small steps. The process was not easy and involved learning, overcoming challenges through persevering, having patience and building confidence. *Success with participation goals* is presented next.

4.2.2.4.2 Success with participation goals.

In the coding framework, the definition of success with participation goals included participants having opportunity to make choices, feeling positive about achievements, feeling able to achieve goals, feeling better able to achieve future goals, and planning to use a problem-solving process for future goals. During coding *new ways of doing* and *lack of success* were added as dimensions under this subcategory.

Despite the challenges faced, all participants indicated that they experienced success either through achieving or making progress on their goals. These positive experiences are illustrated by the following quotes:

> But I did it myself [fishing], I got in and out [of the boat]. And so now I went on Saturday all by myself, I had no problems. (Alex)

> I did walking alone, I can walk alone, and changing my length of my steps of my stride, I think I achieved it. (Bev)

> And then in the process there I got better and I could walk and I went to Toronto for a weekend with all my buddies and we went to a ballgame. So that one worked out. (John)

When participants did not fully reach a goal, they indicated that they felt they would be able to achieve their goals but it would take more time. Bev noted, "The hair, no. […] Well, I can get a clip in, not too badly. I can't braid yet but I think that'll take a while." Doug spoke about his goals being large and therefore taking longer to achieve. In his words, "Those [relationship-related goals] are things that are obviously are very large goals. So over time, but I think it's certainly provided […] a push in the right direction."

Several participants spoke about accomplishing their goals through new ways of doing. These new ways were chosen by participants and included different adaptive approaches and pacing or taking more time to complete tasks. For example, Bev described a new approach she used for undressing. She said, "Maybe lying down on the bed, you could get undressed easier. […] So I did that. And it worked, it was easier for me." Ken spoke about how he was planning a trip to Toronto, planning time to rest before and after the trip and incorporating stops along the way.

For a couple of participants new ways of doing represented an overall new approach to thinking about planning and achieving future goals. Ken spoke about questioning the reasons he was encountering difficulties and looking for alternative. In his words, "And it's

not that, oh, I can't do that. Why? […] So can I do it this way? Can I just take longer to do it?" John spoke about not giving up when he said, "I had to say, 'Look it. I'm not going to say I can't do this anymore. You just do it and get on with it.' And that's what I did."

While some participants were able to accept new ways without much difficulty, others struggled to adopt new habits or ways of accomplishing activities that were different than the ones they were accustomed to before the stroke. Bev seemed to feel liberated by the thought of exploring new approaches to dressing. As she said, "And I never thought of that [different ways of doing things] before. That was eye opening for me." However, Lynn was reluctant to explore new ways that may enable her to resume quilting using one hand. As she noted:

> Oh, I'd love to be able to quilt again. […] I said, "Well, I can't thread a needle. How in the earth can I ever sew if I can't thread a needle?" And she said, "Oh, you can get those little." I said, "That's no good because that little thing moves."

For Lynn, disinclination to adopt new ways of doing activities seemed to contribute to her feeling of not achieving certain goals despite apparent progress. To an outside observer, she appeared to have made progress on her goal of cooking; however, she did not perceive the outcome as successful. She made rice pudding but was not able to take it out of the oven safely until it cooled. In response to the Coach indicating that she thought that was cooking, Lynn reported, "I said, 'No, it's not. Cooking, to me, is cooking.' But I've done rice and I've […] fried something up. Then I decided I'd go to the Red Door and get my food." It seems that, for Lynn, the need to adapt her approach to cooking and baking did not fit with her criteria for goal achievement. A completely new way of doing (ordering out) appeared to be a more acceptable way to ensure she had food to eat, rather than struggling to prepare her

own food. While Lynn appeared to be satisfied with the overall outcome she did not redefine her goal (cooking) and therefore it was not achieved.

Most participants experienced success related to achievement or partial achievement of their goals. Goal achievement frequently involved new ways of doing. However, not all participants were inclined to redefine their goals to include new ways of doing as success. Most participants who did not fully achieve their goals appeared to be confident that they would achieve their goals with time. Personal characteristics may have been a contributing factor to goal achievement. This dimension is presented next.

4.2.2.4.3 Personal characteristics.

During qualitative analysis, personal characteristics were identified as influencing participants' approaches to problem-solving. Findings indicated that participants valued independence and this appeared to be a strong motivator for pursuit of goals. As John said, "I didn't like having to depend on everybody." Similarly Ken reported, "It's not comfortable because you feel that you've been independent for so long."

Related to the value of independence, several participants described themselves as having determination to reach their goals. As Bev stated, "I'm pretty determined, […] my sister says bullheaded." Alex noted, "I'm stubborn, you know. I don't want to ask for help and I won't if I don't have to."

A couple of participants commented on having a positive approach and feeling lucky compared to other people who had experienced stroke. For example Ken said, "I've been positive. With everybody that I've seen, it's been positive." John compared himself with others:

> I had a very mild stroke. And only after did I realize that I was really, really lucky. […] like my numbness in my arm and my staggering around a little bit, that's nothing to the people that can't speak or have no feeling and stuff like that.

Similarly a couple of participants expressed their confidence in their abilities. For example, Alex said, "I'm gonna get it done eventually." Christine elaborated, "J'ai pas l'habitude de demander de l'aide pour savoir ce que je dois faire. J'ai un niveau d'étude qui me permet de m'occuper de moi-même." (I'm not used to asking for help to find out what I should do. I have a level of education that allows me to take care of myself.)

Bev described herself as a "rule follower" prior to the intervention. She reported, "You know, I guess it's, well, you're told you should do it this way, you better do it that way, don't rock the boat." The intervention seemed to provide her with permission to explore and break rules.

Participants' values and personality characteristics appeared to play a strong role in how they approached and carried out the problem-solving process.

In summary, the goal-focused problem-solving process involved a cyclical process of developing and testing plans that included working on small goals, learning and overcoming challenges. Although this process was not easy, participants referred to keeping a positive approach, feeling agency or responsibility for actions, and experiencing success in achieving goals. Personal characteristics and integration of new ways of doing influenced the problem-solving process and definition of success.

Table 4.15. Category of Goal-Focused Problem-Solving Process

Sub-category	Dimensions
Developing and testing plans	Cyclical
	Working on small quantifiable goals
	Learning through testing plans
	Coach non-directive: participant choice in planning
	Agency
	Challenges related to stroke, other health condition and the environment
	Plans not easy
	Positive approach: persevere, have patience and build confidence
Success with participation goals	Positive experiences: achievement of or progress towards goals
	New ways of doing: viewed positively or with reluctance
	Lack of success
Personal Characteristics	Value of independence
	Determination
	Positive approach: feeling lucky
	Rule follower
	Influenced approach to problem-solving

Application of the goal-focused problem-solving process to new goals is presented next.

4.2.2.4.4 Application to new participation goals.

The final step in the problem-solving process is the application of learned strategies and processes to future participation goals. For the coding framework three dimensions related to this application were identified: (1) *generalizing use of the problem-solving process with future goals,* (2) *plans to pursue future participation goals,* and (3) *plans to apply strategies learned to future goals*.

Findings indicated that participants defined future goals as new goals, continuing to work on goals they had not yet achieved and maintenance of achieved goals. A few participants spoke about using strategies that they had applied to past goals and about applying the problem-solving process. When talking about future goals Alex reported “I’m

going to take my time and do everything." His comment reflects self-efficacy for future goals as well as ongoing use of the strategy of "take my time." Ken also spoke of applying the strategy of pacing to new goals when he said, "I guess one of my goals is to be back at the church doing different ministries. I'm doing different ministries, but I'm doing them at my own pace."

Bev set a new goal of returning to knitting and applied aspects of the problem-solving process such as setting small goals. She reported, "I have set small goals for myself. I like to knit. So I did manage to pick up and do knitting […] that's hard to do, one handed." Bev also spoke of evaluating progress and adjusting the pace of expected progress as needed.

> Well, if I set a goal and I'm not achieving […] to sit back and take a more realistic approach. […] Maybe you set the standard too high for yourself and you're going to have to go at it more slowly.

Doug spoke of implementing the problem-solving strategy of breaking a goal down into steps. He said, "I'd probably try to break things down into smaller pieces again and be like, okay what can we do or small pieces and step towards the main goal over a period of time."

A few participants spoke about strategies to continue exercising in order to maintain the goals that they had achieved or to achieve future goals. Two participants reported seeking community-based programs to maintain their motivation and support for exercising:

> I realize if I don't continue on with it [exercising], it's not going to be good. […] I found a place that I'm going to try to go to continue with this. Because if you don't continue it, I understand now, all that work is for nothing. (John)

> But just staying […] in the apartment by myself doing the exercise […] is not that motivating. So I thought if I went to a stay-fit class, […] I would be more enthusiastic. I'd like to […] to keep the mobility I have attained, not let it slip off. (Bev)

For some participants external accountability or support seemed to be needed on an ongoing basis because routines established during the intervention lapsed when it was finished. Ken described starting to walk regularly when the Coach was visiting but not keeping this up afterwards due to "laziness".

The above findings indicate that some participants were able to apply learned strategies and processes to future participation goals. They continued to work towards goals, utilized a problem-solving process or applied learned strategies to new goals. A couple of participants also identified strategies to promote motivation in the absence of a Coach.

4.2.2.5 Summary of components and processes of OPC-Stroke.

The above findings support all components and processes of OPC-Stroke as contributors to the achievement of self-identified participation goals. Establishment of a therapeutic relationship, through provision of emotional support, along with availability of other social support and individualized education on specialized strategies seemed to be critical for engaging in the goal-focused problem-solving process and achieving goals.

Participant-selected goals were highly valued and thereby served to direct attention, and promote action and persistence during the cyclical problem-solving processes. Although most participants experienced challenges in developing and testing plans they were able to experience success and build confidence through achieving or partially achieving their goals.

They also seemed to be generalizing use of strategies learned and the problem-solving process to achieve other goals.

Personal values and characteristics, and readiness to explore new ways of doing were also revealed as important components for success in achieving goals.

These qualitative findings based on interviews with research participants who received OPC-Stroke address the research question, "What is the experience of research participants receiving OPC-Stroke?" and begin to address the question "Which components and processes of OPC-Stroke promote achievement of self-identified participation goals?" The next section further addresses the question "Which components and processes of OPC-Stroke promote achievement of self-identified participation goals?" through integrating quantitative and qualitative findings.

4.3 Integration of Quantitative and Qualitative Findings

In this section, the findings from the quantitative and qualitative analyses are integrated to examine the fourth research question, "Which components and processes of OPC-Stroke contribute to the achievement of self-identified participation goals?" and thereby contribute to the theoretical understanding of how OPC-Stroke works. Using the components and processes described in the theoretical understanding of how OPC-Stroke works (Chapter 2), qualitative and quantitative findings were aligned in a matrix to examine where there was support or lack of support for this theoretical understanding. Table 4.15 presents this matrix.

Table 4.16. Integration of Qualitative and Quantitative Findings

Theoretical understanding	Qualitative findings	Quantitative findings
Therapeutic relationship established through provision of emotional support	Emotional support conveyed through listening, and providing encouragement and feedback in a supportive, non-directive manner.	No measures of therapeutic relationship or emotional support used
Therapeutic relationship creates a milieu of trust, respect and collaboration for information exchange, goal setting and problem-solving	Findings reflect a milieu of trust, respect and collaboration. Therapeutic relationship promoted information exchange and sparked motivation to work towards goals.	No measures of therapeutic relationship or emotional support used
Individualized education facilitates goal achievement	Education tailored towards development of strategies for goal achievement	No measure of knowledge was used.
New knowledge, reinforcement of current knowledge and skills and the opportunity to make choices leads to increased self-efficacy	Participants discovered confidence in ability to achieve goals.	No change in goal self-efficacy scores. Scores were in moderate range initially.
Selection of highly valued goals promotes action, and goal commitment	Goals reflected highly valued activities that were given meaning for personal reasons, social reasons or because the activity was related to individual identity. Goals served to direct attention, and promote action and persistence.	Participants made clinically important changes in COPM performance and satisfaction for goals

Achievement of selected participation goals leads to increased participation	Process to achieve goals involved learning, overcoming challenges, having patience and building confidence. Personal characteristics influenced approach to goal pursuit. Participants experienced success related to achievement or partial achievement of their goals, sometimes through discovering new ways of doing. Findings reflect generalization of strategy use for individual goals and problem-solving process	Participants made clinically important changes in COPM performance and satisfaction for participation goals but improved participation was not reflected in RNLI scores.
Improved participation in valued activities leads to improved emotional well-being	Not reflected in data.	HADS scores increased slightly, indicting poorer overall emotional well-being.
Improved participation in valued activities leads to improved cognition	Findings reflect generalization of problem-solving strategy use, which is a metacognitive skill.	Increased MoCA scores in intervention group

Emotional support is a component of OPC-Stroke that is proposed to be critical for establishment of the therapeutic relationship, which, in turn, promotes a milieu for information exchange, goal setting and problem-solving. As no outcomes measures were used to measure emotional support or the experience of the therapeutic relationship, there are only qualitative findings to support this aspect of OPC-Stroke.

The second component of OPC-Stroke, individualized education, is considered to be an important component for problem-solving and goal achievement. This is reflected in the qualitative data only.

The goal-focused problem-solving process, the third component of OPC-Stroke, is believed to impact on goal achievement in several ways. The overall efficacy of goal-focused problem-solving promoting achievement of individually defined and valued goals is supported quantitatively by the fact that participants made clinically important gains in

perceived performance and satisfaction with performance of identified goals. Qualitatively, the mechanisms by which this occurred are supported. There is qualitative support for goals being highly valued, directing attention, and promoting action and persistence, and for the problem-solving process promoting feelings of success with goal achievement. However, there are conflicting findings with regard to the development of self-efficacy. The development of self-efficacy through the process of learning, taking action, making choices and achieving small successes is supported qualitatively, but the quantitative outcome for self-efficacy showed no change.

