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## **Changes in everyday life after stroke**

Older individuals' and couples' daily occupations  
at home during the first year after stroke

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**Karolinska  
Institutet**

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## ABSTRACT

In designing occupational therapy interventions there is a need of knowledge concerning aspects of change in everyday life through the lens of occupation. The overall aim of this thesis was to explore, describe and understand change in everyday life among older individuals and couples as a unit during the first year at home after stroke from an occupational perspective.

This thesis applied multiple perspectives on changes in everyday life after stroke. Daily occupations have been studied both from the outsiders' perspective in terms of objective measures and from the insiders' perspective through more subjective experiences. All four studies are longitudinal with several (four to six) data gathering points during the first year after stroke. Data has been gathered by qualitative interviews and instruments. The analysis of the data gathered has, in order to answer the research questions, been multiple. Both statistics as well as more qualitative approaches ranging from visual inspections of plots generated from measurements, comparative methods, and hermeneutics have been applied. Further, the unit of analysis has been persons and couples.

This thesis presents new knowledge related to changes in everyday life by examining aspects of change for older persons who have experienced stroke, their spouses, and the couple as a unit during the first year at home after stroke through the lens of occupation. Everyday life for a group of older adults (studies I-IV) and a group of older adults and their spouses (studies III and IV) was, in different ways, altered compared to before stroke after returning home from the hospital. Most participants in the four studies increased their engagement in and performance of daily occupations during the first year after stroke, even if they did not reach the same levels of engagement or performance before their stroke. The findings in study I describe four different patterns of change in functioning in everyday life. Study II found that increased awareness of disability was related to improvements in occupational performance. The findings in Study III can be interpreted as there being a risk of occupational deprivation for both partners after stroke and that daily living includes a struggle to maintain reciprocity after stroke. Study IV described two couples' diverse strategies to change and the consequences of the change in daily occupations.

The knowledge gained in this thesis can be used to guide occupational therapists and other professionals in their judgment of what prerequisites clients have that can support their clinical reasoning and goal-setting for intervention aiming at enabling engagement in occupation and social participation.

Keywords: CVA, rehabilitation, occupational therapy, adaptation, everyday activities, home environment, family function, person-oriented-approach, qualitative approach, constant comparative analysis, hermeneutics

## LIST OF PUBLICATIONS

This thesis is based on the following publications, referred to in the text by their roman numerals:

- Study I: **Ekstam, L.**, Uppgard, B., von Koch, L., & Tham, K. (2007). Functioning in everyday life after stroke: a longitudinal study of elderly people receiving rehabilitation at home. *Scandinavian Journal of Caring Sciences*, 21(4), 434-446.
- Study II: **Ekstam, L.**, Uppgard, B., Kottorp, A., & Tham, K. (2007). Relationship Between Awareness of Disability and Occupational Performance During the First Year After a Stroke. *American Journal of Occupational Therapy* (61), 503-511.
- Study III: **Ekstam, L.**, & Borell, L. (2008 submitted). Challenges, dilemmas and patterns of occupations among couples after stroke.
- Study IV: **Ekstam, L.**, Tham, K & Borell, L (2009 submitted). Couples approaches to changes in everyday life during the first year after stroke.

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## LIST OF ABBREVIATIONS

ADL	Activity of daily living
AMPS	Assessment of motor and process skills
AD	Awareness of disability
AAD	Assessment of Awareness of Disability
OSA	Occupational Self Assessment
FAI	Frenchay Activity Index
FSA	Förbundet Sveriges Arbetsterapeuter
HSL	Hälsa- och sjukvårdslagen
OT	Occupational therapy
SFS	Svensk Författningssamling
SoL	Socialtjänstlagen
WHO	World Health Organisation

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## Papers I-IV

## INTRODUCTION

*When he sees how difficult it is for me to perform some things, he should be able to help me. But he can just stand there watching.... I don't know if he is thinking like, "It's an exercise that I need to practice!"*

Marianne

*She wants me to help her, but at the same time I think there are things she needs to practice to do. Then I keep a low profile, and she is forced to do things. I think that is good for her even if she thinks that I have been a little hard on her at the moment.*

Ragnar

As the above quotations from two individuals in a couple illustrate, stroke causes changes in everyday life that present challenges for more than the individual with stroke. This thesis takes as its point of departure the changes in everyday life after stroke in the lives of individuals with stroke, their spouses, and as a couple from the lens of occupation. In the vernacular or everyday language, occupation is commonly understood as *doing* (McLaughlin Gray, 1997). A basic assumption in the profession of occupational therapy, is that all human beings have a need to engage in occupations to stay healthy (Reilly, 1962; Wilcock, 1998, 2007; Yerxa, 1998). *Doing* activities that are both personally meaningful and culturally relevant (Jackson, 1996) across one's life form patterns of engagement in everyday occupations. A stroke often causes abrupt disruption and change in everyday life and, thus, disruption and change in patterns of performing and engaging in occupations.

Rehabilitation research has shown that the ability to handle changes and to be motivated to engage in everyday life after stroke requires awareness of one's abilities as well as disabilities (Fleming, Strong, & Ashton, 1998; Katz & Hartman-Maeir, 2004; Tham & Borell, 1996). Awareness of disability, itself, is often affected by a stroke (Tham, Bernspang, & Fisher, 1999). However, individuals' experiences of illness and disability and how it affects everyday life is also related to their relationship with family members (Mattingly & Lawlor, 2003). Yet most research on the effects of stroke focus on how it influences either the individual with stroke or the spouse/caregiver (Blake, Lincoln, & Clarke, 2003; Ekstam, Uppgard, von Koch, & Tham,

2007; Forsberg-Warleby, Moller, & Blomstrand, 2002; Larson, Franzen-Dahlin, Billing, Murray, & Wredling, 2005; Steultjens et al., 2003; Tham, Borell, & Gustavsson, 2000). This thesis studied the impact of stroke on everyday life from the perspectives of the individual with stroke, the spouse, *and* the couple as a unit in order to provide knowledge on the complex situation in everyday life at home and how it changes over time after stroke. The concept *couple as a unit*, used through the thesis imply a relationship between two partners where the partners are seen as dependent on each other, in a dialectic way, as one unit.

The mutual interrelationship between the needs of the person with stroke, spouse, and the couple as a unit relative to the characteristics of and aspects contributing to change in everyday life called for a combination of methods to assess and understand the changes in everyday life across time.. This thesis is based on four studies which take different methodological approaches—quantitative and qualitative—in order to explore, describe and understand change in everyday life after stroke from the multiple perspectives of the individuals with stroke, their spouses and the couples as a unit. The provision of care in stroke rehabilitation needs to take into account multiple perspectives in order to develop an understanding of this complex situation.

### **Stroke, everyday life, occupation and change**

In Sweden approximately 20,000 people experience their first stroke out of 30,000 afflicted yearly. Eight thousand people die from experiencing stroke each year, and it is the third most common cause of death. The mean age for having a stroke is 75 years of age, with women being 4.5 years older than men (Socialstyrelsen [The National Board of Health and Welfare], 2004). Biomedical aspects of functioning and effects of stroke are commonly described in the literature. Yet, a stroke is a life event that suddenly disrupts the life course and commonly leads to changes in everyday life that often result in long-term chronic consequences. Although most changes in body function (WHO, 2001)—primarily ascribed to neurological recovery—occur within the first six months post-stroke (Skilbeck, Wade, Hewer, & Wood, 1983), one study showed that only 25 percent of patients return to the level of physical functioning and everyday participation experienced pre-stroke (Lai, Studenski, Duncan, & Perera, 2002). Depression is also common after stroke, affecting both the well-being of the persons with stroke and their families (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Kotila, Numminen, Waltimo, & Kaste, 1998). Despite this bleak picture of rehabilitation after stroke, significant improvements in functioning in everyday life can occur long after the first six months post stroke (Elmståhl, Sommer, & Hagberg, 1996). As has been shown by Nyberg & Gustafson (1995), aspects of occupational



functioning, like mobility, can be a predictor of safety and functioning at one year even though reorganization of everyday life is an ongoing lifelong process.

### **Everyday life from the lens of occupation**

In the following I will introduce the occupational perspective applied in this thesis. Of particular interest in this thesis are the *changes in everyday life after stroke*. Occupations in everyday life mean different things for different people and are usually taken for granted as just the things that humans do everyday (McLaughlin Gray, 1997). As outlined by Fisher (2003) “occupational practitioners have a unique perspective on function that focuses on occupation–meaningful doing.” (p. 1) Thus, humans as occupational beings who need to engage in meaningful activities (Reilly, 1962; Wilcock, 2006; 2007; Yerxa, 1989) served as a point of departure for the occupational perspective. In everyday life, occupations emerge within social contexts. They are co-constructed and situated in sociocultural worlds (Cutchin, 2004; Lawlor, 2003; Molineux, 2006). This thesis’ examination of everyday life through the lens of occupation, then, also underscores the examination of humans as socially occupied beings; that is, that humans are “doing something with someone else that matters” (Lawlor, 2003).

Occupational therapy interventions have a tradition of focusing on enabling participation in life through clients’ occupational performance of occupations (Youngstrom & Brown, 2005). *Occupational performance* was defined (in study I and II) as the “...meaningful sequence of actions in which the person enacts and completes a specified task that is relevant to his or her culture and daily life roles” (Fisher, 2003, p. 24) as it results from the interaction between a person, a task and the environment (Christiansen, Baum, & Bass-Haugen, 2005; Fisher, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007). A central assumption in occupational therapy practice is that a focus on occupational performance supports clients to become actively engaged in activities (Baum & Law, 1997) and can be observed in actions, referred to as skills (Fisher, 2003) and completed tasks. In turn, *occupational engagement* has been linked the changes in or quality of performance or refers to the clients’ doing, thinking, and feeling under certain environmental conditions in the midst of or as a planned consequence of therapy (Kielhofner, 2008). For example, Kielhofner (2008) argued that “...all change in occupational therapy is driven by clients’ occupational engagement” (p. 171) and Lawlor (in press) wrote of engagement as “a kind of barometer of the success of therapeutic action” by grounding engagement as an “investment in the doing of activities” in the social nature of occupations (p. 7).

## **Changes in everyday life**

For most people stroke is related to changes in everyday life. Many studies have shown how stroke is related to change in health, quality of life and life satisfaction (Carlsson, Forsberg-Warleby, Moller, & Blomstrand, 2007; Edwards, Hahn, Baum, & Dromerick, 2006; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007) and quality of life tends to be higher among patients with better functioning than among persons with limited functioning (Samsa & Matchar, 2004). *Functioning in everyday life* after stroke, from an occupational therapy perspective, can be measured by the ability to perform activities of daily living (ADL), which is further divided into process ability and motor ability (Fisher, 2003). A limited ADL process ability versus ADL motor ability after stroke has been shown to impact more on the functioning in everyday life (Bernspång & Fisher, 1995). While individuals' perceived competence and the meaning of everyday activities may affect how they experience recovery of functioning in everyday life (Kielhofner, 2008a).

According to the gerontologist Atchley (1999), adaptation and continuity are processes that individuals apply to handle constant changes. When a sudden disruption such as a stroke occurs, people generally strive for and face a long and demanding process to bring meaning and continuity to their experience (Atchley, 1999; Becker, 1997; Roman, 2004; Tham et al., 2000). Since most people who experience a stroke in Sweden are older adults, with the mean age of 75 years (Asplund et al., 2003), the ageing process, the complexity of the health conditions, and medical complications might further disrupt the process of recovery (Davenport, Dennis, Wellwood, & Warlow, 1996). Becker's (1993) ethnographic study suggested that older adults attempt to preserve and maintain existing internal and external continuity by applying strategies to familiar arenas of life. For example, older adults re-established a sense of continuity in their everyday life after stroke when they were able to return home (Becker, 1993).

