AN EXPLORATION OF PATIENT PERSPECTIVES ON FACTORS AFFECTING PARTICPATION IN STROKE REHABILITATION

By

NICOLE LAST, BSC KINESIOLOGY (HONS)

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Master of Science

MASTER OF SCIENCE (2019) McMaster University

(Rehabilitation Science) Hamilton, Ontario

TITLE: An Exploration of Patient Perspectives on Factors Affecting Participation in Stroke Rehabilitation

AUTHOR: Nicole Last, BSc (University of Guelph)

SUPERVISOR: Jocelyn E. Harris, PhD, OT Reg. (Ont.)

SUPERVISORY COMMITTEE: Tara Packham, PhD, OT Reg. (Ont.), Rebecca Gewurtz, PhD, OT Reg. (Ont.), and Lori Letts, PhD, OT Reg. (Ont.)

NUMBER OF PAGES: xii, 133

Lay Abstract

Rehabilitation is a crucial part of recovery after stroke and patient participation is recognized as an important element of rehabilitation. A less explored perspective is patients' experiences participating in stroke rehabilitation and barriers/facilitators to participation. This study interviewed individuals who participated in stroke rehabilitation to ask about factors influencing their participation. Eleven individuals were interviewed, and four key themes were identified as barriers and/or facilitators to patient-participation in stroke rehabilitation: 1) environmental factors, 2) components of therapy, 3) physical and emotional well-being, and 4) personal motivators. A sub-theme, amount of therapy, was explored further and this work draws attention to the rehabilitation intensity evidence-to-practice gap apparent as a prevalent issue in Canada and elsewhere. This exploration of patients' experiences and factors perceived as influencing participation can help to shape the development of strategies to facilitate participation in rehabilitation and improve implementation of existing recommendations to maximize recovery after stroke.

Abstract

Though patient participation is recognized as an important element of rehabilitation, few studies have used a qualitative lens to specifically examine factors influencing patient-participation in stroke rehabilitation. Thus, the purpose of this work was to explore factors perceived by service users to influence their participation in hospital-based stroke rehabilitation activities and to use this information to generate knowledge relevant for the clinical context of stroke rehabilitation. The following research gaps provided rationale for this work: 1) no published studies from the patients' perspective on influencers of participating in hospital-based stroke rehabilitation programs, and 2) limited studies about influences on participation in hospital-based stroke rehabilitation. The first manuscript (chapter two) was designed to specifically address these gaps while the second manuscript (chapter three) was developed to highlight important findings surrounding rehabilitation intensity from chapter two. This thesis has discussed a number of patient-perceived barriers and facilitators to participating in stroke rehabilitation, which the final chapter conceptualizes into a framework of personalized rehabilitation representing a patient-centred approach to providing rehabilitation that encourages patient participation. Together, this thesis contributes knowledge about: 1) patient perspectives on factors affecting participation in stroke rehabilitation, 2) promoting patient participation, 3) shortcomings in closing the evidence-to-practice gap with respect to therapy intensity during inpatient stroke rehabilitation, and 4) insights into an exploratory framework of personalized rehabilitation developed from service users' perspectives of stroke rehabilitation. In addition, this work emphasizes a call to action for the delivery of user-centered stroke care, specifically in regard to rehabilitation intensity during inpatient stroke rehabilitation. The implications of this work are directed at stroke rehabilitation providers as well as policy makers and stroke health system planners in order to develop appropriate and effective services and strategies for optimal recovery and successful implementation of best practice recommendations.

Acknowledgments

First off, a sincerest thank-you to Dr. Jocelyn Harris, my supervisor, for not only her patience with me throughout this journey but also her continual feedback, support, and expertise. Her ability to challenge me to develop not only my research and writing skills but also my communication and critical thinking skills (among others). I cannot thank my supervisory committee, Dr. Tara Packham, Dr. Rebecca Gewurtz, and Dr. Lori Letts enough for their support and guidance as well as their unbelievable enthusiasm from start to finish! I am so thankful and feel very fortunate to have had such a knowledgeable, supportive, and strong group of women to guide me through my studies. A thank-you to the external examiner at my defense, Dr. Dorothy Kessler, for their time and commitment and whose knowledge and expertise contributed to the quality of this thesis. In addition, I am very grateful for the generosity of the School of Rehabilitation Science in providing me with a Graduate Scholarship and Bursary, which allowed me to complete this graduate program.

This work would not have been possible without the individuals who agreed to participate in this research. Thank-you so much for your honesty and willingness to share your experiences with us. Your voices and stories are a powerful source of information and I truly hope the work contained in this thesis provides others with a greater understanding of the stroke rehabilitation experience from the valuable perspectives of those who have participated in it.

Thank you to all the wonderful people I met on this Master's journey and a special thank-you to Janelle Panday for sharing your learning experiences with me and for your

unwavering dedication to my success. Many thanks to my best friends Jessica and Emily for always checking in on me and being my best cheerleaders and my dog Missy, for being an endless source of comfort and joy! I would like to dedicate this thesis to Rob and my exceptional family for their unfaltering encouragement and unconditional support that guided me throughout this experience. I could not have done this without them.

Table of Contents

List of Figures and Tables

List of Appendices

Declaration of Academic Achievement

I, Nicole Last, declare this thesis to be my own work. My supervisor, Dr. Jocelyn Harris, and the members of my supervisory committee, Dr. Tara Packham, Dr. Rebecca Gewurtz, and Dr. Lori Letts, have provided guidance and feedback throughout the development of this thesis. The primary study within this thesis utilized a data set Dr. Packham had collected with the assistance of MScOT students; however, I performed the data analyses involved with this research with guidance from my supervisor and supervisory committee. The data collection for the third chapter was performed by me. The supervisory committee and my supervisor are listed as co-authors for chapters two and three as they were consulted during the research design and writing processes and provided feedback on drafts that was crucial in helping to shape the final products. This thesis is in partial fulfilment of the requirements for the degree Master of Science, Rehabilitation Science.

Chapter 1: Introduction & Literature Review

Thesis Overview

Stroke is one of the leading causes of disability in adults in Canada (Heart and Stroke Foundation of Canada, 2017). Every 10 minutes someone in Canada has a stroke, which has resulted in an estimated 750,000 individuals living with stroke-related disability (Health Quality Ontario; Ministry of Health and Long-Term Care, 2016). To enhance recovery from stroke, individuals are typically referred to hospital-based (inpatient and outpatient) rehabilitation programs wherein an interdisciplinary approach is used to facilitate community reintegration (Obembe & Eng, 2016). Stroke rehabilitation is the most effective way to a) reduce stroke-related impairments (Hatem, Saussez, della Faille, et al., 2016; Hendricks, Van Limbeek, Geurts, & Zwarts, 2002; Peter Langhorne, Bernhardt, & Kwakkel, 2011), b) improve independence in activities of daily living (ADL) (Gialanella, Santoro, & Ferlucci, 2013; Karges & Smallfield, 2009; Maulden, Gassaway, Horn, Smout, & Dejong, 2005; Wolf et al., 2015; Yagi et al., 2017), and c) improve participation in social, vocational, and leisure activities (Salter, Allen, et al., 2018). The evaluation of stroke rehabilitation interventions and programs is often measured using standardized outcomes and stroke best practice guidelines; however, little research has been dedicated to the stroke survivor's perspective. Further, the participatory efforts of individuals during rehabilitation may be an under-recognized determinant of stroke rehabilitation effectiveness (Lenze et al., 2004; Paolucci et al., 2012); therefore, it is imperative to understand factors that may influence participation. Patient perspectives regarding participation in hospital-based rehabilitation are scarce. Studies utilizing qualitative research methods can respond to this dearth by providing a unique and important lens to this topic of inquiry. Thus, the overall objective of this thesis is to investigate patient-perceived barriers and facilitators to participating in hospital-based stroke rehabilitation in order to inform strategies to enhance participation with the possibility of contributing to stroke rehabilitation effectiveness.

The Importance of Stroke Rehabilitation

The Effects of Stroke on Survivors

Stroke is one of the leading causes of adult disability and the third leading cause of death in Canada (Lindsay et al., 2014). The physical (e.g., paresis, sensory loss), cognitive (e.g., executive functioning, perceptual disorders), and affective (e.g., depression) deficits following stroke subsequently lead to a significant decrease in the person's ability to perform activities of daily living (ADL) and participate in social, vocational, and leisure activities (Cawood, Visagie, & Mji, 2016; Pound, Gompertz, & Ebrahim, 1998; Van Der Zwaluw, Valentijn, Nieuwenhuis-Mark, Rasquin, & Van Heugten, 2011). Further, the effects of stroke often contribute to an inability to fulfill life roles (Corr & Wilmer, 2003; Lawrence, 2010; Satink et al., 2013) and poor quality of life (Opara & Jaracz, 2010; Secrest & Thomas, 1999). To mitigate the magnitude of stroke-related disability, individuals participate in hospital-based stroke rehabilitation which includes inpatient and outpatient programs.

Hospital-Based Stroke Rehabilitation in Canada

In Canada, baseline Functional Independence Measure (FIM) (Keith, Granger, Hamilton, & Sherwin, 1987) scores are widely used in the acute stroke care setting to help determine level of disability and if inpatient rehabilitation is appropriate. A FIM score >80 within the first 3-5 days post-onset is categorized as mild, while FIM scores of 40-80 and <40 are classified as moderate and severe, respectively (Teasell, Hussein, & Foley, 2018). Individuals with less severe impairment and appropriate home supports may be referred home with community care services or to an outpatient rehabilitation program, while individuals who could benefit most from an intensive stroke rehabilitation programs (moderate and severe) are to be referred to an inpatient rehabilitation program (*Program Pathways of Care for People With Stroke in Ontario*, 2012).

Inpatient Rehabilitation. Admission to inpatient stroke rehabilitation programs occurs for those assessed as medically stable and importantly, able to tolerate up to three hours/day of rehabilitation activities. Individuals in inpatient rehabilitation receive 24-hour medical care by a specialized interprofessional team while working on individual rehabilitative goals involving the patient and family (Boulanger et al., 2018). Types of therapies (e.g., physiotherapy, occupational therapy, speech-language pathology) and specific interventions are based on individual assessments of deficits. In addition to one-on-one therapy, individuals are typically given the opportunity to participate in group therapy and engage in social activities. The ultimate goal of inpatient stroke rehabilitation is to prepare the individual, as much as possible, for discharge and to facilitate a smooth transition from rehabilitation back into the community (Boulanger et al., 2018). Length of stay commonly depends on individuals' needs and goals.

Outpatient Rehabilitation. Outpatient therapy is typically prescribed either following discharge from acute care or inpatient stroke rehabilitation units for individuals considered able to safely live in the community but with ongoing rehabilitation goals.

Outpatient hospital stroke rehabilitation programs generally mimic the coordinated and interdisciplinary approach to inpatient rehabilitation and are designed to address ongoing functional rehabilitation needs geared towards achieving individual participation-related goals (Boulanger et al., 2018). For instance, individuals may work on developing skills that will assist in the return to activities/roles that are expected of them and are meaningful (ADL's, work, social). Individuals typically attend outpatient rehabilitation two to five days per week, depending on individual need and goals (Boulanger et al., 2018). As with inpatient programs, the length of outpatient programs commonly depend on individuals' needs and goals.

Clinical Practice Guidelines for Stroke Rehabilitation in Canada

Many national organizations, such as the Heart and Stroke Foundation of Canada (Heart and Stroke Foundation of Canada, n.d.), the American Heart Association/American Stroke Association (American Heart Association/American Stroke Association, n.d.), and the Stroke Foundation Australia (Stroke Foundation, n.d.), produce their own clinical guidelines for stroke care. Typically, these guidelines are not mandated; rather they are intended to facilitate clinicians' and administrators' use of evidence by providing a summary of the most up-to-date quality evidence pertaining to stroke rehabilitation and recovery.

First released in 2006, the Canadian Stroke Best Practice Recommendations (CSBPR), under the leadership of the Heart and Stroke Foundation of Canada, "provides a common set of guiding principles for stroke care delivery, and describes the infrastructure necessary at a system level, and the clinical protocols and processes that are needed to achieve and enhance integrated, high-quality, and efficient stroke services for all Canadians" (Lindsay et al., 2014, p. 6). The CSBPR are based on the highest level of evidence currently available and are reviewed and updated on a rotating schedule every two years by a diverse group of individuals that include those who: 1) are experts in the field, 2) have extensive experience in the topic area, 3) have experience appraising the quality of research evidence, and 4) have experienced a stroke (either personally or a family member) (Lindsay et al., 2014). These recommendations are written for a wide range of stakeholders who have important roles in the planning, delivery, and monitoring of stroke care (e.g., funders, administrators, healthcare professionals, patients/family members) (Boulanger et al., 2018; Lindsay et al., 2014). The CSBPR are organized into separate modules that encompass the continuum of care (e.g., from prevention, rehabilitation, to community participation) (Hebert et al., 2016); the purpose of the rehabilitation module is to provide healthcare providers with a common set of guiding principles for the delivery of high-quality stroke rehabilitation, from admission through to discharge.

In Ontario, Health Quality Ontario (HQO; www.hqontario.ca), a provincial healthcare quality improvement initiative, released a set of clinical practice guidelines covering the continuum of stroke care in 2015. These guidelines are aptly named *quality-based procedures* (QBPs) for stroke and are similar to the CSBPR in that they translate best evidence into clinical standards, recommendations to healthcare professionals and funders, as well as tools health care providers can implement to make improvements in practice. QBPs are developed through collaboration with a multidisciplinary expert advisory panel that includes clinical experts, scientists, and administrators (Health Quality Ontario; Ministry of Health and Long-Term Care, 2016). While the QBPs for stroke base a number of recommendations on the CSBPR, they also consider additional sources of evidence such as the Ontario Health Technology Advisory Committee recommendations, HQO rapid reviews, and empirical analysis of Ontario specific data. Perhaps the biggest difference between the CSBPR and QBPs is the application of provincial data in the development of HQO's quality-based procedures.

Clinical practice guidelines provide a standard of care and can reduce practice variations across the region as well as enhance quality of care by promoting effective clinical interventions and discouraging ineffective practices (Jolliffe, Lannin, Cadilhac, & Hoffmann, 2018). Overall, the guidelines outlined above are designed to be an easily accessible online summary of best evidence for rehabilitation professionals and other healthcare providers. Adherence to these guidelines positively influences rehabilitation effectiveness (Menon, Korner-Bitensky, Kastner, McKibbon, & Straus, 2009).

The modules for stroke rehabilitation contained within these guidelines commonly include practice recommendations for optimal timing, type, and intensity of rehabilitation. Intensity of inpatient stroke rehabilitation specifically is a primary focus of this thesis.

Rehabilitation Intensity

The intensity of rehabilitation (total amount of direct physiotherapy, occupational therapy, and speech-language therapy per day) is an essential component in the delivery of inpatient stroke rehabilitation and has significant implications on patient outcomes (Hebert et al., 2016). Early and intensive stroke rehabilitation has been associated with greater and faster improvements in the performance of daily activities (Hebert et al., 2016; Jette, Warren, & Wirtalla, 2005; Kwakkel, Wagenaar, Koelman, Lankhorst, & Koetsier, 1997; Kwakkel, 2009; Lohse, Lang, & Boyd, 2014). Similarly, excessive sedentary time during inpatient rehabilitation, which is a critical period of recovery, is associated with increased cardiovascular risk (Peiris, Shields, Brusco, Watts, & Taylor, 2013), further increasing patients' risk for secondary stroke. In addition, declines in cardiorespiratory fitness can occur secondary to excessive sedentary time, which can further impact ADL ability (Ivey, Macko, Ryan, & Hafer-Macko, 2005).

There is a staggering amount of evidence demonstrating the benefits of early and intensive rehabilitation after stroke; this evidence has been reviewed and incorporated into best practice recommendations for stroke rehabilitation (Health Quality Ontario; Ministry of Health and Long-Term Care, 2016; Hebert et al., 2016). The most recent practice guidelines for stroke rehabilitation published by the CSBPR (Hebert et al., 2016) were last updated in 2015 and reflect that both the timing and intensity of interventions predict patient outcomes wherein early rehabilitation and intense, task-specific therapy result in improved outcomes following stroke (Andrews, Li, & Freburger, 2015; Jette et al., 2005; Kwakkel et al., 2004; Kwakkel, 2009; Sehatzadeh, 2015; R. Teasell, Foley, Hussein, Wiener, & Speechley, 2018). Specific recommendations for the provision of therapy state that rehabilitation should take place within an active and stimulating environment and "patients should receive a recommended three hours per day of direct task-specific therapy, five days a week, delivered by the interprofessional stroke team" (Hebert et al., 2016, p. 467). These guidelines add that training should also be meaningful, engaging, progressively adaptive, intensive, and goal-oriented. While generally in accordance with the CSBPRs, Health Quality Ontario's QBPs advocate for six days of therapy per week (Health Quality Ontario; Ministry of Health and Long-Term Care, 2016) and note that "hospitals should ensure adequate staffing seven days per week of rehabilitation specialists to provide ongoing rehabilitation care" and "patients should have access to rehabilitation programs seven days a week and in the evenings" (Health Quality Ontario; Ministry of Health and Long-Term Care, 2016, p. 76). These recommendations are in accordance with ones made by the Ontario Stroke Network's Stroke Reference Group which advocate for 7-day a week therapy in order to maximize recovery and reduce risk of deterioration caused by a lack of therapy on weekends (Meyer et al., 2012). Adherence to the minimum therapy recommendations is associated with better outcomes in upper limb function, walking function, ADL ability, and length of hospital stay (Hebert et al., 2016; Stroke Foundation, 2017; Winstein et al., 2016), as well as prevention of physical deconditioning and resultant regression of functional gains in hospitalized stroke patients (Barrett et al., 2018). The sweeping message emerging from the literature on inpatient stroke rehabilitation therapy intensity is: 'more therapy results in better outcomes.'

The Benefit of Rehabilitation After Stroke

Rehabilitation is an essential standard of care for individuals post stroke. Stroke rehabilitation uses an interdisciplinary approach that includes trained rehabilitation professionals (e.g., physicians, nurses, physiotherapists, occupational therapists, and speech-language pathologists) to facilitate recovery from stroke (Hebert et al., 2016).

Rehabilitation is a process of active change wherein individuals acquire knowledge and skills geared towards achieving optimal physical, psychological, and social function. Return to social activities and life roles are an important element of recovery and are a primary goal of stroke rehabilitation. Canadian Stroke Best Practices (http://www.strokebestpractices.ca/), among many others, acknowledge that access to rehabilitation is vital. The physical, mental, and emotional burden stroke can have on an individual makes it imperative for individuals to start the rehabilitation process as early as possible. The consensus of the evidence is that the earlier rehabilitation starts, the better the outcome; early access to dedicated stroke units improves functional status, such as upper and lower limb motor recovery (Hatem, Saussez, della Faille, et al., 2016; Hatem, Saussez, Della Faille, et al., 2016; Hendricks et al., 2002; Peter Langhorne et al., 2011; Maulden et al., 2005), walking mobility (Jorgensen, Nakayama, Raaschou, Olsen, & Jergensen, 1995; Maulden et al., 2005), independence in ADL and self-care (Gialanella et al., 2013; Karges & Smallfield, 2009; Maulden et al., 2005; Wolf et al., 2015; Yagi et al., 2017), participation in leisure activities (Winstein et al., 2016), positive cognitive and communication outcomes (Cicerone et al., 2011; Cumming, Marshall, & Lazar, 2013), increased well-being and social participation (Obembe & Eng, 2016), and more (Lindsay et al., 2010). Further, improvements in physical ability have been shown to positively correlate with daily activity performance and has also been reported as an important behavioural outcome (as recovery progresses, participation in activities increases) (Kaplan, 1990) and lower rates of depression have been shown in stroke survivors in active rehabilitation programs (Kotila, Numminen, Waltimo, & Kaste, 1998). While stroke rehabilitation involves using exercises/activities to restore movement and coordination, it also focuses on improving performance of daily activities (e.g., dressing, bathing, cooking) through task-specific training. Speech therapy is also provided to those who have problems producing or understanding speech. Notably, in addition to therapies that improve physical functions, stroke rehabilitation programs also emphasize patient and family education and focus on individual, psychological, and social issues.

Summary

The interdisciplinary stroke team, the patient, and family work cohesively to generate a personalized comprehensive program designed to address the effects of stroke. By addressing individual needs and goals, stroke rehabilitation can improve multiple outcomes and is designed to help individuals return to independent living. To effectively accomplish this, clinical practice guidelines have been developed to provide rehabilitation professionals with a summary of best evidence in the form of a common set of guiding principles for the delivery of high-quality stroke rehabilitation. Significant efforts have been put towards the dissemination of these guidelines generally focused on frontline staff, as clinician adherence to these guidelines is associated with the effectiveness of inpatient stroke rehabilitation. Additionally, an important assumption is that patients themselves are active participants in rehabilitation. Given that the effectiveness of stroke rehabilitation could be diminished if participation is affected, it is imperative to understand what influences patient participation in rehabilitation after stroke.

Participation in Stroke Rehabilitation

Defining Participation

Participation in rehabilitation lacks a universally excepted definition and has been used to describe anything from an individual completing therapy activities to patient involvement in planning, clinical-decision making, and goal formulation to retuning to individually meaningful roles in the community (Cogan & Carlson, 2017; Wressle, Eeg-Olofsson, Marcusson, & Henriksson, 2002). Cogan and Carlson (2017) define participation broadly as ‘consciously doing an activity’ while The World Health Organization defines participation vaguely as ‘involvement in a life situation (World Health Organization, 2002). Lenze and collegues (2004b) describe participation as an observable behaviour and note that participation in rehabilitation can be noticed when an individual 1) exhibits a maximal effort in all activities, 2) tries to finish all activities, and 3) actively takes interest in activities. In addition, participation is often used interchangeably with engagement though the two can have different meanings. Engagement in the context of stroke rehabilitation has been defined elsewhere as “a deliberate effort and commitment to working toward the goals of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers” (Lequerica & Kortte, 2010, p. 416). Patient engagement is complex and requires high levels of vested interest and is demonstrated through body language (e.g., gaze, gesture, body position), shared laughter, attendance, compliance, working alliance, disclosure, and active participation (Lequerica & Kortte, 2010; Simmons-Mackie & Damico, 2009; Tetley, Jinks, Huband, & Howells, 2011). Though various definitions of engagement exist, many of them include participation (Cunningham, Duffee, Huang, Steinke, & Naccarato, 2009; Duchan, 2009; Lequerica &

Kortte, 2010), suggesting that participation is a precursor for engagement wherein the former does not necessarily require high levels of vest interest. In other words, an individual can participate without purposefully engaging themselves in an activity though it is not possible to engage in rehabilitation without participation. Capturing engagement in rehabilitation would include information about therapy attendance, attitude toward rehabilitation, and participating behaviour (Kortte, Falk, Castillo, Johnson-Greene, & Wegener, 2007).

Cogan & Carlson (2017) suggest participation in rehabilitation (consciously doing activities) can be divided into community-based and interventional contexts and participation in either contexts is largely determined by available opportunities affected by conditions either internal or external to an individual. Much of the existing stroke rehabilitation literature about patient participation/engagement in an interventional context operationalizes participation as an observable performance (Morghen et al., 2017; Paolucci et al., 2012; Skidmore et al., 2010; Yang & Kong, 2013) and while important for quantifying the impact of patient participation, this definition does not take into account the subjective experience of the individual that underpins patient-centered practice fundamental to the rehabilitation professions. For the purposes of this work, participation is defined simply and broadly as doing/performing rehabilitation activities to allow for individuals' perceptions of factors influencing patient participation in stroke rehabilitation (factors that helped or hindered the performance of an activity).

Factors Influencing Participation in Stroke Rehabilitation

Given the important role rehabilitation plays in recovery after stroke, it is critical to develop a thorough understanding of factors that may affect an individual's participation and engagement in rehabilitation activities. Patient participation and engagement are recognized as necessary to obtain maximum benefits from rehabilitation (Bright, Kayes, Cummins, Worrall, & McPherson, 2017; Lenze et al., 2004). Yet, the investigation of participation in rehabilitation is not well developed, particularly from the patient perspective. There are several studies that have explored participation in physical activity and exercise from the perspective of individuals in the chronic stage of stroke recovery (Damush, Plue, Bakas, Schmid, & Williams, 2007; Nicholson et al., 2014; Simpson, Eng, Tawashy, English, & Olawale, 2011; Zalewski & Dvorak, 2011); however, there is little information from those participating in hospital-based rehabilitation. Of importance is determining the barriers and facilitators that could be influential in informing strategies for enhancing participation in rehabilitation activities.

