Université de Montréal

Association between Independence in Daily Activities and Social Roles in Older Adults with Stroke

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Mémoire présenté à la Faculté des études supérieures
en vue de l'obtention du grade de maîtrise en sciences (M.Sc.)
en Sciences biomédicales
option réadaptation

Juin, 2009

Université de Montréal

Faculté des études supérieures

Ce mémoire intitulé:

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and social roles in older adults with stroke

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Résumé

La réadaptation des personnes âgées ayant subi un accident vasculaire cérébral vise à améliorer les capacités et l'indépendance dans les activités de la vie courante. Les personnes âgées reprennent leurs rôles sociaux lorsqu'elles retournent vivre dans la communauté. L'objectif de ce mémoire est de clarifier la relation entre l'indépendance dans les activités de la vie courante au congé de la réadaptation intensive et la reprise des rôles sociaux six mois plus tard.

L'échantillon se compose de 111 participants recrutés au congé et réévalués 6 mois plus tard. L'indépendance dans les activités de la vie courante est mesurée avec les sections pertinentes du Système de Mesure de l'Autonomie Fonctionnelle (SMAF). Les rôles sociaux sont mesurés avec la Mesure des Habitudes de Vie (MHAVIE); un score total ainsi que 4 sous-scores pour les responsabilités civiles, la vie communautaire, les relations interpersonnelles et les loisirs sont générés. Des analyses de régression hiérarchique sont utilisées pour vérifier l'association entre les activités de la vie courantes (variable indépendante) et les rôles sociaux (variables dépendante) tout en contrôlant pour les capacités (variables de contrôle).

Les résultats suggèrent des associations significatives ($p < .001$) entre les activités de la vie courante et les rôles sociaux (score total de la MHAVIE), les sous scores des responsabilités civiles et de la vie communautaire, mais aucune association avec les relations interpersonnelles et les loisirs. Les scores les plus faibles sont obtenus pour les loisirs. Une deuxième phase de réadaptation après le retour à domicile pourrait permettre le développement des loisirs.

Mots-clés : activités de la vie courante, rôles sociaux, réadaptation, personnes âgées, participation sociale, loisir.

Abstract

Stroke rehabilitation emphasizes the remediation of capabilities and independence in daily activities during intensive rehabilitation. Older adults thereafter return to live in the community to pursue their social roles. The purpose of this work was to clarify the relationship between the level of independence in daily activities at rehabilitation discharge and the return to social roles 6 months later in older adults with stroke.

A total of 111 participants were followed over a 6 month period following intensive rehabilitation. Daily activities were measured using portions of the Functional Measurement of Autonomy System (SMAF). Social roles were measured using the Life-H (social roles subsection) which provides a total score and 4 subscale scores for civic responsibilities, community life, interpersonal relationships and leisure. Hierarchical statistical regression models were used to verify the association between daily activities (independent variable) and social roles (dependent variables) by controlling for the effect of capabilities (control variables).

Significant ($p < .001$) associations between daily activities and social roles (Life–H total score), civic responsibilities, and community life subscale scores were found, but none for interpersonal relationships nor for leisure. Leisure had the poorest performance score on the Life-H. Results suggest that a "second phase" of rehabilitation may be warranted upon return home to ensure the maintenance of daily activities and more specifically for accomplishment of leisure activities.
Keywords : daily activities, social roles, rehabilitation, older adults, social participation, leisure.

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List of abbreviations

DCP	**Disability Creation Process**
SMAF	**Système de Mesure de l'Autonomie Fonctionnelle (Functional Autonomy Measurement System)**
Life-H	**Assessment of Life Habits**
FAI	**Frenchay Activities Index**
FIM	**Functional Independence Measure**
ADL	**Activities of Daily Living**
IADL	**Instrumental Activities of Daily Living**
BRAD	**Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral (AVC): Étude multicentrique (BRAD study).**
ß	**Standardized regression coefficients**
p	**Statistical significance value**
R²	**Variance for the sample population**
Adjusted R²	**Variance for the true population value**
ICC	**Intra-class correlation coefficient**

In loving memory of my mom, Suzanne Dumas, who instilled in me a deep appreciation of education and to my father Jacques Plante who shared with me his yearning to learn on a daily basis.

Acknowledgements

My journey through graduate studies has been filled with exponential learning and challenges and I am grateful for many who lent a helping hand along the way.

Tout d'abord, je suis très reconnaissante envers ma directrice Dr. Louise Demers qui m'a encadrée, stimulée et encouragée avec douceur et dynamisme tout au long de ce parcours. Sa disponibilité a été précieuse et grandement appréciée. I am equally grateful to Dr. Bonnie Swaine for her attentiveness and constructive critical editing of all my written work. Je souhaite aussi remercier Johanne Desrosiers pour l'attention qu'elle a portée à plusieurs de mes travaux.

Plusieurs personnes m'ont également offert leur support au cours de ce projet. Les étudiantes du Centre de recherche de l'Institut universitaire de gériatrie de Montréal ainsi que les professionnels de cet établissement ont facilité mes apprentissages. Je tiens à remercier particulièrement Francine Giroux, statisticienne, pour son aide. L'encouragement offert par mes collègues au Soutien à Domicile du CSSS de l'Ouest de l'île (site Lac Saint-Louis) m'a donné l'énergie nécessaire pour persévérer tout au long de ce projet.

It is the courage and life experiences of the participants that fed my reflection and helped stimulate my research question. I am also appreciative of the patience my husband and children afforded me and the encouragement I received from many members of the Roxboro United Church congregation.

I acknowledge the Faculté de Médecine of the Université de Montréal as well as FormSav (Formation interdisciplinaire en recherche Santé et Vieillissement des IRSC) who both granted me scholarships to facilitate this experience.

CHAPTER 1

INTRODUCTION

1.1. Rehabilitation stroke care in Canada

Stroke is a common cause of chronic handicap in Canada (Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002). It is increasing in incidence due to a decrease in morbidity following stroke and an increase in an aging population; the incidence is foreseen to be of epidemic proportion by the year 2030 (Elkins & Johnston, 2003). Yearly, an estimated 50,000 people have a stroke in Canada – this equates to someone having a stroke every ten minutes – resulting in approximately 300,000 individuals who face and cope with stroke's multi-faceted consequences (Canadian Institute for Health Information, 2008). Moreover, this number is rising as a result of reduced mortality rates following medical advances (Flick, 1999).

Impairments, defined as changes in an organic system, (Fougeyrollas et al., 1998a) following stroke lead to panoply of altered capabilities. These may be physical, psychological, emotional, behavioral, cognitive, and/or perceptual in nature (Barnes & Radermacher, 2003; Mukherjee, Levin, & Heller, 2006; Sturm et al., 2002). Recovery of most capabilities occurs within the first three to six months following stroke (Duncan, Jorgensen, & Wade, 2000; Page, Gater, & Bach-y-Rita, 2004). A restriction in participation which refers to daily activities and social roles however extends beyond these first few months. In a cohort of 434 persons who had had a stroke 6 months earlier, 25% needed help with basic daily activities (e.g. mobility, bathing), 50% needed help for daily activities around the house (e.g. meal preparation, housekeeping tasks), and up to 70% described restrictions in their

social roles (e.g. moving about in the community) (Mayo et al., 2002). These restrictions can persist and have been reported up to 5 years later (D'Alisa, Baudo, Mauro, & Miscio, 2005; Desrosiers et al., 2006).

Rehabilitation is recognized as an essential component in post stroke care (Schepers, Visser-Meily, Ketelaar, & Lindeman, 2005). It accounts for 16% of all allocated rehabilitation services and 69% of those with stroke are over 65 years of age (Canadian Institute for Health Information, 2008). Rehabilitation goals for persons with stroke include restoring capabilities, developing new skills and strategies, adapting to physical and social environments, and maximizing participation in the community and in society (Barnes & Radermacher, 2003). Interventions begin in the acute care setting, progress to intensive inpatient therapy units (sub-acute care), and in some cases follow with outpatient and community care (Brandstater & Shutter, 2002; Flick, 1999).

In the acute phase, rehabilitation professionals assess impairments and take initial strides to encourage mobility and resume self-care activities (Brandstater & Shutter, 2002; Duncan et al., 2005). During this phase, the potential for recovery is identified and the need for further rehabilitation is determined. Medical stability and prognosis, functional status, cognitive status, physical endurance, and available social support all factor into the decision of whether an individual requires further rehabilitation (Duncan et al., 2005; Flick, 1999). Short hospital stays are customary at this stage of stroke care.

Subacute and skilled intensive inpatient rehabilitation follows (Brandstater & Shutter, 2002). Daily interventions concentrate on neurological recovery, with the aim of facilitating and maximizing motor, cognitive, and perceptual capabilities (Sabari, 2001). They also focus on improving daily activities through guided

training and learning of new and/or compensatory techniques and facilitating psychosocial adjustment (Brandstater & Shutter, 2002; Teasell, Foley, Bhogal, & Speechley, 2008). An organized and structured multidisciplinary team including the physician, nurse, occupational therapist, physiotherapist, speech language therapist, dietician, social workers, and psychologist work together to provide the required therapies. The mean length of stay for this stage of rehabilitation in Canada is typically 34 days, with 25% discharged within 18 days and 75% discharged within 51 days. Seventy five percent of those discharged return home once they no longer progress in their capabilities and daily activities (Canadian Institute for Health Information, 2008).

The last stage of rehabilitation can take different forms. Outpatient services within a rehabilitation facility or day hospital services can be provided if residual gains are still anticipated (Hahn & Baum, 2004; Park, 2004). In some cases, when individuals cannot safely reach facilities providing outpatient services they can be considered for home based community rehabilitation, if available (Flick, 1999; Russman & Katzan, 2005). General goals are fine tuning capabilities and daily activities in an attempt to reach pre-stroke functional baseline or sufficient independence for the individuals to remain at home (Trigg, Wood, & Hewer, 1999) as well as encouraging the integration of the person with stroke in the community (Brandstater & Shutter, 2002). Although formal rehabilitation may end at this stage, community groups can offer some of the support that further facilitates community reintegration for the post stroke individual (Lindsay et al., 2008).

1.2. Problem and general objective

The present research set out to see if the level of independence in daily activities, an important goal during intensive rehabilitation, would impact the expression of social roles after discharge from rehabilitation. There are two main reasons why this was of particular interest. Firstly, the majority of stroke rehabilitation resources are allocated to inpatient intensive rehabilitation (Barnes & Radermacher, 2003). Often, this phase is the end point of formal rehabilitation (Bertoti, 2004). It is therefore essential that clinicians working in this phase understand the impact of their interventions beyond its doors. Secondly, it would seem imperative that we make sure that this phase not only prepares older adults to return home but to also resume their social roles. Clinicians do seek to have their interventions extend beyond enabling the person to simply get washed, dressed and fed (Albrecht & Devlieger, 1999; Levasseur, Desrosiers, & Noreau, 2004; McKenna, 1993; Radomski, 1995).

Therefore, the objective of this study was to determine the association between the level of independence in daily activities at discharge from inpatient intensive rehabilitation and the pursuit of social roles once persons with stroke have returned to live in the community.

1.3. Organisation of thesis

This master's thesis is composed of five chapters, in addition to this introduction (Chapter 1). The literature review presented in Chapter 2 is comprised of five sections together forming the groundwork from which the research hypothesis is formulated. An overview of the specific aspects of the methodology used in the study is presented in Chapter 3. This includes obtaining the necessary data to supplement an existing data bank and the relevant statistical analyses that were performed. Chapter 4 consists of an article submitted for publication entitled: "Association between daily activities following stroke rehabilitation and social role functioning upon return to the community". Chapter 5 of this master's thesis discusses the clinical implications of the findings with an emphasis on enhancing social role participation in the rehabilitation continuum. To conclude, Chapter 6 highlights striking results and puts forth new research questions.

CHAPTER 2
LITERATURE REVIEW

This chapter is comprised of five sections. The first section provides a conceptual framework in which the variables of interest, daily activities and social roles, are defined. Subsequently daily activities and social roles outcomes, as they pertain to the intensive inpatient rehabilitation period, are discussed in the second and third section. In the fourth section the literature specific to the association between daily activities and social roles is reviewed and critiqued. Other identified variables associated with social roles are also presented in the last section.

2.1. The Disability Creation Process Model

2.1.1. Definition of the concepts and variables

A conceptual model serves to identify and define the variables of interest in a research study (Earp & Ennett, 1991). When variables are clearly defined, the validity of the research design is strengthened. This study uses the Disability Creation Process model (DCP) (Fougeyrollas, Cloutier, Bergeron, Côté, & St. Michel, 1998b) to define its two main variables: daily activities and social roles.

The DCP is a generic anthropological model of human development relevant for all people whether healthy, ill or living with a chronic condition. It highlights the interaction between personal factors (capabilities and characteristics) and environmental factors (e.g. living situation, rehabilitation services received, social support network and socio-political context) (Fougeyrollas et al., 1998b) (see Figure 1). The interaction between personal factors (intrinsic) and environmental factors (extrinsic) determines the individuals' level of participation. Participation is conceptualized in what are described as life habits. Life habits are defined as behaviors or actions expressed by the person and fostering his/her survival and growth within society and throughout a lifetime; it is the person himself that ascribes value to these life habits and thus they are unique to his/her personal characteristics and socio-cultural context (Fougeyrollas et al., 1998b).
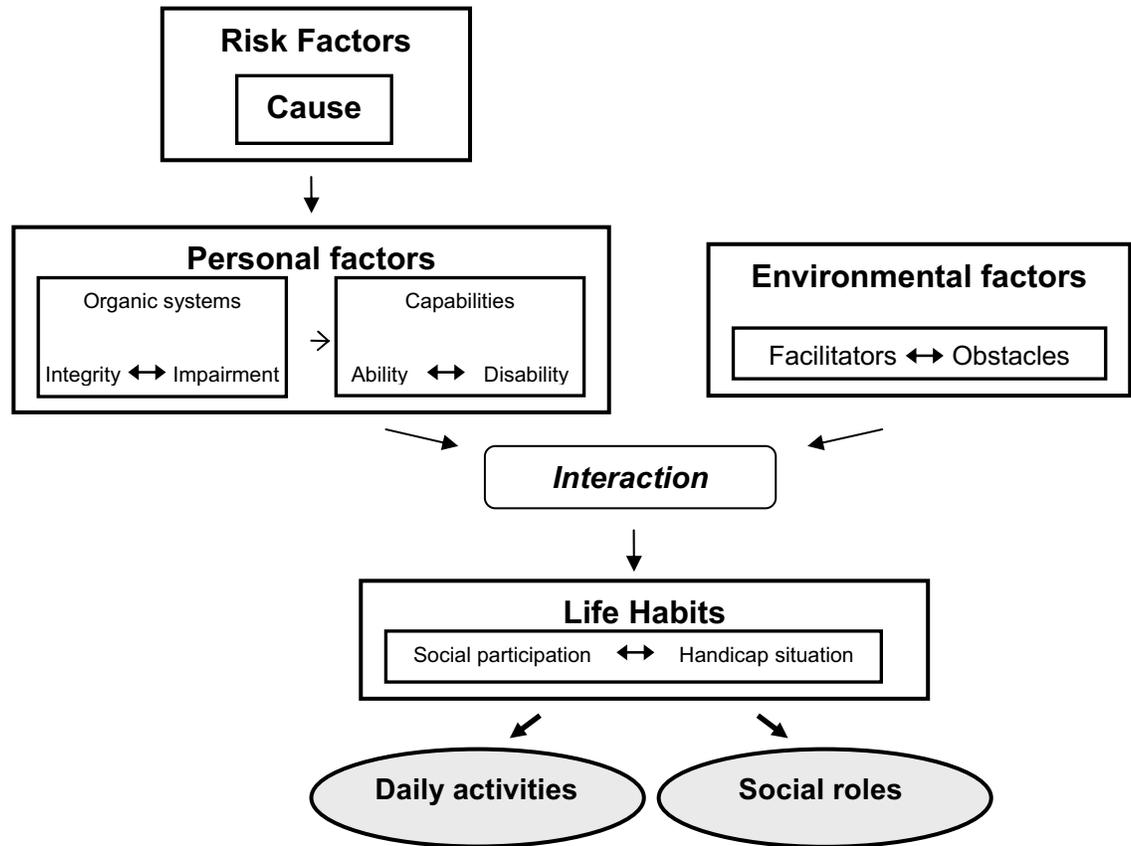
Figure 1. Schematic of the Disability Creation Process Model
(adapted with permission of Fougeyrollas et al., 1998a)

Life habits are categorized into twelve domains, six belonging to the category of daily activities and six others belonging to social roles (see Table 1). It is important to note that daily activities and social roles are distinct terms that are not synonymous with the more commonly used terms of activities of daily living (dressing, bathing, feeding, etc.) and instrumental activities of daily living (meal preparation, housekeeping, leisure etc). Rather, in this model, daily activities include nutrition, fitness, personal care, communication, housing, and mobility and they are activities accomplished on a daily basis (e.g. getting washed and dressed, preparing a meal) (Fougeyrollas et al., 1998a). Social roles include interpersonal relationships, occupation, and leisure (Fougeyrollas et al., 1998b). For the most part activities within these social roles are performed by the person themselves. Furthermore, the intensity and frequency of the level of engagement between activities can vary widely from one individual to another and from one activity to another (Fougeyrollas et al., 1998a).