## **Rehabilitation after stroke in Sweden**

A general aim of rehabilitation is to facilitate recovery and functioning (WHO, 2001). The law that regulates healthcare in Sweden (Hälso- och sjukvårdslagen (HSL, 1982:763)) and the law that regulates social service (Socialtjänstlagen (SoL, 1982:763)) provide the overall broad guidelines for rehabilitation. The HSL regulates the provision of health and care services provided by the county council and the SoL provides additional guidelines for the provision of social service and care in the local municipalities. According to The National Board for Health and Welfare in Sweden (Socialstyrelsen), rehabilitation is provided with the goal to regain and

keep the best possible level of function as well as create the best possible conditions for independence and participation in daily life based on individual needs (SOSFS 2007:10). In addition, there are also guidelines for rehabilitation after stroke stating how effective use of resources should be provided based on systematic and priority needs assessments early after onset (Socialstyrelsen & [The National Board of Health and Welfare], 2006). Subsequently, following strong evidence for the need of specialized services, individuals with stroke are commonly treated in special stroke units and rehabilitation.

The goal for rehabilitation after stroke can be described in different ways. Recent literature based in occupational therapy focus on engagement in occupation and social participation as the main goal for rehabilitation. A more common theme in defining the goal for stroke rehabilitation is to enable the client to become independent in daily activities. Wade (1992) described the goal for rehabilitation “to maximize the patient’s role fulfilment and his independence in his environment, all within the limitations imposed by the underlying pathology and impairments and by the availability of resources; help the person to make the best adaptation possible to any difference between the roles achieved and roles desired”.

### **Awareness of disability and rehabilitation**

Lack of awareness of disability is common after stroke and is known to be an obstacle in the rehabilitation process (Hartman-Maeir, Soroker, Oman, & Katz, 2003; Prigatano & Schacter, 1991) which is related to that awareness is also a prerequisite to consciously make a change (Atchley, 1999). A commonly used definition of *awareness* is “the capacity to perceive the ‘self’ in relatively ‘objective’ terms while maintaining a sense of subjectivity” (Prigatano & Schacter, 1991, p. 13). Although this is a broad definition which does not specify of what to be aware, the concept of *awareness of disability* has been used in the present thesis in congruence with the operationalised definition in the assessment of Awareness of Disability as; no discrepancy between a person’s observed task limitations and the experienced and self-described task limitations after the performance of specific ADL tasks (Kottorp & Tham, 2005; Tham et al., 1999). Disability in this context is different compared to the broad social perspective on disability (Oliver, 1998) and refers more specifically to limitations of ADL-ability. Knowledge about the relationship between awareness of disability and occupational performance and how this relationship changes over time can contribute relevant information to occupational therapy practice for several reasons. A theoretical assumption is that lack of awareness of disability may (1) negatively effect the motivation to engage in reorganization, rehabilitation or change and thus occupational performance as well as (2) decreased judgment of how occupations can be

conducted safely and thus interfere with efficient, safe and independent functioning in everyday life (Hartman-Maeir et al., 2003; Tham, Ginsburg, Fisher, & Tegner, 2001). In addition, effective client-centered care rests on the expectation that the therapist and the client can identify a common platform on what types of changes are wanted in order to engage the client is an active partner in the occupational therapy process (Townsend & Polatajko, 2007). In this sense, client and therapist must agree on the problems (or disabilities) as well as course of action.

### **Change after stroke, occupation and being at home**

Occupational therapy aims to enable people to participate in occupations (FSA, 2005; WFOT, 2004). The Swedish national guidelines for stroke care and rehabilitation state that occupational therapy after stroke has demonstrated an increase in activity and participation (Socialstyrelsen & [The National Board of Health and Welfare], 2006). Several scholars in occupational therapy describe theoretically how the life course is created by and in occupations (Kielhofner, 2008; Fidler & Fidler, 1983; (Wilcock, 1999)). For example Kielhofner (2008) outlines that: “When people work, play, and perform activities of daily living, they shape their capacities, patterns of acting, self-perceptions, and comprehension of our world. To a large extent, people author their own development through what they do” (p.126). An overview of research on older adults with stroke showed a positive effect of occupational therapy intervention on the ability to perform primary activities of daily living, extended activities of daily living such as housekeeping activities and grocery shopping, and social participation (Steultjens et al., 2003). Another systematic review of patients with stroke supported these results by showing occupational therapy as an effective intervention to improve ability in activities of daily living (Legg et al., 2007; Legg, Drummond, & Langhorne, 2006) and that task-specific training on self-chosen activities in familiar settings increased activity as well as participation in society (Ma & Trombly, 2002; Trombly & Ma, 2002).

In Sweden, the national guidelines for stroke rehabilitation conclude that receiving home rehabilitation by a specific multidisciplinary rehabilitation team is advantageous. A study of von Koch et al (1998) comparing the behaviour of clients and therapists in their home versus hospital showed that being at home after stroke contributed to the type of collaboration central to client-centered care. In the hospital, the therapist gave instructions and the patient complied. In the home setting, behaviour was characterized by a dialogue between the patient and the therapist in a more equal manner where the patients also took initiative and expressed their goals (von Koch, Wohlin Wottrich, & Widén Holmqvist, 1998). Accelerated discharge services to home from

hospital did not compromise either functional recovery or endanger life for patients who had a mild to moderate deficit following a stroke (Langhorne et al., 2005). In addition, in a systematic review conducted by Legg & Langhorne (2004) on therapy-based rehabilitation services for stroke patients showed that patients receiving stroke rehabilitation services in the first year after stroke at home were more likely to have a better outcome both in personal activities of daily living and extended activities of daily living.

### **Client centred perspective in a “couple as a unit”**

Stroke rehabilitation can be seen as a client-centred process involving several professions (Sunnerhagen, 2003). In occupational therapy, the centrality of client-centred practice in most practice models (e.g. CAOT and MoHO) underlines how the voice of clients is crucial in any attempts to develop rehabilitation. Building on the individuals’ subjective experience of doing is critical to being able to discover effective strategies of change in everyday life (Kielhofner, 2008; Tham et al., 2000). Such *person-centeredness* underlines that “...each individual possesses considerable qualities” and, particularly when provided with facilitating environments, can use “his/her own resources and find a remedy to his/her difficulties by his/herself” (Leplege et al., 2007). However, there is an ongoing discussion about to what extent any model fully encapsulates a client-centred focus (Cott, Wiles, & Devitt, 2007). Given that the concept of client- or person-centeredness has been given diverse meanings, it is still relevant to ask questions about how and if rehabilitation efforts truly address the needs and requirements of those who use the services. In addition, do such concepts also exclude key individuals who are also integral to those individuals recovery?

The perspective of the client in occupational therapy models has broadened from mainly focusing on the individual with the disease or disability to include those who directly support the client (e.g. caregiver, teachers, parents, spouses), those in the group context of the client (e.g. family, friends, classmates) as well as those within a larger population group (e.g. organization or community) (American Occupational Therapy Association, 2002). Previous studies have also shown how social environment is important in the rehabilitation process after stroke (Tham & Kielhofner, 2003; von Koch et al., 1998). Yet, only a few studies have examined both of the spouse’s or individuals perspective as a couple as a unit in everyday life after stroke. Previous rehabilitation research on the consequences in everyday life after stroke has focused primarily on either (1) the person who had a stroke (Phipps & Richardson, 2007; Steultjens et al., 2003; Tham, Borell, & Gustavsson, 2000) or (2) the spouse/caregiver (Blake, Lincoln, & Clarke, 2003;

Forsberg-Warleby, Moller, & Blomstrand, 2002; Larson, Franzen-Dahlin, Billing, Murray, & Wredling, 2005; Levine et al., 2006).

### **Studies of couples after stroke**

Living together in a relationship influence how daily occupations are done and divided in between individuals. Everyday life after a stroke is shaped not only by the medical consequences of the stroke, but also by how couples handle the changes together in everyday life after one spouse has experienced a stroke. The results from a study by Thommessen et al., (2002) showed that the spouses of elderly with stroke, dementia and Parkinsons disease perceived a similar type and level of psychosocial burden, independent of the disease. In the couples with stroke a lower cognitive function of the patient was associated with a higher psychosocial burden on the spouse. Banks & Pearson (2004) had the couple's perspective when they studied how 38 younger persons with stroke and their partners were coping with crisis, showing how recovery after stroke is a long-term proposition; still 12-15 months after discharge some participants spoke about altered roles, additional responsibility, changed relationships, and communication problems. Also the qualitative study by Jongbloed (1994) focused on one couples experience of adaptation to a stroke. Five interviews were conducted over 2 years. The ethnographic analysis revealed that a stroke cannot be understood as an individual phenomenon, because the life courses of both in the couple were profoundly affected by the stroke (Jongbloed, 1994). These studies underpin the importance of considering the couple as a unit.

Clark & Smith's (1999) study was longitudinal, focusing on the couple and looked at changes in family functioning measured by the self-report instrument McMaster Family Assessment Device (assessing problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and a global measure of general functioning) (Epstein et al., 1983). The stroke event led to a significant lower degree of family functioning. Twelve months after discharge more than half of the patients and over 40% of spouses rated their families as dysfunctional on general functioning (Clark & Smith 1999). Longitudinal approach are needed to develop knowledge on how couples everyday life changes after stroke.

There are a number of interrelated theoretical concepts that can be of help in developing both research and rehabilitation related to stroke. The review of research on couples underlines the importance of examining the concepts of independence and interdependence in rehabilitation research.

## Dependency and interdependency

In the Western world it is highly valued to be independent yet many people who experience a stroke become *dependent* on other people's support and assistance in daily occupations (Warlow, 1998). About half of those who survive a stroke are dependent on others for assistance in personal activities of daily living six months after stroke (L. A. Legg et al., 2006). This means that it is not just the individual directly afflicted with stroke who experiences the consequences of stroke but also other family-members, relatives and friends. Several persons with stroke live with a spouse, out of 4729 persons with stroke in a Swedish national study 63 percent (n=2329) were co-habitant (Hulter Åsberg, Johansson, Staaf, Stegmayr, & Wester, 2005).

It is common that a family member, usually a spouse, is the main care provider responsible for the individual with stroke after returning home from the hospital (Hickenbottom et al., 2002; Åsberg, Johansson, Staaf, Stegmayr & Wester, 2005). After a life course disruption such as a stroke, social relationships are critical in the long term recovery and community integration (Glass, Matchar, Belyea & Feussner, 1993; Beckley, 2006). Often social relationships change after a stroke and that could be experienced as a loss.

Support, assistance and provision of help is most commonly seen as one provider giving something that the other one (the receiver) is in need of (King, Willoughby, Specht, & Brown, 2006). However, support is also seen as a result or a product of interdependence; support is communicated, negotiated, and handled between two (or more) individuals, for example, in the division of housekeeping chores between partners. How support and assistance is viewed by the spouse or the significant other will impact on the rehabilitation efforts, for example by helping "too much", instead of letting the person with stroke practice in occupations to improve everyday life. Social support is not only about practical support (instrumental, aid, tangible) but can also be informational support (advice, guidance), and emotional support (esteem, belonging, moral support) (de Ridder & Schreurs, 1996). However, provision of support, including different styles of support, and overall recovery after a stroke, has not been in focus in previous research.

**In summary**, there is a large amount of research on stroke rehabilitation. Several studies examine variables such as depression, ADL-ability, and how they change over time on a group level, but there is little known about change in everyday life after stroke examined from an occupational perspective aiming to grasp the complex everyday life at home. Change in daily occupations commonly occurs in relation to the situation before stroke and studies have shown a

change among the persons with stroke as well as their relatives. Change in different aspects of everyday life will also occur during the first year after stroke.

