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# **EVALUATION OF A CLIENT-CENTRED ADL INTERVENTION AFTER STROKE**

**- perspectives of occupational therapists, clients  
with stroke and significant others**

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## EVALUATION OF A CLIENT-CENTRED ADL INTERVENTION AFTER STROKE

– perspectives of occupational therapists, clients with stroke  
and significant others

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## ABSTRACT

**The overall aim** of this thesis is to build knowledge of a new client-centred activities of daily living (ADL) intervention (CADL), which takes the unique experiences of persons with stroke as the point of departure, and aims to enable agency in daily activities and participation in everyday life among persons with stroke. The focus of this thesis is an evaluation of CADL after stroke, from the perspectives of occupational therapists (OT), clients with stroke and their significant others.

**Methods:** Study I uses quantitative content analysis to explore how client-centredness is documented in 280 medical records by OTs who received training intended to enhance client-centredness, compared with OTs who had not received such training. Studies II and III are based on a multicentre randomized controlled trial (RCT): Study II studies the effects of CADL compared with usual ADL (UADL), 3 months after the start of interventions on 280 people with stroke regards: independence in ADL, perceived participation, life satisfaction, use of home help service and satisfaction with training; and on the significant others of persons with stroke receiving CADL or UADL as regards caregiver burden, life satisfaction and provision of informal care. Study III compares the effects of CADL and UADL on the caregiver burden, provision of informal care, participation in everyday occupations and life satisfaction of 183 significant others up to one year after the persons with stroke were included in the study. Study IV has a grounded theory approach exploring and describing whether and if so, how CADL was integrated into everyday lives of the significant others of people with stroke who received CADL during the first year after the intervention.

**The findings** in Study I show that OTs with client-centredness training recorded significantly more client participation in goal-setting than therapists without training. In Study II, 3 months after inclusion, there were no differences between the CADL group and UADL group in the outcomes of people with stroke or their significant others, except in the Stroke Impact Scale “Emotion” domain, which favours CADL intervention. Nor were there any differences in outcomes at 12 months between significant others in the two groups, or in changes between 3 and 12 months in Study III. For significant others in the CADL group, however, the odds were significantly lower regarding the “General strain” factor in Caregiver burden at 12 months compared to 3 months. The findings in Study IV indicate that CADL has been integrated into the everyday lives of the significant others. An overall core category “Taking responsibility and achieving balance with respect to self-esteem to get on with everyday life”, and four interrelated subcategories represent a temporal process of interactions between significant others and persons with stroke in their daily activities in which significant others adapted themselves to achieve balance in everyday life. One further key aspect is that as persons with stroke acted upon their own activity goals, their significant others were encouraged to act on their own needs.

**Conclusion:** It is possible to increase client-centredness through training. CADL has beneficial effects on the perceived impact of stroke on emotions at 3 months after stroke, there were no other differences in effects between CADL and UADL for people with stroke or their significant others. Among the significant others in the CADL group, however, the experiences of burden seemed to decrease over time between 3 and 12 months, despite no change in informal care. Findings indicate that it was a transfer of learning from the person with stroke to the significant others, with a new shared learning. By initiating the CADL soon after the stroke, professionals involved such as OTs can support both the people with stroke and their significant others in adjusting to the new life situation. In order to tailor the interventions to meet the individual needs in everyday life, however, conducting follow-up sessions over a longer time period would be of importance.

**Key words:** stroke, rehabilitation, participation, occupational therapy, ADL, goal setting, lived experience, caregiver, client-centred care

## LIST OF SCIENTIFIC PAPERS

This thesis is based on the following scientific publications, and referred in the text with their roman numerals:

- I. Flink M, Bertilsson A, Johansson U, Guidetti S, Tham K, von Koch L. Occupational therapists with training in client-centeredness document more on goal setting in the medical records of patients with stroke than those without training. *Submitted*
- II. Bertilsson AS, Ranner M, von Koch L, Eriksson G, Johansson U, Ytterberg C, Guidetti S, Tham K. A client-centred ADL intervention: three-month follow-up of a randomized controlled trial. *Scand J Occup Ther 2014;21:377-391*
- III. Bertilsson A, Eriksson G, Ekstam L, Tham K, Andersson M, von Koch L, Johansson U. A cluster randomised controlled trial of a client-centred ADL intervention for people with stroke: one year follow up of significant others. *Submitted*
- IV. Bertilsson A, von Koch L, Tham K, Johansson U. Client-centred ADL intervention after stroke: Significant others' experiences. *Scand J Occup Ther 2015 May 14:1-10 [Epub ahead of print]*

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## LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
BI	Barthel Index
CADL	Client-centred ADL intervention
CBS	Caregiver Burden Scale
COPM	Canadian Occupational Performance Measure
GT	Grounded Theory
LiSat-11	Life Satisfaction Scale
ICF	International Classification of Functioning, Disability and Health
I-ADL	Instrumental ADL
KE	Katz Extended ADL Index
LAS II	Life After Stroke II
MMSE	Mini Mental State Examination
OGQ	Occupational Gaps Questionnaire
OT	Occupational Therapist
P-ADL	Personal ADL
RCT	Randomized Controlled Trial
SIS	Stroke Impact Scale
UADL	Usual ADL intervention



# 1 INTRODUCTION

This thesis is a part of a larger project called Life After Stroke II (LAS II), aimed at building knowledge of client-centred rehabilitation after stroke that is, rehabilitation specifically guided by the clients' ability and perceived needs.

About 25 000 people suffer a stroke each year in Sweden (1). Strokes often have consequences in everyday life both for the persons with stroke and for their significant others. People with stroke often perceive everyday life as a challenge owing to their dependency on others in daily activities that were previously taken for granted. The capacity for control and influence in one's own life can be restricted. Decreased life satisfaction and restricted participation in everyday life are common for both the person with stroke and their significant others. Rehabilitation after stroke is important, and there can be several different health professionals involved in supporting the recovery of lost ability and improving participation and life satisfaction.

According to Swedish health care legislation and recommendations (2, 3) rehabilitation should involve the patient as a partner. This perspective is known as patient-centred, person-centred or client-centred. International evaluations of patient-centredness, however, indicate that patients in Sweden are rating lower than patients in other countries (4, 5). Despite national guidelines for stroke (1) and access to rehabilitation services, people with stroke experience dependency in activities of daily living (ADL) and restrictions in participation in everyday life (6-8). Informal care is reported to be common, leading to experiences of burden and need for respite (6, 8, 9). Functioning in ADL has been found to be associated with perceived life satisfaction among the persons with stroke and their significant others (10-12). Some evidence from research supports task specific training being effective to in improving functional self-care (13). The rationales for the interventions were often vaguely described, however, which has made it hard for professionals to implement the intervention in clinical practice.

Research findings related to independence in ADL, has indicated that there is also a need to increase autonomy and participation in daily life (11, 14), which could improve independence in ADL. It has furthermore been assumed that if a person's ability to take control and make their own decisions is enhanced during rehabilitation, then this is likely to contribute to better problem-solving capacity as new ADL problems are encountered in the future. Additionally, it has been proposed that client-centred rehabilitation of this type might decrease the burden for significant others. These assumptions have not been tested empirically, however. Client-centred ADL intervention (CADL) was therefore developed and implemented based on previous research knowledge.

This thesis addresses knowledge regarding the content and effect and significant others' experiences of CADL. Specific focus is on how client-centredness was documented in medical records by occupational therapists (OT) who had received training in enhancing

client-centredness compared to OTs without such training; the effect of CADL intervention compared to usual ADL (UADL) interventions at 3 months with regard to outcomes of both people with stroke and their significant others; and the effect at 12 months and changes between 3 and 12 months of CADL compared to UADL as regards significant others. Additionally, based on significant others' experiences the issue of whether and how CADL intervention was integrated in everyday life is explored and described.

The occupational perspective being applied in this thesis can be defined as “a way of looking or thinking about human doing” (15). The Model of Human Occupation (MOHO) (16) is used as a point of departure for this thesis. Essential to MOHO is that doing things can be seen as a basic all human need. The focus is on human occupations – that is, how people occupy their time and space. Also important is the assumption that occupation influences health. A client-centred perspective and the concept of the lived body are integrated into MOHO. This is crucial, as these are important concepts in line with the phenomenological perspective, integrated into CADL. A few concepts of importance for this thesis will be described in the following section.

### **1.1 OCCUPATION AND ACTIVITIES OF DAILY LIVING (ADL)**

As occupation is central for human beings and a stroke can suddenly change peoples' ability to occupy their time and space in way they would like in their daily activities, the concept of occupation is central to this thesis, focusing on activities of daily living and participation in everyday life. Occupation can be defined “as groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves...” (17). Several definitions of ADL and occupation can be found in the literature, and human occupation can sometimes comprise different areas of activities.

In this thesis, the concept of ADL encompasses all everyday activities that a person wants and needs to perform (18, 19). The choice of ADL encompassing all everyday activities instead of categories such as personal-ADL (PADL) bathing, dressing, eating, for example or instrumental ADL (I-ADL) e.g. house hold activities, transportation, is based on the results of a feasibility study (20) that showed the importance of enabling people with stroke to decide which activities they wanted to do and not restricting the activities to be included. This approach is also in line with arguments that occupation should reflect the diversity of people's priorities and occupational experiences (21), and that it is not the form of occupation that is important for well-being, rather the experience of occupation (22).

As the course of life is shaped by occupation (16), one basic assumption is that occupation is essential and can influence human health (16, 23-26). Enabling a person to acquire experiences of daily activities after a stroke is thus crucial, in order to facilitate their recapturing activities they consider important. When people perform different activities, they shape their capacities, patterns of acting and self-perceptions. What they do therefore influences their development (16).

Thus, it is essential to understand a person's experiences of daily activities after a stroke, which is in accordance with the phenomenological concept of the life-world (27). The life-world is individual, subjective and taken for granted in everyday life. The view and understanding of the life-world can differ between people. What is essential is that the life-world can also be seen as a social world in which people act in and understand each other in other words inter-subjective. After a stroke bodily changes are common and there might also be a change to the life-world. The use of a phenomenological perspective has been found to be important for therapists in understanding peoples' lived experiences of disability (28), which should be the point of departure for client-centred care (29).

## **1.2 CLIENT-CENTREDNESS, INDEPENDENCE, INTERDEPENDENCY AND AGENCY IN EVERYDAY LIFE**

Within occupational therapy literature, client-centred practice is closely linked to concepts such as independence, interdependency and agency in everyday life (16, 17, 30). Concepts used today both in national and international health care literature are patient-centred, person-centred, and client-centred care or practice. The key principles of these approaches have been defined from different disciplines, involvement or active participation are, however, present in all of them (31).

The occupational therapy of client-centred practice is not in agreement with how the concept of treatment is commonly used within medical care. It is rather an enablement which means that things are done together with people instead of to them. The concept of client-centredness which has emerged from the Canadian Model of Occupational Performance (CMOP) (30), and has its roots in C. Rogers' client-centred approach (29) is a core concept in this thesis. In the CMOP, enabling occupation is an important cornerstone in the therapeutic approach. In occupational therapy, enabling is understood as the process of actively involving clients in order to support their occupational performance.

Essential to client-centred occupational therapy is including not just the individual but also including significant others e.g. a partner, children or friends (17) in this thesis the definition of client therefore also includes significant others.

Researchers have described different strategies that contribute to a client-centred intervention, in which opportunities are created for the client to participate in occupation as ADL (18, 32, 33) that is, the intervention should fit the person's goals and resources, and provide specific training in the activities in which the person wants and needs to be engaged in. Law et al. (34) state that key concepts in client-centredness are "individual autonomy and choice, partnership, therapist and client responsibility, enablement, contextual congruence, accessibility and respect for diversity". Clapton (35) added the need to gradually assist the clients in assuming autonomous decision making and action, which is in accordance with the concept of agency in ADL used in this thesis.

