

Department of Neurobiology, Care Sciences and Society
Division of Occupational Therapy
Karolinska Institutet, Stockholm, Sweden

EVALUATION AND EXPERIENCES OF A CLIENT-CENTRED ADL INTERVENTION AFTER STROKE

Maria Ranner



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By

Maria Ranner

Principal Supervisor:

Professor Lena von Koch
Karolinska Institutet
Department of Neurobiology,
Care Sciences and Society

Co-supervisors:

Professor Kerstin Tham
Karolinska Institutet
Department of Neurobiology,
Care Sciences and Society

Associate Professor Susanne Guidetti
Karolinska Institutet
Department of Neurobiology,
Care Sciences and Society

Associate Professor Magnus Andersson
Karolinska Institutet
Department of Clinical Neuroscience

Opponent:

Professor Unni Sveen
Oslo and Akershus University College of Applied
Science

Examination Board:

Associate Professor Ingvar Krakau
Karolinska Institutet

Associate Professor Lisbeth Claesson
Sahlgrenska Academy at the University of
Gothenburg

Professor Gerd Ahlström
Lund University

Dedicated with love to my dear grandma

You were always there for me and were always generous with your love. When I started my studies at Umeå University, you were so happy and proud of me. You came to visit me in my small student room on the fifth floor. Every week, we called each other over the phone and talked about life; we exchanged experiences from our everyday lives in Umeå and the north Sweden where you lived. One day you didn't answer your phone, you had had a stroke. In this great sorrow that you had a stroke, I felt a joy that I studied to be an occupational therapist. With enthusiasm and engagement, I tried to enable you to experience participation in everyday life. We continued to participate with each other, with phone-calls every week. I called you, you answered, I talked and you laughed and made sounds when you disagreed. I guess this is how my journey to becoming a PhD Student in rehabilitation after stroke started.

ABSTRACT

The overall aim: The overall aim of this thesis was to identify and better understand the effects, experiences and meaning of client-centred activity in daily living (ADL) interventions aiming to enable agency in daily activities and participation in everyday life among people with stroke.

Methods: Study I and II are based on a multicentre randomized controlled trial (RCT): Study I evaluated the effects of a client-centred ADL intervention (CADL) compared with the usual ADL intervention (UADL) 3 months after the start of the intervention on 280 people with stroke as regards the following: independence in ADL, perceived participation, life satisfaction, use of home help service and satisfaction with training. It also evaluated the effects on the significant others of people with stroke receiving CADL and UADL as regards caregiver burden, life satisfaction and provision of informal care. Study II compared changes regarding perceived participation, independence in ADL, life satisfaction between 3, 6 and 12 months after start of the intervention of CADL and UADL. Study III applied a phenomenological approach aiming to describe and understand what characterizes the meaning of CADL from the clients' perspective. Study IV applied a grounded theory approach aiming to describe how occupational therapists (OTs) applied the CADL in their clinical practice by studying their experiences and reflections concerning their interaction with the clients with stroke.

The findings: Study I and II showed no statistically significant differences in the primary outcome in the Stroke Impact Scale (SIS) domain eight "participation" at 3 months or in change up to 12 months after inclusion between the CADL and the UADL group. No significant differences were found between the groups in the secondary outcomes at 3, 6 or 12 months. At 3 months a significant difference was found in the SIS domain "emotion", in favour of CADL. In Study II, between 3 and 12 months, there was a trend toward a clinically meaningful positive change in perceived participation that favoured CADL. At 3 months there were no differences in outcome between the significant others in the CADL and the UADL group (Study I). The findings in Study III suggested that therapeutic components in CADL contributed to *transparency*, which seemed to enable agency in the therapeutic process for clients with stroke. The findings in Study IV indicated that therapeutic components in CADL supported the OTs to guide their clients to enable agency in daily activities through *sharing*. Sharing seemed to be a necessary condition throughout the intervention process.