There are several studies describing different aspects of functioning and occupation during the first year after stroke but little is known about patterns of change based on individuals and couples changes in everyday life. The caregivers' situation and burden after for example a stroke cannot solely be understood by studying the caregivers situation, but the whole and multifaceted everyday life of all people involved needs to be considered. This is possible when we apply a perspective that builds on people being interdependent.

There is also a need of knowledge concerning aspects contributing to change in everyday life for the individual with stroke, his/her spouse, as well as for the couple as a unit. Knowledge of complex processes of change is of importance for designing rehabilitation/occupational therapy interventions with departure from the individuals and couples needs and everyday life and after stroke. To generate this knowledge there is a need of new and complementary perspectives and methods focusing on clients change in occupations over time. Longitudinal studies, with an occupational perspective, on how occupations changes during the year at home after stroke are rare and needed. In addition, a subjective perspective on performance of and engagement in occupations can be useful, and person- and client- oriented methodological approaches needs to be developed. The knowledge a situation-oriented approach, in this thesis studied in the homes of older individuals and couples daily occupations during the first year after stroke, can produce must be clinically relevant in rehabilitation.



## **AIM OF THE THESIS**

The overall aim of this thesis was to explore, describe and understand change in everyday life among older individuals' and "couples' as a unit" during the first year at home after stroke from an occupational perspective.

The specific aims in the four studies were to:

- Study I. Describe changes in some aspects of functioning and to explore types of individual patterns of change in functioning in everyday life during the first year after stroke for elderly patients participating in rehabilitation at home.
  
- Study II. Examine the relationship between awareness of disability and occupational performance during the year following a stroke in a group of elderly people.
  
- Study III. Understand how couples at home during the first year after stroke handled challenges in occupations of everyday life.
  
- Study IV. Identify and describe how two couples' approached changes in everyday life during the first year after a stroke. An additional aim was to describe how the couples viewed rehabilitation as well as own personal training relative to changes in everyday life during the first year at home after stroke.

## METHODS

The methods chosen and the overall design of the four studies for this thesis were chosen in order to identify (1) patterns of change (2) over time in older persons' everyday life for one year after stroke. An overview of the longitudinal design (e.g. points of data collection) and methods used in these studies (e.g. data collection and analysis) are given below in Table I.

*Changes in everyday life* were examined by focusing on what the participants were doing. Or, put another way, everyday life was examined through a lens of occupation. Engagement in and performance of occupations across time at home, then, were examined from the perspective of individuals with stroke as well as the perspective of the couple as a unit. All the studies were conducted in the participants' homes following their discharge from the hospital.

Two of the studies (I & II) applied statistical methodologies and person-oriented approaches (Bergman, Magnusson, & El-Khoury, 2003; Fitzmaurice, Laird, & Ware, 2004). Methods were combined in order to investigate if and how different aspects of engagement in and performance of occupation were related to the person with stroke's functioning in everyday life (e.g. perceived competence, everyday and seasonal activities, ADL ability, independence in ADL). Qualitative methodology was applied in study III & IV with the intention to study the perspectives of couples *as a unit*. Study III employed a hermeneutic interpretation (Gustavsson, 2000a, 2000b; Ödman, 1985) of the spouses' separate and shared occupational patterns in order to better understand how couples handled challenges and dilemmas in everyday life after stroke. Study IV shifted to a case study design (Creswell, 1997; Yin, 2003) in order to more closely describe the two couple's diverse strategies to change in engaging in occupations.

Table I: *Overview of the four studies included in this thesis*

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b>Design &amp; Research approach</b>	Prospective, longitudinal  Person-oriented approach	Prospective, longitudinal  Person-oriented approach  Quantitative approach	Prospective, longitudinal  Couple-oriented approach  Qualitative approach  Hermeneutic approach	Prospective, longitudinal  Qualitative approach  Case study design (couple as the case)
<b>Data collection (occasions)</b>	1, 3, 6, 12 months after stroke	1, 3, 6, 12 months after stroke	1 week before discharge, 1 week after, 3, 6, 9, 12 months after discharge	1 week before discharge, 1 week after, 3, 6, 9, 12 months after discharge
<b>Data collection (methods and assessment instruments)</b>	TUG, CES-D, Katz, FAI, AMPS, OSA LiSat-11,	AMPS, AAD	Interview guide, open ended questions  ADL-taxonomy	Interview guide, open ended questions, SF-36
<b>Data analysis</b>	Descriptive statistics, person-oriented, visual inspection	Mixed linear effect model	Comparative analysis and hermeneutic interpretation	Comparative analysis

## Participants

The participants in this thesis included older persons who had experienced stroke and had returned home from the hospital. In addition, studies III and IV also included the spouses of the persons who had experienced the stroke. The demographic characteristics of the participants are given in Table II below.

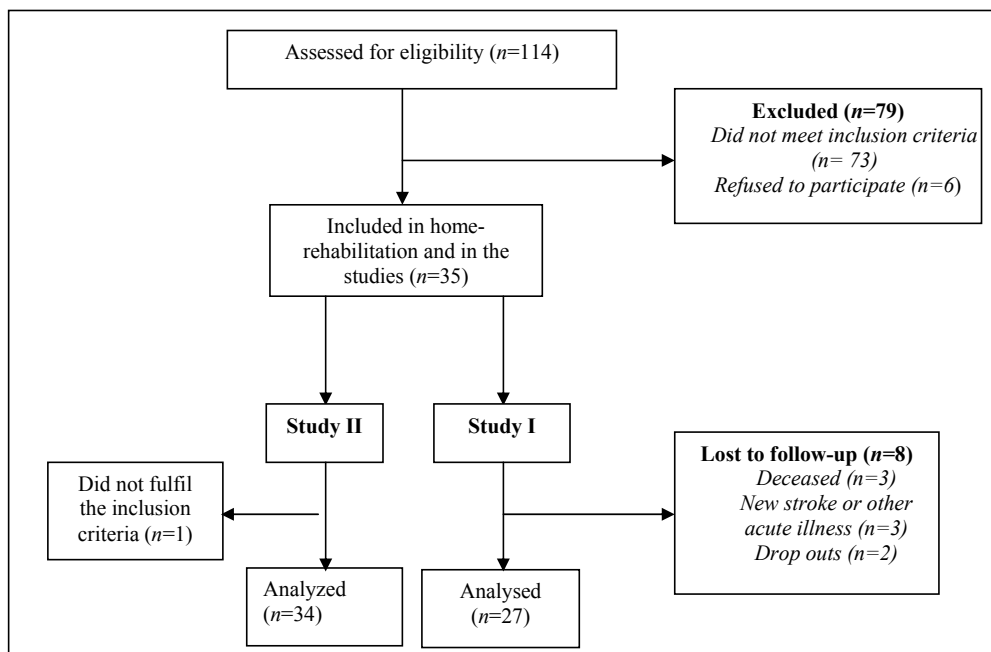
## Studies I and II

The participants in studies I and II were recruited consecutively during the years 2000-2001 from a home rehabilitation program at a stroke unit at a geriatric clinic in a large urban city in Sweden. The inclusion criteria to be enrolled in the home rehabilitation program included the ability to (a) take an active part in home rehabilitation interventions and (b) transfer to the toilet with or without aid. If they lived alone, inclusion criteria for the home rehabilitation program included the ability to (c) be alone at home for some hours per day and during the night, (d) use the alarm connected to a home-help service, and (e) open the front door. During recruitment, there were a total of 114 stroke patients who were assessed for eligibility in the home rehabilitation program

(e.g. See fig 1 for patient flow at the clinic). Further inclusion criteria for the research studies included (a) a period of 1 month had elapsed since they had experienced a stroke, (b) ability to understand instructions and questions, and (c) no diagnosis of dementia. Study I, included the additional criteria of the participants' (d) ability to participate for a full year (e.g. data collection occasions at months one, three, six and twelve). Eight participants were lost to subsequent data collection occasions. Twenty seven out of the 35 patients included in the home rehabilitation program, met all the inclusion criteria for study I. For study II, only one out of the initial 35 patients enrolled in the home rehabilitation program did not fulfil study criteria, leaving a total of 34 total study participants.

### **Studies III and IV**

The participants in studies III and IV included the persons who had experienced stroke and their spouses. The overall sample was recruited during 2002-2003 from different geriatric clinics in a large urban city in Sweden. The criteria in study III included that the person who had experienced stroke (a) intended to return home, (b) was over 64 years of age, and (c) had been living with another person in a long-term relationship for over ten years. Variation in the sample was sought by considering the following characteristics: age, gender of the persons who experienced the stroke, severity of the disease, educational background, and socio-economic status. Seven couples who met a range of these characteristics, in addition to the inclusion criteria, agreed to participate in the study. Based on the analysis in study III, two of the seven couples were selected to study IV. The two couples represented the development of two contrasting patterns of change in their everyday lives during the first year at home.



**Figure 1.** Patient flow (study I and II) at the stroke unit in the geriatric clinic over 10 months

Table II: *Characteristics and demographic of the participants*

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
Number of participants and gender	n = 27 <i>18 female + 9 male persons with stroke</i>	n = 34 <i>25 female + 9 male persons with stroke</i>	n = 14 (i.e. 7 couples) <i>3 female + 4 male persons with stroke</i>	n = 4 (i.e. 2 couples) <i>1 female + 1 male person with stroke</i>
Age mean (range)	78.8 (69-88)	81.5 (69-91)	73.4 (60-83)	77.3 (73-80)
Hemisphere lesion, right/left/other	13/13/1	16/16/2	2/5/0	0/2/0
Katz (A/B/C/D/E/F/G)	7/1/3/6/4/5/0*	7/2/5/7/5/6/0**	4/2/0/0/1/0/0	0/1/0/0/1/0/0
Living with someone /living alone	9/18	10/24	14/0	4/0
Housing before stroke, private homes/apartment	0/27	0/34	6/8	2/2

\*1 missing data, \*\*2 missing data

## The study context

The context of the study was the *everyday life at home*. As stated in the introduction, this study focused on *occupations* as a lens to view the everyday life of persons who had experienced a stroke in studies I and II and for persons who had experienced a stroke and their spouses in studies III and IV. Therefore, all four studies took place at the participants' residences after they had returned home from the hospital. Since rehabilitation is a relevant aspect of everyday life for persons with stroke, it was also included in the study context. In studies I and II, the participants participated in the same home rehabilitation program. In Studies III and IV the occurrence and content of the rehabilitation interventions differed from person to person.

## Studies I and II: The home rehabilitation program

The participants in studies I and II were discharged to home approximately one month after the stroke. The rehabilitation team at the stroke unit of the geriatric clinic continued to provide interventions in the home setting for a mean duration of 29 days (from a range 16-68). The team members included a nurse, an occupational therapist, a physiotherapist, a physician, a social

worker, a speech therapist and a psychologist. The programme was based on a client-centred practice frame (Restall, Ripat, & Stern, 2003) and the interventions were task-oriented and performed in the person's homes or in the community. Once discharged from the program, no follow-up interventions were performed.

### **Studies III and IV: The variability in home and rehabilitation**

In study III, three of the seven couples lived in their own homes and four in apartments when the stroke took place. One of the couples moved to an apartment during the first year after the stroke. By the end of the studies, then, five of the couples lived in apartments and two in houses. The residences were located in either the centre of a large urban city in Sweden or in the nearby countryside. Since the couples lived in different municipalities or districts, their rehabilitation programs differed when returning home after discharge from the hospital. Their rehabilitation programs, based on the interviews, are listed below in Table III.