According to Aarts and colleagues (36), independence in ADL is of importance for a person's sense of agency in daily life "the feeling that one causes one's own actions and their

outcomes”. Central to agency are components such as choice, the power to act (36-37) and found is also that when persons with stroke are able to negotiate they experience enacting agency as successful (38). Townsend and Landry (39) also outlined that recognizing people as active agents is of importance in interventions that aim to enable participation in everyday occupations.

Bandura (40) argues that agency is not only related to independence but also to interdependency and most people involve other participating agents. Joint activities require commitment to a shared intention and coordination of interdependent plans of action. There is a need for interventions that can provide opportunities to optimize performance of ADL and increase agency after stroke. One challenge in collaborative activities, however, is to merge diverse self-interests in the service of common goals and collective effort. A strong sense of efficacy is reported to encourage social attitudes such as cooperativeness, helpfulness and sharing with an interest in each other’s well-being (40).

### **1.3 PARTICIPATION AND LIFE SATISFACTION**

Common consequences of a stroke, are experiences of restricted participation in everyday life and low life satisfaction both for the persons with stroke (41) and their significant others (12).

Participation is a common outcome for rehabilitation after stroke. In this thesis the concept of participation is defined as “involvement in a life situation” according to the International Classification of Disability and Health (ICF) (42). Two dimensions of participation are in focus in this thesis: participation in general in line with ICF (42) and participation in everyday occupations (43), which involves the aspect of doing and the desire to perform different activities in everyday life. For people who experiencing challenges in performing ADL, restrictions gaps between what people want to do and what they really do in everyday life are common (44). Even people who only suffered a mild stroke experienced a great amount of participation restrictions in everyday life at one year after stroke (45). It was also found that several years after a stroke, people still experienced restrictions concerning participation in activities (44, 46).

Life satisfaction can be negatively affected in different areas of life, both for persons with stroke and their significant others (47). Spouses of persons with stroke are at greater risk than children of persons with stroke for lower life satisfaction for at least one year after stroke (48). A review of predictors of life satisfaction (10) confirmed that stroke related impairments and depression, restricted recovery and reduced life satisfaction existed for both the person with stroke and their significant others. The need for new interventions to assist in coping with physical, emotional and environmental changes after stroke was emphasized. Previous research has shown that persons with stroke and their significant others experience decreases in life satisfaction after a stroke and that joint experiences of life satisfaction were linked with functioning in ADL (11).

Life satisfaction is therefore an important outcome for interventions studies. In this thesis life satisfaction is defined as “the degree to which an individual experiences himself as being able

to attain his goals”, according to Fugl-Meyr’s (49) and Melin’s (50) definition of life satisfaction. Happiness has been found to be synonymous with satisfaction with life as a whole (49, 51). In a Swedish population based sample, about 70% was found to be satisfied with life as a whole, regardless of age or gender (52).

Since research findings thus indicate an association between participation in desired everyday occupations and life satisfaction (41), there is a need to develop interventions that enhance participation in everyday activities in order to increase peoples’ health and well-being.

#### **1.4 CONSEQUENCES OF STROKE**

Stroke is a global health challenge that frequently negatively affects everyday life among both the people with stroke and their significant others. A stroke is caused by the interruption of the blood supply to the brain; approximately 85% are caused by infarcts. Stroke is one of the main factors in morbidity and mortality worldwide (53). In Sweden about 25 000 people suffer a stroke (1) every year, 80% of those are over the age of 65. Clinical signs of stroke are related to the area of the brain affected. Some common symptoms of a stroke (54), for example are sudden weakness or sensory impairment in the face, arm or leg, difficulties related to speech or vision, balance, coordination or confusion. More “hidden” symptoms such as fatigue, cognitive and emotional changes (55) and lack of awareness of disabilities are also present (56, 57). Limited awareness can be an obstacle to the rehabilitation process (57, 58) as the person with stroke does not perceive any need for rehabilitation.

After a stroke the organization of care and rehabilitation are crucial. One goal for stroke care in Sweden is that  $\geq 90$  % of people with an acute stroke should be treated in a stroke unit (59). Typical for a stroke unit is a multidisciplinary team with expert knowledge of strokes. The care is organized with a systematic assessment of disability after a stroke, mobilization and rehabilitation initiated early on, and also prompt rehabilitation and discharge plans which involve the person with stroke and their significant others. There is evidence that care in a stroke unit increases survival, independence in ADL and living at home after a stroke (60, 61).

Rehabilitation is recommended (1) in order to increase function, activity and participation in community is important not only for the persons with stroke, but also for the significant others and the community. Yet, there is limited evidence for how effective rehabilitation should be supplied in the process after discharge from stroke units (62). Rehabilitation can be performed in different settings after the initial phase in a hospital, for example in- or outpatient settings with a diversity of rehabilitation programmes and professionals involved. There appears to be an advantage with a specialist rehabilitation team in the home context as well (63). Regardless of the differences in settings, a central aim in rehabilitation is supporting a person in retaining or achieving the vital life goals they themselves desire (2).

The greatest recovery of bodily functions are reported to appear during the first six months after a stroke (64). At that point in time, however, about one third of people who suffered a

stroke (1) experienced restrictions in the performance of ADL and were in a need of support from another person to manage ADL.

As there are large variations in how patterns of functioning in everyday life change over time after a stroke (65) it is important to develop interventions that can meet these variations and also take into the experiences of people with stroke and their significant others into consideration.

Research further indicates a gap between the need for rehabilitation and the rehabilitation service received. A two year follow-up of people with stroke (6), revealed that 37% experienced unmet needs and limited rehabilitation service. Tistad et al. also reported unmet needs at 3 (66) and 12 months after stroke, and that dissatisfaction with care at 12 months was predicted by self-perceived impact on participation at 3 months (67). The need for more flexible rehabilitation service was highlighted with more focus on persons with strokes' experiences and their social networks.

Improvements in functioning can appear a long time after a stroke (68) and the need for rehabilitation with a longer perspective has further been highlighted; how it should be performed, however, seems to be unclear (63).

#### **1.4.1 The lived experience in everyday life after stroke**

CADL is based on findings from a series of mainly qualitative studies (69-74). These studies revealed that people experienced that their daily activities earlier been performed automatically, without thinking were no longer taken for granted as before. Their everyday life situations were characterized more by struggling to master and carry out their earlier occupations. The essential point from these studies is that people gained experiences from performing their daily activities, through doing so they discovered their new ability, how they changed and how occupations were sometimes valued differently. Also found was acceptance of doing activities together with others instead of doing them independently as before. These experiences seemed to be central for setting realistic goals for their future participation in everyday occupations. In order to facilitate recapturing ADL, creating a context which enables support from others during the initial phase as well as expectations and encouragement in reaching own goals, and enabling time for performance of ADL to facilitate reflection of the new life situation, appears to be important (75).

The importance of such experiences is also confirmed in MOHO, and is expressed by Kielhofner as follows: "Learning to do something means that we must grasp the experience – learn how it feels" (16) ( p.73). In order to learn how to solve problems in everyday life, enabling discovery and awareness of disability seems to be a prerequisites for using conscious strategies to solve problems in daily activities (71). Thus, enabling discovery of one's own body and self through performing familiar activities is an important component in CADL.

## **1.5 EVERYDAY SITUATIONS AMONG SIGNIFICANT OTHERS**

Everyday situations are also changed after a stroke for significant others. Studies have shown that this can be a stressful situation, and significant others experience increased responsibility when a family member has had a stroke (76). In this thesis the term significant others will be used to represent for example, partners, sons, daughters or friends, whom the person with stroke has named as their significant others. These are people that persons with stroke refer to as someone who are being there to support them. Caregiver is, however, also used as a term equivalent to significant others in this thesis, since caregivers is a term commonly used in the literature to represent informal caregivers.

A report from Riks-Stroke (77) shows that after a year, a major proportion of significant others of people with stroke felt their opportunities to participate in recreational or leisure activities to be affected, and some significant others under the age of 65, reported having reduced or ended their own work.

Previous studies indicate the importance of performing activities with purpose and meaning in everyday life together with significant others after a stroke (12, 47, 78, 79), as this might enable reciprocity and well-being for persons with stroke and their significant others.

One phenomenon found in research is that people with stroke incorporated their significant others, who became an extension of the persons with stroke bodies in everyday life (71, 80). This seems to be a way to handle the loss of independence that suddenly appeared after the stroke.

### **1.5.1 Informal care**

Significant others have an important role, as support for persons with stroke in everyday life situations comes mostly from spouses, children, friends and neighbours (6). A Swedish study of life situations two years after a stroke (6) shows that use of informal care is great, and more than half of the significant others were reported as assisting in ADL; their life situations were characterized by the experience of constraint and the needs for respite in everyday life (6). The most common problems experienced by significant others during the first months after a stroke was difficulties in assisting the persons with stroke in ADL (81). Research has also found that the severity of a stroke is an indicator of the survivor's need for informal and formal support one year later (82).

Different kinds of social support for people with stroke have been described for example emotional, instrumental, informational and appraisal. The last named relates to help in decision-making, giving feedback or helping to decide what course to act on (83). There are several definitions of support, however, and it can be hard to separate physical from social support as social support is related to peoples' interactions which are constructed in an everyday life situations.

Positive and negative caregiver experiences are found to be related to the life satisfaction of spouses 3 years after a stroke (84). Spouses with many caregiver experiences, both negative

and positive, reported higher life satisfaction, than spouses with an imbalance of negative caregiver experiences over a few positive ones. There are a number of studies that confirm the negative consequences of caregiving or support in activities (85). Additionally, caregiving can also positively affect well-being, particularly for persons and their care recipients who perceive themselves as interdependent (86).

### **1.5.2 Caregiver burden**

The experience of a burden in everyday life after a stroke is common for the significant others of persons with stroke (12). Findings from research literature of caregiver burden reveal that there is a substantial amount of significant others who experience a considerable burden after stroke (85); this is an important area for research.

In the context of long-term caregiving, caregiver burden refers to feeling overwhelmed or the experience of strain when caring for a next of kin, according to Elmståhl et al. (68). Rigby et al. (85) describe the term as the weight or load carried by caregivers as a result of adopting the caregiving role. This thesis has adopted and uses these definitions of caregiver burden.

Caregiver burden is a complex and multidimensional construct seen in relation to e.g. individual health, feelings of psychological well-being, relations, social networks, physical workload and environmental aspects (68). The characteristics of caregiver burden are objective aspects of burden for example caregiving tasks performed as assistance in personal or instrumental ADL, as well as time spent in support of activities and financial problems. Subjective aspects of burden are the psychological, social or emotional impact of caregiving.

A systematic review (85) shows several studies indicating that poor functional status after stroke is associated with caregiver burden, which underpins the need to develop interventions that can increase function after stroke, thereby decreasing the burden for significant others. However, as other studies lack significant association between functioning and burden, there seems to be no consensus in the research literature on what to expect. Nor is there agreement on how characteristics of the person with stroke-age, gender or cognitive impairment, for example influence caregiver burden. Furthermore, the age and gender of the caregiver seem generally unrelated to burden, but there is some evidence related to the importance of relationship between the caregiver and the persons with stroke.

Some important attribute of caregiver burden in the early phase after stroke was found to be time spent on caregiving; more time is associated with greater burden. Uncertainty about the future of the person with stroke and the caregiver also seems to be an important attribute of caregiver burden (87). Passive coping strategies not taking action is reported to be the most important predictor of burden, decreased life satisfaction and depression (88). It has also been found that caregiver burden can be perceived as a burden by the person with stroke a “burden of burden” (89). Being responsible for an increasing amount of new caregiving tasks is associated with decreased life satisfaction (84) and thus might also indicate higher burden. From an occupational perspective, burden can also be related to a disturbed occupational



balance for significant others who might need to take responsibility for more activities than they would like after their family member or partner has had a stroke.

Furthermore, less lifestyle changes and higher levels of mastery – that is, greater control over one's life have also been associated with less depression among caregivers (90). Longitudinal studies have been requested; findings, however, indicate that burden can persist for an indefinite time after stroke (85).