Barriers and facilitators to participating in hospital-based stroke rehabilitation programs from the perspective of patients is an under-explored area in the literature. This dearth of information was highlighted by MacDonald, Kayes, & Bright (2013) who attempted to complete a systematic review with the aim of determining barriers and facilitators to engagement (including participation) in rehabilitation post stroke. Though they ultimately included 14 qualitative and three mixed methods studies, none of them had the specific purpose of investigating influencers of participation/engagement. Instead, the authors extracted findings from each study they thought provided insight into engagement-related issues. Papers were included if they were set in the context of active stroke rehabilitation, which the authors defined as a therapeutic encounter between a rehabilitation professional and person with stroke (MacDonald, Kayes, & Bright, 2013). Seven key themes centered on experiences in stroke rehabilitation were constructed: 1) goal setting, 2) therapeutic connection, 3) personalised rehabilitation, 4) paternalism versus independence, 5) patient-centred practice, 6) knowledge is power, and 7) feedback and achievement. These identified themes offer some insight into factors that can have either positive or negative effects on engagement in rehabilitation. Active involvement in the establishment of clear goals, the provision of feedback, and the provision of education and information on stroke were believed to enhance patient motivation, thereby increasing the likelihood of engagement in rehabilitation. Support from therapists and patient-centered practice that facilitated patient autonomy were suggested as positive influencers of patient engagement in rehabilitation. Lastly, there was increased risk of disengagement if rehabilitation-focused tasks were unfamiliar and not meaningful to the individual. Notably, studies included in the review represented the experiences of individuals in both the acute and chronic phases of stroke. In addition, the thematic analysis combined both patient and therapist perceptions. Thus, the identified themes do not exclusively reflect the patients' perspectives of stroke rehabilitation.

Maclean, Pound, Wolfe, and Rudd (2000) conducted a qualitative study focused on patients' motivations for rehabilitation. Twenty-two participants who were six weeks post stroke and currently undergoing inpatient rehabilitation participated in semi-structured interviews. Fourteen were identified as having high motivation and eight low motivation; the authors considered motivation levels when analyzing the interviews.

Overall findings reported that information from professionals about rehabilitation, favourable comparisons with peers, and the desire to leave the hospital or return home had positive effects on patient motivation for rehabilitation. Conversely, overprotection from family and professionals, lack of information/receiving mixed messages, and unfavourable comparisons with peers were negative influencers. The authors found differences in beliefs about rehabilitation between those with low and high motivation: high motivation patients were more likely to adopt an active role in rehabilitation as it was viewed as their 'ticket' to recovery. While many patients identified independence at home as a personal goal of rehabilitation, those with low motivation were less likely to relate this goal to success in rehabilitation (Maclean, Pound, Wolfe, & Rudd, 2000). The study by Maclean et al. (2000) provides some insight into factors affecting patients' motivation for stroke rehabilitation; however, individuals with language and cognitive impairments, and those diagnosed with disorders considered to affect motivation (e.g., depression) were excluded from this study.

Collectively these studies found the actions, attitudes, and approaches of therapists, other healthcare providers, family, peers, and the patient themselves can play an important role in influencing participation in stroke rehabilitation. These findings suggest awareness of how factors beyond patients' control can influence participation is essential. While there are studies investigating barriers and facilitators to exercise/activity from those living with stroke long-term (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015; MacDonald et al., 2013; Maclean et al., 2000), there appear to be no studies exploring the patient perspective on participating in hospital-based rehabilitation.

MacDonald et al. (2013) state that a deeper understanding of patient engagement in stroke rehabilitation from the perspective of patients themselves can assist service providers in facilitating engagement and enhancing the effectiveness of rehabilitation. Since participation in rehabilitation is a subjective experience, it is imperative we explore these lived experiences through an in-depth examination of the perspectives of patients who are receiving these services.

Research Tradition

Qualitative Inquiry

With roots in anthropology, philosophy, and sociology (Bogdan & Biklen, 2014), qualitative research focuses on examining the experiences of people and how cultural, social, and other factors influence individual experiences and behaviours (Parahoo, 2014). It is utilized to understand a phenomenon within people's lives, a social context, or viewpoint, and recognizes life experiences, personal narratives, and life stories as meaningful information to be appreciated and understood (Vasilachis de Gialdino, 2009). With its emphasis on understanding human experiences, qualitative research can answer questions aimed at exploring participant perspectives and can provide unique insight into the subjective experiences of service users (Parahoo, 2014). It is through the subjective experiences of individuals that we can attain a better understanding of healthcare services and clinical practices.

There are multiple traditions (e.g., ethnography, phenomenology, grounded theory) within qualitative research, all of which serve distinct purposes and are differentiated by their own set of principles. The particular approach taken should align with the belief system underpinning the research approach, the purpose of the research and the research questions, as well as the prospective outcomes (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, and Varpio, 2015). The method chosen to guide the qualitative research study contained within this thesis was Interpretive Description.

Interpretive Description

Pioneered by Sally Thorne, Interpretive Description (ID) (Thorne, Kirkham, & MacDonald-Emes, 1997) was originally developed as a method for research in the field of nursing in response to a need for an improved way of studying clinical phenomena using an interpretative approach that would lead to generating applied nursing knowledge and facilitating a better understanding of human health and clinical practice (Hunt, 2009; Thorne, 2008). ID is influenced by established interpretative traditions (i.e., grounded theory, naturalistic inquiry, ethnography, and phenomenology), but is not confined to strict adherence to principles of these approaches to qualitative research (Thorne, 2008; Thorne, Reimer-Kirkham, & O'Flynn-Magee, 2004). Rather than detailed procedures, Thorne (2016) provides basic guidelines and general criteria to designing an interpretive description study, starting with critical analysis of existing theoretical and clinical knowledge.

Interpretive description proposes to provide methodological direction to applied health science researchers to develop practical research questions, and guide the creation of data analysis such that the researcher's experience and engagement with the data produces an interpretation beyond what is obvious (Thorne, 2016). This research approach utilizes constant comparative methods to uncover associations, relations, and patterns (i.e., themes) which help create a description of the phenomenon under investigation. In applying ID, researchers describe and contextualize the phenomenon, leaving behind the intention to provide an explanatory model for the phenomenon (Thorne, 2016). The final 'interpretive description' product should represent a rich and detailed description of a phenomenon, that has been constructed through merging of participant and researcher views, that provides a better understanding of the phenomenon in such a way that can support clinical practice (e.g., offering practical solutions) (Thorne, 2016).

Why Interpretive Description? ID is considered a viable methodological approach for the production of knowledge in the applied health sciences (Teodoro et al., 2018). While there are commonalities in the experiences of patients with stroke, each patient is unique as is the context within which their stroke is being managed; therefore, "optimal care" should reflect these diversities and distinctive contexts. Interpretive description encourages a shift in focus that allows us to seek both commonalities and diversities (Teodoro et al., 2018). Interpretive description does not aim to advance theorizing by asking questions that suggest unity, such as "what is the lived experience of [a specific group of individuals]?" but instead seeks what can be learned from accounts of the experiences of individuals and how these perspectives could directly inform future practice. An interpretive description approach is compatible with the requirements of applied disciplines, such as those that comprise stroke rehabilitation, as it is based on practical rather than theoretical problems.

An interpretive description approach to qualitative inquiry is aligned with the clinical knowledge base and personal experiences of members of the research team (as rehabilitation professionals), as well as the prospective outcomes of the research contained within this thesis: 1) to provide insight into the subjective experiences of patients involved in hospital-based stroke rehabilitation, specifically barriers and facilitators to participation, and 2) to inform stroke rehabilitation clinical practice and future research.

Research Plan

In light of the reviewed literature, it is clear that within organized stroke rehabilitation, specifically early after stroke and provided by an interdisciplinary team, adherence to clinical practice guidelines are essential to maximizing recovery from stroke-related impairments, facilitating functional independence and community reintegration. Rehabilitation is an active process, and patient participation is an important element in the effectiveness of stroke rehabilitation. It is easy to blame lack of participation on individuals' motivational status and other patient characteristics; however, instead of placing blame and labelling individuals as 'unmotivated,' we could work together with individuals who participate in stroke rehabilitation programs to identify factors perceived to affect patient participation.

Currently, there is a gap in the stroke literature on participation in hospital-based rehabilitation: it appears the literature is missing an in-depth exploration of the barriers and facilitators to participation in hospital-based stroke rehabilitation from the perspective of patients. Therefore, the main research question of this thesis is:

> What do individuals perceive as factors affecting participation in hospital-based stroke rehabilitation and are these factors described as barriers or facilitators to participation in rehabilitation activities?

Specific objectives of this thesis are to 1) illuminate the patient voice about the barriers and facilitators to inpatient stroke rehabilitation, 2) identify and explore factors perceived to influence patient participation, and 3) contribute to the development of knowledge in stroke rehabilitation as well as provide information that could be used in the planning, design, and administration of stroke rehabilitation. To fulfill these objectives, individuals with stroke who were currently involved in or recently discharged from a hospital-based rehabilitation program were recruited for interviews.

This thesis consists of two manuscript entitled "Looking Beyond the Scales of Participation: Exploring Patient Perspectives of Barriers and Facilitators to Participating in Hospital-Based Stroke Rehabilitation" and "Still Inactive and Alone: A Call for Action on Behalf of Hospitalized Stroke Rehabilitation Patients" written to address the study objectives. Findings from the first manuscript highlight the perceived impact of the rehabilitation environments, interpersonal factors, and intrapersonal factors on patient participation in rehabilitation. The social environment, the frequency and consistency of communication with patients about rehabilitation goals and progress, and interventions that include activities that are meaningful and focused on the resumption of valued life roles appear to be key considerations in facilitating patient participation in stroke rehabilitation. Notably, the second manuscript was informed by findings from the first manuscript – the main study within this thesis. A resounding message from participants related to the amount of therapy received and opportunities for therapy during inpatient rehabilitation: there was ‘not enough’ of it. Drawing on participants’ perceptions, the second manuscript further critically explores the pervasive evidence-to-practice gap relating to rehabilitation intensity during inpatient stroke rehabilitation. A final discussion chapter presents the overall findings of the research contained in this thesis and highlights clinical implications as well as future directions. This thesis contributes new insight into patient-perceived factors affecting participation in rehabilitation, which to date has been limited, and provides a better understanding of relevant participation-related issues identified by patients. Ultimately, this research can provide a meaningful contribution to the evidence-based practice environment by broadening the focus from patient characteristics to incorporating patient perspectives, allowing for a more comprehensive understanding of many factors, outside of the patients themselves, affecting participation in stroke rehabilitation.

References

American Heart Association/American Stroke Association. (n.d.). Guidelines and statements. https://doi.org/10.1161/CIR.0000000000000652

Andrews, A. W., Li, D., & Freburger, J. K. (2015). Association of rehabilitation intensity for stroke and risk of hospital readmission. *Physical Therapy*, *95*(12), 1660–1667. https://doi.org/10.2522/ptj.20140610

Barrett, M., Snow, J. C., Kirkland, M. C., Kelly, L. P., Gehue, M., Downer, M. B., … Ploughman, M. (2018). Excessive sedentary time during in-patient stroke rehabilitation. *Topics in Stroke Rehabilitation*, *25*(5), 366–374. https://doi.org/10.1080/10749357.2018.1458461org/10.1080/10749357.2018.1458461

Bogdan, R., & Biklen, S. K. (2014). *Qualitative Research for Education: An Introduction to Theories and Methods* (6th ed.). Pearson.

Boulanger, J. M., Lindsay, M. P., Gubitz, G., Smith, E. E., Stotts, G., Foley, N., … on behalf of the Acute Stroke Management Best Practices and Quality Advisory Committee; in collaboration with the Canadian Stroke Consortium and the Canadian Association of Emergency Physicians. (2018). Canadian stroke best practice recommendations for acute stroke management: Prehospital, emergency department, and acute inpatient stroke care, 6th edition, update 2018. *International Journal of Stroke*, *13*(9), 1–36. https://doi.org/10.1177/1747493018786616 [Epub ahead of print]

Bright, F. A. S., Kayes, N. M., Cummins, C., Worrall, L. M., & McPherson, K. M. (2017). Co-constructing engagement in stroke rehabilitation: A qualitative study exploring how practitioner engagement can influence patient engagement. *Clinical Rehabilitation*, *31*(10), 1396–1405. https://doi.org/10.1177/0269215517694678

Cawood, J., Visagie, S., & Mji, G. (2016). Impact of post-stroke impairments on activities and participation as experienced by stroke survivors in a Western Cape setting. *South African Journal of Occupational Therapy*, *46*(2), 10–15. https://doi.org/10.17159/2310-3833/2016/v46n2a3

Cicerone, K. D., Langenbahn, D. M., Braden, C., Malec, J. F., Kalmar, K., Fraas, M., … Ashman, T. (2011). Evidence-based cognitive rehabilitation: Updated review of the literature from 2003 through 2008. *Archives of Physical Medicine and Rehabilitation*, *92*, 519–530. https://doi.org/10.1016/j.apmr.2010.11.015

Cogan, A. M., & Carlson, M. (2017). Deciphering participation: An interpretive synthesis of its meaning and application in rehabilitation. *Disability and Rehabilitation*, 1–12. https://doi.org/10.1080/09638288.2017.1342282 [Epub ahead of print]

Corr, S., & Wilmer, S. (2003). Returning to work after a stroke: An important but neglected area. *British Journal of Occupational Therapy*, *66*(5), 186–192. https://doi.org/10.1177/030802260306600502

Cumming, T. B., Marshall, R. S., & Lazar, R. M. (2013). Stroke, cognitive deficits, and rehabilitation: Still an incomplete picture. *International Journal of Stroke*, *8*, 38–45. https://doi.org/10.1111/j.1747-4949.2012.00972.x

Cunningham, W., Duffee, D., Huang, Y., Steinke, C. M., & Naccarato, T. (2009). On the meaning and measurement of engagement in youth residential treatment centers. *Research on Social Work Practice*, *19*(1), 63–77.

Damush, T. M., Plue, L., Bakas, T., Schmid, A., & Williams, L. S. (2007). Barriers and facilitators to exercise among stroke survivors. *Rehabilitation Nursing*, *32*(6), 253–262. https://doi.org/10.1002/j.2048-7940.2007.tb00183.x

Duchan, J. (2009). Engagement: A concept and some possible uses. *Seminars in Speech and Language*, *30*(1), 11–17.

Gialanella, B., Santoro, R., & Ferlucci, C. (2013). Predicting outcome after stroke: The role of basic activities of daily living. *European Journal of Physical and Rehabilitation Medicine*, *49*(5), 629–637.

Hatem, S. M., Saussez, G., della Faille, M., Prist, V., Zhang, X., Dispa, D., & Bleyenheuft, Y. (2016). Rehabilitation of motor function after stroke: A multiple systematic review focused on techniques to stimulate upper extremity recovery. *Frontiers in Human Neuroscience*, *10*(442), 1–22. https://doi.org/10.3389/fnhum.2016.00442

Health Quality Ontario; Ministry of Health and Long-Term Care. (2016). *Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute)*. Toronto.

Heart and Stroke Foundation of Canada. (n.d.). Recommendations. Retrieved January 25, 2019, from https://www.strokebestpractices.ca/recommendations

Heart and Stroke Foundation of Canada. (2017). *Different strokes: Recovery triumphs and challenges at any age*.

Hebert, D., Lindsay, P., Mcintyre, A., Kirton, A., Rumney, P. G., Bagg, S., … Teasell, R. (2016). Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015. *International Journal of Stroke*, *11*(4), 459–484. https://doi.org/10.1177/1747493016643553

Hendricks, H. T., Van Limbeek, J., Geurts, A. C., & Zwarts, M. J. (2002). Motor Recovery After Stroke: A Systematic Review of the Literature. *Archives of Physical Medicine and Rehabilitation*, *83*(11), 1629–1637. https://doi.org/10.1053/apmr.2002.35473

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, *19*(9), 1284–1292. https://doi.org/10.1177/1049732309344612

Ivey, F. M., Macko, R. F., Ryan, A. S., & Hafer-Macko, C. E. (2005). Cardiovascular health and fitness after stroke. *Topics in Stroke Rehabilitation*, *12*(1), 1–16.

Jette, D. U., Warren, R. L., & Wirtalla, C. (2005). The relation between therapy intensity and outcomes of rehabilitation in skilled nursing facilities. *Arch Phys Med Rehabil*, *86*(3), 373–379. https://doi.org/10.1016/j.apmr.2004.10.018

Jolliffe, L., Lannin, N. A., Cadilhac, D. A., & Hoffmann, T. (2018). Systematic review of clinical practice guidelines to identify recommendations for rehabilitation after stroke and other acquired brain injuries. *BMJ Open*, *8*, 18791. https://doi.org/10.1136/bmjopen-2017-018791

Jorgensen, H. S., Nakayama, H., Raaschou, H. O., Olsen, T. S., & Jergensen, H. S. (1995). Recovery of walking function in stroke patients: The Copenhagen Stroke Study. *Arch Phys Med Rehabil*, *76*(1), 27–32.

Kaplan, R. M. (1990). Behavior as the central outcome in health care. *The American Psychologist*, *45*(11), 1211–1220.

Karges, J., & Smallfield, S. (2009). A Description of the outcomes , frequency, duration, and intensity of occupational, physical, and speech therapy in inpatient stroke rehabilitation. *Journal of Allied Health*, *38*(1), 1–10.

Keith, R. A., Granger, C. V, Hamilton, B. B., & Sherwin, F. S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*, *1*, 6–18.

Kortte, K. B., Falk, L. D., Castillo, R. C., Johnson-Greene, D., & Wegener, S. T. (2007). The Hopkins Rehabilitation Engagement Rating Scale: Development and psychometric properties. *Archives of Physical Medicine and Rehabilitation*, *88*. https://doi.org/10.1016/j.apmr.2007.03.030

Kotila, M., Numminen, H., Waltimo, O., & Kaste, M. (1998). Depression after stroke: Results of the FINNSTROKE Study. *Stroke*, *29*(2), 368–372.

Kwakkel, G. (2009). *Intensity of practice after stroke: More is better*.

Kwakkel, G., Roland Van Peppen, P. ;, Wagenaar, R. C., Dauphinee, S. W., Richards, C., Ashburn, A., … Langhorne, P. (2004). Effects of augmented exercise therapy time after stroke: A meta-analysis. *Stroke*, *35*, 2529–2536. https://doi.org/10.1161/01.STR.0000143153.76460.7d

Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke care 2: Stroke rehabilitation. *The Lancet*, *377*, 1693–1702. https://doi.org/10.1016/S0140-6736(11)60325-5

Lawrence, M. (2010). Young adults' experience of stroke: A qualitative review of the literature. *British Journal of Nursing*, *19*(4), 241–248. https://doi.org/10.12968/bjon.2010.19.4.46787

Lenze, E. J., Munin, M. C., Quear, T., Dew, M. A., Rogers, J. C., Begley, A. E., & Reynolds, C. F. (2004a). Significance of poor patient participation in physical and occupational therapy for functional outcome and length of stay. *Archives of Physical Medicine and Rehabilitation*, *85*, 1599–1601. https://doi.org/10.1016/j.apmr.2004.03.027

Lenze, E. J., Munin, M. C., Quear, T., Dew, M. A., Rogers, J. C., Begley, A. E., & Reynolds, C. F. (2004b). The Pittsburgh Rehabilitation Participation Scale: Reliability and validity of a clinician-rated measure of participation in acute rehabilitation. *Archives of Physical Medicine and Rehabilitation*, *85*, 380–384. https://doi.org/10.1016/j.apmr.2003.06.001

Lequerica, A. H., & Kortte, K. (2010). Therapeutic engagement: A proposed model of engagement in medical rehabilitation. *American Journal of Physical Medicine and Rehabilitation*, *89*(5), 415–422. https://doi.org/10.1097/PHM.0b013e3181d8ceb2

Lindsay, M., Gubtiz, G., Bayley, M., Hill, M., Phillips, S., & Smith, E. (2014). *Canadian Stroke Best Practice Recommendations Overview and Methodology. On behalf of the Canadian Stroke Best Practices Advisory Committee and Writing Groups*. Ottawa, Ontario Canada.

Luker, J., Lynch, E., Bernhardsson, S., Bennett, L., & Bernhardt, J. (2015). Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, *96*(9), 1698–1708. https://doi.org/10.1016/j.apmr.2015.03.017

MacDonald A., G., Kayes M., N., & Bright, F. (2013). Barriers and facilitators to engagement in rehabilitation for people with stroke: A review of the literature. *New Zealand Journal of Physiotherapy*, *41*(3), 112–121.

Maclean, N, Pound, P., Wolfe, C., & Rudd, A. (2000). Qualitative analysis of stroke patients' motivation for rehabilitation. *BMJ (Clinical Research Ed.)*, *321*(7268), 1051–1054. https://doi.org/10.1136/BMJ.321.7268.1051

Maclean, Niall, Pound, P., Wolfe, C., & Rudd, A. (2002). The concept of patient motivation: A qualitative analysis of stroke professionals' attitudes. *Stroke*, *33*, 444–448.

Maulden, S. A., Gassaway, J., Horn, S. D., Smout, R. J., & Dejong, G. (2005). Timing of initiation of rehabilitation after stroke. *Archives of Physical Medicine and Rehabilitation*, *86*(Suppl 2), S34–S40. https://doi.org/10.1016/j.apmr.2005.08.119

Menon, A., Korner-Bitensky, N., Kastner, M., McKibbon, K. A., & Straus, S. (2009). Strategies for rehabilitation professionals to move evidence-based knowledge into practice: A systematic review. *Journal of Rehabilitation Medicine*, *41*(13), 1024–1032. https://doi.org/10.2340/16501977-0451

Meyer, M., O'callaghan, C., Kelloway, L., Hall, R., Teasell, R., Meyer, S., … in collaboration with Ontario's Stroke Reference Group. (2012). *The Impact of Moving to Stroke Rehabilitation Best Practices in Ontario*.

Morghen, S., Morandi, A., Bozzini, M., Guerini, F., Gatti, R., Santo, F. Del, … Bellelli, G. (2017). The association between patient participation and functional gain following inpatient rehabilitation. *Aging Clinical and Experimental Research*, *29*(4), 729–736. https://doi.org/10.1007/s40520-016-0625-3

Nicholson, S. L., Donaghy, M., Johnston, M., Sniehotta, F. F., Van Wijck, F., Johnston, D., … Mead, G. (2014). A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disability and Rehabilitation*, *36*(22), 1857–1868. https://doi.org/10.3109/09638288.2013.874506

Obembe, A. O., & Eng, J. J. (2016). Rehabilitation interventions for improving social participation after stroke: A systematic review and meta-analysis. *Neurorehabilitation and Neural Repair*, *30*(4), 384–392.

https://doi.org/10.1177/1545968315597072

Opara, J. A., & Jaracz, K. (2010). Quality of life of post-stroke patients and their caregivers. *Journal of Medicine and Life*, *3*(3), 216–220.

Paolucci, S., Di Vita, A., Massicci, R., Traballesi, M., Bureca, I., Matano, A., … Guariglia, C. (2012). Impact of participation on rehabilitation results: A multivariate study. *European Journal of Physical and Rehabilitation Medicine*, *48*(3), 455–466.

Parahoo, K. (2014). *Nursing Research: Principles, Process and Issues* (3rd ed.). Palgrave Macmillan.

Peiris, C. L., Shields, N., Brusco, N. K., Watts, J. J., & Taylor, N. F. (2013). Additional Saturday rehabilitation improves functional independence and quality of life and reduces length of stay: A randomized controlled trial. *BioMed Central Medicine*, *11*(198), 1–11. https://doi.org/10.1186/1741-7015-11-199

Pound, P., Gompertz, P., & Ebrahim, S. (1998). A patient-centred study of the consequences of stroke. *Clinical Rehabilitation*, *12*(4), 338–347.

Program Pathways of Care for People With Stroke in Ontario. (2012).

Salter, K., Allen, L., Richardson, M., Cotoi, A., Iliescu, A., Carr, B., & Teasell, R. (2018). *Chapter 19: Community reintegration*.

Satink, T., Cup, E. H., Ilott, I., Prins, J., De Swart, B. J., & Nijhuis-Van Der Sanden, M. W. (2013). Patients' views on the impact of stroke on their roles and self: A thematic synthesis of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, *94*(6), 1171–1183. https://doi.org/10.1016/j.apmr.2013.01.011

Secrest, J. A., & Thomas, S. P. (1999). Continuity and discontinuity: The quality of life following stroke. *Rehabilitation Nursing*, *24*(6), 240–246.