Conclusion: No significant differences were shown in primary outcome (Study I and II) nevertheless in combination with the findings in the qualitative studies (Study III and IV), a client-centred ADL intervention seemed to enable agency and participation in everyday life. In the findings in Study III and IV, on how sharing and transparency facilitate each other and create change, from both the client's and the therapist's perspective, have not previously been described in the context of rehabilitation after stroke. A client-centred ADL intervention seemed to be of particular importance for the client's rehabilitation process in order to enable agency and for therapists to be able to support to the individual to enact agency. These contrasting findings confirm the importance of using qualitative methods for modeling the content of complex interventions. In addition, in this thesis, they facilitate our understanding of the therapeutic components underlying the rationale of the CADL.

Key words: stroke rehabilitation, participation, occupational therapy, multicentre study, everyday occupation, lived experience, and therapeutic strategies.

LIST OF SCIENTIFIC PAPERS

- I. 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. *Scandinavian Journal of Occupational Therapy* 2014; 21:377-391.
- II. Guidetti S, Ranner M, Tham K, Andersson M, Ytterberg C, von Koch L. A “client-centred activities of daily living” intervention for persons with stroke: one-year follow-up of a randomized controlled trial. *Journal of Rehabilitation Medicine* 2015; 47:605-611.
- III. Ranner M, von Koch L, Guidetti S, Tham K. The lived experience of participating in a client-centred ADL intervention after stroke. In manuscript.
- IV. Ranner M, von Koch L, Guidetti S, Tham K. Client-centred ADL intervention after stroke: Occupational therapists’ experiences. *Scandinavian Journal of Occupational Therapy* 2016; 23:81-90.

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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
EPP method	Empirical Phenomenological Psychological method
FAI	Frenchay Activities Index
GT	Grounded Theory
I-ADL	Instrumental ADL
IPA	The Impact of Participation and Autonomy
KE	Katz Extended ADL Index
LAS-II	Life After Stroke phase II
LiSat-11	Life Satisfaction Scale 11
MMSE	Mini Mental State Examination
MOHO	Model of Human Occupation
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 aims to build knowledge on a client-centred activity in daily living (ADL) intervention after stroke. The four studies in this thesis were conducted in the context of the project, Life After Stroke phase II (LAS-II). The client-centred ADL intervention (CADL) was specifically guided by the clients' ability and perceived needs and his/her unique lifeworld experiences as the point of departure. The aim of the CADL was to enable agency in daily activities and participation in everyday life among persons with stroke. Basic assumptions for CADL were that independence in ADL is important for agency, and that agency is a prerequisite for perceived participation in everyday life.

Three main perspectives were used in this research project. First, the occupational perspective was used as the theoretical and conceptual framework in order to understand the daily activities that people do and engage in with others in the course of everyday life (1). The second perspective, a client-centred perspective was used in order to understand the person as an active partner with own resources (2, 3). The third perspective, the phenomenological perspective was used to understand the client's lived experiences (4).

Every year, about 30,000 people in Sweden suffer a stroke (5). A stroke can be a life course disruption that has consequences on the person's everyday life and the activities that they previously took for granted may not be perceived as before. Despite the national guidelines for stroke care (6) and access to rehabilitation services, people with stroke experience dependence in ADL (5) and restrictions in participation (7). Findings from a series of qualitative studies (8-10) on the lived experiences of people with stroke have showed a need to develop an ADL intervention that takes its point of departure in the client's lived experiences. ADL training is common in occupational therapy rehabilitation after stroke and there is evidence that ADL training is effective (11-13). However, research has also shown a lack of well-defined, scientifically evaluated ADL programs (11, 12). In Sweden, the health care legislation and recommendations (14, 15) emphasize the importance of respecting the client/patient autonomy and integrity and this research aims to provide support in this regard.

The aim of this thesis is to evaluate the effects and improve our understanding of the experience of the CADL. In order to evaluate the effects, the CADL was first compared to a usual ADL intervention (UADL) (i.e. a variety of strategies and ways to conduct customary ADL interventions and not one specific intervention). At three months after inclusion in the study, the outcomes of both persons with stroke and their significant others were analyzed. The effects of the CADL were compared with those of UADL at 12 months and between 3 and 12 months for people with stroke. Furthermore, in order to understand the experiences of the CADL, emphasis was given to the client's lived experiences in the CADL and the occupational therapists' (OTs) experiences of applying the CADL in clinical practice.

