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**PARTICIPATION IN EVERYDAY
OCCUPATIONS AND LIFE
SATISFACTION IN THE
STROKE-CAREGIVER DYAD**

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Institutet**

Stockholm 2012

This thesis is dedicated to my parents, *Grace and Justin Garcia*, for teaching me the meaning of a higher education.

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ISBN 978-91-7457-953-6

Published by Karolinska Institutet. Printed by [name of printer]

ABSTRACT

In order to develop knowledge that can be used within rehabilitation after stroke, the general aim was to explore participation in everyday occupations and the relation to life satisfaction in persons with stroke and within the caregiver dyad. Furthermore, the aim was to understand and describe the lived experience of persons enacting agency in everyday occupations during the first year after stroke.

The aim of **study I** was to understand the lived experience of enacting agency (*i.e.* making things happen by ones' actions in everyday life) and to describe the phenomenon of agency during the year after stroke. This was done with a phenomenological approach. **Studies I and II** had a prospective, longitudinal design and the aim of **study II** was to explore the extent of and the factors associated with restrictions in participation in everyday occupations *i.e.* occupational gaps, 12 months after stroke and to identify factors at 3 months that predicted occupational gaps 12 months after stroke. **Studies III-IV** used a cross-sectional design and **study III** described the combined life satisfaction of the stroke-caregiver dyad and investigated the association of the combined life satisfaction with the perceived impact of the stroke and the caregivers' caregiver burden one year after stroke. The aim of **study IV** was to explore and describe persons' with stroke and their caregivers' restrictions in participation in everyday occupations three months after study inclusion and to depict this in relation to their life satisfaction, the dyads combined life satisfaction, caregiver burden, perceived impact of stroke and ADL ability.

The findings in **study I** showed that persons after a stroke experienced the process of enacting agency as complex negotiations of varied and changing aspects in different situations. The four characteristics that described how the participants enacted agency concerned how they managed their perturbed bodies, took into account the past and envisioned the future, dealt with the world outside themselves, and negotiated through internal dialogues. Restrictions in participation *i.e.* occupational gaps, were perceived by 83% of persons with stroke and almost half of the caregivers, three months after study inclusion (**study IV**), and 45% of the persons with stroke, one year after the incident (**study II**). Three months after stroke, ADL ability, social participation and not being born in Sweden predicted occupational gaps at 12 months (**study II**). Occupational gaps were associated with life satisfaction one year after stroke (**study II**) but there was a low correlation between the number of occupational gaps for the persons with stroke and their life satisfaction, 3 months after study inclusion. This also regarded the caregivers (**study IV**). Almost two-thirds of the stroke-caregiver dyads gave congruent responses regarding their global life satisfaction. Dyads, where both persons had a low life satisfaction; 26% and 38%, respectively (**studies III-IV**), experienced caregiver burden, stroke impact, and occupational gaps to a greater extent, compared with those dyads where both persons were satisfied (**study III-IV**).

Persons use complex negotiations to participate in everyday occupations after stroke and may need client-centered support. Their process of enacting agency challenges existing definitions of agency. Also, determining predictors of occupational gaps may facilitate identification of persons risking participation restrictions. A dyadic perspective regarding life satisfaction and life after stroke can provide information about potential vulnerable persons or dyads. This knowledge can be used clinically to prevent restrictions in participation in everyday occupations for both individuals and dyads affected by stroke.

LIST OF PUBLICATIONS

- I. Bergström, A., Eriksson, G., Asaba, E., Erikson, A., Tham, K. Negotiating on a continuum of complexity: The lived experience of enacting agency after a stroke. In manuscript.
- II. Bergström, A., Guidetti, S., Tistad, M., Tham, K., von Koch, L., Eriksson, G., (2012). Perceived occupational gaps one year after stroke: An explorative study. *Journal of Rehabilitation Medicine*, 44, 36-42
- III. Bergström, A., Eriksson, G., von Koch, L., Tham, K. (2011). Combined life satisfaction of persons with stroke and their caregivers: associations with caregiver burden and the impact of stroke. *Health and Quality of Life Outcomes* 9:1 <http://www.hqlo.com/content/9/1/1>
- IV. Bergström, A., von Koch, L., Tham, K., Eriksson, G. A dyadic perspective on participation in everyday life and life satisfaction after stroke. In manuscript.

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
BI	Barthel Index
CADL	Client-centered ADL
CBs	Caregiver Burden scale
CMOP	Canadian Model of Occupational Performance
EPP	Empirical Phenomenological Psychological
I-ADL	Instrumental activities of daily living
ICF	International Classification of Functioning, Disability and Health
LAS-1	Life After Stroke, phase 1
LAS-2	Life After Stroke, phase 2
LiSat-11	Life Satisfaction Checklist
MMSE	Mini Mental State Exam
MU	Meaning unit
NPR	National Patient Register
OS	Occupational Science
OT	Occupational Therapy
OGQ	Occupational Gaps Questionnaire
RCT	Randomized Controlled Trial
SIS	Stroke Impact Scale
WHO	World Health Organization

INTRODUCTION

This main focus of this thesis is on persons whose lives have been affected by a stroke. The focus is also on persons whose lives have been indirectly affected but have a caring relationship with the person with stroke (here after referred to as caregivers). Persons with stroke and their caregivers may experience difficulties doing things in their everyday lives. Thus, the focus is on participation in everyday occupations as well as on the persons' satisfaction with life. This thesis aims at portraying the persons' perceptions regarding their occupations, life satisfaction and the impact of stroke on everyday life. This thesis focuses also on the lived experiences of a prerequisite to participation, the enactment of agency in everyday life for persons with stroke. The introduction aims at providing a theoretical background and an overview of the terminology relevant to the foci of this thesis. This will include the concepts of participation, life satisfaction, the stroke-caregiver dyad and agency. This thesis aims at contributing knowledge that can be used within rehabilitation after stroke.

THEORETICAL BACKGROUND -AN OCCUPATIONAL PERSPECTIVE

*Occupation*¹ is the foundation for the four papers included in this thesis. This thesis adopts the definition of occupation from Townsend and Polatajko (2007) "groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves...." (Townsend & Polatajko, 2007) (pg. 369).

This thesis strives to have an occupational perspective, a focus on human doing, reflecting what individuals do, either by themselves or collectively (Njelesani, Tang, Jonsson, & Polatajko, 2012). An occupational perspective assumes the connections of participation in meaningful occupations to health and well-being (Hocking, 2009; Law, 2002; Law, Steinwender, & Leclair, 1998; Njelesani et al., 2012). Moreover, an occupational perspective regarding research has to do with discovering and describing how the experience of doing and participation relates to well-being (Borell, 2008). Furthermore, there is empirical evidence that participation in occupations is strongly related to life satisfaction (Eriksson, Kottorp, Borg, & Tham, 2009). Life satisfaction is considered synonymous with happiness (Veenhoven, 1984), and happiness, like occupation, is recognized as a human need (Wilcock, 2002).

¹ The terms occupation and activity have been used interchangeably in the text.

Engagement in occupations is vital for humans (Law, 2002) and needed for humans to flourish (Wilcock, 2002). Therefore, participation in everyday occupations is considered a right for all individuals. An occupational right has to do with being entitled to choose or have access to occupations that are required to promote health, well-being and social inclusion for all persons (Christiansen & Townsend, 2011). However, occupational imbalances can affect health and quality of life or life satisfaction by being over or under occupied (Christiansen & Townsend, 2011). A balance in occupations that are perceived as congruent between desired and actual patterns of occupation can ultimately lead to improved health, and greater life satisfaction (Matuska & Christiansen, 2008). An example of a population with possible occupational needs may involve caregivers because of their burden in caregiving (Whiteford & Hocking, 2012).

Facilitating participation in everyday occupations has been proposed as the grounds for occupational therapy (Law, 2002). Participating in everyday occupations is done in context and the context often includes other people. This is recognized in models such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007). In this model, it is not only the individual that is considered as a potential client in occupational therapy interventions but families, groups and other populations, as well. The term *family* recognizes a broad spectrum to incorporate different types of families (domestic groups of people, affiliated by birth marriage or other relationships) (Townsend & Polatajko, 2007). As in the CMOP-E, this thesis hopes to broaden the term of “client” and includes in two studies, the person who acts as caregiver, beyond the individual client. The term caregiver is used to denote a relationship of a person to another person with possible elements of interdependency or assistance and this term will be presented in more detail, in a latter section.

Enablement in occupations may, therefore, extend to other persons who may traditionally not be perceived as the client but has issues in participating in everyday occupations. This brings us to the question “*who is the client?*” Should it be the individual; the person with stroke with occupational issues, or the caregiver with occupational issues? Should it be both persons together seen as one unit in their engagement of co-occupations? These questions form the basis of studies III and IV in this thesis. These studies, with their dyadic perspective, aspire to shed more light on this area.

Participation

Participation is an important construct and outcome in the field of rehabilitation (Heinemann, 2010; Heinemann et al., 2011; Mallinson & Hammel, 2010; Noonan et al., 2009; Poulin & Desrosiers, 2009; Rochette, Korner-Bitensky, & Levasseur, 2006) as well as occupational therapy (Christiansen & Baum, 2005; Kielhofner, 2008; Law, 2002; Townsend & Polatajko, 2007; Whiteford & Hocking, 2012). In 2001, the concept of participation was introduced via the International Classification of Functioning, Disability and Health (ICF) to replace the word “handicap” and is defined by the World Health Organization (WHO) as involvement in a life situation (WHO, 2001) (p.193). However, the WHO’s definition of participation has been criticized as poorly defined (Mallinson & Hammel, 2010), limited (Dijkers, 2010) and for excluding the subjective experience of the individual (Hemmingsson & Jonsson, 2005).

Mallinson and Hammel (2010) describe participation as the nexus of what a person can, wants and has the opportunity to do, and is not prevented from doing. This description of participation is in congruence with the view of participation in everyday occupations and is, therefore, adopted in this thesis. Participation also involves what the social environment enables and expects a person to do and is found at the crossroads of a person’s skills, desires and preferences. In other words, participation is considered as doing in context and is coupled to the importance of what one is doing (Mallinson & Hammel, 2010). For this reason, participation is considered an individual experience and should be assessed regarding the individuals’ perceptions (Noreau & Boschen, 2010; Poulin & Desrosiers, 2009).

Participation in everyday occupations

Participation, or involvement in everyday occupations (Law, 2002) is the foundation for the concept participation in everyday occupations used in the context of this thesis. Participation in everyday occupations is a dimension of the WHO’s term participation but with the focus on occupations. Participation in everyday occupations involves the aspect of “doing” and “wanting to do” different occupations found in everyday life. Participating in occupations is more than the actual performance but includes the subjective experience of the doing (Kielhofner, 2008). Furthermore, an individual’s perceived “doing” can be on a continuum of fully participating to being partially involved in an activity or occupation. Not performing a desired occupation or performing an occupation that one does not want to do indicates a negative impact on the level of participation in everyday occupations and has been named an occupational

gap (Eriksson, Tham, & Borg, 2006). Experiencing a gap in everyday occupations might affect one's sense of self-esteem and one's sense of self (Eriksson & Tham, 2010). The concept of occupational gaps, built on the premises of the Model of Human Occupation and the CMOP, has been operationalized in the Occupational Gaps Questionnaire (Eriksson, 2012). Occupational gaps are investigated in persons with stroke in study II, and in persons with stroke and their caregivers in study IV.

Participation in persons with stroke and caregivers

A number of studies deal with participation after a stroke (Desrosiers et al., 2008; Desrosiers, Noreau, et al., 2006; Desrosiers, Rochette, et al., 2006; Fallahpour, Tham, Taghi Joghataei, Eriksson, & Jonsson, 2011; N. E. Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002; Ostir, Smith, Smith, & Ottenbacher, 2005; Thonnard, Bouffioulx, Arnould, & Vandervelde, 2010). A composite picture of the finding of different studies showed that a stroke negatively affects levels of participation, even for persons with a mild stroke (A. Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007). Participation was shown to improve in the first three months after discharge from acute care or rehabilitation but remained stable between three and six months post discharge (Desrosiers et al., 2008). Participation in daily activities decreased over time whereas participation in social roles remained stable or even improved, up to 4 years post stroke (Desrosiers, Rochette, et al., 2006). Community participation was associated with better quality of life (N. E. Mayo et al., 2002) and increased functional status (Ostir, Smith, Smith, & Ottenbacher, 2005).

Predictors of participation have also been investigated in studies and show that age, comorbidity, affect and lower extremity coordination (Desrosiers, Noreau, et al., 2006), and fewer depressive symptoms (Desrosiers et al., 2008) predicted participation. Also, performance-based and social-based participation was explained by mood state (Fallahpour et al., 2011). However, there are no studies with the sole focus on predictors of participation in everyday occupations, and this is, therefore, the focus in study II.

Participation has also been studied in relatives or caregivers to the person with stroke. A comprehensive review of the scientific literature regarding participation found that the caregivers' responsibilities increased and included additional responsibilities; interpersonal relations were affected, leisure activities declined, and paid and volunteer work declined (Pellerin, Rochette, & Racine, 2011). However, no studies were found

within this review that had a dyadic perspective regarding participation after stroke (Pellerin et al., 2011). We know little about how the stroke-caregiver dyad perceives participation in everyday occupations and is, therefore, investigated in study IV in this thesis.

An overarching goal is for all persons to fully participate in society (von Groote, Bickenbach, & Gutenbrunner, 2011). Therefore, more knowledge is needed to develop an understanding of how a number of different factors influence participation (Law, 2002). Knowledge regarding participation in everyday occupations for persons with stroke and for their caregivers could potentially lead to effective, new ways of interventions in order to support persons' participation process after a stroke. Studies II and IV in this thesis aspire to add to this knowledge base.

STROKE AND EVERYDAY LIFE

The Swedish national register (Riks-stroke) registered a little more than 25, 500 incidents of stroke in 2010, the greatest number registered since the beginning of the register in 1994. More than 80% of the persons afflicted by a stroke in Sweden are over the age of 65. Stroke is the third most common cause of death after heart attacks and cancer and the most common cause of neurological disorder in the adult population (Riks-stroke, 2011). Persons with stroke receiving care at a stroke unit have increased, leading to an increase in survival after stroke. However, the total length of stay in inpatient care has decreased somewhat to 15 days (Riks-stroke, 2011).

Persons are commonly discharged home and 66% lived in their own homes, one year after their stroke (Riks-stroke, 2011). The percentage of persons after stroke living at home continues to increase slowly (Riks-stroke, 2011). This may be a positive trend, but the need of assistance provided by close relatives is high. One year after stroke, 41% of those afflicted perceived that they were partially dependent on assistance of a relative, while 16% responded that they were totally dependent on assistance. The type of assistance varied and three of 10 persons needed assistance with personal ADL's, 50% needed help with cleaning and 43% with grocery shopping and laundry one year after the stroke (Riks-stroke, 2011).