While qualitative or quantitative findings support all components and processes OPC-Stroke as contributing to the achievement of self-identified participation goals, there is less support for goal achievement subsequently leading to improved participation and overall emotional well-being. Qualitative data reflects generalization of problem-solving strategy use, but this did not translate to increased participation as measured by the RNLI. As well, goal achievement and generalization of strategy use did not result in improved overall emotional well-being as measured by the HADS. Participation and overall emotional well-being were not specifically captured in the qualitative findings.

However, both types of outcomes support OPC-Stroke as contributing to improved cognition. From a quantitative perspective, scores on the MoCA improved, and qualitatively participants developed skill in using a metacognitive problem-solving strategy.

Overall the integration of quantitative and qualitative data provides support for the specific components and processes of OPC-Stroke contributing to achievement of self-identified participation goals and improved cognition. Other relationships in the theoretical understanding of OPC-Stroke are not well supported.

4.4 Feasibility

4.4.1 Recruitment and retention.

Twenty-one out of 32 (65.6%) people approached to be in the study agreed to participate. It is not clear whether all people who were considered eligible were approached by clinicians. However, based on numbers used in planning the timelines for recruitment, it is suspected that not all eligible participants were approached. Recruitment rates by site are reported in Table 4.17. The majority of participants were referred to the study through the outpatient stroke clinic, with a very small number from the acute hospital. Of the participants from the acute care setting who agreed to learn more about the study, only one was able to identify goals and therefore remain in the study.

Table 4.17. Recruitment by Site of Referral

	Acute hospital	Inpatient stroke rehabilitation	Outpatient stroke rehabilitation	Total
Number referred to participate	3 (9%)	7 (22%)	22 (69%)	32
Number consented	1 (5%)	5 (24%)	15 (71%)	21

Overall retention for the study was 81%. All participants in the control group were followed until the end of the study, while 60% (6/10) of participants in the intervention group were retained until the end of the study. Offering the intervention to control group participants may have been a motivator, as seven expressed interest in receiving the intervention post study. Reasons for loss of participants in the intervention group are described above with the CONSORT diagram (Figure 4.1).

4.4.2 Feasibility and acceptability of outcome measures.

Most outcomes measures had all items scored by participants without difficulty. However there were a few exceptions to this. On the RNLI, the item "I am able to take trips out of town as I feel are necessary" was scored by one participant at one time point as "N/A" with a note, "I haven't tried it yet". No other concerns with scoring the RNLI were noted.

A few participants set a goal of return to driving on the COPM. While these participants were not driving at the time, they tended to mark performance on this item as high at pretest and post test because they felt that they could drive if they were allowed. It was difficult for them to rate actual performance in this situation. Also of note for the COPM, one Coach reported that a couple of participants had started to work on their goals following the goal setting session and prior to the first coaching session in which the problem-solving process was introduced.

Six participants had difficulty with scoring the GSAB-DFI at one of the time points. Two had difficulty with alignment of items in that they scored one item twice and then may have missed the next item. Two participants missed one item completely. Three participants demonstrated decreased understanding of or agreement with wording of items. Two of these participants marked "N/A" on one or two items at one time point, and one participant wrote comments in the squares instead of ticking them at one time point only. Her comments included clarification of her thoughts for that item. Overall the GSAB-DFI was completed accurately 90% (51/57 administrations) of the time. Missing item scores were imputed as described in the Methods chapter. For the person that wrote comments, the comments were aligned with item scores and therefore the corresponding number ratings were used. For the participants who scored twice in one row, one of the scores was transferred to the empty row.

The Research Assistant reported that several participants were reluctant to complete the MoCA. However, all MoCA evaluations were fully completed.

4.4.3 Other considerations.

The degree to which the Research Assistant conducting pre and post evaluations remained blinded to group assignment was examined to assess whether measures in place to maintain blinding were effective. The Research Assistant guesses are presented in Table 4.18. The Kappa score, representing agreement corrected for chance, was 0.33.

Table 4.18. RA Guess of Group Allocation

RA Guess	Actual Allocation		
	Treatment	Control	Total
Treatment	3	2	5
Control	3	9	12
Total	6	11	

RA = Research Assistant

4.5 Treatment Fidelity

Digital audio recordings of coaching sessions were reviewed by RA2 and the primary investigator to evaluate treatment fidelity. The plan was to use the Treatment Fidelity Checklist to review the first five sessions for the first five participants and then three sessions for the remaining participants receiving OPC-Stroke. A total of 37 sessions were selected for evaluation. Thirty-five sessions were rated by both evaluators. Audio recordings of two sessions were lost before the second rater could evaluate them. Consequently, these sessions were not included in the overall evaluation of treatment fidelity. Treatment fidelity was reached in 28 (80%) of the 35 sessions evaluated.

Breaches in fidelity were the result of lower scores for collaboration, focus on strengths, empathy and autonomy support for the second to third sessions of the first participant seen by each Coach. As well breaches resulted due to focus on problems versus strengths and lack of promoting generalization of skills during a couple of sessions. Feedback was provided to the Coaches following fidelity checks until they were able to deliver the intervention as planned. Generally, following feedback from the primary investigator the Coaches were able deliver the intervention as planned for the remaining sessions and participants.

Inconsistency was noted between raters with regard to scoring whether education was provided. One rater did not identify education as occurring in any session. This may have been due to the fact that education was directly related to goals and was integrated into the problem-solving process.

OPC-Stroke was designed to consist of up to 10 sessions delivered over 16 weeks. Data from the Coaches' notes showed that of the eight participants in the Intervention Group

who completed the intervention, the average number of sessions was 8.6 with a range of 6 to 11 sessions. Two participants received 11 sessions because the Coach did not count the goal setting session as an intervention session. This was not realized until after the ninth session and therefore an extra session was permitted to allow for closure of the therapeutic relationship. For two participants, only six sessions could be scheduled within the timeframe allotted prior to re-assessment due to other commitments these participants had.

Because durations of sessions were not consistently captured in the Coaches' notes, billing data was used to examine duration of sessions. The duration of sessions ranged from 30 – 90 minutes with a mean of 57 minutes. The intervention was carried out over 10-16 weeks with a mean of 13.75 weeks.

Chapter 5: Discussion

Participation is a concept that has gained popularity since the introduction of the ICF and it is a primary concern for people who have experienced stroke. Healthcare professionals, particularly occupational therapists, recognize the importance of participation or engagement in valued activities following stroke, yet few directly address this problem. One of the barriers to providing therapy to improve participation is the lack of effective interventions. This research adds to the growing body of knowledge on interventions to promote participation following stroke. OPC-Stroke was designed to address important factors related to participation following stroke that have been identified in interventional and observational studies. Emotional support, individualized education, and processes for goal setting and problem-solving have been identified in these studies as important components to promote participation following stroke. OPC-Stroke specifically integrates these components into one intervention.

Preliminary testing of OPC-Stroke was done previously to examine the feasibility and acceptability of the intervention (Kessler et al., 2014). The goals of the current research were to: 1) examine the preliminary evidence for efficacy of OPC-Stroke; 2) understand how the components and processes of OPC-Stroke may or may not contribute to achievement of participation goals i.e. mechanisms of action of OPC-Stroke; and 3) examine the feasibility and acceptability of the pilot RCT design. The overall goal of these objectives was to inform the decision to proceed to larger scale testing.

The findings related to each of these goals are summarized and then discussed with reflection on how the findings inform the planning and implementation of a larger study of OPC-Stroke, the next phase of testing of this intervention.

5.1 Summary of Findings

5.1.1 Preliminary evidence of efficacy.

The quantitative findings of this pilot RCT of OPC-Stroke suggest that OPC-Stroke can lead to clinically important improvements in goal performance and satisfaction with performance, not experienced to the same extent by the control group. However, there was not a related overall improvement in participation for the intervention group. As well, goal self-efficacy did not increase as expected, and contrary to expectations, emotional well-being decreased in both groups. On the other hand, improvements in cognition approached significance in favor of the intervention group.

5.1.2 Mechanisms of action of OPC-Stroke.

Qualitative findings revealed the experience of OPC-Stroke as helpful for most participants but not necessarily a preferred approach. For some, confidence or self-efficacy for goal attainment appeared to emerge as a result of reflecting on the intervention. The qualitative findings also supported several mechanisms of action of OPC-Stroke including a) the role of emotional support in establishing a therapeutic relationship, b) the importance of the therapeutic relationship in creating a milieu for individualized education, goal setting and engaging in the problem-solving process, c) the contribution of individualized education to goal achievement, d) the importance of highly valued goals for promoting goal commitment, persistence and action, e) the role of the problem-solving process for developing and testing plans, and generalizing strategy use, and f) support for building of confidence through experience of success when testing plans.

5.1.3 Feasibility and acceptability of the pilot RCT design.

No major concerns were noted with the design of the study. While recruitment presented some challenges, the lessons learned from these challenges will assist in planning for a larger study. Retention rates, most outcome measures and blinding procedures were acceptable. Further examination of outcomes to promote the accuracy and thoroughness of evaluating participation and goal self-efficacy are required. Other areas for improvement of processes were identified and will inform planning of a larger study.

Overall, findings support the planning of a larger, potentially multi-site RCT to test the efficacy of OPC-Stroke. The next section discusses ways in which this research can inform the planning of a larger study.

5.2 Considerations in Planning for a Larger Study

In this section each of the outcomes are discussed, highlighting strengths, potential implications of findings, lessons learned and suggestions for research going forward. Following this, the components and processes of OPC-Stroke are presented with discussion of where the theoretical understanding of OPC-Stroke is or is not supported. A revised diagram of the mechanisms of action of OPC-Stroke is presented to illustrate relationships that were supported by this research and areas for further investigation. Finally, the feasibility and acceptability of the research design are discussed.

5.2.1 Outcome measures.

5.2.1.1 Participation.

The primary outcome selected for this study was the RNLI, which was selected as a measure of participation. This study was not powered to detect statistical differences between groups therefore the effect size (partial eta squared) and summary data were used to reflect on clinically important trends. In this case, the partial eta squared indicates a medium to large clinically significant difference between groups. However, the meaning of this difference is difficult to interpret given the differences between group means at pretest and six month follow-up, and the lack of difference at posttest. While both groups improved overall, the control group showed more improvement than the interventions group and the intervention group experienced a drop in scores at posttest. The numbers in the study are not sufficient to permit exploration of potential contributing factors to these differences in groups. One consideration is that the high initial pretest score for the intervention group (92/110) compared to the control group (79/110) left little room for the intervention group to show improvement. As well, theoretically, some intervention group participants may have experienced decreased satisfaction with their participation as a result of facing challenges in achieving their goals and realizing that new ways of doing were required. Further testing is needed to explore these possibilities.

While the RNLI has been identified as a preferred measure of participation due to the fact that it captures the participants' satisfaction with a broad range of abilities in the domain of participation (Kessler & Egan, 2012), it only captures satisfaction with participation. Other aspects of participation, such as performance, are not included. It is recognized that participation is a complex construct to define and therefore to measure (Whiteneck &

Dijkers, 2009; Hammel et al., 2008). The dimensions of participation can vary according to individual life situations. It may be important to capture more individualized dimensions of participation, and to measure actual performance as well as satisfaction. A composite outcome that includes different aspects and dimensions of participation may provide a more accurate measure of participation. For example, Mayo and colleagues (2015) used outcomes of the RNLI plus reported time spent in meaningful activities to measure participation in their study of community-based programs to promote participation. Desrosiers and colleagues (2007) also used the number and duration of active versus passive leisure activities to measure leisure participation. Heinemann and colleagues (2013) identified three community participation indicators: engagement (frequency of participation in activities), evaluation (satisfaction with participation), and enfranchisement (value and meaning associated with participation in the community). This group of researchers have been working on tools to capture the objective and subjective aspects of participation (Brown et al., 2004), along with participation enfranchisement (Heinemann et al., 2013).

A combination of tools, such as those mentioned above, to measure more than one aspect or dimension of participation is recommended for future research on OPC-Stroke that includes participation as an outcome.

5.2.1.2 Goal performance and satisfaction.

Preliminary efficacy of OPC-Stroke to improve performance and satisfaction with performance on identified goals was supported by the COPM results. Both groups experienced significant improvements in performance and satisfaction with performance of individually defined participation goals over time and there were no significant between group differences overall. However, the effect size for OPC-Stroke was moderate, suggesting

the difference between groups was clinically significant. Observation of summary data revealed that his difference favored the intervention group. It was also noted that the difference between groups was 1.3 at both posttest and the six month follow-up which approaches a clinically important difference of two. Overall findings suggest that OPC-Stroke may be efficacious for achieving and retaining clinically important progress towards goals.

Future testing of OPC-Stroke should consider using the COPM as a primary outcome measure due to the proposed mechanism of action where participation is believed to be improved through the process of attaining specific participation goals (Medical Research Council, 2000).

Considerations for the administration of the COPM in future trials are discussed later in this chapter under the heading, “The importance of highly valued goals”.

5.2.1.3 Emotional well-being.

At this time there is no support for improved emotional well-being as a result of receiving OPC-Stroke. While participation, goal performance and satisfaction with goal performance improved in both groups over time, albeit to varying degrees, emotional well-being decreased. It was noted that a few participants experienced other events in their lives (such as the illness or death of a spouse) that would be expected to have an impact on their emotional well-being, and therefore could have influenced the findings of this study.

Observational studies have found a reciprocal relationship between participation and well-being. In a longitudinal study of participation following stroke, Egan and colleagues (2014) found that higher participation scores were associated with subsequent improvement in general well-being and vice versa (Egan et al., 2014). Similarly, White, Attia, Sturm,

Carter, and Magin (2014) found that low community participation predicted onset of depression and post stroke depression at baseline predicted low community participation (White et al., 2014). However, studies evaluating the effectiveness of interventions to improve leisure participation have mixed findings related to emotional well-being when improvements in participation were noted. Corr and colleagues (2004) found no difference in anxiety or depression between groups despite a significant increase in COPM performance and satisfaction scores as a result of participation in a day service. While participation outcomes were promising, Nour and colleagues (2002) found no difference in depression scores following a leisure intervention. On the other hand, Desrosiers and colleagues (2007) found a significant increase in active leisure participation and satisfaction with leisure accompanied by a decrease in depression following the leisure intervention.