2.1.2. Application of the model to people with stroke

Stroke impacts personal factors such as the integrity of organic systems (e.g. cardiovascular and nervous systems) and its related subsystems. Changes in these systems can lead to the development of impairments that ultimately impede capabilities. For example, a stroke affecting the right frontal lobe or motor cortex (i.e. a change in the integrity of an organic system) could result in weakness or paralysis of the left lower extremity (i.e. change in capability). The ability to pursue one's life habits will depend on the interaction between one's personal factors (integrity/ability) and one's specific contextual environmental factors. For example, a person with a motor impairment may be able to walk with a quad cane safely

indoors and prepare his/her own meals (i.e. a daily activity), thus reflecting a situation of successful social participation. However, if the same person can no longer cross country ski (i.e. a social role), an activity pursued before the stroke, a handicap situation results. Indeed, the consequences of stroke can influence both the performance of daily activities and social roles, which are key concepts in the rehabilitation process and for this research project.

The following sub-sections of Chapter 2 will refer to daily activities and social roles and their definitions are as per the DCP model. Most of the literature reviewed however uses the more common terms "activities of daily living", "instrumental activities of daily living", participation and social participation. The student assigned the terms daily activities and social roles but was careful to preserve the initial intention of the terms used and reported.

Table 1

Life Habits in the Disability Creation Process Model

1. **Daily activities**	2. **Social roles**

1. **nutrition**
   a) diet
   b) food preparation
   c) meals
2. **fitness**
   a) sleep
   b) physical fitness
   c) mental fitness
3. **personal care**
   a) hygiene
   b) excretory hygiene
   c) dressing
   d) health care
4. **communication**
   a) expression of information
   b) reception of information
5. **residence**
   a) housing
   b) maintenance
   c) furnishing and other household appliances
6. **mobility**
   a) limited mobility
   b) transportation
	1. **responsibility**
	   a) financial responsibility
	   b) responsibility towards others
	2. **family relations**
	   a) affective family relations
	   b) marital relations
	   c) parental care
	   d) other parental relations
	   e) relations with other relatives
	3. **interpersonal relations**
	   a) sexual relations
	   b) affective relations
	   c) social relations
	4. **community**
	   a) consumption of goods and services
	   b) voluntary associations
	   c) religious groups
	5. **education**
	   a) preschool
	   b) school
	   c) occupational
	   d) other training
	6. **employment**
	   a) counselling
	   b) search for employment
	   c) paid employment
	   d) unpaid employment
	7. **recreation**
	   a) sports and games
	   b) arts and culture
	   c) other habits

2.2. Intensive rehabilitation and daily activities

2.2.1. Emphasis on daily activities during intensive rehabilitation

Inpatient rehabilitation following stroke focuses primarily on the remediation of capabilities and increasing independence in daily activities such as self-care and mobility (Kelly, Pangilinan, & Rodriguez, 2007; Park, 2004; Parker, Gladman, & Drummond, 1997). In reports detailing how therapeutic time was spent in six rehabilitation hospitals in the United States (n=713) it was found that 38% of therapy time was spent on activities that focused on the remediation of lost capabilities, 28% on basic daily activities training (i.e. bathing, dressing feeding) and 12% in the practice of other daily activities such as meal preparation (Latham et al., 2006; Richards et al., 2005).

The focus on the remediation of capabilities and daily activities is also evident in stroke research outcome literature. Salter and his colleagues (Salter, Foley, Jutai, & Teasell, 2007) reviewed 491 randomized controlled trials evaluating the effectiveness of stroke rehabilitation published between the years 1968 to 2005. They found that 56% of the studies reported findings related to capabilities and 33% to daily activities. The importance of daily activities during inpatient rehabilitation is thus reflected in the allocated intervention time as well as in measured outcomes.

2.2.2. Effectiveness of rehabilitation that focuses on daily activities

Promoting independence in daily activities appears to be an effective rehabilitation strategy. Trombly and Ma (2002) (Trombly & Ma, 2002) reviewed 36 studies published between 1980 and 2000 that addressed remediation of capabilities, and training in daily activities and social roles. Fifteen of the studies specifically looked at daily activities and social roles (total of 895 participants, mean age of 70 years and evaluated at less than 6 months post stroke). The authors state that four of the studies clearly demonstrate that training in daily activities (these include basic daily activities as well as in home activities such as meal preparation and housekeeping) resulted in a 30% greater success rate in performing basic daily activities (these include primarily self care activities – bathing, dressing and feeding oneself and mobility). Another review of the literature done by Steultjens and her colleagues (2003) (Steultjens et al., 2003) included 32 studies, 18 of which were randomized controlled trials. When pooling only the high quality studies (10/18), the authors report small but significant effect sizes (ES) for basic daily activities (i.e. bathing, dressing, feeding) (ES = 0.46) as well as for complex daily activities (i.e. meal preparation, housekeeping) (ES = 0.32). Unsworth and Cunningham (2002) (Unsworth & Cunningham, 2002) conducted a study with 43 inpatient stroke clients, aged between 61-90 years. They asked therapists and stroke participants to rate the ability to perform daily activities at rehabilitation admission and at discharge. Ratings from both groups showed significant improvements (t tests with p<0.001). Subjectively participants also reported that therapy enabled them to regain confidence and provided them with a sense of "being able to manage" (Unsworth & Cunningham, 2002, p. 26).

2.2.3. Maintaining performance in daily activities after intensive rehabilitation

Studies verifying if gains in independence in daily activities obtained during a period of intensive rehabilitation are maintained long term (i.e. two to five years post stroke) provide inconsistent results. In a follow up of 336 community dwelling participants (mean age about 70 years), daily activities were measured at 1 and either 3 or 5 years post stroke using the Modified Rankin Scale (Bonita & Beaglehole, 1988) and the Stroke Impact Scale (Duncan, Bode, Min Lai, & Perera, 2003). The level of performance remained stable over the course of time (White et al., 2007). Daily activities outcomes following stroke rehabilitation were also examined by Foley, Teasell, Bhogal, Doherty, and Speechley (2003) (Foley, Teasell, Bhogal, Doherty, & Speechley, 2003) in a review of 12 randomized controlled trials involving 2813 individuals. Although varying results were found, most of the studies stated that improvements in daily activities during stroke rehabilitation were maintained one year later (Foley et al., 2003). Another study looked strictly at mobility status using the Rivermead Mobility Index (RMI) (Collen, Wade, Robb, & Bradshaw, 1991) when evaluating long term maintenance of acquired skills during rehabilitation post stroke. With a cohort of 155 individuals with stroke (age 59 to 63 years), 38% maintained their mobility levels, 20% improved and the remaining 43% experienced a decline at a one year follow up (Paolucci et al., 2001) even though some had had therapy following intensive rehabilitation.

In summary, the performance of daily activities receives much attention during the intensive rehabilitation phase following stroke and improvement in persons with stroke is noted up until discharge. Gains in independence in daily activities within this type of clinical setting are maintained for many but not all persons upon return home.

2.3. Intensive rehabilitation and social roles

2.3.1. Importance of social roles during intensive rehabilitation

Inpatient rehabilitation following stroke may address some social roles, albeit not with the same intensity as that afforded to daily activities. In the studies described in section 2.2.1 by Latham et al. (2006) (Latham et al., 2006) and Richards et al. (2005) (Richards et al., 2005) exploring time spent during inpatient therapy activities, therapy time for social roles included time spent in activities focusing on leisure, home management or community integration activities (including community mobility). Specifically, they found that 12% of all therapeutic activity time was devoted to social roles with less than 10% devoted to home management and community integration, and less than 5% to leisure activities. These findings are in keeping with a recent Canada-wide telephone survey of 252 inpatient stroke rehabilitation occupational therapists. Korner-Bitensky and her colleagues (Korner-Bitensky, Desrosiers, & Rochette, 2008) found that only 20% of therapists reported providing some form of intervention in the areas of leisure and social aspects of participation. Others researchers have reported gaps in the rehabilitation of social roles relating to employment (Teasell, Jutai, Bhogal, & Foley, 2003) and to a more sensitive issue, that of sexual relations following a stroke (Duncan et al., 2005; Talbot et al., 2004).

The reasons why inpatient rehabilitation interventions rarely focus on social roles may be twofold. Firstly, facilities tend to encourage short lengths of stay thus limiting available time to address social roles interventions. Secondly, many

believe that social roles are only fully expressed and limitations noted when the person returns to the community (Barnes & Radermacher, 2003; Pamela W. Duncan et al., 2005; MacKenzie & Chang, 2002; Rochette, Korner-Bitensky, & Levasseur, 2006; Russman & Katzan, 2005). One might argue that it may be more appropriate to defer interventions to subsequent phases of rehabilitation. Leisure is one example of a social role for which deferred interventions may be appropriate (Desrosiers et al., 2007; Jongbloed & Morgan, 1991; Parker et al., 2001).

2.3.2. Effectiveness of rehabilitation focusing on social roles

There appears to be limited literature that clearly identifies the effectiveness of interventions pertaining to social roles. In their review of 36 studies addressing remediation of capabilities, and training of daily activities and social roles, Trombly and Ma (2002) found only 3 studies that were specific to interventions focusing on social roles. The authors reported that the results of these studies were inconclusive and suggested that the varying frequencies and types of interventions, as well as the involvement of multiple rehabilitation team members, makes this area of rehabilitation difficult to evaluate. Steultjens and her colleagues (2003), in their review of 32 studies of which 18 were randomized controlled trials, found 4 high quality studies incorporating social participation measures which included some community and leisure items. Small but significant effect sizes (ES = 0.33) were reported. In a study by Unsworth et al. (2002) (n = 43, mean age of 77 years), social roles (domestic and community activities) were measured both by the therapists and by the people with stroke at admission and at discharge. Significant improvements in social roles were reported by both groups (t test with p < 0.001).

To summarize, interventions focusing on social roles appear to receive little attention during inpatient rehabilitation and the effect of these interventions are infrequently evaluated.

2.4. The relationship between daily activities and social roles

A number of studies have examined the relationship between daily activities and social roles (Carod-Artal, Gonzalez-Gutiérrez, Herrero, Horan, & De Seijas, 2002; Hoffmann, McKenna, Cooke, & Tooth, 2003; Ostir, Smith, Smith, & Ottenbacher, 2005; Roth & Lovell, 2007; Schepers et al., 2005; Sveen, Bautz-Holter, Sodring, Wyller, & Laake, 1999). Sveen et al. (1999) studied a group of 65 adults (mean age 74 years) and compared their performance of daily activities with the degree of resumption of social roles at one year after their stroke using the Barthel Index (Mahoney & Barthel, 1965) and subscale scores of the Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983), respectively. They reported that the two concepts were moderately associated (τ=0.58 and τ=0.50). These findings are similar to those obtained by Carod-Artal and his colleagues (2002) with a sample of 90 stroke survivors (mean age of 68 years). These researchers measured daily activities at discharge and at one year after stroke using the Barthel Index and correlated the scores with those of the FAI at one year (r = 0.51 and r = 0.50).

Other studies support an association between daily activities and social roles. Hoffman et al. (2003) conducted an 18-month follow up of 51 individuals (mean

age of 69 years) with stroke and found that individuals who were independent in their basic daily activities using the Modified Barthel (slight, moderate and severe dependence) (Shah, Vanclay, & Cooper, 1989), had significantly (18.3 vs. 14.2, p=0.012) higher scores on the Reintegration to Normal Living Index (RNLI) (a community integration measure) (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988) than those with moderate or severe levels of dependence in basic daily activities. Schepers et al. (2005) in their research involving a cohort of 250 people (mean age 56 years) with stroke found that independence in daily activities' was a factor associated with social roles. Their goal was to develop a "prediction" rule that would indicate the level of social activity someone with stroke would have one year following their stroke. Again the FAI was used to measure social roles, and the Barthel Index was used for daily activities. Univariate analysis revealed a moderate correlation (r = 0.56) between the admission daily activities measure and the social roles measure at one year. Multivariate analysis provided a ß of 0.41 (p<.03) for the daily living variable and cumulatively, age, gender, marital status, motor impairment, communication and ADL dependency explained 43% of the total variance in social roles (i.e. FAI items that include activities such as meal preparation, housekeeping, gardening, reading, going outdoors).

With a slightly different slant, in a large scale retrospective chart review (n=1870; mean age of 69 years), performance in daily activities was found to be significantly (p = 0.0001) associated with participants' subjective satisfaction with their social roles (community participation) (Ostir et al., 2005). Independence in daily activities was measured three to six months after discharge from rehabilitation using the Functional Independence Measure (FIM) (Wright, 2000) and social roles satisfaction was obtained by asking the following question: "Please rate your satisfaction with your ability to participate in community activities (excluding going

out for medical appointments)" (Ostir et al., 2005, p.36). All of the six FIM domains were significantly (p=0.0001) associated with increased levels of satisfaction, and interestingly, it was the cognitive subscale of the FIM (i.e. communication and social cognition) that had the strongest association with the social roles satisfaction measure. The authors however clearly acknowledge that the social roles measure, one of perception and limited scope, was an important limitation of their study,

One last study, and the most recent, was done by Roth and Lovell (2007) with 735 post stroke participants (mean age of 63 years). They looked at changes in the FIM score (daily activities measure) over time (i.e. differences in scores between admission, discharge and one year follow up), and related it to the FAI scores which was the social roles measure used at one year post rehabilitation. Although the results suggested no linear association between the two variables, the authors highlighted a curvilinear association between daily activities and social roles when both are measured at the one year mark. They also concluded that a threshold point exists for performance in daily activities and it is only beyond this point that social roles can truly be pursued (i.e. FIM score of 80 is required in order for social roles to be undertaken).

To summarize, the above studies suggest that an association exists between daily activities and social roles. The studies described above use different time frames and the concepts of daily activities and social roles are neither clearly delineated nor defined. This may be due to conceptual models lacking clear demarcations when referring to components of social participation (Cott, Wiles, & Devitt, 2007; Desrosiers, 2005; Jette, Haley, & Kooyoomjian, 2003). In particular the instruments used, predominantly the FAI, have shortcomings when measuring the concept of social roles. Indeed, 7 of its 15 items are household tasks that according to the DCP model are considered daily activities. Due to these

methodological issues and conflicting results, the relationship between daily activities and social roles deserves further study.

2.5. Identified concepts associated with social roles

Daily activities' is one factor that has been identified as a potential factor that is associated the resumption of social roles; other factors as well have been identified. Sveen et al. (1999) examined factors associated with social roles with a group of 65 individuals (mean age of 74 years) one year after stroke occurrence. Participants had received rehabilitation and were living at home at the time of assessment. The authors measured cognitive, perceptual and motor capabilities using the Sødring Motor Evaluation of Stroke patients (SMES) (Sodring, Bautz-Holter, Ljunggren, & Wyller, 1995) and the Assessment of Stroke and other Brain Damage (ASB) (Sveen, Wyller, Ljunggren, & Bautz-Holter, 1996) measure and they measured social roles using the Frenchay Activities Index (FAI). They reported that arm function and visuospatial construction were correlated with two of three of the social roles subscales of the FAI, the domestic subscale (τ=0.49) and the outdoor mobility subscale (τ=0.48).