Thus, there is research which indicates that caregiver burden exist and there seem to be a complex situation in everyday life after stroke. There is thus a great need for developing and implementing interventions that can decrease burden for significant others. As one hypothesis for this project was that significant others of people with stroke that receive the CADL will perceive lower caregiver burden and higher life satisfaction than significant others of those that receive UADL after stroke. It is therefore crucial to evaluate how caregiver burden is impacted by CADL in order to ascertain that the new intervention does not negatively affect the life situation of significant others, and increase their burden compared to UADL instead of decreasing it.

### **1.5.3 The lived experiences of significant others**

There is a limited amount of studies on the lived experiences of significant others in the context of daily activities in everyday life. A meta ethnographic review of qualitative studies (76) reveals that significant others experience a biographical disruption after stroke, which involving both loss and changes in roles, relationships and sense of identity.

Quinn et al. (9) further find that spouses use different strategies in adapting to caregiving for a partner who has suffered a stroke. Such strategies could, for example, be searching for new meaning within their relationship, striving to achieve a sense of normality, and making adjustments to include their partners in shared activities. Many spouses, however, experience adapting to their new caregiver role as challenging and upsetting; this indicates that spouses may need support in the process of adaptation. Spousal caregivers felt also that stroke related information and training in practical care tasks should facilitate coping more effectively for them in their new situation. Highlighted from this research was also the need of respite care.

The perspective of caregivers, as revealed in qualitative studies, suggests that caregivers' need for support changes over time; during the first months at home their need of support is at its greatest (91). Experiences of being an outsider and not being included in care after a stroke is also highlighted by Bäckström (92). These findings regarding experiences of significant others' emphasize the need for rehabilitation interventions that also include significant others, this is also confirmed in several studies on stroke rehabilitation (9, 12, 47, 78, 79).

## **1.6 CLIENT-CENTRED AND OCCUPATION BASED INTERVENTION**

A systematic review of qualitative and quantitative studies (93) shows that there is support for a client-centred approach, as persons with stroke experience more involvement and have

higher survival rate when they receive rehabilitation focused on their own activity goals. The systematic review also provides evidence for occupational therapy intervention that enhances outcomes for the persons with stroke in everyday life occupations. Another review (94) that examined evidence for occupation-based interventions after stroke, finds also support for such interventions, but identifies a need for studies on larger scale, better descriptions of the interventions evaluated and sensitive outcomes to capture the effects of an intervention.

It is suggested that active involvement in setting goals be central in order to improve rehabilitation after a stroke (95, 96). It is also important to consider that the experiences of professionals and clients can differ for example, rehabilitation professionals believe they are working on a client-centred basis and they are taking the clients' experiences in account, but the clients may not have the same experience (97). Whether professionals in practice really use a client-centred approach, or if it is more rhetoric, has also been questioned (98). Professionals believe they are involving the patients in setting goals; patients' social and occupational needs, however, are reported as not to being covered by the goals (99). Previous research gives support to the idea that clients want to be actively involved in setting goals and that rehabilitation is performed with them (100) that is in partnership. The need to involve people in their own care is highlighted in both national and international health care (101). It has also been reported that there is ample room for improvement as regards implementing client-, person-, and patient-centred care, and therefore a need for further development and evaluations (101).

### **1.6.1 Development and evaluation of complex interventions**

Client-centred interventions are complex. Complex interventions are commonly described as interventions containing several components that interact (102). The use of qualitative studies is recommended when developing complex interventions in order to reach an understanding of the client's experiences and what kind of underlying mechanisms of change the intervention comprises (103). Several years of empirical research have generated the assumption that client involvement (104) in the rehabilitation process may have a greater effect on ADL functioning (105, 106) and findings from qualitative studies (69-71, 74, 75) of the lived experience of people with stroke underscored the need for developing an ADL intervention that takes its point of departure in the client's unique lived experience. Client-centred ADL self-care intervention was developed and evaluated in a pilot study (20, 107); with some modifications for example to not only include self-care but to encompass all everyday activities that a person wants and needs to perform, client-centred ADL intervention could be suitable for a fullscale randomized control trial (RCT).

In the context of this thesis, a better understanding of whether there are any differences in the therapeutic approaches used by OTs delivering CADL and UADL would be of interest. The effects of the intervention are still unknown; determining if the intervention works in everyday practice is crucial when developing and evaluating a complex intervention (102). Thus, trials comparing the intervention to usual treatment are important in obtaining this knowledge. Another important question is whether CADL would increase burden and

decrease life satisfaction for significant others. What is essential, however, in evaluating interventions (102) is understanding how the intervention works in practice and addressing the active components in the intervention. Important questions for this thesis are therefore whether and if so, how a client-centred intervention was integrated in everyday life after stroke based on the experiences of the significant others, and whether and if so, how a client-centred approach affected their life situation.

### **1.6.2 Caregiver and family focused intervention**

The CADL evaluated in this thesis focused on enabling agency in daily activities and participation in everyday life among the person with stroke. It was expected that increases in independence in ADL among the persons with stroke should also positively influence that is, decrease significant others' caregiver burden. There are also, however, other approaches aimed at enabling health and well-being among caregivers, such as approaches for caregiver- and family-focused interventions. A systematic review of evidence for stroke family caregiver and dyadic interventions showed that interventions directed at the caregivers yielded the best results on caregivers outcomes compared to dyadic interventions (108). Kalra et colleagues (109) used goal-setting, hands-on training with psychosocial educational strategies; these components seemed to have effect on both the person with stroke and their significant others, decreasing anxiety and, depression and increasing quality of life. However, this intervention was most focused on needs of significant others.

Active involvement and information seems to be of importance for persons with stroke and their significant others, however, there is still little clarity about how to provide information in the best way (110).

### **1.6.3 ADL intervention after stroke**

Previous research has shown that ADL-intervention after stroke has an effect; ADL intervention is therefore recommended in national guidelines (1). As limitations on activity and participation restrictions in everyday life are thus commonly related to the impairments after stroke, there is a need of intervention with focus on how to improve functioning in ADL.

A systematic review indicate that occupational therapy focused on improving the ability to perform ADL after stroke has an effect on performance and decreases the risk of a decline in ADL ability (13). Task-specific training, and the intensity of training in practice and the environment, are found to be of importance (111-113). There is also support for (114) implementing compensatory strategies when remediation is not achievable, in order to promote independence in ADL for the person with stroke. Recommendations developed from a synthesis of the effects of occupational therapy for people with stroke (32) are; to using structured instruction in activities identified by the client; adapting in order to enable performance in activities; and a familiar context to practice in. Giving feedback is essential to improving performance. It has also been highlighted, however, that further empirical research

is needed in order to verify the findings in practice and to identify key therapeutic mechanisms associated with desired outcomes.

There is evidence, therefore, showing that occupational therapy in stroke rehabilitation can improve outcomes such as ADL and participation in everyday life (93). Despite evidence of occupational therapy interventions that improve ADL ability after stroke, there is a need for clearer descriptions of the rationales and strategies of the interventions (13, 115) in order to integrate the interventions into clinical practice or to enhance the possibility of replicating the intervention in future for scholars.

## **1.7 RATIONALE FOR THE THESIS**

A sudden stroke can change life dramatically not only for the person him or herself, but also for their significant others for example a partner, a child or a friend.

Despite national guidelines for stroke care and access to rehabilitation services, people with stroke experience dependence in ADL and participation restrictions in everyday life situations. Use of informal care in ADL is common, and significant others have reported experiencing a feeling of constraint and the need for respite from everyday life. Furthermore, functioning in ADL has also been found to be associated with perceived life satisfaction among people with stroke and their significant others. Additionally, agency –“the feeling that one causes one’s own actions and their outcomes”– is crucial for the experience of participation.

There is thus a need to develop and implement ADL interventions that better enable independence and participation in ADL after stroke, could also contribute to lower caregiver burden and might support the significant others in the rehabilitation process.

Against this background, client-centred activities in daily living intervention were developed; CADL aimed to enable agency in daily activities and participation in everyday life for the person with stroke.

One important step in building knowledge about this new CADL, was evaluating the intervention empirically with both quantitative and qualitative studies.

## 2 AIMS

The overall aim of this thesis was to build knowledge regarding the content, effect and experiences of client-centred ADL intervention i.e. an intervention tailored to the client's ability and perceived needs, which takes the client's unique lived experiences as the point of departure. It was a process aimed to enable agency in activities and participation in everyday life among persons with stroke and to decrease caregiver burden among the significant others.

The specific aims were:

- I To explore how client-centeredness, including goal setting was documented in medical records by occupational therapists who had received training intended to enhance their client-centredness, compared with occupational therapists who had not received such training.
- II To study the effects of a client-centred activities of daily living (ADL) intervention (CADL) compared with usual ADL intervention (UADL) three months after the start of intervention in: 1) people with stroke regarding: independence in ADL, perceived participation, life satisfaction, use of home-help service, and satisfaction with training, and 2) the significant others of persons with stroke receiving CADL or UADL regarding: caregiver burden, life satisfaction, and informal care.
- III To compare the effects of a client-centred ADL intervention to usual ADL interventions on the caregivers' burden, provision of informal care, participation in everyday occupations and life satisfaction during the first year after the person with stroke was included in the study.
- IV To explore and describe if and how a client-centred ADL intervention (CADL) was integrated in the everyday lives of significant others to people with stroke.

### 3 MATERIAL & METHODS

#### 3.1 STUDY DESIGN

This thesis is a part of a larger project LAS II, aimed at building knowledge regarding client-centred rehabilitation. LAS II was a multicentre randomized controlled trial (RCT).

The study design for this thesis comprises both quantitative and qualitative methods, in order to build knowledge regarding the content, effect and experiences of the new CADL. Different designs and methods are used in Studies I-IV. This is in line with the recommendations for evaluating complex interventions (116, 117). An overview of the studies and methods used are presented in Table 1.

Table 1. Overview of Studies I-IV.

	Study I	Study II	Study III	Study IV
Study design	Review of medical records, a retrospective study conducted in a context of a cluster randomized controlled trial	A cluster randomized controlled trial	A cluster randomized controlled trial	Qualitative approach and longitudinal design
Participants	Occupational therapists. Medical records from the 280 included persons with stroke	Persons with stroke (n=280) Significant others (n=180)	Significant others (n=183)	Significant others of persons with stroke who received CADL intervention (n=7)
Data Collection (Occasion)	OT records from inclusion to the end of rehabilitation	At inclusion of the person with stroke and at 3 months. For significant others at 3 months	At 3 and 12 months after the person with stroke was included	4 times during one year, after inclusion
Data collection (Methods and instruments)	OT records of the person with stroke rehabilitation	KE <sup>1</sup> , BI <sup>2</sup> , SIS <sup>3</sup> , OGQ <sup>4</sup> , LiSat-11 <sup>5</sup> , CBS <sup>6</sup> , Provision of informal care	OGQ <sup>4</sup> , LiSat-11 <sup>5</sup> , CBS <sup>6</sup> Provision of informal care	Interviews with broad open ended questions
Methods of analysis	Quantitative content analysis Univariate logistic regression	Descriptive statistics, univariate and multi/binomial logistic regression	Descriptive statistics, logistic regression and mixed models for analyses of changes	Grounded Theory

<sup>1</sup>Katz Extended ADL Index, <sup>2</sup>Barthel Index, <sup>3</sup>Stroke Impact Scale, <sup>4</sup> Occupational Gaps Questionnaire, <sup>5</sup> Life satisfaction Scale-11, <sup>6</sup>Caregiver Burden Scale

#### 3.2 STUDY CONTEXT

All four studies in this thesis are in the study context of LAS II, an RCT evaluation of the effects of CADL intervention compared to UADL interventions. The hypotheses for this RCT were that: People with stroke who receive CADL will be more independent, and have less restriction in perceived participation. They will perceive higher life satisfaction than those who receive UADL. Another hypothesis is that the significant others of people with stroke receiving CADL will perceive lower caregiver burden and higher life satisfaction than significant others of those who receive UADL after stroke.

A description of the recruitment and procedures will follow below.