In a 2 year follow-up after stroke, 52 % of the close relatives (average age 70), acted as caregivers and assisted in one or more primary ADLs, and 30% reported that the person with stroke managed without supervision at the most a half day, meaning a high degree

of dependency and need of relief. Additionally, 62 % had taken over other responsibilities and 14% of the relatives could not partially or totally partake in their previous leisure activities (The National Board of Health and Welfare, 2004), indicating potential risks for occupational imbalances. Due to this an amendment to Swedish law was made in 2009 (Social Services Act 2001, chapter 5, paragraph 10) (5 kap. 10 § SoL) and recommends offering support to caregivers in order to facilitate everyday life. As few as 11% of the caregivers responded that they received support in any form which gave them relief from daily chores (The National Board of Health and Welfare, 2004). Unfortunately, a recent Cochrane review found little evidence for effective interventions for caregivers to persons with stroke (Legg et al., 2011).

Hence, a stroke is considered a long-term condition with a complex and diverse array of problems that face the person with stroke and their families (Murray, Young, & Forster, 2007). Even the level of assistance is great when the person with stroke lives in another facility outside the home. Surprisingly, 85% of persons with stroke living in assisted living facilities, 3 months post stroke reported a partial or total dependency on assistance of a relative. This assistance was usually in the form of emotional support and assistance with practical things like, paying bills and purchasing items (Riks-Stroke, 2010).

Stroke is considered to be a disabling chronic condition due to the impact a stroke has on a number of different functions such as gross and fine motor ability, speech, mood, perception and cognition (Mayo et al., 1999). The WHO's World Report on Disability states that rehabilitation is essential to enable people with disabilities, and to eliminate potential barriers to participation in everyday life (von Groote et al., 2011). However, stroke management has been described as asymmetrical, with the greatest efforts during the first weeks after stroke, followed by lesser or negligible input after the acute phase (J. B. Young, 2001). For this reason, research regarding the long term effects of the sequel of stroke may be needed to help inform policy makers, and to alleviate this imbalance.

CAREGIVERS

The term caregiver used in studies III and IV has been adapted from Pearlin et al (1990) and refers to “activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves” (Pearlin, Mullan,

Semple, & Skaff, 1990) (p. 583). Thus, the term *caregiver* has to do with behavior and *giving care* (the affective component) is an extension of caring about another person (Pearlin, Mullan, Semple, & Skaff, 1990). The caregiver role can be assumed by a spouse or partner, a child, a parent, a friend or other person, residing or not with the care recipient, the person with stroke. The term caregiver was chosen to be used in this thesis since it is the term predominantly found in stroke literature. Also, when used in this thesis, caregiver implies an informal caregiver, denoting a person that is not paid. The term caregiver indicates a person with a caregiving behavior, as opposed to the term significant other, which does not necessarily imply this. The caregiver role is found on a continuum of time spent, frequency, and magnitude or extent of the assistance (Tooth, McKenna, Barnett, Prescott, & Murphy, 2005).

Caregiver burden

The term caregiver burden in this thesis is based on Rigby (2009) and used to describe the load or weight carried by caregivers as a result of adopting the caregiver role (Rigby, Gubitzi, & Phillips, 2009). Caregiver burden, a complex and multidimensional construct (Rigby et al., 2009) is seen in relation to the individual's health, feeling of psychological well-being, relations, social network, physical workload, and in environmental aspects (Elmstahl, Malmberg, & Annerstedt, 1996). This thesis examined the subjective or self-perceived caregiver burden (Scholte op Reimer, de Haan, Pijnenborg, Limburg, & van den Bos, 1998).

Caregivers to persons with stroke experiencing significant burden varied in different studies from 25% to 54% (Bugge, Alexander, & Hagen, 1999; Rigby et al., 2009; Tooth et al., 2005). Caregivers in their role are more susceptible to physical and psychological illness such as depression (Han & Haley, 1999), anxiety, social restraints (Anderson, Linto, & Stewart-Wynne, 1995), and decreases in psychosocial function (Visser-Meily et al., 2009; Visser-Meily, Post, van de Port, van Heugten, & van den Bos, 2008).

However, there is conflicting information regarding findings in the literature concerning caregiver burden after stroke, due to diversity in time since the stroke and heterogeneous lengths of follow-ups (Gaugler, 2010). A systematic review of the longitudinal ramifications of stroke caregiving found several studies that showed that caregivers' emotional, social, psychological and physiological well-being worsened over time whereas other studies suggested adaptation over time for the caregiver

(Gaugler, 2010). Even positive aspects of care giving have been reported (Han & Haley, 1999), and this is in agreement with the stance that caring for oneself and others positively influences health (Law et al., 1998).

Caregivers play an essential role in maintaining the person with stroke in the community (Anderson et al., 1995). The costs of informal care giving are substantial (Hickenbottom et al., 2002) and informal caregivers contributions should be considered beneficial to society. Without gratis services of informal caregivers, there could be a potential threat to the welfare system.

There is a need to identify vulnerable caregivers in need of support (Rigby, 2009). This is in accordance with The National Board of Health and Welfare's (2009) recommendations of preventative measures within stroke rehabilitation (The National Board of Health and Welfare, 2009). The identification of vulnerable persons, whether they are persons with stroke or their caregivers, is imperative in order for appropriate interventions to be implemented.

LIFE SATISFACTION

Life satisfaction is considered an important goal for rehabilitation, as well as a goal for persons close to the person receiving rehabilitation services (Fugl-Meyer, Brännholm, & Fugl-Meyer, 1991). The studies in this thesis dealing with life satisfaction (studies II, III, IV) have adopted the definition of life satisfaction first presented by Fugl-Meyer (1991) and further used by Melin (2003). Life satisfaction is "the degree to which an individual experiences himself as being able to attain his goals" (Melin, 2003) (p.11). Life satisfaction is an individual's subjective experience, based on a cognitive assessment of a current situation in relation to external standards or personal levels of aspiration. Satisfaction occurs when aspirations and achievements meet and low levels of life satisfaction may be due to gaps between the person's aspirations and achievements (Brännholm, Lundmark, Månsson, & Fugl-Meyer, 1996; Fugl-Meyer et al., 1991; Melin, 2003). Satisfaction with life as a whole, in a reasonable duration of time, is considered to be synonymous with happiness (Fugl-Meyer et al., 1991; Veenhoven, 1984).

Life satisfaction was measured in a normative Swedish sample with the Life Satisfaction checklist, the same measure used in this thesis. A nationally represented Swedish sample showed that 70% were either satisfied or very satisfied with life as a

whole (*i.e.* global life satisfaction), with no gender or age related differences (Fugl-Meyer et al., 2002).

Life satisfaction after stroke

Life Satisfaction decreases in persons after a stroke, compared with the general population (Ostwald, 2008). Several studies have examined this and showed that approximately 50% to 63% of persons with stroke were dissatisfied with life, one to six years post stroke (Brännholm et al., 1996; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Lundgren Nilsson, Aniansson, & Grimby, 2000; Viitanen, Fugl-Meyer, Bernspang, & Fugl-Meyer, 1988).

Life satisfaction (in all life domains) had a strong relationship to participation in everyday occupations (G. Eriksson et al., 2009) and to social activity after stroke (Boosman, Schepers, Post, & Visser-Meily, 2011). Participation in personally relevant meaningful activities appears to contribute to life satisfaction for persons one year post stroke (Hartman-Maeir et al., 2007). Activity participation and emotional well-being were significant factors predicting life satisfaction for persons with mild stroke, whereas motor and cognitive functions were not predicting factors (D. F. Edwards, Hahn, Baum, & Dromerick, 2006).

Caregivers life satisfaction

Life satisfaction for caregivers to persons with stroke was also shown to be below the level of the general population in a review (Ostwald, 2008) with life satisfaction decreasing after the stroke as compared to before (Forsberg-Warleby, Moller, & Blomstrand, 2004). Dissatisfaction with life as a whole was found in 41% - 51% of the caregivers (Forsberg-Warleby et al., 2004), one year after their partners' stroke, and increased only slightly to 52% after 3 years (Visser-Meily et al., 2008). Persons with stroke were less satisfied than their caregivers one year post stroke (Carlsson, Forsberg-Warleby, Moller, & Blomstrand, 2007). Conversely, more spouses than persons with stroke (50% *c.f.* 28%) were dissatisfied with their global life satisfaction three years post stroke (Achten, Visser-Meily, Post, & Schepers, 2012).

The caregivers' life satisfaction has been analyzed in relation to a number of different factors residing with the person with stroke, or characteristics of the caregiver. For example, the caregivers life satisfaction and persons with stroke participation in social activities were significantly related to the persons with stroke' life satisfaction (Achten

et al., 2012). Life satisfaction of the caregiver was negatively associated with caregiver burden (White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). Additionally, life satisfaction decreased between 1 and 3 years post stroke, but the caregivers' perceived less burden during that time (Visser-Meily et al., 2008). These different studies exemplify the many different factors and complex relationships that have been studied concerning the person with stroke and their caregiver.

Studies of life satisfaction have mainly addressed either persons with stroke or their caregivers or spouses separately, and few have had a dyadic perspective (Achten et al., 2012). Even in an encompassing 2 year follow-up after stroke (The National Board of Health and Welfare, 2004) including the person with stroke and their next-of-kin, the persons responsible for the questionnaire decided to present the responses separately and no attempt was made to see the two persons as one entity. Knowledge regarding the stroke-caregiver dyad could potentially facilitate the development of interventions directed at improving life after stroke for both persons. Studies III and IV in this thesis, with a dyadic perspective concerning life satisfaction aspire to do so.

A DYADIC PERSPECTIVE

The term dyad (a group of two; couple; pair) ("Webster's Encyclopedic Unabridged Dictionary of the English Language," 1989) (p. 445) used in this thesis, refers to the person with stroke together with another person, who is considered to be his or her caregiver. A dyadic perspective is considered to be achieved when both persons' perspectives are taken into account, and the two individuals are seen as a single entity and is in agreement with the definition of Thompson and Walker (1982)

Theoretical assumptions regarding a dyadic perspective

In order to have a dyadic perspective in research, clarity regarding the conceptual assumptions underlying the dyadic study is imperative (Thompson & Walker, 1982). Thus, the assumptions that are used as a basis for the dyadic perspectives in studies III and IV are based on an occupational perspective and the possible mutuality and interdependency between the caregiver and care receiver. Caregiving is considered to be a dynamic process, and the theories and themes from qualitative studies suggest that transitions influence the relationships between the caregiver and care recipient (Gaugler, 2010). Qualitative studies have shown that different patterns of mutuality and interdependency in everyday activities are created between caregivers and persons with

stroke because of the consequences of stroke in occupations in everyday life (Ekstam, Tham, & Borell, 2010; Jongbloed, 1994; van Nes, Runge, & Jonsson, 2009). Mutuality refers to the ability of the caregiver to find meaning in the caregiving situation as well as gratification and reciprocity in the relationship with the care recipient (Archbold, Stewart, Greenlick, & Harvath, 1990). Mutuality improves caregiver role strain (Archbold et al., 1990) and is a significant predictor of life satisfaction for persons with stroke, as well as their spouses. (Ostwald, Godwin, & Cron, 2009). Also, a higher level of mutuality with a spousal caregiver predicted lower stress in the person with stroke (S. K. Ostwald, Bernal, Cron, & Godwin, 2009).

Interdependency, based on the premise that people rely on the support of social networks (Nolan, 2001), is defined as the shared dependence between two persons based on reciprocity and where their thoughts, values and actions are seen as a result of communication and interaction (Beeber, 2008). In order to broaden the understanding of participation, interdependence has been suggested, emphasizing social networks rather than independence when considering participation (Cott, Wiles, & Devitt, 2007). Inspired by Asaba (2008), interdependency within the stroke-caregiver dyad is seen as a complex relationship, ever changing depending on context, and where agency can be expressed through tending to the needs of another person (Asaba, 2008). Even the term co-occupations, or two persons engaging in an activity where each person influences the other (Pierce, 2009) can be considered within the realm of participation in everyday occupations of the stroke caregiver dyad.

A dyadic perspective regarding life satisfaction

There are surprisingly few studies with a dyadic perspective within stroke rehabilitation research. However, a dyadic perspective regarding life satisfaction has been used after stroke (Achten et al., 2012; Carlsson, Forsberg-Warleby, Moller, & Blomstrand, 2007) and after acquired brain injury (G. Eriksson, Tham, & Fugl-Meyer, 2005). These three studies, (all using the Life Satisfaction Checklist, as in the studies in this thesis) showed that 30% (Carlsson et al., 2007) and 41% (Achten et al., 2012) of the couples, one respectively three years after stroke agreed that they were satisfied with life as a whole. Only 29% of the couples were satisfied one to five years post acquired brain injury (Eriksson et al., 2005). It is interesting to note that the dyads were not always in agreement, and between 40 to 43% were discordant one to three years post stroke (Achten et al., 2012; Carlsson et al., 2007). Despite these studies, there is a lack of knowledge regarding a dyadic perspective on life satisfaction and the relation to three

main concerns within rehabilitation after stroke; caregiver burden, impact of stroke and participation in everyday occupations.

A dyadic perspective within stroke rehabilitation

Considering the above and together with the importance of the role of broader social systems, (Windsor, 2009) a dyadic perspective is needed within stroke rehabilitation. This is in agreement with a number of other authors calling for the need for family-centered care within stroke rehabilitation (Achten et al., 2012), the-need for a shift in rehabilitation philosophy from a patient-focused approach to a combined patient- and caregiver-focused approach (Blake, Lincoln, & Clarke, 2003; Kalra et al., 2004; Low, Payne, & Roderick, 1999; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Vincent, Desrosiers, Landreville, & Demers, 2009), throughout all phases of stroke rehabilitation (Visser-Meily et al., 2006). Accordingly, there is a need for valid measures regarding variables, both within and between individuals in the dyad (Gaugler, 2010). The need of a dyadic perspective is compounded by little evidence regarding optimal interventions supporting the dyad (Legg et al., 2011) or for the dyad to manage in the community (Cameron, Tsoi, & Marsella, 2008). A better understanding of the stroke-caregiver dyad may facilitate effective rehabilitation interventions that are aimed at preventing problems in the daily lives of both persons in the dyad. Taking this into account, this thesis argues for a dyadic perspective in research in hopes to inform rehabilitation interventions.