Given the mixed findings, it would be important to include emotional well-being as an outcome in future testing of OPC-Stroke to further examination the relationship between emotional well-being and participation. The HADS is considered to be a suitable measure of emotional well-being as it has proven psychometric properties including sensitivity to change, and it captures anxiety and depression, both of which can be a concern post stroke (Hackett & Anderson, 2005; Langhorne et al., 2000).

5.2.1.4 Goal self-efficacy.

Goal self-efficacy did not change over time in either group in this study. At baseline, both groups scored at a moderate level of goal self-efficacy and on average, this did not change with time. The potential reasons for this lack of change are discussed in section 5.2.2.7 which discusses revisions to the mechanisms of action of OPC-Stroke. However, it is

also important to consider that the GSAB-DFI measure has not been previously tested for reliability, validity and sensitivity to change **w**ith people who have experienced stroke.

There are few outcome measures for goal-self-efficacy, and a search of the literature did not reveal a goal self-efficacy measures that had been used or validated with people who had experienced stroke prior to the start of this study. Other research has used broader measures of self-efficacy. For example, Glass and colleagues measured recovery self-efficacy (Glass et al., 2004) and McEwen and colleagues used the Self-efficacy Gauge (Gage, Noh, Polatajko, & Kaspar, 1994) to measure confidence in ability to perform daily occupations (McEwen et al., 2014). Recently, Ziviani and colleagues (2014) developed a tool that could be used to complement the COPM by measuring confidence in goal pursuit, the Belief in Goal Self-Competence Scale. This scale was tested for use in pediatric occupational therapy practice (Ziviani, Poulsen, Kotaniemi, & Law, 2014) but may be useful for stroke rehabilitation research when the COPM is being used. Further review of the literature, and perhaps testing to validate a measure of goal self-efficacy following stroke, is recommended to prepare for a larger study of OPC-Stroke.

5.2.1.5 Cognition.

The finding that the difference between the two groups in cognition closely approached significance ($p = .065$) is highly supportive of the possibility that OPC-Stroke improves cognition. While it could be argued that the intervention group tended to be fewer weeks post stroke than the control group, and therefore more likely to demonstrate spontaneous recovery, the average time post stroke for the intervention group was approximately six months. Therefore, the initial period of spontaneous recovery would have passed by study enrolment. Studies examining the progression of cognitive recovery or

decline following stroke provide some support for this assumption. In a study examining the progression of cognitive recovery in the first 90 days after a minor stroke, Sivakumar and colleagues (2014) found that there was significant improvement between stroke onset and 90 days; however most improvement was in the first 30 days. Rasquin, van Oostenbrugge, Verhey, and Lodder (2006) tested participants at one and 24 months for the presence of vascular mild cognitive impairment (VMCI) following a lacunar stroke. They found that of the 71 participants who demonstrated VMCI at one month, 10 were identified as having no deficits at 24 months. The remainder of participants either remained stable or experienced cognitive decline (Rasquin et al., 2006).

This study provides preliminary evidence that OPC-Stroke may improve cognition. In planning for studies that will further test the impact of OPC-Stroke on cognition, it will be important to consider potential mechanism of action in cognitive improvement so that these may be measured as potential explanatory variables.

One potential mechanism of action that warrants consideration is based on the findings of a systematic review that examined the evidence for cognitive rehabilitation following traumatic brain injury (TBI) and stroke. Findings from this review indicate that interventions that incorporate training in metacognitive strategies can facilitate the treatment of attention, memory, language deficits, and social skills after TBI or stroke (Cicerone et al., 2011). OPC-Stroke is an intervention that incorporates metacognitive strategies in goal setting and working through the problem-solving process in real life situations, and thereby may enhance cognition. An alternate mechanism of action is that the actions required to achieve goals resulted in increased physical activity, and that increased physical activity is linked to improved cognition. A systematic review conducted to evaluate the relationship between increased physical activity after stroke and cognitive performance found that there

is some evidence to support the role of increased physical activity in optimizing cognitive function following stroke (Cumming et al., 2012).

It is important to note that the MoCA, although commonly used following stroke, was developed as a screening tool and is not a comprehensive measure of cognition. Subsequent research is needed to test the potential for OPC-Stroke to improve cognition using more in-depth cognitive assessment tools, and, as noted above, to examine the mechanisms by which OPC-Stroke may promote improved cognition

Based on the overall preliminary evidence of efficacy, there is support for further testing of OPC-Stroke in a larger trial. However, prior to this testing, there is some work to do with regards to selection and potential testing of outcome measures to improve the accuracy and thoroughness of measurement of important potential outcomes of OPC-Stroke, namely participation and goal-self-efficacy.

5.2.2 Mechanisms of action of OPC-Stroke.

In this section, the mechanisms of action of OPC-Stroke are discussed considering the integrating qualitative and quantitative findings where possible. Following this, the theoretical understanding of how OPC-Stroke works is re-visited and revised based on the current findings.

5.2.2.1 The role of emotional support in establishing a therapeutic relationship.

In OPC-Stroke, the goal of the Coach is to convey emotional support through active listening, empathizing, reframing, guiding and encouraging (Kessler et al., 2014; Graham &

Rodger, 2010). Qualitative findings revealed that emotional support received from the Coach was indeed conveyed through active listening, and through providing encouragement and feedback in a supportive non-directive manner that validated both participants' struggles and their achievements. Participants' experiences of OPC-Stroke as helpful centred on this emotional support provided by the Coach and the hope and motivation she instilled. Helpfulness seemed to be intrinsically linked to the relationship with the Coach.

The importance of emotional support following stroke was highlighted in the literature review presented in Chapter 2. Support in the form of being listened to (Beckley, 2006), enhancing confidence (Kessler et al., 2009; Reed et al., 2012; Wood et al., 2010) and providing guidance (Reed et al., 2012) was identified as contributing to enhanced participation. Participants experienced the support provided as part of OPC-Stroke in a similar manner.

Findings of this research reflect that participants felt a connection with the Coach, and experienced trust, collaboration and respect; all of which point to an effective therapeutic relationship. The therapeutic relationship was nurtured through both emotional support for goals and provision of emotional support generally. The Coach took time to listen to and be with participants. In this way interactions were tailored to meet participants' overall needs.

5.2.2.2 The importance of the therapeutic relationship.

The therapeutic relationship is recognized as an important component for promoting engagement in therapy (Morrison & Smith, 2013; Graham & Rodger, 2010; Palmadottir, 2006) and has been proposed as enhancing engagement in neurorehabilitation which, in turn, should promote neuroplastic changes and functional outcomes (Danzl, Etter, Andreatta, &

Kitzman, 2012). Yet, there is little research that investigates the impact of the therapeutic relationship on stroke outcomes.

In OPC-Stroke, the therapeutic relationship promoted sharing of information, motivation and a readiness to work towards goals, thereby contributing to goal attainment. For some participants, motivation was partially externally driven in the form of being accountable to the Coach or having someone to share progress with. Guidetti, Asaba, and Tham (2009) also found that the therapeutic relationship created a sense of accountability. They examined the influence of context on self-care with people who had experienced stroke and spinal cord injury. In the context of self-care training in stroke rehabilitation, participants described the therapeutic relationship with the occupational therapist as one of creating expectations for performance (Guidetti et al., 2009). In the initial pilot of OPC-Stroke, participants reported the encouragement and support from the Coach as being different from support available from others, suggesting a therapeutic relationship. This relationship was helpful particularly in promoting problem-solving and confidence when goals were challenging (Kessler et al., 2014).

In the broader field of rehabilitation, Morrison and Smith (2013) took a prospective approach to studying the evaluation of the working alliance, or therapeutic relationship, between client and therapist during community-based therapy. Findings present an evolution of the therapeutic relationship, established through effective communication, empathy, warmth and respect that appeared to create an impetus for clients to take actions to achieve goals (Morrison & Smith, 2013).

The current study also informs the contribution of the therapeutic relationship to engagement in therapy. Establishment of a therapeutic relationship is a key component of OPC-Stroke that seems to contribute to goal achievement. However, the therapeutic

relationship was not the only element that contributed to goal achievement and participation following stroke. Individualized education and goal-focused problem-solving were also shown to be important.

5.2.2.3 The contribution of individualized education.

In OPC-Stroke, individualized education is designed to consist of exchange of information related to health conditions and impairments, specialized strategies, provision of information about community resources and entitlements, typical development related to the person's stage of life, and teaching and learning strategies. This exchange provides opportunity to demonstrate knowledge and skills, acquire new knowledge and master new techniques, and is integrated in the problem-solving process. Individualized education thereby contributes to goal attainment and building of competence in problem-solving (Graham & Rodger, 2010; Locke & Latham, 2002).

Consistent with the design of OPC-Stroke, qualitative findings reveal that the process of individualized education involved collaborative discussion of ideas presented by both the participant and the Coach. In this research, individualized education was directed primarily towards identification of specialized strategies that were relevant for goal achievement. Strategies included suggestions of ways to alter approaches to activities, such as changing sequences during dressing, use of pacing to prevent fatigue, or sitting in a chair to fish. Strategies were tested during the problem-solving process and often led to new ways of doing to achieve goals. In some cases these strategies were applied beyond the stated goals. The qualitative data lends support to the theoretical understanding that individualized education contributes to goal attainment.

Other studies highlight the importance of strategy development for achieving goals

following stroke. Hammel and colleagues (2006) used a participatory action approach with individuals following stroke to examine barriers and support to participation. Participants established goals and then visited venues related to these goals with an access specialist to develop strategies to promote access and participation. These participation goals were met by 98% of participants following these visits with or without supports such as cognitive assists, assistive technology and environmental modifications (Hammel et al., 2006). During testing of the CO-OP approach, clients who had experienced stroke were guided to discover strategies to achieve their self-selected functional goals and showed improvement in performance of these goals (McEwen et al., 2014; McEwen et al., 2010).

While the primary area of individualized education was related to strategies for goal achievement, other topics of education in OPC-Stroke included information related to stroke recovery and available community resources. Although this type of information did not appear to contribute to goal achievement, in other studies the need for information related to stroke recovery and community resources has been identified by people living with stroke (Eames, Hoffmann, Read, & Worrall, 2010).

The areas of education revealed through the analysis did not encompass all those theoretically included in OPC-Stroke. Exchange of information related to typical development in the context of the person's stage of life, and teaching and learning strategies did not appear to occur. Further investigation is needed to determine if all of the topics of education included in the description of OPC-Stroke are relevant and need to be included. It does seem to be clear that specialized strategies are an essential aspect of education for facilitating goal achievement and contributing to the building of competence in problem-solving.

5.2.2.4 The importance of highly valued goals.

The goal-focused problem-solving process consisted of the Coach using the COPM and Personal Project Analysis to facilitate goal setting and promote the selection of highly valued goals. Following this, the Coach guided participants through a process of problem-solving that used the Person-Environment-Occupation model included steps of planning actions, carrying out plans, checking performance and generalizing.

The goal-focused problem-solving component of OPC-Stroke is informed to a large degree by goal setting theory. Qualitative findings support several aspects of goal setting theory particularly the belief that having highly valued goals serves to direct attention, trigger action and promotes persistence in working towards goal achievement.

Goals chosen by participants in this study reflected highly valued activities. These activities were given meaning for personal and social reasons as well as reasons related to identity. Review of the types of goals selected by participants reveals that a broad range of participation goals were selected. The act of formally setting goals promoted a sense of ownership of goals and a focus for actions that directed participants' attention. Subsequently, participants began to take action to achieve their goals.

The act of setting goals appeared to promote action for participants in both the intervention and control groups. Both groups made progress towards their goals as indicated by the COPM scores over time. While the intervention group made greater gains in goal performance and satisfaction with performance, the fact that the control group made progress suggests that the act of reflecting on and selecting personally valued participation goals with a health care professional may have provided participants with a direction for action.

In a study exploring the level of goal achievement at six months post inpatient stroke rehabilitation, Brock and colleagues (2009) found that 20% of participants had achieved all

goals and 73% had achieved some of the goals that they had set with a healthcare professional at the end of inpatient rehabilitation, despite the fact that no additional therapy was provided for these goals. Only 7% of participants made no progress towards their goals. Thus goal setting in itself may promote improved participation (Brock et al., 2009). As well, "over-protectiveness" by family members that limits participation has been described in some studies (Pound, 1998; Wood et al., 2010). Goals setting with a healthcare professional may have provided participants (and their family members) with permission to begin to work towards valued goals.

The potential impact of goal setting with a healthcare professional on outcomes was considered in the planning of this study. At this stage of testing OPC-Stroke, it was decided that including perceived goal achievement as an outcome measure was important for providing information regarding the potential efficacy of the intervention. The process of goal setting is considered to be an important component of OPC-Stroke and therefore the COPM was administered by the Coach instead of a research assistant. Other studies using the COPM as an outcome measure have used a research assistant to administer the COPM but commented on the potential impact on outcomes of this not being done by the treating therapist (Polatajko et al., 2012; McEwen et al., 2014). The pros and cons of each approach need to be considered in planning a larger trial. As well, the effectiveness of goal setting on its own warrants further testing with people who have experienced stroke including exploration of the characteristics of people who may or may not benefit from this simple type of intervention.

The fact that participants in the intervention group appeared to make larger gains in goal performance and satisfaction suggests that goal achievement may be enhanced by the

inclusion of a therapeutic relationship, individualized education and a structured problem-solving process.

5.2.2.5 The role of the problem-solving process.

Participants spoke about working towards their goals through setting small, quantifiable goals, checking in on their progress, re-evaluating, and making new plans. Persistence seemed to be fueled in part through achievement of small steps taken and achieved. As well, the ongoing emotional support from the Coach and individualized education related to strategies may have been important for promoting persistence when progress was slow or goals were particularly challenging. This is consistent with goal-setting theory. Locke and Latham (2002) noted that feedback about goal progress promotes the adjustment of efforts and strategies. When goals are complex, performance may be facilitated by use of short-term goals or steps that lead to the goal. As well, if one is successful in discovering strategies and achieving small steps towards goals, continued effort will be exerted.