In the following chapter, I will shed light on the perspectives and concepts relevant for this thesis; the three different perspectives (occupational, client-centred and phenomenological), the concept of participation and agency and moreover provide an overview of stroke and its

consequences in everyday life and of client-centred and occupation-based interventions. This thesis aims at providing knowledge that can be used within rehabilitation after stroke.

1.1 THEORETICAL AND CONCEPTUAL FRAMEWORKS

1.1.1 An occupational perspective

This thesis has applied an occupational perspective grounded in theories and models within occupational therapy and occupational science. The original work on the development of the CADL was focused on self-care activities (16, 17) but the research group decided to widen the use of ADL to include the activities based on what the individual clients wanted and needed to do in their everyday life after the stroke (1, 18, 19). Thereby, the concept of ADL has been used interchangeably with the concept of occupation in this thesis. An occupational perspective can be defined as “a way of looking at or thinking about human doing” (1, 20) which is in line with the perspective used in this thesis referring to the things that people do and the activities they engage in with others in the course of their everyday life.

Many of the activities that a person performs every day are taken for granted but these activities give structure and meaning to a person’s everyday life. The Model of Human Occupation (MOHO) is an occupational therapy model (1) that emphasizes on understanding what people do in everyday life; how occupation is motivated, patterned and performed. In MOHO, a client-centred and a lived body perspective (21) is embraced, which is in line with the phenomenological perspective integrated in CADL. In order to understand the person’s subjective experience (1, 3, 18) in the context of CADL, self-reported instruments and qualitative interviews were used in this research.

In this thesis, life satisfaction was chosen as a secondary outcome since life satisfaction is shown to be strongly related to participation in everyday occupations for persons with stroke (22).

1.1.1.1 Participation

In occupational therapy, enabling participation in everyday life has been identified as an overall goal (23). Participation is described as engagement or involvement in activities that are a part of one’s sociocultural context and that hold personal and social significance (1, 18, 23). Thus, participation can be understood as both the actual performance of an activity as well as its significance and can be considered to be used both as means and a goal of occupational therapy interventions.

Participation is a multifaceted and nuanced phenomenon that can be experienced differently for different persons at individual, community and societal levels. In this thesis, two dimensions of participation are used. The first definition, which is more general, and is in line with the International Classification of Functioning, Disability and Health (24), defined as a person’s involvement in a life situation. The second definition is participation in everyday

occupation (23) which can be seen as a part of the more general dimension of participation and comprises doing and the person's desire to perform activities in everyday life.

After a stroke, restricted participation in everyday life up to several years after stroke is a common consequence (22, 25-27). Hence, participation is an important concept and outcome in the field of rehabilitation (28, 29). Participation should therefore be evaluated continuously during the client's recovery process (7). Previous research has also described how people's experience of participation is related to their need to enact agency when dealing with challenging situations (25, 30, 31). Hence, a sense of agency has been described as a prerequisite for everyday occupation (31).

1.1.1.2 Agency

Independence in ADL is closely linked to a person's sense of agency in daily life, i.e. the feeling that one is responsible for one's own actions and their outcome (32). The term 'agency' also suggests an element of choice and the power to act (33, 34). As previous research has suggested, there is a relation between agency and participation (30, 31, 35), and according to Lindström et al (36), agency can be rediscovered through engagement in occupations. Agency can be seen as necessary for participation in everyday occupation and enacting agency entails that a person makes things happen in everyday life, by negotiating different aspects in complex situations (31). However, there is a need to further understand how the conditions for enacting agency are created when people engage in occupations. After a stroke, people may experience a feeling of loss both in terms of independence and control over their lives. The feeling of choice and the opportunity to act on those choices may be lost (37). Furthermore, when developing interventions with the objective of enabling participation in everyday occupations, Townsend and Laundry (38) emphasize the need to recognize the person as an agent and/or as Bandura (39) states, through interdependence where the people involve other participating agents.