### **3.2.1 Recruitment for the multicentre randomized controlled trial**

To recruit from rehabilitation units, and to educate and train the OTs who were to provide CADL, contact was taken with managers of rehabilitation units in Gävleborg, Stockholm and Uppsala. The units agreed to participate and to be randomized to either provide CADL or UADL. In addition, it was agreed that the OTs in the units randomized to provide UADL would receive CADL training after the RCT was completed. Sixteen rehabilitation units representing inpatient and outpatient home-based rehabilitation gave their consent to participate. A randomization procedure was then carried out by the researchers, in which the name of each unit was written on a separate piece of paper. The units were then randomly drawn to provide CADL or UADL intervention, stratified by the rehabilitation: inpatient geriatric rehabilitation for ages 65 and over, inpatient medical rehabilitation for those under age 65, and home-based rehabilitation. A researcher coordinated the RCT for each county council.

### **3.2.2 Recruitment of people with stroke and significant others**

Recruitment of people with stroke to the RCT was conducted by OTs at the rehabilitation units. Eligible for inclusion in the study were people who were: a) treated for acute stroke in a stroke unit 3 months or less after stroke; b) dependent in at least two ADL domains according to the Katz Extended ADL index (KE) (118); c) not diagnosed with dementia; d) able to understand and follow instructions; and e) referred for rehabilitation to one of the participating units.

In order to account for the sample size, a power calculation was performed using the Stroke Impact Scale and the primary outcome was assessed with the domain eight "Participation" (119). A difference of 15 points was sought, which is recommended as a clinically important difference and a variance based on the pilot study (20). Assuming for a 20% drop out rate, 280 persons with stroke were required.

People with stroke who met the inclusion criteria and consented to participate were asked by a data collector at the first assessment to name a significant other for example partner, son daughter or friend to participate in a three month follow-up. At three months information about the study was presented and consent to participate was obtained, if the significant others were not present at the three months follow-up, they received information and the questionnaire to be filled in and returned by mail in a pre-stamped envelope. The sample of persons with stroke, was followed for one year. Their significant others were included and followed from 3 to 12 months.

### **3.2.3 CADL training workshop for OTs**

CADL was provided by 44 OTs who had participated in a training workshop on CADL intervention. The workshop comprised five days. The workshops included lectures by experienced researchers on concepts, theories behind the intervention, and reading and

discussions of articles as well as working through dialogue and collaboration with focus on their own experiences and cases, with the objective of facilitating the OTs' integration of the research-based knowledge into praxis.

*The content of the CADL and UADL interventions*

The feasibility of CADL intervention, that comprises nine components, was in a first version (CCSCI) tested in a pilot study (20, 120). The first component of CADL is creating a relationship based on trust by understanding and taking the client's life-world experiences as the point of departure (27). The Canadian Occupational Performance Measure (COPM) (121) was used to identify goals for activities the client wants and needs to perform. Central to this is learning problem-solving strategies through using a *goal-plan-do-check* strategy (122). Including experiences of performing ADL activities is an important component in discovering and identifying difficulties in reaching goals. Thereafter, the participant and the therapist together identify specific strategies to enable successful performance of the chosen activity. The results of the training are evaluated by the client and the therapist for each goal. Clients are taught how to use a training diary and reflect on their ADL. OTs support the client in informing the team, significant others and/or home help service. In the last session, the therapist and the client review all the strategies used during the sessions in order to facilitate transfer of learning to activities and situations outside therapy.

The content of the UADL is not one specific intervention, but rather a variety of strategies and methods. UADL interventions vary in extent and methodology according to the routines and praxis of the OTs in the participating rehabilitation units.

**3.3 PARTICIPANTS, PROCEDURES AND DATA COLLECTION**

The participants in all the studies were people who participated in the LAS II, between October 2009 and September 2012. The participants were OTs who provided the CADL or UADL at the rehabilitation units and documented the rehabilitation in the medical records, and people with stroke who received either CADL or UADL intervention. Participating were also the significant others of the persons with stroke who received CADL or the UADL. Figure 1, below, shows when the four different studies were performed in relation to each other.

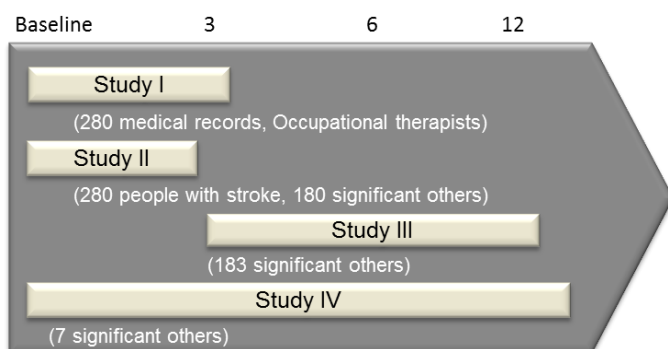


Figure 1. Timeline for the four studies.



### 3.3.1 A multicentre randomized controlled trial

RCT design was used in Studies II and III for comparing CADL intervention to UADL interventions, based on outcomes related to both the persons with stroke and their significant others. An RCT is a rigorous design in which the researcher tries to control for other variables than the intervention and threats that might have an impact on the outcome. The RCT were performed as recommended and adhere to the CONSORT statement (123).

### 3.3.2 Data collection – measurements and questionnaires

Data collection for Studies II and III was performed through visits by data collectors who were blinded to which group had received CADL or UADL and to the content of the intervention. The data was collected by interviews with the person with stroke and their significant others. If the significant other could not be present at follow-up, protocols for the significant others were delivered at the visits or sent and returned by post. The researchers also contacted the OTs in both the CADL and UADL groups on a regular basis in order to monitor the fidelity of the CADL interventions. The researchers had also regular meetings with OTs who collected data in the different counties, intended to manage the procedure of data collection and to ensure inter-rater reliability.

In Study II, demographic data and different outcome variables for significant others and persons with stroke were collected at 3 months. In Studies II and III, the same instruments were used at 3 and 12 months to evaluate significant others' life situations with a focus on caregiver burden, informal care, perceived participation in everyday occupations and life satisfaction. Baseline data were also collected for the persons with stroke. Persons' with stroke medical history and health conditions were obtained from medical records. Table 2, below, provides an overview that outlines the measurements and instruments applied in the four studies.

Table 2. Overview of measurements and instruments applied in the four studies.

	Persons with stroke			Significant others	
	Baseline	3 months	12 months	3 months	12 months
MMSE	✓				
Scandinavian Stroke Scale - Speech Production	✓				
Scandinavian Stroke Scale - Gait Capacity	✓				
Katz Extended ADL Index (KE)	✓	✓	✓		
Barthel Index	✓	✓	✓		
Stroke Severity	✓	✓			
Stroke Impact Scale (SIS)		✓			
Perceived recovery scale (SIS)	✓	✓			
Occupational Gaps Questionnaire		✓		✓	✓
Life Satisfaction Scale (LiSat-11)		✓		✓	✓
Satisfaction with training		✓			
Home-help service		✓	✓		
Caregiver Burden Scale				✓	✓
Informal care				✓	✓

### *3.3.2.1 Measurements for people with stroke*

#### Cognitive

At baseline in Study II, the Mini Mental State Examination (124) was used to screen cognitive function for the persons with stroke. In clinical settings this is a commonly used test (124), and the reliability and validity of the screening test is considered good (125).

#### Communication

The Scandinavian Stroke Scale (126) was used to categorize speech production as follows: no aphasia, limited vocabulary, more than yes/no, only yes/no or less.

#### Mobility

To categorize gait capacity a modified item in the Scandinavian Stroke Scale (126) was used. The gait capacity was categorized as follows: unable to walk, walk with aid and help of another person, walks with aid, or walks 5 m without aid.

#### Independence in ADL

The Katz Extended ADL Index (KE) (118, 127) was used to assess self-reported personal and instrumental ADL. The KE comprises six personal ADL (PADL): feeding, bathing, dressing, continence, toileting and transfer. Four instrumental activities are included: as cooking, cleaning, transportation and shopping. The KE was trichotomized into either independent in both, independent in P- or I-ADL, or dependent in both. The reliability and validity of the instrument is found to be satisfactory (118, 127).

The Barthel Index (BI) (128) was used to assess independence/dependence in ADL. The BI comprises 10 items measuring independence in self-care and mobility activities. The items are scored with 0 = if the person is dependent, 5 = if assistance or supervision from another person is needed, or 10 = if the person is independent. The score ranges from 0 to 100, and a higher score indicates greater independence.

#### Stroke Severity

The BI was also used to categorize stroke severity. BI scores are as follows: <15=severe; >15-49=moderate; and >50-100=mild (129). BI is considered reliable and valid for people with stroke (130-132).

#### Stroke Impact Scale

The Stroke Impact Scale 3.0 (SIS) (119) measures the perceived impact of the stroke and was used at 3 months. SIS consists of 59 items divided in the following domains: strength, memory, emotion, communication, ADL/I-ADL, mobility, hand function, and participation. The SIS score ranges from 0 to 100; the greater the score is the smaller the impact. The SIS also consists of a recovery scale from 0 to 100, where 0 is “not recovered at all” and 100 is “completely recovered”. Perceived recovery was scored at baseline and at 3 months follow-up. Participation is a domain focusing on how the stroke has affected the ability to participate in activities that the person used to do, activities that are important to the person and help give

that person's life meaning. A proxy version of SIS was used in Study II, when appropriate that is, when a person with stroke did not have the ability to answer the SIS on their own (133). The SIS has been sensitive to change, and is considered reliable and valid (119, 134).

Questions about home help service and satisfaction with training were included in the protocols.

### *3.3.2.2 Measurements for people with stroke and significant others*

#### Occupational Gaps Questionnaire

In Studies II and III the Occupational Gaps Questionnaire (OGQ) (135) was used to assess perceived participation in everyday occupations both for the person with stroke and their significant others. OGQ is a checklist comprising 28 activities in areas such as instrumental ADL, work or work related activities, leisure and social activities. For each activity there are two questions, to be answered with yes or no. The first question is whether the person performs the activity, and the second question is if the person wants to perform the activity. The OGQ measures occupational gaps that is a discrepancy between the responses of the two questions. An occupational gap can appear, for example if a person cooks meals but doesn't want to cook, or if a person doesn't cook but wants to cook. An optimal outcome is a low number of gaps. The OGQ has established validity and reliability for persons with stroke (135).

#### Life Satisfaction Scale

The Life Satisfaction Scale (LiSat-11) (52) was used to measure overall satisfaction with life for both the persons with stroke and their significant others. One global statement in the LiSat-11 is used: "My life as a whole is". The items in LiSat-11 are scored on a six-step, ordinal scale ranging from (6) "very satisfying" to (1) "very dissatisfying". For the analysis, the score for the global item was dichotomized into satisfied (score 5-6) or not satisfied (score 1-4). Scale reduction using this dichotomy is considered valid, and the LiSat-11 has been shown to have acceptable test-retest reliability, specificity and sensitivity (52).

### *3.3.2.3 Measurements for significant others*

#### Caregiver Burden Scale

The Caregiver Burden Scale (CBS) (68) was used in Studies II and III to assess caregiver burden. The CBS comprises 22 items, scored on a scale from 1 to 4, related to caregivers' health, feelings of psychological well-being, relations, social network, physical workload and environmental aspects. The range of score for the total CBS is from 22 to 88; higher scores reflect a greater burden. CBS score is the calculated mean of all items. The instrument comprises five factors: General Strain, Isolation, Disappointment, Emotional involvement and Environment. A mean value is calculated for each of the five factors. Severity of burden can be expressed as proportion with the following ranges of mean scores; low (1.00-1.99), moderate (2.00-2.99) or high burden (3.00-3.99) The construct validity and the test-retest

reliability has been shown to be good (68, 136) with regard to persons with stroke and significant others (20, 68, 137-139).

### Informal Care

For studies II and III questionnaires containing questions about informal care were used at 3 and 12 months. The significant others were asked to report whether or not they assisted in a) personal ADL, b) instrumental ADL, or c) other activities that the person with stroke had performed independently prior to stroke.

#### **3.3.3 OT records and reviews**

For Studies I and II data were collected from OT records of 280 persons with stroke. The units were informed that all OT records for both the CADL and the UADL groups of people with stroke included in the RCT should be reviewed after the rehabilitation ended.