Table III. *Rehabilitation programs for the individual with stroke in study III & IV*

	<b>Rehabilitation programs for the individual with stroke</b>
<b>Couple 1</b>	<b>Day care rehabilitation once a week during the first year at home.</b> - <i>Improving speech problems (individual treatment).</i>
<b>Couple 2</b>	<b>No rehabilitation after returning home</b>
<b>Couple 3</b>	<b>Day care rehabilitation twice a week during the first year at home.</b> - <i>First improving perception problems, reading and writing (individual treatment) .</i> - <i>Second, improving balance and physical training in a gym (individual treatment) .</i>
<b>Couple 4</b>	<b>Day care rehabilitation twice a week for 6 months.</b> - <i>Increasing hand function and mobility (group treatment).</i>
<b>Couple 5</b>	<b>Day care rehabilitation twice a week during the first year at home.</b> - <i>Water gymnastics (group treatment)</i> - <i>Physical training in a gym (individual training in a group format).</i>
<b>Couple 6</b>	<b>Home rehabilitation for one month</b> - <i>Enabling engagement in occupations and improving mobility and transfer (individual treatment.)</i>  <b>Day care rehabilitation once a week for 5 months.</b> - <i>Increasing physical activation and improving hand function (group treatment).</i>
<b>Couple 7</b>	<b>Home rehabilitation twice a week first month</b> - <i>Enabling engagement in occupations and improving mobility and transfer (individual treatment.)</i>  <b>Day care rehabilitation twice a week for approximately 6 months.</b> - <i>Increasing mobility and hand function (individual treatment).</i>  <b>Day-centre rehabilitation once a week for 8 weeks.</b> - <i>Keep strength and dexterity in hand, arm and legs (group treatment).</i>

## **Data collection and procedure**

In studies I and II, data collection took place at one, three, six, and twelve months after stroke. Data collection for the first data collection occasion was conducted at the hospital with the remaining three in the participants' homes. In studies III and IV, data collection took place over six occasions. The first data collection took place at the hospital, with the remaining five taking place in the participants' homes (e.g. at one week and then at three, six, nine and twelve months). The data consisted of material collected by instruments and observations (studies I & II) and



interviews (studies I, II, III & IV). The instruments, observations and interviews are described in more detail below.

## Instruments

The data collection instruments used in studies I, II & IV are listed in Table III below.

Table IV. *Overview of instruments relating to occupation and life satisfaction used in the thesis.*

<b>Instrument</b>	<b>Used in study</b>	<b>Outcome measure</b>	<b>Data collection method</b>	<b>Rating scale (range and total score)</b>
<b>Assessment of Motor and Process Skills</b> <i>(Fisher, 2003)</i>	I, II	Occupational performance ( <i>ADL-motor ability</i> <i>ADL-process ability</i> )	Observation	1 (deficient) – 4 (competent) <i>3.0 logits</i>
<b>Assessment of Awareness of Disability</b> <i>(Kottorp &amp; Tham, 2005; Tham et al., 1999)</i>	II	Awareness of disability	Observation Self-report	1 (major discrepancy) – 4 (no discrepancy)
<b>Frenchay Activity Index</b> <i>(Holbrook &amp; Skilbeck, 1983)</i>	I	Everyday activities Seasonal activities	Self-report	0 (never) – 3 (often) 0 (inactive) – 45 (active)
<b>Katz-Extended</b> <i>(Hulter-Åsberg &amp; Sonn, 1988)</i>	I	Independence in ADL	Self-report	1 (dependent) – 2 (independent) <i>20 points</i>
<b>Occupational Self Assessment</b> <i>(Baron, Kielhofner, Iyenger, Goldhammer, &amp; Wolenski, 2002)</i>	I	Perceived competence and values of everyday activities	Self-report	Competence scale: <i>1 (I have a problem doing this)</i> <i>3 (I do this well)</i>  Value scale: <i>1 (This is not so important to me)</i> <i>3 (This is extremely important to me)</i>  <i>100%</i>
<b>Life Satisfaction-11</b> <i>(Fugl-Meyer, Melin, &amp; Fugl-Meyer, 2002)</i>	I	Perceived life satisfaction	Self-report	1 (very dissatisfied) – 6 (very satisfied)
<b>SF-36</b> <i>(Sullivan, 1994)</i>	IV	Health-related quality of life	Self-report	1 (excellent) – 4 (bad)

## Interviews

### Studies I & II

The focus of the interviews for studies I and II were structured to gather information of the participants' environments and self reports of occupational performance. In study I, structured interviews (Kvale & Torhell, 1997) were used to collect data on the number and types of barriers in the physical and social environment six months post-stroke. This information was combined with data on the age, gender, living situation and type of lesion gathered from the medical records. In study II, the *Assessment of Awareness of Disability (AAD)* structured the interviews (Tham et al., 1999). The AAD evaluation is based on a semistructured interview with 11 questions. Examples of questions are: "*How was it for you to use your hands when you...? Can you describe?*" and "*How was it for you to move or transfer your body when you...? Can you describe?*" The therapist evaluated a person's awareness of disability by assessing the discrepancy between the level of skill experienced and reported by the person for a specific ADL task on a scale from 1 (*major discrepancy*) to 4 (*no discrepancy*) and the level of skills observed by the therapist using the *AMPS* (Fisher, 1997). For examples see figure 2 below.

Question 3: How did it work for you to use your hands when you make “green salad, served in a large bowl with dressing on the side”?

Example of relevant AMPS skills: Grips, Manipulates, Coordinates, Flows, Calibrates, Handles						
OT' assesement		ADL-limitations		Clients description		AAD
"The patient has general problems with gripping objects steady and safe. On one occasion he cut his hand"		None		"I had troubles holding both the knife and the vegetables all the time. I also cut my finger. "	4	X
			Minimal			3
		Moderate/Obvious			2	
	X	Major	X		1	

4 = No discrepancy 3 = Minimal discrepancy 2 = Moderate/obvious discrepancy 1 = Major discrepancy

Example of relevant AMPS skills: Grips, Manipulates, Coordinates, Flows, Calibrates, Handles						
OT' assesement		ADL-limitations		Clients description		AAD
"The patient has general problems with gripping objects steady and safe. On one occasion he cut his hand"		None	X	"I think it went well"	4	
			Minimal			3
		Moderate/Obvious			2	
	X	Major			1	X

4 = No discrepancy 3 = Minimal discrepancy 2 = Moderate/obvious discrepancy 1 = Major discrepancy

Figure 2. An AAD assessment of two different patients that during the performance of task H-4: Green salad, served in a large bowl with dressing on the side, showed the same kinds of difficulties in using their hands. The patients own experience of the observable problems differs largely in question 3 in AAD, which leads to different points in the AAD assessment.

### Studies III & IV

The interviews for studies III and IV were focused on eliciting the participants' experiences of engagement in occupations more broadly. Studies III and IV utilized semi-structured interviews (Kvale & Torhell, 1997) that focused on their experiences in occupations of everyday life after stroke. These interviews were conducted separately with (1) the person who had experienced the stroke and (2) his/her spouse. Open-ended questions were developed, such as: "Can you tell me how your everyday life is different compared to before the stroke?" and "When you think about the future, is there anything you are hoping for and/or worrying about?" These individual interviews lasted between 20 to 90 minutes. Additionally, study III utilized the ADL taxonomy (Törnquist, 1995) to structure interviews with the couple as a unit to collect information about the specific personal and instrumental activities that the participants who had experienced a stroke: (1) could do, (2) actually did, (3) wanted to do, and (4) needed help doing and how this help was provided. All interviews for studies III and IV were recorded and transcribed verbatim. These interviews were analyzed and discussed with the responsible researchers prior to

subsequent interviews. Thus, the topics for the interviews were consistent over time, although examples drawn from the interviews of particular individuals and couples shaped specific interview questions for the same persons and couples respectively. The meetings in which the interviews took place lasted between 40 minutes (i.e. at the hospital) to four hours (i.e. in the home) including breaks for refreshments and small talk.

### **Field notes**

In study I, field notes indicated the life events that occurred for each participant after each test. A group of researchers identified and categorized all life events according to their severity and type. Based on the participants' reports, the researchers then classified the life events that had a clear impact on functioning as major and all others as minor. In studies III and IV, the researcher took field notes immediately following each meeting in which the interviews took place. These field notes described the researcher's general impressions of the visit, including notes on particular events (e.g. other individuals visiting) that impacted the meeting and differences in participants' actions or interactions (e.g. being in a hurry, or stating they were tired). As recommended by Glaser & Strauss (1967), memos on the researcher's reflections, comments and questions were consistently recorded.

### **Data analysis**

The common focus in all four studies was to describe, identify or explore changes in everyday life in the year following a stroke. In study I, the focus was on patterns of functioning in everyday life. Thus, study I combined a both quantitative and qualitative analytic strategies to the data generated by the instruments by using both: (1) descriptive statistical analysis and (2) visual inspection (Kazdin, 2003) of longitudinal case plots using a person-centered approach (Bergman et al., 2003). In study II, the focus was on the pattern of the relationship between awareness of disability and occupational performance and utilized a mixed-linear-effect model (Fitzmaurice, Laird, & Ware, 2004). Studies III and IV expanded this person-centered analytic unit to include the perspective of the person's spouse. Thus, the perspective of the *couple as unit* relied on qualitative methodology using both: (1) constant comparative (Glaser & Strauss, 1967), and (2) hermeneutic approaches (Gustavsson, 2000a, 2000b; Ödman). Study III focused on identifying and interpreting seven couple's patterns of change in daily occupations during the year from both of their perspectives, while study IV focused analysis on two contrasting patterns of change by comparing the experiences of two couples. Further descriptions of these analytic strategies are given below.

## **Studies I and II: Analysis of quantitative data**

### **Descriptive statistics**

Study I used descriptive statistics in order to describe and visualize the group's levels of functioning across the year (e.g. one, three, six and twelve months) after experiencing a stroke). Friedman's Test (Altman, 1999) was used on a group level for all variables of the instruments identify whether a significant change in aspects related to functioning occurred, and if so, when this change occurred during the year (e.g. mobility, mood, ADL-ability, everyday and seasonal activities, independence in ADL, self-rated and perceived competence and values of everyday activities). The *p*-value was set at  $<0.05$  (Altman, 1999) but, with the adjustment for the multiple (four) comparisons with Bonferroni correction a *p*-value of  $<0.0125$  was considered to be statistically significant (Altman, 1999). In study II, Friedman's test (Altman, 1999) was used to identify any changes in persons' awareness of their disability and in their ability to perform ADL during the year. A *p* value of  $< 0.05$  was considered to be statistically significant (Altman, 1999).

### **A mixed-linear-effect model**

In order to describe the time-effect of the influence of awareness of disability on ADL motor ability and ADL process ability, study II utilized a mixed-linear-effect model (Fitzmaurice, Laird, & Ware, 2004). This model takes into account (1) any covariance between repeated measures (e.g. ADL motor ability, ADL process ability, awareness of disability) obtained from the same participant, and (2) any data that includes situations in which there are different numbers of repeated measurements or different intervals for different cases or both. Time was viewed as a continuous variable. The model displays the measures for the distribution of awareness of disability, ADL motor ability, and ADL process ability over time (see fig 3 & 4 in the findings).