Success in achieving participation goals often involved discovery of new ways of doings including adapting the approach to the activity (e.g., pacing) or the activity demands (e.g., sitting versus standing to fish). As well, a few participants adopted the structured problem-solving approach as a new way of approaching future goals. Other studies also report the finding of development of new ways of doing as promoting participation in valued activities. Kubina and colleagues (2013) described a process of return to participation in meaningful activities following stroke. Some participants experienced lack of success when testing out activities, lowered expectations and made adaptation to allow engagement in the

activity in a changed form. In a longitudinal study of resumption of activities following stroke, Robison and colleagues (2009) noted that some participants were able to adapt the way or the extent to which they took part in activities and were still able to derive satisfaction from these activities.

However, not all participants in this study embraced new ways of doing. Other research has found that some people choose to drop activities as opposed to accepting performance of the activity in a new way following the experience of stroke. Personal standards for activity completion may influence this decision. Morgan and Jongblood (1990) found that personal standards for activity performance had a marked impact on leisure activity resumption for 73% of the 30 stroke survivors in their study of factors that influence social and leisure activities following stroke. In the above study by Kubina and colleagues, the ability for participants to have a sense of control and set the criteria for performance seemed to be important when adapting the way in which an activity was performed (Kubina et al., 2013).

In this study two participants indicated a *Desire for a different approach*. These participants appeared to be looking for a more directive approach that was focused on remediation of specific motor impairment as opposed to focusing on achievement of participation-related goals. Studies of the process of return to participation following stroke have identified that accepting help and adaptation may represent abandoning of hope for full recovery (Reed et al., 2012). As well, the idea of resuming previous activities in a less proficient manner than before stroke can pose a threat to identity (Robison et al., 2009).

Thus, personal standards for activity performance, preferences regarding the approach and focus of therapy, and the degree to which a participation goal relates to

personal identity may need to be more fully explored during the goals setting and problem-solving processes of OPC-Stroke.

Similarly, personal characteristics warrant consideration during these processes. The influence of personal characteristics during the problem-solving process emerged during qualitative analysis. Several participants spoke about being determined, which could promote persistence and confidence for eventually achieving goals. Robison and colleagues (2009) noted that personality and outlook, including optimism, determination and perseverance, influenced approaches to addressing barriers to participation in valued activities following stroke. Given that some participants expressed a desire for a different approach and that personal characteristics appear to play a role in the problem-solving process, the characteristics of participants who do not appear to respond to OPC-Stroke should be examined in a larger trial.

The final step in the problem-solving process is *Generalize,* that is, the application of learned strategies and processes to future goals. Participants spoke about future goals in terms of new goals, and continuing to work on goals they had not yet achieved or had achieved but wanted to maintain. A few spoke about using strategies that they had applied to past goals and about applying the problem-solving process to new goals. A couple of participants had identified new strategies on their own to promote motivation. Perhaps these participants had insight into the ways in which the Coach provided motivation and recognized the need for ongoing structure.

Qualitative findings support that participants learned to apply strategies and processes to new goals. The ability to address future participation challenges is an important objective of OPC-Stroke. To confirm the qualitative findings relating to generalization, more objective ways to evaluate the ability to generalize knowledge and strategies following OPC-Stroke

should be explored when planning a larger trial. The CO-OP approach also specifically promotes generalization of use of the CO-OP problem-solving strategy; researchers are beginning to develop evidence to support generalization post stroke through examining improvement in performance of untrained goals (McEwen et al., 2014; McEwen et al., 2010). Examination of performance in untrained goals could be used to more objectively evaluate the ability of participants to generalize use of knowledge and strategies following OPC-Stroke.

5.2.2.6 Support for development of confidence or self-efficacy.

Theoretically, self-efficacy for current and future goals is developed through the process of developing and testing plans, the experience of success in addressing challenges and achieving smaller goals that lead to achievement of their larger goals (Bandura, 1977).

All participants, who completed the intervention, indicated that they experienced success in working towards and achieving some, if not all, of their goals. In the qualitative findings, self-efficacy for goals was reflected in participants' confidence in their ability to eventually achieve partially met current goals and future goals following the OPC-Stroke intervention. Self-efficacy was also reflected in the analysis of the experience of OPC-Stroke. The category, *OPC-Stroke provided opportunity for insightful reflection*, portrays the experience of a few participants who conveyed confidence in their ability to have achieved their goals on their own when reflecting back on the intervention. The design of the intervention as a truly client-centered approach where clients' strengths and skills are identified and developed, means that participants may not attribute success to receiving the intervention but to themselves instead. Examination of specific scenarios, through review of

audiotaped sessions, revealed that participants took ownership of and built on ideas and strategies that came from the Coach during conversations around goals and plans. This highlights the skill of the Coach in guiding and empowering participants. Thus, it does not appear that participants initially had the knowledge and confidence to achieve their goals. Instead, self-confidence or self-efficacy appears to have emerged as a result of reflecting on the intervention and progress made towards goal achievement.

The qualitative findings indicated that OPC-Stroke promoted the development of self-efficacy for addressing future participation challenges. However, contrary to the qualitative findings, quantitative findings showed no change in goal self-efficacy over time for either group. At baseline, both groups scored at a moderate level of goal self-efficacy and this did not change with time on average. Given that self-efficacy beliefs have been tied to goal achievement (Bandura, 1977; Maddux, Sherer, & Rogers, 1982), it is surprising that participants rated goal performance and satisfaction higher over time but self-efficacy beliefs related to these goals did not change. It could be that individual scores varied based on achievement or lack of achievement of individual goals and that these variations were not reflected in the average scores for goals at each time point. It could also be that participants had a high enough initial level of self-efficacy to achieve their goals. These ideas warrant further investigation in a larger study.

Self-efficacy may also be a difficult concept to change. While McEwen and colleagues (McEwen et al., 2014) found a medium effect of CO-OP on self-efficacy for daily occupations in their study, other approaches appear to have made little impact on self-efficacy. For example, studies evaluating the effectiveness of Chronic Disease Self-Management, which is designed to improve self-efficacy for illness self-management, have found no sustained change in self-efficacy for people who have experienced stroke

(McKenna et al., 2013; Kendall et al., 2007). Similarly, the Families in Recovery from Stroke Trial tested an intervention designed to improve self-efficacy and found no change in recovery self-efficacy (Glass et al., 2004). It could be that self-efficacy may take longer to change following stroke. The experience of stroke can lead feelings of loss of control over oneself and one's environment. This loss of control may delay the development of self-efficacy for specific goals. Self-efficacy may also be harder to change if a person has already experienced lack of success in attempting to reach goals following stroke.

This study was designed to examine mechanisms of action using primarily qualitative methods to further develop the theoretical understanding of OPC-Stroke. The above examination of the components and processes that contribute to goal achievement along with the quantitative results suggest that the theoretical understating of OPC-Stroke, as described in Chapter 2, requires some adjustments. These are discussed and illustrated below with a revised model of the mechanisms of action of OPC-Stroke.

5.2.2.7 Revised mechanisms of action of OPC-Stroke.

The mechanisms of action of a complex intervention assist in determining explanatory variable to measure and analyze during testing of the intervention (Medical Research Council, 2008; Campbell et al., 2007). As well, examination of the mechanisms of action provides insights into the structure, process and key ingredients needed to promote participation in valued activities in general. This knowledge can be used to inform other interventions, as well as to apply OPC with other populations.

As noted in the previous section, there is support for most aspects of the mechanisms of action previously described. Specifically, provision of emotional support promotes

formation of a therapeutic relationship, i.e., a milieu of trust, respect and collaboration, when combined with a process for facilitating goal setting and individualized education, leads to selection of highly valued and important participation goals. Ongoing emotional support and individualized education, combined with goal-focussed problem-solving can result in readiness to engage in and assume responsibility for developing and testing out plans, which in turn promotes success with participation goals.

However findings do not fully support that the above process leads to the development of self-efficacy for achieving future participation goals, nor that achievement of success with participation goals translates into improved participation, which in turn leads to improved emotional well-being. While preliminary findings suggest that cognition improved, this improvement does not seem to be directly related to increased participation. Revisions to the mechanisms of action, or how OPC stroke works, are depicted in Figure 5.1.

The most significant change to the figure is the addition of the therapeutic relationship that creates the milieu for all processes of OPC-Stroke. While the therapeutic relationship is described in relation to emotional support in the initial theoretical understanding, it is now formally recognized as a critical component through representation in the diagram. Provision of emotional support promotes the establishment and maintenance of the therapeutic relationship, which provides a milieu for individualized education, setting of highly valued goals and developing and testing plans to achieve these goals.

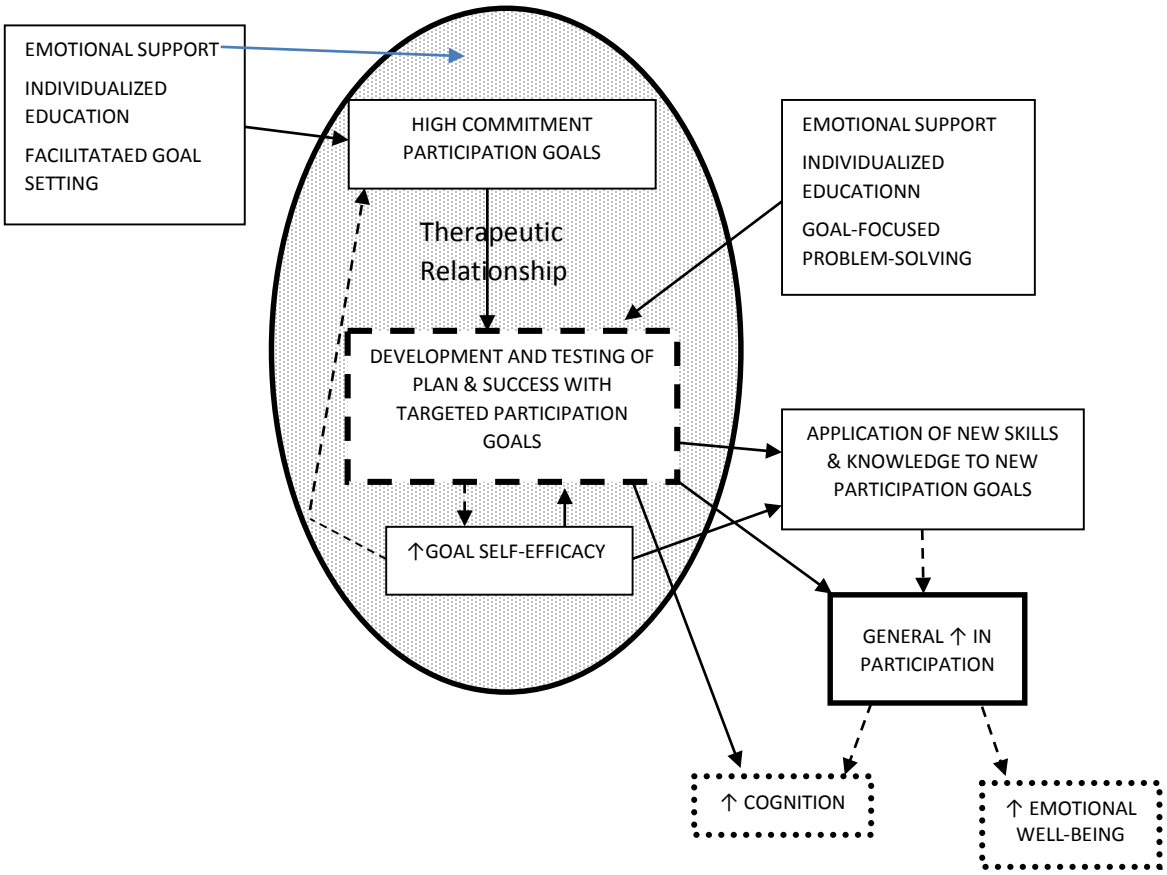

Figure 5.1 How OPC-Stroke Works (version 2)

Initially the components of OPC-Stroke were conceptualized as separate discreet components. This study has highlighted the interconnections between these components, and the importance of these components being integrated as one package. Provision of emotional support is integral to the individualized education and the goal-focused problem-solving processes. Individualized education is provided in the context of, and directly related to, the problem-solving process. The three components are now represented as being in one box instead of three separate boxes.

Based on some of the quantitative findings, the relationships between some items are more tentative as indicated by dashed lines. As well, a new arrow has been added from the processes of OPC-Stroke to improved cognition. Since overall participation did not improve, the apparent improvement in cognition cannot necessarily be explained by an increase in participation. Instead, this improvement is more likely attributable to participation in the problem-solving process.

It is not clear whether self-efficacy develops during the developing and testing of plans with experience of success, or whether, given a moderate level of goal self-efficacy to begin with, it merely contributes to this process as well as contributing to the testing of future goals.

Findings support the processes of OPC-Stroke as promoting success with participation goals and therefore increased participation as it related to these goals. However the support for OPC-Stroke improving general overall participation is not supported at this time.

Finally, the findings of this study do not support that OPC-Stroke improved emotional well-being by improving participation. While there is research evidence from other studies to support a link between emotional well-being and participation, the impact of interventions designed to increase participation on emotional well-being needs further exploration.

The revised theoretical understanding of OPC-Stroke maintains the key ingredients of OPC-Stroke but highlights explanatory mechanisms that require further investigation during future testing of OPC-Stroke.

5.2.3 Feasibility and acceptability of the research procedures.

Demonstration of the effectiveness of a new intervention requires at least one large, multisite RCT. Pilot testing of research procedures is recommended as part of the process of planning such a large multisite RCT. In this section, I will discuss processes that worked well, lessons learned and suggest strategies to overcome challenges that were experienced. These are presented under the heading of recruitment, retention, general procedures and outcome measures.

5.2.3.1 Recruitment.

While recruitment presented some challenges in this study, having an established relationship with the clinicians who were assisting with recruiting was important for the degree of success attained. Although the target number of participants could not be recruited within the timeframe of this project, a sufficient number of participants were recruited to inform planning of a larger trial.

Several of the challenges related to recruitment could be avoided in future studies through planning. For example, this study provided insights into the settings that might be most appropriate for recruitment. Few participants from the acute care setting were appropriate for the study, as they could not identify unmet goals. Therefore, the outpatient stroke rehabilitation setting appears to be a better setting for recruitment of participants for future studies.