No instructions were given to the OTs as to how they should document their work in the records. The OT records were printed out, and the patients' personal data were omitted and replaced with the study participant code and then sent to the researchers. One of the records, however, was excluded owing to there being no OT interventions provided or documented. For both studies the 279 OT medical records were reviewed according to protocols, developed to categorize the data.

In Study I, the protocol was based on the model developed by Steward et al. (140) which is valid (141) for assessing patient-centeredness in meetings between patient and physician. The model has also been used assessing medical records (142). In Study I the model and its components were modified in order to be more suitable for reviewing the OT records in the context of the study. For Study II, a protocol with predefined categories was developed based on the conceptual terminologies of The Swedish Association of Occupational Therapists (143), in order to account for the amount of OT contacts and their content. Each OT contact could contain one or several foci for example training in daily activities and evaluation of the environment.

#### **3.3.4 Interviews**

Study IV has a longitudinal design and the participants in this study were significant others of persons with stroke. One criteria for participation in this study is that the significant others are cohabiting with a person with stroke who had received CADL intervention. In order to ensure variation in the data, the participants were also recruited based on age, gender, working or retired, and finally on if they reside in an urban or a rural environment. Suitable participants were suggested to the research group by OTs who participated in the RCT in units randomized to provide CADL intervention. Contacts were taken and if the significant others verbally consented to participate in the study; then an agreement of appointment for the first interview was made. After the initial sampling which was ongoing over a period of four months, the sample for this study consisted of seven participants with a mean age of 62 years and an age range of 49 to 73 years. There were six women and one man; all were spouses.

Four of them were working and three were retired; four lived in small villages and three in cities. In Study IV the data was collected through interviews after the intervention had started, after the intervention had ended, and at six and twelve months after the participant was recruited to the study. The sampling and interviewing continued until saturation was obtained and no new themes were identified. The total number of interviews was 27 instead of 28, owing to the fact that one of the interviews was too close related to the second interview. The interviews focused on the participants' experience of rehabilitation and their narratives of interactions in everyday life activities. The interview guides contained broad open-ended questions, for example, "Tell me what is happening in your everyday life". Questions for the second interview were selected and developed based on the previous interview. There was a constant exchange between the analytical procedure and the interviews conducted during the first year after the intervention started.

### **3.4 DATA ANALYSIS**

Several methods were used to analyse the data in the four studies. In Studies I-III, the main authors, data collectors and statisticians were blind to which group had received CADL or UADL and to the content of the interventions.

#### **3.4.1 Manifest content analysis**

Manifest content analysis of the OT records with a deductive approach (144, 145) was used in Studies I and II. In study 1, the OT records were reviewed in order to find statements that met the defined criteria of the aspects in the protocol related to: Exploring patient disease and illness, Understanding the whole person, Finding common goals for rehabilitation, and Information and responsiveness. The statements were registered as yes or no. An aspect was considered covered when at least one statement in the OT records agreed with the definitions in the protocols.

The multi professional research group developed a study protocol and the authors worked in an iterative process to reach a common understanding of how to categorize the text (Studies I and II). To ensure inter-rater reliability, each aspect or categorization was defined and illustrated with examples.

#### **3.4.2 Statistical analysis**

In Studies I, II and III, descriptive statistics as well as univariate and multivariate statistical methods were used. Covariates were included in all the statistical analyses for Studies I-III to adjust for factors that could influence on the result. In Study III, a model involving generalized estimating equations was fitted with the Genmod procedure in SAS<sup>®</sup> (Statistical Analysis System) version 9.3 in order to evaluate and compare CADL and UADL in changes over time. The generalized estimating equation strategy was used for repeated measurements of binomial and ordered categorical data. Persons with missing data were included in the generalized estimating equation models, as this procedure can accommodate for missing data.

The model was set up with the Group inter group factor (CADL or UADL), the Time intra group factor (3, 12 months) and the interaction Group\*Time.

The statistical significance level was set to a p-value of 0.05 for all these analyses in Studies I-III. Intention to treat was used for all statistical analyses in Studies II and III. For the statistical analysis the SAS<sup>®</sup> (Science Analysis System) version 9.3 and SPSS version 22 (Statistical Package for the Social Sciences) were used.

### **3.4.3 Qualitative analysis guided by the principles of Grounded Theory**

A grounded theory (GT) approach (146, 147) was used in Study IV to explore and describe whether and if so, how CADL is integrated into the everyday lives of the significant others of people with stroke. According to Charmaz (146), GT is a method that can be viewed “as a set of principles and practices”; flexible guidelines are emphasized instead of methodological requirements.

There was a constant exchange between the analytical procedure and the interviews conducted during the first year after the intervention started. The data was analysed using open coding to facilitate understanding. A focused coding was then carried out, in which the codes were assigned to categories and reassigned in an iterative process of moving back and forth in the data to compare it and its categories using a constant comparative method. Memo writing was used throughout the process of data collection and analysis. The memos provided a basis for hypothetical ideas and the principles of theoretical sampling were used to fill the categories and explore their interrelationships (146). The categories were discussed and reviewed during data collection and analysis by experienced peers in the research group.

## 4 SUMMARY OF RESULTS

### 4.1 PARTICIPANTS FLOW AND CHARACTERISTICS

In Study II, 280 persons with stroke were included at baseline, at the three months follow-up, 252 persons participated along with 180 significant others. In Study III, the initial 180 significant others, plus another three were included for follow-up during the period from three to twelve months. The total sample in Studies II and III consisted of 463 participants. The participants were recruited and followed up between October 6, 2009 and September 5, 2012. The flowchart for Studies II and III is presented in Figure 2.

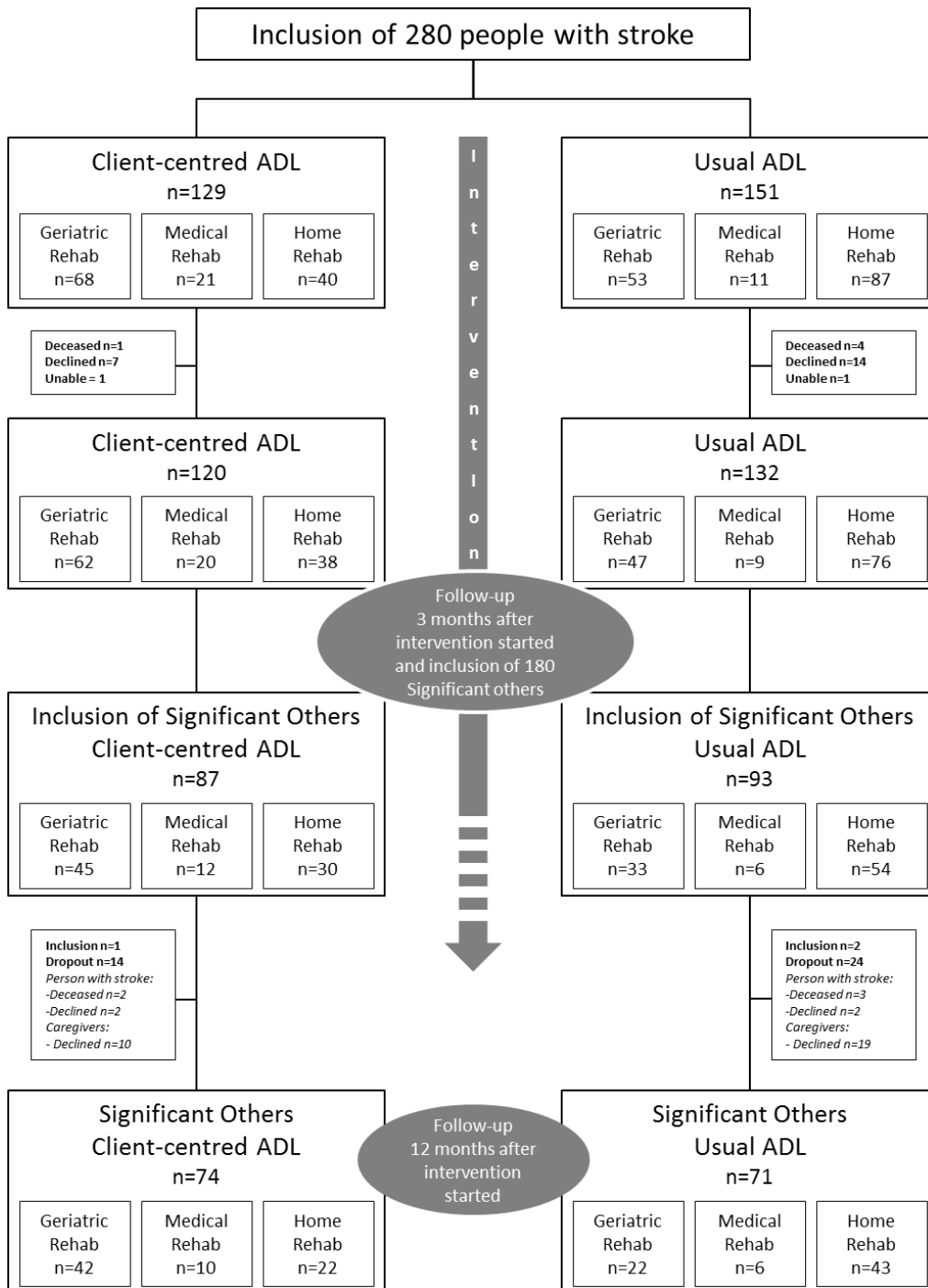


Figure 2. Flowchart

Table 3 gives an overview of the persons with stroke and their significant others at 3 and 12 months. One hundred eighty significant others were included at 3 months. Two thirds were cohabiting with the persons with stroke. The significant others in the CADL group were younger, with fewer women and cohabitants than in the UADL group. The participants with stroke in the CADL group were older, and had more moderate and severe strokes. The characteristics of the significant others and the persons with stroke included in Studies II-III are described below in Table 3.

Table 3. Characteristics of the participants in Studies II-III. Outcomes including imputations.

	Study II (3 months)		Study III (12 months)	
Significant others:	CADL (n=87)	UADL (n=93)	CADL (n=88)	UADL (n=95)
Age, year mean (SD)	60 (14.6)	64 (13.1)	60 (14.6)	64 (13.1)
Men/ women, n (%)	31/56 (36/64)	23/70 (25/75)	32/56 (36/64)	23/72 (24/76)
Cohabiting, n (%), yes/no	51/36 (59/41)	63/30 (68/32)	51/37 (58/42)	64/31 (67/33)
Persons with stroke:	CADL (n=129)	UADL (n=151)	CADL (n=88)	UADL (n=95)
Age, year mean (SD)	74 (10)	71 (10.8)	74 (9.5)	71 (10.1)
Men/women, n (%)	73/56 (57/43)	95/56 (63/37)	47/41 (53/47)	59/36 (62/38)
Barthel Index, 0-100, mean	81.7	77.7	84.0	84.7
Katz Index, n (%)				
Dependent in P- and I-ADL	72 (55.8)	70 (46.4)	44 (50.0)	40 (42.1)
Independent in P- or I-ADL	38 (29.4)	52 (34.4)	29 (33.0)	36 (37.9)
Independent in P- and I-ADL	19 (14.7)	29 (19.2)	15 (17.0)	19 (20.0)
Stroke severity, n (%)				
Mild (BI=50-100)	94 (72.9)	129 (85.4)	64 (72.7)	80 (84.2)
Moderate/severe (BI=0-49)	35 (27.1)	22 (14.6)	24 (27.2)	15 (15.8)
Home-help service yes, n (%)	57 (44.2)	60 (39.7)	30 (34.1)	18 (18.9)

## 4.2 EFFECTS OF CADL COMPARED TO UADL

Study II aims at studying the effects of CADL compared to UADL three months after the start of interventions: on people with stroke regarding their independence in ADL, perceived participation, life satisfaction, use of home help service, and satisfaction with training; and on their significant others regarding caregiver burden, life satisfaction and informal care. Study III, aims at evaluating whether there were any differences between significant others in CADL and UADL at 12 months, or in changes between 3- and 12 months in the outcomes regarding caregiver burden, provision of informal care, perceived participation in everyday occupations and life satisfaction.