AGENCY

Persons after a stroke often perceive everyday life as challenging (Palmer & Glass, 2003; J. Young & Forster, 2007) with difficulties performing occupations in their everyday life (Mayo et al., 2002). Individuals describe their life world as chaotic during the year after injury with changes in their taken for granted performance leading to a breakdown in habit patterns in their everyday lives (Erikson, Karlsson, Borell, & Tham, 2007). Occupational therapists have the possibility of supporting persons after stroke regarding these challenges. An understanding of the clients' lived experience of their process of making things happen after a stroke is essential, in order to support the person. Therefore, the capacity to make things happen in their everyday life, (*i.e.* agency) needs to be studied.

The term agency, is defined in study I as “making things happen by ones actions in the context of their everyday life”. The definition is derived from Aarts et al (2009); “the feeling that one causes one’s own actions and their outcomes” (Aarts, Custers, & Marien, 2009). Agency has been suggested as an important feature in the performance of occupations in everyday life of older adults with disabilities, and a better understanding of the multifaceted nature of agency is warranted as a goal for future research (Vik, Nygard, Borell, & Josephsson, 2008). Agency is considered to be associated with health (Herzog, Franks, Markus, & Holmberg, 1998) and well-being and fundamental to the understanding of social interactions (Al Zidjaly, 2009).

Agency as seen by other disciplines

In order to understand the concept of agency and how it is elucidated in Study I, it may be of value to understand how other disciplines regard the concept of agency. The term agency can be found in the disciplines of social psychology, psychology, sociology, philosophy, and in the neurosciences (Gallagher, 2010). There have been marked difficulties regarding a consensus of what agency might be (Campbell, 2009; Gallagher, 2010) and agency is referred to as an intriguing phenomenon (David, Newen, & Vogeley, 2008), complex, (Arthos, 2006; Bayne & Pacherie, 2007; David et al., 2008), and frustratingly elusive to pin down (Campbell, 2009). The ambiguity regarding the concept of agency comes most likely from a debate concerning “agency vs. structure” (Fuchs, 2001; Hitlin & Elder, 2007) where the extent of individual autonomous action (*i.e.*, agency) has been pitted against the extent society has on affecting the individuals actions.

In all its simplicity, the definition of agency used in this thesis, was influenced by both the psychological and the sociological aspects of agency to address the reciprocal nature of person and society (Hitlin & Elder, 2007) in everyday life and in order to have an occupational perspective regarding the concept of agency.

Agency and the relevance with OT/OS

In a presentation of terminology in the Journal of Occupational Science, Lentin (2005) refers to a dictionary definition of agency. Agency is the state of being in action or exerting power, a means of producing effects; instrumentality (Lentin., 2005). However, there are no references to empirical studies supporting the definition.

The concept of agency, despite the apparent relevance for the field, has been studied relatively sparsely within occupational therapy and science. Different authors have written about agency as impacting daily routines (Gallimore & Lopez, 2002; Polkinghorne, 1996) and in relation to potentiality (Asaba & Wicks, 2010) and identity (Huot & Laliberte Rudman, 2010). However, studies with the focus on enacting agency from the perspective of persons with a disability such as a stroke have not been found.

Agency and the relation to participation

Even though other studies in this thesis (*i.e.*, studies II and IV) do not explicitly refer to agency, there is conceptually a connection between agency and participation. Since participation in everyday occupations includes the performing of desired occupations one can readily see the connection to the concept of agency since agency refers to acts done intentionally (Bandura, 2001). However, agency does not only have to do with direct performance. Agency can also entail getting others to act, and one can assume that there is a certain element of engagement in this type of enacting agency. Enabling participation in occupations is through the recognition that persons are active agents (Townsend & Landry, 2005).

The lived experience of agency

Since knowledge is lacking regarding how persons experience enacting agency after a stroke, it would be beneficial to study persons lived experience of agency. An understanding of how persons enact agency may benefit occupational therapists and facilitate how occupational therapist can empower and support clients in endeavors to participate in everyday occupations. Phenomenology is considered to be an appropriate method to study the essence of occupation (McLaughlin Gray, 1997; Park Lala & Kinsella, 2011) and is especially suited to study complex phenomenon such as agency.

Phenomenology is both a method and a philosophy. As a method, phenomenology involves examining a phenomena as lived and directly experienced (Husserl, 1970/1936) and seeks to describe instead of explain. Phenomenology focuses on persons' experience in relation to a phenomenon and seeks to trace out the essential constituents of the experience (Karlsson, 1995) (p. 14) in order to describe and deepen our understanding of the phenomenon.

Phenomenology has its basis in the philosophy of Edmund Husserl. Husserl, in defiance to the positivistic scientific stance in the early 20th century, called for investigations to

get “Back to the things themselves! (Husserl, 1970/1936). In order to do this, Husserl addressed the nature of human consciousness (through intentionality) in everyday life. Intentionality refers to the relationship or directed awareness between a person (subject) and the person’s orientation towards an object (Husserl, 1970/1936). The “object” could be a thing, but also even an idea, an event, a memory, a fantasy, or an experience. Objects are taken as *intended* objects, or objects as they are meant. This yields descriptive results, which discloses the intentional relationship between the subject and the object of experience. Intentionality is basic for the understanding of human experience (Husserl, 1970/1936) and forms a philosophical foundation in phenomenology.

This directed awareness or consciousness towards an object, is the meaning-bestowing, continuous, stream of “activity” (intentional acts) that is directed towards an object. This “continuous stream of activity” is through the perceptions of the lived body (Merleau-Ponty, 2002/1945) and can include a subject’s senses (seeing, hearing, etc.) and even feelings, memories, and thoughts, in other words, things taken in through the lived body. Thus, “man is seen as determining the meaning of his/her world, and not as a passive receiver of stimuli” (Karlsson, 1995) (p.18). Through intentionality, the subject and object are linked together (Karlsson, 1995).

RATIONALE FOR THE THESIS

Persons often perceive challenges in performing occupations in everyday life after a stroke. Occupational therapists have the possibility of supporting persons regarding these challenges. In order to do this, occupational therapists need to understand how people experience their ability to make things happen in their everyday lives (*i.e.* a persons’ agency). Agency has been studied relatively little with an occupational perspective. To lessen the gap in knowledge, there is a need to study how persons experience enacting agency after they have had a stroke.

Previous studies have given us a varied picture regarding persons that risk restrictions in participation after a stroke. However, knowledge is lacking about factors that predict participation in everyday occupations specifically. With this knowledge, rehabilitation professionals may be able to identify persons at risk and work to prevent restrictions regarding participation in everyday occupations.

Persons with stroke often receive assistance from a caregiver and studies have shown that life satisfaction of both persons is impacted. However, we know little regarding reciprocal influences of life satisfaction within the dyad, and the relation to caregiver burden and the perceived impact of stroke. With this knowledge, we could hopefully facilitate identification of vulnerable dyads in order to provide targeted support.

Persons with stroke, as well as their caregivers, perceive participation restrictions after stroke. However, we know little about the caregivers' participation in everyday occupations specifically. Furthermore, combined life satisfaction is negatively associated with perceived impact of stroke for those afflicted, and burden for the caregivers, suggesting a link between the life satisfaction of the dyad and the effects of stroke on the individual. There is a knowledge gap regarding combined life satisfaction and the relationship to participation in everyday occupations. This knowledge can facilitate effective rehabilitation interventions, aimed at preventing restrictions in participation for both persons in the dyad.

GENERAL AIMS

In order to develop knowledge that can be used within rehabilitation after stroke, the general aim was to explore participation in everyday occupations and the relation to life satisfaction in persons with stroke and within the caregiver dyad. Furthermore, the aim was to understand and describe the lived experience of persons enacting agency in everyday occupations during the first year after stroke.

SPECIFIC AIMS

-to understand the lived experience of enacting agency (*i.e.*, making things happen by ones' own actions in their everyday life) and to describe the phenomenon of agency during the year after a stroke. (Study I)

-to explore the extent of and the factors associated with occupational gaps, 12 months after stroke. Also, to identify factors at 3 months after stroke that predicts occupational gaps 12 months after stroke. (Study II)

-to describe the combined life satisfaction of two individuals making up the dyad, to investigate the association of the combined life satisfaction with persons with stroke perceived impact of stroke in everyday life one year after onset and to investigate the association of the combined life satisfaction with the caregivers' perceived level of caregiver burden one year after the stroke. (Study III)

-to explore and describe persons' with stroke and their caregivers perceived participation in everyday occupations three months post study inclusion and to depict this in relation to their life satisfaction, the dyads combined life satisfaction, caregiver burden, perceived impact of stroke and ADL ability. (Study IV)

METHODS

The four studies in this thesis aim to explore aspects of life during the first year after stroke for the persons directly afflicted and for their caregivers. In order to do so, both qualitative and quantitative approaches were chosen as well as instruments reflecting the perceptions of the individuals. Study I, based on a qualitative method, aimed at capturing the lived experience of enacting agency, during the year after stroke. Study I serves as a foundation for the remaining studies since enacting agency can be considered a prerequisite for participating in everyday occupations. Study II builds upon the concept of performing desired occupations during the year after stroke, but employs quantitative methods in order to predict factors that may influence the participation in everyday occupations. Study III approaches the life satisfaction within the stroke-caregiver dyad and study IV builds upon the results of studies II and III, using a quantitative approach to investigate participation in everyday occupations and life satisfaction within the stroke-caregiver dyad.

An overview of the studies and methods can be found in Table 1.

Table 1. Overview of the studies: design, data collection, analyses, study context and focus.

	Study I	Study II	Study III	Study IV
Design & research approach	Prospective, longitudinal, phenomenological approach	Prospective, longitudinal, explorative, descriptive approach	Cross-sectional, descriptive approach	Cross-sectional, descriptive approach
Data collection (occasions)	4 times during the year after stroke. (2-3 weeks after rehabilitation's start, 1 week after rehabilitation ended, 6 & 12 months post stroke)	Inclusion (3-5 days post stroke), 3 & 12 months post stroke	Inclusion (3-5 days post stroke) & 12 months post stroke	Inclusion (3-5 days after inclusion in the study) & 3 months post inclusion
Data collection (methods and instruments)	Qualitative, open-ended interviews	OGQ (at 12 months post stroke) SIS, LiSat-11, (at 3 & 12 months) BI (at inclusion)	LiSat-11, SIS, CBs (at 12 months post stroke) and BI (at inclusion)	OGQ, SIS, LiSat-11, CBs, BI (at 3 months post inclusion), BI (at inclusion)
Methods of analyses	Empirical Phenomenological Psychological method	Descriptive statistics, Rasch analysis, univariate and multiple regression analyses	Descriptive and non-parametric statistics (Kruskal-Wallis, Mann Whitney U test)	Descriptive and nonparametric statistics (Mann Whitney U test, Spearman's correlation)
Study context	Rehabilitation facility, participants' home	Rehabilitation facility, participants' home	Rehabilitation facility, participants' home	Rehabilitation facility, participants' home
Focus	Lived experience of agency	Participation in everyday occupations after stroke	Dyads' combined life satisfaction	Dyads' participation in everyday occupations

PARTICIPANTS IN THE STUDIES FROM TWO SAMPLES

The participants in the studies included in this thesis were from two different samples Life after stroke (LAS-1) and Life after stroke (LAS-2).

Life after stroke (LAS-1)

The overall aim of the LAS-1 was to follow persons with stroke and their caregivers during the year after stroke. This prospective study of life after a stroke included 349 persons with stroke. All persons with a stroke diagnosis admitted to one of three stroke units included in Karolinska University Hospital (Huddinge and Solna) between May 15, 2006 and May 14, 2007 were eligible for inclusion. Two of these stroke units were acute care and included initial rehabilitation. The third stroke unit was a geriatric stroke unit with acute care and in-patient rehabilitation. The number of patients admitted to the stroke units during this period determined the sample size in this data set. The period for data collection (one year) was chosen to reflect any possible seasonal variations in admissions in order to retrieve a representative sample as possible.

Occupational or physical therapists at the stroke units received information about potential patients and these potential patients (or their significant others) were informed (verbally and in writing) regarding the study, and then asked if they would participate. A total of 373 persons accepted to participate, but 24 persons were excluded because the preliminary diagnosis was not confirmed and was subsequently changed. Following consent, they received information (verbally and in writing) regarding the overall plan and purpose, confidentiality and their right to terminate their participation. The participants were also asked, after they consented to joining the study, to identify a significant other or person otherwise close to them (a spouse, relative, friend or acquaintance, that they were living together with or not). Participants remained included even if they did not identify a significant other. The participants were then asked for permission if that person could be contacted to receive information regarding the study. That person was then considered to be the informal caregiver for study III in this thesis. The occupational or physical therapist at the stroke unit collected baseline data and assessments during the first week after admittance.

Subsequent data was collected by specially trained occupational or physical therapists, three, six and 12 months post stroke. The data collection at three and 12 months was via visits to the participants' home or wherever the participant was at that time (*e.g.*, nursing home). Data collection at six months post stroke was collected by telephone. Data collection for the caregivers (at three and 12 months post stroke) was performed in conjunction with these home visits when possible or questionnaires were left for the caregiver to be returned via mail in a stamped envelope. Socio-demographic data for

the caregivers were collected at three months. Persons with stroke unable to answer the question had the possibility of receiving assistance, which was noted in the protocol.

Life after stroke (LAS-2)

The overall aim of the LAS-2 was to compare two groups of persons with a stroke that had received different ADL interventions. There were 280 persons with stroke included in this sample, and they participated in a randomized control trial (RCT). The persons in this sample were diagnosed with stroke (either hemorrhagic or ischemic), were recruited between September 2009 and September 2011 and followed for one year. They were initially treated at a stroke unit in Stockholm, Uppsala or Gävleborgs' county councils. They were included in the RCT three to five days after being admitted to a rehabilitation unit (in-patient, outpatient or community based rehabilitation). The potential participants were asked to join the study by the occupational therapist if they met the criteria that they had their stroke < 3 months prior, they were able to follow instructions, have at least two activity limitations according to the Katz ADL-index and in need of personal or instrumental ADL interventions according to the occupational therapist, and had no dementia diagnosis. They were informed orally and in writing and were included after informed consent was obtained.

Prior to the start of the study, the rehabilitation sites were assigned to either an intervention group or control group. The participants in the control group received ordinary occupational therapy interventions along with other rehabilitation services. Prior to the start of the study, occupational therapists working at the intervention sites took part in a five day workshop comprising of a client-centered ADL intervention (CADL). The CADL intervention is based on research knowledge and is presented elsewhere (Guidetti, Andersson, Andersson, Tham, & Von Koch, 2010; Guidetti & Ytterberg, 2011).

Data was collected by blinded, independent, specially trained occupational therapists at inclusion to the study, three, six and 12 months post inclusion. The data was collected in the person's home with the exceptions of those persons that were inpatients at the time of the data collection. Data was also collected for the informal caregivers at the same time whenever possible or left with the study participant to be returned by the caregiver via mail in a stamped, addressed envelope.