Outpatient stroke rehabilitation clinics may follow people for varying lengths of time post stroke or may readmit people for therapy to restore deteriorating function. There may be a need to establish a maximum time post stroke as an inclusion criterion.

Not all eligible patients were able to identify goals. To facilitate recruitment by clinicians, further screening by a research assistant could be done following consent. This would help avoid initial meetings with a Coach for individuals not likely to participate.

As well to increase the likelihood of contacting all people potentially interested in taking part in the study, it would be advisable to collect an alternate contact number.

5.2.3.2 Retention.

Overall retention was acceptable at 80%. Loss of participants in the intervention group due to the experience of other illnesses following stroke could not be predicted or avoided. Only one participant withdrew from the intervention group because she was not experiencing the intervention as helpful. It is not clear whether or not she would have agreed to participate in the study if she had better understood the approach being used in OPC-Stroke. A similar concern was raised during initial feasibility testing of OPC-Stroke (Kessler et al., 2014), and an effort was made in this study to explain the intervention more clearly to participants.

The strategy for retention of the control group appeared to be effective as all control group participants remained in the study and seven out of 11 expressed an interest in receiving the intervention.

5.2.3.3 General procedures.

The communication strategies that were established to maintain blinding appear to have been effective. The assessment of maintenance of blinding of the research assistant conducting outcome evaluations revealed that blinding was generally maintained.

In this research, fidelity of the delivery of the intervention was examined. Achieving treatment fidelity of complex interventions, such as OPC-Stroke, is recognized as being more challenging than achieving treatment fidelity of simple interventions (Carroll et al., 2007). Therefore, achieving treatment fidelity in 80% of the sessions evaluated was considered satisfactory. However, enhancement of therapist training could improve treatment fidelity, particularly for delivery of the intervention to the first couple of participants. Practice of the intervention with people who have experienced stroke prior to delivery of the intervention with study participants is recommended. This practice should focus on communicating to provide emotional support and establish a therapeutic relationship, developing competence in use of a non-directive, solution-focused approach, and use of intervention processes such as goal setting and problem-solving.

Reliability of the Treatment Fidelity evaluation tool was not established prior to use in this study. Prior to use in a larger study, it is recommended that training procedures for use of the tool and the reliability of the tool be established.

5.2.3.4 Acceptability of outcome measures.

Most of the outcome measures were completed by participants without difficulty; however, the GSAB-DFI posed challenges for six participants, albeit at only one of the time points. Although these challenges were not noted consistently, it is important to address them for future studies to promote accuracy of data collection. Issues were noted with alignment of scoring and with understanding of the meaning of items. To avoid future problems with alignment of items, careful attention to the layout of the measure is recommended. Three participants experienced decreased understanding of, or agreement with wording of items.

One of these participants completed the French version of the measure. As this version has not been fully validated through formal testing, the specific words used may have led to difficulties with rating items. It is noted, however, that this only occurred at posttest and two participants using the English version also displayed some difficulties at one time point. Alternative measures for goal self-efficacy should be explored for future studies to address this concern.

While the MoCA was completed by all participants at all time points, some participants were reluctant to engage with it. It will be important for research assistants in future studies to be aware that cognitive assessment tools are potentially threatening to participants. They should therefore be prepared to explain how cognitive test results will be used in the research.

Concerns with regards to acceptability of outcomes measures from a measurement perspective had been presented, as applicable, under the discussion of specific outcomes earlier in this chapter. In particular it is recommended that a composite measure for participation be used and that further review of measures of goal self-efficacy be conducted to select the most appropriate tool.

5.3 Limitations

There are four main limitations to this study. The first limitation is lack of masking of the participants and providers. In an ideal situation, participants, providers and evaluators are masked to treatment allocation. In this study, only the evaluators were masked. That is, the Coach administered the initial COPM and the GSAB-DFI prior to randomization and therefore did not know whether the participant would be assigned to the intervention or

control group. The research assistant administering the other evaluations pretest, posttest and at the six month follow-up was also masked to each participant's group allocation. Consistent with many RCT's conducted in rehabilitation, it was not possible to mask the person administering the intervention. As well, delivery of an inactive sham treatment in order to mask participants was problematic both from an ethical and a feasibility standpoint. Nonetheless, bias may have been introduced in that participants in the intervention group may have rated themselves more favorably so as not reflect negatively on the Coach with whom they had developed a relationship.

The second limitation is related to the use of self-report measures as outcome evaluations. Self-report measures may be more susceptible to bias when participants are not masked. However, the individualized nature of participation requires use of a subjective measure. As mentioned earlier, a composite measure of participation may better capture all aspects and dimensions of participation in future studies. This composite measure could include objective as well as subjective measures.

Third, as noted earlier, the use of goal setting with both the intervention and control group presents challenges to identifying the impact of OPC-Stroke compared to usual care**.** In fact, one could say that this study compared OPC-Stroke to facilitated goal setting with a health care professional. To assist in understanding the potential impact of goal setting by itself, interviews could have been conducted with the control group. However, these interviews would have needed to be conducted at the six month follow-up to avoid contamination by discussing goals. At this time point, recall may not have been as accurate. To further examine this question, future studies of the efficacy of OPC-Stroke could include three arms, one of which does not include goal setting.

The fourth limitation is this study excludes stroke survivors with moderate to severe functional deficits. OPC-Stroke is a verbal metacognitive approach, requiring ability to share ideas and participate in problem-solving. Proof of efficacy with participants who clearly have these abilities is important prior to testing and adapting the intervenient for those with more severe communicative and cognitive deficits. Although the aim was to exclude only those with more severe cognitive and communicative deficits, discharge FIM™ scores indicate that participants in this study had only mild functional deficits. Therefore, those with moderate to severe functional deficits were not represented in this study**.**

This is an initial pilot study with a small number of participants. The purpose was to inform a larger RCT of OPC-Stroke. Therefore it is understood that findings cannot be generalized.

5.4 Summary

This research provides preliminary evidence for the efficacy of OPC-Stroke and provides valuable insights to inform the theoretical understanding of OPC-Stroke as well as the planning of a larger multisite RCT.

From a clinical perspective this research highlights the role the therapeutic relationship can play in promoting engagement in therapy. Clinicians may gain insights into important ways in which emotional support can be provided to promote the establishment of the therapeutic relationship, including taking time to be with clients and listen to their day-to-day concerns.

OPC-Stroke provides a structure and processes for truly client-centered goal setting, along with planning and decision making to achieve goals. As such, this research may help to

inform occupational therapists, and other healthcare professionals, as to ways to integrate more client-centred principles into their practice and thereby promote client autonomy in rehabilitation.

As well as supporting further testing of OPC-Stroke, this research identifies related areas for ongoing inquiry. These include the need to develop ways to measure participation that consider the complexity surrounding its definition, the need to validate measures of goal self-efficacy with people who have experienced stroke, and the need to further examine how the therapeutic relationship contributes to engagement in rehabilitation and contributes to outcomes.

Chapter 6: Conclusions

Effective interventions to promote participation following stroke are needed to address a primary concern of those living with stroke: the ability to occupy their time in meaningful ways.

OPC-Stroke is a novel intervention, adapted from OPC, which was developed for parents of children with participation challenges. The adaptations made to create OPC-Stroke were based on a review of the stroke literature to determine factors associated with participation in that population. OPC-Stroke is a complex intervention in that it is multi-modal, tailored to the person and involves multiple outcomes. To understand the potential mechanisms of action of OPC-Stroke, a theoretical model of how OPC-Stroke works was developed. Within this model, OPC-Stroke integrates key components that have been identified as being important for promoting participation following stroke: emotional support, individualized education and goal-focused problem-solving. Other interventions have included some of these components but none were found that integrate all components.

Prior to this study, and consistent with the process for developing and evaluating a complex intervention, initial testing of OPC-Stroke was done to get input on the acceptability of the intervention design and tools from people who have experienced stroke (Kessler et al., 2014). This input resulted in changes to the number of sessions and overall duration of OPC-Stroke.

6.1 Contributions to the Literature

This thesis presents the next step in testing OPC-Stroke, a pilot RCT with an embedded qualitative component to begin to examine the efficacy of OPC-Stroke, gain

further insights into the mechanisms of action and test study procedures for feasibility and acceptability. Findings from this evaluation indicated that the research procedures are generally feasible and that OPC-Stroke is potentially efficacious for improving performance and satisfaction with performance of individually identified participation goals and for improving cognition. Therefore, testing should proceed to a larger trial to test the efficacy of OPC-Stroke.

In going through the above phases of development and evaluation, this research utilized best practice for the development and evaluation of complex interventions as defined by the Medical Research Council (Medical Research Council, 2008). This work thereby provides a practical example of the cyclical process and the key elements of development and evaluation processes outlined for complex interventions.

The mixed methods design of the pilot RCT allowed greater insights into the potential efficacy of OPC-Stroke and its mechanisms of action. The quantitative findings indicated that OPC-Stroke may contribute to the achievement of clinically important improvements in goal performance, satisfaction with goal performance and cognition following stroke rehabilitation. While it was surprising that the primary outcome of participation did not show similar trends, this may be due to the fact that participation is a complex concept to define and therefore broader strategies for measurement are needed.

The qualitative findings supported the primary mechanisms of action of OPC-Stroke. Emotional support contributed to the formation of a therapeutic relationship, which created a milieu of trust, respect and collaboration for individualized education, goal setting and problem-solving. Individualized education, primarily in the form of information exchange related to specialized strategies, promoted goal attainment. Facilitated goal setting led to the

formation of highly valued goals, which directed attention, and promoted persistence and action to achieve these goals. Finally, the problem-solving process led to success in achieving or partially achieving goals with application of learned strategies to future goals. This understanding of how OPC-Stroke works contributes to the understanding of how interventions may facilitate re-engagement in valued activities by people who have experienced stroke or other chronic conditions.

Integrating the qualitative and quantitative findings illustrated areas of agreement and contradiction within the theoretical understanding of how OPC-Stroke works. For example, both qualitative and quantitative findings support that participants achieved their identified goals. However, while quantitative findings showed no change in self-efficacy, qualitative findings suggest that self-efficacy improved as participants worked through the problem-solving process. This difference in findings indicates a need for further research into the role of self-efficacy in achieving goals post stroke and how it develops during the process of pursuing goals.

While mixed methods studies are espoused as being important for examining complex interventions, few have integrated the qualitative and quantitative findings. This research provides an example of such an integration of findings based on methods described by Bazeley (2009).

Although the findings of this research are preliminary, insights gained may be used to inform clinical practice. For example, OPC-Stroke provides a structure to promote involvement of clients in goal setting and problem-solving that can contribute to client autonomy or responsibility for decision-making in rehabilitation. The fact that both groups showed improvements in goal performance, satisfaction with goal performance and

participation suggests that setting individually valued goals with a healthcare professional by itself may be beneficial. This provides more support for the inclusion of client-selected goals in rehabilitation.

As well, support for the role of the therapeutic relationship in promoting engagement in therapy is provided in this thesis. Whether using OPC-Stroke or another intervention approach, clinicians can provide emotional support through active listening, empathizing, reframing, providing encouragement and taking time for clients everyday concerns in order to promote an effective therapeutic relationship and thereby enhance engagement in therapy.

6.2 Areas for Future Research

Larger scale testing of OPC-Stroke is now needed to demonstrate efficacy. In preparation for this trial, selection of a composite measure of participation that encompasses dimensions such as time spent in meaningful activities is recommended. As well, a measure of goal self-efficacy that has been validated with people who have experienced stroke and has demonstrated sensitivity to change is needed. Testing of a goal self-efficacy measure may be required to establish psychometric properties with people who have experienced stroke.

Other areas for future inquiry identified in this thesis are: a) the potential benefits of goal-setting with a healthcare professional as an intervention; b) the role of self-efficacy in goal achievement following the experience of stroke; c) whether involvement in a problem-solving process to achieve personally valued goals can improve cognition and the mechanisms by which this may occur; and d) further examination of how the therapeutic relationship contributes to engagement in rehabilitation and to rehabilitation outcomes.

Methods to examine these areas could be incorporated into a larger scale testing of OPC-Stroke.

As medical treatment for stroke improves and as the population ages, the number of people living with the effects of stroke has been increasing. The majority of these people, even those with mild strokes, experience challenges with participation. While participation has been gaining exposure as an important outcome following stroke, it is still not adequately addressed. The focus of rehabilitation remains on recovery of impairment and promoting independence in basics activities of daily living. The value of promoting participation has not fully been recognized. To gain the recognition needed for participation to be addressed as part of the standard of care in mainstream rehabilitation, effective interventions are needed that promote participation during rehabilitation and beyond. OPC-Stroke is an intervention that is poised to meet these criteria.

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Appendix A: Theoretical Background of OPC-Stroke Components

OPC-Stroke Component	Theoretical Background	Key Concepts
Emotional Support	Humanism	• Holistic approach, based on a collaborative relationship, client is valued and respected • Client is viewed as having the knowledge and internal resources to resolve his/her own issues
	Social Support Models	• Consideration of both the structure and process of social support • Provision of emotional support
Individualized Education	Adult Education	• Goal oriented • Promotes self-direction or responsibility for actions and choices, • Builds upon knowledge, skills and life experiences, • Individualized approach
Goal-Focused Problem-Solving	Goal Theory	• Goals serve to direct of attention, enhance energy, promote persistence, and promote action • Goal commitment is influenced by the importance assigned to goal attainment and self-efficacy for goal attainment • Feedback about goal progress allows a person to adjust his/her efforts and strategies • Amount of effort exerted depends upon ability to discover appropriate strategies to address the complexity of the task
	Social Cognitive Theory	• Behavior is influenced by knowledge of performance, self-evaluation of how performance outcomes meet personal standards and self-efficacy beliefs • Self-efficacy is considered to be a major determinant of activity or goal choice, effort expenditure and sustainability of effort under stress • Self-efficacy is influenced primarily by performance accomplishment or mastery
	Metacognition	• Learning and use of metacognitive skills or strategies: selecting meaningful goals, consciously planning, monitoring progress, allocating effort, use of specific strategies
	Social Solution-Focused Therapy	• People are healthy, competent and capable of constructing solutions to improve their lives • Focuses on finding solutions • Draws on a person's strengths and positive experiences to achieve goals
	PEO Model	• Model for analysis of interaction between person, environment and participation goal
	Social Support Models	• Considers social roles and social resources

Appendix B: Outline of OPC-Stroke Sessions

Preparation for Sessions:
Provide a folder with blank paper.
Encourage participant to write things down during sessions and keep their notes in the folder. (You may assist them with this.)