1.1.2 A client-centred perspective

A client-centred perspective has been defined as addressing the person's specific and holistic properties and seeing the person as an expert. The client-centred perspective is not centred on healthcare or the person's disease, but around the person as a whole (40). The concept of client-centredness in this thesis it's roots in psychotherapy and was founded by the American psychologist Carl Rogers (2, 40) in the 1940s. The principles of Roger's theory are that all individuals have considerable capacity and can draw strength from their own resources to find a remedy to their difficulties. The individual should not be treated as an object rather as a subject of their therapy. From Roger's principles the client-centredness has been developed in occupational therapy and has been essential in occupational therapy models (3, 18).

In client-centred practice, the OTs should demonstrate respect for clients, involve them in decision-making, meet their needs and be aware of their experience and knowledge (18). Occupational therapy's philosophy of client-centred practice is interpreted in practice through

processes of enablement (18), which means that the rehabilitation intervention as ADL are performed together with the person instead of to them (23, 41, 42). In client-centred practice, (43) respect and collaboration are elements of the therapeutic relationship that are key to the rehabilitation outcome. In order to meet the clients' needs and support the planning of the intervention, the OTs need to use themselves as therapeutic tools (44). The principles of client-centred practice (18) are in line with the phenomenological perspective and focus of understanding the clients' lived experiences (45), which are incorporated in the CADL and are a cornerstone of this thesis.

Previous research has studied the concept of client-centred and identified how therapists used different therapeutic strategies in their ADL interventions for people with stroke, such as giving structured instructions or feedback on specific client-identified activities and initiating adaptations within a familiar context (46, 47). Furthermore, research in client-centred practice has shown the importance of establishing a relationship with the person, understanding the person's experiences, of formulating goals together with the person and of using activities as goals and/or as therapeutic agents in the rehabilitation process (46, 48-51).

However, there has been some criticism within occupational therapy research that the OTs take for granted that they have a client-centred approach with their clients and that there is an absence of self-criticism in the profession (52). According to Hammel (52), the OTs do not always have the client's perspective as the point of departure and she further has stated that "occupational therapy" and "client-centred practice" are not synonymous. However, the client-centred perspective is not unique to psychology and occupational therapy. Client-centredness is applied in other health-care professions and is also an approach acknowledged in Swedish healthcare legislation (14) stated that the health-care should be based on respect for the client/patient autonomy and integrity. The concept of client-centredness is used in different ways in health-care: person-centred, individualized-centred or patient-centred. In this thesis, the concept of client-centredness was chosen and "client" not only includes people with stroke but could also include significant others e.g. partners, children or friends (18).

1.1.3 A phenomenological perspective

A phenomenological perspective was used in the CADL in order to better understand the client's lifeworld experiences as the point of departure for the intervention. The phenomenological concept of lifeworld was described by Husserl (4) as the world we live in and to study the lifeworld is to examine the particularities of daily life. The lifeworld is taken for granted i.e. its existence is never questioned. Though, when something new and unexpected happens, for example when a person is confronted with a major life event such as a stroke, activities may not be performed as before the stroke.

Building on Husserl's lifeworld concept, Merleau-Ponty (45) has introduced the "lived body" which is described as it "is" through their body that people perceive their world. The person "is" the body and the body is viewed as always present in a person's daily activities. The body is the basis from which the person acts and understands his/her lifeworld. The concept

of the lived body has been adopted by the MOHO (21) and has been linked to the concept of occupational performance within the model.

Using a phenomenological perspective is to better understand the lived experience and how the studied phenomenon presents itself through individuals' lifeworld experiences in their lifeworld (4, 45). The understanding and the awareness of the lifeworld is subjective and might be viewed differently by different people (4). According to Kielhofner, Tham et al (21) the subjective experience is complementary to the objective approach. Paying careful attention to subjective experiences reveals a great deal about the person's performance capacity and limitations of performance – the experiences of performing. The CADL emphasizes the importance of understanding the client's experiences.