Desrosiers and her colleagues (Desrosiers et al., 2006; Desrosiers, Noreau, Rochette, Bravo, & Boutin, 2002) identified predictors of social roles using data obtained from 102 participants with stroke (mean age of 61 years) who had received rehabilitation. Capability measures were taken at discharge and six months later using a variety of measurement instruments (e.g. Chedoke-McMaster

Stroke Assessment, Boston Naming test). Social roles were measured using the LIFE-H assessment (3.1 version), which includes separate scores for daily activities and social roles (Desrosiers et al., 2002). Predictors of social roles at six months, explaining a substantial amount of the variance (R^2 = 57%), included expressive language ability, walking endurance, lower extremity motor coordination, affect and length of rehabilitation stay (Desrosiers et al., 2006). In a subsequent study with the same cohort (n = 66 remaining participants), predictors of social roles two to four years post-stroke were slightly different than those identified at six months post stroke and included comorbidity, age, lower and upper extremity coordination, affect, and upper extremity ability; these variables explained a smaller proportion of variance (R^2 = 37%). Predictors for social roles were also identified in a study that compared participants discharged from rehabilitation facilities (n=111) with those discharged from acute care centers (n=86) six months following rehabilitation (Desrosiers et al., 2008). Walking ability, reading ability, executive function, affect, visuo-perceptual abilities and motor function of the affected foot explained 59% of the social roles variance for the participants discharged from rehabilitation facilities. Interestingly, affect and lower extremity coordination were the common predictors of social roles across all of the time frames. In the previous studies, independence in daily activities as defined in the DCP was not included within the many factors that were verified for their ability to predict social roles.

The factors considered thus far as predictors of social roles have primarily been capability measures (e.g. motor function of the affected foot, or reading ability). Beckley (2007) however verified the impact of social support (measured by the Social Support Inventory for People with Acquired Disabilities [SSIPAD]) (McColl & Friedland, 1989) on social participation (measured by the Reintegration to Normal Living Index). She assessed a group of 95 post stroke participants during an

interview 3 to 6 months post discharge and found that the qualitative and quantitative elements of social support explained 31% and 35% of the variance of this social participation measure, respectively. Thus environmental factors such as social support also appear to be related to social roles outcomes.

In summary, social roles are affected by several factors in addition to daily activities, including various capability and environmental variables.

2.6. Problem, study objective and research hypothesis

This literature review defined the variables under study, daily activities and social roles, in the context of inpatient stroke rehabilitation. The review also brought to the forefront that much of inpatient stroke rehabilitation focuses on the assessment and intervention that promotes independence in daily activities. Social roles remain an area that receives little attention during the rehabilitative process. The studies reviewed above suggest that there is an association between independence in daily activities and the pursuit of social roles. Other capability and environmental factors such as motor function of the affected foot and available social supports have also been identified as factors that affect the accomplishment of social roles. However, the terms used within the studies were not always clearly defined and thus the subsequent choice of instruments to measure these concepts was poorly justified.

The objective of this study was thus to clarify if the ability to perform daily activities at discharge from inpatient rehabilitation is associated with the ability to pursue social roles in the future in an adult population with stroke. In light of the lack of conceptual clarity within the studies reviewed, this study will use instruments that classify daily activity and social role items more distinctly. Hence, with clearer boundaries between these two terms and their respective instruments, it was hypothesized that daily activities would be weakly associated with social roles measured six months following discharge and living in the community. Clarifying this association should help clinicians from various disciplines reflect and reevaluate their interventions provided during inpatient rehabilitation. Subsequently this may assist them to better prepare older adults resume their social roles once they return to the community.

CHAPTER 3
METHODS

This study involved two data sets, one collected as part of a larger prospective study described below and another collected retrospectively for a subgroup of subjects from the larger study. The student participated as a research assistant in the larger study by assisting in the recruitment of participants and in the testing of subjects in their home (administration of measurement tools). She was also solely responsible for the second data set that involved in-depth data extraction from the medical files of a subgroup of participants from the larger study.

3.1. Context of larger study

Between 2003 and 2006 a team of geriatric rehabilitation researchers in Quebec (Desrosiers and, in alphabetical order, Belleville, Bravo, Demers, Landreville, Mercier, Paquet, Payette, Rainville, Robichaud, Rousseau, Ska, Talbot, Verreault, and Vincent) conducted a study entitled «Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cerebral (AVC): Étude multicentrique» (BRAD study). The BRAD study, funded by the Canadian Institute of Health Research (grant number 62953), was a multi-stage longitudinal study that involved recruiting participants with stroke, documenting

rehabilitation services they received, and then measuring participants' expressed and objective rehabilitation needs upon their return to their community. The data were collected from participants during home visits following discharge from one of three types of facilities: acute care, subacute care and intensive rehabilitation facilities.   The visits were over a six month period: the first one month after discharge, the second three months after discharge and the last, six months after discharge.

Participants for the BRAD study were recruited within three regions in Quebec: Montreal (metropolitan area; administrative region 06), Eastern townships (urban and rural area; administrative region 05), and Chaudière-Appalaches (urban and rural area; administrative region 12). A convenience sampling strategy was used to recruit participants prior to their discharge from acute care units (Centre hospitalier universitaire de Sherbrooke, Centre hospitalier universitaire de Montréal, and Centre de santé Paul-Gilbert), intensive rehabilitation units (Centre hospitalier Villa Medica, Institut universitaire de gériatrie de Sherbrooke (IUGS); Centre de santé Paul-Gilbert), and day hospitals (Centre Jacques Viger, IUGS, and Centre de santé Paul-Gilbert).

Eligibility criteria were defined as follows. To be included, participants had to : i) be able to communicate in French; ii) be 65 years of age or older; iii) had at least one stroke as per the WHO criteria (World Health Organization (WHO), 1990), and iv) be awaiting discharge to live in the community within a 75 km radius of their recruitment/clinical setting. Participants with severe communication or cognitive difficulties were excluded from the study as well as those with secondary neurological conditions.

A total of 253 older adults were recruited from the three regions of Quebec providing complete data for 197 of these participants. For the purposes of this master's degree, data for participants discharged from acute care facilities were excluded (n=86) because the student's study focused only on the interventions provided during subacute and intensive rehabilitation, thus leaving a total of 111 participants. Figure 2 provides a visual overview of the participants that were recruited in the larger study and of those that were retained for analysis in this study.

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                    ┌─────────────────────────┐
                    │   Recruited individuals  │
                    │    from all facilities   │
                    │          253             │
                    └─────────────────────────┘
                              ⇩
   ┌────────────────────────────────────────┐        ┌──────────────────┐
   │ Total number of individuals followed over│  ⇨    │   Participants   │
   │   a 6 month period after discharge       │        │ discharged from  │
   │        from rehabilitation               │        │    acute care    │
   │              197                         │        │        86        │
   └────────────────────────────────────────┘        └──────────────────┘
         ⇩                       ⇩
┌──────────────────┐    ┌──────────────────┐
│   Participants   │    │   Participants   │
│ discharged from  │    │ discharged from  │
│  rehabilitation  │    │   geriatric day  │
│     centers      │    │     hospitals    │
│        90        │    │        21        │
└──────────────────┘    └──────────────────┘
              ⇩
       ┌──────────────────┐
       │ Participants retained│
       │   for this study  │
       │        111        │
       └──────────────────┘
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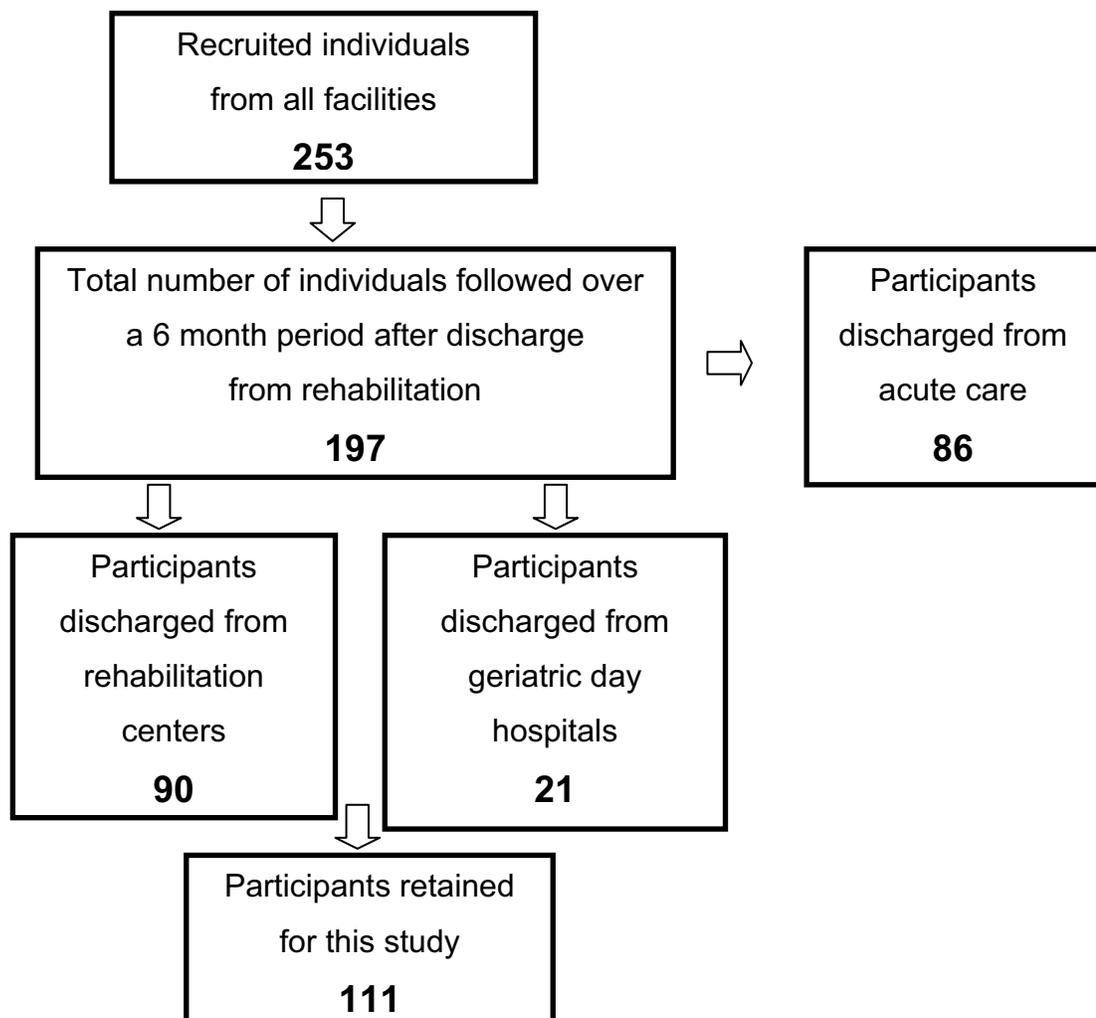
Figure 2. **Schematic of recruited participants for the present study.**

A complete dataset was available for 111 older adults with stroke discharged from intensive rehabilitation (n=90) and day hospitals (n=21). It included socio-demographic characteristics (i.e. age, gender, education level, type and location of stroke, comorbidities, civil status, length of time since the stroke), capabilities (physical, cognitive, perceptual, language and psychological) as well as life habits (daily activities and social roles). Data on these variables were collected from the participants' medical charts in the last clinical setting attended (socio-demographic characteristics), and during the home visits (capabilities and life habits) conducted at 3 weeks, 3 months, and 6 months following discharge. This master's study used the sociodemographic data collected from the participants' medical charts, the capability data collected at 3 weeks and the life habits data collected at 6 months.

3.2. Data specific to the master's thesis

The present study required data on the subjects' performance of daily activities at discharge that were not collected as part of the larger study. This new information was obtained by reviewing participants' medical charts and extracting the necessary data. Chart reviews with a focus on discharge summaries and progress notes were thus conducted for the 111 participants discharged from intensive rehabilitation or day hospital facilities.

The Functional Autonomy Measurement System (SMAF) (Hébert, Carrier, & Bilodeau, 1988) was the tool chosen to collect data about daily activity

performance because its subscales in the areas of basic activities of daily living, mobility and instrumental activities of daily living are conceptually congruent with the DCP definition of daily activities which is not the case with instruments used in previous studies such as the Barthel or the FIM. Furthermore, this instrument was created specifically for older adults (Hébert et al., 1988). This instrument and its psychometric properties are described in detail in the article found in Chapter 4.

SMAF data were retrieved from the participants' medical charts by the master's student. To ensure the quality of the data extraction, a second reviewer (an occupational therapist), well acquainted with the SMAF, independently completed two randomly chosen charts from each of the four recruitment sites (i.e. the sites were either inpatient rehabilitation units or day hospitals or a combination of thereof; n=8). Three SMAF sections were retained (Activities of Daily Living, Mobility and Instrumental Activities of Daily Living) for a partial SMAF total score that varied from 0 to – 63. The scores collected by the other extractor were then compared with those of the master's student scores and percentages of agreements were computed. The results are summarized in table 2. The percentages of agreement for the partial SMAF total scores varied between 89% and 100% (mean 95%).

3.3. Ethical considerations

Prior to performing the chart reviews, approval for additional data collection on the BRAD study participants was obtained from all of the relevant institutional review boards and scientific committees. Scientific and ethical certificates of approval were first delivered by the Centre de recherche de l'Institut universitaire de gériatrie de Montréal, a centre which oversaw the master's student work and that was affiliated with the original research project. Once these approvals were obtained, the Professional advisory boards (Direction des Services professionnels) for the individual centres were contacted and permission for the chart reviews was requested. The Centre de Santé de Service Social Jeanne Mance, representing the Centre Hospitalier Jacques Viger, chose to assess the research project independently by their local institutional board. Copies of all certificates of approval are found in Appendix II.

Table 2

Interrater reproducibility of partial SMAF scores by recruitment sites

Recuitment site	Type of facility	Subject number	Partial SMAF scores		Difference in partial SMAF scores between reviewers	Agreement (%)
			Reviewer 1	Reviewer 2		
Villa Medica	**Inpatient rehabilitation**	127[1]	-16.0	-20.0	4.0	94
		128[1]	-6,5	-6.0	0.5	99
Centre Hospitalier Jacques Viger	**Day hospital**	129[2]	-6.5	-13.5	7.0	89
		130[1]	-19.0	-18.0	1.0	98
IUGS	**Inpatient rehabilitation**	37[2]	-19.5	-25.5	6.0	90
		52[2]	-4.0	-3.0	1.0	98
Centre de santé Paul Gilbert	**Inpatient rehabilitation and Day hospital**	251[2]	-10.0	-10.0	0.0	100
		261[1]	-25.5	-21.0	4.5	93

Reviewer 1 = independent evaluator; Reviewer 2 = master's student

IUGS = Institut universitaire de gériatrie de Sherbrooke

[1] = URFI (unité de réadaptation fonctionnelle intensive); [2] = Hôpital de Jour

Note. Participants who had been recruited from inpatient rehabilitation or day hospital services services in the Quebec city region (i.e. Centre de Réadaptation en Déficience Physique -Chaudière Appalaches region and Centre de Santé Paul Gilbert respectively in 2004-2006), were under the jurisdiction of the Centre de santé et de service sociaux du Grand Littoral in 2007 and their charts were kept in the archives located at the Centre de Santé Paul Gilbert.

3.4. Statistical analyses

The article included in Chapter 4 provides a complete description of the statistical analyses performed in this study. The following sections describe preliminary analyses that were not included in the manuscript. These analyses were undertaken to ensure the homogeneity of the participant groups, to facilitate the selection of the control variables, and to adequately prepare the data for regression analyses.