### **Categorization based on visual inspection**

Study I adopted a person-oriented approach in order to analyze individual patterns of change in functioning in everyday life across the year. A person-oriented approach is based on the assumption that the complexity of an individual's processes of change can be conceptualized as containing many interacting variables (Bergman et al., 2003). Variables under study (e.g. ADL motor and process ability, everyday and seasonal activities and perceived competence) were plotted across a longitudinal axis of time in STATISTICA 7 in order to visualize each individual's direction of change (Kazdin, 2003). The direction of each variable of each participant's longitudinal plot was then categorized with visual inspection (Kazdin, 2003) by the group of

researchers as a (1) stable positive slope, (2) stable neutral slope, (3) stable negative slope or (4) unstable (fluctuating) slope. The direction of the case plots concerning aspects reflecting functioning in everyday life activities (listed above) were inspected simultaneously for each individual to arrive at a final individual pattern based on the directions of change. These individual patterns were then compared across participants in order to identify group patterns of change, such as: (1) *disrupted functioning in everyday life*, (2) *moderate change in functioning in everyday life*, and (3) *minor change in functioning in everyday life*. When all aspects under study were compared in an attempt to identify any patterns of similarities and differences among the participants within the same group, a new pattern of change in functioning emerged: (4) *minor change despite major life events*.

### **Studies III and IV: analysis of qualitative data**

#### **Comparative method**

Both studies III and IV used a constant comparative approach to data analysis (Glaser & Strauss, 1967). The data was coded by using the research questions as a guide, such as: “How do couples experience occupations in their everyday life at different points in time during the first year after stroke?” and “How does couples approach changes in doing during the year?” The codes that emerged (e.g. the spouse is taking over occupations; individuals regaining occupations, thoughts about future) were then compared with previous incidents in the same interview, and then across all interviews for each participant over time. Second, the codes of each individual in *a couple as a unit* were compared, followed by a comparison between all couples as a unit. This back-and-forth process of constant comparisons revealed the differences as well as similarities for (1) each individual, (2) each couple and, finally, (3) across all seven couples in study III and the two couples of study IV. The categories emerged through this process.

In study III, data that indicated changes in everyday life were identified in the text and coded. Data that indicated changes in everyday life focused on: (1) occupations each of the seven persons with stroke and his or her spouse maintained, lost, or regained, and (2) individual occupations as well as occupations common to the couple that each of the seven person’s with stroke and his or her spouse deemed as more or less important or valuable. This initial step in the analysis revealed each person’s pattern of occupation as lost, maintained, or regained over time. These patterns of occupations across time, therefore, contained the views and experiences of both of the persons in the couple as unit. This analysis indicated a core finding; that is, the changed patterns of occupations after stroke related to how support, assistance, and help was

provided by the spouse. Thus, the second step of analysis explored how the seven spouses of the person's with stroke handled challenges and, more precisely, how each of the spouse's provided and viewed the provision of support, assistance, and help in occupations of everyday life. This step of the analysis also raised questions about how the seven persons' who had experienced strokes viewed their needs and aspirations for help and support. One example of a category that emerged from the analysis, representing the couple as a unit, was *Making conscious choices and using advanced strategies*.

The analysis in study IV focused *first* on how two couples experienced their everyday life at the end of the first year home after stroke. And *then* the analysis focused on comparing the two couples *during* the year concerning goals, expectations, concerns, worries, experiences and needs in everyday life, in addition to their perspectives of their own personal training. Through this process categories emerged from the analysis such as: *Getting experience and thereby feedback from doing and Contributing to a picture of a possible future*. In addition, the questionnaire data of participants' self-rated general health were compared to the interview data to triangulate information about the participants' health status. In both studies III and IV, in order to firmly establish rigour, experienced researchers critically examined the findings as they emerged. Thereafter, all findings were further scrutinized and revised until all researchers reached agreement.

### **Hermeneutic tradition**

In addition, the final step of study III utilized a hermeneutic approach (Gustavsson, 2000a, 2000b; Ödman) in order to try to better understand and explain, by interpretation, the couples' patterns of occupations and the challenges and dilemmas related to values of occupations and support and assistance. Throughout the analytic process, the researchers discussed and inductively reasoned about how to understand the challenges and dilemmas; that is, by using all of the available data without presupposing or establishing the dimensions in advance. Drawing concepts from (1) existing occupational therapy theory, such as *occupational disruption* and *occupational deprivation* (Whiteford, 2000), and (2) literature on illness experience, such as *reciprocity* (Murphy, 1990), also proved useful for interpreting the findings in the final step and will be discussed in more detail in the Findings.

## FINDINGS

This thesis presents new knowledge about changes in everyday life, by examining change for older persons who have experienced stroke, their spouses and the couple as a unit during the first year at home after stroke through the lens of occupation. Everyday life for a group of older adults (studies I-IV) and a group of older adults and their spouses (studies III and IV) was, in different ways, altered compared to before stroke after returning home from the hospital. Most participants in the four studies increased their engagement in and performance of daily occupations during the first year after stroke, even if they did not reach the same levels of engagement in or performance before their stroke.

### Patterns of change in everyday life

Based on a central premise of this thesis, changes in everyday life could be viewed by examining changes in daily occupations for persons with stroke during the first year. Study I identified four different patterns of change in everyday life for older persons during the first year after they had experienced a stroke by examining the changes of engagement in and performance of occupations. For the same sample, study II further showed how the relationship between these older persons' performance of occupations and awareness of disability changed over time. In addition, there were two other time-related patterns of change in everyday life. First, changes of functioning in everyday life (as measured by all instruments used in study I) were most frequent during the first 6 months after stroke (study I). Second, although most participants made improvements during the year, they were not satisfied with life as a whole at 12 months after stroke (study I). These findings will be presented in more detail below in *Persons with stroke: patterns of change in engagement in and performance of occupations*. Taking a multiple perspective approach (e.g. individuals with stroke, their spouses, and couple as a unit) to these changes in occupations in everyday life, studies III & IV provided qualitative information on how the patterns of engagement in and performance of daily occupations not only changed for the person with stroke, but also for their spouses. As a consequence, the *couples as a unit* experienced challenges and dilemmas in everyday life, that each handled differently. Study IV was a case study of two divergent ways of handling these challenges and dilemmas by focusing more in depth on two couples' experiences in engaging in occupations.



## Persons with stroke: patterns of change in performance of and engagement in occupations

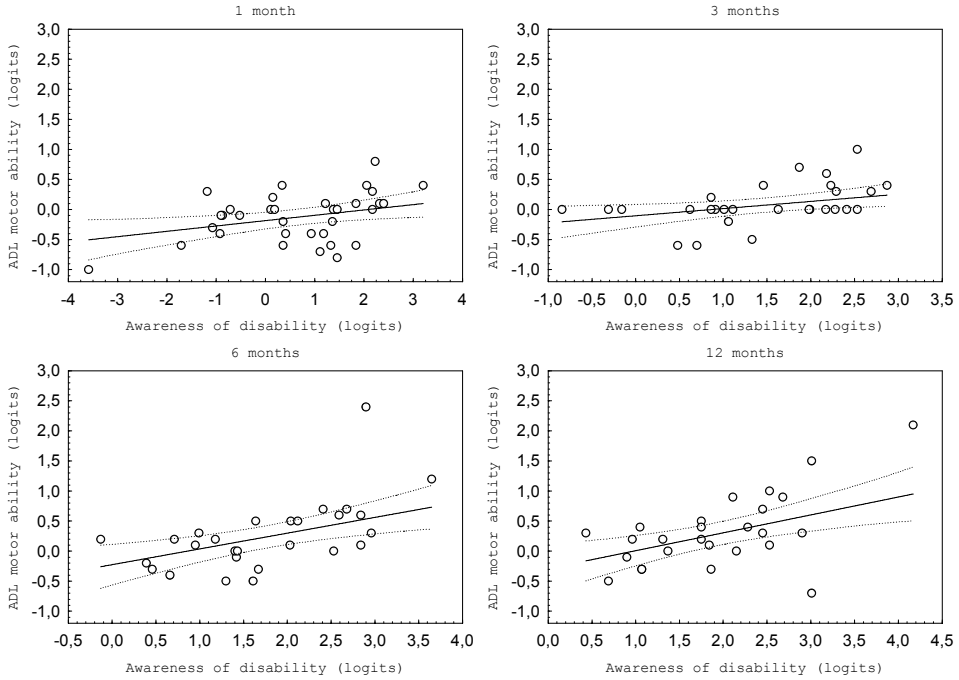
Overall, study I identified four different individual *patterns of change in functioning in everyday life* during the first year after stroke. Aspects of functioning defined as the engagement in and performance of occupations captured by the instruments were: everyday and seasonal activities, ADL motor and process ability, and perceived competence. The following four patterns of change in functioning were identified.

1. Group (A) included persons ( $n = 5$ ) who had experienced a disrupted change in functioning after a major life event. All these participants rated their level of life satisfaction as low at 12 months.
2. Group (B) included persons who demonstrated a minor change in functioning ( $n = 11$ ). The participants in group (B) pattern of change had limited or low level of motor and process skills and a minor to moderate increase in activities and motor skills during the year.
3. Group (C) experienced minor change despite a major life event ( $n = 7$ ), which pointed to an interesting finding suggesting a relationship between major life events and perceived competence. This finding will be explored in more depth in the Discussion section.
4. Group (D) included persons who experienced a moderate change in functioning ( $n = 4$ ), which was characterized by the participants having frequent number of everyday and seasonal activities measured by the FAI (Holbrook & Skilbeck, 1983) before their stroke and increased their activities during the year after stroke. These participants identified no perceived environmental barriers (e.g. social or physical) and experienced no major life events (e.g. another disease or loss of a significant other) during the year. The participants also had a relatively good process ability measured by the AMPS (Fisher, 1997) as well as a high and increasing level of perceived competence during the year.

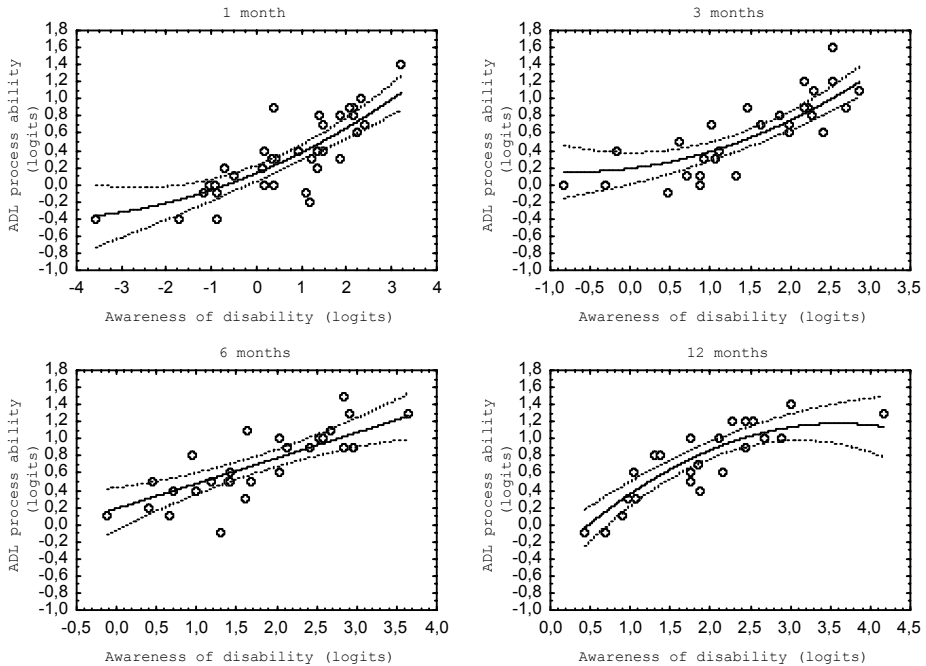
These findings implied that aspects not directly related to the stroke—such as the loss of a significant other or a new disease—still had an impact on the patterns of change over time. For example, there was a difference between the participants in group (C) who experienced a minor change *despite* a major life event and the participants in group (A) who experienced a disrupted change in functioning after a major life event. For the participants in group (A) and (C), major life events occurred. However, after the major life event, group (C) had stable or increased perceived level of competence whereas group (A) had a decreased perceived level of competence. The relationship between perceived competence and major life events will be explored in more depth in the Discussion.