Table 2. Overview of the participants in the studies

	Study I	Study II	Study III	Study IV
Number of participants	6 persons with stroke	200 persons with stroke	81 dyads (162 persons)	105 dyads (210 persons)
<i>persons with stroke</i>				
Male/female	3/3	117/83	54/27	77/28
Age, years, median (range)	(63-89)	71 (24-93)	71 (32-92)	70 (46-90)
<i>caregivers</i>				
male/female	NA	NA	24/57	25/80
Age, years median (range)			66 (19-84)	68 (18-88)
co-habiting	4 of 6 persons	113 of 198 (missing; n = 2)	46 of 81 (missing; n = 27)	105 of 105
Study group	LAS-II	LAS-I	LAS-I	LAS-II

NA = not applicable

Participants

Study I

The six participants in study I were from the LAS-2 sample and selected from the rehabilitation sites that received the client-centered intervention in the RCT. In addition to the LAS-2 inclusion criteria, the participants were required to be able to recount their activities during a normal day. The participants were suggested to the responsible researcher at the site by the treating occupational therapist, and then referred to the author. They were then chosen on the basis of obtaining a variation in the participants' gender, age, living location and situation, and stroke severity (Dahlberg, Dahlberg, & Nyström, 2008). The persons considered for participation were then asked if they would consider being involved in an interview study by the occupational therapist that was responsible. Upon accepting, they were informed both verbally and in writing concerning their participation. The first meeting was then arranged by the occupational therapists or by the researcher who contacted them directly by phone.

Study II

The 200 participants in study II represent a subsample from the LAS-1 sample. They were selected on the grounds that they had completed the Occupational Gaps

Questionnaire (OGQ) one year post stroke. The data used in study II was from the time points; inclusion, three and 12 months post stroke.

Study III

The participants in Study III were persons with stroke and their caregivers one year post stroke and were from LAS-1. Of the original 349 persons with stroke included in the data set, 54 persons were deceased, 45 persons had incomplete data, 76 declined or were lost in follow-up at one year post stroke. Furthermore, 93 persons with stroke had not identified a caregiver leaving 81 dyads, persons with stroke and their caregivers, (*i.e.*, 162 persons) included in study III. The data used in study III was from the time points; inclusion and 12 months post stroke.

Study IV

The participants in Study IV were persons with stroke and their caregivers, from the LAS-2 sample. Inclusion criteria were, besides the inclusion criteria for the LAS-2 sample, *i.*) if the person with stroke had named a caregiver partaking in the study *ii.*) if the person with stroke was residing together with their caregiver and *iii.*) if information regarding global life satisfaction and occupational gaps were available. One hundred and five persons with stroke and their caregivers (210 persons) met the criteria and were included in study IV. The data used in study IV was from the time points; inclusion and three months post inclusion to the RCT.

DATA COLLECTION

Interviews

In study I, the data was collected through interviews of the 6 persons in the study, four times during the year after their stroke. The first interview was performed approximately two to three weeks after the start of rehabilitation, the second interview approximately one week after being discharged from rehabilitation, and then six and 12 months after stroke. Each interview lasted approximately one hour, somewhat less in the initial interviews and somewhat more in the latter interviews. The initial interviews were performed at the clinic for those four persons that were inpatients at that time and at the persons' home for the remaining two persons. All remaining interviews were performed in the persons' home environment, the location of their choice. The initial interview was performed on two separate occasions for one participant due to her lack of endurance at that time.

The data collection focused on the participants lived experience of “making things happen” in everyday life during the year after their stroke. The open-ended questions (Dahlberg et al., 2008; Kvale & Brinkman, 2009) concentrated on how the persons experienced planning or doing things in their everyday lives. This was done by asking the participants to describe a situation that illuminated what led up to what they were doing; what influenced them to do what they had done or were planning on doing, and how they experienced this. Questions like “*Why did you do that?*”, “*What is it that made you do that?*”, “*How did that come about?*”, “*Tell me about your plans to do ...!*” as well as “*How did you experience that?*” were posed. The interviewer encouraged the person to tell more (Kvale & Brinkman, 2009) in order to gain rich data. The completed previous interviews were either read through or re-listened to prior to the new interview and questions were developed to follow-up on the activities and plans that had been discussed. All of the interviews were recorded and transcribed verbatim. Field notes were taken directly after the interviews.

INSTRUMENTS

An overview of the instruments used in the different studies is presented in table 1. The instruments are presented below in the order of usage. Instruments used in this thesis are based on self-reports and reflect the individual’s perspective (with the exceptions of the BI and MMSE).

Life Satisfaction Checklist

The LiSat-11 (Fugl-Meyer, Melin, & Fugl-Meyer, 2002) is a generic, self-report checklist, assessing overall and domain specific life satisfaction in 11 different questions. The first question concerning global life satisfaction in the LiSat-11 was used in studies II, III and IV. The remaining questions in the LiSat-11 refer to satisfaction with vocational situation, financial situation, leisure situation, contacts with friends and acquaintances, sexual life, ability to manage self-care, family life, partner relationship, physical health, and psychological health. The responses range along a six-grade ordinal scale from 1 (very dissatisfied) to 6 (very satisfied). The responses to the global life satisfaction question were dichotomized, and scores of 5-6 indicated “satisfied” and the scores 1-4 indicated “dissatisfied”. This is considered to be a valid scale reduction (Fugl-Meyer et al., 2002) and has been used in a number of other studies with a stroke sample (Ekstam, Uppgard, von Koch, & Tham, 2007; G. Eriksson et al., 2005; Forsberg-Warleby et al., 2004). The validity of using the global question as

a measure of life satisfaction has been validated (Viitanen et al., 1988) and has been used in other studies concerning stroke (Ekstam, Uppgard, von Koch, et al., 2007) (Guidetti, Andersson, Andersson, Tham, & Von Koch, 2010). The basis of the LiSat-11 was first developed with persons with neurological disorders, including persons with stroke (Brännholm et al., 1996) and a number of the items in a previous version (LiSat-9) have shown acceptable test-retest reliability, specificity and sensitivity (Fugl-Meyer et al., 2002).

Combined life satisfaction was built on the question regarding global life satisfaction in the LiSat-11 checklist and was used in studies III and IV. Combined life satisfaction categorization aims at giving a dyadic perspective of global life satisfaction. Combined life satisfaction was determined by each person in the dyad's results of the global life satisfaction question, dichotomized into satisfied or dissatisfied. These two results were then joined as a 'dyad score' and classified into three groups *i.* satisfied, *ii.* dissatisfied, and *iii.* discordant (not in agreement). Combined life satisfaction has been used in this manner in a previous study dealing with acquired brain injury (G. Eriksson et al., 2005).

The Stroke Impact Scale

The Stroke Impact Scale (SIS) was used in studies II, III, and IV. Version 2.0 (Duncan et al., 1999) was used in study III, and version 3.0 (Duncan, Bode, Min Lai, & Perera, 2003) was used in studies II and IV. The SIS aims to measure the perceived impact of stroke by the person that has been inflicted and was developed with input from both persons with stroke and caregivers (Duncan et al., 1999). In the SIS version 2.0 there are 64 items and in the SIS version 3.0, 59 items. In both versions, the items are divided into eight different domains; strength, hand function, mobility, activities of daily living (ADL) and instrumental ADL, emotion, communication, memory, and social participation. There are five to 12 separate questions in each domain, and each question is rated on a five point scale. SIS domain scores range from 0-100 and the greater the score, the less impact. The domains are individually scored (Duncan et al., 1999). However, the domains of strength, hand function, mobility and ADL/I-ADL can be summed to create a physical function score, which was done in study II and IV. In addition to the eight domains, there is a visual analogue scale from 0-100 measuring self-assessed stroke recovery. Zero indicates no recovery and 100 full recovery from the stroke. The SIS has shown to be reliable, valid and sensitive to change (Duncan et al., 1999) and has been frequently used (Carod-Artal & Egido, 2009; B. Edwards &

O'Connell, 2003; Lai, Studenski, Duncan, & Perera, 2002). A proxy version of the SIS has been used when appropriate and has been found to provide valid information (Duncan et al., 2002).

The Occupational Gaps Questionnaire

The Occupational Gaps Questionnaire (OGQ) was used in studies II and IV. The OGQ measures participation in everyday occupations by assessing perceived occupational gaps, in 28 different activities in the areas of instrumental ADL's, leisure, social and work or work related activities (Eriksson et al., 2009). An occupational gap occurs when a person does something they do not want to do or wants to do something they do not do. The questionnaire is comprised of a checklist with two questions pertaining to each of the 28 different activities; Do you perform this activity now (yes/no) and Do you want to perform this activity (yes/no). A gap is present when there is a discrepancy in the answers to the two questions. An optimal outcome is the absence of gaps. Four or more occupational gaps indicate a restriction in participation in everyday occupations. This cut-off is based on an unpublished study regarding occupational gaps in a Swedish reference sample (n=771) of persons 20 to 85 years of age. A median amount of gaps, calculated to match the age groups in studies II and IV, was found to be 3, and this was used as a cut-off (>3 gaps) as restrictions in participation in studies II and IV.

The development of the OGQ was based on previous instruments (Baum & Edwards, 2001; Törnquist & Sonn, 1994; Wallgren, 2007) and has its theoretical underpinnings in *The Model of Human Occupation* (Kielhofner, 2008). The OGQ has also shown to have acceptable validity and reliability for persons with stroke (Eriksson, Tham, & Kottorp, 2012).

The OGQ has been used in other studies dealing with persons with stroke (Eriksson, Asasnes, Tistad, Guidetti, & von Koch, 2012; G. Eriksson & Tham, 2010; Fallahpour et al., 2011), acquired brain injury (Eriksson et al., 2009; G. Eriksson et al., 2006), and stress related ill health (T. Eriksson, Jonsson, Tham, & Eriksson, 2011).

The Caregiver Burden Scale

The Caregiver Burden scale (CBs) was used in studies III and IV. The CBs was developed in Sweden for caregivers to patients with stroke and dementia (Elmstahl, Malmberg, et al., 1996) and assess the subjective burden of the person assisting a

person with stroke. There are 22 items dealing with the caregiver's health, feeling of psychological well-being, relations, social network, physical workload, and environmental aspects. Each question is rated from 1 to 4 (not at all, seldom, sometimes, often). The total scores range from 22 to 88, with the higher score representing a greater burden. The scale has been shown to have good construct validity and test-retest stability (Elmstahl, Malmberg, et al., 1996; Visser-Meily, Post, Riphagen, & Lindeman, 2004) and has been used in studies regarding caregivers to persons with stroke (Bjorkdahl, Nilsson, & Sunnerhagen, 2007; Elmstahl, Sommer, & Hagberg, 1996; Guidetti et al., 2010; McCullagh et al., 2005).

The Barthel Index

The Barthel Index (BI) (Collin, Wade, Davies, & Horne, 1988; Mahoney & Barthel, 1965) was used in studies II, III and IV as descriptive information. In study IV, the BI was also correlated with the number of occupational gaps. The Barthel Index measures 10 aspects of self-care and mobility. The scores range from 0 to 100 with a lower score indicating a greater level of dependency.

The scores of the Barthel Index in the acute phase were also used to determine stroke severity (Govan, Langhorne, & Weir, 2009). BI scores of 100-50 signified a mild stroke, 49-15 a moderate and ≤ 14 a severe stroke. This was used in studies II and III and as a complement in determining stroke severity in study IV.

The National Institute of Health Stroke Scale

The National Institute of Health Stroke Scale, a common method of determining stroke severity in the acute phase (Goldstein et al., 1989), was taken from the medical records. This was used in study IV as descriptive data.

Mini Mental State Exam

The Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) is a tool used to screen cognitive function after stroke. The MMSE was measured in the acute stage and was used in studies II-IV as descriptive data.

DATA ANALYSIS

Empirical Phenomenological Psychological Method

The Empirical Phenomenological Psychological (EPP) (Karlsson, 1995) method was used in study I. The EPP is a qualitative method and a descriptive approach aiming to

answer questions regarding *what* and *how* something is rather than *why* (Karlsson, 1995)(p. 14). The EPP method, based on Husserl's philosophy, searches for *meaning* or the meaning–structure of a phenomenon. This meaning comes from the facts in a person's description of a lived experience, and it is the researchers aim to trace out the essential constituents that make up the phenomenon, illuminated through the participant's life world experiences. The EPP does not focus on the progression of happenings over time, but the meaning persons give to the experience.

The phenomenon in Study I was agency or how agency was characterized through the lived experiences of making things happen during the year after the participants' stroke.

A modified version of the EPP was used during the data analysis replacing the psychological perspective with an occupational perspective in order to ensure the focus on the participants' everyday occupations. This perspective has been adopted in a number of other studies with persons with stroke or acquired brain injury (Erikson et al., 2007; Erikson, Karlsson, Soderstrom, & Tham, 2004; G. Eriksson & Tham, 2010; Tham, Borell, & Gustavsson, 2000).

In order to focus on the participant's lived experiences, an attempt was made to "bracket" all theories, hypotheses, models, previous assumptions, beliefs and otherwise that could be used to explain the particular phenomenon.

The data in study I was analyzed according to the EPP method in five different steps. In the first step, an individual interview was read with an empathetic understanding, a reading that links to the participant's original experience with the aim of bringing forth the meaning structure of the text.

In the second step, the interview transcript was reread to identify and divide the text into smaller sections or meaning units (MU's). The MU's were created based on the participants shift in meaning in the text (*i.e.*, a shift in topic, experience or an idea). In the third step, the MU's were interpreted and understood in relation to the whole text and the phenomenon. In other words, the focus was on the meaning that was infused in the facts in the text.

In the fourth step, a synthesizing of the MU's took place and formed a "situated structure" for each interview. This step involved returning to the original interview text in a hermeneutic circle or going from parts of the text to the whole (Dahlberg,

Dahlberg, & Nyström, 2008). Steps one to four were conducted for each one of the four interviews for an individual and then a short synopsis was written based on all of the interviews for the individual. In the fifth step, the situated structures from all the participants were used to create a general meaning structure, based on the characteristics running through all of the interviews. All of the analyses were discussed and refined by the research group and a “horizontally consistent interpretation” between the authors was sought. This was done to discover the most valid interpretation making sure that the individual characteristics fitted well with the other characteristics in the analysis (Karlsson, 1995) and was sought in order to ensure credibility (Rose, Beeby, & Parker, 1995). The findings were also presented to and discussed with a group of other researchers experienced in occupational therapy and science.