1.2 STROKE AND CONSEQUENCES IN EVERYDAY LIFE

A stroke is a major life-course disruption that can contribute to negative consequences in everyday life activities (11, 12). The person's lifeworld may change and ADL can no longer be taken for granted in everyday life (53, 54). A stroke can also have consequences in the significant others' everyday life (55).

Stroke is a generic term for brain damage caused by a hemorrhagic or ischemic stroke and is the third most common cause of death after cardiovascular disease and cancer (56).

According to Riks-stroke the Swedish national register, in 2014 (5), slightly more men (52%) than women (48%) were registered and the average age was 76 years (73 years among men and 78 years among women). More people survive a stroke today than in the past, but for a large proportion a stroke will have a negative effect on the person's everyday life (57). Stroke is considered to be a disabling chronic condition due to the impact. The usual symptoms after a stroke are weakness or sensory impairment, most often on one side of the body. Other symptoms can be related to speech and seeing (58) and to more 'hidden' symptoms such as fatigue, emotional and cognitive changes (59).

After a stroke, rehabilitation is recommended (6) in order to increase function, activity and participation. Rehabilitation can involve several professional disciplines, vary in content and can be performed in different settings, e.g. inpatient or outpatient settings (60). There is evidence that patients receiving organized stroke care were more likely to survive, regain independence and return home than those who received a less-organized service (61).

According to National guidelines for stroke in Sweden (6), clinical experience suggests that enhanced activity and participation can be achieved by rehabilitation more than a year after the stroke. However, it is unclear if the body functions will improve. Even though there are National guidelines for stroke care (6), people with stroke experience unmet needs in rehabilitation services received (62, 63).

1.2.1 The lived experience in everyday life after stroke

An understanding of the lived experience in everyday life after stroke may benefit occupational therapy and rehabilitation. Using a phenomenological perspective to study the

essence of occupation is considered a suitable method (64, 65) to study the complex phenomenon of everyday life after stroke. In order to study the experience-based phenomenon, there is a need to understand the people with stroke and their significant others' unique lifeworld experiences.

The foundation of the CADL was built on findings answering different research questions which have been reported in previous studies (8, 9, 27, 48, 66, 67). According to these studies, everyday life situation for people after stroke could be characterized by a struggle to master and carry out their earlier occupations. After the stroke, the people experienced how they could no longer perform their daily "taken for granted activities" i.e. activities that they performed automatically and without thinking (e.g. eating, dressing, washing, working and hobbies) before the stroke. When people with stroke performed their daily activities, they gained experiences from performing them and discovered their new ability i.e. how they changed and how occupation sometimes could be valued differently. According to Tham et al (8), enabling discovery and awareness of disability seemed to be necessary for using conscious strategies to solve problems in daily activities and in everyday life. Hence, in the CADL, the important component of enabling discovery of one's own body and self by performing familiar activities was present. One common theme across the previous studies was the importance of enabling significant experiences contributing to change in the rehabilitation process after stroke, which also served as an important general strategy in the development of CADL.

After a stroke, people may become dependent on others to perform daily activities. In a study by Guidetti et al (10), support from others in the initial phase was essential to help people with stroke to recapturing self-care. People with stroke described how support could be in the form of expectations and encouragement from others in reaching their own goals and receiving enough time to perform ADL and reflect on their new life situation.

1.2.2 Significant others – informal care and caregiver burden

After a stroke, the significant others (e.g. partners, children, friends) have a significant role in supporting the person with stroke in everyday life situations. According to research, informal care is used widely, for instance, in a study more than half of the significant others in the Swedish Riks-stroke reported as assisting in ADL (55) and previous research has shown that the significant others' experience of burden after stroke is common (68, 69). In a recently published study of dyads in stroke (70), the caregivers reported taking greater responsibility for household chores and needing to take more initiatives and responsibility for safety, planning and creating routines for everyday life. However, another study (71) showed that when people with stroke acted as agents in their daily activities, it also influenced the significant others in their interaction and seemed to support the significant others who "took responsibility and achieved a balance with respect to self-esteem in order to get on with everyday life".