Sehatzadeh, S. (2015). Effect of increased intensity of physiotherapy on patient outcomes after stroke: An evidence-based analysis. *Ontario Health Technology Assessment Series*, *15*(6), 1–42.

Simmons-Mackie, N., & Damico, J. (2009). Engagement in group therapy for aphasia. *Seminars in Speech and Language*, *30*(1), 18–26. https://doi.org/10.1055/s-0028-1104531

Simpson, L. A., Eng, J. J., Tawashy, A. E., English, C., & Olawale, O. A. (2011). Exercise perceptions among people with stroke: barriers and facilitators to participation. *International Journal of Therapy & Rehabilitation*, *18*(9), 520–530. https://doi.org/10.1167/iovs.07-1072.Complement-Associated

Skidmore, E. R., Whyte, E. M., Holm, M. B., Becker, J. T., Butters, M. A., Dew, M. A., … Lenze, E. J. (2010). Cognitive and affective predictors of rehabilitation participation after stroke. *Archives of Physical Medicine and Rehabilitation*, *91*, 203–207. https://doi.org/10.1016/j.apmr.2009.10.026

Stroke Foundation. (n.d.). Guidelines. Retrieved January 25, 2019, from https://informme.org.au/en/Guidelines

Stroke Foundation. (2017). *(Australian) Clinical Guidelines for Stroke Management*

2017. Chapter 5 of 8: Rehabilitation. Melbourne, Australia.

Teasell, R., Foley, N., Hussein, N., Wiener, J., & Speechley, M. (2018). Chapter 6: The elements of stroke rehabilitation. Retrieved August 8, 2018, from www.ebrsr.com

Teasell, R., Hussein, N., & Foley, N. (2018). Chapter 4: Managing the stroke rehabilitation triage process. Retrieved September 8, 2018, from www.ebrsr.com

Teherani, A., Martimianakis, T., Stenfors-Hayes, T., Wadhwa, A., & Varpio, L. (2015). Choosing a qualitative research approach. *Journal of Graduate Medical Education*, 669–670. https://doi.org/10.4300/JGME-D-15-00414.1

Teodoro, I. P. P., Rebouças, V. C. F., Thorne, S. E., Souza, N. K. M., Brito, L. S. A., & Alencar, M. P. G. (2018). Interpretive description: A viable methodological approach for nursing research. *Escola Anna Nery*, *22*(3), 1–8. https://doi.org/10.1590/2177-9465-EAN-2017-0287

Tetley A, Jinks, M., Huband, N., & Howells, K. (2011). A systematic review of measures of therapeutic engagement in psychosocial and psychological treatment. *Journal of Clincal Psychology*, *67*, 927–941.

Thorne, Sally. (2008). *Interpretive Description.* Walnut Creek, CA: Left Coast Press Inc.

Thorne, Sally. (2016). *Interpretive Description* (2nd ed.). Walnut Creek, CA: Left Coast Press Inc.

Thorne, Sally, Reimer-Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, *3*, 1–21.

Thorne, SE, Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, *20*(2), 169–177.

Van Der Zwaluw, C. S., Valentijn, S. A. M., Nieuwenhuis-Mark, R., Rasquin, S. M. C., & Van Heugten, C. M. (2011). Cognitive functioning in the acute phase poststroke: A predictor of discharge destination? *Journal of Stroke and Cerebrovascular Diseases*, *20*(6), 549–555. https://doi.org/10.1016/j.jstrokecerebrovasdis.2010.03.009

Van Osch, M., Scarborough, K., Crowe, S., Wolff, A. C., & Reimer-Kirkham, S. (2018). Understanding the factors which promote registered nurses' intent to stay in emergency and critical care areas. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.14167

Vasilachis de Gialdino, I. (2009). Ontological and epistemological foundations of qualitative research. *Forum: Qualitative Social Research*, *30*(2), 1–18.

Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., … and Council on Quality of Care and Outcomes Research. (2016). Guidelines for adult stroke rehabilitation and recovery: A guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*, *47*(6), e98–e169. https://doi.org/10.1161/STR.0000000000000098

Wolf, T. J., Chuh, A., Floyd, T., Mcinnis, K., Williams, E., & Student, G. (2015). Effectiveness of occupation-based interventions to improve areas of occupation and social participation after stroke: An evidence-based review. *The American Journal of Occupational Therapy*, *69*, 6901180060. https://doi.org/10.5014/ajot.2015.012195

World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva: World Health Organization.

Wressle, E., Eeg-Olofsson, A. M., Marcusson, J., & Henriksson, C. (2002). Improved client participation in the rehabilitation process using a client-centred goal formulation structure. *Journal of Rehabilitation Medicine*, *34*(1), 5–11. https://doi.org/10.1080/165019702317242640

Yagi, M., Yasunaga, H., Matsui, H., Morita, K., Fushimi, K., Fujimoto, M., … Fuhitani, J. (2017). Impact of rehabilitation on outcomes in patients with ischemic stroke. *Stroke*, *48*, 740–746. https://doi.org/10.1161/STROKEAHA.116.015147

Yang, S.-Y., & Kong, K. H. (2013). Level and predictors of participation in patients with stroke undergoing inpatient rehabilitation. *Singapore Medical Journal*, *54*(10), 564–568. https://doi.org/10.11622/smedj.2013201

Zalewski, K. R., & Dvorak, L. (2011). Barriers to physical activity between adults with stroke and their care partners. *Top Stroke Rehabil*, *18*(Suppl 1), 666–675. https://doi.org/10.1310/tsr18s01-666

Chapter 2: Looking beyond the scales of participation: Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation

Nicole Last, Tara L. Packham, Rebecca E. Gewurtz, Lori Letts and Jocelyn E. Harris

Submitted to *Disability and Rehabilitation*

Looking beyond the scales of participation: Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation

Nicole Last[a], Tara L. Packham[a], Rebecca E. Gewurtz[a], Lori Letts[a] and Jocelyn E. Harris[a]*

[a]*School of Rehabilitation Science, McMaster University, Hamilton*

*Correspondence: Jocelyn Harris, PhD, McMaster University, School of Rehabilitation Science, IAHS Rm 438, 1400 Main Street West, Hamilton, ON, Canada, L8S 1C7. Tel: (905) 525-9140 ext. 27813. Fax: (905) 524-0069.
E-mail: jharris@mcmaster.ca

Word count: 7485 excluding abstract and references

Looking beyond the scales of participation: Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation

Background: Patient participation is recognized as an important element of rehabilitation. However, few studies have used a qualitative lens to specifically examine factors influencing patient participation in stroke rehabilitation. *Aim:* The purpose of this study was to investigate patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation. *Methods:* Semi-structured interviews were conducted with 11 patients, with confirmed diagnoses of stroke, recruited from three separate rehabilitation settings. Analysis of the interviews was guided by a process of interpretive description to identify key barriers and facilitators to participation in stroke rehabilitation. *Results:* Four main themes and corresponding sub-themes were constructed concerning participation in rehabilitation: (i) Environmental Factors, (ii) Components of Therapy, (iii) Physical and Emotional Well-Being, and (iv) Personal Motivators. *Discussion:* Study findings highlight the pivotal role of the environment in impacting patient participation in stroke rehabilitation. Interpersonal and personal factors were also found to influence patient participation. The barriers and enablers experienced by patients in this study contribute to the existing knowledge of the patient experience of stroke rehabilitation and may be used to inform clinical practices and future research.

Keywords: stroke; rehabilitation; barrier; facilitator; participation; qualitative; interpretive description

Introduction

Hospital-based (inpatient/outpatient) multidisciplinary rehabilitation programs are reported to be the most effective way to minimize disability and enhance community integration after stroke [1,2]. The effectiveness of stroke rehabilitation programs, however, requires participatory efforts from the patient [3]. Moreover, poor participation in inpatient rehabilitation after stroke is associated with significantly lower Functional Independence Measure (FIM) scores and a longer stay [4]. Conversely, greater participation is significantly associated with larger improvement in activities of daily living (measured using the Barthel Index) and mobility (measured using the Rivermead Mobility Index), as well as a shorter length of stay in hospital-based rehabilitation programs [5].

Since level of participation in hospital-based rehabilitation programs after stroke can change rehabilitation outcomes, it is important to discern factors that influence participation. However, few studies have examined the factors impacting patient participation in hospital-based stroke rehabilitation programs. Cognitive and affective deficits are common after stroke: both executive function and depressive symptoms have been shown to reduce participation among individuals admitted to inpatient stroke rehabilitation [6]. Further, Yang and Kong [7] reported patients with stroke undergoing inpatient rehabilitation who had a lower level of rehabilitation participation, as measured on the Pittsburgh Rehabilitation Participation Scale [4], were more likely to a) be cognitively impaired (measured using the Elderly Cognitive Assessment Questionnaire), b) have poor functional status (measured using the FIM), and c) have higher levels of fatigue (measured using the Fatigue Severity Scale). Thus, the quantitative literature suggests cognitive impairment, depressive symptoms, fatigue, and higher levels of disability are barriers to participation in inpatient stroke rehabilitation.

Qualitative studies regarding participation in stroke rehabilitation can generate different forms of knowledge. Qualitative methods provide insight into the uniqueness of individuals' experiences and perspectives. The focus is on people's lives, behaviours, and interactions [8]. By exploring individuals' experiences in health care programs, awareness of patient-perceived issues is heightened, and their voice can be a focal point of consideration. To date, there are few qualitative studies that have examined factors influencing participation in stroke rehabilitation.

MacDonald, Kayes, and Bright [9] conducted a systematic review to identify barriers and facilitators to participation or engagement in stroke rehabilitation and included quantitative and qualitative designs (N=14/17 qualitative studies). However, due to the absence of studies with the specific aim of exploring influencers of participation/engagement, authors included studies exploring patient and therapist experiences that might provide insight into engagement-related issues. From these studies, seven key themes relating to factors perceived to help or hinder engagement in stroke rehabilitation were constructed from participant experiences: 1) goal setting, 2) therapeutic connection, 3) personalised rehabilitation, 4) paternalism versus independence, 5) patient-centred practice, 6) knowledge is power, and 7) feedback and achievement. While the review by MacDonald et al. begins to shine a light on the topic of participation in stroke rehabilitation, it is important to remember the included studies themselves did not directly explore factors of participation or engagement in stroke rehabilitation. Also, the review does not isolate the perspectives of patients from that of health professionals; nor does it separate the different experiences of hospital-based rehabilitation from community-based rehabilitation. Since the review was published in 2013, others have explored specific components of stroke rehabilitation from patients' perspectives, such as: goal-setting in rehabilitation [10,11]; aerobic exercise during inpatient rehabilitation [12]; physiotherapy [13,14]; music therapy [15]; exposure to an enriched environment [16]; weekend passes during inpatient rehabilitation [17]; tablet technology [18] and other novel interventions [19,20]. However, consistent with the findings reported in the review by McDonald et al., most of these studies focus on a single intervention or component and do not examine barriers or facilitators to participating and engaging in stroke rehabilitation.

Although rehabilitation science research has recognized the key role participation plays in successful rehabilitation outcomes, no studies have applied a qualitative lens to investigate factors influencing participation in hospital-based stroke rehabilitation programs from patients' perspectives. Qualitative research is often used to explore problems about which relatively little is known [21] and is useful for producing contextual understandings of a phenomenon through the analysis of rich and detailed textual data [22]. Qualitative research focused on patients' perspectives can be of significant use in healthcare as patients may provide new knowledge and understanding of a phenomenon and assist in shaping quality care. Therefore, the research question explored in this study was: What are the patient-perceived barriers and facilitators to participating in hospital-based stroke rehabilitation? The main objectives were to: 1) identify factors perceived by patients to influence their participation in hospital-based stroke rehabilitation activities and 2) use a patient lens to generate knowledge relevant for the clinical context of stroke rehabilitation.

Methods

This study was guided by an interpretive description (ID) methodological approach [23]. ID is an inductive form of qualitative analysis used to generate knowledge of a subjective healthcare experience for the purposes of informing clinical care and research [23], and draws on methods from both grounded theory and phenomenology [24]. An ID approach was chosen because the research question was generated from a clinical phenomenon in which little is known from the patient perspective and our study aim is to use generated findings to inform stroke rehabilitation care and research. This study was approved by a university and hospital-based research ethics board.

Participants

Recruitment and Inclusion/Exclusion Criteria. Recruitment was open to patients of three distinct rehabilitation programs within a regional integrated stroke network in south central Ontario. Participants were referred by program therapists who screened patients for eligibility. During the process of recruitment (May-October 2017), all current or recently discharged patients of the three recruitment sites (see below) with a confirmed diagnosis of stroke were considered for eligibility. In addition, participants had to be able to converse in and comprehend English and provide informed consent. Participants were excluded if they were unable to understand questions because of cognitive impairments.

The research team had aphasia-friendly documents (consent form, interview guide, and visual aids) available if needed, therefore presenting with expressive aphasia did not exclude participants from this study.

Sampling Strategy and Sample Size. A purposive sampling strategy was employed to attain maximal variability in the sample with respect to diversity in individual characteristics that may impact the experience of, and participation in, rehabilitation after stroke (e.g., stroke severity, presence of post-stroke pain, presence of aphasia, and rehabilitation site).

Setting

The three recruitment sites were part of a regional Integrated Stroke Program and represent different stages of rehabilitation.

Inpatient Stroke Rehabilitation. This designated 28-bed speciality stroke rehabilitation unit [25] admits approximately 325-340 new patients annually. The main goal of this program is to collaboratively work on functional goals with regards to functional limitations. The interdisciplinary team (physicians, nurses, occupational therapists [OTs], physiotherapists [PTs], speech-language pathologists [SLPs], social workers, dieticians, etc) provides goal-directed rehabilitation to individuals with moderate to severe stroke (AlphaFIM® of 40-80). Individuals are scheduled for one-on-one therapy sessions daily and are also provided with additional opportunities for group therapy (hand therapy, communication groups, therapeutic recreation). From here, individuals are discharged home, to outpatient rehabilitation, or a higher level of care.

Outpatient Rehabilitation. This neuro-rehab program admits approximately 300 new patients annually, with approximately two thirds being patients discharged from the inpatient stroke rehabilitation program (described above). The main goal of this program is to assist patients to resume meaningful activities and roles and integrating back into their community. Individuals attend the program 1-3 times per week, for an average of 8-10 weeks, and work with OTs, PTs, SLPs, and recreational therapists, based on individual needs.

Restorative Care. This 44-bed inpatient unit admits approximately 190 new patients annually and is intended for those requiring complex care and who could benefit from an interdisciplinary, low intensity, longer duration rehabilitation program. Individuals who sustained a severe stroke (AlphaFIM® <40) are admitted to this time-limited program and comprise approximately one third of the patients. The restorative care team is similar to that of the inpatient stroke rehabilitation unit (described above). The average length of stay is 45-60 days and from here, individuals are discharged home or to an alternate level of care as required.

Data Collection

Written, informed consent was obtained prior to data collection. Author TP and pairs of MScOT students conducted 30-60-minute semi-structured interviews at the respective rehabilitation sites. Families and carers were invited to listen and participate in the interviews at the participants' discretion for the purpose of supporting communication and to provide clarification if necessary; however, all questions were directed to the participants. Informed consent was also obtained from family members/carers who were present during interviewing prior to beginning the interview process. An interview guide was developed from clinical knowledge as well as previous research [26] and key informant interviews with occupational therapists and occupational therapy assistants from each of the three rehabilitation settings. A detailed interview guide is included as supplementary material – this includes questions about participants' rehabilitation experience and participating in therapy activities. All interviews were audio recorded and transcribed verbatim by NL to allow for increased engagement with the data and greater attentional awareness to the words of participants; Thorne [27] describes transcription as a powerful experience and encourages researchers to take a more active role in the transcription process.

Analysis

Data analysis to identify barriers and facilitators to participating in rehabilitation began at completion of data collection. ID requires the researcher to move beyond formulaic approaches, using iterative reasoning, and making informed decisions aligning with the research question [27]. Here, data were analyzed inductively guided by qualitative content analysis [28]; this approach is commonly utilized in ID as it allows for the uncovering of commonalities and patterns across cases within human experiences and is appropriate to use when prior knowledge of what is being explored is limited [29]. Immersion in the data was extended and sustained throughout the analysis process to enhance the credibility of research findings; to ensure that assigned themes, categories, and codes reflected the experience of the participants. Thorne [27] cautions that in interpretive description it is important to avoid excessive precision in early coding. As such, the analytic approach in this study was stepwise: beginning with describing the data and leading to conceptualizing and interpreting meaning within the data.

Initial coding included highlighting key passages, adding memos, and the development and assignment of broad codes. Code definitions were discussed between research team members to establish conceptual consistency before the next cycles of coding began. The transcripts were read several times and assessed each time for the emergence of new codes. As the analytic process continued and our understanding of the data set as a whole evolved, coding became increasingly explicit and codes were refined, condensed and integrated into main themes. After discussing codes, patterns, and emerging themes with members of the research team, the final coding scheme was developed and the main themes and sub-themes were deemed a proper fit for organizing and interpreting the data. Reflexivity was maintained throughout the study process through the critical examination of preconceptions and constant reflection of personal biases, as well as journaling thoughts, feelings, and ideas throughout the analysis process.

Findings

Participant Characteristics

Interviews were conducted with 11 participants (4 women and 7 men) (Table 1). Five carers/family members (3 spouses, all female; 2 children, both male and female) were present in four of the interviews and all participated in conversations to varying extents; however, the findings reported here focus on patient perspectives and therefore will only include quotes from family members that directly reflect the patients' experience or provide clarification on the patients' behalf. Median age of patient participants was 60 years and the median time since stroke was 4 months. Two participants were currently on an inpatient stroke rehabilitation unit, 5 were on a slow-stream rehabilitation unit, and 4 were currently enrolled (n=1) or recently discharged from (n=3) outpatient rehabilitation. Notably, the 4 outpatient participants had completed inpatient rehabilitation on the inpatient stroke rehabilitation unit described in this study.

[Table 1 near here]

Themes

Four main themes were constructed in relation to the research question of “what are the patient-perceived barriers and facilitators to participating in hospital-based stroke rehabilitation?" The themes and corresponding sub-themes are illustrated in Figure 1 and are described in detail below.

[Figure 1 near here]

1. Environmental Factors

Environmental factors were described as impacting patient participation and experiences in all three rehabilitation settings. Here, the environment is defined broadly as the hospital environment in which rehabilitation took place and encompassing the corresponding environments within the rehabilitation setting (e.g. physical, social) as well as program resources.

Physical and Social Environments

The majority of participants commented on the rehabilitation environment and most commonly described aspects of the physical and social environments within the hospital, as well as the program atmosphere, as influencing their participation in rehabilitation.

Noise and disruptions in the hospital environment were identified as particular concerns by both patients and their family members. Participants described situations where other patients, visitors, and the daily/nightly hospital activity were disruptive to rest and sleep. Further, this was described as negatively affecting performance in therapy, and the healing and recovery process. For example, one participant stated, "…a lot of us don't sleep well here cause it's noisy - if you don't have a good sleep . . . you're not going to have a good physio" [Lola].

Peer interaction among patients was another prominent environmental factor identified by participants. Participants often reflected on their experiences in relation to other patients and described situations of making friends and planning social events, such as going for coffee together. Participants specifically described how these interactions contributed to their progress. One participant, for example, recalled a patient he met that was 'worse off' than himself and how befriending him had a positive impact on them both: "…I'm helping him and I'm being a friend to him. And apparently since I've been doing that - and it's not easy - he's been doing a lot better to try to talk and stuff. That helps me" [Ringo].

Indirect peer interaction, or observing other patients, was also described as influential. It was not uncommon for participants to compare their abilities amongst each other. One participant admitted to using the abilities of others to motivate himself in therapy:

> Because it's large group therapy . . . seeing other people succeed and being rewarded. . . . suddenly their rollator is taken away from them and they're given a cane. Suddenly the cane is taken away from them and they're walking on their own. And you looked over and they worked hard! And then you look at somebody else who is not working very hard - just going through the motion - and they're still in a wheelchair. That's a good part . . . because you can quickly say, 'I'm not gonna be that person.' [Cliff]

Family and friends were also described as an important aspect of the social environment. Their role as facilitators for participation in rehabilitation was noted through the encouragement and emotional support they provided as well as their involvement in the patients' rehabilitation processes and their overall presence. "Well, my family is the reason I'm doing the therapy" [Ringo]. One participant described how support from family allowed him to participate in the inpatient rehabilitation program: "I depend on them, you know, that they have to look after my life outside this place right now" [Pete].

Program atmosphere was another aspect of the environment perceived to impact the participant experience. Typically, participants used words such as "awesome" or "enjoyable," and the people and their attitudes were characterized as "the friendliest people ever," "patient," or "fantastic."

> I think this place was built in heaven…I'd say that ninety-nine percent of everything that goes on here is, is just amazing. . . . like the kitchen staff…they're fantastic and compassionate and patient and, and those people are well chosen too. [Ringo]

Another participant, who had completed both inpatient and outpatient rehabilitation, cited:

> I enjoyed the therapy because I could have fun in there, and if the music was on I could dance . . . it was a happy place for me. . . . you know, people weren't glum and down and everything. . . . I mean, overall, not that I wanted to have a stroke, but it wasn't a bad experience being here [chuckles]. [Sadie]

Resources

Availability of resources was discussed in most participant interviews, with the majority of participants referring to ratio of patients to staff/therapist and having to wait for therapy.

Many participants noted the low therapist-to-patient ratio as a concern and emphasized how this impacted their efforts to participate in rehabilitation. For example, when describing his rehabilitation experience, one participant stated: "…it's not that the . . . people there are doing nothing – they're dealing with another person. So, I think . . . for the therapist, it's just too many people to look after" [Rocky]. Other participants further highlighted a lack of therapy and therapy staff on weekends and holidays. Participants expressed frustration because of the impact of this scheduling issue on their progress. For example:

> …it was the Family Day weekend I think. And I thought, what do I do now? Well you just lie in bed, you know. And even, like, the Tuesday when I came back, they had nothing scheduled for me. So, to me it was a four-day weekend, you know, and like, they're saying, 'oh you're sort of slow.' Well, yeah, when you haven't done anything for four days! [Rocky]

Some participants felt the quantity of therapy received was negatively influenced by a lack of physical resources, which resulted in further delays and wait times and consequently affected participation in rehabilitation. One participant, who was currently undergoing outpatient stroke rehabilitation, illustrated this point:

> The only thing, and this is no person's fault, this is just a matter of there's so much to do and so little time and so few resources . . . it's not unusual for people to have to sit there and wait for a long period of time from one exercise to the next because the next exercise piece is not free yet. [Cliff]

Overall, it was evident the physical and social environments were important factors in the rehabilitation experience. Perceived environmental barriers were a noisy environment and the availability of resources, while peer interactions, support from family and friends, and program atmosphere were mostly descripted positively and were identified as motivating.

2. Components of Therapy

Aspects of therapy that were highlighted as influential in the experiences of persons participating in stroke rehabilitation were: a) interactions between patients and therapists, b) the quantity of physio- and occupational therapy, and c) personalized rehabilitation.

Patient-Therapist Interactions

Consistently, participants described their relationship with therapists in a positive manner; "We all praise our therapists" [Ringo]. However, further analysis revealed nuances of how interactions between therapists (and other rehabilitation staff) and patients were perceived and seemed to have a significant impact on how patients engaged in the program.

Participants reported they found information shared by their therapists to be infrequent and sometimes unclear. They expressed confusion about what they were being asked to do, why they were being asked to do certain things, and how it would impact their progress. Participants expressed how they wanted the therapists to educate them on the underlying therapeutic value of activities. For example, one person stated:

> They wanted me to work with the silly putty stuff there . . . I found that it hurt me more to use it so I didn't know whether I was using it right. . . . I tried that a few times but I didn't find it was doing anything. But if they explained to me what it did, maybe I would do it more. [Ringo]

Another participant described he appreciated how his therapist explained the purpose of the exercises he was performing in relation to performing daily activities, such as putting away groceries.