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STATISTICAL ANALYSES

Descriptive statistics, as well as univariate and multivariate statistical methods, were used in studies II-IV. Parametric and non-parametric statistics were used depending on sample size, whether data was normally distributed or not, and whether the data was nominal, ordinal or interval. The descriptive statistics that were used consisted of means and standard deviation (SDs) for interval or ratio level data, median and quartile range/range for ordinal level data and numbers and percentages for nominal level data. The significance level in studies II and IV was $p < 0.05$ and in study III $p < 0.01$. Statistica (StatSoft Inc., version 8.0 - 10.0) was used in studies II-IV.

In study II, in order to use the scores from the OGQ in a regression analyses, a Rasch analysis was performed (Linacre, 2002; Tesio, 2003). Rasch analysis converts raw scores into equal-interval measures or logits (log-odds probability units) (Winsteps was used). Univariate regression analyses were performed to assess the association of occupational gaps with baseline factors (age, gender, born/not born in Sweden, MMSE dichotomized, stroke severity) and factors at three and 12 months post stroke (SIS domains of emotions, ADL/I-ADLs, participation, physical functions, self-rated recovery, and global life satisfaction at 12 months). The results of the univariate regression analyses were used to guide the choice of which variables should be included in the multiple regression analysis. The variables that were significantly associated with occupational gaps ($p < 0.05$) were selected as independent variables in the multiple regression analysis. Two different multiple regression analyses were performed; one to ascertain factors that were associated with occupational gaps one

year post stroke, and one to ascertain factors that could predict at 3 months the extent of occupational gaps one year post stroke. In this study, the confidence levels were set at 95%.

In Study III, the Kruskal-Wallis (ANOVA by Ranks) was used to determine if there were differences between the groups of combined life satisfaction. The combined life satisfaction was determined by each person in the dyad's results of the global life satisfaction question, dichotomized into satisfied or dissatisfied and then combined. The Mann Whitney U test was used for pair wise comparisons between the three groups of combined life satisfaction (*i.e.*, the 'dyad scores' *i.* satisfied, *ii.* dissatisfied, or *iii.* discordant or not in agreement) and scores of the CBs and for the scores of the SIS domains.

In study IV, differences in the amounts of occupational gaps in persons with stroke and caregivers and in relation to combined life satisfaction were analyzed with the Mann-Whitney U test. Correlations between the number of occupational gaps for persons with stroke and for the caregivers three months post stroke were determined with Spearman's correlation. Correlations were also determined with Spearman's between the persons' with stroke occupational gaps and their global life satisfaction, domains of the SIS and the Barthel Index as well as the caregivers' occupational gaps and their global life satisfaction and the results of the CBs all at three months after inclusion to the study. The levels of correlation 0-0.25 were considered as 'little if any correlation', 0.26-0.49 as 'low correlation', 0.50-0.69 as 'moderate correlation', 0.70-0.89 as 'high correlation' and 0.90-1.0 as 'very high correlations' (Altman, 1995).

RESULTS

In this section, the results from the empirical studies will be presented. The findings in study I showed that enacting agency in everyday life after stroke was done by negotiations involving complex, and changing aspects and situations. Additionally, the results showed that participation in everyday occupations is impacted for both persons with stroke and their caregivers and the dyads combined life satisfaction was related to stroke impact for the persons afflicted, caregiver burden for caregivers and participation in everyday occupations for both persons in the dyad. These results will be presented in more detail in the following section.

THE PHENOMENON OF AGENCY

In study I, the lived experience of enacting agency during the year after a stroke was sought after through a phenomenological approach and with an occupational perspective. The phenomenon of agency was defined, as “making things happen by one’s own actions in the context of everyday life”. The findings in study I show that the six persons during the year after their stroke experienced enacting agency in their everyday lives as negotiating complex, varied and changing aspects in different situations. The general overarching theme concerned how the participants, over the course of the year after their stroke, negotiated different aspects on a continuum of complexity in order for them to enact agency. The four main characteristics illuminated the different aspects of the participants’ negotiations, that is, how they managed their perturbed bodies, how they took into account their past and envisioned their future, how they dealt with the world outside themselves (which included navigating barriers and doing things through and involving others) as well as how the participants negotiated through internal dialogues regarding their, for example, goals and fears. These negotiations or their dealings with the different characteristics were found to be on a continuum of complexity. The continuum of complexity refers to the sliding scale of different occupations that varied in extent or magnitude as well as the complex aspects that the participants dealt with.

To illustrate, an example might be useful. A number of the participants valued going out for walks, either by themselves or together with another person and did this often before their stroke. The characteristic of *taking account their past* acted as a catalyst to going out for a walk again. However, the participants found themselves negotiating or dealing with different aspects. For example, they were too tired at the time, and when

they were ready to go out, they may have found that they had to deal with the weather which had changed. Furthermore, their negotiations were facilitated or hindered by their internal dialogues that dealt with their own perceptions of, for example, fear (perhaps of falling due to their feelings of being fatigued or changes in the weather that may have created more/or less of a risk) or of the enjoyment they could potentially perceive that the occupation of taking a walk would give.

Negotiating on a continuum of complexity meant that the persons realized and managed or dealt with different aspects over a span of time, a range of difficulty and a gamut of activities that the participants faced during the year after their stroke. The participants expressed that their negotiations of the different characteristics of making things happen were entwined and interlocked, influencing each other, and at times happening spontaneously. Their feelings of enacting agency were not expressed as if they had made things happen through their own actions, but agency was expressed through their capacity to negotiate. This finding challenges traditional definitions of agency.

OCCUPATIONAL GAPS IN PERSONS WITH STROKE AND THEIR CAREGIVERS

Both study II and study IV dealt with the presence of occupational gaps after stroke. Study II dealt with persons with stroke and their occupational gaps whereas study IV dealt with both the persons with stroke and their caregivers.

The aim of study II was to describe occupational gaps and the factors associated with occupational gaps, 12 months post stroke, as well as to identify the factors at 3 months that predicted occupational gaps at 12 months post stroke. A partial aim in study IV was to explore and describe the persons with stroke and their caregivers' occupational gaps three months after inclusion to the study.

Extent of occupational gaps

In study II, the mean number of occupational gaps for the persons one year after their stroke was 4.6 (median 3, range 0-22) whereas the mean number of occupational gaps at 3 months post study inclusion reported in study IV was 7.9 (median 7, range 0-23). The caregivers in Study IV reported a mean of 3.9 occupational gaps (median 3, range 0-19) at this same time point. Almost half of the participants in study II, one year after their stroke, reported a greater number of gaps compared with a reference group (Eriksson, 2012). In study IV, 83% of persons with stroke and 47% of their caregivers

had more gaps than the aged matched group in the reference sample (*i.e.*, 4 or more gaps). Also in study IV, the caregivers had a greater amount of occupational gaps than the person with stroke in 15% of the dyads.

Occupational gaps per activity

The activity that presented with the greatest number of gaps in both studies and both groups was *travelling for pleasure*, where 68% (study IV) and 38 % (study II) of the persons with stroke had an occupational gap. Also, 48% of the caregivers experienced a gap in *travelling for pleasure*.

Other activities that presented with gaps in greater percentages for persons with stroke in studies II (one year post stroke) and IV (3 months after study inclusion) were *participating in outdoor life, participating in cultural activities, participating in hobbies, cleaning, and performing heavy duty maintenance*. This ranking differed slightly from the caregivers that rated the most gaps (besides *travelling for pleasure*) in the activities *participating in cultural activities, participating in sports, and visiting restaurants and bars*.

The least amount of occupational gaps was found in the activity *visiting partner/children* for persons with stroke and for the caregivers in study IV. The prevalence of gaps in this activity was also very low one year post stroke, but the least amount of gaps, one year post stroke, was found in the activity *listening to/watching TV/radio/video* (study II).

Types of occupational gaps

An aim in study IV was also to describe the type of occupational gaps. The predominant type of occupational gap for persons with stroke was “I do not do the activity but would like to do it”. This was also the predominant type of occupational gap for the caregiver with the exception of six of the eight I/ADL activities. For the activity *cleaning*, 22% (of a total of 25%) had the type of gap that they did the activity but did not want to do it. This relationship was also present in the activity *cooking* (14% *c.f.* the total of 16%), *performing light maintenance* (11% *c.f.* the total of 17%), *grocery shopping* (7% *c.f.* the total of 10%) and *managing personal finances* (6% *c.f.* the total of 10%).

Analyses of occupational gaps

In study II, factors associated with the extent of occupational gaps among persons with stroke at one year were found to be SIS participation at 12 months post stroke, born or not born in Sweden, SIS recovery at 12 months, global life satisfaction at 12 months and stroke severity determined at inclusion. Factors at three months that predicted the extent of occupational gaps at one year post stroke were found to be SIS participation, SIS ADL/I-ADL (both measured at three months post stroke) and born in Sweden or not.

The number of occupational gaps for persons with stroke and the number of occupational gaps for the caregivers, in study IV, presented with a low correlation ($R = 0.36$). The correlation between the number of occupational gaps for persons with stroke and their global life satisfaction ($R = -0.33$) was considered low. There was a moderate correlation ($R = -0.50 - -0.56$) between the occupational gaps for persons with stroke and for the results of the SIS physical function, memory, participation and recovery domains. There was a low correlation ($R = -0.47 - -0.48$) between the occupational gaps for persons with stroke and for the SIS domains of communication and emotions and the results of the Barthel index.

For the caregivers, there was a low correlation between the number of occupational gaps and global life satisfaction as well as between occupational gaps and caregiver burden ($R = 0.31$ and 0.38) (study IV).

COMBINED LIFE SATISFACTION IN THE STROKE-CAREGIVER DYAD

The combined life satisfaction of persons with stroke together with their caregiver (making up the dyad) was examined in studies III and IV. In study III, the combined life satisfaction was associated with persons with stroke perceived impact of the stroke and the caregivers perceived caregiver burden one year post stroke. In study IV, the combined life satisfaction of the dyad was investigated in relation to the occupational gaps of persons with stroke and their caregiver, three months after inclusion to the study.

Combined life satisfaction

In study III, after one year post stroke, 40% of the dyads were both satisfied with life as a whole, while 26% were both dissatisfied. Thirty-four percent were discordant (*i.e.*, they responded differently). In study IV, 24% were both satisfied with life as a whole,

while 38% were both dissatisfied, 3 months after study inclusion. Thirty-eight percent were discordant.

Combined life satisfaction and occupational gaps

The persons with stroke in the dyads with combined low compared with the dyads with combined high global life satisfaction presented with a significantly greater amount of occupational gaps ($p = 0.003$). This relationship was also significant for the caregivers ($p = 0.007$) (Study IV).

Combined life satisfaction and stroke impact

In study III, the results of the combined life satisfaction showed that persons with stroke in the dyads that were dissatisfied rated that their stroke had a greater impact on their life compared with those in the dyads that were satisfied. Furthermore, there were significant differences in the perceptions of persons with stroke in the discordant dyads compared with the satisfied dyads regarding three aspects of physical functions of the SIS (strength, ADL and hand function) as well as participation and emotions. In contrast, the more cognitive aspects of the SIS, memory and communication, differed significantly between the discordant dyads and the dissatisfied dyads.

Combined life satisfaction and caregiver burden

In study III, there was a significant difference between the dyads that were satisfied and the dyads that were dissatisfied concerning the caregiver's perceived burden ($p < 0.01$). There was also a significant difference in caregiver burden between the discordant group (where all the caregivers had a low level of life satisfaction and persons with stroke a high level) and caregivers in the satisfied group ($p < 0.01$). There were no significant differences in the levels of caregiver burden between the two discordant groups. In other words, caregivers that were satisfied but their care recipients were not reported caregiver burden.

CONCLUSIONS

The main conclusions in this thesis deal firstly with persons' enacting agency in their everyday life, during the year after their stroke. Secondly, the conclusions deal with participation in everyday occupations (operationalized as occupational gaps) among persons with stroke and the stroke-caregiver dyad and thirdly, the dyad seen as a unit.

Persons after a stroke experience the process of enacting agency, that is, making things happen in one's everyday life, as complex negotiations of varied and changing aspects in different situations. The four characteristics that described how the participants enacted agency concerned; how they managed their perturbed bodies, took into account the past and envisioned the future, dealt with the world outside themselves, and negotiated through internal dialogues. This finding, from an occupational perspective, of enacting agency through complex negotiations, challenges the traditional definition of agency as the individual's capacity to act and exert power through willful acts (Study I).

Despite receiving rehabilitation services, a large percent of persons (83%) with stroke reported a greater number of occupational gaps compared with a reference group. Almost half of the caregivers in this group perceived restrictions in participation in their everyday occupations, and 15% of the caregivers perceived a greater level of participation restrictions compared with their care recipient (Study IV). In a hospital-based population, nearly half of the persons, one year after their stroke, reported a greater number of occupational gaps compared with a reference group. There were three factors at three months post stroke that predicted the extent of occupational gaps one-year post stroke. The factors were perceived social participation, not being born in the country, and self-perceived ADL ability (Study II).

Almost two thirds of the stroke-caregiver dyads gave congruent responses regarding their global life satisfaction (Studies III and IV). Dyads, where both persons had a low life satisfaction, experienced caregiver burden and stroke impact to a greater extent compared with those dyads where both persons were satisfied. Even if the caregiver was satisfied with life, but the care receiver was not, the caregiver could experience caregiver burden (Study III). In addition, dyads where both persons had low life satisfaction perceived a greater number of occupational gaps compared to the dyads that had combined high life satisfaction (Study IV).

GENERAL DISCUSSION

The studies in this thesis explored participation in everyday occupations and the relationship to life satisfaction for persons with stroke and for their caregivers, contributing to the knowledge base regarding life after stroke. A dyadic perspective was sought by combining life satisfaction in two of the studies, and this perspective led to new insights regarding stroke impact, caregiver burden and participation in everyday occupations. In addition, enacting agency during the year after a stroke was described as the participants' negotiations of different aspects, providing further knowledge regarding how persons participate in everyday life after stroke. These results indicate the importance of focusing on participation from an occupational perspective as well as including a dyadic perspective.

In this section, the results of the empirical studies and in relation to different theories will be discussed. The discussion will cover results regarding predictors of restrictions in participation in everyday occupations (*i.e.*, occupational gaps), caregivers' occupational gaps and more specifically what they did, but did not want to do, as well as traveling for pleasure, as a manifest occupational gap. Moreover, combined life satisfaction, as a means of having a dyadic perspective, will be discussed. Further, results concerning persons enacting agency through negotiations will be discussed. In addition, conceptual, methodological and ethical considerations will be discussed and lastly, I will present clinical implications of the findings and suggestions for future studies.