In study I, changes in everyday and seasonal activities and the perceived competence were more frequent during the first six months after the stroke. In addition, the participants in study I improved significantly during the year in most studied aspects. In both study I and II, changes in ADL ability were also more frequent during the first six months after stroke. However, the participants' perceived values of everyday activities (study I) did not change statistically during the year. Further, by end of the year, the participants in study I and II still scored low on the AMPS, which indicated a continued need of assistance in ADL. At twelve months, most participants (n = 20) were dissatisfied with life as a whole (study I).

The relationship between occupational performance (ADL motor ability and ADL process ability) and the participants' awareness of disability also changed during the year. The relationship between awareness of disability and ADL motor ability was positive and became stronger over time (see fig 3). The relationship between awareness of disability and ADL process ability was positive, stronger and changed in relation to time (see fig 4). The awareness of disability as measured by the AAD (study II) was, as expected, lower at one month after the stroke compared to at the end of the year. The methodological and clinical implications of these findings will be elaborated on in the discussion.



**Figure 3.** Scatter plots post stroke, showing the regression line and confidence interval. plots for each occasion on which the participants were assessed, 1, 3, 6, and 12 month



**Figure 4.** Scatter plots for each occasion on which the participants were assessed, 1, 3, 6, and 12 months post stroke, showing a regression line and confidence interval.

## **The couples as a unit: patterns of change in occupations of everyday life**

In addition to changes in patterns of engagement in and performance of occupations found in study I for the persons with stroke, there were also changes in the patterns of daily occupations for their spouses *as well as the couple as a unit*. When one spouse had a stroke, both individuals as well as the couple as a unit faced the challenge of losing valued and everyday occupations. Although, the spouses without stroke expressed the importance of regaining his or her own personal interests, it was found that they often cut down on engaging in valued occupations in the beginning of the year. Not being able to engage in valued occupations after a stroke is an example of *occupational disruption* (Whiteford 2000).

Many of the occupations—such as gardening, doing the laundry, cleaning—that the spouses did separately before the stroke were performed together after the stroke. Doing more things together mirrored the spouses becoming more dependent on each other after the stroke or it can also be seen as reflections of being *interdependent*. For several participants this was experienced as something positive. *Doing more things together* was interpreted as being one way that couples faced the challenge of accomplishing what the person with stroke previously had done independently. For others, however, not being able to do valued occupations or handing them over to the partner was not satisfying.

The differences in how the couples experienced the altered patterns of occupations called for a closer examination of how the spouses in the couple provided for each other. The challenges and dilemmas that the couples experienced also resulted in qualitative differences in how and in what types of support, assistance and help they provided after stroke. In doing so, some of the spouses of the persons with stroke altered their performance of and engagement in occupations. While other spouses did not think that the stroke influenced so much of one's "own" everyday life. Thus, the studies III and IV found that the couples developed different ways to handle challenges and dilemmas in everyday life after stroke that ranged from (1) *making conscious choices and using advanced strategies* to (2) *not finding a satisfactory solution for dilemmas in everyday life and avoiding conflicts*. These different ways to handle challenges and dilemmas in everyday life was interpreted as the couples' struggle to maintain reciprocity (Murphy, 1990) in the couple. Reciprocity was a term that helped to provide a richer picture of the complexity of the exchanges going on within particular couples as a unit that could not just be labelled as either "being

dependent” or “providing support.” Drawing from Murphy’s (1990) illness experience, reciprocity was defined as *a shifting of give-and-take that changes according to personal situations in a couple and within changed contexts*. Thus, *reciprocity* provided a more complex view of everyday interdependency and included the couples’ ability to maintain a balance in responsibilities that also could shift across time with changing circumstances.

Additionally, couples as unit’s perspective experience of change included facing the challenges and dilemmas that related to the different values they gave to daily occupations, such as how often to vacuum clean or what kinds of food to cook. These values could also be viewed as related to both culture and gender. For example, gender may have had an impact on the patterns of change in daily occupations in the couple’s everyday life during the first year even though the number of participants was small. For example, the women who experienced stroke (study III) clearly demonstrated how they struggled to get back to doing housekeeping tasks, a struggle that was not demonstrated by the men. A gender difference was also apparent when providing support and assistance. If the women living with men who experienced a stroke generally took over the housekeeping which was a previously shared occupation, the men living with women who experienced a stroke encouraged them to regain housekeeping activities.

In order to explore the particularities of these patterns more closely, study IV focused more on two couples drawn from study III because they illustrated diverse changes in their patterns of engagement in occupations. For example, one spouse with stroke seemed more engaged in occupations while the other spouse with stroke was less engaged in occupations. The diverse pattern provided a more complex view of how the couples approached the challenges and dilemmas post stroke. One of the five areas, in particular, seemed to be the driving force in the process of change in everyday life change—*getting experience and feedback from doing*—and mutually influenced the couple as a unit’s *engaging in occupations* and *changing occupational performance needs and demands* while *contributing to a picture of a possible future*. In turn, how the two couples approached challenges also influenced how they integrated training into their everyday lives and, ultimately, their performance of and engagement in occupations.

## GENERAL DISCUSSION

Overall the findings in this thesis contributed how older individuals' and couples approached change in their everyday life at home following stroke. Three areas, however, will be brought out in the discussion: (1) relationship between occupational performance, values and well being, (2) perceived competence as a mediator of change, and (3) interdependency and reciprocity followed by implications.

### **Occupational performance, values, and wellbeing**

Earlier studies and theories have suggested that occupational performance is influenced by awareness of disability. For example, not being aware of one's disability influences a person's motivation to engage in rehabilitation (Tham & Borell 1996). The definition of awareness of disability applied here is, according to the Assessment of Awareness of Disability, is "no discrepancy between a person's experienced and self-described task limitations after the performance of specific ADL tasks and observed task limitations" (Kottorp & Tham, 2005; Tham et al 1999). In turn, experiences from doing can also increase one's awareness of disability (Tham, 2000). Thus, as expected, awareness of disability was lower at one month after the stroke compared to at the end of the year in Study I. This raised questions about how experiences from doing influenced occupational performance *across time*.

Issues of time are relevant to consider in the design of rehabilitation studies. Studies with a cross-sectional design that examine the relationship between cognitive function and occupational performance in clients with stroke (Kizony & Katz, 2002; Mercier, Audet, Hebert, Rochette, & Dubois, 2001) and do not consider the time elapsed since the stroke, might overestimate or underestimate the relationship between awareness of disability and occupational performance. The influence of time on change was also studied by Petersson (2009) who found that time (i.e. waiting for home modification to take place) had an impact on reported difficulty in everyday life also after home modification. In addition, Petersson (2009) discussed how a person's ability to perform occupations (e.g. doing everyday life tasks in an environment) cannot be regarded as a static condition but something that is in constant change. This view on change as something that is taking place constantly could serve as a pre-given condition in the design of research in rehabilitation after stroke for future studies.

The exploration of the relationship between awareness of disability and occupational performance *over time* in study II showed that increased awareness of disability was related to

improvements in occupational performance (ADL motor and process ability). More specifically, the relationship between awareness of the disability and ADL *motor ability* was positive and became stronger over time (see fig 1). It is informative, however, that relationship between awareness of disability and *ADL motor ability* was not as strong as the relationship between awareness of disability and *ADL process ability*. For example, one common characteristic of the four women with moderate change in functioning in everyday life/engagement was high ADL process ability. This supports previous findings that a high ADL *process ability* influences performance of everyday activities, or occupational performance (Bernspang 1995, Fisher, 2003). However, at the end of the year the participants in study I and II still had low scores on the AMPS that, according to Fisher (2003), indicated a continued need of assistance to be able to live satisfactorily in the community.

Awareness of disability as measured by AAD provided a lot of information about how persons with stroke perceived their own ADL-ability, and such awareness of disability—as discussed above—could be a strong motivation for engaging in rehabilitation (Fleming, Strong & Ashton, 1998; Katz & Hartman-Maeir, 2004; Tham & Borell, 1996). The question of living satisfactorily in the community also, however, raises questions about how the use of instruments in rehabilitation may influence one's sense of capacity and how and this also may related to aspects of motivation. A pronounced awareness of one's capabilities for living the life one wants to live is about what one is capable of doing, while a negative sense of capacity can be even more limiting than the impairments on which it is based (Kielhofner, 2008). This indicates that studies I and II need to be understood in its context. For example, study I showed that each person's values did *not* change during the year after their stroke while most participants were dissatisfied with life as a whole 12 months after their stroke. On one hand, these findings could be understood from the perspective that values do not change easily or promptly as theory suggests (Atchley, 1999; Kielhofner, 2008). But it also raises the question about how assessments may also need to consider the importance of persons' values as a motivation for engagement in and performance of activities.

If occupations were valued, then they may become driving force to regain occupational performance. These values are often gender and culturally related. For example, the women's interest in study III in getting back to do the housekeeping was identified as a driving force for progress during the first year after the stroke. Others have suggested that women may find offers of domestic help more threatening if they have been used to having responsibility for domestic

occupations throughout their lives (Quershi and Walker, 1989). In Sweden, as in other cultures, there are traditional gender related values regarding who has the responsibility for carrying out household tasks, especially among older generations. The women in study III who experienced a stroke had strong opinions on how the housekeeping should be handled and fought hard to regain housekeeping, whereas the men who had experienced a stroke in most cases more easily lost or gave up the housekeeping activities. This finding can be seen in relation to the findings in the study of Quershi and Walker (1989), where it is suggested that women may find offers of help with domestic tasks more threatening if they have been used to having responsibility for these domestic occupations throughout their lives.

Values that are culturally and gender based may also create additional dilemmas in rehabilitation. For example, a gender difference was also apparent and related to the value of providing support and assistance. A population-based study of 377 stroke survivors by Appelros, Nydevik and Terént (2006) showed that female spouses more often helped their male counterparts, and also that women tended to accept a heavier burden compared to men. In studies III and IV, the women living with a man who experienced a stroke generally took over and did those occupations, while the man living with a woman who experienced a stroke encouraged the woman to regain housekeeping activities to a greater extent instead of taking over occupations. This can be exemplified by contrasting the experiences of Marianne and Ragnar, who were presented in the introduction of this thesis as well as Gert and Ingrid in study IV. Ragnar wanted Marianne to regain her housekeeping tasks, stating, “She wants me to help her, but at the same time I think there are things she needs to practice to do. Then I keep a low profile, and she is forced to do things.” Marianne, in her way, understood that Ragnar “could just stand there” was also her husband “thinking like, ‘It’s an exercise that I need to practice.’” On the hand, Gert had been the one responsible for the household task of cooking prior to his stroke. Yet Ingrid took over this task, feeling that it was too complicated for him to regain. For Gert, this made him feel a loss because it also reminded him that he could not provide for his wife Ingrid as he was use to do before the stroke. He said, “I think it is sad that I cannot help her. [...] I must have the walker with me and then I am just in the way if I shall help.”

These findings about values, and how they added complexity to what motivated or drove certain action, also raises some questions about the findings in study I where the participants did not change their values about everyday life activities during the year. On one hand, Kielhofner (2008) argued that “Disabled persons must often achieve a fine balance between necessary hope



for the future and unrealistic expectations” (p. 39). Thus, following Kielhofner (2008), it could be interpreted that the values held by the persons with stroke and their spouses created unrealistic goals for the future particularly if the persons with stroke no longer had the capacity or ability to perform those occupations related to those values. If the participants had not reflected on their expectations to their new everyday life, this would also have implications on how occupational therapists assess and approach their clients in therapy. However, assuming that the persons with stroke had “unrealistic expectations” does not account for how values also shape what is desired for the future. A question can be raised about who it is to decide on what goals that is realistic or not. How values influence or become a driving force in crossing or minimizing occupational gaps (Eriksson 2007) may be more relevant than whether the goals are realistic or unrealistic. Eriksson (2007) developed the concept occupational gaps and a questionnaire measuring occupational gaps. An occupational gap is defined as the gap that occurs between what an individual wants and needs to do and what he or she actually does (Eriksson, Tham, & Borg, 2006). This suggests that values influence what one *wants and needs to do* as opposed to whether those expectations are realistic or unrealistic.