### 4.2.1 Outcomes for people with stroke

At 3 months, there was no difference in the outcomes between the CADL group (n=129) and the UADL group (n=151), except in the SIS domain “emotion” in favor of CADL (p=0.04). The CADL group received more occupational therapy than the UADL group, and more focus was on goal setting, planning and evaluation and ADL. At 3 months most of the participants were discharged from the rehabilitations units. Only half as many participants deceased and declined at 3 months in the CADL group compared to the UADL group.

### 4.2.2 Outcomes for significant others

There were no differences at 3 months between the CADL group (n=87) and the UADL group (n=93) in the outcomes regarding caregiver burden, participation in everyday occupations, provision of informal care or life satisfaction. See Table 4.

There were no differences in any outcomes between the significant others in the CADL (n=88) and the UADL (n=95) group at 12 months. See Table 5.

Nor were there any differences in changes between the CADL and the UADL group between 3 and 12 months. For significant others in the CADL group, however, the odds were significantly lower regarding Caregiver burden, and in the factor General Strain at 12 months as compared to 3 months, odds ratio 1.74 (CI 1.12-2.70) with a p-value of 0.01. Significant changes over time were also found within the UADL group, for a smaller proportion of significant others providing assistance at 12 months than at 3 months, odds ratio 3.42 (CI 1.23-9.50), with a p-value of 0.02.

Table 4. Significant others, outcomes at 3 months. Including imputed values.

Measure, range, Significant others	Total sample group		
	CADL (n=87)	UADL (n=93)	p-value
Caregiver Burden Scale (CBS) 22-88, mean	42.5	43.9	0.59
Occupational Gaps Questionnaire 0-28, mean	4.9	5.0	0.91
Lisat-11 Satisfied with life, n (%)	47 (54.0)	38 (40.9)	0.36
P-ADL Support, yes n (%)	35 (40.2)	43 (46.2)	0.67
I-ADL Support, yes n (%)	60 (69.0)	61 (65.6)	0.45
Other Support, yes n (%)	54 (62.1)	66 (71.0)	0.31

Table 5. Significant others, outcomes at 12 months. Including imputed values.

Measure, range	Client-centred ADL (n=88)	Usual ADL (n=95)	p-value
<b>Outcome at 12 months:</b>			
<b>Caregiver Burden Scale</b>			
22-88, mean	42.7	41.8	0.75
General strain (freq. low/mod./high)	44/34/10	42/38/15	0.83
Isolation (freq. l/m/h)	52/22/14	51/25/19	0.60
Disappointment (freq. l/m/h)	42/35/11	48/31/16	0.64
Emotional involvement (freq. l/m/h)	54/22/12	54/32/9	0.51
Environment (freq. l/m/h)	57/23/8	64/19/12	0.82
<b>Occupational Gaps Questionnaire</b>			
0-28, mean	3.5	4.0	0.52
Categorized, n (0/1/2)*	24/21/43	24/17/54	0.92
Lisat-11 Satisfied with life, n (%)	47 (53.4)	47 (49.5)	0.87
<b>Provision of informal care, yes, n (%)</b>			
P-ADL Support	42 (47.7)	50 (52.6)	0.51
I-ADL Support	67 (76.1)	68 (71.6)	0.88
Other Support	65 (73.9)	76 (80.0)	0.09

\* 0= participants with no gaps, 1=participants with 1 gap to median numbers of gaps in respectively age group, 2= > median numbers of gaps in the age groups.

### 4.3 DOCUMENTATION OF CLIENT-CENTREDNESS

In Study I it was explored whether OTs who had received enhancement training documented client-centredness, including goal setting, in medical records compared to OTs without training. The results from the review of the medical records showed that 133 OTs were involved in rehabilitation, and each person with stroke had a mean of 2.1 OTs involved, with a ranging from one to seven OTs per person with stroke. Clients receiving rehabilitation from OTs with client-centred training had overall significantly more documentation on all aspects of “finding common goals for rehabilitation” as well as the aspects of client engagement, motivation and capacity for training. Clients in the UADL group, however, had significantly more documentation on the aspects of family and social support. The aspects of significance covered in the OT records are presented in Table 6 below. The focus of OT contacts up to 12 months is also included.

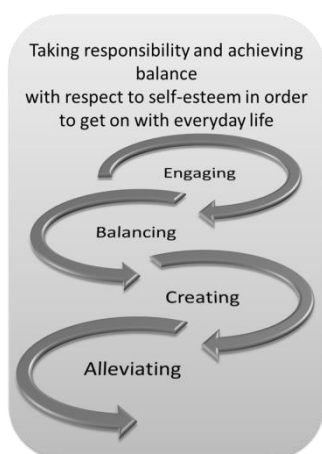
Table 6. Difference in content and documentation between CADL and UADL groups.

	CADL (n=129) n (%)	UADL (n=151) n (%)	P-value
<i>Exploring patient disease and illness</i>			
Engagement, motivation and capacity for training	96 (74.4)	95 (63.3)	0.05
<i>Understanding the whole person</i>			
Emotional support	19 (14.7)	42 (28)	< 0.001
Family	114 (88.4)	146 (97.3)	< 0.001
<i>Finding common goals for the rehabilitation</i>			
Goal setting	120 (93)	115 (76.7)	< 0.001
Patient participation goal setting	115 (89.1)	63 (42)	< 0.001
How goals are to be reached	93 (72.1)	72 (48)	< 0.001
Participation in how goals are to be reached	75 (58.1)	35 (23.3)	< 0.001
Follow up on goals	119 (92.2)	101 (67.3)	< 0.001
Patient participation in follow-up	101 (78.3)	49 (32.7)	< 0.001
<i>Focus on contacts mean (range):</i>			
Goal setting, planning and evaluating	3 (0-14)	1 (0-5)	
ADL* leisure and work included	22 (3-93)	15 (0-200)	
Training of function*	10 (0-57)	7 (0-44)	
Environment* investigation, technical aid and home modifications	5 (0-24)	4 (0-26)	
Family* information about home care and rehabilitation	1.4 (0-17)	1.5 (0-15)	
Other* information about home care and rehabilitation	0.2 (0-6)	0.2 (0-2)	

Note\* Face to face, in group or by telephone

#### 4.4 CADL INTEGRATION IN EVERYDAY LIFE

Study IV aims to explore and describe whether and if so, how CADL is integrated into everyday life during the first year after stroke, based on the experiences of significant others. Findings from Study IV indicated that CADL was integrated into significant others' everyday lives. One core category "Taking responsibility and achieving balance with respect to self-esteem in order to get on with everyday life", was identified, as well as four interrelated subcategories. The categories represented a process of how spouses interacted with their partner with stroke in performing activities with them and adapting themselves in their everyday life, in the context of CADL intervention. Figure 3 illustrates how spouses took



their portion of responsibility in everyday life and balanced the amount of their support in activities; they thus acted with respect to both their own self-esteem and that of their partners in order to get on with everyday life.

The integration of CADL was a temporal, but not linear, process during the first year after inclusion. It consisted of loops of changes in which the spouses managed their responsibility and achieved a balance when they interacted in performing activities in everyday life. One key aspect was that as the person with stroke acted upon their own desired activity goals, the significant others

Figure 3. Process of how spouses acted in the context of CADL.

were encouraged to act on their own needs. It seemed to emerge a shared learning through interaction in everyday situations.

A description of the subcategories and what characterises them follows:

***Engaging for the future***, through engagement in everyday life and rehabilitation, significant others seem to change how they viewed activities. *“Before, you didn’t feel like it was a training. It was just a natural part of everyday life, like in your own life. Things you just do. I mean, you do a lot of chores at home without thinking of it as training. I didn’t either, and neither did he, until now, when he’s become like this”*. This transition, in which activities were seen as training for the persons with stroke, seems to influence significant others’ awareness of a shared responsibility in everyday life. By sharing experiences, persons with stroke also invited their significant others to gain awareness of and knowledge of their life-world.

Significant others struggled to master their own actions and it was a challenge, but in the activities they seemed to be aware of their own actions and the consequences for the persons with stroke. *“It’s everything, actually. I mean, washing the dishes – he’ll wash a couple of plates, and then he’ll say, “You take over, I don’t have the energy”. Then, of course, I do take over, and I’ve told him, “Stop, I’ll do it myself.” It’s like I take something away from him at that point – his self-esteem.”* When persons with stroke also strove to master the activity, however, the challenging was facilitated. Over time significant other developed skills and learned to modulate the amount of support; providing support became a habit, and they were ***achieving balance in interactions to support activity***.

When new habits were incorporated into everyday life, the significant other felt a sense of frustration over restrictions and a limitation of freedom. They struggled to manage the new situation; by taking breaks or engaging in social activities, however, they were re-energized and inspired to handle the challenge of restrictions that had appeared. They were ***creating space for personal activities in order to manage new challenges***.

Significant others’ feelings of restrictions and their thoughts about the future seemed to change at different points in time. Thus, when they saw the person with stroke practising in everyday life, and they engaged in shared activities outside the home, it seemed to influence ***alleviating responsibilities to open up the future***.

These findings suggest that supporting persons with stroke is not only a matter for significant others. It appears that persons with stroke also encourage their significant others to focus on their own needs, which makes it easier to find respite. This reciprocal support seems to facilitate their maintaining activities.

## 5 DISCUSSION

### 5.1 MAIN FINDINGS

The overall aim of this thesis is to build knowledge of a new CADL, which takes the person with stroke unique experiences as the point of departure, and aims to enable agency in daily activities and participation in everyday life among persons with stroke. The focus of this thesis is an evaluation of CADL after stroke, from three different perspectives the OTs, clients with stroke and their significant others. The perspective of significant others, however, was explored in three of the studies (Studies II-IV) and was therefore explored in more depth than the other two perspectives. The four studies included in this thesis have generated new knowledge that can provide a better understanding of the content, and effect of CADL, as well as significant others' experiences of it. Together with other studies in Life After Stroke II (LAS II) project, these findings will contribute a broader perspective on the complexity of client-centred ADL intervention after stroke.

It was expected that the OTs who had participated in the training and provided CADL would work more on a more client-centred basis than the UADL group; that the participants in the CADL group would be more independent and, have less restriction in perceived participation and higher life satisfaction; and that their significant others would perceive lower caregiver burden and higher life satisfaction compared with the UADL group. The main findings in Study I show that OTs who were trained to enhance client-centredness, documented significantly more in medical records on components such as common goals for rehabilitation, client engagement, motivation and capacity for training, than OTs who provided the UADL. The differences between the groups regarding participation in goal-setting and client involvement, however, did not result in any differences in the primary outcomes at 3 months except in favor of the CADL on the perceived impact of stroke on emotions (Study II). Study III shows that CADL intervention did not appear to negatively affect the life situations of significant others at 3 or 12 months. On the contrary, it seemed as if the significant others of people with stroke who received CADL experienced a decrease in General Strain between 3 and 12 months after the intervention. The findings from the qualitative Study IV show that when the person with stroke and the significant other support each other in daily activities, a reciprocal support appeared; when the person with stroke acted upon their own desired activity goals, their significant others were encouraged to act on their own needs. It seemed as if the significant others had, via the person with stroke, integrated the client-centred approach into their own everyday life. This is important new knowledge of the process of integrating a client-centred approach into the everyday life of significant others, in which they were "taking responsibility and achieving balance with respect to self-esteem in order to get on with everyday life". The findings from this study suggest that significant others learned from their partners with stroke, how to interact with each other, the process of integration, however, was not linear and it entailed challenges.

The findings from the four studies will now be discussed and thereafter the methodological considerations.

### **5.1.1 The OTs enhanced client-centredness by training**

The results from study I show that it is possible to increase client-centeredness through training. This is also in line with a previous Cochrane systematic review study, which provides evidence that short training sessions can improve provider skills in sharing control with patients (148). Despite no instructions being given to any OTs in any of the groups regarding how to document, participation in the workshop seems to have enhanced client-centredness as revealed in the difference in documentation. These findings confirm other reviews of medical records, which show that documentation of client participation is poor when traditional approaches are applied (149). The possibility of influencing the OTs' through training to focus on shared goal setting, a continuous process to decide how goals are to be reached and to be followed up is an important finding which suggests that there is a transfer of learning from theory to practice.