1.3 CLIENT-CENTRED AND OCCUPATION BASED INTERVENTION

As described earlier in the introduction, the CADL is both client-centred and occupation-based, which is supported by both legislation and previous research in the field of rehabilitation. A systematic review of RCTs of person-centred interventions (including the term client-centred) reported person-centred care as beneficial to the emotional well-being but there was little evidence for any impact on clinical outcomes (72). Another systematic review of qualitative and quantitative studies by Kristensen et al (73) showed that people who participated in client-centred rehabilitation experienced more involvement in the rehabilitation, were better able to recall goals and were better able to manage daily activities after the rehabilitation. The review also provided evidence of the use of everyday life occupations within occupational therapy.

Goal setting is considered a fundamental concept in rehabilitation. A synthesis of quantitative and qualitative studies concluded that participation in goal setting after stroke can have beneficial effects on psychological outcomes, but further research with robust methodology is required (74). Furthermore, studies (75, 76) has shown that active involvement in goal setting is crucial in order to improve rehabilitation after stroke and a client-centred goal instrument was shown to improve client participation in the rehabilitation process (74, 77-79). According to a recent study published in the Cochrane review (80), the selection of goals was described as a collaborative activity between the participants and the therapists. The therapists worked as guides to coach and assist the people receiving services in order to set relevant goals for the intervention. The review also showed that the majority of the studies employed an approach to goal setting in which the participants were actively involved in the selection of goals for therapy. However, the actual extent of patient involvement in the goal setting process has been found to be unclear where the patients were often uncertain about their role in the process (76) and where the patients thought differently about goal setting in rehabilitation than did their health professionals (75).

There is evidence of the beneficial effects of ADL interventions after stroke (13, 81) and interventions enabling ADL (6, 11, 12, 41, 82) are recommended. In rehabilitation, empirical studies (10, 67) have shown how the therapeutic relationship with the OT, the social interaction with others and being in a supportive context all seem to be necessary for recapturing ADL. Despite evidence of the beneficial effects of occupational therapy interventions to improve ADL ability after stroke, earlier research has emphasized the importance of describing the content and rationale for the interventions in a better way (11, 12).

1.3.1 Development and evaluation of a client-centred ADL intervention – a complex intervention

A client-centred intervention is complex and according to Craig (83), a complex intervention contains several interacting components. The CADL was developed following the Medical Research Council (MRC) guidelines for complex interventions (84) consisting of three steps;

identifying the evidence base, identifying/developing appropriate theory and modelling process and outcomes. When developing complex interventions, the recommendation is to use qualitative studies in order to reach an understanding of the clients' experiences and the underlying mechanisms of change that the intervention comprises (85).

In this thesis, in order to answer the research questions, the interest was to examine and evaluate if there were any effects of the CADL, if the people with stroke who received the CADL perceived increased participation in everyday life compared with people with stroke who received the usual ADL intervention (UADL) during one year. According to Craig (83), experiments comparing the intervention to usual treatment are appropriate in gaining this knowledge. Furthermore, by creating a better understanding of how the CADL was experienced from the perspective of people with stroke and OTs performing the CADL, the eventual therapeutic components in the CADL were to be addressed.

1.4 RATIONALE FOR THE THESIS

After a major life-course disruption due to stroke, the person's lifeworld may change. People with stroke often perceive challenges performing activities in everyday life and do not feel that their needs are met.

In Sweden, there are National guidelines for stroke care and access to rehabilitation services. Even though, people with stroke experience limitations in ADL and restrictions when participating in everyday life, there is limited knowledge on the client's lived experience and the underlying mechanisms of change that the intervention comprises. Therefore, there was a need for developing and evaluating a client-centred ADL intervention that enables agency in daily activities and participation in everyday life after stroke based on the person's lived experience and better describes the rationale of the intervention.

A client-centred ADL intervention aiming to enable agency in daily activities and participation in everyday life for people with stroke was developed. Both quantitative and qualitative studies were conducted to evaluate and build knowledge and to understand the meaning of CADL from the perspective of people with stroke and the therapists.