Participants also valued feedback and validation from the therapists, which helped them to improve performance and gauge progress. One participant expressed one of the best parts of his therapy was the validation he received from his therapists, stating that, "it feels good to know that you are actually doing better" [Cliff]. Conversely, participants described feeling discouraged when therapists told them they would likely be unable to progress to the extent they hoped. For example, one participant tearfully described an interaction with one therapist that impacted her willingness and motivation to continue to participate:

> And then someone in therapy told me after practicing walking again with a walker in between the bars, and he says, 'I don't think you're ever going to get out of the wheelchair' . . . I don't even know why I go because well, what good is it to me? . . . It was so demeaning, so low – cause I was always taught, you know, you try and you try, 'til you can't try no more. Like you don't give

> up. And here [the therapist] says you'll never walk again. Well, how do you know?! That just put such a big damper [crying]… [Marie]

Participants acknowledged that communication is two-sided and noted the importance of communicating their own healthcare needs and keeping their therapists and other healthcare providers informed. The following quote is an example of this recognition: "…you have to tell them [the therapists] what you find is working and what you're worried about, because 9 times out of 10, they've got something in place to help you." [Cliff]

Amount of Therapy

The majority of participants who discussed quantity of therapy during rehabilitation felt they did/were not spending enough time actively participating in therapy activities. Participants perceived they were not getting enough therapy because of limited resources (previously mentioned) or they were not being offered enough opportunities for therapy. For example:

> Well, it's not much . . . you figure we're here 24/7, that we would go twice a day - we only go once a day. I go at 10 in the morning - I'm done by 10:30. . . . Then at around 2:00, I have arm therapy - that lasts about 25 minutes, not even. . . . There should be more therapy and a lot of patients have been complaining. [Lola]

Personalized Rehabilitation

Participants described instances where therapy was enhanced when activities were tailored to individual needs, preferences, and goals. While some participants perceived therapy to be challenging, others criticized the simplicity of activities. If activities or exercises were perceived to be too easy, there was a risk of becoming bored and losing interest: “At first – I said let's go, let’s get a try. But… I'm bored. Before it's hard, but [now] it’s okay” [Shannon; participant presented with expressive aphasia]. Another participant made implications of pointlessness when describing therapy activities: “…they got me to make a sandwich, use the toaster, make coffee - little things like that - they weren’t challenging at all for me. But I imagine for some people they probably would be” [Rocky]. Some participants noted that therapy was sufficiently challenging. For example, one outpatient participant stated, “I did enough here and I don't feel that I had to do anymore when I was at home” [Dick].

In addition, therapy activities seemed to be most meaningful to participants when they were developed or refined to match the needs and goals of the individual. One participant talked about how she and her therapists would collaborate to think of new and unique activities for her and how this made therapy enjoyable and made her excited to participate. Personalized rehabilitation through meaningful activity is illustrated in the following quote by one participant who had a goal of kayaking - it was a valued pre-stroke activity - and her therapists incorporated it into therapy:

> …I had a goal - I wanted to get into my kayak - she brought a kayak into the pool for me to use. . . . I get in the kayak, but they had to literally pull me out of the kayak in the pool. But that was really great, you know. . . . I looked forward to coming [Sadie]

Participants also shared examples of aspects or events that were individually meaningful to them and revealed the impact they had on the patient experience. Some participants described situations specific to the program, such as how family could join in on classes and “see the progress you’ve made” [Lola] or how being able to go home on weekends added a sense of normalcy to the experience and “gives you a boost” [Sadie]. Another participant expressed how meaningful it was that his pet could visit him on hospital grounds: “And my pet is huge therapy to me - that's one of the biggest things I think about all of the time” [Ringo].

Overall, participation in stroke rehabilitation seemed to be supported when there was frequent and clear communication between the patient and therapist, and patients felt informed and educated. In addition, participants appeared to be more motivated to participate in activities when their needs, goals, and preferences were considered in the administration of therapy.

3. Physical and Emotional Well-Being

Tasks such as getting dressed, using a fork, and going to the bathroom/showering were new challenges participants encountered after stroke. While all participants experienced some form of physical deficit, this was not typically described as limiting their participatory efforts. However, post-stroke fatigue was described by some participants as having overwhelming effects on their ambitions to participate. Further, the undercurrent of the emotional impact of having a stroke and all that it entailed was expressed by some participants in this study.

Fatigue

Participants described how being tired and having strength and energy ‘taken away’ from them made participating in activities a challenge. When questioned about what prevented her from being able to engage in therapy, one participant explicitly stated, “fatigue stopped me from doing some stuff" [Sadie]. In addition, participants often appeared astonished by the impact post-stroke fatigue had on their physical capability:

> …it's amazing what a stroke takes out of you. Because I thought I was fairly fit before this happened and when I had it they told me the hardest part is yet to come because you've got to go to rehab, I figured Christ, I'm no baby and I can do exercise and get myself up and going in no time. . . . But I'll tell ya, that sucker (the stroke) took every bit of strength I had . . . it's amazing what it does to ya. [Pete]

Emotional Adjustments

Participants frequently described how physical deficits post stroke created new challenges for them and how these deficits led to difficulties in daily activities (e.g. dressing, toileting, bathing) and mobility. The process of adapting to these new challenges and living with a changed body appeared to trigger an emotional response. This emotional response appeared to impact desire to participate in rehabilitation for some individuals. Specifically, participants described their stroke as a life-changing event, often resulting in profound loss, leading to feelings of sadness, anger, frustration, and depression. One participant cited, "You don't control your life, it controls you. . . . it affects everything - your mentality, your willing[ness] to do things…" [Marie]. Similarly, a family member reflected on her husband's experience and described how the emotional impact of stroke influenced his willingness to participate in rehabilitation:

> Everything was different. . . . And it led to a tremendous amount of stress for [Dick] and myself. I had to go back to work and . . . leaving him by himself all day and all he'd do is sit there and worry and get more and more depressed. And along with that came a lack of exercise and the lack of therapy and the lack of wanting to do anything to help himself. [Sue, Spouse (P11)]

Overall, post-stroke fatigue and threats to emotional well-being (e.g., depressive symptoms) were described as barriers to participating in stroke rehabilitation. Fatigue seemed to affect participants' ability to participate while post-stroke depressive symptoms was more likely to affect desire, or willingness, to participate in rehabilitation program activities.

4. Personal Motivators

The findings reported here focus on personal circumstances that appeared to influence participatory efforts in rehabilitation. Both the desire to resume life roles after stroke and persons' attitudes towards rehabilitation are described in relation to participation in therapy.

Resuming Life Roles

Life roles were additional aspects of participants' personal lives that appeared to influence participation. Participants reflected on their roles and appeared eager to resume their 'regular' roles after stroke. For example, referring to his role as husband and how his wife had to go back to work as a result of his stroke, one participant stated, "with you working… that's gonna push me" [Dr. Strange]. Motivation to participate in therapy was seemingly driven by the desire to recover and resume life roles and to alleviate the burden of their stroke on others. One participant, however, revealed how his role as son and caregiver impacted his experience participating in inpatient rehabilitation:

> Well, there are certain times I don't feel motivated cause I'm under a lot of stress [on] my end – it's got nothing to do with anybody else. My mother's got Alzheimer's and she, of course, is all by herself, and she wants me to call her every day and I gotta tell her everything over and over and over again, and that's pretty stressful for me. [Ringo]

Others noted their motivation for participating or ‘working hard’ was to be able to resume previously valued activities, regain independence, and get back to ‘normal.’ In response to a comment about his hard work and effort, one participant cited, “I want to get out of here. I don't want this to become. . . my home…” [Pete].

Attitude Towards Rehabilitation

Participants expressed different attitudes towards rehabilitation during the interviews, which appeared to relate to effort and participation in therapy. One participant noted how his attitude towards rehabilitation set him apart from others:

> I know that it isn’t a closed door at the end of three months but optimal rehab is in the first three months. So I have two more months to go, so I need, I need to do everything I can to maximize those two months. . . . So, that’s, that's my thinking . . . maximize everything. But that's why I’m not like everybody else, or not everybody, cause some of the other people I see in there, when they're told to do ten of these they do it and then they go sit down – I just wait until I’m told to stop – fifteen, twenty, twenty-five, thirty… just keep going. [Cliff]

The importance of a person’s attitude, such as “determination,” and effort were seen as an influential aspect of success in rehabilitation. Determination was contrasted by some participants who felt they were not making progress and made inferences of discouragement and lost hope. Talking about the amount of therapy she was receiving, when asked if she had ever wanted to request more, one participant replied, “No, because . . . it’s not gonna do nothing for me. I’m not gonna get nothing out of it . . . I don’t think it’s helping me” [Marie].

Overall, the desire to resume life roles was mostly perceived as a motivator to participate in rehabilitation. It also appeared optimism and determination were facilitators of participation; however, those who viewed their rehabilitation, or the progress they were making, in a negative manner seemed less motivated to continue participating.

Discussion

This qualitative study aimed to identify and explore barriers and facilitators to participating in hospital-based stroke rehabilitation from the patients' perspectives. Indeed, participants described several factors influencing their participation in rehabilitation which generated four key themes: 1) Environmental Factors; 2) Components of Therapy; 3) Physical and Emotional Well-Being; and 4) Personal Motivators.

An interesting finding of this study was participants shared more negative than positive aspects of their experience participating in rehabilitation, and barriers were identified more frequently than facilitators. One possible explanation is that when given 'a voice,' or the opportunity to share their experiences, participants are more inclined to highlight areas they feel need improvement along with suggestions to enhance participation [30]. In the present study, the most frequently reported factors influencing participation related to the environment within the rehabilitation setting and components of therapy; these concepts will be the focus of this discussion.

Noise disruption was a commonly reported issue in the context of inpatient rehabilitation. Participants described noisy roommates and visitors and typical hospital disruptions (e.g. nursing rounds, medical equipment) within the hospital as impacting their ability to rest and sleep. Participants recognized the importance of rest and sleep in relation to their participatory efforts during rehabilitation activities. Our findings are consistent with other hospital setting studies stating how these types of environment factors impede sleep and recovery [31–33]. In many cases, noise and other causes of sleep disruptions in hospitals are modifiable and the implementation of innovative solutions to reduce noise and improve patient sleep can improve health outcomes as well as patient satisfaction; Yoder et al. [33] reported staff conversation, roommates, alarms, intercoms, and pagers as the most common sources of noise disruptions in the hospital.

Other commonly identified environmental factors influencing participation were the social environment and the program's positive atmosphere. Participants mostly spoke of these two factors in a positive manner, indicating their role as facilitators of participation. First, in this study, patient-patient interaction and support from family and friends were included as part of the social environment and were important components of the social support system during hospitalization and rehabilitation. Consistent with our findings, research has shown a) the social environment can have an important role in recovery after stroke [34] and b) social interaction plays a vital role in the process of recovery from injury and debilitation [35]. We postulate that peer socialization amongst patients may create a sense of universality over their common experience and provide much needed peer support. Additionally, seeing other patients working hard and improving can serve as a motivator to maintain or improve their own participatory efforts [3]. Secondly, program atmosphere appeared to tie in components of both the physical and social environments to describe the overall 'feel' of the rehabilitation setting. A friendly and welcoming atmosphere was appreciated by participants and seemed to positively influence participation. Research has shown that healthcare worker satisfaction is associated with quality of care and impacts patient satisfaction [36,37], suggesting that employee satisfaction may be an integral aspect of the rehabilitation experience. A friendly atmosphere can have a positive psychological impact on patients helping them to feel welcome and comfortable [38]. Participants in this study were more enthusiastic about and motivated to participate in rehabilitation when the environment was perceived to be a friendly and welcoming one.

Aspects of therapy addressed by the majority of participants in this study included interactions with therapists, amount of therapy, and personalized rehabilitation. Most participants described positive relationships with their therapists which seemed to facilitate participation. An important component of the therapist-patient relationship perceived to be lacking was communication about the purpose of therapeutic activities. The value of imparting information/education about stroke and therapeutic activities has been found to be an influential motivator for participation in rehabilitation [3,9]. The information-giving role of the therapist seems critical as we found when patients were unclear about the purpose of what they are being asked to do and what is expected of them, it compromised their desire to participate in activities. Additionally, participants valued feedback and validation from therapists, which helped them recognize progress and provided reassurance. This is similar to findings from the review by MacDonald et al. [9] which indicate that provision of feedback, encouragement, attention, and support from therapists enhance patients' receptiveness and motivation to engage in tasks. Good therapeutic communication is not only associated with higher levels of patient compliance with treatment, but higher levels of patient satisfaction as well as positive clinical outcomes, such as emotional health, blood pressure, and pain control [39]. These findings resemble the concept of therapeutic alliance [40] which has been reported to be associated with engagement in stroke rehabilitation [41].

Lack of therapy and ostensibly large amounts of sedentary time was a resounding concern shared by participants. Despite the evidence suggesting levels of therapy intensity [42], too little therapy and too much sedentary time in inpatient rehabilitation is a recognized issue in Canada [42–44], United States [45], Europe [46,47], and Australia [48]. A recent Canadian study examining individuals attending inpatient stroke rehabilitation reported that 86.9% of patients' waking hours, 61.6% of physical therapy, and 76.8% of occupational therapy was spent sedentary [43]. A likely factor contributing to this dissonance amongst patients' request for more therapy, evidence of high levels of sedentary activity, and recommendations of therapy intensity is the healthcare system [43,49], rather than patient-related factors. Restricted therapy time has serious implications: patients are at risk for physical or cognitive decline, resulting in deconditioning [43]. Findings from this study indicate that participants are aware of the consequences of restricted activity and were fearful of regression in areas of previous gain, and that their hard work would be for nothing. Participants in this study shared the belief with those from other studies [50] that more physical activity is better for recovery and therefore they wanted more of it during inpatient rehabilitation. Luker et al. [50] also found that perceived lack of therapy opportunities was associated with the rehabilitation environment and the inability to accommodate additional practice outside of formal therapy time.

Participants described a need for personalized rehabilitation focusing on their goals, resumption of daily activities and roles, and including activities of value and meaning. ‘Personalized’ or ‘meaningful’ rehabilitation has been found to be a key factor influencing patient participation or engagement within rehabilitation in other studies as well [9,50]. In this study, participants were motivated by the desire to resume their daily lives and reaffirm their identity. These findings are analogous with other studies reporting patients’ desire to leave the hospital and the desire to resume activities of everyday life were motivating factors for participating in rehabilitation activities [3,51]. Participants were enthusiastic to participate in activities that were individually meaningful to them. This was especially true when activities were clearly related to the resumption of pre-stroke valued activities (e.g. kayaking in the therapy pool). Supporting our findings is the nearly 200 surveyed physio- and occupational therapists who reported their most common practice for enhancing engagement in rehabilitation was making therapy tasks meaningful and explicitly related to patients’ personal goals [52]. While these findings are neither novel or surprising, they provide further support for personalized programming in hospital-based rehabilitation programs.

An important component of personalized rehabilitation includes the consideration of the emotional impact of stroke. Understandably, participants struggled with the emotional impact of changed abilities and autonomy after stroke. Here, depressive symptoms were interpreted as impeding motivation to participate in rehabilitation, which is consistent with other research [53,54]. Post-stroke depression (PSD) is common after stroke, with a reported prevalence of 22% among inpatients and 24% among individuals in outpatient settings [55]. Stroke severity and the resultant degree of functional impairment are predictors of PSD [56], which may partially explain the relationship between low FIM scores and poor participation in inpatient rehabilitation after stroke [57]. Our findings indicating that PSD negatively influences participation in rehabilitation are consistent with the existent literature [53,56] which suggests that psychosocial aspects of stroke recovery require attention and need to be prominent in interdisciplinary assessments and intervention in order to enhance participation and recovery [58].

Looking at aspects of therapy in the context of this study, participants expressed the desire for a program that is tailored to their individual needs and preferences, based on individual characteristics and personal goals, as these factors were all characterized as facilitators of participation. Their ideal therapy program includes i) an environment supportive of rest and relaxation but also one that provides space and opportunities to participate in therapeutic activities individually, with peers, or with family; ii) establishing a trusted relationship with rehabilitation professionals centered around communication wherein individuals feel informed and their voice is being heard; iii) the recommended therapy intensity and decreased amount of time in bed and sedentary; iv) activities that are individually meaningful and are geared towards the resumption of valued personal care, vocational, social, and leisure activities and life roles; and v) easily accessible physiological services for the patient and their family in order to attend to the impact of stroke.

Limitations of Study

Although the results of this study highlight the patient voice regarding participatory factors in hospital-based stroke rehabilitation, the work is not without limitations. First, recruitment of participants relied on clinician referrals working at the respective rehabilitation sites, thus allowing the potential for bias in the selection of patients referred. Though our sample was small, it appeared to be sufficient to capture a range of diverse experiences, provide rich reflections, support data sufficiency for theme development, and identify critical areas for further exploration. The research examined a small sample within a large urban region and therefore the transferability of the findings requires further investigation using different health care settings, and perhaps larger samples. Finally, we did not perform member checks with study participants. While some qualitative researchers advocate for member-checking to test confirmability [59,60], Thorne [27] cautions against this technique as it can lead to false confidence or potentially derail researchers from good analytic interpretations. Instead, we used other techniques to enhanced credibility of findings, such as reiteration during data collection and analyst source-triangulation during the analysis process.

Clinical Implications

The findings reported here reaffirm that the rehabilitation setting constitutes a unique context in which patients participate and should be considered as an integral part of the recovery process. Clinical awareness of factors beyond patients' control and how these factors can affect participation in stroke rehabilitation can help facilitate an environment that promotes rather than impedes participation. For example, strategies to reduce noise and disruptions include providing patients with ear plugs and eye masks [61] or limiting overhead paging by equipping staff with personal devices [62]. Perhaps the most effective strategy would be private rooms, thus effectively eliminating the negative effects of noisy roommates and their visitors; however, this would be extremely costly.

Our findings also support the facilitation of social interaction among patients (e.g. support groups, social outings, and accessible common spaces for communal activity), which could reduce time spent alone, increase time doing therapeutic activities, and provide a mutually beneficial source of emotional and affirmational support [63,64]. There appears to be an inherent interdependence between many of the factors identified in this study, suggesting that participation is determined by the opportunities available to a person and that these opportunities are affected by other conditions. For instance, it may be important to consider how the physical environment impacts therapy and thus how changes in the environment might help mitigate therapy-related barriers. For example, therapy space dedicated to family/self led activities could facilitate increased therapy time, decreased time spent sedentary, and enhance family interaction.

The implementation of additional opportunities for therapy has the potential to address many of the identified barriers in this study. For example, the issues of low therapist to patient ratios and not enough therapy could be mitigated by interventions such as group therapy [65], robotic devices [66], virtual reality/video games [67], family-mediated activities [68], and self-administered activities [69,70]. Increased utilization of physio- and occupational therapist assistants is another possible strategy to provide patients with additional opportunities for therapy without intensifying the demand on therapists [71,72]. Further, patients' perspectives of therapy time in this study may advocate for patient education on 'what constitutes therapy' (e.g. recreational activities, completing ADL's). Finally, rehabilitation professionals can use the opportunity to capitalize on patients' desire and motivation to resume life roles by understanding the individual priorities of patients. Getting to know the patient and what is meaningful to them is fundamental to personalized rehabilitation. Study findings also indicate a need for greater attention to the psychosocial aspects of recovery and how it is addressed within the rehabilitation setting.

Conclusions

This study has identified several patient-perceived barriers and facilitators related to participating in hospital-based stroke rehabilitation. It highlights the significant influence of the treatment setting and program design, as well as the pivotal role that others (peers, family, rehabilitation staff) play in influencing patient participation. Further, this study adds the unique perspectives of patients to current stroke rehabilitation knowledge and encourages rehabilitation professionals to reflect on the ways and means of incorporating patient perspectives into daily practice.

Declaration of Interest

No potential conflict of interest was reported by the authors.

Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Acknowledgements

We would like to thank patients and staff at our recruitment sites as well as Nick Blenich, Magdalena Mirkowski, Milica Stojanovic, and Amelia Secord who participated in data collection as part of their student occupational therapy research project.

References

1. Belagaje SR. Stroke Rehabilitation. Contin Lifelong Learn Neurol. 2017;23(1):238–53.

2. Teasell R, Foley N, Hussein N, Cotoi A. Chapter 5: The efficacy of stroke rehabilitation [Internet]. Evidence-Based Review of Stroke Rehabilitation. 2018. Available from: www.ebrsr.com

3. Maclean N, Pound P, Wolfe C, Rudd A. Qualitative analysis of stroke patients' motivation for rehabilitation. BMJ. 2000 Oct 28;321(7268):1051–4.

4. Lenze EJ, Munin MC, Quear T, Dew MA, Rogers JC, Begley AE, et al. Significance of poor patient participation in physical and occupational therapy for functional outcome and length of stay. Arch Phys Med Rehabil. 2004;85:1599–601.

5. Paolucci S, Di Vita A, Massicci R, Traballesi M, Bureca I, Matano A, et al. Impact of participation on rehabilitation results: A multivariate study. Eur J Phys Rehabil Med. 2012 Sep;48(3):455–66.

6. Skidmore ER, Whyte EM, Holm MB, Becker JT, Butters MA, Dew MA, et al. Cognitive and Affective Predictors of Rehabilitation Participation After Stroke. 2010;

7. Yang S-Y, Kong KH. Level and predictors of participation in patients with stroke undergoing inpatient rehabilitation. Singapore Med J. 2013;54(10):564–8.

8. Vasilachis de Gialdino I. Ontological and epistemological foundations of qualitative research. Forum Qual Soc Res. 2009;30(2):1–18.

9. MacDonald A. G, Kayes M. N, Bright F. Barriers and facilitators to engagement in rehabilitation for people with stroke: A review of the literature. New Zeal J Physiother. 2013;41(3):112–21.

10. Alanko T, Karhula M, Kröger T, Piirainen A, Nikander R. Rehabilitees perspective on goal setting in rehabilitation – A phenomenological approach. Disabil Rehabil. 2018 Apr 27;1–9.

11. Berg K, Askim T, Balandin S, Armstrong E, Rise MB. Experiences of participation in goal setting for people with stroke-induced aphasia in Norway. A qualitative study. Disabil Rehabil. 2017 May 22;39(11):1122–30.

12. Prout EC, Mansfield A, McIlroy WE, Brooks D. Patients' perspectives on aerobic exercise early after stroke. Disabil Rehabil. 2017 Mar 27;39(7):684–90.

13. Bennett L, Luker J, English C, Hillier S. Stroke survivors' perspectives on two novel models of inpatient rehabilitation: Seven-day a week individual therapy or five-day a week circuit class therapy. Disabil Rehabil. 2016;38(14):1397–406.

14. Pak P, Jawed H, Tirone C, Lamb B, Cott C, Brunton K, et al. Incorporating research technology into the clinical assessment of balance and mobility: Perspectives of physiotherapists and people with stroke. Physiother Canada. 2015;67(1):1–8.

15. Pohl P, Gunnel C, Bunketorp Käll L, Nilsson M, Blomstrand C. Experiences from a multimodal rhythm and music-based rehabilitation program in late phase of stroke recovery – A qualitative study. Soundy A, editor. PLoS ONES. 2018 Sep 18;13(9):e0204215.

16. White JH, Bartley E, Janssen H, Jordan LA, Spratt N. Exploring stroke survivor experience of participation in an enriched environment: A qualitative study. Disabil Rehabil. 2015;37(7).

17. Cameron J, Bastawrous M, Marsella A, Forde S, Smale L, Friedland J, et al. Stroke survivors', caregivers', and health care professionals' perspectives on the weekend pass to facilitate transition home. J Rehabil Med. 2014 Oct;46(9):858–63.

18. White J, Janssen H, Jordan L, Pollack M. Tablet technology during stroke recovery: A survivor's perspective. Disabil Rehabil. 2015 Jun 19;37(13):1186–92.

19. Brady M, Jamieson K, Bugge C, Hagen S, McClurg D, Chalmers C, et al. Caring for continence in stroke care settings: A qualitative study of patients' and staff perspectives on the implementation of a new continence care intervention. Clin Rehabil. 2016 May 4;30(5):481–94.

20. Galvin R, Stokes E, Cusack T. Family-mediated exercises (FAME): An exploration of participant's involvement in a novel form of exercise delivery after stroke. Top Stroke Rehabil. 2014 Jan 30;21(1):63–74.

21. Morse JM, Field P-A. Nursing research: The application of qualitative approaches.

Springer Nature; 1996. 208 p.

22. Mason J. Qualitative researching. SAGE Publications; 1996. 192 p.

23. Thorne S. Interpretive Description. Walnut Creek, CA: Left Coast Press Inc; 2008.

24. Thorne S, Reimer-Kirkham S, O'Flynn-Magee K. The analytic challenge in interpretive description. Int J Qual Methods. 2004;3:1–21.

25. Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke. Cochrane Database Syst Rev. 2013 Sep 11;9(CD000197).

26. Sahely A. How do therapists understand and intend to implement practice guideline recommendations for rehabilitation of the uppper limb following stroke? [master's thesis]. McMaster University, Ontario, Canada; 2015.

27. Thorne S. Interpretive Description. 2nd ed. Walnut Creek, CA: Left Coast Press Inc; 2016.

28. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005 Nov;15(9):1277–88.

29. Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107–15.

30. Baumeister RF, Bratslavsky E, Finkenauer C, Vohs KD. Bad is stronger than good. Rev Gen Psychol. 2001;5(4):323–70.

31. Cunha M, Silva N. Hospital noise and patients' wellbeing. Procedia - Soc Behav

Sci. 2015 Jan 16;171:246–51.

32. Grossman MN, Anderson SL, Worku A, Marsack W, Desai N, Tuvilleja A, et al. Awakenings? Patient and hospital staff perceptions of nighttime disruptions and their effect on patient sleep. J Clin Sleep Med. 2017;13(2):301–6.

33. Yoder JC, Staisiunas PG, Meltzer DO, Knutson KL, Arora VM. Noise and sleep among adult medical inpatients: Far from a quiet night. Arch Intern Med. 2012;172(1):68–70.

34. Anderson S, Whitfield K. Social identity and stroke: “They don’t make me feel like, there’s something wrong with me.” Scand J Caring Sci. 2012;27:820–30.

35. Venna VR, Xu Y, Doran SJ, Patrizz A, McCullough LD. Social interaction plays a critical role in neurogenesis and recovery after stroke. Transl Psychiatry. 2014 Jan 28;4(1):e351–e351.

36. Atkins PM, Marshall BS, Javalgi RG. Happy employees lead to loyal patients. Survey of nurses and patients shows a strong link between employee satisfaction and patient loyalty. J Health Care Mark. 1996;16(4):14–23.

37. Janicijevic I, Seke K, Djokovic A, Filipovic J. Healthcare workers satisfaction and patient satisfaction - where is the linkage? Hippokratia. 2013;17(2):157–62.

38. Narang R, Polsa P, Soneye A, Fuxiang W. Impact of hospital atmosphere on perceived health care outcome. Int J Health Care Qual Assur. 2015;28(2):129–40.

39. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a

difference in conversations between physicians and patients. Med Care. 2007 Apr;45(4):340–9.

40. Babatunde F, MacDermid J, MacIntyre N. Characteristics of therapeutic alliance in musculoskeletal physiotherapy and occupational therapy practice: A scoping review of the literature. BMC Health Serv Res. 2017;17(1).

41. Lawton M, Haddock G, Conroy P, Sage K. Therapeutic alliances in stroke rehabilitation: A meta-ethnography. Arch Phys Med Rehabil. 2016;97(11):1979–93.

42. Hebert D, Lindsay P, Mcintyre A, Kirton A, Rumney PG, Bagg S, et al. Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015. Int J Stroke. 2016;11(4):459–84.

43. Barrett M, Snow JC, Kirkland MC, Kelly LP, Gehue M, Downer MB, et al. Excessive sedentary time during in-patient stroke rehabilitation. Top Stroke Rehabil. 2018;1–9.

44. Foley N, McClure AJ, Meyer M, Salter K, Bureau Y, Teasell R. Inpatient rehabilitation following stroke: Amount of therapy received and associations with functional recovery. Disabil Rehabil. 2012;34(25):2132–8.

45. Mattlage AE, Redlin SA, Rippee MA, Abraham MG, Rymer MM, Billinger SA. Use of accelerometers to examine sedentary time on an acute stroke unit. J Neurol Phys Ther. 2015 Jul;39(3):166–71.

46. Astrand A, Saxin C, Sjoholm A, Skarin M, Linden T, Stoker A, et al. Poststroke physical activity levels no higher in rehabilitation than in the acute hospital. J Stroke Cerebrovasc Dis. 2016;25(4):938–45.

47. Putman K, De Wit L. European comparison of stroke rehabilitation. Top Stroke Rehabil. 2009;16(1):20–6.

48. Sjoholm A, Skarin M, Churilov L, Nilsson M, Bernhardt J, Linden T. Sedentary behaviour and physical activity of people with stroke in rehabilitation hospitals. Stroke Res Treat. 2014;2014(Article ID 591897):1–7.

49. Hakim AM, Silver F, Hodgson C. Organized stroke care: A new era in stroke prevention and treatment. Can Med Assoc J. 1998;(6 Suppl):1.

50. Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J. Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. Arch Phys Med Rehabil. 2015;96(9):1698–708.

51. Lee A, Gudex C, Larsen T. Resuming everyday life after stroke and early home supported discharge. 2005. p. 1–24.

52. Lequerica AH, Donnell CS, Tate DG. Patient engagement in rehabilitation therapy: Physical and occupational therapist impressions. Disabil Rehabil. 2009;31(9):753–60.

53. Shoemaker N. Depression & stroke. Improving patient outcomes with a team approach. Caring. 2001 Jan;20(1):6–8, 10, 12.

54. Schubert DS, Taylor C, Lee S, Mentari A, Tamaklo W. Physical consequences of depression in the stroke patient. Gen Hosp Psychiatry. 1992 Jan;14(1):69–76.

55. Robinson RG, Spalletta G. Poststroke depression: A review. Can J Psychiatry. 2010 Jun;55(6):341–9.

56. Salter K, Mehta S, Wiener Bhsc J, Cotoi A, Teasell R, Foley N, et al. Chapter 18: Post-Stroke Depression and Mood Disorders [Internet]. Evidence-Based Review of Stroke Rehabilitation. 2018. Available from: www.ebrsr.com

57. Granger C V., Hamilton BB, Keith RA, Zielezny M, Sherwin FS. Advances in functional assessment for medical rehabilitation. Top Geriatr Rehabil. 1986;1(3):59–74.

58. Wu D-Y, Guo M, Gao Y-S, Kang Y-H, Guo J-C, Jiang X-L, et al. Clinical effects of comprehensive therapy of early psychological intervention and rehabilitation training on neurological rehabilitation of patients with acute stroke. Asian Pac J Trop Med. 2012 Nov;5(11):914–6.

59. Harper M, Cole P. Member checking: Can benefits be gained similar to group therapy? Qual Rep. 2012;17(T&L Article 2):1–8.

60. Lincoln YS, Guba G. E. Naturalistic inquiry. Beverly Hills, CA: Sage; 1985.

61. Dubose JR, Hadi K. Improving inpatient environments to support patient sleep. Int J Qual Heal Care. 2016;28(5):540–53.

62. Johnson PR, Thornhill L. Noise reduction in the hospital setting. J Nurs Care Qual.

2006;21(4):295–7.

63. Morris R, Morris P. Participants' experiences of hospital-based peer support groups for stroke patients and carers. Disabil Rehabil. 2012;34(4):347–54.

64. Kessler D, Egan M, Kubina L-A. Peer support for stroke survivors: A case study. BMC Health Serv Res. 2014;14(256).

65. De Weerdt W, Nuyens G, Feys H, Vangronsveld P, Van de Winckel A, Nieuwboer A, et al. Group physiotherapy improves time use by patients with stroke in rehabilitation. 2001;

66. Stefan Hesse, Henning Schmidt CW and AB. Upper and lower extremity robotic devices for rehabilitation and for studying motor control. Curr Opin Neurol. 2003;16:705–10.

67. Pietrzak E, Cotea C, Pullman S. Using commercial video games for upper limb stroke rehabilitation: Is this the way of the future? Top Stroke Rehabil. 2014 Mar 22;21(2):152–62.

68. Galvin R, Cusack T, Stokes E. To what extent are family members and friends involved in physiotherapy and the delivery of exercises to people with stroke? Disabil Rehabil. 2009 Jan 21;31(11):898–905.

69. Harris JE, Eng JJ, Miller WC, Dawson AS. A self-administered graded repetitive arm supplementary program (GRASP) improves arm function during inpatient stroke rehabilitation: A multi-site randomized controlled trial. Stroke.

2009;40(6):2123–8.

70. Mäkelä P, Gawned S, Jones F. Starting early: integration of self-management support into an acute stroke service. BMJ Qual Improv Reports. 2014;

71. Munn Z, Tufanaru C, Aromataris E. Recognition of the health assistant as a delegated clinical role and their inclusion in models of care: A systematic review and meta-synthesis of qualitative evidence. Int J Evid Based Healthc. 2013;11:3–19.

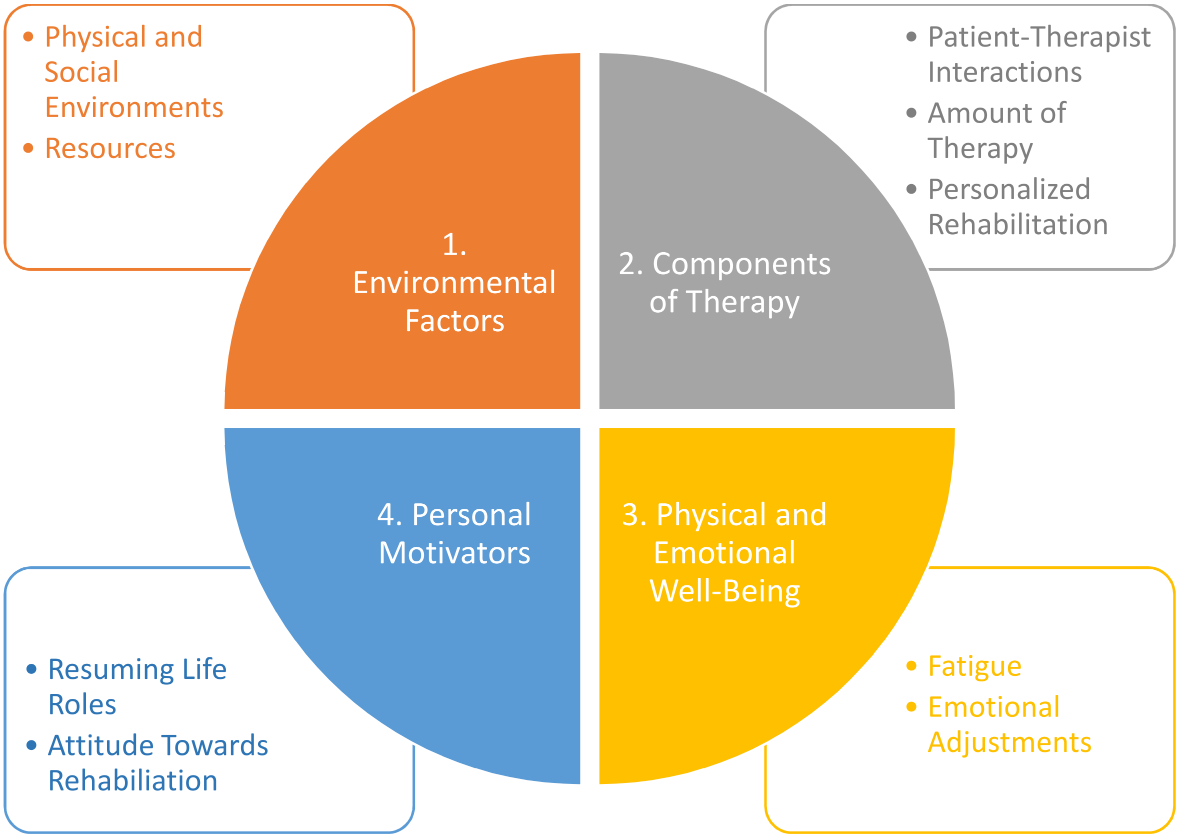
72. Pullenayegum S, Fielding B, Du Plessis E, Peate I. The value of the role of the rehabilitation assistant. Br J Nurs. 2005;14(14):778–84.

Table 1: Participant Characteristics

Pseudonym	Age	Sex	Time since stroke (mths)	Rehabilit-ation Site	Location of stroke	CMSA arm/hand	Motor FIM	Cog FIM	Total FIM	Mobility
Shannon	44	F	4	OUT	L FRONTAL HEMM	1/1	24	10	34	walking with aid but w/c or scooter for longer distances
Dr. Strange (Sally)	56	M	2	IN	L THALAMIC INTRACRANIAL HEMM	5/6	13	12	25	Independent
Rocky (Steve, Victoria)	68	M	4.5	SSR	R LACUNAR	2/2	19	21	40	manual w/c, independent
Pete (Mary)	60	M	4	SSR	L LACUNAR	2/2	25	25	50	manual w/c, independent
Marie	69	F	5	SSR	R MIDBRAIN LACUNAR INFARCT	3/2	34	30	64	manual w/c, independent
Brian	42	M	3	SSR	R HEMIPONS INFARCT	1/1	56	30	86	walking with rollator
Lola	56	F	6	SSR	R PARIETAL ISCH	2/3	20	25	45	walking with aid but w/c or scooter for longer distances
Ringo	66	M	1	IN	R MCA	4/4	40	30	70	walking with aid but w/c or scooter for longer distances
Cliff	81	M	1	OUT	L MCA	3/2	75	28	103	Independent
Sadie	70	F	7	OUT	R INTERNAL CAPSULE	3/2	74	35	109	Independent
Dick (Sue)	52	M	9	OUT	L MCA	2/3	16	12	28	walking with aid but w/c or scooter for longer distances

*CMSA, Chedoke-McMaster Stroke Assessment; FIM, Functional Independence Measure; HEMM, hemorrhagic; IN, inpatient stroke rehabilitation; ISCH, ischemic; L, left; MCA, middle cerebral artery; OUT, outpatient stroke rehabilitation; R, right; SSR, slow stream rehabilitation; w/c, wheelchair

Fig. 1 Main themes and corresponding sub-themes



Chapter 3: Still inactive and alone: A call for action on behalf of hospitalized stroke rehabilitation patients

Nicole Last, Tara L. Packham, Rebecca E. Gewurtz, Lori Letts, and Jocelyn E. Harris

Prepared for submission to *Topics in Stroke Rehabilitation*

Still inactive and alone: A call for action on behalf of hospitalized stroke rehabilitation patients

Nicole Last[a], Tara L. Packham[a,b], Rebecca E. Gewurtz[a], Lori Letts[a], and Jocelyn E. Harris[a]*

[a]School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada; [b]Regional Rehabilitation Program, Hamilton Health Sciences, Hamilton, Ontario, Canada

*Correspondence: Jocelyn Harris, PhD, McMaster University, School of Rehabilitation Science, 1400 Main Street West, Hamilton, ON, Canada, L8S 1C7.
Tel: (905) 525-9140 ext. 27813. Fax: (905) 524-0069.
E-mail: jharris@mcmaster.ca

Still inactive and alone: A call for action on behalf of hospitalized stroke rehabilitation patients

During stroke rehabilitation, many individuals who can benefit from intensive therapy are largely inactive during hospitalization. Canadian best practice recommendations for stroke suggest a minimum of 180 minutes of direct therapy per day at least 5 days a week for individuals undergoing inpatient rehabilitation. The purpose of this article is to explore the issue of inactivity in individuals with stroke during inpatient rehabilitation. In this article, we introduce participant perspectives of amount of therapy during inpatient stroke rehabilitation as well as information obtained through consultations with program managers, including rehabilitation intensity workload data, to help us understanding findings from our previous study in the context of two practice settings. In addition, we review studies reporting on inpatient stroke rehabilitation activity levels as well as relevant implementation science literature. The literature shows there is an obvious and long-standing evidence-practice gap regarding stroke rehabilitation intensity, indicating hospitalized individuals with stroke continue to spend too much time inactive and alone. Our findings support the literature with patient participants and managers echoing 'not enough therapy,' and workload data indicating less than half the minimum recommended amount of direct therapy per individual per day. It appears that best-evidence stroke rehabilitation intensity is difficult to provide, and it is obvious better application of recommendations is necessary, and thus a review of implementation strategies is needed. The resolution will likely require a collaborative multi-pronged approach involving all stakeholders and changes at multiple levels in the health care system to address the challenge of intensity.

Keywords: stroke; rehabilitation; inpatient; intensity; knowledge translation; implementation

Word count: 2735 excluding abstract and references

Introduction

Since Bernhardt et al's[1] landmark study, published in 2004, on low activity levels among stroke inpatients there have been advances in strategies to increase therapy time, identification of key intervention components and dosage, evidence-based practice stroke rehabilitation guidelines, and knowledge dissemination strategies. Yet, in a recent study exploring barriers and facilitators to participation in hospital-based stroke rehabilitation, we found the patient voice held an overwhelming sentiment that has echoed for nearly 40 years:

> *''We're here 24/7 and half of the time we're just sitting around - what the hell are we supposed do?"*

Most of the literature mapping time spent in therapeutic or sedentary activities during inpatient stroke rehabilitation are observational studies. What is missing is the patient voice – what do patients think of the amount of therapy received? We recently conducted a study[2] [submitted for publication] exploring patients' thoughts about hospital-based stroke rehabilitation. We interviewed 11 participants currently involved in, or recently discharged from, inpatient and outpatient stroke rehabilitation programs from 2 hospital facilities within a large Central Canadian province. Participants were asked questions about their experiences participating in stroke rehabilitation, and about barriers and facilitators that may have influenced their participation in therapy activities. Not enough therapy and too much sedentary time was a prevalent discussion point. Participants commented on lack of therapy, wait times (for clinicians, equipment/space), little to no therapy on weekends, and little to do when therapists left for the day. Several quotes illustrate this commonly expressed concern:

'I don't get enough of it,'

'There should be more therapy and a lot of patients have been complaining,'

'We're talking about my health here – if I can get more time in therapy, I'm gonna take it.'

There is a need to explore the problem of inactivity among individuals in inpatient stroke rehabilitation in light of Canadian best practice recommendations and patient preferences.

Exploring the Problem

Upon initial reflection, we wondered if patients were actually receiving recommended amounts of therapy but perceived otherwise. We conducted informal interviews with the two program managers of the inpatient rehabilitation programs from our previous study[2] as key informants to help us consider the data. The managers were sent study findings and asked to specifically reflect on why participants might be perceiving low levels of time spent in therapy. In addition, we ascertained rehabilitation intensity workload measurement data (i.e., documented face-face physiotherapy, occupational therapy, and speech language therapy time) from the program managers to get a sense of the average amount of direct therapy (i.e., one-on-one) patients were receiving from the three core therapies (physiotherapy [PT], occupational therapy [OT], and speech-language pathology [SLP]). These findings are presented here and considered in light of the Canadian best practice recommendations and findings from previous qualitative research which highlights that patients want more therapy time.

Program manager consultations and workload measurement data

Results from the manager interviews found patient need (indicative of stroke severity and current abilities), tolerance, as well as therapist capacity (i.e., therapist to patient ratio) are the main determinants of the amount of therapy scheduled for each patient. For example, some individuals in the slow stream rehabilitation program may only be scheduled for therapy twice per week because it was determined they are not able to tolerate more. Managers were aware of individuals' desire for more therapy and were not surprised by their perspective of 'not getting enough.' Common explanations provided by the managers for perceived low therapy time were: 1) individuals' misconception of what qualifies as therapy, and 2) therapists' working hours. Managers perceived therapy as encompassing all aspects of the rehabilitation program (i.e., direct therapy as well as group therapy and sessions with therapy assistants, consultations with pharmacists and dieticians, recreation and leisure activities); however, the managers commented that patients tended to emphasize physiotherapy above all other aspects of rehabilitation. They explained that patients viewed physiotherapy as their main avenue home and, therefore, other activities such as cooking breakfast, practicing transfers, and getting dressed were not always acknowledged as critical factors of rehabilitation. It is these views which managers suggested may contribute to the perspective of 'not enough therapy.' Additionally, the working hours of therapists were suggested as a possible factor in perceived low levels of therapy time. There is little to no therapy beyond 8am-4pm, Monday to Friday, and this includes involvement with therapy assistants. This is particularly pronounced on holiday weekends where people may go three consecutive days without therapy. Managers stated this would also relate to patients' feelings of spending extended periods of time alone.

The workload measurement data received from the dedicated stroke unit showed on average patients received a combined OT, PT, and SLP total of approximately 74 minutes of direct therapy per day based on a 5-day week (Monday-Friday therapy) and 55 minutes per day based on a 7-day week. Notably, the data from the dedicated stroke unit includes a portion (up to 33%) of therapy assistant time, and although the unit has therapists and therapy assistants scheduled on weekends, time per patient is minimal and priority driven. The data indicated that patients on the slow stream rehabilitation unit received a combined average of approximately 50 minutes of therapy per day, calculated based on a 5-day week as there are no weekend therapists. During the interviews, managers stated although patients may be scheduled for 60 minutes of direct therapy per discipline, this time typically includes unplanned aspects of indirect activities (e.g., talking with family and or patients in the hall way, clearing therapy areas, retrieving equipment), thus direct therapy time is reduced.

Drawing on findings from patient interviews, stroke rehabilitation program manager interviews, and therapy workload measurement data, our initial objective was to further explore the patient-perceived notion of not enough therapy. The conclusion from all three sources is that patients are not receiving the recommended amount of therapy outlined in the Canadian Best Practice Stroke Recommendations.[3] Although patients participate in various therapeutic activities on a daily basis, it appears they are receiving less than 50% the recommended amount (180 min/day x a minimum of 5 days/week) of direct therapy time. To be allocated a dedicated stroke unit, Canadian Stroke Best Practice Recommendations outlines the core elements;[4] although, the criteria for slow stream stroke rehabilitation programs are less clear, they typically involve a longer stay (60-120 days) and consist of lower intensity rehabilitation based on individual patient tolerance.[5] Our findings highlight that both patients and mangers are voicing concerns regarding low direct therapy time, and that therapy workload data gathered for administrative purposes supports these concerns. However, there appears to be little initiative from administrative levels of the health care system to meet guideline recommendations.

The findings from our data review are similar to a 2015 systematic review which explored stroke survivors' experiences of rehabilitation.[6] The review included 31 qualitative studies involving 560 inpatients undergoing stroke rehabilitation in 10 countries.[6] Participants from many of the included studies voiced valuing and wanting more physical activity during and outside of formal therapy sessions; however, rehabilitation environments were generally unable to accommodate patients' request for additional therapy opportunities. Further, participants commonly reported feeling bored and alone during inpatient rehabilitation, which negatively affected their mood and motivation. Given early and intensive rehabilitation after stroke promotes better overall outcomes,[7] and inpatient rehabilitation is a critical time for recovery,[3,8–10] is it not ironic that stroke rehabilitation patients continue to spend most of their day inactive and further, that this is substantiated by multiple sources (e.g., behavioural mapping, patients, therapists, workload data, administrators)?

Physical inactivity in hospitalized stroke patients

The study of activity levels in hospitalized stroke patients began in the 1980's; beginning with a study by Keith,[11] published in 1980, the findings were consistent: patients were spending over 60% of their waking hours inactive and typically less than one hour per day with therapists.[11–14] While there appears to be a lag in research in the 1990s, the study of activity levels resurged in 2004[1] and continues to present day.[15] In a review by West and Bernhardt[16] investigating observational studies from 1980-2010 pertaining to the amount and type of physical activity in hospitalized stroke patients, patients were inactive or involved in nontherapeutic activity for a median of 48% (range 24-98%) of the day, spent 2 hours of their time with clinicians, and were inactive during 20-58% of therapy sessions. Recent research from Australia reported hospitalized stroke rehabilitation patients spent an average of 74% of the observed day in sedentary activities.[17] Additional findings from Australia, New Zealand, and Canada revealed patients in stroke rehabilitation receive less than 1 hour of therapy per weekday with each required core discipline (i.e., OT, PT, SLP),[18–20] and even less on weekends.[21,22] Importantly, within a Canadian context, Barrett et al[15] found more than 85% of patients' waking hours were spent in sedentary activities on weekdays, reaching almost 90% on weekends. Further, the majority of time patients spent during therapy was recorded as sedentary.[15] Despite the accumulating evidence that 1) patients in a critical stage of stroke recovery are mainly involved in sedentary activities,[1,15–17,21–23] and 2) immobility post stroke poses a danger to both health and recovery,[24–26] levels of activity for inpatient stroke rehabilitation do not appear to have changed substantially since 1980.

Why is evidence not being adopted into practice?

Canadian Stroke Best Practice Recommendations state inpatients should receive a minimum of 1 hour of direct therapy from each relevant core therapy for a minimum of 5 days per week,[3,7] while provincial guidelines (Ontario Quality-Based Procedures) target a total of 3 hours per day, 6 to 7 days per week, with a maximum of 33% being provided by therapy assistants.[27] These guidelines are based on evidence demonstrating the importance of intensive therapy after stroke; however, implementation into practice generally falls short. Why?