3.4.1. Homogeneity of participant groups

It was important to verify the homogeneity of the total sample because participants were recruited from two types of centers: rehabilitation centers (n=90) and day hospitals (n=21). Mann-Whitney tests (non parametric test used to compare two independent groups for continuous variables) (Field, 2005; Pallant, 2007) or Kruskal-Wallis tests (non parametric test to compare continuous variable scores for several categories of a categorical variable) (Field, 2005; Pallant, 2007) were used to determine if significant statistical differences existed between the participants on a number of clinical and socio-demographic data.

Participants from both facility types were found to be similar in age, gender, side of stroke, occurrence of previous stroke, number of co-morbidities, and years of schooling. Large and expected differences were noted in the lengths of stay for

the two types of facilities (mean 235.4, range of 87-617 days for day hospitals; and mean 88.9 range of 15 to 414 days for intensive rehabilitation). Day hospital stays involved longer but infrequent visits over a longer time period. Other minor differences were noted. Participants discharged from day hospitals had slightly higher Canadian Neurological scores (9.95 versus 9.40) and slightly lower daily activities scores (adapted SMAF scores of -12.8 ± 9.9 and -17.8 ± 9.9)[1]. More importantly, no significant differences in scores for the measures of capabilities (e.g. motor recovery of the arm and foot, perception, language), and for social roles scores were found. Therefore, the data from the participants discharged from day hospitals and rehabilitation centers were pooled to create one sample.

3.4.2. Selection of control variables

Capability variables that define the potential one has to accomplish mental or physical activities, (Fougeyrollas et al., 1998b), were chosen as control variables so that their potential influence on social roles could be accounted for. The original BRAD study data had previously been analyzed to identify the best predictors of social roles (Life-H total score only) (Desrosiers et al., 2008). These included walking ability, executive function, depressive symptoms, reading, visual perception, and foot function. In the present study, walking ability, as measured by the Timed Up and Go was not included as a control variable because it could be considered a daily activity and walking ability is included in the SMAF. Reading capability was replaced by another variable available for language expression, the

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[1] The SMAF score indicates level of independence and thus a lower negative score means greater independence in daily activities performance.

Boston Naming test (BNT), which is less prone to an educational bias (i.e. influence of years of schooling). The final choice of variables also considered the strength of the bivariate correlations between the individual capability and the total and subscale social roles scores (i.e. stronger correlates were better candidates). These results are presented in the article found in Chapter 4 (table 3).

Selected control variables included physical capability (foot function and arm function), cognitive capability, language capability, perceptual capability, and psychological capability, for a total of six control variables. With the independent variable (i.e. daily activities), the total number of variables to be included in the regression analysis was seven, which constitutes an appropriate number of variables in light of the available sample size (n=111 participants). Although there are several ways of determining the appropriate sample size required for regression analysis, the general rule of thumb is 15 participants per independent variable (including control variables). This provides an adequate sample size for a reasonable effect size (approximately medium to large) (Field, 2005).

3.4.3. Preparation for regression analyses

Necessary criteria had to be met prior to performing regression analysis (Field, 2005; Tabachnick & Fidell, 2001). Firstly, data had to be relatively free of outliers (i.e. cases that could unduly influence the model and thus misrepresent findings). One statistic used to detect outliers is the Mahalanobis distance statistic (i.e. distance of a case from the meeting point of all means of all the variables) and the allowable distances depends on the number of dependent variables used in the

regression analysis. Using this strategy, few significant outliers[2] (1% of the data and only for the Leisure social role model) were identified and these were deemed inconsequential in number as they were not *influential* as evaluated by leverage and Cook's distance statistics. Thereafter, the student verified the data to ensure that they met the assumptions of normality (i.e. verified by looking at the differences between predicted and obtained scores, and ensuring that their distribution is symmetric), linearity (i.e. verifying that the relationship between the residuals and the predicted dependent variable is linear in nature), and homoscedascity (i.e. verifying that the variability in scores for a continuous variable is similar to that of other continuous variables). The independent variables were also examined to ensure that they were void of evidence of multicollinearity (i.e. a strong correlation between two or more predictors in a regression model). In sum, the data were deemed satisfactory. These preliminary analyses therefore ensured that the regression models obtained could be generalized to other samples.

Hierarchical regression was the method of choice as it allows for the entry of variables or sets of variables in steps (blocks) (Pallant, 2007). This study's specific research question wished to determine how independence in daily activities was associated with social roles after controlling for several capabilities. Therefore, capability variables were entered as a block in Step 1 and then daily activities in Step 2. The resulting models (presented in the article in Chapter 4) describe the level of association between daily activities and social roles and each of its domains.

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[2] A significant outlier in a sample population of $N < 1000$ with a criterion of $p = .001$ is a conservative way of evaluating outliers when looking at standardized residuals. To be deemed a significant outlier, the residual must be in excess of ± 3.3. (Tabachnick & Fidell, 2001)

CHAPTER 4
RESULTS

The results of this research project are presented in the following manuscript:

4.1 Association between daily activities following stroke rehabilitation and social roles functioning upon return to the community.

Michelle Plante B Sc, Louise Demers PhD, Bonnie Swaine PhD, Johanne Desrosiers PhD (submitted to the journal *Topics of Stroke Rehabilitation*)

The principal author confirms her original contribution to the data collection and interpretation of the results as well as in the writing of the research article.

4.1. Association between daily activities following stroke rehabilitation and social roles functioning upon return to the community

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4.1.1. Abstract

Purpose: To test the hypothesis that independence in daily activities at discharge from rehabilitation is weakly related to the degree of resumption of social roles 6 months later in older adults with stroke.

Method: One hundred and eleven adults participated (mean age 77 years). Daily activities were measured using portions of the Functional Measurement of Autonomy System (SMAF). Social roles, measured using the Life-H, included responsibilities, interpersonal relationships, community life, and leisure domains. Regression analyses were performed evaluating the association between daily activities and social roles in conjunction with several capability variables.

Results: Independence in daily activities increased the variances by 7% to 8% for social roles (total score), responsibilities and community life regression models. The total explained variances ranged from 47% to 52% with corresponding beta values for daily activities ranging from -0.37 to -0.41. The lack of association between independence in daily activities and both leisure and interpersonal relationships were striking results. The lowest scores were in the leisure domain.

Conclusion: The association between daily activities at discharge and social roles 6 months following rehabilitation varies depending on the social role domain. Leisure may not be sufficiently addressed during rehabilitation warranting a "second wave" of rehabilitation upon return to the community.

4.1.2. Introduction

Stroke incidence may reach epidemic proportions by the year 2030[1]. In Canada presently, an estimated 50,000 people per year have a stroke[2] leaving many living with important stroke sequelae[3] as well as restrictions in participation[4].

The concept of participation can be defined as the person's involvement in a life situation concerned with the overall functioning of the person[5, 6]. Fougeyrollas and his colleagues have greatly contributed to the knowledge and understanding of this concept through the development of the Disability Creation Process (DCP) model[7]. In this model, participation is described using the term "life habit" which incorporates both daily activities and social roles. These life habits are of unique value to an individual and are relevant to his/her socio-cultural environment. Daily activities include basic activities often essential for survival such as nutrition, fitness, personal care, communication, housing, and mobility. Social roles include involvement in financial or civic responsibilities, interpersonal relationships, community life, employment, education, and leisure.

Reduced independence in daily activities and restrictions in social roles have been described for people who have had a stroke[8-10]. Six months after their stroke, 25% of a cohort of 434 persons (mean age of 68 years) reported needing help with basic daily activities (e.g. bathing, mobility) and up to 50% with more complex daily activities (e.g. meal preparation). Restrictions within their social roles were even more apparent: 70% had difficulties moving beyond their community and 72% stated being unable to pursue a meaningful social role[4] (i.e. a significant activity that could be social, recreational or productive in nature). In a smaller cohort of 56 participants 1 year post stroke (mean age of 58 years), 70-82% reported needing help with complex daily activities (housekeeping and meal preparation) and only

42% of participants were able to pursue the same social roles as before their stroke[11].

Rehabilitation is well recognized as an integral part of post stroke care[12, 13]. Goals are set during the intensive inpatient rehabilitation period with a focus on the remediation of capabilities (ex: stimulation of movement of extremities, inhibiting spasticity, retraining of language skills etc.) and on the restoration of independence in daily activities[14-16]. In contrast, social roles interventions do not appear to be explicitly part of intensive rehabilitation[15-17] or they are infrequently reported in the literature[18]. Gains in social roles after a stroke occur mainly within the first 6 months upon return to the community[19, 20].

The relationship between the performance of daily activities and the resumption of social roles has been studied among persons with stroke[21-26]. Three studies used the Barthel Index[21a] to measure daily activities and the Frenchay Activities Index (FAI)[21b] to measure social roles. In a study involving 65 adults (mean age 74) with stroke, Sveen et al.[21] reported a strong correlation ($\tau=0.76$) between the two concepts both measured at 1 year follow-up. These results are consistent with those obtained by Carod-Artal et al.[22] with 90 people with stroke (mean age 68 years) (r= 0.50). Shepers et al.[24] recruited a younger sample of 250 people with stroke (mean age of 56 years) and measured daily activities at admission and social roles 1 year later. They found a moderate correlation (r=0.56) between the two concepts and identified daily activities as a good predictor of social roles (beta = 0.41). They also reported that age, gender, marital status, motor and communication capabilities were significant determinants of social roles at 1 year post stroke.

Two additional studies, by Hoffman et al.[23] and Ostir et al.[25] generated similar results using different measurement tools and timeframes. In an 18-month follow up of 51 individuals following a stroke, Hoffman[23] and her colleagues (2003) found that those independent in daily activities, measured using the Modified Barthel[23a], had significantly (p=0.012) higher Reintegration to Normal Living (RNLI)[23b] scores on this community reintegration tool. The sample studied by Ostir et al.[25] included 1870 participants (average of 68 years) assessed at discharge from rehabilitation and 3-6 months later. They found a significant association ($p < 0.01$) between a change score in daily activities obtained using the Functional Independence Measure (FIM)[25a], and a measure of satisfaction with social roles expression (a question specifically developed for their study) while adjusting for sociodemographic characteristics.

Roth and Lovell's[26] findings, obtained with 735 participants (mean age 63 years), differed from their predecessors. They found no association between daily activities at discharge from rehabilitation using the Functional Independence Measure (FIM) and that of social roles using the FAI measured 1 year later.

The studies described above suggest an association between daily activities and social roles. However, daily activities were not all measured at time of discharge from rehabilitation, a point of time of particular interest for addressing outcome. As well, within these studies, the concepts of daily activities and social roles were rarely clearly defined/delineated and this is an important step that many authors advocate as this is the basis for which appropriate instruments are chosen.[27-29] Moreover, the instruments used to measure social roles were not comprehensive in nature. Due to these methodological issues and conflicting results, the relationship between daily activities and social roles warrants further investigation. By clarifying this relationship, clinicians would better understand if

the interventions they provide during intensive rehabilitation sufficiently prepare older adults with stroke for a return to the community and a resumption of their social roles.

The objective of this study was to determine if the ability to perform daily activities upon discharge from inpatient rehabilitation is associated with the ability to pursue social roles six months later in an older adult population with stroke. We hypothesized that scores for independence in daily activities obtained at discharge would be weakly associated with social roles six months later as measured by a comprehensive specific tool.

4.1.3. Methods

4.1.3.1.   Participants and procedures

The present study was part of a longitudinal prospective study aimed at identifying residual rehabilitation needs of older adults with stroke recruited from acute care hospitals and rehabilitation facilities within 3 regions of the province of Quebec, Canada[20]. Participants recruited from acute care facilities would not have necessarily been screened by rehabilitative personnel and they would have also been those with few limitations. Participants recruited from rehabilitation facilities are more likely to have had noticeable limitations and would have received comprehensive assessment and treatment from rehabilitation professionals. Data for 197 participants was available and these participants were assessed 3 times

over a 6 month period: 3 weeks, 3 months, and 6 months following discharge. Data collected included sociodemographic variables and scores on measures of the participants' physical, cognitive, perceptual, language and psychological function (i.e. capabilities) and their performance of life habits (daily activities and social roles). Trained research assistants collected these data during interviews and testing in the participants' homes (see description of instruments below). Sociodemographic data were extracted from their medical chart. This study used sociodemographic data collected at 3 weeks and capability and social roles measures recorded at 6 months from participants recruited from rehabilitation facilities (i.e. n=111). For these 111 participants, additional information was obtained from their medical chart about their level of independence in daily activities at discharge. Approvals for the chart reviews (conducted by MP) were obtained from the Institutional Review Boards and Research Committees of all the establishments concerned.

To be eligible for the study, participants had to: (a) be 65 years of age or older, (b) have incurred at least one stroke as defined by the WHO,[30] and (c) be awaiting discharge from a rehabilitation facility with an anticipated return home or to a community residence. Participants presenting with severe cognitive disorders (based on chart review and clinical judgement) or other neurological diagnoses were excluded, however those with aphasia and with sufficient understanding were included.

4.1.3.2. Variables and measurement instruments

Independent variable

The independent variable was the level of independence in daily activities measured with the Functional Autonomy Measurement System (SMAF) 2002 revised version[31]. This measure includes 5 domains of function: basic activities of daily living (7 items); mobility (6 items); communication (3 items); mental functions (5 items); and instrumental ADL (8 items). These 29 items are scored using a 5 point scale: 0 (independent), -0.5 (difficulty), -1 (needs supervision), -2 (needs help), -3 (dependent) for a maximum score of -87. A large negative score reflects reduced independence in daily activities. To maintain conceptual conformity with the definition of daily activities proposed by the DCP model (Fougeyrollas 1998)[7], the areas of communication and mental functions were excluded, thus providing a maximum score of -63 for the SMAF scores used in this study.

The SMAF demonstrates excellent reliability for the global score (test retest ICC of 0.95; interrater ICC of 0.96)[32] and for individual items (interrater mean weighted kappas of 0.75)[33]. Excellent concurrent validity with the Older Americans Resources and Services Scale (r=0.80)[34], and the PLAISIR, an instrument that records the amount of nursing care time (r=0.88), have also been demonstrated[33]. The SMAF domain scores (activities of daily living, mobility) and the total SMAF score have also been correlated with the equivalent counterparts of the FIM (r = 0.87 to r = 0.96)[35]

The SMAF is meant to be completed by a health professional who gathers the data from observations, and /or during an interview with the person or with a significant other. In this study, SMAF scores were calculated from data extracted

from comprehensive discharge rehabilitation reports included in the participants' medical charts. Data recorded in these discharge reports were based on extensive observations by members of the multidisciplinary rehabilitation team. To ensure the quality of the data extraction, eight charts from four different sites from three geographical regions were used to score the SMAF independently by a second person and comparisons between the two SMAF scores were done. Percent agreement obtained ranged from 89% to 100% with an average of 95% agreement between reported scores.

Dependent variables

Data for four dependent social roles subscale scores and a social roles' total score were measured with the Assessment of Life Habits (Life-H), short version 3.1[36] during a semi-structured interview with the participant or significant other. The Life-H measures the performance of 77 life habits covering the 12 domains of the DCP model, six of which relate to social roles: responsibilities, community life, interpersonal relationships, employment, education, and leisure. The employment and education domains were excluded in this study as they were not pertinent for this older adult population, therefore four domains with 30 items remained. A 9-point scale describes how individual life habits are performed (level of difficulty and type of assistance required), ranging from 0 (no participation) to 9 (complete participation)[36, 37]. A total score and four subscale scores were recorded for each participant (social roles total, responsibilities, community life, leisure and interpersonal relationships subscales).

Since its development, the LIFE-H has undergone extensive reliability and validity testing with different patient populations[38] With a group of 84 older adults with disabilities, the reliability coefficients of the LIFE-H score obtained were found

to be good to excellent (test-retest ICC of 0.55 to 0.95, interrater ICC of 0.64 to 0.89)[37]. The construct validity of the Life-H has also been demonstrated with 87 older adults discriminating between different participation levels according to participants' living environment (own home, private nursing home, long-term care center)[39]. Good reliability was demonstrated when using proxies as respondents (intrarater ICC of 0.73)[40].

Control variables

The instruments used to measure various capabilities (i.e. physical, cognitive, perceptual, language, and psychological) are described below.