2 AIMS

The overall aim of this thesis was to identify and better understand the effects, experiences and meaning of a client-centred ADL intervention aiming to enable agency in daily activities and participation in everyday life among people with stroke.

The specific aims were:

- I To study the effects of CADL compared with UADL three months after the start of the intervention in: (I) people with stroke regarding: (a) independence in ADL, (b) perceived participation, (c) life satisfaction, (d) use of home help service and satisfaction with training, and (II) the significant others of persons with stroke receiving CADL or UADL regarding: (a) caregiver burden, (b) life satisfaction, and (c) provision of informal care.
- II To compare changes regarding perceived participation, independence in ADL and life satisfaction between 3, 6 and 12 months after inclusion in a study of a CADL and UADL after stroke.
- III To describe and understand what characterize the meaning of client-centred ADL intervention from the clients' perspective.
- IV To describe how occupational therapists applied the client-centred ADL intervention in their clinical practice by studying their experiences and reflections concerning their interaction with the clients with stroke.

3 MATERIALS AND METHODS

3.1 STUDY DESIGN

This thesis is a part of a larger project called LAS-II and its objective is to build knowledge on client-centred rehabilitation. In order to evaluate complex interventions, the use of mixed methods is recommended in order to better understand the process of change and the therapeutic components involved (83). In accordance with these recommendations, different designs and methods were used to capture and build knowledge regarding the effects, experiences and meaning of the CADL. An overview of the studies and methods is given in Table I.

Table I. Overview of studies I-IV

	Study I	Study II	Study III	Study IV
Study design	A cluster randomized controlled trial	A cluster randomized controlled trial	Qualitative method	Qualitative method, longitudinal design
Participants	People with stroke (n=280) Significant others (n=180)	People with stroke (n=280)	People with stroke who received the CADL (n=10)	Occupational therapist who applied the CADL (n=6)
Data Collection (Occasions)	At inclusion and at 3 months for people with stroke. At 3 months for significant others – after people with stroke were included	At inclusion, 3, 6 and 12 months after people with stroke were included	2 times; 2-3 weeks after the CADL intervention started and 1-2 week after intervention ended	4 times during one year, after OT inclusion
Data Collection (Methods and instruments)	Self-reported questionnaires	Self-reported questionnaires	Interviews with broad open ended questions	Interviews with broad open ended questions
Methods of analysis	Descriptive statistics, univariate and multi/binomial logistic regression	Descriptive statistics, linear mixed-effect models and generalized estimating equations	Empirical Phenomenological Psychological method	Grounded Theory, constant comparative method

3.2 STUDY CONTEXT

The LAS-II was conducted in the context of 16 rehabilitation units where OTs performed either the CADL or the UADL. The OTs who performed the CADL learned how to conduct the CADL in a researcher-led workshop. The hypotheses for the LAS-II were that people with stroke who receive the CADL will be more independent, have less restriction in

perceived participation and perceive higher life satisfaction at 3, 6 and 12 months than those who receive UADL. Another hypothesis was that the significant others of people with stroke receiving CADL would perceive lower caregiver burden and higher life satisfaction than significant others of those who received UADL after stroke at 3 months.

3.2.1 The multicentre randomized controlled trial – recruitment

Rehabilitation units in Stockholm, Uppsala and Gävleborg counties were asked to participate in the LAS-II project. The researchers contacted the managers of rehabilitation units and informed them about the project; the planned recruitment of clients/people with stroke and the workshop for the participating OTs who would provide CADL. The OTs at the units randomized to provide UADL were to receive the CADL training after the study was completed. Sixteen units agreed and gave their consent to participate in the LAS-II. The units were stratified by type of rehabilitation unit: inpatient geriatric rehabilitation for ages 65 and over, inpatient medical rehabilitation for patients/clients under 65 and home-based rehabilitation. In order to randomize the units, the researchers wrote the name of each unit on a piece of paper and the units were then randomly drawn to provide either CADL or UADL.