RESTRICTED PARTICIPATION IN EVERYDAY OCCUPATIONS

The results from study II showed that 45% of the persons one year after their stroke had restrictions in participation in everyday occupations, or more occupational gaps compared with a reference sample. The study also found three factors at three months post stroke that were predictors of occupational gaps, at the one year mark after stroke. Two of these factors will be discussed below. In addition, results from study IV showed that 47% of the caregivers perceived restrictions in their participation in everyday occupations. However, they perceived both types of occupational gaps and this will also be discussed. Lastly, the results of both studies II and IV showed that the most common activity that was an occupational gap was travelling for pleasure, and this will be discussed in relation to other studies.

Self-perceived ADL as a predictor of occupational gaps

An important knowledge contribution is the information gleaned from Study II regarding predictors of occupational gaps. The three predictors were participation at three months, born/not born in Sweden and self-perceived ADLs/I ADLs at three months. These results differ from other studies regarding participation predictors, that found factors such as walking and acceptance of the stroke (Desrosiers et al., 2008), age, co-morbidity, affect and lower extremity coordination (Desrosiers et al., 2006), or physical functions and mood states (Fallahpour, Tham, Joghataei, & Jonsson, 2011) as predictors of participation. However, it is difficult to compare the results due to differences such as measurement time points used and participation measures.

Even though the predictors only explained a relatively small portion of the variance (adjusted R squared = 0.27), it is of interest to look more closely at these predictors. It is important for clinicians to be informed of predictors of occupational gaps in order to identify persons that may run the risk of participation in everyday occupation issues at a later time, and to be able to work preventively to minimize these issues. Certain predictors can be modifiable through rehabilitation interventions and are even more important to recognize.

One of the predictors that fit this description is the self-perceived ADLs/I ADLs. This result, to the best of my knowledge, has not been found in other studies. This could be of special interest to clinicians for many reasons. First off, there is the possibility to intervene in this area at an early stage in the rehabilitation process, and there is empirical support for improvements after ADL training (Legg et al., 2007). ADL may have more importance for the clients' participation at the start of rehabilitation, which was evident since ADL at 12 months was not one of the five variables that were associated with occupational gaps. Also, being dependent in self-care and in instrumental ADLs influences life satisfaction negatively (Ekstam, Uppgard, von Koch, et al., 2007; G. Eriksson et al., 2009). Secondly, ADL was self-perceived and not rated by a professional, which indicates the importance of listening to clients and his or her own judgment of their abilities. This new knowledge generated from the study has the potential to inform both clinicians and planners of rehabilitation interventions after stroke to help prevent participation restrictions, one year post stroke.

The participation domain in the SIS was another variable that was a predictor of and associated with the extent of occupational gaps 12 months post stroke. This was in

accordance with our pre-understanding since both SIS participation and OGQ are considered as measures of participation, albeit different types of participation. The OGQ measures participation in everyday occupations and the SIS participation domain is considered a measure of social functioning (Lai, Perera, Duncan, & Bode, 2003). The OGQ will be further discussed in a coming section regarding methodological considerations.

Caregivers not-want-to-do occupational gaps

The OGQ is a unique measure as far as it acknowledges the activities that a person does but does not want to do, or “not-want-to-do gaps”. This provides another dimension to participation in everyday occupations in a new and interesting angle. A noteworthy result regarding the type and extent of “not-want-to-do gaps” was applicable for the caregivers in study IV, however, not for persons with stroke in either study II or IV. The caregivers performed activities that they did not want to do in six of the eight instrumental ADL activities. For example, 22% of the caregivers performed the activity cleaning but did not want to do it, while only 3% experienced the opposite type of gap (want-to-do-gap) in this same activity. The other activity areas affected in this way were cooking, performing light maintenance, doing the laundry, grocery shopping and managing personal finances. This result indicates that the caregivers may feel that they need to do mandatory activities, and this may be at the cost of leisure or social activities that one wants to do, as indicated by the want-to-do gaps results. This interpretation is also supported by the literature (Pellerin, Rochette, & Racine, 2011).

Exposing the not-want-to-do gaps of the caregivers adds a unique dimension to the dyads participation but also creates further research queries. What is the total situation for those dyads where this type of gap occurs? Can we ascertain certain trends by examining the dyads regarding different variables such as gender, life satisfaction, or caregiver burden in relation to occupational gaps? More research is needed to answer these questions and in turn, facilitate identifying vulnerable persons or dyads at an early stage after stroke.

This new outlook on participation in everyday occupations in the stroke-caregiver dyad may also help inform occupational science regarding the complex concept of occupational balance. Occupational balance is defined as “the individuals’ perception of having the right amount of occupations and the right variation between occupations” (Wagman, Hakansson, & Bjorklund, 2012) (p. 322). This is an important concept since

a balance of engagement in occupation can lead to well-being (Matuska & Christiansen, 2008; Wagman et al., 2012). Occupational balance is also proposed as an occupational right (Christiansen & Townsend, 2011; Stadnyk, Townsend, & Wilcock, 2011). However, the definition of occupational balance is directed towards individuals. Research in this area may benefit by extending the definition to include a dyadic perspective on occupational balance.

A desired activity - Travelling for pleasure

An interesting finding has to do with the activity that was the most pronounced occupational gap; “travelling for pleasure”. This occupational gap was found in the two groups of persons with stroke in studies II and IV, as well as in the group of caregivers. This is supported in the findings of other studies where persons with a mild stroke reported reductions in recreational activities (A. Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007) as well as limitations of community accessibility and transportation (Laliberte-Rudman, Hebert, & Reid, 2006). Travelling for pleasure requires executive functions, motor skills and endurance, any of which could be affected after a stroke. Health status in older persons was found to be an important variable in prohibiting or curtailing travel activities (Lefrancois, Leclerc, & Poulin, 1998).

The reciprocal effects within the stroke-caregiver dyad regarding travelling were not analyzed in detail, but one may consider travelling for pleasure as something that one does with a significant other. This assumption is supported in studies reporting the most frequent problems reported by spouses to persons with stroke concerned going away on holiday (Thommessen et al., 2002). A qualitative study showed that close relatives to persons with stroke expressed sorrow and loss concerning travel (Bäckström & Sundin, 2009). More generally, a number of studies have reported a decline in leisure activities according to relatives to persons with stroke. (Pellerin et al., 2011; A. Rochette, Desrosiers, Bravo, Tribble, & Bourget, 2007; Rodgers, Francis, Brittain, & Robinson, 2007).

From a theoretical perspective, the findings regarding occupational gaps in travelling for pleasure has potential interest for occupational science. One can assume that the activity travelling for pleasure is a valued activity for both persons in the stroke-caregiver dyad considering the responses in both groups. However, it might be interesting to seek the answer to the question “What does travelling for pleasure mean

for these persons?” Meaning and values of occupations are corner stones for occupational therapy and science (Christiansen & Townsend, 2011; Elizabeth Townsend & Polatajko, 2007; Wilcock, 2006). Future possible research could delve into investigating the meaning of participating in travelling for pleasure. This research may be important considering the desired focus of rehabilitation on leisure activities and life satisfaction (Vincent et al., 2007) and the relationship of recreation with health.

Traveling for pleasure may represent an engaging occupation or “the good life” (Jonsson, 2008) and something positive that one looks forward to doing. Also, travelling means leaving your home environment and being involved in activities outside the home and may represent a break from the mundane. Negotiating aspects to create change, for example, a change of scenery was a characteristic that came forth in the narratives of the participants regarding enacting agency in study I. With this in consideration, more research in the future may be warranted concerning the value of temporary and positive changes in both the environment and everyday routines. Changes of this nature could have positive effects on the health and well-being of individuals and dyads.

Considering the above, it is important for clinicians to explore and take into consideration the activities that are recognized as occupational gaps by individuals in the dyad. Taking the point of departure in the participants lived experiences, five of the six persons in Study I voluntarily talked about travelling in relation to their narratives on enacting agency. Possible clinical implications within occupational therapy could be the initiation and support of “self-help” groups led by persons, for example, dyads with experience of successful travels after a stroke. Considering the complexity, the demands of travelling, and the possible issues persons have in enacting agency after a stroke, clinicians should consider novel ways to support negotiations in order to enable valuable occupations such as travelling for pleasure.

A DYADIC PERSPECTIVE: UNIQUE INFORMATION ABOUT LIFE AFTER STROKE

Studies III and IV have a dyadic perspective by combining the life satisfaction of the stroke-caregiver dyad. The results of these studies found that there is a relation between combined low life satisfaction and a greater level of stroke impact, caregiver burden as well as a greater number of occupational gaps. These findings indicate that a dyadic perspective provides unique information regarding life after stroke.

A dyadic perspective by combining life satisfaction

Combining the life satisfaction of the person with stroke and the caregiver can be discussed conceptually and methodologically, and the latter will follow in the discussion of the methods. Conceptually, life satisfaction appraisal is considered to be highly individual (Achten et al., 2012) and one can question the legitimacy of combining life satisfaction as was done in studies III and IV. However, combining life satisfaction is conceptually based on a conceivable reciprocal influence within the dyad as explained in the introduction. In combining life satisfaction, an attempt was made to preserve the individuals' standpoint while attempting to gain a dyadic perspective simultaneously, through describing the dyad as in agreement or discordant.

Conceptually, this idea is built on the relationship between the dyads life satisfaction and is supported in the findings of other studies. In a sample of older adults, significant relationships were found between husband and wives subjective well-being, and that the well-being of one person in the dyad significantly predicted the other person's well-being (Bookwala & Schulz, 1996). Furthermore, measures of global life satisfaction in the stroke-caregiver dyad showed significant associations between patient and spouse, three years post stroke (Achten et al., 2012). These findings help support the reasoning behind combining life satisfaction in order to achieve a dyadic perspective.

Appraisal of global life satisfaction compared with everyday life

Global life satisfaction may be appraised in conceptually different ways compared with the different life satisfaction domains (*i.e.*, satisfaction with ability in self care, leisure, vocational life, etc.). In studies III-IV, global life satisfaction was used in the combined life satisfaction and not other domains that are included in the LiSat-11 checklist.

Global life satisfaction may conceivably be appraised on an existential level as opposed to the other domains that may reflect levels of satisfaction on a more everyday life level. This premise is supported by findings by Achten (2012) that showed significant associations between the patient and spouse only in global life satisfaction and finances but not in seven of the nine other life satisfaction domains (Achten et al., 2012).

One could hypothesize that all 11 domains of the LiSat-11, reflecting both global life satisfaction and domains reflecting more everyday life would correlate with results from the OGQ. This was shown in a study of persons post acquired brain injury where there was a significant correlation between all of the domains of the LiSat-11 and occupational gaps (Eriksson, Kottorp, Borg, & Tham, 2009). This may help explain the findings of study IV that showed low correlations between occupational gaps and

global life satisfaction for persons with stroke as well as for the caregivers. In other words, findings from the OGQ reflecting everyday life may not always coincide with global life satisfaction only. On the other hand, global life satisfaction and occupational gaps, both measured one year post stroke, were associated in study II. Because of these somewhat contradicting results, it is important that research in the future continues to measure both life satisfaction and participation with an occupational perspective.

A dyadic and occupational perspective

A dyadic perspective on participation in everyday occupations has to the best of my knowledge not been attempted before, and this was sought in study IV. Granted, a dyadic perspective, according to the definition given in the introduction of this thesis, was not totally achieved. Participation in everyday occupations was correlated between the numbers of occupational gaps of the person with stroke and the caregivers, but this resulted in a low level of correlation ($R = 0.36$). The low level of correlation of occupational gaps indicates that the amount of issues in participation in everyday occupations can differ within the couple. Some plausible explanations of the low correlation level within the dyad may be the short amount of time passed since the stroke (between three and six months post stroke). It is conceivable, at this time point, that persons with stroke have recently returned home after rehabilitation and may not have faced all possible issues in their everyday lives. This also could apply to the caregivers and warrants a study of a dyadic perspective on participation in everyday life in a longer time perspective after stroke. Ascertaining factors that predict the dyads participation at an early stage in the rehabilitation process may facilitate identifying vulnerable dyads. There is a need for future research focusing on the complexity of participation at levels involving others (Hammel et al., 2008).

A dyadic perspective to recognize vulnerable caregivers and dyads

The life satisfaction of the dyads was combined in study III and then compared with persons with stroke perceived impact and the caregivers' perceived burden. Approximately one quarter of the dyads in study III were both dissatisfied and perceived greater levels of both stroke impact and caregiver burden. This may indicate the vulnerability of these dyads and their need of support. To the best of my knowledge, this is a new approach in identification of vulnerable dyads.

In study III, approximately one third of the dyads had a discordant life satisfaction. Nineteen of the 28 caregivers in the discordant group were dissatisfied with life as a

whole, and these caregivers presented with caregiver burden. This was a noteworthy result and indicates that it is not sufficient to focus on the person with stroke if the aim is to identify vulnerable caregivers or persons. If the focus had solely been on the person with stroke, there is a risk that these individuals and their precarious situation would not have been recognized. This result emphasizes the importance of a dyadic perspective. Even the caregivers in the discordant group that were satisfied with life but whose care recipients were not satisfied reported caregiver burden, emphasizing the reciprocal influences of the two individuals in the dyad. This is important information and may aid in the identification of possible vulnerable dyads.

Clinical implications for vulnerable caregivers and dyads

The clinical implications of the findings from studies III and IV are two-fold; there is a need to identify and intervene regarding individuals (*i.e.* caregivers) and dyads that may be vulnerable. Caregivers are under-considered in health care (Lawlor & Mattingly, 2009), and should be acknowledged and offered interventions, despite that they may not be recognized as traditional recipients. Client centered interventions directed toward the caregivers may prevent future health and/or occupational issues. The notion of occupational justice including rights such as rest, leisure, and participation in the cultural life of a community (Stadnyk et al., 2011) warrants this position. Even though there is a need to identify vulnerable caregivers (Rigby, Gubitz, & Phillips, 2009) the results of studies III and IV suggests that this may be enhanced by having a dyadic perspective.

Also, a dyadic perspective is lacking in clinical care and potentially vulnerable dyads need to be identified in order to work preventively. Future studies are needed to focus on effective interventions directed toward the dyads. The results of studies III and IV together with knowledge about interdependencies and co-occupations emphasizes the clinical implications of regarding the dyad as the client. This may be especially conducive to client-centered support in the home environment (von Koch, Widén Holmqvist, Wohlin Wottrich, Tham, & Pedro-Cuesta, 2000) where individual and dyadic interventions should be considered.

AGENCY

The findings in study I in this thesis contribute to the knowledge base regarding participation in everyday life after stroke with unique information regarding how persons enact agency in everyday life. The six persons interviewed in study I described

their capacity to make things happen in their everyday lives during the course of the year after their stroke. The findings regarding enacting agency will be discussed below in relation to other empirical studies and are supported by the concept of place integration. Based on the findings, the definition of agency used in study I is challenged, and a new definition is proposed. Clinical implications will also be presented.