Many have recognized these challenges within stroke rehabilitation services and have invested significant efforts into strategies to narrow the evidence-practice gap, mainly in the form of implementation science and knowledge-translation research (e.g., The Knowledge to Action Process). In the Knowledge to Action cycle,[28] after adapting knowledge to local context (i.e., stroke best practice guidelines) the next step is to assess barriers to knowledge use. Bayley et al[29] sought to identify barriers to implementation of stroke rehabilitation evidence through the experiences of rehabilitation professionals from a multi-site pilot implementation project. Nurses, occupational therapists and physiotherapists, physicians, and hospital managers participated in focus groups at the completion of the pilot implementation study. The most common barriers voiced were: 1) lack of time, 2) inadequate staffing (e.g., due to high turnover and funding cutbacks), 3) staff education (e.g., nurses reported difficulty understanding terminology and therapists reported feeling a lack of authority to teach other disciplines), 4) therapy selection and prioritization (e.g., patients too severely impaired to complete all recommendations and concerns for safety), 5) lack of equipment, and 6) insufficient interdisciplinary collaboration (e.g., lack of discussion among providers).

In order to minimize the barriers, the next step in the Knowledge to Action Process is to select, tailor, and implement interventions for improving the uptake of stroke rehabilitation best practice guidelines into clinical practice. Critically, although many of the barriers identified point to factors at a systems level and/or outside the control of frontline staff[29–31], many of the existing intervention studies focus on the provision of education and training for frontline staff.[32,33]

An in-depth analysis of 10 of Ontario's 11 Regional Stroke Networks' (RSN) knowledge translation interventions found interventions targeted to clinicians (e.g., educational meetings, distribution of staff educational materials) were the primary approach used to implement evidence-based practices.[34] In this multi-stage study, the authors surveyed key stakeholders (i.e., Local Health Integration Network representatives, senior leadership (including Chief Financial Officers), frontline clinician/staff, RSN members) and found respondents reported having knowledge of and the skills to implement best practice guidelines. However, 63% of respondents indicated lack of funding at the systems level was a barrier to implementing quality-based procedures. This highlights the onus placed on clinicians while seemingly ignoring the institutional and governmental factors identified in the existing literature, and in our recent study findings. Pointedly, there is still a clear, consistent, and concerning gap related to the amount of therapy patients receive during inpatient stroke rehabilitation. We propose that meeting best practice guidelines for therapy intensity not only requires a change in clinician practices but will require action, such as the evaluation and reallocation of funds, at the regional and provincial health system levels.

Funding for post-stroke rehabilitation appears to be a low priority in Ontario as the Ontario Stroke Strategy invested heavily in stroke prevention and acute stroke services, but comparatively little in rehabilitation.[35] It would be naïve to suggest this issue could be fixed simply by increasing funding. In fact, in a report by Meyer et al,[36] data from the National Rehabilitation Reporting System were used to estimate the potential economic impact of adopting stroke rehabilitation best-practice recommendations in Ontario and the authors explain how adoption of best-practice recommendations can result in annual net savings. In regard to inpatient stroke rehabilitation, applicable recommendations included the provision of greater intensity therapy including 3 hours per day and 7-day a week therapy. Estimates suggest the application of 3 hours of therapy per day, 7 days a week would require essentially no change to the number of inpatient rehabilitation beds annually in Ontario.[36] Further, this noteworthy report estimated a 14% reduction in hospital length-of-stay for every week of 3-hour per day therapy and in addition, reported hiring an additional 123 therapists to facilitate the therapy intensity requirements would not increase annual rehabilitation costs. There is tremendous potential for improved efficiency relative to current stroke rehabilitation practices and Meyer et al[36] propose compelling suggestions for restructuring the system that need to be considered. In addition, it is possible that smaller-scale reorganization of resources might help to increase patient activity. For example, 1) incorporating evening and weekend therapists and/or therapy assistant coverage,[37–39] 2) promoting the uptake of therapy activities outside of formal therapy time through self-administered and/or family-mediated activities,[40,41] and use of adjunct therapies such as video gaming,[42,43] and 3) perhaps educating patients/families on what constitutes therapy (e.g., therapeutic recreation, music and art therapy). We acknowledge that these suggestions are common practice in some hospital-based rehabilitation programs, though not all - even with the evidence to support their effectiveness. Strategies for re-organization or redistribution of resources are important to implement and evaluate given funding structure is not likely to change quickly.

A Call to Action

Individuals with stroke are not receiving the required amount of therapy[1,15–18,21,44–48]and persons with severe stroke appear to be the most negatively affected by the current model of care.[49] Persons who have undergone stroke rehabilitation in an inpatient setting identify quantity of therapy as a priority concern.[2,6] Much of the pressure for implementing stroke therapy guidelines is off-loaded to frontline clinicians and managers, even though the most common reported barrier to implementation is inadequate resources (i.e., people, space, and equipment) frequently due to insufficient funding. In other words, clinicians and program managers are told to embrace evidence-based practice without sufficient support.

Perhaps part of the reason knowledge-translation and implementation strategies have not been effective is work is being done in silos rather than exploring the impact of change across the system. Thus, we challenge all stakeholders to take an active, collaborative approach to tackling the critical issue of 'not enough' therapy, as changes at multiple levels in the health care system are required. It appears the dialogue has hardly begun.

Our call is to act upon:

- the overwhelming evidence reported in this paper on high levels of sedentary activity and low levels of therapy during inpatient stroke rehabilitation;
- the evidence suggesting the institutional and most importantly the funding environment is inhibitive to implementation of therapy intensity; and
- the patient voices stating, 'We want more.'

Summary

It is important to acknowledge that this is a perspective article inspired by findings from a previous study. This article was designed to explore the problem of inactivity among individuals in inpatient stroke rehabilitation in light of Canadian best practice recommendations and patient preferences. Indeed, there is evidence supporting the patient perception of 'not enough' therapy during inpatient stroke rehabilitation. A large part of the problem surrounding closing the rehabilitation intensity evidence-to-practice gap appears to be that service providers are stuck at the implementation stage. Implementation efforts targeting point-of-care issues are not enough. Action is needed at the system level and the time for action is now.

References

1. Bernhardt J, Dewey H, Thrift A, Donnan G. Inactive and alone: Physical activity within the first 14 days of acute stroke unit care. *Stroke*. 2004;35(4):1005-1009. doi:10.1161/01.STR.0000120727.40792.40

2. Last N, Packham T, Gewurtz R, Letts L, Harris JE. Looking beyond the scales of participation: Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation [submitted for publication].

3. Hebert D, Lindsay P, Mcintyre A, et al. Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015. *Int J Stroke*. 2016;11(4):459-484. doi:10.1177/1747493016643553

4. Boulanger JM, Lindsay MP, Gubitz G, et al. Canadian stroke best practice recommendations for acute stroke management: Prehospital, emergency department, and acute inpatient stroke care, 6th ddition, Update 2018. *Int J Stroke*. 2018;0(0):1-36. doi:10.1177/1747493018786616 [Epub ahead of print]

5. Leung G, Katz PR, Karuza Phd J, et al. Slow Stream Rehabilitation: A New Model of Post-Acute Care. *J Am Med Dir Assoc*. 2016;17:238-243. doi:10.1016/j.jamda.2015.10.016

6. Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J. Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. *Arch Phys Med Rehabil*. 2015;96(9):1698-1708. doi:10.1016/j.apmr.2015.03.017

7. Teasell R, Foley N, Hussein N, Wiener J, Speechley M. *Chapter 6: The Elements*

of Stroke Rehabilitation.; 2018.

8. Bo Lee K, Hoon Lim S, Hoon Kim K, et al. Six-month functional recovery of stroke patients: A multi-time-point study. *Int J Rehabil Res*. 2015;38:173-180. doi:10.1097/MRR.0000000000000108

9. Sivenius J, Pyörälä K, Heinonen OP, Salonen JT, Riekkinen P. The significance of intensity of rehabilitation of stroke: A controlled trial. *Stroke*. 1996;16(6):928-931. doi:10.1161/01.str.27.1.18

10. Wade DT, Wood VA, Hewer RL. Recovery after stroke: The first 3 months. *J Neurol Neurosurg Psychiatry*. 1985;48(1):7-13.

11. Keith RA. Activity patterns of a stroke rehabilitation unit. *Soc Sci Med*. 1980;14(6):575-580.

12. Keith RA, Cowell KS. Time use of stroke patients in three rehabilitation hospitals. *Soc Sci Med*. 1987;24(6):529-533.

13. Lincoln NB, Gamlen R, Thomason H. Behavioural mapping of patients on a stroke unit. *Int Disabil Stud*. 1989;11(4):149-154. doi:10.3109/03790798909166666

14. Tinson DJ. How stroke patients spend their days: An observational study of the treatment regime offered to patients in hospital with movement disorders following stroke. *Int Disabil Stud*. 1989;11(1):45-49.

15. Barrett M, Snow JC, Kirkland MC, et al. Excessive sedentary time during in-patient stroke rehabilitation. *Top Stroke Rehabil*. 2018:1-9.

doi:10.1080/10749357.2018.1458461org/10.1080/10749357.2018.1458461 [Epub ahead of print]

16. West T, Bernhardt J. Physical activity in hospitalised stroke patients. *Stroke Res Treat*. 2012;2012(Article ID 813765):1-13. doi:10.1155/2012/813765

17. Sjoholm A, Skarin M, Churilov L, Nilsson M, Bernhardt J, Linden T. Sedentary behaviour and physical activity of people with stroke in rehabilitation hospitals. *Stroke Res Treat*. 2014;2014(Article ID 591897):1-7. doi:10.1155/2014/591897

18. Foley N, McClure AJ, Meyer M, Salter K, Bureau Y, Teasell R. Inpatient rehabilitation following stroke: Amount of therapy received and associations with functional recovery. *Disabil Rehabil*. 2012;34(25):2132-2138. doi:10.3109/09638288.2012.676145

19. Kaur G, English C, Hillier S. How physically active are people with stroke in physiotherapy sessions aimed at improving motor function? A systematic review. *Stroke Res Treat*. 2012;2012(Article ID 820673):1-9. doi:10.1155/2012/820673

20. McNaughton H, McRae A, Green G, Abernethy G, Gommans J. Stroke rehabilitation services in New Zealand: A survey of service configuration, capacity and guideline adherence. *N Z Med J*. 2014;127(1402):10-19.

21. Janssen H, Ada L, Bernhardt J, et al. Physical, cognitive and social activity levels of stroke patients undergoing rehabilitation within a mixed rehabilitation unit. *Clin Rehabil*. 2014;28(1):91-101. doi:10.1177/0269215512466252

22. King A, McCluskey A, Schurr K. The time use and activity levels of inpatients in a co-located acute and rehabilitation stroke unit: An observational study. *Top Stroke Rehabil*. 2011;18(Suppl 1):654-665. doi:10.1310/tsr18s01-654

23. Astrand A, Saxin C, Sjoholm A, et al. Poststroke physical activity levels no higher in rehabilitation than in the acute hospital. *J Stroke Cerebrovasc Dis*. 2016;25(4):938-945. doi:10.1016/j.jstrokecerebrovasdis.2015.12.046

24. Coletta EM, Murphy JB. The complications Of immobility in the elderly stroke patient. *J Am Board Fam Pract*. 1992;5:389-397.

25. Langhorne P, Stott DJ, Robertson L, et al. Medical complications after stroke: A multicenter study. *Stroke*. 2000;31:1223-1229. doi:10.1161/01.STR.31.6.1223

26. Appelros P, Jonsson F, Asplund K, et al. Trends in baseline patient characteristics during the years 1995–2008: Observations from Riks-Stroke, the Swedish Stroke Register. *Cerebrovasc Dis*. 2010;30(2):114-119. doi:10.1159/000314714

27. Health Quality Ontario; Ministry of Health and Long-Term Care. *Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute)*. Toronto; 2016.

28. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: Time for a map? *J Contin Educ Health Prof*. 2006;26(1):13-24. doi:10.1002/chp.47

29. Bayley MT, Hurdowar A, Richards CL, et al. Barriers to implementation of stroke rehabilitation evidence: Findings from a multi-site pilot project. *Disabil Rehabil*. 2012;34(19):1633-1638. doi:10.3109/09638288.2012.656790

30. Munce SEP, Graham ID, Salbach NM, et al. Perspectives of health care professionals on the facilitators and barriers to the implementation of a stroke rehabilitation guidelines cluster randomized controlled trial. *BioMed Cent Heal Serv Res*. 2017;17(440):1-13. doi:10.1186/s12913-017-2389-7

31. Sahely A. How do therapists understand and intend to implement practice guideline recommendations for rehabilitation of the uppper limb following stroke? 2015.

32. Menon A, Korner-Bitensky N, Kastner M, McKibbon KA, Straus S. Strategies for rehabilitation professionals to move evidence-based knowledge into practice: A systematic review. *J Rehabil Med*. 2009;41(13):1024-1032. doi:10.2340/16501977-0451

33. Petzold A, Korner-Bitensky N, Salbach NM, Ahmed S, Menon A, Ogourtsova T. Increasing knowledge of best practices for occupational therapists treating post-stroke unilateral spatial neglect: Results of a knowledge-translation intervention study. *J Rehabil Med*. 2012;44(2):118-124. doi:10.2340/16501977-0910

34. Moore JE, Marquez C, Dufresne K, et al. Supporting the implementation of stroke quality-based procedures (QBPs): a mixed methods evaluation to identify knowledge translation activities, knowledge translation interventions, and determinants of implementation across Ontario. *BMC Health Serv Res*. 2018;18(1):466. doi:10.1186/s12913-018-3220-9

35. Lowry F. Stroke rehabilitation services inadequate, experts say. *Can Med Assoc J*.

2010;182(7):E283-284. doi:10.1503/cmaj.109-3214

36. Meyer M, O'callaghan C, Kelloway L, et al. *The Impact of Moving to Stroke Rehabilitation Best Practices in Ontario*.; 2012.

37. English C, Shields N, Brusco NK, et al. Additional weekend therapy may reduce length of rehabilitation stay after stroke: a meta-analysis of individual patient data. *J Physiother*. 2016;62(3):124-129. doi:10.1016/j.jphys.2016.05.015

38. Peiris CL, Shields N, Brusco NK, Watts JJ, Taylor NF. Additional Saturday rehabilitation improves functional independence and quality of life and reduces length of stay: A randomized controlled trial. *BioMed Cent Med*. 2013;11(198):1-11. doi:10.1186/1741-7015-11-199

39. Pullenayegum S, Fielding B, Du Plessis E, Peate I. The value of the role of the rehabilitation assistant. *Br J Nurs*. 2005;14(14):778-784.

40. Galvin R, Stokes E, Cusack T. Family-mediated exercises (FAME): An exploration of participant's involvement in a novel form of exercise delivery after stroke. *Top Stroke Rehabil*. 2014;21(1):63-74. doi:10.1310/tsr2101-63

41. Harris JE, Eng JJ, Miller WC, Dawson AS. A self-administered graded repetitive arm supplementary program (GRASP) improves arm function during inpatient stroke rehabilitation: A multi-site randomized controlled trial. *Stroke*. 2009;40(6):2123-2128. doi:10.1161/STROKEAHA.108.544585

42. Pietrzak E, Cotea C, Pullman S. Using commercial video games for upper limb

stroke rehabilitation: Is this the way of the future? *Top Stroke Rehabil*. 2014;21(2):152-162. doi:10.1310/tsr2102-152

43. Laver KE, Lange B, George S, Deutsch JE, Saposnik G, Crotty M. Virtual reality for stroke rehabilitation. *Cochrane Database Syst Rev*. 2017;(11). doi:10.1002/14651858.CD008349.pub4

44. Bernhardt J, Chan J, Nicola I, Collier JM. Little therapy, little physical activity: Rehabilitation within the first 14 days of organized stroke unit care. *J Rehabil Med*. 2007;39(1):43-48. doi:10.2340/16501977-0013

45. Lang CE, Macdonald JR, Reisman DS, et al. Observation of Amounts of Movement Practice Provided During Stroke Rehabilitation. 2009. doi:10.1016/j.apmr.2009.04.005

46. Lohse KR, Lang CE, Boyd LA. Is more better? Using metadata to explore dose-response relationships in stroke rehabilitation. *Stroke*. 2014;45(7). doi:10.1161/STROKEAHA.114.004695

47. West T, Bernhardt J. Physical activity patterns of acute stroke patients managed in a rehabilitation focused stroke unit. *Biomed Res Int*. 2013;2013(Article ID 438679):1-8. doi:10.1155/2013/438679

48. English C, Healy GN, Coates A, Lewis LK, Olds T, Bernhardt J. Sitting time and physical activity after stroke: physical ability is only part of the story. *Top Stroke Rehabil*. 2016;23(1). doi:10.1179/1945511915Y.0000000009

49. Teasell R, Pereira S, Cotoi A. *The Rehabilitation of Severe Stroke*.; 2018.

Chapter 4: Discussion & Conclusion

Introduction

This thesis places the perspectives of individuals with stroke at centre stage. Using interpretive description (ID) as the qualitative approach, persons with stroke who were currently enrolled in or recently discharged from, hospital-based rehabilitation were interviewed to construct new knowledge regarding factors both impeding and promoting participation in stroke rehabilitation. The following research gaps provided rationale for this work: 1) no published studies from the patients' perspective on influencers of participating in hospital-based stroke rehabilitation programs and 2) in general there are limited studies about influences of participation in hospital-based stroke rehabilitation. Chapter two (manuscript one) was designed to specifically address these gaps. Chapter three (manuscript two) was developed to highlight important findings surrounding rehabilitation intensity from chapter two.

The second chapter presents the findings from the ID study stemming from the research question: what do patients perceive as barriers and facilitators to participating in stroke rehabilitation? The main objectives were to: 1) identify factors perceived by patients to influence their participation in hospital-based stroke rehabilitation activities and 2) use a patient lens to generate knowledge relevant for the clinical context of stroke rehabilitation. This study utilized semi-structured interviews with 11 individuals who were currently enrolled in, or recently discharged from, hospital-based stroke rehabilitation to gather information pertaining to factors influencing participation. Patient and researcher experiences contributed to the co-construction of four main themes: 1)

Environmental Factors, 2) Components of Therapy, 3) Physical and Emotional Well-Being, and 4) Personal Motivators. Overall, findings from chapter two highlight the significance of the environment, as well as external, interpersonal, and personal factors as both barriers and facilitators of participation.

The third chapter is a position paper which explores and discusses participants' description regarding the impact of low levels of therapy during inpatient rehabilitation. Given the widely acknowledged importance of early and intensive rehabilitation after stroke (Hebert et al., 2016), it was decided that this topic required further investigation. To accomplish this, participant and stroke program manager perspectives were examined alongside rehabilitation intensity workload measurement data. This chapter also provides a review of clinical practice guidelines for stroke rehabilitation in Canada, literature pertaining to disseminating and implementing these guidelines, and a review of studies examining activity levels in stroke rehabilitation. Despite stroke rehabilitation best practice guidelines, low therapy intensity levels during inpatient stroke rehabilitation are pervasive. Implementation science frameworks have primarily focused on educating front line clinicians to reduce knowledge-to-practice gaps in stroke rehabilitation. However, this strategy has been largely unsuccessful in increasing therapy intensity levels during inpatient stroke rehabilitation across Canada and elsewhere. In concluding this chapter, we suggest a joint partnership with all stakeholders needs to be considered a priority strategy.

Considering chapters two and three in the context of the presented knowledge gaps, study findings, and methods employed, this thesis contributes knowledge about: 1) patient perspectives on factors affecting participation in stroke rehabilitation; 2) promoting patient participation; and 3) shortcomings in closing the evidence-to-practice gap with respect to therapy intensity during inpatient stroke rehabilitation. This fourth and final chapter elaborates on these contributions and the clinical implications of this work, strengths and limitations of this thesis, and directions for future research.

Contributions to Knowledge and Clinical Implications

Putting Patients First: Patients Want Personalized Stroke Rehabilitation

The work contained in this thesis uses patient voices to identify factors impacting participation in hospital-based stroke rehabilitation from three different rehabilitation programs in Ontario, Canada. The four main themes were environmental factors, components of therapy, physical and emotional well-being, and personal motivators. Asking the question 'so what might this all mean?' in ongoing reflection and sense-making of these themes led to an evolving interpretation of study findings. It was noted the identified themes seemed to relate both directly and indirectly to participants' desire for personalized rehabilitation (Figure 1). From these reflections, an exploratory framework of personalized rehabilitation was developed which depicts the direct and indirect influence of main and sub-themes.

The purpose of this framework is to illustrate and describe what an ideal stroke rehabilitation program includes, with personalized rehabilitation as the core concept. This framework is not intended to be prescriptive and acknowledges that personalized rehabilitation is unique to each individual; rather, it provides insight into patient perspectives of 'ideal therapy' and demonstrates relationships between the components as well as other factors that may influence the provision of personalized stroke rehabilitation. As this framework was inspired by patients' perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation, there is an underlying assumption that addressing each of the components, will enhance patient participation in stroke rehabilitation. The six circles are considered the main components of personalized rehabilitation while the three outside factors are interrelated factors that may influence personalized rehabilitation in differing contexts.

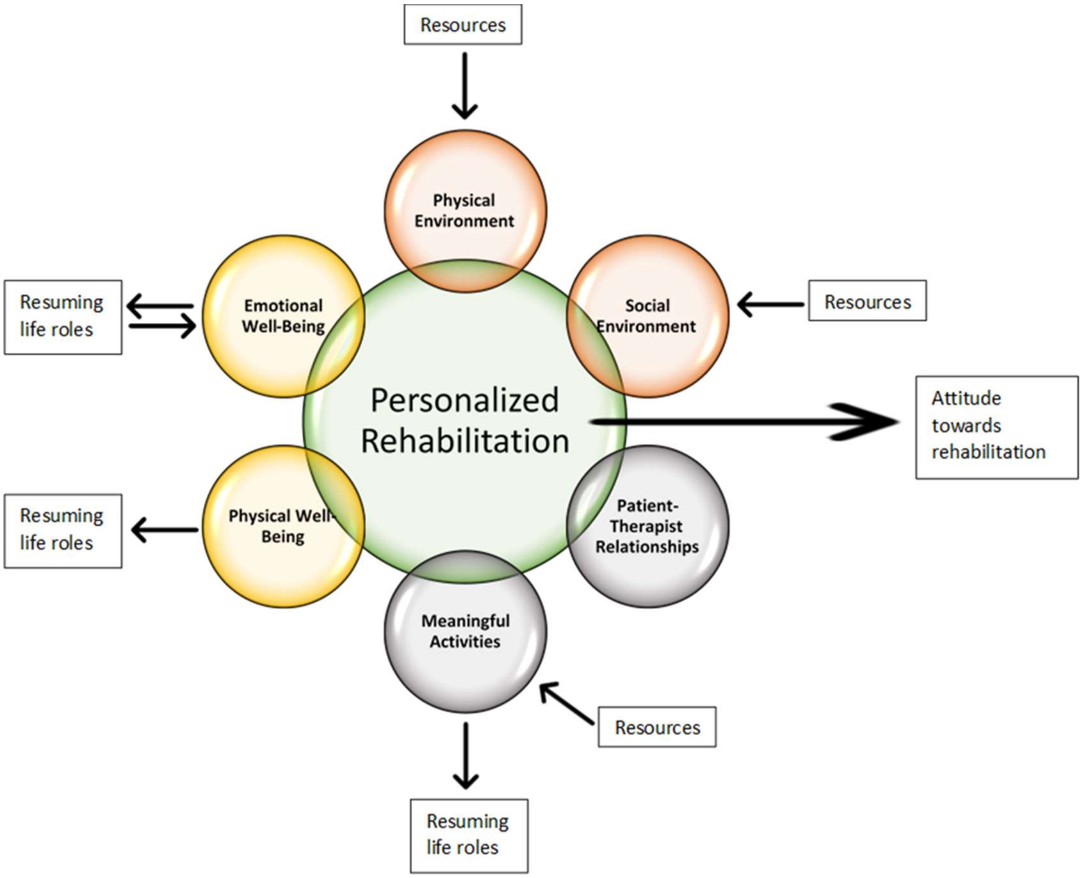


Figure 1: Exploratory framework of personalized rehabilitation constructed from patient perspectives of stroke rehabilitation illustrating six key components of personalized rehabilitation. Environmental factors are depicted in orange, components of therapy in gray, and personal well-being in yellow. Three additional factors are represented as interrelated factors with directional influences via key components.