Session 1
Goals:

- Establish rapport
- Identify and document goals

Tasks:
Identify Goals
Personal Project Analysis (PPA) is used to identify goals. The PPA is used to assist with thinking about projects and to reflect on different aspects that might influence their selection as a goal. The PPA is used to develop a list of projects and then to select and rate 3 blocked or new projects for which to apply goal setting

Setting Goals
As much as possible goals should be specific, measurable and attainable within 10 sessions. Ask the person to visualize what attainment of the goal looks like. You may ask, "What would be different from now?" "What does it look like when you are...?" Document this as the goal.
Goals that are perceived by the therapist to be unrealistic should not be discouraged. In this case the therapist should strive to understand the essence of the goal and capture this in the wording. As the person begins to work towards this goal, the therapists can guide him/her to break it down into attainable steps.

Preparation for next session
Provide participant with a written copy of his/her goals (Do not include the ratings)
Inform participant that the next step for the research project is randomization to receive intervention now or possibly later, and that you will contact/him/her to let him/her know
Establish preferred method of contact.

Session 2
Goals:

- Rapport building
- Begin goal-focused problem solving process for one goal

Tasks:
Explain problem solving process
Provide participant with a written copy of the goal-focused problem solving process and explain each step – Set goal, Explore options, Plan actions, Carry out plan, Generalize

Have participant select one goal to apply the process to.

Explain the PEO model
The PEO model is used as part of the explore options phase. Provide the participant with a copy of the PEO model and explain how it can be used to analyze ways to achieve a goal. Discuss personal strengths/challenges, environmental facilitators/barriers and specific demands of one occupational participation goal. Worksheets may be used to facilitate this.

Define action steps to achieve goal
Following review of goal-focused problem solving process and PEO model have participant identify one-two action steps to complete over the next week.

Homework
Complete agreed upon action steps

Confirm next meeting time

Sessions 3
Goals:

- Progress towards goal achievement using goal-focused problem solving process for first goal
- Begin goal-focused problem solving process for remaining goals

Tasks:
Check progress and plan next steps for first goal
Review goal-focused problem solving process and PEO model focusing on remaining goals. Have participant identify one-two action steps to complete for each goal over the next week.

Sessions 4 – 8
Goal:

- Progress towards goal achievement using goal-focused problem solving process for all goals

Tasks:

- Check progress and plan next steps for each goal

Session 9
Goals:

- Progress towards goal achievement using goal-focused problem solving process for all goals
- Prepare client for ending of coaching sessions – begin to close the therapeutic relationship

Tasks:

- Check progress and plan next steps for each goal
- Remind participant that there is only one session left. Identify any outstanding concerns related to the OPC intervention. Apply problem solving process to these concerns with participant, as appropriate.

Session 10

Goals:

- Identify state of goal achievement
- Promote ongoing work towards goals that are not fully achieved
- Close therapeutic relationship

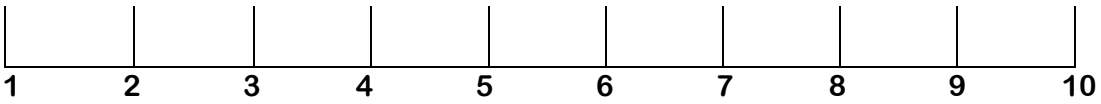
Tasks:

- Review progress towards goal achievement for each goal including strategies, tools and resources used.
- Encourage participant to continue to use goal-focused problem solving process
- Discuss options to address any remaining concerns related to the OPC intervention.
- Close relationship

Appendix C: The Reintegration to Normal Living Index

1. I move around my living quarters as I feel is necessary.

   (Wheelchairs, other equipment or resources may be used).



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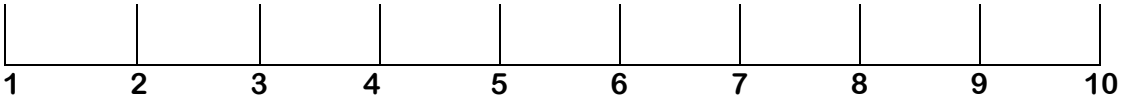
2. I move around my community as I feel is necessary.

   (Wheelchairs, other equipment or resources may be used).



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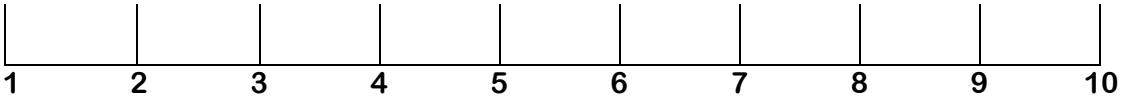
3. I am able to take trips out of town as I feel are necessary.

   (Wheelchairs, other equipment or resources may be used).



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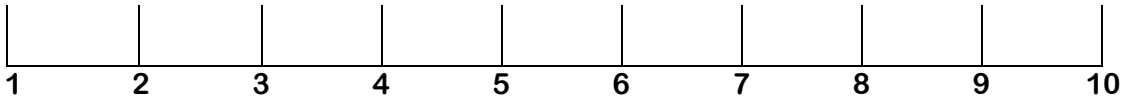
4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met.

(Adaptive equipment, supervision, and/or assistance may be used).



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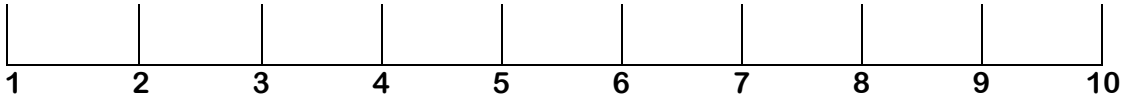
5. I spend most of my days occupied in a work activity that is necessary or important to me. Work activity could be paid employment, housework, volunteer work, school, etc.

(Adaptive equipment, supervision, and/or assistance may be used).



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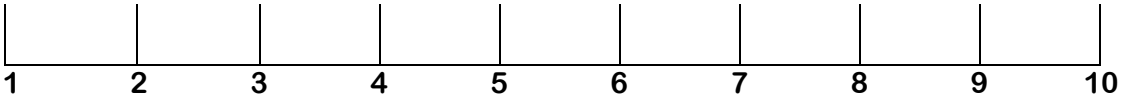
6. I am able to participate in recreational activities – hobbies, crafts, sports, reading, television, games, computers, etc., as I want to.

(Adaptive equipment, supervision or assistance may be used).

does not describe my situation at all ***fully describes my situation***

7. I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me.

(Adaptive equipment, supervision or assistance may be used).



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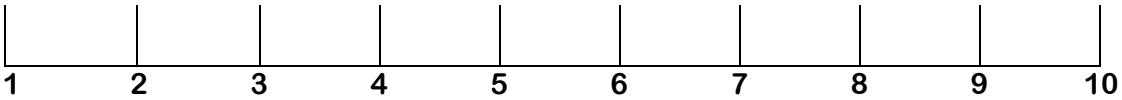
8. I assume a role in my family which meets my needs and those of other family members. Family means people with whom you live and/or relations with whom you don't live but see on a regular basis.

(Adaptive equipment, supervision, and/or assistance may be used).



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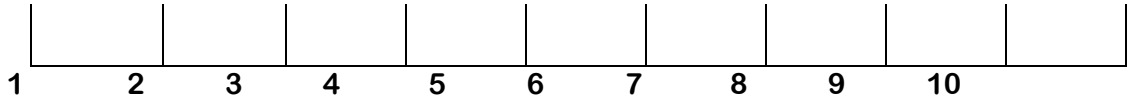
9. In general, I am comfortable with my personal relationships.



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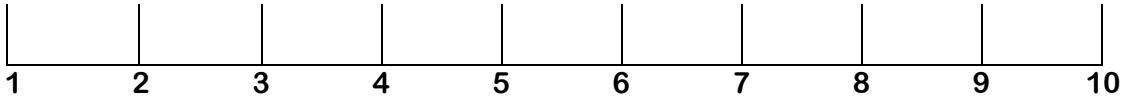
10. In general, I am comfortable with myself when I am in the company of others.



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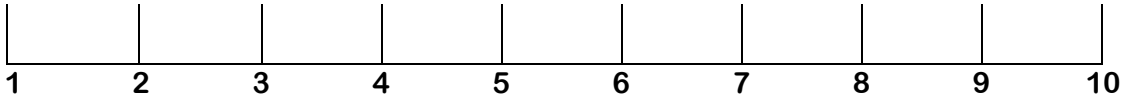
11. I feel I can deal with life events as they happen.



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Appendix D: Goals Systems Assessment Battery - Directive Function Indicators (French)

But :

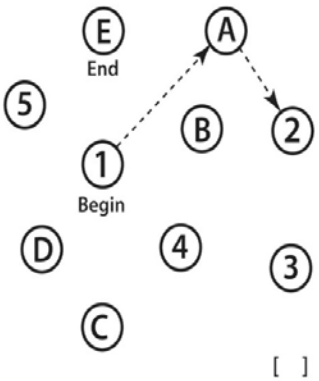
	Pas du tout	Légèrement	Modérément	Beaucoup	Extrêmement
Je possède les compétences requises pour atteindre ce but					
Ce but est valable pour moi					
J'ai les connaissances requises pour atteindre ce but					
Ce but en vaut la peine					
Ce but est important pour moi					
J'ai ce qu'il faut pour atteindre ce but					
Ce but est significatif pour moi					
J'ai la capacité d'atteindre ce but					

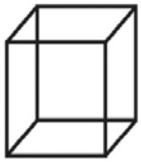
Appendix E: The Montreal Cognitive Assessment

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE





Copy cube

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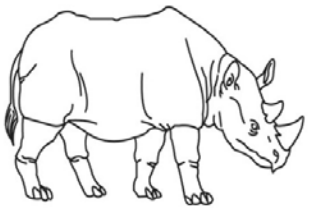
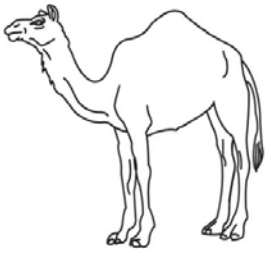
Draw CLOCK (Ten past eleven)
(3 points)

[ ] Contour [ ] Numbers [ ] Hands

POINTS __/5

NAMING





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__/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

__/3

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ]

__/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)

__/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler

__/2

DELAYED RECALL

	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
		[ ]	[ ]	[ ]	[ ]	[ ]	
Optional	Category cue						
	Multiple choice cue						

__/5

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30

TOTAL __/30
Add 1 point if ≤ 12 yr edu

Administered by: _____

Appendix F: Semi-structured Interview

This interview consists of 7 primary questions with sub- questions that can be used as prompts. As well the interviewer will use prompt such as "tell me more about that", "yes...", "anything else"

The purpose of this interview is to gather your thoughts and feedback about the Occupational Performance Coaching intervention that you participated in.

1. To start, can you tell me about the intervention?
    a. What did you do during the visits with the Coach?
    b. What did you talk about?
    c. What was the Coach like?
        i. Was she easy to talk to?
        ii. How did you feel during the visits?

2. Tell me a bit about the goals you chose.
    a. How did you come to choose these goals?

3. What did you do to work towards your goals?
    a. Did you achieve your goals? Why do you think you achieved/did not achieve your goals?
    b. For goals that you progressed on, what helped? What did not help

4. Thinking about future goals, how will you approach these goals?
    a. How successful do you think you will be in achieving your future goals?
    b. What will help or hinder you form achieving them?

5. Was there anything you really liked about the intervention?
    a. Tell me about these?
    b. What was most helpful?
    c. Did it help to meet any of your needs related to getting back to you activities following stroke? Please explain.

6. Was there anything you didn't like about the intervention?
    a. Tell me about these?
    b. What was least helpful?
    c. What needs related to getting back to your activities were not addressed? Please explain.
    d. What would you change?