Physical capability

The Chedoke McMaster Stroke Assessment[41] determines the severity of motor impairment of the affected limbs and includes arm, hand, leg and foot components. Only scores for the arm and foot were used as these two measures had higher statistically significant correlations with the Life-H social roles measure than the hand for the upper extremity and the leg for the lower extremity. The scale ranges from 1 to 7, where 7 is indicative of better recovery. Reliability (test retest, intra-rater and inter-rater) was shown to be excellent (ICC ranging from 0.97 to 0.99).[42] Construct and concurrent validity studies yielded excellent results as seen in the correlations with the Fugl-Meyer Test ($r = 0.95$, $p < 0.001$) and with the FIM ($r = 0.79$, $p < 0.05$).[42]

Cognitive capability

The Stroop Test[43, 44] was used to evaluate the ability to inhibit automatic processing by voluntary control. This is a timed test in which the participant must name a set of 24 colored dots on a page (baseline task), and on a subsequent task, name the color of the ink of the word in which the word is written (the word is a different color than what is written). The resulting score is the difference in time

between completing the first task (colored dots) and the second task (colored words). This test has good test-retest reliability (ICC ranging from 0.67 to 0.86) [45, 46] and it has been shown to be valid for the evaluation of executive function.[44, 47]

Perceptual capability

The Motor-Free Visual Perception Test (vertical version)[48] was used to estimate visuo-perceptual ability. It consists of 36 items with a choice of 4 responses targeting 5 components of visual perception: visual discrimination, figure-ground differentiation, visual memory, form constancy, and visual synthesis. A high score (maximum 36) indicates better visuo-perceptual ability.[49] Test retest reliability between this vertical version and the original is excellent (ICC of 0.92 to 0.94).[50]

Language capability

The Boston Naming Test[51] evaluates naming abilities or more generally verbal expressive ability. Picture cards of objects are shown and the person is asked to name them. The 60-item version is standardized and a score of 60 indicates better naming ability. This test is sensitive to change, and has been found to be valid and reliable in an adult population[46, 52, 53].

Psychological capability

The Geriatric Depression Scale[54, 55] is a validated questionnaire that is widely used to screen for depressive symptoms in older adults[56]. It consists of 30 items requiring simple "yes/no" answers and has excellent internal consistency (Cronbach α values ranging from 0.80 to 0.99)[57]. A score of 11/30 or more indicates the presence of depressive symptoms (sensitivity of 92-95% and specificity of 84-89%)[54].

Sociodemographic data

Sociodemographic data and clinical characteristics including age, gender, schooling, side of stroke, and living environment following stroke were collected. To estimate stroke severity, the Canadian Neurological Scale (CNS)[58] obtained at discharge from the rehabilitation facility was used. CNS scores can range from 1.5

to 11.5 where a higher score indicates a less severe stroke. The number of comorbidities was estimated using the Charlson Index, [59] accounting for up to a total of 22 comorbidities.

4.1.3.3. Statistical analysis

Data were first checked for completeness. Less than 6% of data had missing entries and this was primarily due to the participants' inability to complete the tests. Data were not substituted except for the Boston Naming Test (language expression test) whereby participants who could not complete the test (i.e. had missing data) were given a score of "zero", the lowest score possible. Regression analyses were thus performed with a slightly reduced sample size (varying from 100 to 102 depending on the test) when data were missing. Upon review of the distribution of the social roles total and subscale scores, we chose to use nonparametric statistical analysis as not all test data had normal distributions.

A series of analyses were conducted. Univariate statistics (means and standard deviations for continuous variables and frequency and percentage for categorical variables) were used to describe the sociodemographic characteristics of the participants. Bivariate Spearman correlation analysis between capability measures and the social roles total and domain subscale scores (responsibilities, community life, leisure, and interpersonal relationships) were calculated.

Hierarchical regression was conducted to investigate the relationship between each dependent variable and the independent variable (daily activities) while suppressing statistically the effect of the control variables (capability variables).[60, 61]

Thus the control variables were entered in as one block whereas the independent variable was entered in a second step. For the interpersonal relationships subscale other relevant correlates (age, gender and marital status) were deemed important and thus they were entered in as the first step, the capability measures as the second step and the independent variable in the third step. Residual analysis was done for each of the five regression analyses to ensure that the basic assumptions were met. Multicollinearity was verified using the Variance inflation factor (VIH) statistic. Statistical analyses were done with version 15.0 of SPSS (Statistical Package for Social Sciences) software.

4.1.4. Results

Sociodemographic data for the participants are presented in Table 1. Participants were evenly distributed according to gender, and their mean age was 76.7 years. The majority had had an ischemic stroke, and presented with on average 2 out of a possible 22 co-morbidities. Thirty seven percent had had a previous stroke. Following rehabilitation, the majority returned home, more than half had a spouse or a partner, and approximately one quarter of the sample presented with language difficulties. At 6 months, more than a third required a walking aid and less than 14% reported driving a car.

[INSERT TABLE 1]

Data on the participants' daily activities, social roles and capabilities are summarized in Table 2. Participants' independence in daily activities was found to be reduced with a mean SMAF score at discharge of -16.9/63 which reflects

moderate losses in independence. The expression of social roles varied according to individual domains, with highest LIFE-H scores for relationships (mean score of 8.34) and lowest scores for leisure (mean score of 3.83). On average, physical, cognitive, language, cognition and psychological capability scores appear to be moderately high but the scores varied extensively.

[INSERT TABLE 2]

Bivariate Spearman correlations between daily activities, social roles total score and its four subscale scores and capability variables are presented in Table 3. The total and subscale social roles scores for responsibilities and community life were strongly correlated with daily activities (-0.64 to -0.66) and weakly to moderately correlated (0.25 to 0.47) with all capabilities. The negative sign for daily activities and psychological and cognitive capabilities was expected as higher scores for these indicate poorer performance scores for social roles. Leisure was weakly to moderately correlated (0.28 to 0.33) with most of the variables except that of language. Interpersonal relationships were weakly correlated (absolute correlations ranging from 0.02 to 0.22) with language, psychological (negative correlation), physical foot capabilities as well as with the daily activities variable.

[INSERT TABLE 3]

The results of the hierarchical regression are presented in Table 4. Results were similar for the three regression models involving total social roles, responsibilities and community life. After entering the capability variables for each of the three regression analyses, the variance ranged from 39% to 45% ($F_{(7, 94)}$ = 11.86 to 14.45, $p < .001$). After entry of daily activities, the total variance increased and ranged from 47-52% (R^2 change = .08; F change $(1, 94)$ = 13.02 to

14.96, p < 0.001). The best predictor was daily activities ($ß$ = -0.37 to -0.41, p < 0.001) for all three models, followed by physical foot capability ($ß$ = 0.19 to 0.24, p < 0.05) for total social roles and responsibilities and by perceptual capability for community life ($ß$ = 0.19, p = 0.04)

[INSERT TABLE 4]

For leisure, capability variables explained 21% of the variance and daily activities did not influence the variance (F change (1, 92) = .10, p = 0.75). Perceptual capability ($ß$ = 0.28, p = 0.02) was the only significant (p < 0.05) variable associated with Life-H leisure scores.

For the interpersonal relationships domain, age, gender and marital status explained 12% of the variance. The addition of the capability variables explained 21% of the variance (*F* (9, 92) = 2.67, p < 0.001), although the R² change of 0.09 was not significant (*F* change (6, 92) = 1.74, p = 0.12). With the addition of daily activities, there was no change in variance. Being female was the only variable that explained participation in interpersonal relationships ($ß$ = 0.33, p < 0.002).

4.1.5. Discussion

Stroke rehabilitation aims to help individuals return home to pursue their social roles. Our study sought to verify if an important discharge rehabilitation outcome, independence in daily activities, would be associated with social roles functioning upon return to the community.   This knowledge would assist clinicians in

understanding whether the impact of their interventions goes beyond that of the rehabilitation setting. We hypothesized that there would be a weak association between independence in daily activities at discharge and the pursuit of social roles six months following rehabilitation in our population of older adults with stroke. This was verified using an extensive dataset including several capability measures for 111 participants in addition to daily living and social roles scores. Such a dataset permitted a sophisticated exploration of the interrelationship among a large set of important rehabilitation variables.

Our results show that independence in daily activities at discharge from rehabilitation was associated with social roles (total score) but this was not true for all domains of social roles. These results thus both partially refute and support our hypothesis. Indeed, the findings indicate that not all social roles are the same and they emphasize the importance of clearly defining the term social roles and its components/domains of interest. Comparing our results with those of others is tenuous since the operational definitions of daily activities and social roles vary across studies. For example, in our study, household tasks are part of daily activities, yet in most studies, these tasks are considered as social roles. In spite of these differences, our results for social roles (i.e. total scores) are similar to those of Carod-Artal et al.[22] and of Shepers et al.[24] who had measured social roles 1 year following rehabilitation. However, our results are at odds with those of Roth et al.[26] who found no association between daily activities at discharge and social roles 1 year later.

Social roles were also examined as four separate domains with the use of the Life-H and each in relation to daily activities at discharge from rehabilitation. Civic responsibilities and community life domains were both associated with daily activities at discharge, daily activities explaining an additional 8% of the variance

above and beyond that of the six capability variables. Moreover, it was the strongest contributor (largest standardized beta) of the total variance among the comprehensive set of capability variables. These findings are not unlike those of Sveen et al.(1999)[21] who linked basic daily activities with what they termed 'outdoor' activities, a close equivalent to responsibilities and community life domains.

Leisure showed no association with daily activities at discharge. This finding is consistent with Sveen et al.'s[21] who found a weak association between leisure, as measured with the Frenchay Activities Index and activities of daily living, as measured with the Barthel index. The FAI however provides a much less detailed measure of social roles than the Life-H and thus provides only a partial profile of social roles. Perceptual capability, reflecting the ability to move around comfortably in the environment, was the only significant capability measure within the regression model that explained 21% of the variance for the leisure Life-H scores. However there still remains 79% of the variance that is likely explained by other variables not measured in the present study. Leisure differs from the other social roles; it is specific to the individual and his/her interests. This is in contrast with activities such as being responsible for one's errands, doing one's banking or even fostering family relationships which are more fundamental activities that occur on a regular basis. Therefore it is likely that other factors likely influence one's leisure choices such as availability of the activity, availability of social support or transportation.

An interesting finding was that participants with stroke had the lowest scores for leisure among all of the social roles. These results are consistent with other studies[62-64] suggesting that leisure may not necessarily be a priority in rehabilitation. Leisure has however been linked to life satisfaction in older adults

and in persons with stroke [14, 65, 66]. Clearly, more emphasis could be put on helping older stroke adults return to previous leisure activities or develop new ones [67].

As with leisure, the interpersonal relationships domain was not associated with daily activities, and female gender was the only factor that significantly explained 13% of the variance. In a population of healthy older adults, female gender also was responsible for higher scores for this social role[68]. In the present study scores for this social role were overall high with little variability among participants. In fact, previous research showed that interpersonal relationship scores among healthy participants (matched for age, sex and living environment) were similar to those of persons with stroke[63].

After the addition of the daily activities variable following the entry of all capability variables in one block, only two capability variables remained significant for the social roles total score, and civic responsibilities, community life, and leisure domains. These were physical foot capability, a known proxy for impairment severity, [69] and perceptual capability. Thus the ability to perceive and move about confidently in one's environment could facilitate a person's engagement in several social roles.

The limitations pertaining to this study need to be acknowledged. Inherently, the design of this study has limits. First, without a pre-stroke baseline measure of social roles, it is not clear if social roles' functioning at 6 months is solely a consequence of stroke. This is likely since changes in social roles expression after stroke has been reported [63]. Second, some degree of association could be attributed to the partial overlapping of measurement tools. The instruments chosen for this study had minimal item and conceptual overlap; two items, "doing errands" and "managing one's budget", found within the SMAF, are similar to items within

the responsibilities domain of the Life-H. Third, environmental factors unrelated to stroke could also be limiting factors in the expression of social roles. As per the Disability Creation Process, these factors interact with personal factors (capabilities) and influence the expression of life habits of which social roles are a part[62, 70]. Finally, the results can be generalised to persons with stroke who receive rehabilitation services including those with some degree of aphasia. They cannot however extend to those with severe stroke as they were excluded from the study.

This study has important clinical implications. The emphasis rehabilitation presently places on capabilities and independence in daily activities is warranted in light of the association found between daily activities at discharge and the specific social role domains of responsibilities and community life at 6 months. Nevertheless, this association does not mean that the person who returns to the community does not face challenges in these areas. On the other hand, leisure, with its lack of association with daily activities, combined with the fact that it is rarely a major focus of the rehabilitation process, may deserve more attention. Indeed leisure activities are important to older adults [14, 71]. However, like most social role domains, leisure is best expressed once the person returns to live in the community so it is unclear when rehabilitation should address this need. Based on these results, clinicians treating persons with a stroke may question whether leisure or other social roles be addressed more extensively during the initial rehabilitation process or should they be integrated within a community rehabilitation format? Is a "second wave" of rehab necessary once the stroke survivor returns home and has spent some time in the community to identify the social roles' areas that need to be further addressed? Answers to these questions require more research. What remains clear is that rehabilitation needs to be considered a journey rather than a destination whereby necessary means are provided to enable persons with stroke to lead more productive, fulfilling lives [72].

4.1.6. Conclusion

Previous research led us to question the hypothesis that independence in daily activities at discharge from rehabilitation would be related to the degree of resumption of social roles 6 months later among older adults with stroke. An association was found between the level of independence in daily activities at discharge and the responsibilities one assumes and the community activities one pursues upon return to the community. Leisure and interpersonal relationships had no association with daily activities. Leisure, of great importance to older adults, may not be sufficiently addressed during the intensive period of rehabilitation. Subsequent to a return to the community, a "second wave" of rehabilitation may be warranted.