The essential point is that learning from the workshop to take the client's lived experience as the point of departure for rehabilitation influenced the OTs' documentation of training sessions for the people with stroke. One component of CADL is to creating a relationship based on trust, which is also prerequisite to understanding a person's life experiences (150). Paying attention to the person's subjective experiences is of utmost importance when starting therapy according to Kielhofner (16), as this can reveal central information about the subjective experience of performance capacity and restrictions. The increased focus on shared goal setting that found in Study I might reflect the structure of CADL intervention, in which the COPM was used for goal setting. Previous research into OTs experiences (151) shows that the COPM can be a useful tool for goal setting when focusing on the client's needs.

The difference in how OTs in the two groups documented indicates that they implemented in practice what they had learned in the workshops. According to Craig (102), successful implementation depends on changing behaviours. The implementation of CADL might also reflect that the OTs believed in and valued the theoretical understanding of CADL and had altered their behaviour, as revealed in their documentation in the occupational therapy records. This is in line with a qualitative study (152) which unveiled that personal values and clinical experiences are central for implementing new interventions in stroke rehabilitation. A dialogue between researchers and practitioners seems to also be central when implementing an intervention (153).

The findings from Study I indicate that implementing CADL in the practice of occupational therapy professionals is important. The need to involve persons in their own care is emphasized in both international reports (101) and national guidelines for stroke (1). It can be shown that OTs, through applying CADL, took responsibility for sharing goal-setting and for enabling their client's occupation – in line with client-centred practice (17) – and involved

persons with stroke in their rehabilitation to a greater extent than did those who provided UADL.

It was also found that OTs without training in enhanced client-centeredness produced more documentation on other aspects such as family and emotional support. This might be related to the OTs in the UADL group using a compensatory approach (19), which can result in a more immediate change in occupational performance compared to remedial approach such as the CADL intervention, with the use of problem solving strategies in an individualistic approach in order to strengthen the persons agency in daily activities and participation in everyday life. The CADL approach might be more useful as regards a longer perspective related to the capacity to manage new challenges that appear during life. There seem to be a need of long-term follow-up and monitor advantages in outcome of CADL.

### **5.1.2 Effects of CADL compared to UADL intervention**

Despite that the results from study I showed that it is possible to enhance client-centeredness through training, Study II shows there are no differences at 3 months between the CADL and UADL groups in the primary outcome perceived impact of stroke on participation according to the SIS (119). Nor were there any differences in effect on the other outcomes. The result is in line with an RCT of client-centred intervention for people with multiple sclerosis, in which no differences in outcomes neither were found (154). Thus, client-centred ADL intervention did not have the expected effect on these outcomes for the persons with stroke and their significant others at 3 months compared to UADL, except for a significant difference in perceived impact of stroke on emotions in favour of the CADL group. This result confirms those of a systematic review by Mc Millan et al. (155), which also found that there seem to be mixed effects on patients' outcomes with a client-centred approach.

The "Emotion" domain in SIS (119) focuses on feelings, mood changes and the ability to control feelings after stroke. The OTs that provided CADL were trained in the workshop to enable the person with stroke to set goals and perform valued occupations in rehabilitation, which might have contributed to this difference in the perceived impact of stroke on emotion. CADL focused on the client's involvement in desired activities which might have contributed to experiences of self-control; according to MOHO (16) this is a prerequisite for self-efficacy and essential for well-being. Experiences of occupational competence and performance of valued activities early on in rehabilitation has previously been shown to be of importance (65) and could influence the effect of intervention on emotions. The result of Studies I and II showed in the documentation that people with stroke who received CADL were more involved in their own rehabilitation and received more training in activities. According to Study I, the OTs in the CADL group also involved the people with stroke in follow-up on goals more than the OTs in the UADL group did. The person with stroke experienced significantly less perceived impact of stroke on emotions, suggesting that the therapeutic approach in CADL can be supportive during the period immediately after stroke, which often is experienced as chaotic (69). Furthermore the importance of applying a client-centred approach early after stroke is underpinned.

The findings from Studies II and III show that there was no significant differences between the groups as regards caregiver burden, provision of informal care, participation in everyday occupations and life satisfaction for significant others at 3 and 12 months, nor were there any differences in changes between the two points in time. The hypothesis that the significant others of persons with stroke who received CADL would perceive lower caregiver burden and higher life satisfaction was thus not confirmed in the quantitative studies. This result is not surprising since the first hypothesis was not confirmed based on the results of Study II, in which the person with stroke perceived neither higher participation nor less dependency in ADL at 3 months or at 12 months follow-up (156).

The results of Study III, however, show that the odds for caregiver burden in General Strain were lower at 12 months for significant others in the CADL group compared to 3 months, despite the provision of informal care not changing over time. Study IV also indicates that within the context of CADL the, burden for the significant others did not increase; instead, the result suggests that during the first year after the intervention the burden may have decreased. Since caregiver burden is a complex, and multidimensional construct (68), there may be several different aspects that influenced the experience of burden, one of which is the type of rehabilitation received. Thus, the findings from Study IV with the qualitative grounded theory approach seem to indicate that CADL intervention had enabled agency in daily activities for the person with stroke and also that reciprocal support appeared between the person with stroke and their significant others which is probably central to understanding the different aspects that influence a decrease in burden. These different aspects will therefore be discussed in the two next sections.

### **5.1.3 Enabling agency in daily activities and participation in everyday life**

The results from Study IV suggest that the person with stroke acted as agents who also influenced their significant others in their interactions when they “took responsibility and achieved a balance with respect to self-esteem in order to get on with everyday life”. The process by which significant others’ integrated CADL consists of short-term and long-term changes. According to C. Rogers (29), change or new learning only takes place when a client finds it necessary to maintain or develop the self. This is understandable, as it is only the person him or herself that can be the agent of change. A supportive environment, however, is also important in the process of change (16). As the results of Study I show that the therapeutic approach focuses on common goals for rehabilitation and shared partnership, this can be seen as a supportive influence for change. Also crucial in guidelines for client-centred practice is that the OT should support the client through this change by listening, facilitating, encouraging with trust, and belief in the client’s ability to succeed (17). A necessary step for change is exploration doing things with altered performance capacity, trying new ways of doing things and examining possibilities for occupational participation in one’s context (16).

The findings from Study IV indicate that persons with stroke acted on own activity goals and shared their experiences with their significant other. This sharing of experiences or storytelling, when clients reflects on their lives has been found to be a way to connect



experiences of occupation and illness; this use of storytelling has been found to empower people to participate in activities (157). Sharing experiences may have increased significant others' awareness of their partners' life-worlds; through that they may have gained a better understanding of how training in activities are linked to recovery. As high-intensity, repetitive task-specific practice is central for recovery (158) and as Eyssen et al. (159) have indicated, a client-centred approach may result in less intensive treatment because a large proportion of the client-centred therapy is focused on diagnostic evaluation of goals. Sharing experiences seems to be a key aspect in understanding how CADL intervention is transferred to significant others. As the results of Studies I and II show, focus on significant others or contacts between the OTs in the CADL group and the significant others were rare.

Through engagement, significant others became aware of their responsibility and role in rehabilitation in everyday life. This awareness might also contribute to power being more equally shared between the persons with stroke and their significant others, which is in line with the elements of empowerment (30). In negotiating power between health care professionals' and clients, creating a collaborative context in which the clients can negotiate seems to be important. Activity goals seem to be important for willingness to cooperate (16); this is interesting because it seems as if the person with stroke also negotiated with their significant others in order to redistribute activities in everyday life. This awareness of shared responsibility appeared as the significant others gained experiences in providing support in concrete everyday life activities. This might also have contributed to the person's with stroke increase in control over feelings and a decrease in experiences of being a burden to others. Earlier research indicates that the experience of caregiver burden also burdens persons with stroke (89), when they are unable to change the situation. Shared responsibility seems to be central in order to decrease experiences of burden and inability, which can otherwise be an obstacle to experiencing feelings of belonging to the social world (89).

#### **5.1.4 Supporting each other in everyday life after stroke**

The findings from Study IV suggest that significant others also develop skills in providing support in everyday life. It is a challenge for significant others, however, that requires energy; sometimes they were also unsure on how to act in the right way. This is in line with Quinn et al. (9), who also found that the adaptation process for caregiving can be experienced as a challenge. Sustaining that is, persisting in occupational performance or participation despite feelings of uncertainty or difficulties is necessary for successful interventions, according to Kielhofner (16). The findings from Study IV indicate that both significant others and persons with stroke persisted in their interaction in daily activities. Awareness of goals gave the significant others direction and security in the new life situation, which could reduce uncertainty or feelings of stress for significant others while figuring out how to provide the best care for their partner (160).

Balancing the amount of support becomes easier when the persons with stroke strive to master interaction. It seems as if significant others, through their experience of modulating the amount of support, adapted their support over time. Repetition and practice (79) in

providing support seems to be essential for developing reciprocal support. Persistence requires energy, however; in line with the MOHO, it contributed with new learning and development of a sense of efficacy (16). As significant others learned how to handle the new situation and achieved a balance in their shared activities, this seemed to contribute to strengthening both their own and their partners' self-esteem. Self-esteem contains dimensions as competence and worthiness. When persons cannot perform activities, as they would like to, this can be perceived as a threat to their self-esteem (16). It thus seems that skill-building together with the person with stroke appeared, and was integrated into everyday life without direct instruction of significant others by the OTs. The mutual support that appeared between the persons with stroke and their significant others, even if CADL intervention was not directed at the significant others, is of utmost importance in understanding how to support the significant others. Integrating skill building that is, problem-solving or goal setting has also been found to be more effective than using only psycho-educational strategies (108), which can sometime worsen outcomes, such as social functioning, for significant others.

Enabling agency in daily activities seems to influence significant others to create space for their own activities and thus manage feelings of restrictions. Engaging in favourite activities and finding joy and satisfaction are crucial to maintaining an active lifestyle (16, 90).

Performing activities has previously been reported to be of importance for couples' health and satisfaction, even if the person with stroke had to lower demands and expectations of performance to reach goals of importance (79). It is important to consider that the perception of interdependence in shared occupations (161, 162) could have contributed to well-being. Engagement in one's own desired or shared activities could then have contributed to significant others experiencing lower general strain at 12 months.

### **5.1.5 Further development of the CADL intervention**

Life satisfaction, which reflects a person's feelings of happiness with life as a whole, is an important subjective outcome when evaluating CADL intervention. Studies II and III showed that there were no differences between CADL and UADL for significant others. About 53% of the significant others in the CADL group were satisfied with life as a whole at 12 months. This compared with a Swedish population based sample, where about 70% was found to be satisfied with life as a whole, regardless of age or gender (52). Acting on formulated goals for people with stroke seems to be important, but it is not enough for an effect on life satisfaction for the significant others either. One way of supporting significant others and persons with stroke could be if health professionals such as the OTs introduce a follow-up with focus on whether and if so, how goal setting works in the home setting. Tailored support and skill building during the recovery phase (108) is also highlighted in research. The results of Study II indicate that the intervention ended about 3 months after it started, and the findings in Study IV reveal that it seems to be challenging for significant others when intervention ends and the participants continue to struggle on their own in everyday life situations even when the findings indicate it was a transfer from CADL intervention to new shared learning, which seems to be necessary in order to maintain persons' with stroke and significant others' own

selves in their adjustment to the new life situation. A follow-up might also support the persons with stroke and their significant others, as the findings from Study II indicate that persons with stroke perceived less impact from the stroke on their emotions when there was an ongoing shared process of goal setting with follow-ups from the OTs. This might be one way to influence well-being for both persons with stroke and their significant others, as a mutual influence has been found between dyads' life satisfaction (11, 12, 47) and caregiver burden. The results of this thesis contribute new knowledge of CADL and confirm that CADL intervention does not appear to negatively affect either persons with stroke or their significant others. Continued follow-up sessions, however, could potentially enhance clients' and significant others agency in daily activities. Follow-ups might also facilitate the initiation of dialogue with significant others to explore their experiences and needs in rehabilitation. This is in line with Forster et al. (110), who found in their Cochrane review that there seems to be some evidence for including planned follow-up. In order to clarify whether persons with stroke and their significant others need further support from health care professionals. This might also prevent an imbalance of negative caregiver experiences, which is reported to be crucial for spouses' life satisfaction (84) or caregiver burden.