7. Is there anything else you would like to tell me that I might have missed?

Appendix G: Coding Structure

1. Participant experience of OPC-Stroke

Codes not predefined

- Likes/dislikes
- Helpful/unhelpful
- General comments

2. Which components and processes of OPC-Stroke contribute to goal achievement?

Components of OPC-Stroke	**Code**	**Definition**
Support	Therapeutic relationship	Participants trusted the Coach
		Participants respected coach and felt respected by Coach
		Working together to achieve goals
		Client was ready to work toward goals
	Emotional Support from Coach	Encouragement from Coach Coach listened to me Coach non-critical Appreciated visits
	Social support for goals	Support from family and other sources for goals
	Other – not defined	
Education	Individualized education	Coach provided information specific to goals
	Comfortable information exchange	Participant felt comfortable sharing information
	Information provided was relevant	Coach provided information that met participant's needs or was related to his/her goals
	Other – not defined	
Goals	Goals chosen by client	Participant selected own goals
	Goals important	Having goals was important
	Goals of highly valued	Goals were valued/important to the participant. Selecting own goals was important
	Goals promoted action	Goals served to direct attention, promote persistence and promote action
	Other – not defined	
Goal-focussed problem-solving	Developing plans	Drew on strengths, resources and positive experiences
		Breaking down goals into steps is important

	Testing plans	Participant felt responsible for action and choices
		Checking on goals progress is helpful
		Coach provided guidance during problem-solving
		Coach was non-directive
	New codes	Plans not easy
		Stroke challenge - Deficits following stroke that present challenges: decreased balance, limb weakness/incoordination, decreased memory, impaired communication/language
		Goal challenge - Challenges achieving goal not related to stroke
	Success with participation goals	Participant had opportunity to make choices
		Feel positive about achievements
		Participant feels able to achieve goals
		Participant feels better able to achieve future goals. Participant will use problem-solving process for future goals.
		New ways of doing
		Lack of success - Goal not achieved Uncertainty re goal achievement
	Personal characteristics	e.g. Value of independence, internally motivated, stubbornness
	Other – not defined	
Application to new participation goals	Generalizing of problem-solving	Participant plans to use problem-solving process for future goals
	Future goals	Participant plans to pursue future participation goals
	Future strategy use	Participant plans to use specific strategies learned in future
	Other – not defined	

Appendix H: Treatment Fidelity Checklist

Participant #_____ Session #_____ Date_____

Tick the items that occurred during the session and rate the related times that follow

___ **Facilitated Goal Setting**

a) PPA was used to set goals

YES NO

b) Participant was provided with a written copy of his/her goals

YES NO

c) Collaboration during Goal Setting[1]

1	2	3	4
The Coach actively assumes the expert role for the majority of the interaction with the participant. The Coach minimizes participant ideas for goals	The Coach favors supplying knowledge or expertise. The Coach seeks participant input into goals but directs the selection and definition of the goals	The Coach promotes the participant's goals, ideas and values but does not do so consistently. The Coach may implicitly influence participant's selection of goals.	The Coach fosters collaboration and power sharing so that goals are selected, and defined by the participant. The Coach explicitly identifies the participant as the expert

___ **Problem-Solving Process** *(Tick steps and compete a) below)*

___ Explore options *(Complete b), c), d), e) below)*

Goal #1 Goal#2 Goal #3

___ Plan action steps *(Complete f) below)*

Goal #1 Goal#2 Goal #3

___ Carry out plan (review of what was done)

Goal #1 Goal#2 Goal #3

___ Check performance

Goal #1 Goal#2 Goal #3

___ Generalize (Review of strategies, tools and resources used to achieve goals Encouragement provided to continue to use goal-focussed problem-solving process)

a) Participant received a handout illustrating the problem-solving process

YES NO

b) The Coach presented and explained the PEO model

YES NO

c) Participant received a handout illustrating the PEO model

YES NO

d) Collaborative performance analysis process was used

For: None

Tick the aspects of collaborative performance analysis used

___ Identification of personal strengths and resources Goal: 1 2 3

___ Identification of environmental facilitators/barriers Goal: 1 2 3

___ Identification of specific demands of one occupational participation goal.
Goal: 1 2 3

___ Participant was asked to identify what currently happens Goal: 1 2 3

___ Participant was asked Identify what the participant would like to happen Goal: 1 2 3

___ Participant was asked explore barriers and bridges to enabling performance
Goal: 1 2 3

___ Participant was asked identify his/her needs in planning and taking actions to achieve goals. Goal: 1 2 3

e) Collaboration during analysis[1]

1	2	3	4
The Coach actively assumes the expert role for the majority of the interaction with the participant. The Coach minimizes participant ideas	The Coach favors supplying knowledge or expertise and may not perceive or may ignore opportunities for mutual problem-solving.	The Coach incorporates client's goals, ideas and values but does not do so consistently. The Coach may sacrifices some opportunities for mutual problem-solving in favor of supplying knowledge or expertise	The Coach fosters collaboration and power sharing so that participant's ideas impact the analysis The Coach explicitly identifies the participant as the expert

f) Collaboration during Planning[1]

1	2	3	4
The Coach actively assumes the expert role for the majority of the interaction with the participant. The Coach minimizes participant ideas	The Coach favors supplying knowledge or expertise and may not perceive or may ignore opportunities for mutual planning	The Coach incorporates client's goals, ideas and values but does not do so consistently. The Coach may sacrifices some opportunities for mutual planning in favor of supplying knowledge or expertise	The Coach fosters collaboration and power sharing so that participant's ideas impact the session The Coach explicitly identifies the participant as the expert

___ **Education**

a) Education was provided in the following areas:

___ Health Conditions and Impairments

___ Specialized Strategies

___ Community Resources and Entitlements

___ Typical Development

___ Teaching and Learning Strategies

b) The Content of the educations was:

1	2	3	4
General, not specific or responsive to participant's needs.	Mostly general, with some content related to participant's goals	Related to identified goals of the participant but not consistently responsive to participant's concerns.	Individualized for participant's needs and goals and responsive to the concerns of the participant

Rate the following general items

Focus of approach:

1	2	3	4
The approach focused on participant's problems and barriers to solutions. There was minimal discussion about strengths and finding solutions	The primary focus was on problems and barriers with occasional discussion of strengths and solutions	The primary focus was on strengths and finding solutions to problems with occasional focus on problems and barriers.	While problems and barriers were acknowledged, the approach focused on participant's strengths (knowledge, skills, experience, resources and intuition) and on solutions to identified problems

Empathy[1]:

1	2	3	4
The Coach gives little or no attention to the client's perspective. Seeks factual information. Does not attempt to understand the client's Perspective. The participant maintains a distance from the Coach and provides limited factual and superficial information	The Coach makes occasional efforts to explore the client's perspective. The Coach attempts to understand the participant's perspective are shallow may detract from the participant's true meaning. The participant openly communicates factual information the Coach but does not elaborate or share feelings in responses	The Coach makes active and repeated efforts to understand the participant's point of view. The Coach encourages minimal elaboration and understanding is mostly limited to explicit content. The participant begins to elaborate on thoughts and share feelings	The Coach shows evidence of deep understanding of participant's point of view, not just for what has been explicitly stated but what the participant means but has not yet said. The Coach attempts to put self in the participant's shoes and encourages elaboration. The participant freely elaborates on thoughts and shares deeper feelings

Autonomy/Support[1]:

1	2	3	4
The Coach discourages participant's perception of choice The Coach is not genuine when discussing participant's choice and implies that external consequences remove choice	The Coach does not deny options or choice, but makes little effort to actively instill it The Coach does not bring up the topic of choice in the session and may dismiss it when raised by the participant	The Coach is accepting and supportive of participant autonomy. The Coach explores options genuinely with participant but provides minimal support to take action to pursue control	The Coach is proactive in eliciting comments from the participant that lead to a greater perceived choice regarding the goal achievement. The Coach provides multiple opportunities to discuss participant's options and ability to control if s/he does not respond at first attempt

[1] Adapted from:
Revised Global Scales: Motivational Interviewing Treatment Integrity 3.1.1 (MITI 3.1.1)
T.B. Moyers, T. Martin, J.K. Manuel, W.R. Miller, & D. Ernst
University of New Mexico
Center on Alcoholism, Substance Abuse and Addictions (CASAA)
January 2010

Appendix I: Ethical Approval Letters

Bruyère Continuing Care Research Ethics Board

The Ottawa Health Science Network Research Ethics Board

The University of Ottawa Research Ethics Board

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Téléc./Fax: 613-562-6367

Hôpital Saint-Vincent Hospital
60, rue Cambridge St. N.
Ottawa ON K1R 7A5
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-782-2785

Résidence Élisabeth-Bruyère Residence
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-562-4223

Résidence Saint-Louis Residence
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-683-5001

Village Bruyère Village
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-683-5001

Centre de médecine familiale Bruyère
Bruyère Family Medicine Centre
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-241-3344
Téléc./Fax: 613-241-1971

Centre de médecine familiale Primrose
Primrose Family Medicine Centre
35, rue Primrose St.
Ottawa ON K1R 0A1
Tél./Tel.: 613-230-7788
Téléc./Fax: 613-230-7778

Institut de recherche Bruyère
Bruyère Research Institute
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

Fondation Bruyère Foundation
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6319
Téléc./Fax: 613-562-6023

Affilié à / Affiliated with

uOttawa

December 13, 2012

Ms. Dorothy Kessler,
M.Sc., O.T. Reg (Ont), PhD Candidate
Bruyère Continuing Care

RE: "Occupational performance coaching for stroke survivors: A novel patient centered intervention to improve participation in personally valued activities"
(Bruyère REB Protocol # M16-12-045)

Final Approval

Dear Ms. Kessler,

Thank you for your response to our conditional approval letter. With the revisions, the application has satisfied all ethical requirements.

As such, the Bruyère Continuing Care Research Ethics Board (REB) is pleased to give ethical approval for the period December 13, 2012 to December 13, 2014.

Please be advised that any complaints made by participants must be reported to the REB.

All changes to the approved protocol must be approved by the REB.

Please complete an Annual Project Update/Notification of Termination form by the approval end date as noted above.

Note: No French participants may be recruited until the Department of the Bruyère Continuing Care receives all french documentation.

Please provide us with the contract upon signature.

We wish you the best of luck with your research endeavors.

Sincerely,

[redacted]

Dr. Steve Joncas, C.Psych
Vice Chair
Research Ethics Board

UNIVERSITY OF OTTAWA HEART INSTITUTE
INSTITUT DE CARDIOLOGIE DE L'UNIVERSITÉ D'OTTAWA

THE OTTAWA HOSPITAL
L'HÔPITAL D'OTTAWA

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Ottawa Hospital Research Ethics Boards / Conseils d'éthique en recherches

725 Parkdale Avenue, Box 411, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311
http://www.ohri.ca/ohreb

Monday, March 11, 2013

Ms. Dorothy Kessler
Elizabeth Bruyere Research Institute
[redacted]

Dear Ms. Kessler:

Re: Protocol # 20120844-01H Occupational performance coaching for stroke survivors: A novel patient-centered intervention to improve participation in personally valued activities

Thank you for the letter dated February 26, 2013. The Protocol Amendment Report dated February 11, 2013 is approved.

Approval is for the following:
- Revised Protocol received February 27, 2013
- Revised English Appendix F: Montreal Cognitive Assessment (MOCA) dated December 7, 2012
- French Appendix B: Personal Projects Rating/COPM dated February 11, 2013
- French Appendix C: Reintegration to Normal Living Index dated February 11, 2013
- French Appendix D: Hospital Anxiety and Depression Scale dated February 11, 2013
- French Appendix E: Goals System Assessment Battery- Directive Functions Indicators (GSAB- DFI) dated February 11, 2013
- French Appendix F: Montreal Cognitive Assessment (MOCA) version dated December 7, 2012
- French Appendix G: Semi- Structured Interview dated February 11, 2013
- French Information Sheet and Consent Form, dated February 11, 2013

We acknowledge the addition of Monika Matuszewski, Rebecca Robertson, Lucy Ann Kubina and Katrina Sauvé as staff. The file has been updated accordingly.

Approval is conditional upon receipt of the Bruyere REB and the University of Ottawa REB approval letters. No recruitment may begin until these approval letters have been received.

Ethical approval has been extended to December 12, 2013.

Yours sincerely,
[redacted]

Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

/kd

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

January 17, 2012

Dorothy Kessler
PhD Candiate
School of Rehabilitation Sciences
University of Ottawa
[redacted]

Mary Egan
Professor
School of Rehabilitation Sciences
University of Ottawa
[redacted]

Re: U of O Ethics file no. A01-13-02 – "Occupational performance coaching for stroke survivors: A novel patient-centered intervention to improve participation in personally valued activities"

Dear Dr. Kessler and Dr. Egan,

Thank you for the protocol documents and Certificate of Approval from Bruyère Continuing Care REB (REB # M16-12-045) and from OHREB (REB # 20120844-01H) for your project named above.

This is to confirm that, in accordance with the agreement between the University of Ottawa and Bruyère, the University of Ottawa has authorized this board to act as Board of Record for the review and oversight of research involving human subjects conducted at or through the hospital.

We remind you of your obligation to:
- Follow all procedures of the Bruyère REB including reporting and renewal procedures;
- Submit to the authority of the Bruyère REB and that you are subject to Bruyère REB requirements, including, without limitation, the requirement to modify or stop the research on demand of the Bruyère REB.

If you have any questions, please contact our ethics office at 562-5387.

Sincerely yours,

[redacted]

Catherine Paquet
Director, Office of Research Ethics and Integrity

550, rue Cumberland 550 Cumberland Street
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

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Appendix J: Copyrighted Contents

List of Permissions

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Table 2.2. Domains of enabling - Permission for adaptations

Figure 2.1. The Person Environment Occupation Model – Permission to use

Figure 2.2. OPC-Stroke Structured Problem-Solving Process

HADS License – English

HADS License - French

Permission to Translate the GSAB-DFI Items

Re: GSAB

From: **Linda Ruehlman** (linda.ruehlman@goalistics.com)
Sent: December-04-12 6:00:43 PM
To: Dorothy Kessler
Hello Dorothy,

I think this sounds fine. Our only limitation is that you do not have permission to sell it to others. But, you may use it for your research.

Best wishes,
Linda

On Fri, Nov 30, 2012 at 12:12 PM, Dorothy Kessler < > wrote:
Hi
I apologize for the delay in following up on this. I have been focussed on getting my project through ethics.
For my project, I am planning to use only the Directive Function subscale and therefore would only translate this portion. As well, I do not have the resources to pay for translation of the whole scale. The translation will follow a process adapted from the guidelines of Benton, Bombardier & Guillemin (2000) for cross-cultural adaptation of self-report measures. The GSAB-DFI will be translated into French by a translator with knowledge of the concepts. The measure will then be translated back into English and the French version revised as needed. The French version will then be reviewed by four older adults (two of whom are stroke survivors) whose first language is French to determine if items are clear and are not ambiguous.
Following the translation process I will send you the French version for your records. I would like permission to continue to use the translation for future research and I may like to try to publish this work.
Pease let me know if you are in agreement with the above and if you have concerns/requirements
Sincerely

dorothy

Date: Wed, 3 Oct 2012 12:22:19 -0700
Subject: Re: GSAB
From: linda.ruehlman@goalistics.com
To:

Hi Dorothy,

I think that should be fine. Of course, we would still retain ownership. Why don't you tell me

more of the details and we will work something out.

Linda

On Wed, Oct 3, 2012 at 12:10 PM, Dorothy Kessler < > wrote:
Hi
Too bad. I have spoken to my thesis advisor and I would like to translate it for use in my research. Could you let me know the process for obtaining permission to do this
Thanks

dorothy

Date: Fri, 14 Sep 2012 12:54:49 -0700
Subject: Re: GSAB
From: linda.ruehlman@goalistics.com
To:

Hi Dorothy,

No it has not been translated and validated in French.