In viewing these themes as components of personalized rehabilitation, similarities to the widely accepted healthcare concept of client/patient-centred care were noted (Bamm, Rosenbaum, Wilkins, Stratford, & Mahlberg, 2015); however, there is no universal definition or model for practical application (Bamm et al., 2015). Regardless, as in our framework, adopting a patient-centred approach puts the user at the centre of healthcare. The following sections discuss how the framework was conceptualized to represent components of personalized rehabilitation constructed from patients' points of view. In addition, elements of patient/client-centred care will be discussed comparatively to this conceptualized framework for personalized rehabilitation.

Considering the Environment in Providing Personalized Stroke Rehabilitation. Chapter two discussed how various aspects of the physical and social rehabilitation environments impacted patients' participation in rehabilitation, as perceived by study participants. One example given was a noisy hospital environment and its impact on sleep. Disrupted sleep was then perceived to negatively impact level of physical and cognitive functioning and, therefore, performance. This conceptualization that the physical and social environments are primary components of personalized rehabilitation flows from participants' recollections of how the environment hindered or supported participation. Aspects that were important to some individuals were not necessarily important to others. For example, two participants mentioned the temperature of the rehabilitation environment and noted it was not conducive to rehabilitation. Thus, this exploratory framework of personalized rehabilitation recognizes service users as unique individuals with varying needs and perceptions of an 'ideal' physical environment conducive to optimal rehabilitation and maximum recovery. Further, this framework suggests ongoing 'check-ins' are necessary to determine individually consequential aspects of the physical environment that could hinder achievement of individual goals.

Peer and family interactions and friendly encounters with others all contributed to a positive social environment that was described as motivating. In the context of personalized rehabilitation, positive peer interactions and family involvement in rehabilitation appeared to be integral elements of individual social support systems and were desired by service users. Not putting restrictions on visiting hours and allowing family members to both observe and be involved in rehabilitation activities are some of the examples provided by study participants. The importance of family social support after stroke has been previously emphasized (Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000), as has family involvement in supporting and enhancing the rehabilitation process (Galvin et al., 2014). Therefore, this conceptual framework of personalized rehabilitation emphasizes the importance of a welcoming environment that encourages social activity and accommodates individual desires to engage and connect socially.

Therapy Activities and Relationships Matter. Personalized rehabilitation incorporates the components of therapy which in this study included patient-therapist interactions and the various aspects of therapy itself (e.g., type of activities chosen and amount of therapy). In other words, components of therapy combine therapy service providers and the services provided.

The provision of information regarding stroke in general and stroke resources, as well as specific information regarding the individual's recovery progress was valued by study participants, as noted in chapter two. Specifically, good communication and providing information as well as feedback on performance were elements of patient-therapist interactions that were valued when present and noted when absent. Communication plays a primary role in service quality in healthcare and clinical communication skills are a prevalent factor in patient satisfaction (Newell & Jordan, 2015). A qualitative study by Peiris, Taylor, and Shields (2012) reported rehabilitation patients valued friendly, compassionate, and knowledgeable physiotherapists. Positive personal interactions with physiotherapists contributed to an overall pleasurable rehabilitation experience, thus acknowledging the influence of communication ability and personal attributes of therapists. Further, results from a systematic review of stroke survivors' experiences of physical rehabilitation indicated poor communication between participants and the treating team threatened patient autonomy, confidence, and motivation, ultimately resulting in patient disempowerment (Luker et al., 2015). Thus, as a component of personalized rehabilitation, patient-therapist interactions should include clear and consistent communication that addresses individual questions and concerns, including patient education and providing feedback on performance and progress throughout. Interactions that allow for timely education for the patient (and family) can result in increased participation in rehabilitation and improved patient outcomes (Bamm et al., 2015).

Meaningful activities are another element of personalized rehabilitation identified from participant responses. Rehabilitation activities that were clearly linked to individual goals and the resumption of meaningful activities were highly valued. The occupational therapy profession, which is one of the core therapies in stroke rehabilitation, advocates for the inclusion of meaningful activities as a health promoting factor and the underlying belief that meaningful activity is central to human existence (Kielhofner, 2009). Advantages of this approach to stroke rehabilitation include the enhancement of patient participation in rehabilitation activities, as indicated by participants in chapter two, and a potential relationship between the resumption of meaningful poststroke activities and higher quality of life (Edwards, Hahn, Baum, & Dromerick, 2006; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Mayo et al., 2002). Personalized stroke rehabilitation, therefore, is interpreted to require investigation into personal goals and subsequent incorporation of strategically designed tasks and activities that are distinctly linked to individual goals.

Fostering Physical and Emotional Well-Being. Physical and emotional challenges were discussed in detail in chapter two. In the context of providing personalized rehabilitation, both physical and emotional well-being need to be addressed in a way that provides individuals the best opportunity to recover from stroke. Indeed, the main objective of stroke rehabilitation is to optimize functional, cognitive and emotional recovery (Hebert et al., 2016), a daunting task given the wide range of significant physical, cognitive, and emotional deficits common after stroke. The complexity of stroke, and the array of consequences, present a challenge for a) service providers to deliver and facilitate optimal recovery and b) individuals who have experienced a stroke and are suddenly faced with a multitude of new obstacles to adapt to or overcome. Physical well-being addresses a person’s physical impairments and function and considers physical activity as well as nutrition. In order to put effort into rehabilitation, physical health and well-being should be addressed and accommodated to allow for maximum effort from service users and, in turn, support maximal outcomes. Emotional well-being considers factors such as self-efficacy, coping behaviours, stress, depression, and anxiety and is as important as physical health. Attending to both is an essential component of providing personalized stroke rehabilitation.

Interrelated Factors Influencing Personalized Rehabilitation. The exploratory framework of personalized rehabilitation (Figure 1) includes three additional elements derived from sub-themes within chapter two. *Resources* was originally a sub-theme of environmental factors while both *resuming life roles* and *attitude towards rehabilitation* were situated as personal motivators. Conceptually, these three ‘outsiders’ are external factors with associations to the six previously discussed components of personalized rehabilitation. The arrows illustrate the directional influences of the external factors and the influential nature of these factors are described below.

There appears to be an association between resource availability, adapting both the physical and social environments, and providing meaningful activities in a way that corresponds with the needs and preferences of service users. Thus, resources are indirectly linked to personal rehabilitation via these three components. Program resources can limit the extent to which redesigning and remodelling of the environment can occur;

however, improving the physical and social environments has clinical benefits. Patients exposed to an enriched environment are more likely to participate in therapeutic activities, and less likely to be inactive, alone, or asleep during waking hours (Janssen et al., 2014b; Rosbergen et al., 2017). The provision of meaningful activities (amount and type) can also be limited by resource availability, such as adequate staffing, space, and equipment (Bayley et al., 2012; Clarke, Stack, & Martin, 2018; Kwakkel, 2006). While recognizing the constraints of publicly funded programs, this framework involves doing what can realistically be done within the means of the service provider while also advocating for creativity, resourcefulness, and collaboration with service users.

The desire to resume life roles can be linked to the inclusion of meaningful activities throughout stroke rehabilitation. Often, a main goal of patients after stroke is to be able to return to their lives (Merz, Patten, Mulhauser, & Fucetola, 2016; Tutton, Seers, Langstaff, & Westwood, 2011) and returning to previously valued roles (e.g., worker, spouse, parent, grandparent). Incorporating activities with a distinct association to the ability to return to individually meaningful life roles both personalizes the rehabilitation experience and can help in maintaining motivation throughout the rehabilitation process. The ability to return to life roles can also be impeded by an individual's physical and emotional well-being, thus demonstrating additional linkages between personalized rehabilitation and resuming life roles (Figure 1) while also emphasizing the importance of physical and emotional well-being. Physical and emotional challenges can hinder one's ability to return to work, for example, and therefore part of providing personalized rehabilitation involves addressing, as best as possible, factors of physical and emotional well-being that may interfere with this goal.

A patient's attitude towards rehabilitation can be impacted by each of the main components in the sense that service users' attitudes towards rehabilitation can be influenced by their experience of and satisfaction with rehabilitation. If the experience is negative, motivation or desire to continue to participate in rehabilitation is likely to decline (Karageorghis & Terry, 2011; Niall Maclean & Pound, 2000). In this way, providing personalized rehabilitation through consideration of the physical and social environment, patient-therapist interactions, meaningful activities, and physical-emotional well-being could increase the likelihood of positive patient experiences and therefore attitude. Notably, a negative attitude towards rehabilitation, due to negative experiences or otherwise, can present as a challenge to the provision of personalized rehabilitation.

Inherent to the personalized rehabilitation framework is the idea that key components are interrelated. For instance, physical well-being can affect emotional well-being, as can the social environment. In addition, it is recognized that factors will have different levels of relevance depending on individual situations. For example, an individual who does not have family support may rely more heavily on support from the patient-therapist relationship and the social environment whereas an individual who is well-supported by family may be more concerned with and responsive to other components, such as meaningful activities they can do independently or with family involvement.

Personalized Rehabilitation Exemplifies Patient Centricity. As described earlier in this discussion, the exploratory framework of personalized rehabilitation was inspired by participant interviews, and closely relates to the familiar concept of patient-centred (or client-centred) care. Patient-centred care is a main tenet of Canada's health care system, with many hospitals and health service providers citing this approach in the organization's mission statement. The Ontario Medical Association (Ontario Medical Association, 2010) defines a patient-centred care system as:

> …one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that considers the individual needs of patients and treats them with respect and dignity. (p. 34)

The Institute of Medicine defines patient-centred care similarly but also emphasizes shared decision-making that represents patients' needs as well as wants and preferences, and patient education and support to participate in their own care (Institute of Medicine (US) Committee on the National Quality Report on Health Care Delivery, 2001). Commonly identified key characteristics of patient-centered care include the provision of information, good communication, ready access, continuity and coordination of care, empowerment, and emotional support (Bamm et al., 2015).

Though patient-centred care is widely accepted in healthcare and claimed to be adopted by many health service providers, it appears to have defied clear operationalization in the literature. Hammell (2006) suggested patient-centred practice in rehabilitation is predominantly about the relationship between the service user and the service provider, rather than specific rehabilitation interventions. While personalized rehabilitation as outlined throughout this chapter certainly underscores the patient-provider relationship as a key feature, it also recognizes the significance of the environment and specific rehabilitation interventions. Further, Bright, Boland, Rutherford, Kayes, and McPherson (2012) noted patient centricity is linked to interpersonal skills of therapists, which coincides with this framework as therapists and other rehabilitation professionals have a key role in facilitating personalized rehabilitation, such as ensuring the patient feels valued and respected. Ultimately, this exploratory framework of personalized stroke rehabilitation, like patient-centred practice, engages patients as partners, putting the service user at the centre of care. Overall, personalized rehabilitation can be considered a key element of patient-centredness in stroke rehabilitation, as providing personalized stroke rehabilitation means respecting patient needs, wants, and preferences and prioritizes patient empowerment. In order to conceptualize rehabilitation in a more holistic fashion, it is necessary to consider multiple factors that influence rehabilitation. By representing rehabilitation in a personalized and inclusive manner, the framework suggests that new, responsive strategies should be developed to address patients' rehabilitation concerns. Demonstrating linkages among the various aspects of personalized rehabilitation may guide future research to be holistic and contribute to the development of more extensive and effective stroke rehabilitation programs.

Putting Patients First: Is Inpatient Stroke Rehabilitation Patient-Centred?

'Patients First: A Proposal to Strengthen Patient-Centred Care in Ontario' is the title of a 2015 discussion paper released by the Ontario Ministry of Health and Long-

Term Care (OMHLTC) and includes the promise to “put patients first” (Ontario Ministry of Health and Long-Term Care, 2015). Patients who are supposed to be the ‘centre of care’ have indicated inpatient stroke rehabilitation is not there yet. A resounding message from study participants was inadequacies relating to the amount of therapy during inpatient stroke rehabilitation, and that more therapy was important to them. Further exploration into the topic of stroke rehabilitation intensity resulted in the shocking realization that others have reported the same issue for decades previous: that is, hospitalized stroke rehabilitation patients spend much of their time inactive and alone. A review of the literature to investigate why rehabilitation intensity appears to be a pervasive issue in inpatient stroke rehabilitation led to studies utilizing implementation science strategies to improve the uptake of evidence into practice (Bayley et al., 2012; Connell, Klassen, Janssen, Thetford, & Eng, 2018; Donnellan, Sweetman, & Shelley, 2013; Moore et al., 2018; Munce et al., 2017; Pollock, Legg, Langhorne, & Sellars, 2000; Purvis, Moss, Denisenko, Bladin, & Cadilhac, 2014; Salbach et al., 2017; R. W. Teasell, Foley, Salter, & Jutai, 2008). Findings from these studies signify that closing stroke rehabilitation evidence-practice gaps is difficult due to multi-level barriers, and implementation strategies often targeted at frontline staff, ignoring commonly identified system level barriers.

A recent point of view article from Australia discusses the ‘research translation pipeline’ in stroke rehabilitation (Lynch, Chesworth, & Connell, 2018). The authors posit the evidence-practice gap in stroke rehabilitation may be linked to a paucity of new evidence available to clinicians and researchers striving to translate stroke rehabilitation research into practice. In a review of the literature in eight leading journals in the field of stroke rehabilitation, Lynch et al. (2018) found only 2.5% (n=7) of the stroke rehabilitation research published in these journals in 2016 (not including pharmacological and surgical interventions) addressed implementation or evaluation. Five additional implementation publications were identified in health service journals and the authors note that information regarding strategies to implement evidence-based interventions was only published in the nonstroke or rehabilitation journals. This is concerning given clinicians have a tendency to scan only a discrete selection of journals to keep up-to-date with current research and this 'scatter' of research in nonspecialty journals can reduce clinical awareness and uptake of this research (Lynch et al., 2018). Coinciding with the 'call to action' issued in chapter three, Lynch and colleagues concluded future research needs to focus and prioritize how to best translate research findings into clinical practice, and this needs to be supported by publishers, funders, and professional bodies.

In summary, the rehabilitation intensity evidence-to-practice gap in stroke rehabilitation has significant consequences: patients who can benefit from intensive therapy are largely inactive during hospitalization. Even with targeted dissemination strategies and implementation interventions to close the evidence-to-practice gap, the issue remains. It is possible that widespread uptake of best practice recommendations for amount of therapy has not yet been achieved because a) there is a shortage of implementation research specific to stroke rehabilitation, b) scattering of this research throughout specialty and nonspecialty journals presents as a barrier to dissemination and implementation, and c) existing strategies and interventions to promote the uptake of evidence into practice appear to be focused on frontline staff when frontline staff are not always in control of the context in which they practice and often require more space, equipment, staff, time, and active support (i.e., champions/leaders) to sustain successful implementation. This one-pronged approach is not effective; all stakeholders need to be present and collaborate to develop a multi-pronged approach in order to incite meaningful change. If patients are not at least being offered the opportunity to benefit from the best possible evidence-based care (i.e., to participate in direct therapy activities for the minimum recommended number of minutes per day), then stroke rehabilitation is not sufficiently patient-centred. To quote the German literary figure Johann Wolfgang von Goethe, "Knowing is not enough; we must apply. Willing is not enough; we must do."

How is Rehabilitation Intensity Currently Defined?

The question of 'what is intensity' depends on who you ask. Recognizing the need for a standardized definition of the intensity of therapy, CorHealth Ontario (formerly known as the Ontario Stroke Network) (CorHealth Ontario, 2017) defines Rehabilitation Intensity (RI) as:

> the amount of time the patient spends in individual, goal-directed rehabilitation therapy, focused on physical, functional, cognitive, perceptual and social goals to maximize the patient's recovery, over a seven day/week period. It is time that a patient is engaged in active face-to-face treatment, which is monitored or guided by a therapist.

Similarly, the Canadian Stroke Rehabilitation Best Practice Guidelines (Hebert et al., 2016) refer to intensity as the amount of minutes per day a patient receives direct, task-specific therapy; more intensive therapy equates to an increased number of therapy minutes. This is likely because available evidence has demonstrated better outcomes for stroke rehabilitation patients who receive more time in face to face therapy (Hebert et al., 2016; Ontario Stroke Network, 2012).

In exercise science, intensity is often measured objectively by heart rate and therefore increasing the intensity would mean making the task more strenuous for the human body and requiring greater effort. Rate of perceived exertion is also commonly used in exercise science to gauge intensity (Borg, 1982). These measures of intensity have little to do with amount of time spent in a therapy session. The FITT principle (Oberg, 2007) is one of the foundations of exercise; it includes four important elements to consider when planning an exercise program (frequency, intensity, time, and type). In the context of stroke rehabilitation: 1) frequency would mean how many sessions per day and how many days per week an individual is receiving therapy, 2) intensity would relate to the level of exertion experienced during the activity, 3) time is how long is the activity or session, and 4) type corresponds to the specific activity (e.g., walking, balance, resistance, fine motor) being performed. The FITT principle is a widely recognized standard for the development of exercise/activity programs (American College of Sports Medicine, 2014) and yet current stroke measures of intensity incorporate only two principles (frequency and time spent in rehab sessions).

Chapter 3 discusses the issue of ‘not enough’ therapy, as made evident from an accumulation of data that included patient perspectives, RI workload measurement data, and current literature. While it was concluded a clear gap exists between stroke rehabilitation guidelines and clinical practice, it should also be noted that RI as typically defined in the stroke rehabilitation literature neglects critical components. For one, it does not provide a measure of patient effort and, second of all, RI does not take into account type of activity aside from it being ‘task-specific.’ In addition, RI only focuses on the three core therapies (physiotherapy, occupational therapy, and speech language therapy) and does not fully capture all activities common in stroke rehabilitation, such as group therapies, self-administered and family-mediated activities, recreational activities, and therapeutic activities done with other healthcare professionals (i.e., nurses, therapy assistants).

Perhaps stroke rehabilitation research should redefine intensity to incorporate other types of therapy as well as patient effort level in order to obtain a more wholesome picture of patient activity during inpatient stroke rehabilitation. This way, a more complete description of rehabilitation intensity could include 1) a frequency, time, effort, and type of activities done with core therapists and other members of the rehabilitation team, 2) group activities, and 3) therapeutic activity performed in the absence of healthcare professionals. Redefining rehabilitation intensity and therefore, how it is documented would provide stroke rehabilitation healthcare providers, policy makers, and researchers with a more complete depiction of patient activity levels. In turn this could help inform correlates of stroke recovery, best practice guidelines, and inpatient stroke care.

Thesis Strengths and Limitations

Strengths

The use of qualitative methods brings service users’ perspectives to the fore to explore their experiences of what influences participation in stroke rehabilitation, while also addressing gaps in the literature. Prior to data collection, discussions with stroke rehabilitation professionals assisted in decision-making related to research design (e.g., development of the interview guide), which helped in establishing parameters of the research. Collaboration with service users (participants), service providers (program managers), as well as the research team contributed to the co-construction of this research, contributing breadth to the inquiry and resulting in findings that a) reflect service users' perspectives, b) contribute further understanding of patient participation in stroke rehabilitation, and c) provide relevant application for stroke rehabilitation practitioners. In addition, the broad inclusion criteria and purposive sampling strategy allowed for a diverse sample of participants with respect to age, time since stroke, location of stroke, stage of recovery, and levels of physical and cognitive functioning, within the context of the recruitment sites. After data collection, I transcribed all of the audio-recorded interviews, which allowed for greater immersion and familiarity with the data; this process, paired with writing synopses of each interview helped me in remaining mindful of the context of individual experiences.

Interpretive description, the specific methodological approach used to guide the primary research study contained in this thesis, is considered a viable methodological approach for the production of knowledge in the applied health sciences (Teodoro et al., 2018). An interpretive description study requires the clinical researcher to step out of the role of clinician or health professional and into the role of researcher and learner (Thorne, 2016). As a 'non-clinician' student researcher without previous experience working on a stroke unit and little experience working with individuals affected by stroke, it was less challenging for me to take on the role of someone who does not know and is seeking the subjective experiences of patients themselves in order to know. Initially, I viewed the fact that I was conducting an interpretive description study without experience as a practitioner in the field I was studying as a weakness of this research. I thought, “how could I, an outsider, generate knowledge relevant for the clinical context of stroke rehabilitation and who is going to listen?” Later, however, I began to view this position as a study strength rather than a weakness. I was not an applied practitioner researcher, but I was also not well acquainted with the subtleties of stroke rehabilitation practice, and it was therefore easy for me to be open-minded and well positioned to question ‘taken-for-granted’ practices with a neutral lens. Ongoing discussions with Dr. Jocelyn Harris, my research supervisor and a clinical expert in the field of stroke rehabilitation, helped to keep potential biases in check. Our differing perspectives and experiences were well-matched and ongoing discussions and reflections on the emerging findings contributed to the depth of analysis throughout the research process. Although ID allows for flexibility with regard to data collection and analysis, the originators of this qualitative approach provide key elements of an ID inquiry as well as guidance and suggestions for ensuring adequate coherence and rigor throughout the research process. Using ID to guide the work contained within this thesis resulted in findings that have real world application and will hopefully assist healthcare professionals in particular situations that arise in clinical practice to help orient clinical reasoning. For example, as a result of findings from the primary study, I elected to write a second findings article to discuss in greater detail the issue of rehabilitation intensity during inpatient stroke rehabilitation. I, along with input from the thesis supervisor and supervisory committee, chose rehabilitation intensity as a focus over other options because it was believed that this inquiry would be of greater use for clinicians and other key stakeholders.

Acknowledging and understanding the implications your positionality may have on your research is an important element of qualitative inquiry (Savin-Baden & Howell Major, 2012), which can be accomplished by maintaining reflexivity throughout the research process, that is, self-awareness of one's relationship to the field of study, their own feelings, motives, and preconceptions (Berger, 2015). Strategies used to ensure a reflexive process throughout data analysis included writing notes, memos reflections, and perspectives, which helped in recognizing the role I had in interpreting the data. In addition, I consistently reflected on steps taken and decisions made. For example, by constantly asking myself if findings represented what the data was actually saying.

Limitations

Despite steps taken to avoid researcher bias, bias is inevitable in research. The qualitative approach used to guide the main study contained within this research is a relatively new approach and therefore is less exhaustively employed and discussed in the literature than other well-established qualitative traditions. In addition, my role as a novice researcher inexperienced with ID resulted in a learning experience not without limitations: for instance, the process of writing memos and keeping a reflexive journal is one that takes practice, to know what to make note of and when and how to use these notes.

We used purposive sampling to seek diversity in representation; however, we are unable to ascertain whether sampling selection bias was introduced because therapists recruited study participants from their patient group. Although conventional member-checking was not a viable option within the constraints of this study, in ID, the researcher is considered an interpretive instrument influential to uncovering insights from a collection of data sources (Thorne, 2016). Therefore, conventional member-checking is not recommended as Thorne warns it can lead to false confidence and derail the researcher from good analytic interpretations (Thorne, 2016). As such, the limitation with not performing conventional member-checks only came into play when participants presented with aphasia with whom the risk of misinterpreting findings was greater due to challenges during the transcription process and transcriptional uncertainties. These limitations were minimized during the interview process through reiteration, and in the analysis process through the verification of transcripts between researchers; however, the use of audio only recording with one participant who presented with severe aphasia and utilized communication aids (i.e., word guides, pictures) can be considered a limitation of this study. Thorne (2016) does, however, support the use of strategic repeat interviews not to confirm if what was heard was correct but to help clarify and expand on tentative associations being made from the context of the whole. Recognizing that repeat interviews could have been a powerful tool to enhance credibility of the interpretive understandings within this thesis, this strategy was not employed due to time constraints.

Perhaps the most note-worthy limitation of this work is that analysis of interview transcripts was not performed concurrently with data collection; the downfall being insights developed during early interviews could not be incorporated into subsequent interviews and therefore resulting in a missed opportunity to explore further and elaborate on potentially meaningful aspects of participants' stroke rehabilitation experiences.