Continued work on a model of client-centred rehabilitation approach based on not only occupational therapists perspective, but also an inter-professional perspective, is also essential to further work in this research area. Developing a structured, client-centred model with the specialist rehabilitation team in the home context (63) might also enhance stroke rehabilitation to a greater extent.

## **5.2 METHODOLOGICAL CONSIDERATIONS**

The following section contains a discussion of strengths and weaknesses related to design, sampling, analysis and generalization. The discussion will start with a focus on design and procedure, in which the RCT is essential as it is the context for the studies in this thesis.

### **5.2.1 Design and procedure**

The use of both qualitative and quantitative methods in accordance with recommendations for evaluating complex interventions (102), is crucial to this evaluation, as these methods complement each other, which is in agreement with recommendations concerning triangulation (163). The use of this design made it possible to both evaluate the effects of the new intervention and also to understand the experiences of significant others in everyday life. The methods contributed to a deeper understanding of the content and how this intervention works in practice.

One strength of Studies II and III is the RCT design, which is generally considered the gold standard when evaluating interventions (164). A strength in the design of the RCT, is the choice of randomization of rehabilitation units, which was applied in order to avoid the risk of contamination that can otherwise appear when individuals in the same unit are randomized to receive different interventions (164). Based on the results of the pilot study, the rehabilitation units in this RCT were randomized to provide CADL interventions or UADL

interventions. Other strengths of the design and procedure are that the data collectors and statisticians were blind to which intervention the rehabilitation site provided or which intervention the participants received (164). There were several persons who collected data; the data from each participant in the RCT, however, were generally collected by the same data collector over time.

One limitation with the chosen outcomes could be that they do not capture the effects of the intervention. A single primary outcome and a small number of secondary outcomes might be preferable; when evaluating complex interventions, however, there can be several components that can contribute to change (102). Participation was chosen as a primary outcome; the various activity goals and the variety of participants' experiences of participation, however, were perhaps not reflected in the chosen instruments. Research confirms that participation is a complex concept (165), reflecting unique experiences, and therefore differs among people. Another consideration, however, is that increased awareness of disability and performance of activities could also influence the use of self-reported instruments. The components of the CADL intervention performing activities is one way of exploring and gaining experience, which can increase awareness of the disability. The use of activities, on the other hand, is the way to rediscovering the body and its potentially altered capabilities, which is also prerequisite for the learning how to solve problems (71, 166). It should furthermore be considered that an instrument measuring agency and self-efficacy over time should be important for future studies. The instruments used on the significant others and the people with stroke were chosen based on the hypotheses to be tested. One strength of the instruments, however, is that they are commonly used in research; their reliability and validity have been tested. In Studies II and III, there were no tests for the data collectors of inter-rater and test-retest reliability; the procedure for data collection, however, was discussed on a regular basis before and during the RCT in meetings with the research coordinators and the data collectors. Inter-rater reliability was evaluated in Study I and was high for all aspects except for two; responsiveness and shared decision-making. The evaluation was of importance to ensure that the researchers made subjective assessments which were in consensus (164).

### **5.2.2 Study sample**

When evaluating complex interventions, gaining knowledge of whom the interventions will work for is important. CADL interventions are aimed at people with stroke dependent in at least two daily activities, who are referred for rehabilitation after care in a stroke unit.

Including significant others was important in obtaining knowledge about the effects of the interventions, as the consequences of stroke in everyday life affect them as well as the people with stroke it was also of particular importance in order to ensure that the intervention did not increase their burden.

For Studies II and III, the power calculations for the RCT were performed on primary outcomes related to the participants with stroke and not with regard to outcomes related to

significant others. The sample size not being calculated on outcomes related to significant others could be regarded as a weakness of the study.

One strength of the study, however, is the recruitment of significant others as it was the people with stroke who named the significant others. Recruitment bias cannot fully be eliminated since the OTs recruited the people with stroke; if the OTs abandoned the inclusion criteria, recruitment bias could appear. The RCT design, on the other hand, ought to be the same for both groups. Another strength is that the research coordinators in the county councils were in contact with all participating units on a regular basis, which served as reminder to adhere to the inclusion criteria for the RCT and additionally for the OTs in the CADL group to monitor their fidelity to the CADL manual. Study I also shows that the OTs who provided CADL had another approach than the OTs who provided UADL; to a greater extent. OTs who provided CADL involved the clients in determining what their goals should be and how those goals should be reached, and in evaluating goal attainment in other words, there was indeed a difference in the approaches applied by the OTs in the two groups.

### **5.2.3 Analyses**

#### *5.2.3.1 Statistical analyses*

The intent to treat analysis can be seen as a strength (167), as this handles the attrition that can appear over time with a longitudinal design (164, 168).

Another aspect, which is essential when evaluating complex interventions, is that there may be several factors affecting the outcomes. The findings from the quantitative studies show that different factors could affect the outcome for example Study I shows that the healthcare setting and client factors such as age, education and stroke severity were associated with whether goal setting and client involvement in it was documented. When adjusted for variables such as healthcare setting and clients factors, however, the association remained between OTs trained in client-centredness and aspects of client-centredness in the OT's medical records. Covariates were included in all the statistical analyses of Studies I-III to accommodate for factors that could affect the outcomes.

### **5.2.4 Qualitative research**

It was not known whether and if so, how CADL entered everyday life of significant others; the grounded theory approach was therefore an appropriate method (146, 147) to use. The interview guide consisted of broad, open ended questions; according to this method, interview guides were also developed based on the previous interviews. This method therefore facilitated and strengthened opportunities to explore and describe social interactions and processes over time, and it facilitated to obtaining knowledge of how the intervention worked in everyday life when the rehabilitation staff was not present.

In considering the trustworthiness of the data, it is important to emphasize that the longitudinal design with several meetings might contribute to create a sphere of safety which

is essential when sharing experiences and feelings (169). Establishing a relationship between researchers and significant others could have both deepened the interviews and contributed to increasing the trustworthiness of the data. The longitudinal design was also important for studying the social process and reaching an understanding of how CADL was integrated over time, based on significant others experiences.

Pre-understanding is often considered in qualitative research; according to Glaser and Strauss (147) the emergence of the theory is separate from the researchers. According to Charmaz (146), however, researchers are a part of the world and construct grounded theories through interactions with people and involvement in experiences from the past and present. This method was therefore useful, as analysis of the qualitative data is an ongoing process in following changes over time and the analysis was an interactive process that took place in meetings with the significant others while collecting the data. This is in line with guidelines for grounded theory, which suggest that data analysis starts at the beginning when collecting data (146, 147) and continues. In order to restrict bias and establish trustworthiness, data collection and interactive analysis were peer reviewed by experienced researchers (163).

### **5.2.5 Generalizability of the findings from the studies**

The combining of qualitative and quantitative methods is of utmost importance for the evaluation (102) and the different methods have contributed new knowledge of both the content, effects and experiences of CADL intervention. The issue of the ability to generalize the findings, however, is also crucial (164).

The design of the RCT consists of different health-care settings in-patient and outpatient, rural and urban, as well as clients with different characteristics. Treatment in a stroke unit before inclusion was an essential criterion for the people included in the study, as treatment in stroke units is in line with the national guidelines for stroke (1). This design strengthens the possibility of generalizing the findings, as the sample had been treated in a stroke unit and the people with stroke were included in different settings where they had received CADL or UADL interventions. This was a rehabilitation sample, however, that included people with stroke who are dependent in at least two daily activities and were admitted to rehabilitation; the inclusion in the study could vary up to 3 months after stroke, and their significant other were also included. When considering generalization of the findings, it is essential to note that it was a rehabilitation sample and that the time could vary for inclusion.

What should be considered, however, when using qualitative methods is the limitation in generalizing the findings to other populations than the participants in the study and its context. Also essential is that, since only significant others in the CADL group in Study IV were included, we don't know if this phenomenon can appear without an enhanced client-centred approach. The fact that the recurrent interviews might influence the participants to reflect on and manage the challenge of how to interact the everyday life is also important.

On the other hand, only a qualitative approach can explore participants' own experiences of the processes involved (163). This new knowledge is essential, as the participants themselves

are the experts and can contribute to increasing knowledge of the critical phases in the implementation, which could be facilitated by support from health care professionals.

### **5.2.6 Ethical considerations**

Ethical approval for the studies was obtained from the Regional Ethical Board in Stockholm. Trial registration was performed for the RCT to announce that the trial started, gov. identifier: NCT01417585.

One ethical dilemma in randomized control trials could be that participants who did not receive the intervention they preferred might feel that they didn't get the best available intervention. A cluster randomization of the rehabilitation units was applied, however, which contributed to the participants at each treatment unit included in the study not being given different ADL training than other participants in the same treatment unit. There is also evidence that unspecified ADL training is effective. When collecting data for the study, participants were invited to respond and share their experience linked to their current life situation after stroke. This is something that could cause feelings of anxiety and sadness. However, our experience from studies where similar methods has been applied, most participants expressed appreciation for the opportunity to share their experiences if they could be useful for others in similar situations. Furthermore, reflecting on their situation might facilitate their re-orientation to a new everyday life after stroke.

## **5.3 CONCLUSIONS AND CLINICAL IMPLICATIONS**

According to the Swedish Health Care legislation and National guidelines for stroke, health care professionals are obliged to involve the persons with stroke in their own rehabilitation. The findings confirm that it is possible to increase a client-centred approach through training, and that this enhanced client-centredness is maintained over the rehabilitation period. The findings also support for CADL intervention being used in different health care settings and in- or outpatient rehabilitation. The findings show, however, that there is need for training to enhance OTs' client-centredness in order to apply a client-centred approach in goal setting and patient participation in it.

The result also highlights the importance of healthcare professionals trained in client-centredness initiating a CADL intervention soon after stroke. This is based on the findings that persons with stroke who received CADL experienced less of an impact on their emotions at 3 months. The CADL intervention appeared to promote feelings of well-being in persons with stroke.

By using CADL and its problem-solving component, healthcare professionals can support significant others in developing skills to master providing support to persons with stroke. It seems as though significant others experienced a lower level of general strain, despite the formal support provided to persons with stroke. The client-centred approach therefore seems to contribute to decreased general strain at 12 months.

The findings also suggest, however, that there seem to be a need for more directed support from the healthcare professionals, with a focus on persons with stroke and their significant others. One suggestion would therefore be follow-up by health professionals of the goals set after some time, when persons with stroke and their significant others have gained some experiences of the new situation in everyday life. A follow-up may contribute to initiating a dialogue during the ongoing process of adjustment to the new life situation. Through including significant others' experiences and roles in the rehabilitation process in the context of everyday life, it could be possible to tailor an intervention for the needs of both persons with stroke and their significant others.

#### **5.4 FUTURE STUDIES**

The need for more knowledge in how a client-centred approach could work within an inter-professional team, and how it could affect people with stroke and their significant others, is crucial. Developing a model for client-centred rehabilitation not only based on an occupational therapy perspective, but also on an inter-professional perspective, seems to be importance in facilitating a unified client-centred approach.

Since cognitive impairment is common after stroke, a better understanding of how people with cognitive impairment can learn and implement the global problem solving strategy integrated in CADL could be of importance.

Based on the findings from Study IV, investigating the possibility increasing significant others' life satisfaction and decreasing burden, using a more directed support with follow-ups during the time when CADL is being integrated in to everyday life would appear to be essential.

A health economic evaluation could be important when comparing CADL intervention to UADL interventions.

Long-term follow-up and monitor advantages in outcome of CADL.



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