Agency and negotiations

The participants in study I described enacting agency over the course of the year after their stroke as negotiating or dealing with different aspects over a span of time, a range of difficulty and in a number of different activities. Through the analysis process of the interviews, four themes were ascertained; managing their perturbed bodies, taking into account the past and envisioning the future, dealing with the world outside themselves, and negotiating through internal dialogues. These findings could be likened to the findings of a recent qualitative meta-synthesis of very old persons managing changes in their everyday lives. Haak and colleagues (2011) used place integration as a theoretical base and found that the participants negotiated with themselves concerning the ability to perform activities and through their negotiations, the older persons created different courses of action to perform and participate in valued occupations. Like the findings in study I, the authors of the meta-synthesis found the process of negotiations as intertwined and ongoing (Haak, Malmgren Fange, Iwarsson, & Dahlin-Ivanoff, 2011).

The findings from study I can also be likened to a qualitative study regarding older women's aging-in-place. The authors found that meaning was experienced through occupation and that the participants underwent a process of negotiating changes included coordinating occupations and place integration (Heatwole Shank & Cutchin, 2010).

Furthermore, the findings regarding the complexity of agency are supported by other studies, however, from other than an occupational perspective. Based in social science theory, and with a discourse analysis, Al Zidjaly (2009) found that, through linguistic strategies, agency was co-constructed, mediated and continually negotiated in interaction (Al Zidjaly, 2009). With a life history approach and grounded in a sociological theory, Berger (2008) interpreted the life history of a young man with a spinal cord injury as a practical-evaluative agentive process in the man's adaptation to his disability (Berger, 2008).

A proposed new definition of agency

Agency was defined in study I as “making things happen in the context of one’s everyday life”, and the lived experience of enacting agency has been studied. The definition used in study I was influenced by a conglomerate of other common definitions of agency (Aarts, Custers, & Marien, 2009; Christiansen & Townsend, 2011; Huot & Laliberte Rudman, 2010), and the definition was coined at the beginning of the study as a pragmatic definition fitting for a phenomenological study. Considering the findings illuminated by the study regarding the complex negotiations of various aspects to make things happen, one could discuss if the definition of agency used in the study, is sufficient. In order to understand agency from an occupational perspective and to realize the importance for researchers to define agency carefully (Al Zidjaly, 2009), we may have to rethink the presiding definitions of agency. Therefore, a tentative, new definition of agency is proposed;

Agency is the capacity of a person to make things happen in everyday life through realizing and dealing with different aspects and in various situations that may arise as part of a continuous and changing transactional process. Agency, from an occupational perspective, may be seen as a prerequisite to participation in everyday occupations.

In the above definition, I have chosen to replace the term negotiation with *dealing* to facilitate clarity. Dealing with various situations in an ever changing, process, as in the proposed definition of agency, encompasses a number of different aspects, stemming from the findings of study I. An example from the study may help illustrate this. One of the participants described her process of visiting a relative, realizing the social expectations and her own desires. She felt that she had to negotiate these aspects in relation to her own, poor walking ability seen in light of changing environmental challenges (*i.e.*, climbing the outside stairs that at times were covered with snow). She relied on others for clearing the snow. In her negotiations or dealings with different aspects, she was interdependent in order to participate in her everyday occupations.

Accordingly, a new definition of agency is supported in other ways, as well. Prevailing definitions of agency have been criticized for being linked to power, independency, and autonomy (Johansson, Josephsson, & Lilja, 2009; S Wray, 2004). For example, acting autonomously, relates to being self-sufficient and not dependent on others. Likewise, power is associated with independence and fails to recognize the importance of

interdependency. Power, independence, and autonomy are not in congruence with enacting agency in everyday life in older age (Johansson et al., 2009; Wray, 2003; Wray, 2004).

Enacting agency in relation to place integration

The findings from study I can be seen in light of the concept of place integration and can also help understand the proposed definition of agency. *Place integration* as defined by Cutchin (2004) has to do with a process of ‘coordination’ of elements and actions and then a reconstruction of a situation (Cutchin, 2004). This reconstruction is used to bring the situation together as a new whole with new meaning for the person (p. 309). The findings in Study I, reflecting the participants’ negotiations of a variety of aspects, indicate the participants’ process of coordination of different elements. It appears that the participants attempted to remake different situations in their everyday lives by their negotiations.

This view also stresses the constant coordination between environment and person. After a stroke, taken for granted coordination can be disturbed. For example, taken for granted coordination is used when walking up stairs. One climbs the stairs without thinking of the width or height of each stair. After having a stroke, this situation may be different and the taken for granted functionality may be limited, and the process of coordination, as named above, may be disturbed (M. Cutchin & Dickie, 2012). Also, the environment can change. An example of this from study I can be found in the narrative of one woman that climbed stairs despite snow and ice and had to coordinate other people to assist her. In the findings of study I, the participants’ negotiations can be seen as attempts of coordinating and reconstructing and thereby remaking different situations in their everyday lives (Cutchin, 2004). Hence, the findings of negotiations in the process of enacting agency after stroke can be seen as an empirical example of place integration.

This new knowledge is of interest, in so far as it could contribute to different and innovative approaches in supporting persons in their enactment of agency in their everyday life after stroke. Occupational therapy clinicians could explore different ways to support clients’ negotiations skills, by, for example, problem-solving in different situations in everyday life. They might also benefit from a life-world perspective as a foundation for realizing the meaning of an occupation. Since negotiations in everyday occupations after a stroke are a complex process involving ever changing situations,

client-centered, individualized follow-ups possibly involving other relevant persons are recommended.

METHODOLOGICAL CONSIDERATIONS

The four studies in this thesis employed different samples and designs, as well as analyses methods and instruments. The qualitative and quantitative designs offered different perspectives and together contributed to the findings of this thesis. However, the sample and designs, methods and instruments need to be critically reflected upon, and a discussion regarding this follows.

Sample and design

The studies in this thesis are based on two different samples, LAS-1 and LAS-2.

LAS-1

The LAS-1 sample was used in studies II and III and had a number of strengths. One strength of the LAS-1 sample was that it was hospital based, and all persons with a stroke were eligible for inclusion in LAS-1. Also, the data for persons with stroke were collected in person by specially trained research assistants (occupational therapists or physical therapists) as opposed to having postal questionnaires. This assured accurate data collection. The research assistants had received instructions on how to administer the instruments, and could determine if the participant with stroke had difficulties in responding or could not tolerate the procedure and needed a rest. The research assistants even had the possibility of returning to the study participant on another day if needed. Yet another strength of the study was that persons with stroke with difficulties communicating (either because of not speaking the language or to aphasia) were included in the study and were able to participate with the help of interpreters or via proxy.

All measures used in LAS-1 are self-reported instruments reflecting the participants' perceptions in a number of different areas. There were two exceptions, however. First, ADL in the acute stage was measured by the occupational therapists with the Barthel Index. The MMSE, administered at inclusion and used as descriptive data, was also an exception. The research assistants used interviews for most of the data collection in order to reduce any levels of misunderstanding on the part of the participant, which was an advantage in the data collection. Using instruments that reflect the perceptions of the participants can be considered a strength of the study, but could also present

difficulties. Persons with stroke with cognitive issues may lack awareness of their difficulties in everyday life, and this may have affected their responses (Ekstam, Uppgard, Kottorp, & Tham, 2007).

In the LAS-1 sample, 349 persons with stroke were included. This amount can be compared to the National Patient Register (NPR) for those persons receiving care for a stroke at Karolinska University Hospital (in Huddinge and Solna) where 1231 persons with stroke were registered. However, there may be a tendency for stroke to be over diagnosed in the NPR (Riks-stroke, 2011). Participation in the LAS-1 study was voluntary, which may have affected the numbers of persons recruited for the study. Other reasons for this discrepancy can be two-fold. Firstly, persons with a severe stroke may be underrepresented in the LAS-1 sample due to medical and/or ethical considerations. For example, the patient's condition might have been so poor that it was not appropriate or reasonable to ask the person with stroke or their family member regarding study participation. Secondly, persons with a very mild stroke may also be underrepresented and may have been discharged after a very short stay in the hospital. The research assistants did not work on weekends, and this may have contributed to persons not being included in the sample. These underrepresentation factors may affect the representativeness of the study sample and in turn affect the ability to generalize the study results to a larger population of persons with stroke. Study III included data from the caregivers. It was not always possible to collect data from the caregivers at the same time as persons with stroke, resulting in a higher rate of attrition since caregivers sent in their responses per post.

Both studies II and III used subsamples of LAS-1. In study II, 200 persons of the original 349 were included in the study and thereby reducing the generalizability properties. The participants were included in the study if the results of the OGQ were available. The OGQ was the last instrument in a battery of numerous other instruments. Persons who could not tolerate the length of time it took to cover the whole battery were not administered the OGQ. This most likely led to a number of persons not included and could have affected the participants with a more severe stroke to a greater extent. In study II, 70% had a mild stroke, and this can be compared with 63% with a mild stroke in the whole LAS-1 sample. This small difference may have influenced the representativeness of the sample.

In study III, 81 persons with stroke were included in the study. The inclusion was based on if they had named an acquaintance that could assist them and gave permission to contact that person. Only after the acquaintance gave permission to be included in the study, did the dyad become study participants. Furthermore, the dyad needed to be present for the one-year follow up, leading to a rate of attrition. The representativeness of stroke severity in the subsample used in study III was relatively accurate for persons with mild or moderate strokes compared with the persons not included in the study, but persons with severe strokes were underrepresented (6% severe stroke in the study sample *c.f.* 24% of those not included in the study). This was most likely due to the longitudinal design of the study (data collection at one year). There was missing data from the caregivers on certain questions, for example, age and if they were living together or not. This missing information may make it difficult to compare the study group to other studies, but since it was descriptive data, did not affect the results.

LAS-2

The study sample from LAS-2 is from a multi-center RCT including 280 persons with a need for ADL interventions. The participants were included in the study three to five days after being admitted to rehabilitation, which could mean inclusion in the study up to three months after the stroke. The time after stroke for the main data collection could vary (between three and six months) and this should also be taken into consideration when comparing these results with other studies. In study IV, a subgroup of 105 persons with stroke was used. The persons were included to participate in the study if they had named a consenting caregiver and if there were life satisfaction and OGQ responses available. Like the LAS-1, the data was collected in a similar fashion by specially trained research assistants (occupational therapists) and gives credibility to the data.

The LAS-2 sample is based on a rehabilitation population and the subsample used in study IV includes only persons with stroke living together with their caregiver, which makes it difficult to generalize the findings to a more heterogeneous population.

Instruments

A number of instruments have been used in studies II, III and IV and two are discussed below; the OGQ and combined life satisfaction.

Combined Life Satisfaction

This thesis argues for the importance of a dyadic perspective regarding life after stroke.

Unfortunately, there are no measures, to my knowledge, with a dyadic, occupational perspective. This is surprising in light of the need to see the impact of stroke in a larger context, of family or significant other/caregiver (Rigby et al., 2009). This thesis has attempted to fill this gap with the use of combined life satisfaction and associations to occupational gaps.

However, a dyadic perspective can be challenging methodologically (McCarthy, Lyons, & Powers, 2011), and one can discuss the validity behind combining life satisfaction. As discussed earlier, the measure of combined life satisfaction is built on a conceptual foundation. Even though combined life satisfaction has been used in previous studies to describe the dyad and in statistical analysis (Achten et al., 2012; Carlsson et al., 2007; Eriksson, Tham, & Fugl-Meyer, 2005), combined life satisfaction has not been tested for psychometric properties. The cut-off point for dichotomization between satisfied and not satisfied has been previously determined (Fugl-Meyer, Melin, & Fugl-Meyer, 2002), but it is interesting to note that there were relatively high percentages of persons on each side of the cut off. This may motivate other methods in analyzing combined life satisfaction. However, combination of data from two persons can enable the researcher to get a fuller understanding of the situation as well as retaining information from each individual (Thompson & Walker, 1982). This should be considered in future studies, and further investigations regarding the use of combined life satisfaction are needed. It may be appropriate to build further knowledge on findings from qualitative investigations of the combined life satisfaction of the dyad. It is important that future studies help find new ways of viewing the dyad that will be legitimate conceptually, as well as methodologically.

Occupational Gaps Questionnaire

The OGQ is a participation measure focusing solely on human doings and thus, has an occupational perspective (Eriksson, Tham, & Borg, 2006). This is an important feature and may distinguish the OGQ from other participation measures. For example, other authors consider that participation can be viewed as community integration (Rochette, Korner-Bitensky, & Levasseur, 2006), which may include other aspects other than human doing. This distinction may also be important when using the OGQ in clinical praxis and may facilitate interventions from an occupational perspective. Furthermore,

the OGQ is based on what the individual perceives, which is fundamental to a participation measure (Hammel et al., 2008) and responds to the need of measures that approach participation from a client-centered standpoint (Cott, Wiles, & Devitt, 2007). There is a conceptual congruency between the OGQ and the definition of participation involving “what a person can and wants to do” (Mallinson & Hammel, 2010) presented in the introduction.

It is important to recognize that the OGQ does not only focus on if the person is performing the activity or not (represented by the first question) since performance is not synonymous with participation (Hammel et al., 2008). In conjunction with every question about performance of an activity, there is a question about wanting to do the activity. The second question can be seen as a form of a decision of wanting to do the activity or not and is consistent with the right to be active in decision making (decisional autonomy) (Cardol, De Jong, & Ward, 2002). The outcome of the OGQ is based on the relationship of the two questions, the person’s perception of doing an activity (or not) and wanting to do an activity (or not). This represents a unique focus on participation in everyday occupations as the performing in relation to the desire to perform a given activity.

The OGQ does, however, have some limitations. The OGQ is a screening tool with relatively general areas of activities. For example, the leisure activity “hobbies” could involve a number of different hobbies relevant for an individual and the one question regarding performance and desire to perform may limit the response. The responses do not give information regarding the individual’s satisfaction regarding frequency, quantity or quality of the activities, which could be important factors when considering participation (Hammel et al., 2008). It is necessary to be aware of limitations of this or any participation measure when using the results.

The psychometric properties of the OGQ were tested in Study II and found acceptable. This was performed by a Rasch analysis (Linacre, 2002; Tesio, 2003) and is considered to be important in the analysis of data from ordinal scales (Grimby, Tennant, & Tesio, 2012). Yet another strength of using the OGQ is the availability of normative data to compare findings (G. Eriksson, 2012).

Outcome measures regarding participation are limited (Cott et al., 2007; von Groote et al., 2011), and participation measures with an occupational perspective are needed. In

this respect, the OGQ is a functional measure because it is user-friendly and generic (Eriksson, Tham & Kottorp, submitted) and aims at ascertaining if and to what extent an individual perceives him or her selves to be restricted in their participation in everyday occupations.