4.17   References

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Table 1 Sociodemographic and clinical characteristics of participants
(n=111)

Variable	Mean (± SD)	Range	Frequency (%)
Age (years)	76.7 (7.0)	(65-92)	
Sex (males)			57 (51.4)
Years of schooling	8.1 (4.1)	(0-20)	
Co-morbidities (/22)*	2.4 (2.4)	(0-22)	
Type of stroke (ischemic)*			95 (85.6)
Side of stroke			
– Right			49 (44.1)
– Left			56 (50.5)
– Bilateral			6 (5.4)
Neurological score (/11.5)*	9.5 (1.4)		
Time between stroke	115.6 (90.1)	(15-617)	
& discharge from rehabilitation (days)			
Previous stroke (yes)			37 (33.3)
Discharge destination (home)			94 (84.7)
Marital status (married / with a partner)*			57 (51.4)
Able to drive a car*			14 (12.6)
Uses a walking aid (yes)			
- 3 weeks after discharge			47 (42.3)
- 6 months after discharge			40 (36.0)
Reduced language comprehension *			26 (23.4)
Reduced language expression *			25 (22.5)
Urine incontinent (yes)			29 (26.1)

*n varied between 104-110 due to missing data

Table 2 Mean scores for participants' daily activities, social roles and capabilities
(n=111)

Variable : Measurement instrument (max. score)	Mean (SD)	Range of scores
Daily activities at discharge (independent variable)		
Daily activities: adapted SMAF (/-63)	-16.9 (10.0)	-1.0 – -44.0
Activities of daily living (/-21)	-2.86 (2.87)	0 – -12.0
Mobility (/-18)	-2.62 (2.83)	0 – -12.0
Instrumental activities of daily living (/-24)	-11.40 (5.71)	0 – -22.0
Social roles at 6 months (dependent variables)		
Social roles (total score): Life-H (/9)	5.86 (1.82)	1.7 – 9.0
Responsibilities (/9)	6.56 (2.14)	1.6 – 9.0
Community life (/9)	4.97 (3.01.)	2.5 – 9.0
Leisure* (/9)	3.83 (2.77)	0.0 – 9.0
Capabilities at 6 months (control variables)		
Physical: Chedoke arm (/7)	5.3 (1.6)	1– 7
Physical: Chedoke foot (/7)	5.3 (1.5)	1– 7
Language: Boston Naming test (/60)	25.4 (19.4)	0 – 58
Perceptual: Motor-Free Visual Perception Test* (/36)	28.6 (5.3)	10 – 36
Cognitive: Stroop test* (seconds)	39.9 (39.6)	3.6 – 264.7
Psychological: Geriatric Depression Scale* (/30)	9.3 (6.0)	0 – 28

*n varied between 104-110 due to missing data

Table 3 Correlations between daily activities, social roles total and subscale scores and capabilities

	Social roles (total)	Responsibilities	Community life	Leisure	Interpersonal relationships
Daily activities	-0.66**	-0.66**	-0.64**	-0.33**	-0.31**
Physical (foot)	0.47**	0.38**	0.43**	0.33**	0.20*
Physical (arm)	0.36**	0.36**	0.30**	0.31**	0.05
Cognitive	-0.30**	-0.30**	-0.25**	-0.29**	0.02
Perceptual	0.44**	0.39**	0.45**	0.28**	0.05
Language	0.39**	0.41**	0.35**	0.12	0.22*
Psychological	-0.44**	-0.33**	-0.39**	-0.29*	-0.21*

Spearman correlations (r); N varied between 102-111 due to missing data

 * Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Table 4 Effect of independence in daily activities at discharge on social roles at 6 months

Dependent variables	Independent variables	ß	p	R² (Adjusted R²)
Social roles				
Step 1			**0.001**	**0.45 (0.42)**
Step 2	**Daily activities**	**-0.37**	**0.001**	
	Physical ability: foot	0.24	0.01	
	Psychological	-0.14	0.07	
	Perceptual	0.16	0.07	
	Language	0.14	0.08	
	Physical ability: arm	-0.04	0.62	
	Cognitive	-0.02	0.83	
	Constant		0.007	
			0.001	**0.52 (0.48)**
Responsibilities				
Step 1			**0.001**	**0.43 (0.40)**
Step 2	**Daily activities**	**-0.40**	**0.001**	
	Physical ability: foot	0.19	0.04	
	Cognitive ability	-0.12	0.12	
	Language	0.11	0.15	
	Perceptual	0.11	0.22	
	Psychological	-0.08	0.32	
	Physical arm	0.02	0.82	
	Constant		0.002	
			0.001	**0.51 (0.47)**

Community life

Step 1			0.001	0.39 (0.35)
Step 2	Daily activities	-0.41	0.001	
	Perceptual	0.19	0.04	
	Physical ability: foot	0.19	0.06	
	Psychological	-0.13	0.11	
	Language	0.10	0.24	
	Physical ability: arm	-0.07	0.43	
	Cognitive ability	0.02	0.82	
	Constant		0.35	
			0.001	0.47 (0.43)

Leisure

Step 1			0.001	0.21 (0.16)
Step 2	Daily activities	-0.04	0.75	
	Perceptual	0.28	0.02	
	Physical ability: foot	0.22	0.07	
	Physical ability: arm	0.10	0.41	
	Psychological	-0.04	0.73	
	Cognitive ability	0.03	0.74	
	Language	-0.006	0.95	
	Constant		0.23	
			0.75	0.21 (0.15)

Interpersonal relationships				
Step 1			**0.001**	**0.12 (0.09)**
Step 2			**0.12**	**0.21 (0.13)**
Step 3	**Daily activities**	**-0.04**	**0.75**	
	Sex (female)	0.33	0.002	
	Physical ability: foot	0.18	0.14	
	Cognitive ability	0.15	0.15	
	Psychological	-0.15	0.15	
	Physical ability: arm	-0.16	0.16	
	Language	0.10	0.33	
	Age	-0.06	0.59	
	Perceptual	0.009	0.94	
	Civil status (married)	-0.003	0.98	
	Constant		0.000	
			0.76	*0.21 (0.12)*

*n varied between 100-102 due to missing data

ß = standardized regression coefficients

p = statistical significance value

R² = variance explaining the dependent variable for the sample population

Adjusted R² = variance explaining the dependent variable for the true population value

CHAPTER 5
DISCUSSION

The general objective of this master's thesis was to clarify the association between the level of independence in daily activities at discharge from intensive rehabilitation and the pursuit of social roles of older adults with stroke. The specific hypothesis tested was that daily activities measured at discharge would only be weakly associated with social roles measured six months later. Several points related to the results have been discussed in the article in Chapter 4. This discussion will briefly highlight other striking results and is divided into three sections. The first section discusses the lack of association between daily activities and the specific social roles of interpersonal relationships and leisure. The second section addresses the clinical implications of the results and the need to integrate social roles within the rehabilitation continuum. It also provides an example of a particular approach that could be used to enhance social roles participation. Finally, the third section presents some study limitations with respect to the choice of measurement instruments, the absence of pre-stroke data, and the restricted age distribution of the study sample.

5.1. Association between daily activities and social roles

Daily activities at discharge, as measured with relevant sections of the SMAF, were shown to be strongly associated with the social roles global score of the Life-H when measured at six months following rehabilitation. This study's overall result thus refutes the hypothesis put forth. However, the results were nuanced and diversified when individual social roles domains were investigated. The civic responsibilities and community life domains were strongly associated with daily activities however the interpersonal relationships and leisure domains were not. Interestingly, these social roles (interpersonal relationships and leisure) had extreme high and low mean scores on the LIFE-H, respectively. The findings for these two domains are discussed in the following paragraphs.

5.1.1. Interpersonal relationships

A high mean score of 8.34 ± 1.17 was found for interpersonal relationships in our sample of people with stroke. This value would typically be assigned to a person who engages in relationships without difficulty or possibly requiring slight modifications or minimal assistance. For example, someone with very mild aphasia might require that family members be patient because of slower communication skills.

These high scores could imply that interpersonal relationships are generally preserved (or even solidified) in people with stroke, regardless of their level of independence in daily activities. Although this may be true at the six month mark following rehabilitation, it may not be true in the long term. Relationships could become strained and difficult with time, especially for those with greater levels of dependence in daily activities (Robinson, Murata, & Shimoda, 1999). The first six months may still be a "honeymoon" period for those having returned home. Time elapsed since stroke may affect interpersonal relationships and this would only be evident if repeated measures of this social role were to taken over several time intervals.

Furthermore, this study's sample was characterized by moderate losses secondary to stroke, as evidenced by the mean scores on the Canadian Neurological scale (9.5/11), SMAF (-16.9/63), Chedoke (5.3/7 arm and foot), Boston Naming Test (25.4/60), Motor-Free Visual Perception Test (28.6/36), and Stroop test (39.9 seconds). Our results may have been different with a group of participants with severe stroke.

5.1.2. Leisure

Leisure is the other social role that draws our attention with a low mean score of 3.83 ± 2.77. This value typically describes a person who pursues his/her hobbies with difficulty while requiring modifications or physical assistance in order to complete them. For instance, someone who belongs to a bridge club may need to be driven to the club and may need to use an adapted card holder in order to play. Our findings suggest that the level of independence in daily activities is not associated with the pursuit of leisure. This could be in part explained by the

importance that personal choice plays as a determinant of engagement in leisure, over and above the level of independence in daily activities. This view is supported by Desrosiers et al. (2007) (Desrosiers et al., 2007) and by Ryan and his colleague (2000) (Ryan & Deci, 2000). Furthermore, leisure activities are not crucial in order to live at home (Desrosiers et al., 2007; Parker et al., 1997), therefore, it may be the first social role to be put aside (or given the least importance).

Another important factor that may deter people with stroke from pursuing leisure activities is fatigue, a common consequence of stroke (van de Port, Kwakkel, Schepers, Heinemans, & Lindeman, 2007). Many of our participants would be expected to have exhibited fatigue; however, no measure was available for this potential influencing factor. Also, the pursuit of leisure activities may be more sensitive to issues of accessibility (for example going out infrequently because negotiating stairs is difficult) or opportunity (for example seasonal changes that prevent avid golfers from golfing in the winter) as compared to other social roles domains. For instance, the ability to obtain groceries (a civic responsibility social role) can be performed in several ways. Persons can go and shop for themselves, order by phone with delivery included, or have a family member do the groceries for them. In comparison, attending theatre (a leisure social role) is an activity difficult to perform for someone who can no longer easily go out. The pursuit of this activity may be restricted due to the availability of resources (i.e. lack of a person to accompany the individual or lack of access to adapted transport). In sum, other factors than those able to be verified in this study (i.e. daily activities and capabilities) may affect one's involvement in leisure activity. Clearer identification of these factors would help rehabilitation personnel better address leisure activities during the rehabilitation process.

5.1.3. Originality of results

The results obtained for the two social roles domains discussed above, contribute to the existing literature. The results pertaining to the interpersonal relationships social role are distinct. This specific social role is not found within the instruments used in the research literature reviewed. For instance, the FAI, a common social roles measure, does not incorporate interpersonal relationships within its measure. In the present study, the interpersonal relationships subscale is one that is specific to the Life-H social roles measure. Therefore, the lack of association between daily activities and interpersonal relationships found in this study is an original contribution to existing rehabilitation research knowledge.

Our findings with regards to the lack of association between leisure and daily activities also contribute important information to the field. Sveen et al.'s (1999) results (a low association of $\tau= .11$) are in line with ours. However, their measures of activities and leisure (as measured by a subscale of the FAI) were done concomitantly (at 1 year post stroke) rather than at discharge and follow up as in our study. The results obtained by Carod-Artal (2002) and his colleagues are unlike ours as they found a moderate correlation ($R^2 = 0.32$) between leisure (a subsection of the FAI; measured at 1 year) and daily activities (at discharge). Additional studies looking at daily activities and leisure over the course of time would also further clarify if the lack of association in our study is one that is maintained or evolves with time.

5.2. Clinical implications

5.2.1. The need to attend to social roles in rehabilitation

In theory, rehabilitation aims at improving performance in social participation which includes both daily activities and social roles (Salter et al., 2007). Social roles are acknowledged as having significant value both for healthy older adults (Raymond, 2007) and for those with stroke (Hammell, 2004; Levasseur et al., 2004; Mayo et al., 2002; Sabari, 2001) The lack of meaningful activities (Mayo et al., 2002; Sabari, 2001) has been recognized in the literature as an important consequence of stroke. Also recognized, is the paucity of attention given to social roles from both the clinical (Desrosiers et al., 2003; Korner-Bitensky et al., 2008) and research outcomes perspective (Salter et al., 2007).

Attention to social roles may need to be formally incorporated within the continuum of rehabilitation care. This study's results are reassuring because they suggest that the present emphasis on daily activities during intensive rehabilitation is far reaching, impacting to some degree certain social roles' domains six months following discharge. For these reasons, as well as those stated in the previous paragraph, we purport that attention to the resumption of social roles need to be systematically integrated within the rehabilitation continuum of care. This will be discussed in the following sections.

5.2.2. Integrating social roles within the rehabilitation continuum

Stroke rehabilitation begins for most individuals within the acute care setting. It can progress to an intensive rehabilitation facility (including inpatient and outpatient day hospital rehabilitation services) and, when important sequelae remain, can continue within the community. Presently, attention to social roles is scant (Korner-Bitensky et al., 2008; Salter et al., 2007), and social roles need to be addressed throughout the rehabilitation continuum of care but not with the same priority at each stage.

In the event of a stroke, social roles are suddenly interrupted. Within the acute care phase of rehabilitation, attention to social roles cannot justifiably be the main emphasis of interventions. At this stage, however, it would be ideal if the persons' social roles prior to their stroke could be documented as well as the significance they attribute to them. This would allow clinicians working in intensive rehabilitation settings, with their focus on remediation of capabilities and facilitation of daily activities, to begin to explore the possibilities of which social roles may be resumed, modified or new ones initiated for the first time. However, we recognize that, at this phase, it may not be possible to address the complete spectrum of social roles as lengths of stay are short (Canadian Institute for Health Information, 2008). More importantly, social roles are complex since they interface directly with the person and his/her environment. Therefore, to optimize social roles interventions, they should be undertaken within the actual environmental context of the person (i.e. home or community setting).

The full expression of social roles only occurs upon return to the community and it is at this time that it would be most beneficial to intervene to enhance social

roles. A return home is important as it serves as a reality check; at this point, the person with stroke is often confronted with difficulties pertaining to his/her social participation. These difficulties could be the impetus to motivate the person to seek further rehabilitation. Elements that constrain or facilitate a person's social roles could also be more easily identified by community rehabilitation clinicians.

Presently, in Canada, outpatient and day hospital services can follow the intensive inpatient rehabilitative phase yet it is offered but to a small of percentage of those with stroke (Canadian Institute for Health Information, 2008). Not only are few persons with stroke actually offered these services, but the mandates of these services often confine interventions to within the premises of the respective institutions rather than being community-based. Thus community-based rehabilitation services may need to be reviewed and expanded in order to have them integrate social roles interventions intentionally within their mandates. Moreover, it would be beneficial if these services along with intensive inpatient rehabilitation facilities and those of day hospitals and day centers worked in a deliberate and concerted way with community organizations and municipal recreational services to offer adapted services for those having had a stroke. The accomplishment of social roles within the community could be enhanced for the person with stroke if professionals (e.g. occupational therapists, physiotherapist, social workers, recreational therapists and specialized educators) from these varied institutions had common goals.

5.2.3. Introducing a second wave of rehabilitation

In order to properly address social roles, rehabilitation may have to occur during what could be coined a second wave of rehabilitation. Firstly, a return home enables the person with stroke to identify remaining areas of difficulty or new areas of difficulty especially in the realm of social roles. The person could display greater readiness and motivation to remedy these difficulties with some passage of time. Secondly, gains are believed still possible beyond the intensive phase although progress during the intensive phase may stopped (i.e. plateau was reached) for capability measures and level of independence attained in daily activities. This is supported by the progression of research in the area of neuromuscular adaptation which has shown observable functional improvements with repeated practices of physical activity (Page et al., 2004). Therefore, a second wave of rehabilitation could well challenge the boundaries of these so called plateaus and especially for social roles if these were to be practiced within the respective environments of people with stroke.

Interestingly, this idea of a second wave of rehabilitation is one that appears to follow in line with the 2008 updated version of the "Canadian best practice recommendations for stroke care" (Lindsay et al., 2008). The recommendations advocate regular follow up after intensive rehabilitation for those with moderate to severe strokes. Moreover, one recommendation stipulates that individuals facing declining activity levels six months or later after their stroke should be reassessed and considered for appropriate targeted rehabilitation, with social roles being part of that rehabilitation. However the best context whereby this follow up would occur is not clear that is whether it be within an institution or community based.

Heightened social participation could potentially alleviate/prevent the development of secondary conditions often associated with stroke such as depression (Robinson et al., 1999). If depression sets in, isolation can also follow. As a person becomes more isolated and housebound, a vicious cycle of immobility could begin (Latham et al., 2005; Paolucci et al., 2001). Introducing a second wave of rehabilitation could mean an initial increase in cost output. However, the escalating health care costs associated with secondary conditions could be offset with potential long term savings (Turner-Stokes, 2007).

The success of social roles interventions would depend on the approach taken to enhance their expression. One approach that could be better (or formally) integrated within the rehabilitation process is that of response shift. When a person is confronted with needing to adapt to a new life circumstance (i.e. stroke) and /or manage a new situation or challenge (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007), a "response shift" is desired (Sprangers & Schwartz, 1999). Response shift is defined as one's re-evaluation of a situation as a result of: (a) a change in their internal standards of measurement (recalibration) (b) a change in their values (importance given) or (c) a redefinition of the desired target situation (reconceptualization) (Howard & Dailey, 1979; Schwartz & Sprangers, 1999). It is suggested that people with stroke could be taught to review and reframe their expectations according to their values and priorities in order to modify the pursuit of specific social roles or encourage the development of new ones (e.g. leisure activities). This process can occur naturally and unconsciously, yet directed intervention does seem necessary as the literature often reports that those with stroke have a lack of meaningful activity in their lives indicating that social roles do not undergo this process naturally (Mayo et al., 2002; Sabari, 2001). To illustrate, a man with stroke who can no longer participate in golf tournaments and may at first feel despair. However, through therapy he could learn to reframe his

expectations by wanting to be participating in a golf game as opposed to playing the game. For instance, he may learn to be satisfied teaching the game to others. Thus, response shift interventions may need to be incorporated more explicitly into the rehabilitation process.