Linda

On Fri, Sep 14, 2012 at 10:43 AM, Dorothy Kessler < > wrote:
Dear Dr Ruehlman,

I recently purchased the Goals System Assessment Battery for use in my doctoral research. I am wonderng if it has been translated and validated in French.
I look forward to your reply
Sincerely,

dorothy

Dorothy Kessler
PhD Candidate
University of Ottawa
Canada

Permission For Adaptations for Table 2: Domains of Enabling

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Jan 02, 2015

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Special requirements	I wish to adapt Figure 10.1 for non-commercial academic use in my PhD thesis/dissertation. My final dissertation will be available in electronic format via the University of Ottawa or Library and Archives Canada. No translations are planned. I have adapted the Occupational Performance Coaching originally described by the authors of Chapter 10 in this book to better fit the needs of adults who have experienced stroke. The intervention described in this book was developed for parents of children with occupational performance challenges. I have made minor revisions to Figure 10.1 to fit with the adapted approach The presentation of the information is also changed to table format.
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Permission to Use Figure 1: The Person Environment Occupation Model

Canadian Association of Occupational Therapists
Association canadienne des ergothérapeutes
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Copyright Request

December 19 2014

Dear Dorothy

According to your request, you would like permission to use the Figure 1a. PEO model from the following article:

Law, M., Cooper, B., Strong, S., Stewart, C., Rigby, P., & Letts, L. (1996). The Person-Environment-Occupational Model: A transactive approach to occupational performance. *Canadian Joumal of Occupational Therapy: 63,;*1-15.

We understand that you will be using this figure in your PhD thesis, at the University of Ottawa, titled "Occupational performance coaching for stroke survivors (OPC-Stroke): A novel patient-centered intervention to improve participation in personally valued activities".

Permission for the above is granted on a one time basis only and provided that you acknowledge the source. Please ensure that a full reference is rinted with the figure to indicate that it is reprinted with the permission of CAOT Publications ACE. This does not include the right for uses other than the above-mentioned.

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Permission to Reprint for Figure 2: OPC-Stroke Structured Problem-Solving Process

RE: question

From: **Binur, Michelle** (Michelle.Binur@sagepub.com) on behalf of **permissions (US)** (permissions@sagepub.com)
Sent: December-15-14 2:02:53 PM
To: Dorothy ()

Dear Dorothy Kessler,

Thank you for your request. You can consider this email as permission to reprint a figure as detailed below in your upcoming thesis. Please note that this permission does not cover any 3rd party material that may be found within the work. We do ask that you properly credit the original source, Canadian Journal of Occupational Therapy. Please contact us for any further usage of the material.

Best regards,

Michelle Binur
Rights Assistant
SAGE Publications, Inc.
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From: PermissionsUK
Sent: Monday, December 15, 2014 3:01 AM
To: Dorothy
Cc: permissions (US)
Subject: RE: question

Dear Dorothy Kessler,

Thank you for your email.

The title Canadian Journal of Occupational Therapy is published by our sister company in the US. I have copied their department on this email and you will receive a response from them regarding your request.

Best Wishes,

Ellie Hodge
Permissions Assistant
SAGE Publications Ltd

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London, EC1Y 1SP
UK
www.sagepub.co.uk

From: Dorothy [mailto:]
Sent: 13 December 2014 16:42
To: PermissionsUK
Subject: question

Hi
I published an article in the Canadian Journal of Occupational Therapy.

Kessler, D. E., Egan, M. Y., Dubouloz, C. J., Graham, F. P., & McEwen, S. E. (2014). Occupational Performance Coaching for stroke survivors: A pilot randomized controlled trial protocol Protocole pilote d'un essai clinique randomisé sur l'Occupational performance coaching for stroke survivors (OPC-Stroke). *Canadian Journal of Occupational Therapy*, 0008417414545869.

I would like to use a figure from that publication in my doctoral thesis. I wanted to clarify whether my thesis qualifies as a "book" and I am therefore able to use the diagram as per the copyright agreement. Or do I need to seek permission?
Sincerely

Dorothy Kessler

HADS License – English

GL Assessment Ltd
Hospital Anxiety and Depression Scale (HADS)
USER AGREEMENT

Agreement Dated : …December 17, 2012……..

1. LICENSEE'S NAME Please type all details and send back as Word doc attachment

LICENSEE : : Dorothy Kessler ……***(note 1)***
Address : Bruyère Research Institute, ...
Country : Canada
VAT Number (if applicable) : ***(note 2)*** .....
Contact Name if Different from above:
Name : …As above……..
Title : …PhD Candidate, University of Ottawa;
Phone : …….. Fax :…… ……..
Email : ……
Invoice Address if Different from above: (*credit account form is required for invoicing – **note 3**)*
……
For Credit Card Payments please phone 0845 602 1937 or fax to 0845 601 5358
…….. ……
GL READER CODE (Mandatory- *note 4*)…… 58794…..
GL QUALIFICATION CODE (Mandatory – *note 4*)… 10110……

*For student licensees the following are also required- (**note 5**)*:
University Course and supervisor's name : ..... ……..
Supervisor's GL Reader Code .....
Supervisor's GL Qualification Code .....

---

2. CONTEXT OF HADS USE

- **PROJECT (*note 6*): Occupational Performance Coaching for stroke survivors (OPC-Stroke**)
- **Number of expected study participants :** **45**
- **Number of administrations of the questionnaire per participant :** **4**
- **TOTAL NUMBER OF ADMINISTRATIONS (*note 7*)** : 180
- **Planned study date**: *start* Jan | 2013 (month/year) *end* Dec | 2014 (month/year)

3. STUDY FINANCING

PLEASE INDICATE HERE IF YOUR USE OF HADS WILL BE FOR COMMERCIAL USE, OR ACADEMIC RESEARCH/NON-COMMERCIAL USE. (See FAQs in Permission Information Doc for definitions) :
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4. HADS VERSIONS & TRANSLATIONS (*NOTE 9*) *(THIS WILL BE SENT TO YOU AS A PDF ATTACHMENT)*

DO YOU REQUIRE THE HADS IN ENGLISH? .....YES.....

IF SO, WHICH VERSION; ORIGINAL TEMPLATE, WORD, OR US VERSION? ……WORD……..

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Languages:	**French**				

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(c) If the Licensee is declared insolvent or bankrupt or goes into liquidation (other than voluntary liquidation for the purpose of reconstruction only) or if a Receiver is appointed or if the Licensee is subject to any similar event anywhere in the world.

Termination shall be without prejudice to any monies which may be due to the Publishers from the Licensee and without prejudice to any claim which the Publishers may have for damages and/or otherwise.

Upon termination of this Agreement for any reason the Licensee shall immediately cease to use the Material.

15. This Agreement constitutes the entire agreement between the parties in respect of the Material and supersedes all prior oral or written proposals, agreements or undertakings concerning the same.

16. This Agreement shall not be amended or modified in any way other than by an agreement in writing and signed by both parties or their duly authorised representatives and shall come into effect on receipt of the payment in full as specified above and a counter-signed copy of this Agreement.

17. This Agreement shall be governed by and construed in all respects in accordance with English Law and the courts of England and Wales shall have exclusive jurisdiction to settle any dispute arising out of or in connection with this Agreement, its subject matter and formation, including non-contractual disputes or claims.

AS WITNESS THE HANDS OF THE PARTIES
hereto the day and year first above written

Signed on behalf of GL Assessment Limited
……

Signed by the Licensee: ***Please print this page, sign, and attach this signature page as a scanned document along with your typed User Agreement form, sent as a Word doc and email to : permissions@gl-assessment.co.uk***

User's Signature (handwritten): _____ Title: PhD Candidate/Research Trainee _____ Company/Organisation: University of Ottawa/Bruyère Research Institute _____ _____ Date: December 17, 2012 _____	**Company/Organisation Stamp (if applicable):**

(c) If the Licensee is declared insolvent or bankrupt or goes into liquidation (other than voluntary liquidation for the purpose of reconstruction only) or if a Receiver is appointed or if the Licensee is subject to any similar event anywhere in the world.

Termination shall be without prejudice to any monies which may be due to the Publishers from the Licensee and without prejudice to any claim which the Publishers may have for damages and/or otherwise.

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AS WITNESS THE HANDS OF THE PARTIES
hereto the day and year first above written

Signed on behalf of GL Assessment Limited

[redacted] 16/1/2013

Signed by the Licensee: ***Please print this page, sign, and attach this signature page as a scanned document along with your typed User Agreement form, sent as a Word doc and email to : permissions@gl-assessment.co.uk***

User's Signature (handwritten): [redacted]	**Company/Organisation Stamp (if applicable):**
Title: PhD Candidate/Research Trainee	
Company/Organisation: University of Ottawa/Bruyère Research Institute	
Date: December 17, 2012	

HADS License - French

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Education Information Dissemination

USER AGREEMENT
Existing translations

HOSPITAL DEPRESSION AND ANXIETY SCALE (HADS)

Date : !_1_!_8_!!_0_1_! !_20_!_13_!
day month year

PART 1. LICENSEE'S DETAILS

LICENSEE Name: ***Please have the information type written*** **Dorothy Kessler**
LICENSEE Title: PhD Candidate
Company : Bruyere Research Instutue
Address : [redacted]
[redacted]
[redacted]
Country : Canada
Phone : [redacted] **Fax :**
Email : [redacted]
VAT number (if applicable):

Contact name if different from above: ***Please have the information type written***
Contact Title:
Company :
Address :
Country :
Phone : Fax :
Email :

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2. CONTEXT OF HADS USE

1. **Individual clinical practice** ☐

- Expected duration of use: Indefinite ☐ or Number of years _____

2. **Research study** X☐

- **Title**: Occupational Performance Coaching for Stroke Survivors _____

- **Disease or disorder**:____Stroke_____
- **Type of research**:
  - ☐ X clinical trial - Phase II x / Phase III ☐ non drug study
  - ☐ epidemiologic/observational
  - ☐ other: .....
- **HADS used as primary end point**: yes ☐ no X
- **Number of expected patients (total):** 45
- **Number of administrations of the questionnaire per patient**: 4
- **Length of the follow-up (if any) for each patient**: 6 months
- **Planned study/project date**: *start* 02 | 2013 (month/year) *end* 12 | 2014 (month/year)
- **Mode of administration:**

X Paper ☐ Electronic version

If electronic administration, please precise the type of medium:
- PDA ☐ - Web-based ☐
- CDr / DVD ☐ - Other ☐ (please precise):.....

3. **Other project** ☐

- **Title**: _____
- **Disease or** condition: _____
- **Expected duration of use:** _____
- **Brief description of the project:**

.....
.....
.....

- **Presentation Format:**
  - x☐ Article
  - ☐ Book
  - ☐ Electronic version (please precise type of medium): .....
  - ☐ Other (please precise): ....

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3. STUDY FINANCING *(tick the appropriate box)*

Not funded academic research, individual medical practice ☐
Projects not explicitly funded, but funding comes from overall departmental funds or from the University or individual funds.

Funded academic research X
Projects receiving funding from commerce, government, EU or registered charity.
Funded academic research– sponsored by industry fits the "commercial study" category.

Commercial study ☐
Industry, CRO, any for-profit companies

Granting / Sponsoring from (if any) *(name of the governmental/foundation/company or other funding/sponsoring source): University of Ottawa Brain and Mind Research Institute*.....

T4. TRANSLATIONS

Please indicate in which language(s) and for which country(ies) the **HADS** is needed:

Language:	***For use in the following country***	***Language:***	***For use in the following country***	***Language:***	***For use in the following country***
e.g. English	*USA*				
e.g. Spanish	*USA*				
French	Canada				

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  - White D, Leach C, Sims R, Atkinson M, Cottrell D. Validation of the Hospital Anxiety and Depression Scale for use with adolescents. Br J Psychiatry. 1999 Nov;175:452-4
  - Herrmann C. International experiences with the Hospital Anxiety and Depression Scale - a review of validation data and clinical results. Journal of Psychosomatic Research 1997;42(1):17-41
  - Snaith RP. The Hospital Anxiety and Depression (HADS) scale. Quality of Life Newsletter 1993;6:5-5
  - Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand 1983;67:361-370

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- Insert the copyright: "This form may only be reproduced for use within the purchasing institution only within the terms stated in the permission agreement from the publisher. HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica, 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983". on all pages/screens on which the HADS will be presented
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Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfil any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party.

Upon expiration or termination of this Agreement MAPI Research Trust may retain in its possession confidential information it acquired from HADS while under contract.

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This Agreement and any of the rights and obligations of LICENSEE are specific to LICENSEE and cannot be assigned or transferred by LICENSEE to any third party or by operation of law, except with the written consent of MAPI Research Trust notified to LICENSEE.

11. Separate Agreement

This Agreement holds for the above-mentioned study only. The use of the HADS in any additional study of LICENSEE will require a separate agreement.

12. Entire Agreement, Modification, Enforceability

The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

13. Governing law

This Agreement is made in and shall be governed by and interpreted in accordance with the substantive laws of France, without regard to conflicts of laws.

14. Forum

Any controversy arising under this Agreement if litigated, shall be adjudicated in the court of the competent jurisdiction in Lyon, France, notwithstanding the plurality of defendants or claim in warranty, even in the event of emergency procedures or protective procedures, and the parties hereby submit to the exclusive jurisdiction of such court.

(c) If the Licensee is declared insolvent or bankrupt or goes into liquidation (other than voluntary liquidation for the purpose of reconstruction only) or if a Receiver is appointed or if the Licensee is subject to any similar event anywhere in the world.

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17. This Agreement shall be governed by and construed in all respects in accordance with English Law and the courts of England and Wales shall have exclusive jurisdiction to settle any dispute arising out of or in connection with this Agreement, its subject matter and formation, including non-contractual disputes or claims.

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hereto the day and year first above written

Signed on behalf of GL Assessment Limited

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User's Signature (handwritten): [redacted]	**Company/Organisation Stamp (if applicable):**
Title: PhD Candidate/Research Trainee	
Company/Organisation: University of Ottawa/Bruyère Research Institute	
Date: December 17, 2012	