The OGQ and the participation domain of the SIS

There are certain similarities and differences in the areas covered in the items, in the OGQ and the SIS participation domain. For example, work, leisure, social, and religious activities are covered in both measures. The SIS participation domain covers social roles and feelings of control while the OGQ focuses solely on occupations. For example, the OGQ asks questions about leisure and social activities, more relevant to the span of occupations in everyday life. This span is not covered in such detail in the eight items comprising the participation domain in the SIS. However, the greatest difference in these two measures is not the activities covered but underlying constructs in the questions. The SIS asks the individuals' feelings of limitations for each activity (i.e., none of the time/all of the time). In contrast, the OGQ reflects the autonomy of the individual in asking if the individual wants to do the activity suggesting that the individual connects a certain value to the performance of the activity. The notions of meaning, value, and choice are considered to be prerequisites for effective participation (Cardol, De Jong, & Ward, 2002; Cott et al., 2007) and are considered beneficial to measure (Ostir, Smith, Smith, Rice, & Ottenbacher, 2005).

The OGQ and caregiver burden

A result from study IV showed that the caregivers experienced not-want-to-do gaps. In other words, they did things that they did not want to do. One can discuss if this facet of participation in everyday occupations can be related to burden for the caregivers. One author has considered that the concept of burden can be likened to that of social participation restrictions (Pellerin et al., 2011) and considered the term burden as a surrogate for social participation restrictions. In light of the findings of Study IV where occupational gaps were not correlated with caregiver burden, one could question using burden for a surrogate for social participation restrictions. However, in the correlation in study IV, both types of occupational gaps were taken into consideration and a higher correlation may have been attained by only analyzing the caregivers' not-want-to-do gaps with caregiver burden instead. Conceptually, one could assume not-want-to-do-gaps as more of a load on a person than the opposite of desiring to do an activity but not

doing it. Future studies are needed to shed more light on this area, by investigating the correlations of different types of occupational gaps.

A phenomenological approach to understanding agency

To expand on how persons participate in everyday life after stroke, I chose a qualitative approach to delve into the lived experience of enacting agency. Qualitative research, like all science, falls under the scrutiny of objectivity, validity and generality (Dahlberg et al., 2008) and will be discussed below.

In study I, the aim was to understand the lived experience of enacting agency, which is suited for a phenomenological approach. The study design of interviewing six persons four times during the course of a year after their stroke made it possible to pose follow-up questions, and thereby follow the participants long range plans. This gave a chance for the researcher and participant to establish a trusting relationship and helped generate rich and detailed descriptions of enacting agency after stroke. Rich descriptions, in turn, strengthen the trustworthiness of the data and the analysis (Dahlberg et al., 2008). The interview data was analyzed with the help of the EPP method (Karlsson, 1995) fulfilling the requirements of academic rigor by using an established method (Rose, Beeby, & Parker, 1995). This method also encouraged the use of empathetic understanding to delve into the original experiences of each participant.

Phenomenology is not just a methodological approach but a philosophy as well (Husserl, 1970/1936) and is, therefore, important for the author to understand and incorporate the philosophical foundations in which phenomenology is based (Dahlberg et al., 2008). Objectivity and validity in the philosophies of phenomenology means being open and sensitive to the phenomena in focus (Dahlberg et al., 2008). This is reached through the reduction or a way of putting prior understanding out of reach for the researcher. This bracketing of ones prior understanding in order to open oneself to the phenomenon is challenging but imperative (Karlsson, 1995) and was supported by the group of researchers involved in the study. In this case, the bracketing of previous knowledge and clinical experiences was necessary. Validity was also supported by discussions in the research group and by seeking a “horizontally consistent interpretation” (Karlsson, 1995). This is a way of assuring the fit or logic of the interpretations with other parts of the data.

The aim of phenomenological studies is not to generalize knowledge but to contribute with an increased understanding of the phenomenon. For example, generalization of findings from phenomenological studies can be achieved by applying the results to new contexts (Dahlberg et al., 2008). An example of this may be the application of the finding of study I, negotiating different aspects to enact agency in everyday life, in a group of persons with other neurological disabilities beside stroke.

In conclusion, study I provides an understanding of the phenomenon of agency, representing a relative unusual methodological approach compared with other qualitative approaches (L. Borell, Nygard, Asaba, Gustavsson, & Hemmingsson, 2012).

ETHICAL CONSIDERATIONS

Ethical approval for the studies in this thesis has been obtained from the Regional Ethical Review Board.

Receiving a request for participation in a study shortly after a person has had a stroke may be somewhat trying for the person with stroke or for their significant other. A major event has just happened, and they may have difficulties comprehending the situation due to stress or cognitive difficulties, leading to possible difficulties in responding. The prospective participants may have difficulties understanding the demands of being involved in a longitudinal study. At the time of the request in both samples used in the studies, the prospective participants were in close contact with professionals coupled to the stroke unit or the rehabilitation team. The professionals were available to answer any questions that may have arisen regarding the study, easing the situation for the participants.

Persons after stroke may have difficulties comprehending information. Because of this all prospective participants received written information regarding the study and then verbal information from an occupational or physical therapist, nurse or physician.

All contacts with persons, considered as caregivers regarding the studies, were taken after receiving permission from the study participant. This is important from an ethical perspective foremost to respect the wishes of the person with stroke. The identified caregiver also received written information regarding the project, confidentiality, and the right to forfeit participation at any time during the study.

Most of the questions in the different questionnaires have to do with different aspects of everyday life, but some questions regarding challenges could be perceived negatively. However, the different measures were for the most part filled in together with a research assistant. The research assistants, occupational or physical therapists familiar with persons with neurological disorders were attentive to any possible problems and had the capacity to deal with any unexpected situations where the participant may have reacted to a question. Furthermore, the participants' contacts with the research assistants may have had a certain therapeutic effect and gave the study participants a possibility to express concerns and receive support from a professional. Also, the research assistants were sensitive to any of the participants expressed needs or problems and could assist in making contacts or offer suggestions to the participants.

In the interviews used in study I, the questions also regarded doing things in everyday life. Again, certain questions may have stirred emotions, which the interviewer became aware of and could deal with in a professional way. The persons in study I agreed to participate at an early stage after their stroke, not knowing what to expect. However, the participants expressed interests in the study, curiosity about the results and welcomed the researcher for follow-ups indicating a positive experience.

CLINICAL IMPLICATIONS

1. Making things happen in everyday life may be complicated after a stroke as shown in study I. Persons with stroke describe this process as negotiating or dealing with aspects that have to do with their own bodies that are not working in the same way, their past valued activities and their hopes for activities in the future, obstacles in their environment, and their own wishes and fears. In setting up a goal with a client, it is not only imperative to discuss what goal it is but also how the person plans to achieve the goal. The client with stroke and relevant caregivers may need information and support on how to make things happen in everyday life. It may be advisable to reason with the involved persons and discuss possible scenarios of problems they might encounter and how they may deal with them. Extra follow-ups may be needed to support the person (and possible caregiver's) ways of dealing with problems that may be a hinder in making things happen in everyday life. Reassurance might also be necessary so they do not give up before reaching their goal.
2. In order to give effective support to prevent restrictions in participation in everyday occupations, it is important to investigate the clients' occupational gaps at different time points after a stroke and intervene accordingly.
3. If the long-term goal of the occupational therapy intervention is participation in everyday occupations, then it may be advisable to be aware of the clients' descriptions of his or her ADL capacity (both personal and instrumental) and the person's perceptions regarding participation, at the end of rehabilitation services. If the person considers their ADL ability to be poor, and feels that they have difficulties in participating in everyday occupations, than one can suspect that the person may experience issues in participation after a longer period. Preventative measures, such as more frequent follow-ups and client-centered interventions aimed at lessening participation restrictions, may be appropriate. Also, if the person was not born in the country, the clinician should be aware that the person with stroke may risk participation restrictions in a longer perspective and may plan for preventative measures.
4. It is important for the clinician not only to incorporate the caregiver in goal and intervention planning, but it is of utmost important to be receptive for signs of caregiver burden, occupational imbalances (*e.g.*, in the form of not-want-to-do gaps) and participation restrictions for the caregiver as well. Caregivers'

occupational rights must be respected. It may be necessary to acknowledge the caregiver as a separate client and offer client-centered interventions directed towards perceived restrictions in participation.

5. A client-centered perspective may mean focusing on the dyad. It is important for clinicians to be aware of how two persons may possibly affect each other in different ways. This especially regards participation in everyday occupations and how the two persons may be involved in doing things together, or co-occupations. The clinician may have to intervene, recognizing both individuals and the dyad as the client and their participation in everyday life together. An example of this might be that the clinician can facilitate leisure activities, taking into account both of the individuals' needs, as well as their co-occupations.
6. Studies in this thesis identified possible vulnerable dyads. Those dyads where both persons have a low life satisfaction will most likely experience burden, impact of stroke, and restrictions in participation. These dyads may need additional client-centered interventions directed either at the individuals or both persons together.

FUTURE RESEARCH

Even though this thesis has contributed with new knowledge regarding everyday life after stroke, the thesis has also brought forth new questions, ideas and challenges. These were found in the areas of agency, participation in everyday occupations and having a dyadic perspective.

Agency is still a relatively new area within occupational science and therapy. A new, tentative definition of agency was proposed in study I, based on the study findings. This definition should be tested, with an occupational perspective, in future studies to ascertain the applicability to other groups of persons and in other contexts or situations. Furthermore, clinical implications of supporting complex negotiations such as creative and innovative ways to problem solve should also be studied in order to determine how clinicians can enable participation in everyday occupations after a stroke.

Study II examined participation in everyday occupations and presented variables predicting occupational gaps. However, these predictors need to be empirically studied. One can hypothesize that client-centered interventions directed toward those that risk participation restrictions, could have an effect on future occupational gaps. Future studies could test interventions in controlled trials with the preferential outcome of a decrease in occupational gaps. Studies measuring occupational gaps over a longer time perspective are needed. Moreover, the three predictor variables explained only a small portion of what can predict future occupational gaps, and there is a need of more studies to shed light on the whole picture. Ascertaining variables that predict future participation restrictions combined with effective preventative interventions are important research areas, and those results can help support clinical practice.

Information regarding occupational gaps from studies II and IV presented interesting results leading to further research questions. First off, widespread occupational gaps such as travelling for pleasure, participating in outdoor life or cultural activities could be approached through participatory action research involving the person with stroke and/or the dyad. This would hopefully lead to persons involved in finding their own solutions, resulting in fewer occupational gaps in relevant areas. Secondly, certain caregivers had a greater number of occupational gaps than their care receivers. There is a need for more research in this area, to expose persons that could risk experiencing other issues, such as caregiver burden. This information is imperative to work preventively. Thirdly, a number of caregivers' perceived doing activities that they did

not want to do. Again, research is needed in this area to identify these persons, at an early stage after stroke, in order to prevent further restrictions in participation in everyday occupations in a longer time perspective. One could also apply a qualitative approach on each of these three areas, to better understand the meaning of traveling for pleasure, experiencing occupational gaps as a caregiver or exploring not-want-to-do gaps in relation to caregiver burden.

Several studies point to the need of having a dyadic perspective, but there are definite challenges in doing research. To begin with, outcome measures applicable to both persons in the dyad are needed, as well as valid methods of analysis, to obtain outcomes on a dyadic level. More specifically, there is a need to explore alternative ways to analyze a dyadic perspective of occupational gaps. Also, models are needed to identify factors pertaining to the caregivers and the persons with stroke, which predict the caregivers' restrictions in participation in everyday occupations. This would enable clinicians to identify vulnerable caregivers at an early stage. Even qualitative studies with a longitudinal approach could explore how persons experience participation where both persons in the dyad perceive restrictions.

ACKNOWLEDGEMENTS

I am very grateful to have had this opportunity to partake on this journey. This has been a dream come true! There have been many people involved along the way and have made this adventure possible. Without them, I would never have arrived at my destination, nor be encouraged to keep going. They all deserve my gratitude!

First off, my sincere thanks go to all the *people in the studies* that so generously gave their time and energy to make this possible.

My deepest and heartfelt thanks go to my main supervisor *Gunilla Eriksson*. Gunilla, this thesis would never have been without you! It started years ago, with your encouragement and you being there as a role-model. Thank you for believing in me, listening, supporting, guiding, encouraging me and knowing what I needed and when I needed it. All of that has meant so much to me. Your professionalism is proof that you can combine being a supervisor and a friend! What would I have done without you!

I would like to thank *KerstinTham*, who was also my main supervisor for a good portion of this adventure. Thank you for opening the door into the world of research for me! I am so grateful for this opportunity and that you enabled me to have this experience. I have learned so much!

A special thanks goes to my supervisor *Lena von Koch*. You have not only been generous with your knowledge, but also with your enthusiasm, your time and your warm hospitality. Thank you for all your support, when I needed it the most. Your energy and your “eagle eyes” never cease to amaze me!

Also, my thanks go to *Magnus Andersson* for support.

To my co-authors in study I, *Eric Asaba* and *Anette Erikson* and to my co-authors in study II, *Malin Tistad* and *Susanne Guidetti*; thank you all for your valuable help!

Thanks to all in the *HELD* research group! To *Lena von Koch & Kerstin Tham, Ann-Sofie Bertilsson, Lisa Ekstam, Anette Erikson, Gunilla Eriksson, Susanne Guidetti, Ulla Johansson, Maria Ranner, Malin Tistad, and Charlotte Ytterberg*: Thank you for all of

the discussions, and comments on papers, presentations, and projects! Doing enjoyable things together makes working together even more special! Thanks to *Malin Tistad* and *Susanne Palmcrantz*, it has been enjoyable working with you both on LAS-1!

All of our seminars, doctoral students week and “kreativa konditoriet” wouldn’t happen if not for the work of *Louise Nygård* and *Lena Borell*. Thank you for such a learning experience! And also, to all the *doctoral students*, past and present at the Division of Occupational Therapy, for being there, helping, laughing, and sharing in this experience. Special thanks to *Mandan Fallahpour*, for listening and for the comments on my thesis.

Travelling may not always be for pleasure, but riding the train with the Uppsala train gang, over the years, has been a pleasure! *Anna, Therese, Gunilla, and Helene*, you all make the train rides so much more interesting, enjoyable and even a learning experience!

Thank you *Bosse*! Having one of your original pieces of artwork on the cover of my thesis makes it even more special!

To my amazingly, resilient mother! Thank you for caring so much!

And last, but not least, to *Lars*. Thank you for all the years, and all the encouragement...and thanks for never asking me *if* I was going to get my PhD...just when! Without you, we would not be a dyad! You are my travelling partner and give meaning through my journey through life.

My deepest appreciation goes to Karolinska Institutet’s *Health Care Sciences Postgraduate School* for financial support.

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