In sum, social roles require rehabilitation interventions that are deliberate and that incorporate both an approach that helps the person to adapt to a new life situation and sessions that permit the trial of new or modified ways of pursuing particular social roles. This focus could be orchestrated during a second phase of rehabilitation.

5.3. Limits of the study

The most important limits of this study were addressed in the article in Chapter 4. Four particular limits will be further discussed including our choice of measurement instruments, the lack of pre stroke data on social roles, the recruitment of participants from three geographic regions in the province of Quebec, and the potential confounding effect of age.

The results of this study are in part inextricably linked to the choice of measurement instruments that were used, including the partial SMAF for daily activities and the Life-H for social roles. The SMAF was scored using reliable information extracted from multiple written reports from the participants' medical charts. The reports reviewed did vary in style from one facility to another and information within the charts was not always explicit. In some cases this meant

that information had to be inferred or extrapolated from the reports in order to complete the SMAF. In turn, this could lead to errors in data interpretation, and daily activities scores. The risk of having interpretative errors was in part minimized by having a small percentage of charts (7%) reviewed by a second evaluator. The percentage of agreement was very high (89-100%) denoting good inter-extractor reliability. However, it is worthwhile to note that there remains a risk for potential error as only a small percentage of charts were reviewed by two evaluators. The risk of error would also have been lessened if data had been based on direct observation or a participants' report.

The Life-H instrument used in this study similarly did not cover all dimensions of social roles. It addressed the respondents' perspective (i.e. perceived level of difficulty and level of assistance required to perform individual activities) but it did not include any objective performance indicators. Low performance scores do not indicate if a particular social role is a problem or not. For example, a person with a low score (needs modifications or assistance to perform the activity), could report being completely satisfied with his/her level of engagement in a particular social role. Although, satisfaction with social roles' items within the Life-H was rated, there is no proposed method of incorporating these scores within the total scores. Furthermore, the Life-H does not document or identify environmental factors that facilitate or hinder the pursuit of social roles. Such additional information, if available, would have perhaps better qualified the level of association between daily activities and social roles (Hammel, Jones, Gossett, & Morgan, 2006).

This study did not have pre-stroke data on social roles. Such data, if available, would have told us if social roles performance post stroke had truly changed as a result of the stroke. This research proceeded with the premise that social roles did change as a result of stroke, based on a previous study comparing mean social

roles performance of stroke participants with those of healthy older adults (Desrosiers et al., 2005). Also, data on pre stroke social roles would have provided greater insight as to whether some social roles change more than others following a stroke.

Participants were recruited from three geographic regions in Quebec thus providing a wider representation of a population of older adults having had a stroke. The regions included a metropolitan region, an urban region and a rural region. In an article yet to be published but under review, Vincent and her colleagues (Vincent et al., accepted) found that there were disparities in service provision for those with stroke. The disparities were notable for services that were capability based and much less evident for those relating to social participation, (i.e. social roles being one aspect of social participation). Warranting sufficient numbers in each geographic region further regression analysis of data may have led to slightly altered results.

Social roles in this study were not associated with age. It was anticipated that older participants would have had different patterns of involvement in their social roles compared to younger ones as evidenced in Lefrançois and his colleagues (Lefrançois, Leclerc, Dube, Hamel, & Gaulin, 2001) study with 224 very old (80-85 years of age) community dwelling individuals. These authors found that the very old preferred activities that were emotional, spiritual and social in nature rather than activities linked to physical activity. The participants in the present study were predominantly (66%) under the age of 80 and therefore, the lack of association between age and social roles could be due to the lack of variance in age in our sample. With a larger sample of very old adults, social roles expression post stroke may have been different. The results of our study can thus only be generalized to younger individuals with stroke.

CHAPTER 6
CONCLUSION

In conclusion, this thesis provided an opportunity to clarify the relationship between daily activities measured at discharge from inpatient intensive rehabilitation and that of social roles measured at six months later in older adults with stroke. This was possible because of an available extensive data base to which data from an additional chart reviews for 111 participants were added. This comprehensive data set for an adequately sized sample permitted the use of regression analysis, a sophisticated method of statistical analysis for clarifying the association between the variables of interest.

In general, our results reveal that the level of independence in daily activities at discharge impacts social roles that are pursued six months later, with varying degrees for the individual social roles domains. The discussion proposed possible explanations for these results and explored the potential clinical implications including the examination of an approach to encourage resumption of social roles. The limits of the instruments used, as well as the limits inherent to the study methodology, were elaborated.

The findings discussed stimulate several new research questions. First, research has yet to clearly identify factors that explain why an older adult with stroke engages in leisure or not. In this study, capability measures explained a small percentage of the variance (20%) for the leisure domain for social roles. It would be important to identify other important determinants that would further

explain leisure involvement, such as aspects of the adaptation process (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007). Identification of such factors may assist clinicians in their interventions when trying to promote leisure involvement.

Second, our interpretation of the results suggests that a second wave of rehabilitation should be developed to enhance social roles engagement post stroke. New research could evaluate the success of specific intervention approaches such as integrating formal response shift training for social roles during this phase. The burden of cost, as well as the long term benefits of this second wave of rehabilitation, would also need to be evaluated.

Lastly, research pertaining to social roles needs to be comprehensive. Social roles research necessitates the expertise of several professionals and, due to its multi-faceted nature, it requires thorough assessments. Any future measurement of the resumption of social roles requires the consideration of personal choices, performance, level of satisfaction, and environmental barriers and facilitators that may hinder or foster their expression. The ultimate goal in mind with all new research is to seek ways in which those with stroke can reach an 'optimal' level of social participation.

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Appendix I

Data Collection Form

La relation entre les activités de la vie courante et les rôles sociaux suite à un accident vasculaire cérébral (AVC) chez les personnes âgées.

Cueillette de données – lecture des dossiers

No de sujet :

Nom du centre :

No. du dossier :

Sexe :   □ M   □ F

Type de rapports consultés :

Responsabilités / rôles sociaux *avant* l'AVC (si disponible):

SMAF :

   i.   Score ***AVQ*** :

   ii.   Score ***mobilité*** :

   iii.   Score ***communication***:

   iv.   Score ***fonctions mentales***:

   v.   Score ***tâches domestiques*** :

   vi.   Score pour SMAF parties pertinentes (i. + ii. + v.) :

   vii. Score pour SMAF total:

Nom et signature de l'évaluateur :

Date :

Appendix II

Ethics Committees Approval Certificates

CENTRE DE RECHERCHE
INSTITUT UNIVERSITAIRE DE GÉRIATRIE DE MONTRÉAL

Affilié à l'Université de Montréal

Le 11 juillet 2007

Centre de recherche
Institut universitaire de gériatrie de Montréal
a/s Mme Michelle Plante
4565 Chemin Queen-Mary
Montréal, Québec H3W 1W5

Votre projet intitulé : " La relation entre les activités de la vie courante et les rôles sociaux suite à un accident vasculaire cérébral (AVC) chez les personnes âgées."

Madame Plante,

Il me fait plaisir, au nom du Comité d'évaluation scientifique, d'approuver votre projet cité en rubrique. Comme vous pourrez le constater en parcourant les grilles d'évaluation ci-jointes, votre projet a été jugé favorablement pour la totalité des critères d'évaluation. De plus, nous tenons à souligner la qualité de votre projet, autant pour son contenu scientifique bien documenté que pour sa clarté et sa mise en forme.

Je recommande au CÉR d'examiner votre projet lors de sa prochaine réunion. Je vous souhaite le meilleur des succès dans la réalisation de votre projet, tout en vous rappelant que vous devez attendre l'approbation définitive du CÉR avant de débuter votre recherche.

Je vous prie d'accepter, Madame Plante, l'expression de mes meilleurs sentiments.

Normand Carpentier, Chercheur
Président substitut du comité scientifique

cc: Paule Savignac, Présidente du CÉR
         Gisèle Semerjian, Secrétariat, CÉR

INSTITUT UNIVERSITAIRE DE GÉRIATRIE DE MONTRÉAL

Université **nh**
de Montréal

Montréal, le 31 juillet 2007

Madame Louise Demers, Ph.D.
Madame Michelle Plante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen Mary
Montréal, Québec   H3W 1W5

OBJET : Votre projet de recherche intitulé : **«Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral: Étude multicentrique (2)»** (réf. : 2007-0701A)

Mesdames,

Le comité d'éthique de la recherche a pris connaissance de votre projet et, à votre demande, l'a soumis à une évaluation accélérée. Votre projet est accepté.

Vous trouverez ci-joint le rapport de l'établissement valide jusqu'au 30 juin 2008. Un suivi annuel, sous forme de questionnaire, vous sera envoyé avant l'expiration de ce délai, et la réalisation de cette démarche vous permettra de renouveler le rapport tout au long de votre étude.

Nous vous rappelons que vous devez nous avertir de toute modification au projet de recherche ou au formulaire de consentement.

Par ailleurs, conformément aux directives du Ministère de la Santé et des Services sociaux et tel qu'inscrit au Cadre réglementaire de l'Institut universitaire de gériatrie de Montréal, vous devez constituer un registre des sujets participant à votre projet de recherche. Ce registre comportera les éléments suivants : le titre du projet de recherche, le nom et le prénom du sujet, sa date de naissance et ses coordonnées. Il est à noter que ces informations seront tenues confidentielles dans un registre à part, avec un niveau de sécurité adéquat.

Nous vous remercions de votre collaboration et vous souhaitons la meilleure des chances dans ce projet. Veuillez recevoir, Mesdames, l'expression de nos sentiments les meilleurs.

CENTRE DE RECHERCHE

1982-2007

25 ans

Paule Savignac
Présidente du comité d'éthique de la recherche

PS/gs

Pavillon Côte-des-Neiges

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📠 (514) 340-2802

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INSTITUT UNIVERSITAIRE DE GÉRIATRIE DE MONTRÉAL

Affilié à l'Université de Montréal

CERTIFICAT D'ÉTHIQUE

Le comité d'éthique de la recherche de l'Institut universitaire de gériatrie de Montréal a examiné la demande pour le projet intitulé:

«Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral: Étude multicentrique (2)» (réf. : 2007-0701A)

présenté par : **Mme Louise Demers, Ph.D. et Mme Michelle Plante**

et juge la recherche acceptable au point de vue éthique.

31 juillet 2007

_____

Paule Savignac, présidente

_____

Date

_____

Ce rapport est valide jusqu'au :   30 juin 2008

_____

CENTRE DE RECHERCHE

1982-2007

25 ans

INSTITUT UNIVERSITAIRE DE GÉRIATRIE DE MONTRÉAL

Université
de Montréal

Montréal, le 7 août 2007

Madame Michelle Plante
A/S Madame Louise Demers, Ph.D.
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen-Mary
Montréal (Québec) H3W 1W5

OBJET : Les modifications de votre projet intitulé : **«Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral: Étude multicentrique (2) »** (réf. : 2007-0701A)

Madame,

Le comité d'éthique de la recherche a pris connaissance des modifications apportées au projet mentionné ci-dessus (cf. votre courriel du 3 août 2007), soit le remplacement de l'instrument de mesure MIF par l'Index de Barthel – version modifiée à 15 items et le remplacement de l'ergothérapeute désignée, madame Malgo Depa par madame Lisanne Rhéaume.

À ce sujet, le Comité attire votre attention sur le fait qu'il faudra changer le nom de l'ergothérapeute dans les lettres que vous adresserez aux établissements.

Les modifications proposées sont acceptées sur le plan éthique. Néanmoins, nous les transmettons au comité d'évaluation scientifique qui communiquera avec vous si nécessaire.

Nous vous remercions de nous avoir informés de ces modifications et nous vous souhaitons bonne chance dans la suite de vos projets. Veuillez recevoir, Madame, l'expression de nos sentiments les meilleurs.

Paule Savignac
Présidente du comité d'éthique de la recherche

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**Centre de santé et de services sociaux
Jeanne-Mance**

Centre affilié universitaire

COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Le 28 juin 2007

Madame Michelle Plante, étudiante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen Mary
Montréal, Québec
H3W 1W5

Objet : Décision du Comité d'éthique de la recherche concernant votre projet «La relation entre les activités de la vie courante et les rôles sociaux suite à un accident vasculaire cérébral (AVC) chez les personnes âgées»

Madame Plante,

Le Comité d'éthique de la recherche du CSSS Jeanne-Mance a évalué votre projet de recherche en comité restreint. Votre projet a été accepté par les membres de ce comité. Nous vous rappelons que votre engagement à respecter la confidentialité auquel vous avez déjà souscrit, se poursuit dans cette collecte de données.

Étant donné la mission du Centre de santé et de services sociaux Jeanne-Mance et les thèmes de la programmation de son Centre de recherche – *inégalités sociales, discriminations et pratiques alternatives de citoyenneté* – nous vous encourageons à diffuser les résultats de votre recherche auprès des personnes qui y ont pris part, directement et indirectement. Le Centre de recherche du CSSS Jeanne-Mance organise chaque année une série de conférences-midis où sont invités les chercheurs ayant réalisé un projet en collaboration avec le CSSS. La coordonnatrice de l'enseignement et de la recherche du CSSS Jeanne-Mance pourra vous aider, si nécessaire, à planifier une activité de diffusion de ce type.

Les membres du comité d'éthique de la recherche croient que les chercheurs demeurent responsables des dimensions éthiques pendant tout le déroulement de leur projet. Ils vous invitent donc à les contacter en tout temps si vous rencontrez des problèmes dont vous voulez discuter avec eux. Le CÉR profite de l'occasion pour vous rappeler certaines exigences relatives au suivi continu des projets de recherche. Conformément au Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (Québec, 1998), vous devrez :

    a)   conserver les noms et coordonnées des participants de votre recherche en respectant la confidentialité et ce, aussi longtemps que vous en conserverez les données, afin que ces personnes puissent être retracées si un problème se révélait en cours ou après le projet (mesure 9 du Plan d'action);

b) aviser le Comité de toute modification devant être apportée au projet de recherche;

c) rapporter rapidement au Comité tout effet indésirable grave ou incident inattendu survenu au cours du projet;

d) rapporter au Comité tout nouveau renseignement susceptible d'influer sur la décision d'un participant de continuer sa participation au projet;

e) informer le Comité d'un retrait d'autorisation pour le projet;

f) informer le Comité en cas de rupture de l'équilibre inconvénient-bénéfice au vu des données cumulées;

g) informer le Comité advenant un problème identifié par un tiers lors d'une vérification;

h) informer le Comité d'une cessation temporaire ou définitive du projet (avis accompagné d'un rapport de cessation);

i) informer le Comité de la fin du projet;

j) faire rapport du déroulement du projet au moins une fois par année avec la demande de renouvellement, s'il y a lieu.

Pour joindre le comité d'éthique de la recherche, vous devez contacter :

Madame Ginette Beaulieu.
Technicienne en administration
1250, rue Sanguinet
Montréal, QC
H2X 3E7
Tél. : 514 527-9565 poste 3785
ginette.beaulieu@ssss.gouv.qc.ca.

En attendant, nous vous prions d'accepter, Madame, nos salutations distinguées.

Carol Gosselin
Présidente du Comité d'Éthique de la Recherche
CSSS Jeanne-Mance

Le 4 juillet 2007

Madame Michelle Plante, étudiante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen Mary
Montréal, Qc
H3W 1W5

Objet :-   Demande d'accès à l'information dans le cadre d'une recherche

Madame,

À la suite de votre demande de consultation de dossiers médicaux dans le cadre d'une recherche complémentaire au projet «Besoins et services de réadaptation pour les personnes aînées ayant subi un AVC», nous avons acheminé votre projet au comité d'éthique de la recherche du CSSS pour fins d'évaluation.

Vous trouverez ci-joint le certificat d'éthique ainsi que la lettre qui vous est adressée par la présidente du comité.

Afin de compléter la démarche pour vous donner accès aux renseignements requis pour votre projet, vous devrez me communiquer les noms des usagers dont vous désirez consulter les dossiers ainsi que le nom des personnes qui pourraient y avoir accès dans le cadre de votre étude.