Future Research

Qualitative exploration of patient experiences in participating in stroke rehabilitation has allowed for the identification of perceived barriers and facilitators to participation. Personalized rehabilitation appears to be fundamental in facilitating participation, and therefore, future research should focus on developing strategies to enhance personalized stroke rehabilitation. The only way to enhance the provision of truly personalized rehabilitation is to incorporate patient perspectives; listening to patients' experiences of each aspect of providing personalized rehabilitation can be a starting point in the development process and a step toward improved stroke rehabilitation services. Study findings and a review of the literature indicate that immediate action is needed regarding rehabilitation intensity during inpatient stroke rehabilitation. To tackle this pervasive issue, a collaborative approach involving all levels of the healthcare system is needed to determine the best strategies to move evidence into practice. In the meantime, future research should continue to focus on low-cost initiatives to promote physical and social activity in hospitalized stroke rehabilitation patients, to reduce time spent inactive and alone, bored and depressed.

Conclusion

This thesis has discussed a number of patient-perceived barriers and facilitators to participating in stroke rehabilitation, which this final chapter has conceptualized into a framework of personalized rehabilitation representing a patient-centred approach to providing rehabilitation that encourages patient participation. Writing this thesis inspired an interesting comparison, in that providing patient-centred stroke rehabilitation requires similar techniques to conducting a good interview for a qualitative research study. Both should: 1) prioritize listening; 2) take time to build relationships with the patient/participant; 3) move at the pace of the patient/participant; 4) encourage the individual to prioritize what is important to them; 5) help the patient/participant see themselves as experts with the control; and 6) view the role of therapist/researcher as facilitator. Qualitative methods enable researchers to identify ways of delivering healthcare services to best meet the needs and priorities of patients – an approach that is compatible with patient centricity. The goal of patient-centredness is to provide care that is customized to individual needs and circumstances. Personalized stroke rehabilitation acknowledges the importance of addressing the environment as well as both interpersonal and personal factors in an approach to care that responds to the person, not the person to the care. If patient-centred care, or 'putting patients first,' is a core tenant of healthcare in Ontario and elsewhere then research evidence needs to reflect patients' voices. Currently, patients are saying there is room for improvement.

References

American College of Sports Medicine. (2014). *ACSM's Guidelines for Exercise Testing and Prescription* (Ninth). Philadelphia: Lippincott Williams & Wilkins.

Bamm, E. L., Rosenbaum, P., Wilkins, S., Stratford, P., & Mahlberg, N. (2015). Exploring client-centered care experiences in in-patient rehabilitation settings. *Global Qualitative Nursing Research*, 1–11. https://doi.org/10.1177/2333393615582036

Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Borg, G. A. (1982). Psychophysical bases of perceived exertion. *Medicine and Science in Sports and Exercise*, *14*(5), 377–381.

Bright, F. A. S., Boland, P., Rutherford, S. J., Kayes, N. M., & McPherson, K. M. (2012). Implementing a client-centred approach in rehabilitation: An autoethnography. *Disability and Rehabilitation*. https://doi.org/10.3109/09638288.2011.629712

CorHealth Ontario. (2017). *Stroke rehabilitation intensity frequently asked questions*.

Edwards, D. F., Hahn, M., Baum, C., & Dromerick, A. W. (2006). The Impact of Mild Stroke on Meaningful Activity and Life Satisfaction. https://doi.org/10.1016/j.jstrokecerebrovasdis.2006.04.001

Galvin, R., Stokes, E., & Cusack, T. (2014). Family-mediated exercises (FAME): An exploration of participant’s involvement in a novel form of exercise delivery after stroke. *Topics in Stroke Rehabilitation*, *21*(1), 63–74. https://doi.org/10.1310/tsr2101-63

Hammell, K. W. (2006). *Perspectives on disability & rehabilitation: Contesting assumptions, challenging practice*. Edinburgh; New York: Churchill Livingstone/Elsevier.

Hartman-Maeir, A., Soroker, N., Ring, H., Avni, N., & Katz, N. (2007). Activities, participation and satisfaction one-year post stroke. *Disability and Rehabilitation*, *29*(7), 559–566. https://doi.org/10.1080/09638280600924996

Hebert, D., Lindsay, P., Mcintyre, A., Kirton, A., Rumney, P. G., Bagg, S., … Teasell, R. (2016). Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015. *International Journal of Stroke*, *11*(4), 459–484. https://doi.org/10.1177/1747493016643553

Institute of Medicine (US) Committee on the National Quality Report on Health Care Delivery. (2001). *Envisioning the National Health Care Quality Report*. Washington, DC.

Janssen, H., Ada, L., Bernhardt, J., Mcelduff, P., Pollack, M., Nilsson, M., & Spratt, N. J. (2014). An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. *Disability and Rehabilitation*, *36*(3), 255–262. https://doi.org/10.3109/09638288

Kielhofner, G. (2009). *Conceptual Foundations of Occupational Therapy Practice* (4th ed.). Philadelphia: F.A. Davis Company.

Luker, J., Lynch, E., Bernhardsson, S., Bennett, L., & Bernhardt, J. (2015). Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, *96*(9), 1698–1708. https://doi.org/10.1016/j.apmr.2015.03.017

Lynch, E., Chesworth, B., & Connell, L. (2018). Implementation--The missing link in the research translation pipeline: Is it any wonder no one ever implements evidence-based practice? *Neurorehabilitation and Neural Repair*, *32*(9), 751–761. https://doi.org/10.1177/1545968318777844

Mayo, N. E., Wood-Dauphinee, S., Côté, R., Durcan, L., Carlton, J., Victoria, R., & Mayo, M. (. (2002). Activity, Participation, and Quality of Life 6 Months Poststroke From the Division of Clinical Epidemiology. *Arch Phys Med Rehabil*, *83*. https://doi.org/10.1053/apmr.2002.33984

Merz, Z. C., Patten, R. Van, Mulhauser, K., & Fucetola, R. (2016). Exploratory factor analysis of the reintegration to normal living index in a stroke population. https://doi.org/10.1080/10749357.2016.1215398

Newell, S., & Jordan, Z. (2015). The patient experience of patient-centered communication with nurses in the hospital setting: a qualitative systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, *13*(1), 76–87. https://doi.org/10.11124/jbisrir-2015-1072

Oberg, E. (2007). Physical activity prescription: Our best medicine. *Integrative Medicine*, *6*(5).

Ontario Medical Association. (2010). Patient-centred care. *Ontario Medical Review*, 34–49.

Ontario Ministry of Health and Long-Term Care. (2015). *Patients first: A proposal to strengthen patient-centred health care in Ontario*.

Ontario Stroke Network. (2012). *Provision of Greater Intensity Therapy in Inpatient Rehabilitation: Three Hours of Therapy per Day*.

Peiris, C. L., Taylor, N. F., & Shields, N. (2012). Patients value patient-therapist interactions more than the amount or content of therapy during inpatient rehabilitation: a qualitative study. *Journal of Physiotherapy*, *58*(4), 261–268. https://doi.org/10.1016/S1836-9553(12)70128-5

Rosbergen, I. C., Grimley, R. S., Hayward, K. S., Walker, K. C., Rowley, D., Campbell, A. M., … Brauer, S. G. (2017). Embedding an enriched environment in an acute stroke unit increases activity in people with stroke: A controlled before–after pilot study. *Clinical Rehabilitation*, *31*(11), 1516–1528. https://doi.org/10.1177/0269215517705181

Savin-Baden, M., & Howell Major, C. (2012). *Qualitative Research: The essential guide to theory and practice*. London: Routledge.

Teodoro, I. P. P., Rebouças, V. C. F., Thorne, S. E., Souza, N. K. M., Brito, L. S. A., & Alencar, M. P. G. (2018). Interpretive description: A viable methodological approach for nursing research. *Escola Anna Nery*, *22*(3), 1–8.

https://doi.org/10.1590/2177-9465-EAN-2017-0287

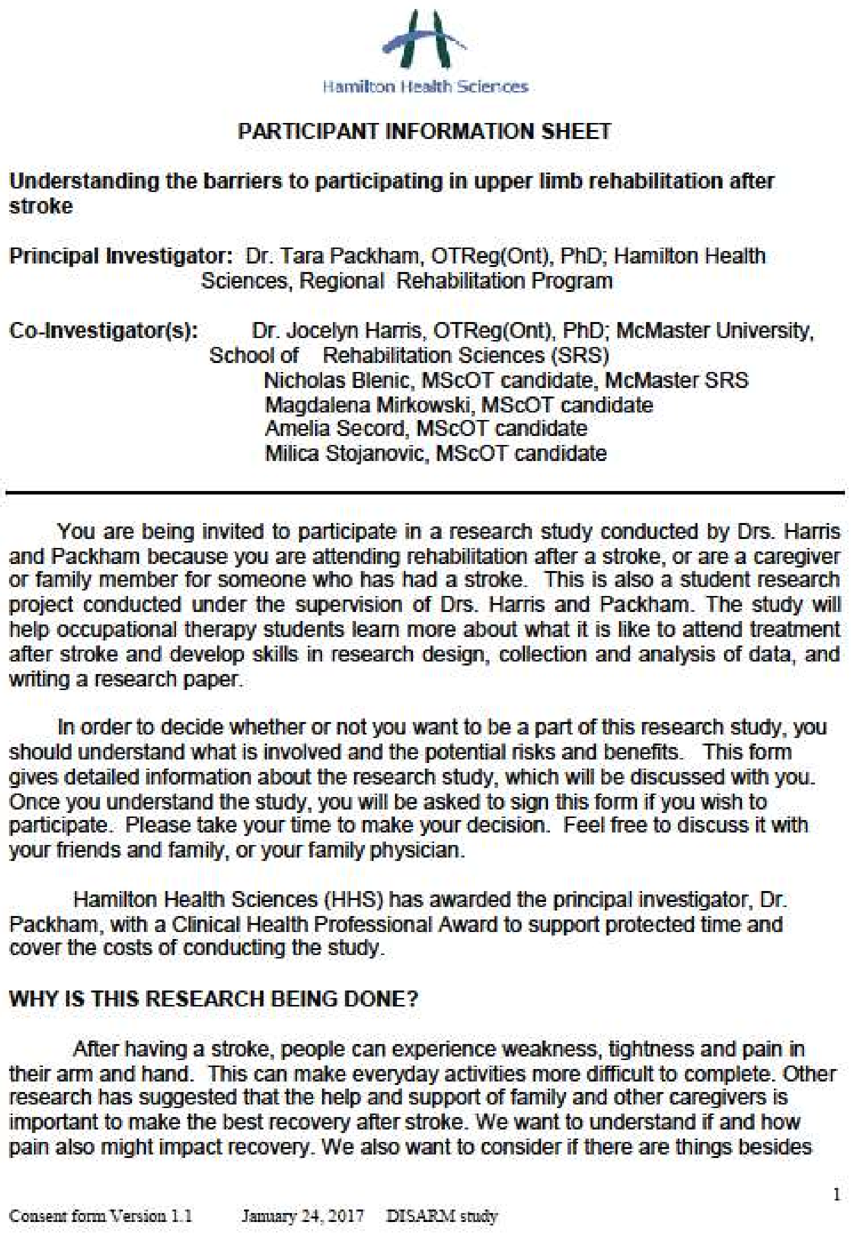
Thorne, S. (2016). *Interpretive Description* (2nd ed.). Walnut Creek, CA: Left Coast Press Inc.

Tsouna-Hadjis, E., Vemmos, K. N., Zakopoulos, N., & Stamatelopoulos, S. (2000). First-stroke recovery process: The role of family social support. *Archives of Physical Medicine and Rehabilitation*, *81,* 881–887. https://doi.org/10.1053/apmr.2000.4435

Tutton, E., Seers, K., Langstaff, D., & Westwood, M. (2011). Staff and patient views of the concept of hope on a stroke unit: A qualitative study. *Journal of Advanced Nursing*, *68*(9), 2061–2069. https://doi.org/10.1111/j.1365-2648.2011.05899.x

Appendices

Appendix A: Participant Consent Form



Hamilton Health Sciences

PARTICIPANT INFORMATION SHEET

Understanding the barriers to participating in upper limb rehabilitation after stroke

Principal Investigator: Dr. Tara Packham, OTReg(Ont), PhD; Hamilton Health Sciences, Regional Rehabilitation Program

Co-Investigator(s): Dr. Jocelyn Harris, OTReg(Ont), PhD; McMaster University, School of Rehabilitation Sciences (SRS)
Nicholas Blenic, MScOT candidate, McMaster SRS
Magdalena Mirkowski, MScOT candidate
Amelia Secord, MScOT candidate
Milica Stojanovic, MScOT candidate

You are being invited to participate in a research study conducted by Drs. Harris and Packham because you are attending rehabilitation after a stroke, or are a caregiver or family member for someone who has had a stroke. This is also a student research project conducted under the supervision of Drs. Harris and Packham. The study will help occupational therapy students learn more about what it is like to attend treatment after stroke and develop skills in research design, collection and analysis of data, and writing a research paper.

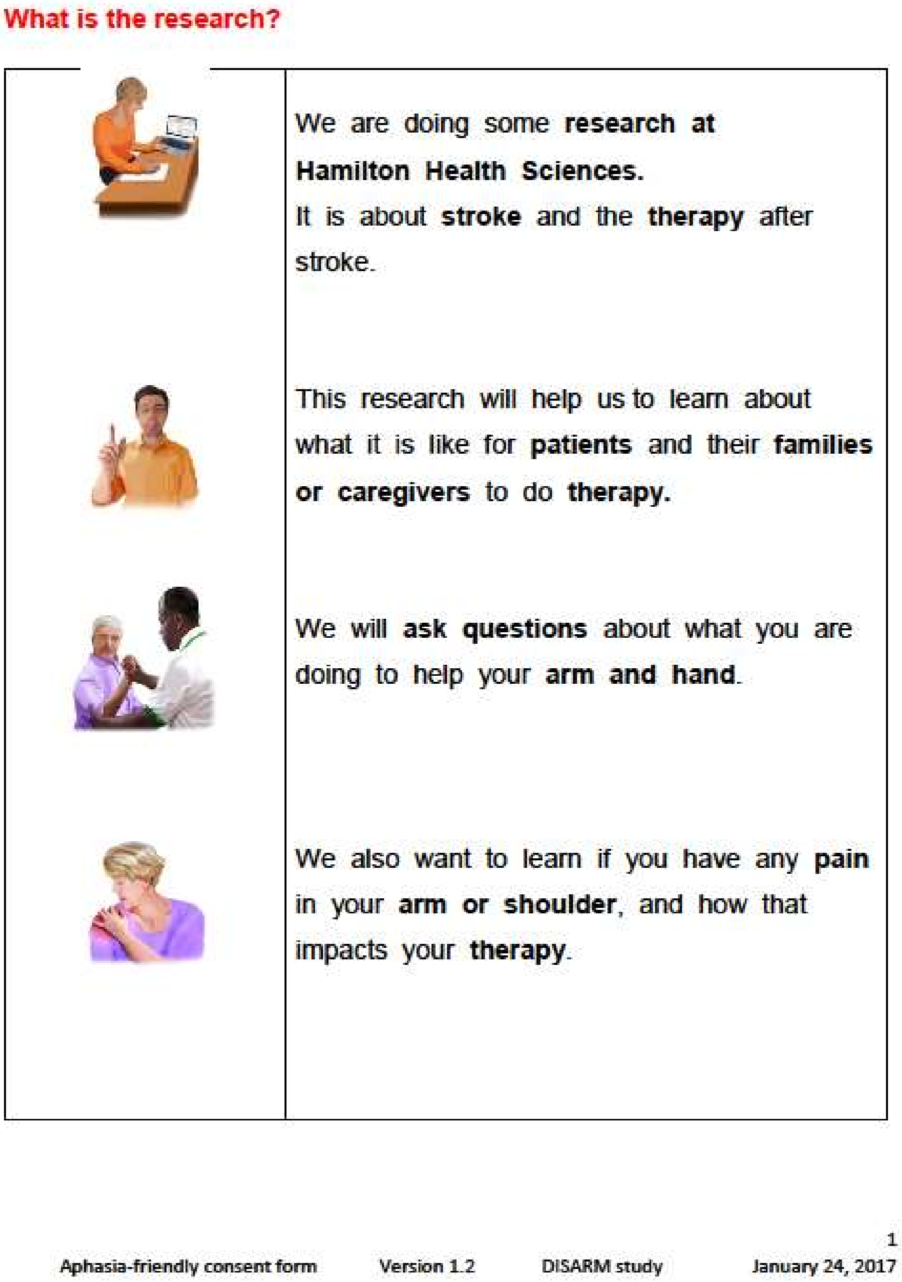
In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

Hamilton Health Sciences (HHS) has awarded the principal investigator, Dr. Packham, with a Clinical Health Professional Award to support protected time and cover the costs of conducting the study.

WHY IS THIS RESEARCH BEING DONE?

After having a stroke, people can experience weakness, tightness and pain in their arm and hand. This can make everyday activities more difficult to complete. Other research has suggested that the help and support of family and other caregivers is important to make the best recovery after stroke. We want to understand if and how pain also might impact recovery. We also want to consider if there are things besides

Appendix B: Aphasia Friendly Participant Consent Form



What is the research?

We are doing some **research at Hamilton Health Sciences.**
It is about **stroke** and the **therapy** after stroke.

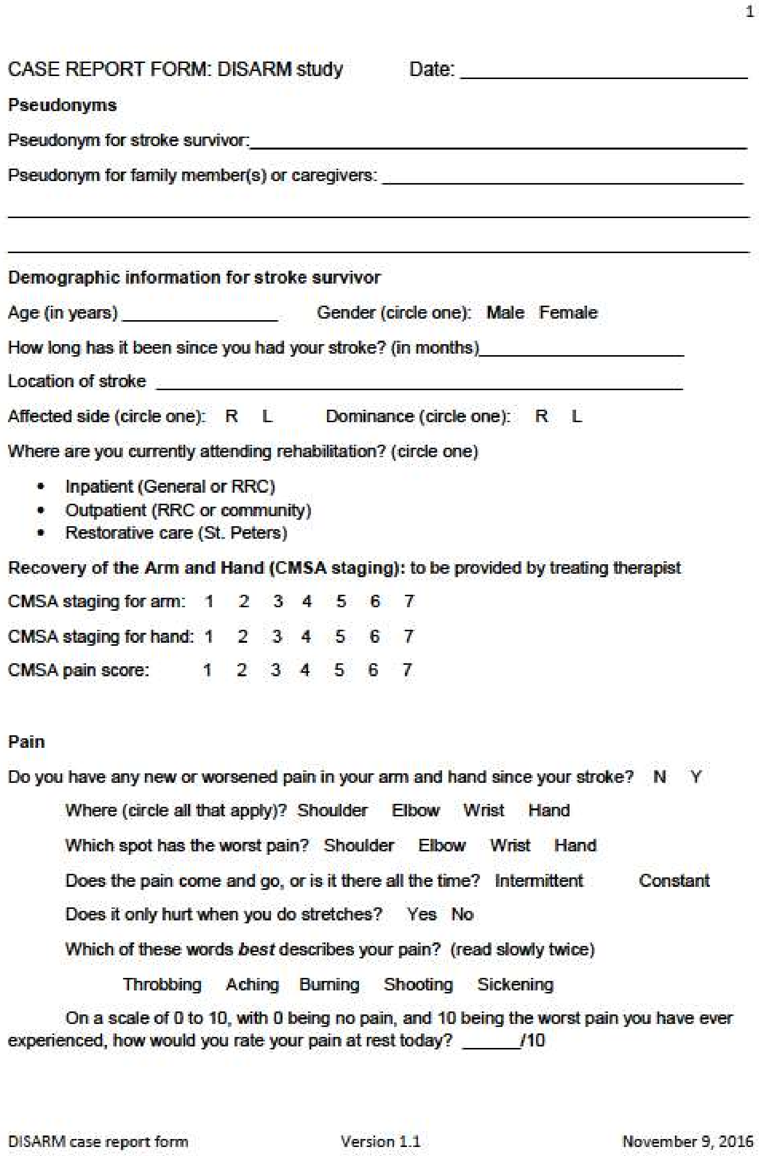
This research will help us to learn about what it is like for **patients** and their **families or caregivers** to do **therapy.**

We will **ask questions** about what you are doing to help your **arm and hand**.

We also want to learn if you have any **pain** in your **arm or shoulder**, and how that impacts your **therapy**.

1
Aphasia-friendly consent form Version 1.2 DISARM study January 24, 2017

Appendix C: Case Report Form



CASE REPORT FORM: DISARM study Date: ____________________

Pseudonyms

Pseudonym for stroke survivor: ____________________

Pseudonym for family member(s) or caregivers: ____________________

____

____

Demographic information for stroke survivor

Age (in years) __________ Gender (circle one): Male Female

How long has it been since you had your stroke? (in months) ____________

Location of stroke ____________________

Affected side (circle one): R L Dominance (circle one): R L

Where are you currently attending rehabilitation? (circle one)

- Inpatient (General or RRC)
- Outpatient (RRC or community)
- Restorative care (St. Peters)

Recovery of the Arm and Hand (CMSA staging): to be provided by treating therapist

CMSA staging for arm: 1 2 3 4 5 6 7

CMSA staging for hand: 1 2 3 4 5 6 7

CMSA pain score: 1 2 3 4 5 6 7

Pain

Do you have any new or worsened pain in your arm and hand since your stroke? N Y

Where (circle all that apply)? Shoulder Elbow Wrist Hand

Which spot has the worst pain? Shoulder Elbow Wrist Hand

Does the pain come and go, or is it there all the time? Intermittent Constant

Does it only hurt when you do stretches? Yes No

Which of these words *best* describes your pain? (read slowly twice)

Throbbing Aching Burning Shooting Sickening

On a scale of 0 to 10, with 0 being no pain, and 10 being the worst pain you have ever experienced, how would you rate your pain at rest today? ______/10

Appendix D: Participant Interview Guide

1. Can you tell me about your experience participating in therapy?
    a. (*clarification*: therapy meaning working with the OT, PT, OTA/PTA (name some therapists))
    b. (*clarification*: name some therapy programs if necessary, e.g. functional activity program)
    c. Tell me about a typical day in therapy
    d. How does participating in therapy make you feel?
    e. What are the good parts? What are the not so good parts?
    f. Tell me about the activities or exercises that you are doing for your arm and hand
    g. How often do you do these in a day? For how long?
2. Are some activities or exercises more difficult or easier for you than others?
    a. What makes them challenging to do? Why do you think this may be challenging?
    b. Do you need any help to do your activities and exercises?

USE THE FOLLOWING TWO QUESTIONS TO PROMPT FOR WHERE PATIENTS' CHALLENGES MAY BE STEMMING FROM, IF THIS HASN'T OCCURRED NATURALLY DURING THE INTERVIEW

3. Is there anything challenging about doing these activities or exercises that comes from how your body feels?
    a. (*clarification*: e.g. feeling tired, feeling pain, how your muscles feel, how your mind feels)
4. Is there anything outside of yourself that makes doing these activities difficult? (*clarification*: e.g. things in the hospital environment, with your family/friends/supports/insurance, your education)

Appendix E: Program Manager Consultation Guide

ABSTRACT

Background: Rehabilitation is an effective way to reduce disability in individuals after stroke. The effectiveness of rehabilitation, in part, requires participation and engagement from patients, however, qualitative research pertaining to patient perceived factors that may influence participation is limited. **Purpose:** To explore the experience of participating in inpatient and outpatient stroke rehabilitation programs specifically seeking the perceived barriers and facilitators to participating in therapy activities. **Methods:** An interpretive description framework was used for this study. Stroke survivors were recruited from 3 different stroke rehabilitation programs through clinician referrals. Semi-structured interviews were audio-recorded and a constant comparative approach was used to identify key themes across the participant experiences. **Results:** From 11 stroke participants, the key findings on perceived barriers and facilitators related to the following themes: 1) Institutional Environment; 2) Therapy Services; 3) Impact of Stroke; and 4) Personal Influencers. Within these main themes, participants most often spoke of limited resources, not getting enough therapy, adapting to altered abilities, and support from family and friends.

WHAT WE ARE LOOKING FOR FROM YOU:

1. One of the most prevalent comments from participants was regarding therapy time and feeling they were not 'getting enough' – we are looking for different perspectives regarding these comments in an effort to further understand why participants may be feeling this way.

2. I would like to arrange for a face-to-face consultation where we can discuss your thoughts and opinions around these findings. Specific questions I would like to ask you are included below.

Program Manager Consultation Questions

1. Can you please describe the typical amount of rehab provided to patients by OT, PT, and SLP? For example: How much time per discipline is allotted to each patient/day and for how many days/week?
    a. How is the total amount of rehab time given determined? For example, based on policy, practice guidelines, hospital resources, severity of patients on the unit, clinician judgement?

2. Our study findings indicate that patients perceive they are not getting enough therapy or time in therapy – why do you think this might be?