### **Mediators of change: Perceived competence in and through occupations**

Becker’s (1995) ethnography study of individuals after stroke suggested that life-course disruption caused by a stroke was a major life event that influenced continuity and change in everyday life. Further, study I suggested that additional life events or aspects not directly related to the stroke also impacted patterns of functioning or course of developments over time. An examination of perceived competence as measured by Occupational Self Assessment (OSA, Baron, 2002) suggested that perceived competence could mediate the effects of these additional major life events. Perceived competence is, as defined by Kielhofner, “the degree to which one sustains a pattern of participation that reflects one’s occupational identity”. In study I it was found that when persons’ perceived competence increased or remained stable over the year, they were able to maintain functioning in daily living even when facing major life events. In addition, study I also demonstrated the opposite. When persons’ perceived competence decreased over the year, then their pattern of functioning was disrupted when a major life event occurred. Thus, perceived competence was one aspect that can be seen as related to change that stood out as influencing change in pattern of functioning across the year for the participants.

Relating the experiences of the persons with stroke from studies III and IV to *doing* provided some additional dimensions to perceived competence as a mediator of change. For example, the belief that one can sustain a pattern of engagement in occupations is important for change. Kielhofner (2008) referred to this as self-efficacy. Self-efficacy begins with self-control and is about “the person’s beliefs about whether he/she can use own capacities to influence the course of events or circumstances in the external world” (p. 38). The findings in study IV showed that a driving force in the process of change was *getting experience and feedback from doing*, and thus an important mediator of change could be interpreted as continued process of receiving feedback on one’s capacity and competency from being engaged in occupations. This was demonstrated in the case of Marianne who recounted, “I am trying, for instance, when I lay in my bed to switch on the bed lamp (with her paretic hand). And I have managed. Well, it is by doing such things that I discover that I have improved.”

On the other hand, when a spouse did not also see the person with strokes as competent, this could undermine the person with stroke’s opportunity to engage in occupations. This is clear in Ingrid’s story of Gert, “Well we tried a bit with the cooking (to engage him in that). But, well, it does not work if I stand and should fry something and he shall be there with his walker and turn a slice of sausage. It is just so worthless.... He is in my way all the time, so I think he has accepted it (not to cook).” Neither Ingrid nor Gert are able to see him as either competent or able to use his capacities to influence the course of events or circumstances in the external world. This couple, according to Ingrid, has lost hope: “We have totally lost our hope that he will be better, we don’t think for a minute, any one of us, that it can be better.” As Mattingly (1998) pointed out in her ethnography of occupational therapy practice suggested stories that motivate engagement in occupations are less about finding coherence, then desire. This suggests then how important being able to perceive competence in doing is linked to a vision of a future. In contrast, not being able to perceive competence or capacities through doing can also close down “hope” or a vision of a different future.

### **Interdependence and reciprocity**

The studies III and IV showed how the spouses became more dependent on each other after the stroke and how that could influence their life satisfaction. For example, when both spouses experienced an occupational disruption, they also risked being deprived from occupations. There was a struggle in their ability to maintain balance in their tasks because they could no longer provide for each other as they always had done. This could be a result from the shift in the

provision of and receiving care between spouses after the stroke. Yet, if some couples experienced this as being *forced to* do more things together, while other couples *wanted to* do more things together. *Doing things together* was one way that couples in study III handled their everyday lives when the spouse with stroke lost occupations. Shifting the focus to interdependency showed how doing together could enable the spouse with stroke to participate in an occupation even though he or she had problems to independently perform the occupation him or herself.

Since humans are social beings, the entire context of the rehabilitation process and the person's unique situation must be taken into account. It is therefore important to acknowledge the interdependence between the person and his or her friends and family and to involve families in goal setting and decision-making (Cott, 2004). In addition, from the lens of occupations, humans are socially *occupied* beings, "doing something that matters with someone" (Lawlor, 2003, p. 423). In that way, interdependency as *doing together* can be a way to discover more about each other as a type of meeting place (Josephsson, 1994). Andersson-Sviden (2008, thesis) study of older people in daycare also demonstrated how *doing together* was experienced as being *more* together. Further, shifting from doing alone to doing together could enable the spouse with stroke to participate in an occupation even though he or she had problems to independently perform the occupation him or herself. Thus, it is important to consider that the experience of stroke disrupts the occupational patterns for both spouses, and thus shifts or creates different patterns of interdependency.

Drawing from Murphy's (1990) concept of reciprocity reframes interdependency as a give-and-take flexible enough to incorporate shifts over larger spans of time within different contexts. Reciprocity rests on the idea of *interdependence* in between people, where thoughts, values and also actions and doings are seen as a result of communication and interaction in between people (Asplund 1987). One of the spouses, Christina, stated this in this way, "When living together for such a long time you are dependent on each other, it is not about equal amount of help. It is natural helping each other. It is not a burden. It is probably because I love him so much." After a stroke or any disability, *reciprocity* (Murphy, 1990) affords a larger temporal and situational perspective on the balance in everyday life.

## **Implications of findings**

The knowledge gained in this thesis can be used to guide occupational therapists in their

judgment of clients (individuals with stroke and spouses of persons with stroke) prerequisites for change, and thus support their clinical reasoning and goal-setting for interventions aiming to enable engagement in occupation and social participation. The findings also indicate that the participants' needs for rehabilitation and support shifted during the first year after stroke. Yet, for most participants in studies I and II, it seemed as if these needs were not fulfilled at 12 months since many of them reported low life-satisfaction. One reason could be that the rehabilitation program ended at three months and that the participants needed continued support to reformulate their goals for continued change in everyday life. Findings implied that there is a need for supporting the clients to reformulate goals from the beginning of rehabilitation by focusing on body function to becoming more occupation based and focused on social participation in the later phases. It is possible that the participants perceived a discrepancy between their expectations of recovery and the achievement of their rehabilitation goals in the later phases of the year. Also the two couples in study IV expressed different needs for and expectations on rehabilitation as well as goals for the future.

From studies I and II, we can conclude that information derived from instruments or checklists can provide occupational therapists with a broad picture of the clients' prerequisites for change. Findings indicate that prerequisite for change might be better for clients who are aware of their disability, perceive their competence as high and are leading an active life (are engaged in and perform occupations) than for clients who are not active, have low ADL-process ability, low awareness of disability and low perceived competence. Previous research has, in agreement with the findings in this thesis, shown that clients with low scores on the AMPS at the end of the year can have difficulties living in the community without assistance (Fisher, 2003) and are more likely to have reduced awareness of disability (study II) and, therefore, might have more difficulties compensating for low ADL-process ability. It is therefore important for occupational therapists to be observant of clients with low ADL process ability and low awareness of disability. Earlier studies support the conclusion that not being aware of disabilities may have negative influence on persons' engagement in their own rehabilitation and change (Fleming, Strong, & Ashton, 1998; Katz & Hartman-Maeir, 2004; Tham & Borell, 1996).

Findings from study II also indicate that occupational therapists should pay attention to their clients' awareness of disability at the end of the year in order to maximize improvements in ADL motor skills, since the relationship between awareness of disability and ADL motor skills gets stronger over time. In this thesis, the AAD was used to measure awareness of disability and it

seems to be a useful instrument closely related to occupational performance measured by the AMPS. However, the conclusion is that in order to understand the complex phenomenon of awareness of disability and its relation to engagement in occupation, occupational therapists could not merely use AAD. They also need to collect complementary and qualitative information focusing on clients' experience and desire of engaging in occupation.

Another clinical implication based on study I is the importance of supporting clients perceived competence after stroke. One way of doing this might be to focus client-centred rehabilitation interventions on improving individuals' occupational performance of activities they value highly. Performing these activities in familiar contexts is also suggested since previous research has shown that rehabilitation in the home environment facilitates the use of purposeful and meaningful activities which empowers the person to resume responsibility for and influence his or her own rehabilitation process (von Koch et al. 1998; Wohlin Wottrich 2007). In addition, findings from study I implied that rehabilitation professionals need to pay more attention to how new life events, that may occur during the year after stroke, threaten or interfere with how persons engage in occupations and perceive their competence after having a stroke. Since professionals need to modify the rehabilitation interventions when clients experience new major life events, follow-ups several times at clients' homes would be of significant importance after stroke.

The assumption in and occupational therapy goals of being independent can be questioned. Studies III and IV showed that the interdependence with spouses supported engagement in occupations and perceptions of competence among the individuals who had a stroke. In addition, in order to support the perceived competence for people who have had a stroke it seems to be of equal importance to support the spouses' beliefs and expectations of the persons with stroke ability to perform occupations. Further, studies III and IV clarify that some of the spouses without stroke might have needed support from professionals (or others) to be able to continue doing their own valued occupations, do things on their own and thus also care for their own health and well-being. However, it is clinically well known that professionals in rehabilitations do not always view the health of spouses as their concern or responsibility. The spouses' provision of support and assistance was not necessarily seen as a "negative form of dependency," which is not an unusual viewpoint in rehabilitation (Fine & Glendinning, 2005). The findings from the present studies, in fact, would argue the opposite: It is important to include the primary care provider, who is often a spouse, in health care interventions for the person with stroke.

There is a need to offer guidance, support or relief to *the couple as a unit* based on a view of the spouses as being interdependent. This is in line with an anticipated change in the Swedish law that regulates the provision of social service. This proposed law would require the department of social services (in the local communities/municipalities) to facilitate and offer support or relief to the persons that care for family members with long-term disability, chronic illness or are elderly. As pointed out by Johansson (2007) all rehabilitation efforts, as well as the stroke, are in a way interfering with the couple as a unit or system. Therefore it is of utter importance that professionals intend to build on the couples own competence and own approaches in their everyday life (Johansson, 2007).

The results of studies III and IV not only underline how critical it is to view the couple as a unit and within their own context over time, but also the importance of taking an occupational perspective. The shifts in occupational patterns after the stroke made some differences between the spouses in the couple more visible; for example, how the spouses sometimes valued occupations differently and had different views on provision of support and assistance following the new situation after stroke. These differences in values and views of provision and support caused challenges and dilemmas for how the couples handled daily living. For example, one way to handle these challenges and dilemmas was by making conscious choices and using advanced strategies. Another way to handle these challenges and dilemmas was by avoiding conflicts. However, the couples did not always find satisfactory solutions.

Based on the findings from study III and IV I would argue that occupational therapists could play an important role in assessing couples' needs as well as providing guidance, support or relief in everyday life after stroke by designing rehabilitation interventions together with the couple as a unit based on a view of the spouses as being interdependent.

## **Methodological considerations**

This thesis has taken multiple perspectives on changes in everyday life after stroke. Multiple perspectives in the sense that changes have been studied using multiple methods through the lens of occupations in everyday life during the year after stroke at home. Occupations have been studied both from the outsiders' perspective and from the insiders' perspective. In the design, all four studies have been longitudinal with several (four to six) data gathering points during the first year after stroke. Data has been gathered by qualitative interviews and instruments. The

analysis of the data gathered has, in order to answer the research questions, been multiple. Both statistics as well as more qualitative approaches ranging from visual inspections of plots generated from instruments, comparative methods and hermeneutics have been applied. Further, the unit of analysis has been persons and couples.