Je serai par la suite en mesure de vous donner les autorisations requises et d'en informer l'archiviste concernée.

Espérant le tout conforme à vos attentes, recevez mes salutations distinguées.

La directrice de la qualité des services, de la santé publique
et de l'administration de la recherche et de l'enseignement,

Sylvie Simard

Centre de santé et de services sociaux Jeanne-Mance

Centre affilié universitaire

COMITÉ D'ÉTHIQUE DE LA RECHERCHE

CERTIFICAT D'APPROBATION ÉTHIQUE

Dossier no. : 2007-07

Titre du projet : *La recherche entre les activités de la vie courante et les rôles sociaux suite à un accident vasculaire cérébral (AVC) chez les personnes âgées*

Sous la direction de : Michelle Plante, étudiante à la maîtrise, Université de Montréal

Les membres du Comité d'Éthique de la Recherche du CSSS Jeanne-Mance ont jugé le projet mentionné ci-haut conforme à l'éthique de la recherche sur les êtres humains.

Ce certificat est valide à compter du 3 juillet 2007 pour la durée du projet.

Carol Gosselin
Présidente du Comité d'éthique de la recherche
CSSS Jeanne-Mance

**Centre de santé et de services sociaux
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Le 27 août 2007

Madame Michelle Plante, étudiante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen Mary
Montréal, Qc
H3W 1W5

Objet :-   Demande de consultation de dossiers médicaux au CH Jacques-Viger
           Projet de recherche

Madame,

À la suite de votre lettre du 30 juillet dernier, la présente vous autorise à consulter sur place les dossiers médicaux dont la liste est ci-jointe et ce, dans le cadre d'une recherche complémentaire au projet «Besoins et services de réadaptation pour les personnes aînées ayant subi un AVC».

Avant de vous présenter au Centre d'hébergement Jacques-Viger, il serait important de prendre rendez-vous avec l'archiviste, Madame Jessica Boulard Demers, au numéro de téléphone 514-842-7180 poste 7006.

Il est entendu que l'utilisation de ces renseignements devra se faire dans le respect de la *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels*.

Espérant le tout conforme à vos attentes, recevez mes salutations distinguées.

La directrice de la qualité des services, de la santé publique
et de l'administration de la recherche et de l'enseignement,

Sylvie Simard

c.c.   Josée Hébert, adjointe au chef des archivistes
        Jessica Boulard Demers, archiviste

CLSC des Faubourgs
1250, rue Sanguinet
Montréal (Québec) H2X 3E7

Téléphone : (514) 527-2361
Télécopieur : (514) 847-9278

Centre de santé et de services sociaux –
Institut universitaire de gériatrie de Sherbrooke
Health and Social Services Centre –
University Institute of Geriatrics of Sherbrooke

CXII

Le 27 août 2007

Madame Michelle Plante
Étudiante à la maîtrise
Université de Montréal

Objet : Projet : «Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire et cérébral : Étude multicentrique»

Madame,

J'ai pris connaissance de votre lettre adressée à madame Nicole Veilleux concernant le sujet en titre. Par la présente, je vous autorise à avoir accès aux dossiers des usagers ayant fait partie du projet de recherche entre 2003 et 2005 avec la clientèle post AVC. Cette autorisation est valable jusqu'au 31 décembre 2007.

Il est important d'avoir en votre possession cette autorisation lors de vos contacts éventuels avec le personnel des archives du CSSS-IUGS afin de faciliter les communication d'information.

Suzanne Gosselin, M.D.
Directrice des services professionnels par intérim

SG/cd

c.c. Caroline Pigeon, responsable des archives
Johanne Desrosiers, centre de recherche sur le vieillissement

Hôpital et centre
d'hébergement D'Youville

1036, rue Belvédère Sud
Sherbrooke (Québec) J1H 4C4

Téléphone : 819 821-1150
Télécopieur 819 829-7153

Centre affilié UNIVERSITÉ DE SHERBROOKE

Centre de santé et de services sociaux
du Grand Littoral

Le 24 septembre 2007

Mme Michelle Pante
Centre de recherche
Institut Universitaire de Gériatrie de Montréal
4565 chemin Queen-Mary
Montréal
H3W 1W5

Objet : **Demande d'accès aux dossiers dans le cadre d'un projet de recherche sur les besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral : étude multicentrique ref : 2003-2004.**

Madame,

Pour faire suite à votre requête concernant l'objet en rubrique, nous autorisons vous-mêmes et/ou des chercheurs désignés à avoir accès au dossier des sujets identifiés pour la recherche et ce, pour la période débutant le 1er octobre 2007 et se terminant le 30 mars 2008.

Nous vous référons à M. Mattieu Audet, chef du services des archives, au 380-8992 poste 2606 qui va assurer le soutien aux modalités d'accès aux dossiers.

Veuillez agréer, Madame, l'expression de mes sentiments les meilleurs.

Le directeur des services professionnels,

Bernard Jean MD M.Sc.

c.c.   M. Mattieu Audet, chef du service des archives
        Mme Isabelle Barrette, directrice du programme personnes en perte d'autonomie liée au vieillissement, soins à domicile et déficience physique
        M. Claude Soucy, directeur général adjoint

CRDP-CA

Centre de réadaptation
en déficience physique

Chaudière-Appalaches

SIÈGE SOCIAL :

2055, boul. de la Rive-Sud
Saint-Romuald (Québec) G6W 2S5
Téléphone: (418) 834-5888
Télécopieur: (418) 834-0018

CRDP

Centre
de réadaptation
en déficience
physique

Le 10 octobre 2007

Madame Michelle Plante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen-Mary
Montréal   H3W 1W5

Objet : Demande d'accès aux dossiers dans le cadre d'un projet de recherche sur
les besoins et services de réadaptation pour les personnes âgées ayant subi
un accident vasculaire cérébral : étude multicentrique ref : 2003-2005

Madame,

Pour faire suite à votre requête concernant l'objet en rubrique, nous autorisons vous-mêmes et/ou des chercheurs désignés à avoir accès au dossier des sujets identifiés pour la recherche et ce, pour la période débutant le 1er octobre 2007 et se terminant le 30 mars 2008.

Nous vous référons à madame Julie Perron, chef du service des archives, au 834-5888, poste 1112, qui va assurer le soutien aux modalités d'accès aux dossiers.

Veuillez agréer, Madame, l'expression de mes sentiments les meilleurs.

Le directeur des services professionnels,

Dr Marc-André Moreau

AM/db

c.c. :   Madame Louise Lavergne, directrice générale – CRDP-CA
Pierre Gendreau, directeur des programmes – CRDP-CA
Madame Julie Perron, chef du service des archives

POINTS DE SERVICE:

CHARNY
9330, boul. du Centre-Hospitalier,
Charny (Québec) G6X 1L6
Téléphone: (418) 380-2064
ATS: (418) 380-2089
Télécopieur: (418) 380-2091

SAINT-ROMUALD
2055, boul. de la Rive-Sud,
Saint-Romuald (Québec) G6W 2S5
Téléphone: (418) 834-5888
Télécopieur: (418) 834-0018

BEAUCEVILLE
253, Route 108, Beauceville
(Québec) G5X 2Z3
Téléphone: (418) 774-3304
ATS: (418) 774-6381
Télécopieur: (418) 774-6916

THETFORD MINES
1717, Notre-Dame Est,
Thetford Mines (Québec) G6G 2V4
Téléphone: (418) 338-7778
Télécopieur: (418) 338-7762

MONTMAGNY
350, boul. Taché Ouest,
Montmagny (Québec) G5V 3R8
Téléphone: (418) 248-0630 poste 2216
Télécopieur: (418) 248- 8449

Le 10 octobre 2007

Madame Michelle Plante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen-Mary
Montréal   H3W 1W5

Objet : Demande d'accès aux dossiers dans le cadre d'un projet de recherche sur
les besoins et services de réadaptation pour les personnes âgées ayant subi
un accident vasculaire cérébral : étude multicentrique ref : 2003-2005

Madame,

Pour faire suite à votre requête concernant l'objet en rubrique, nous autorisons vous-mêmes et/ou des chercheurs désignés à avoir accès au dossier des sujets identifiés pour la recherche et ce, pour la période débutant le 1ᵉʳ octobre 2007 et se terminant le 30 mars 2008.

Nous vous référons à madame Julie Perron, chef du service des archives, au 834-5888, poste 1112, qui va assurer le soutien aux modalités d'accès aux dossiers.

Veuillez agréer, Madame, l'expression de mes sentiments les meilleurs.

Le directeur des services professionnels,

Dr Marc-André Moreau

AM/db

c.c. :   Madame Louise Lavergne, directrice générale – CRDP-CA
Pierre Gendreau, directeur des programmes – CRDP-CA
Madame Julie Perron, chef du service des archives

HÔPITAL DE RÉADAPTATION
VILLA MEDICA

Le 18 septembre 2007

Mme Michelle Plante
Centre de recherche
Institut universitaire de gériatrie de Montréal
4565, chemin Queen-Mary
Montréal (Québec)
H3W 1W5

OBJET : **Projet de recherche «Besoins et services de réadaptation pour les personnes âgées ayant subi un accident vasculaire cérébral : Étude multicentrique»**

Madame,

Veuillez excuser mon retard à répondre à votre lettre du 7 août denier.

De retour de vacances récemment, j'ai pris connaissance des précisions apportées à votre demande et je constate que, comme votre projet porte effectivement sur des données secondaires déjà disponibles dans les dossiers étudiés lors de la première phase du projet, il ne s'agit pas d'une autre recherche et qu'une nouvelle démarche auprès des usagers ne m'apparaît pas requise.

Compte tenu du nombre de dossiers visé et du temps requis pour les consulter, je souhaiterais obtenir quelques précisions quant au processus de révision que vous prévoyez appliquer afin d'évaluer la nature et l'importance des ressources qu'il nous faudrait y allouer.

Vous assurant, dans les limites de nos ressources, de notre entière collaboration à faciliter la réalisation de votre projet, je vous prie d'agréer, madame, l'expression de mes salutations sincères.

Laurent Trempe, M.D.
Président du comité d'éthique et de la recherche

LT/sp

cc : Hazel Lefebvre
Michèle Aumais-Hénuset

Appendix III

Authorization Forms from

Faculté des études supérieures

Université ᒡᒥ
de Montréal

Faculté de médecine
Vice-décanat
Recherche et études supérieures

Le 24 octobre 2007

Madame Michèle Plante
66, 5e Avenue Sud
Roxboro QC H8Y 2V1

Objet : **Autorisation de déposer votre mémoire de maîtrise sous forme d'articles**
 PLAM09516106 Programme de Sciences biomédicales (2-484-1-0)

Madame

Suite à votre demande, j'ai le plaisir de vous autoriser à présenter votre mémoire maîtrise sous forme d'articles. Il est entendu que vous devrez vous soumettre aux conditions minimales de dépôt décrites dans le *« Guide de présentation des mémoires de maîtrise et des thèses de doctorat »*, édition de mars 2001. Ce document est disponible sur le site de la FES, www.fes.umontreal.ca. Vous pouvez également vous le procurer à la Librairie de l'Université de Montréal. La norme minimale pour le dépôt par articles est d'un article comme premier auteur soumis (soumettre la lettre de l'éditeur).

Cependant, afin de respecter la loi canadienne sur les droits d'auteurs, vous devrez, au moment du dépôt de votre mémoire, remettre, avec les formulaires de reproduction et diffusion dûment complétés et signés, les déclarations écrites de tous les coauteurs des articles inclus dans votre mémoire autorisant la reproduction et la diffusion de votre mémoire de maîtrise.

Veuillez agréer, Madame, l'expression de mes sentiments les meilleurs.

Le directeur du programme
de Sciences biomédicales

Daniel Lajeunesse, Ph.D.

c.c. :　Louise Demers
　　　FES – Études

C.P. 6128, succursale Centre-ville
Montréal QC H3C 3J7 　　Télécopieur : 514 343-5751 　　www.med.umontreal.ca/recherche

Université de Montréal

Faculté de médecine
Vice-décanat
Recherche et études supérieures

Le 25 octobre 2007

Madame Michèle Plante
66, 5e Avenue Sud
Roxboro QC H8Y 2V1

Objet : **Autorisation de soumettre votre mémoire de maîtrise dans une autre langue**
PLAM09516106 Programme de Sciences biomédicales (2-484-1-0)

Madame,

Suite à votre demande, j'ai le plaisir de vous autoriser à soumettre votre mémoire de maîtrise en langue anglaise, en raison de vos études antérieures qui ont été réalisées dans cette langue.

Il est entendu que vous devrez vous soumettre aux conditions minimales de dépôt décrites dans le *« Guide de présentation et d'évaluation des mémoires de maîtrise et des thèses de doctorat »*, édition de mars 2001 (la langue de rédaction du mémoire figurant au point C.9.1). Ce document est disponible sur le site de la FES,
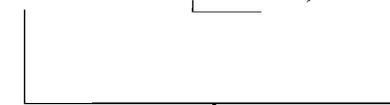http://www.fesp.umontreal.ca/etudiants_actuels/memoire_these.html.
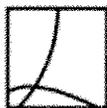Vous pouvez également vous le procurer à la Librairie de l'Université de Montréal.

Veuillez agréer, Madame, l'expression de mes sentiments les meilleurs.

Le directeur du programme
de Sciences biomédicales,

Daniel Lajeunesse, Ph.D.

c.c. :   Louise Demers
FES – Études

Appendix IV

Confirmation of Article Submission

and Co-authors Accord

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Your signature at the place marked below will indicate your acceptance of this letter.

Accepted: [Please SIGN below.]

Michelle Plante
Author Printed Name

Author Signature   _Feb 9th 2009_
                        Date

LOUISE DEMERS
Author Printed Name

Author Signature   _Feb 9th, 2009_
                        Date

BONNIE SWAINE
Author Printed Name

Author Signature   _Feb 9 2009_
                        Date

JOHANNE DESROSIERS
Author Printed Name

Author Signature   _2009/02/09_
                        Date

www.thomasland.com • fax: + 314-963-9345 • editor@thomasland.com

The publisher of Topics of Stroke Rehabilitation, Mr. Kenneth Killion agreed that the article in Chapter four could be included in this master's thesis. 2009-06-17

YAHOO! MAIL Classic

A manuscript number has been assigned to Association between daily activities following stroke rehabilitation and social role functioning upon return to the community.

Monday, February 9, 2009 1:36 PM

From:

"Topics in Stroke Rehabilitation" <TSReditor@thomasland.com>

To:

m.plante@umontreal.ca, mplante_ca@yahoo.com

Dear Ms. Plante,

Your submission entitled "Association between daily activities following stroke rehabilitation and social role functioning upon return to the community." has been been assigned the following manuscript number: STROKEREHAB-D-09-00003.

You will be able to check on the progress of your paper by logging on to Editorial Manager as an author.
The URL is http://strokerehab.edmgr.com/.

Thank you for submitting your work to this journal.

Kind regards,

Kenneth Killion
Managing Editor
Topics in Stroke Rehabilitation

ACCORD DES COAUTEURS

1) Identification de l'étudiant et du programme

Michelle Plante
Étudiante à la maîtrise, École de réadaptation
Faculté de médecine, Sciences biomédicales (option réadaptation)

2) Description de l'article

Titre: Association between daily activities following stroke rehabilitation and social roles functioning upon return to the community
Auteurs : Michelle Plante Erg., Dr. Louise Demers, Dr. Bonnie Swaine,
Dr. Johanne Desrosiers.
Revue ou l'article a été soumis: Topics of Stroke Rehabilitation
Éditeurs : Thomas Land Publishers
Date de soumission : 9 février 2009
État de la demande : en révision

3) Déclaration de tous les coauteurs
À titre de coauteur de l'article identifié ci-dessus, je suis d'accord pour que Michelle Plante inclut cet article dans son mémoire de maîtrise intitulé :
Association between Independence in Daily Activities and Social Roles in Older Adults with Stroke.

 Louise Demers
| Coauteur | Signature | Date |

 Bonnie Swaine   March 10, 2009
| Coauteur | Signature | Date |

Johanne Desrosiers   March 9, 2009
| Coauteur | Signature | Date |