The above approaches have been complementing each other. The use of multiple perspectives and methods has been shown to strengthen the validity of research. Knowledge for occupational therapy practice needs to be built up from a range of measures, self-reports, observations, structured interviews to more qualitative information about the person's experience of occupations (performance of and engagement in) or doing (Molineux, 2006) By using multiple perspectives and multiple methods, research can address complex clinical questions, such as "How can this client benefit from rehabilitation", which may better inform practice. When studying change there are some advantages in using a longitudinal design (Polit & Beck, 2004), which is quite uncommon in stroke research which has commonly used cross-sectional design. One advantage with a longitudinal design is that data is also collected prospectively. In prospective longitudinal studies it is possible to compare data from different time points in a process and thereby identify change (Saldaña, 2003). Longitudinal designs that include narratives or stories can capture both retrospective and prospective accounts (Mattingly, Garro, 2000).

There are several studies using a longitudinal design based on qualitative interviews in stroke research (Dowswell & Lawler, 2000; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Rochette, Tribble, Desrosiers, Bravo, & Bourget, 2006), but the descriptions of the methods used to identify change is sparsely described and there is no consensus.

One advantage with conducting several qualitative interviews during a process is that the researcher and participant build up a relationship which strengthens the richness and thoroughness of data (Dahlberg, Drew, & Nyström, 2001; Kvale & Torhell, 1997) and thereby the possibilities to interpret and understand aspects of change. Our methodological attempt in study III to focus equal interest on both of the partners in a couple and view the couple as an interdependent unit has been a methodologically interesting challenge. One of the challenges was to give equal importance and attention to both of the spouses in the interviews, in the analysis, and also in the presentation of the findings. This approach to research is different compared to qualitative analysis of interviews with either the person who has experienced a stroke or of that

person's spouse, which is most common in stroke research (Blake et al., 2003; Ekstam, 2007; Forsberg-Warleby et al., 2002; Steultjens et al., 2003). Only a few studies have focused on couples' perspective or viewed as a couple as a unit's experience of a stroke (Jongbloed, 1994; Robinson-Smith & Mahoney, 1995). The study of couples by Jongbloed (1994) demonstrated, as did the findings for these studies, how everyday life after stroke cannot be understood as an individual phenomenon but in terms of how the life courses of both spouses are profoundly affected. Also, the study by Robinson-Smith & Mahoney (1995) acknowledged how both spouses in a couple were affected by the occurrence of stroke in one of the spouse.

The focus on the couple as a unit questions the high priority given the concept of independence has been in occupational therapy models and in clinical reasoning and calls for further discussion. Study III also implies a need for new and more sophisticated interventions based on the concepts related to interdependence, instead of independence. Using a methodology that viewed the couple as an interdependent unit in the analysis seems to be of importance to understand the complex everyday life after stroke and this methodology needs to be further developed in future research. In this thesis, my intentions have been to use methods examining and reflecting the clients' (individual, spouse and couple as a unit) perspective. The motive was to develop knowledge that can be useful in client-centred rehabilitation after stroke. See table 1 for the designs and methods used in the different studies. In the following I will discuss different aspects of the methods used. First, study context and participants will be discussed for studies I-IV and, thereafter, the methods for data gathering and analysis will be discussed separately for studies I-II and III-IV. Finally I will give some general comments on validity and generalizability of findings.

## **Study contexts and participants**

### **Study context**

The study contexts for studies I-II and III-IV differed which may interfere with the conclusions of findings. In studies I and II, all participants were discharged from rehabilitation three months after stroke. The whole group received approximately the same type of rehabilitation interventions built on a client-centred, task-oriented approach. In studies III-IV, the participants received varied types of rehabilitation and the aim was to establish a close relationship to the couples and to follow their natural process of change in their everyday lives. The aim of the studies I-IV was not to evaluate intervention, but instead to examine the natural process of change during the first year after stroke. However, in study I-II using a more homogenous study



context than study III-IV it has been easier to relate aspects of change to when in time rehabilitation was implemented.

### **Participants**

The two samples (studies I-II and III-IV) had both similarities and differences. The selection procedures were different which was related to the different research questions in the studies. In general, both groups were older adults, but their living situations differed. In one sample (studies I-II), participants lived in apartments and one third lived alone. In the other sample (studies III-IV), some participants lived in private houses and all lived of them lived with a spouse. Due to the different sampling methods and differences in living situation, it is difficult to compare the two samples. Due to the small samples it is also difficult to discuss whether the samples were representative of the larger population.

One important experience that can be drawn from studies III-IV is that too little attention might have been paid to developing criteria for the inclusion of the spouses. In retrospect it could have been important to acknowledge what the implications for the study might have been if some of the spouses had also suffered from illnesses or disabilities common in groups of older people. In addition, the included couples were only heterosexual elderly couples living in long-term relationships. It is acknowledged that the relevance to other constellations of couples may be insufficient (younger couples, homosexual couples, couples with short histories of living together, people with other cultural backgrounds than Swedish). For these studies, a conscious choice was made to have a sample with a common history (platform) of performing and engaging in occupations in everyday life (and thus included heterosexual Swedish people who had developed long relationships, lived together, and shared everyday life for a long time).

### **Data gathering and analysis: Person-oriented approach in study I and II**

Studies I and II utilized several assessment instruments in order to capture different aspects of individuals' everyday life. The chosen instruments have both strengths and limitations concerning psychometric properties. All data was gathered by one experienced occupational therapist, which could be said to strengthen the reliability of data. The AMPS is a widely used and standardised measure, but AAD is an instrument under development that could be seen to limit the conclusions that can be drawn from these studies. Advantages of using both the AAD and the AMPS are that they are occupation-based, client-centered, and top-down assessments. The AAD additionally measures the discrepancy between (1) individuals' perceived and self-described ADL limitations after the performance of a specific client-relevant and self-chosen

ADL tasks and (2) observations of ADL limitations of this task. In adopting this approach, the AAD fulfils the criteria laid down by Simmond and Fleming (2003) that stated that the phenomenon of awareness of disability is best captured in an assessment that combines observations of occupational performance and well-timed questions.

One methodological implication of the result in study II is that it is clinically important to pay attention to the relationship between awareness of disability and ADL motor ability when conducting the AMPS. The scores the researchers assign to the ADL motor skills represent a judgment of how competent, or skilled, a person is at performing motor actions within a relevant context when conducting a meaningful and purposeful task. However, this is also one of the limitations with the AAD and all assessments of awareness that are using occupational performance as a reference: When occupational performance changes this also affects awareness. However, there is a lack of alternative ways to measure awareness and using occupational performance as a reference has been recommended (Gist & Mitchell, 1992; Katz & Hartman-Maeir, 1997). Another assessment that has occupational performance of a task as a point of departure is the Executive Function Performance Test (Baum et al., 2008). This instrument has been developed to measure executive performance. It is also designed to “provide the practitioners with information that will help family members understand and support their loved ones performance”.

In study I a new person-oriented approach was developed for the purpose of this study, which included visual inspection. Using a new approach is considered to be a limitation. However, in clinical practice it is valuable to have knowledge of different communities in patterns of change based on individuals’ patterns of change. This knowledge from study I can assist rehabilitation professionals in their assessment of individual client’s prerequisites of change and, thus, his or her needs during different phases of the rehabilitation process. When using a person-oriented approach, different methods can be used. However, the sample size in study I was considered too small for cluster analysis and instead a visual inspection of longitudinal case plots were employed (Kazdin, 2003). In order to strengthen the validity of using this new person-oriented approach the researchers conducted the visual inspections separately and had an agreement on the different patterns that were identified.

In study II the mixed-linear-effect model was used, which is a development of regression and ANOVA allowing a model of “within-subject dependence”. This model gives a picture of

individuals' level and pattern of change, not just the populations' mean pattern of change. Therefore the mixed-linear-effect model fits well on small dependent sets of data as in study II. The mixed-linear-effect model is sparsely used in rehabilitation research. Based on the experience from study II it can be recommended in future studies.

### **Data gathering and analysis: Person-oriented, spouses and couple as a unit**

“Because individuals are social beings, the entire context of the rehabilitation process and the person's unique situation must be taken into account. It is therefore important to acknowledge the interdependence between the person and his or her friends and family and to involve families in goal setting and decision-making” (Cott, 2004) [p. 1420].

One of the methodological strengths in study III and IV is the use of a *multiple-perspectives*; that is, the study of both person with stroke and their spouse from their perspectives. In study III the interviews were both conducted separately and together.

### **Interviews**

Studies III and IV were based on a series of open interviews (Kvale & Torhell, 1997). All the interviews were conducted by the same researcher, which could be said to strengthen the richness of data since a relationship was created between the researcher and the participants. When meeting with other people, what is said is constructed in the unique situation. Using structured observations could have contributed to a better understanding of the participants' experiences and could have provided a platform for the interviews. It was sometimes difficult to talk about things that the participants took for granted like, for example, how they experienced their everyday occupations and observations in these situations could have added important information (Kvale & Torhell, 1997).

### **Co-joint interviews**

In study III, co-joint interviews were conducted with the couples. A structured interview guide was used as the point of departure to gather data from the couple as a unit. One strength of using co-joint interviews is that they provide opportunity for the partners to negotiate and jointly construct their responses, particularly when the couple is the unit of study and the couple is the topic of interest (Gilliss & Davis, 1992; Racher, 2003). In this sense, narratives are developed between the couples. When interviewing the partners separately, the individual narrative is in focus. Although based on individual interviews, the unit of analysis was the couple.

### **Comparative method and Hermeneutic interpretation**

Couples' perspectives in research on everyday life after stroke are rare but needed. The methodological approaches to study the couple as a unit also need to be further developed. It was a challenge to find solutions on how to focus the attention on the couple as the unit during analysis of data in study III. It is easy to fall into the habit of taking one individual's perspective at the time instead of trying to understand the couples' values and experiences, in a sort of dialogue, with each other (Asplund 1987). The two researchers worked closely together to keep the focus on the experience of the couple as a unit. The challenge needs to be addressed in future research.

### **Generalizability and validity**

In this thesis, the studies are built on either a person-oriented approach (studies I-II) or a qualitative approach where the aim is not to generalize the findings to a larger group of people. The aim is rather to increase the understanding of certain phenomena (studies III-IV) that can be transferred to other individuals, couples or situations. The small sample size in study I limited the range of possible methods that could be used for data analysis. We therefore applied a new person-oriented approach that included a visual inspection of the data. The strength of these methods is their point of departure from the individual. Given the limitations of the study, the results should be interpreted with caution and not be extended through generalization to other groups of elderly participants in rehabilitation at home after stroke. Despite the limitations of the study, knowledge of different patterns of change identified in these studies continues to have clinical value and can assist rehabilitation professionals in their assessment of individual clients' needs during different phases of the rehabilitation process. The findings need to be verified in future studies.

### **Ethical considerations**

All studies in this thesis have been approved by the ethical committee at Karolinska Institutet, in Stockholm, Sweden. All participants received verbal and written information about the studies and gave informed consent to participate. Participation in the studies was voluntary and persons could stop participating at any time without further explanation. The data collection took place in the homes of the participants, which could be experienced as an intrusion on their privacy. However, the two research assistants (one in study I-II and one in study III-IV) were occupational therapists, one with an extensive clinical experience from the area of rehabilitation at home after stroke which was valuable experience in their social interactions in the participants' home settings and the other one with not such a long experience had close guidance

from an experienced researcher. Due to the longitudinal design they also established a relationship with the participants and most participants expressed their positive experiences from participating in the studies. Participants liked to share their experiences from everyday life after stroke with the research assistants. An ethical dilemma in study I-II was that a few participants, during the home visits, told about major problems in their present life situation. The research assistant handled these situations by supporting the participants to come in contact with health care professionals.

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