3.2.2 People with stroke and the significant others – recruitment

The OTs at the rehabilitation units recruited people with stroke to LAS-II. People who were eligible for inclusion were those who were treated for acute stroke in a stroke unit, \leq three months after the onset of stroke, dependent in at least two ADL domains according to the Katz Extended ADL Index (KE) (86), not diagnosed with dementia, able to understand and follow instructions, and referred for rehabilitation to one of the 16 participating units in LAS-II.

A power calculation was performed based on the variance in a preceding pilot study (17) and on a difference of 15 points in the Stroke Impact Scale (SIS) domain eight “participation”, which is recommended as a clinically meaningful change (87). Allowing for a 20% dropout rate, 280 people with stroke were required (alpha set at 0.05 and beta at 0.80).

People with stroke who met the inclusion criteria and agreed to participate in LAS-II were, during the first assessment, asked by an independent data collector (experienced OTs) to name a significant other to participate in a 3-month follow-up. The significant other could be a partner, son/daughter or a friend. At the 3-month follow-up, information about the study was presented to the significant other and informed consent was obtained. If the significant others were not present at the 3-month follow-up, they received information (including the form for consent) and the questionnaire to be filled in and returned by email in a pre-stamped envelope. People with stroke were followed for one year after the inclusion in LAS-II and the significant others between 3 and 12 months.

3.2.3 CADL – workshop and content of the CADL

Before the inclusion of people with stroke in LAS-II, 44 OTs who were about to provide the CADL participated in a collaborative training workshop (five full days spread over one month) in order to bridge the gap between research and clinical practice (88). The workshop was held by experienced researchers and the content of the workshop included lectures on client-centredness and the clients' lived experiences (45). The workshop included reading and discussing articles (10, 16, 46, 67) as a basis for the intervention. To facilitate the OTs' integration of research-based knowledge into practice, the workshop session included dialogue and collaboration with focus on the OTs' own experiences and clinical cases. The overarching goal of the workshops was to give the OTs knowledge and tools to enable agency in daily activities and participation in everyday life among people with stroke. The CADL was to be adjusted to the client's ability, motivation, experiences and needs.

The content of the CADL comprised nine components. The CADL was to be planned in close collaboration between the client and OT and the structure of the CADL was to discover and solve problems encountered in daily activities after the stroke. During the nine components in the CADL, two general strategies were combined in order to enable change. The strategies were using the client's lived experience as the point of departure and enabling significant experiences to be gained from doing valued daily activities. The nine components applied to the therapeutic process of CADL are described below:

1. The OTs needed to focus on the first meeting with the client in order to establish a relation for starting the ADL intervention. The OTs needed to understand the client's unique lived experience of the new situation after the stroke in order to meet the client where he/she needed to be met as a basis for the intervention process. The OTs tried to create an atmosphere of empathy in order to develop a relationship based on trust that was sustained throughout the intervention process.
2. The OTs observed the client performing a familiar ADL activity that the client wanted to do. The OT and the client needed to understand the client's actual ability to perform activities and create a similar picture of the client's ability to perform and his/her need to participate in the ADL intervention.
3. Scoring the activity together created a "seeing situation" for the client to enable him/her to learn to understand his/her ability. Scoring the ADL performance showed the client's value of the activity and performance and guided both the client and the OT to discover and identify difficulties in performing the activity.
4. The client formulated three-activity goals that he/she wanted to achieve and needed to perform using the Canadian Occupational Performance Measure (COPM) (42). The COPM is an individualized, client-centred measurement for eliciting performance issues from the client perspective and for capturing perceived changes in performance over time. To be ready to collaborate with the OT in a partnership, the client needed to understand the expectations and goals in the intervention.

5. A problem-solving strategy was introduced to enable the clients to discover their new situation (8). The Goal-Plan-Do-Check strategy inspired by Polatajko (89) was used to provide a structure for both the client and the OT to discuss the performance of the ADL. The OT guided the client to discover and formulate an intervention plan to meet the goals formulated in the COPM. Further, the client was to perform the activity according to the plan in order to gain the experience of doing, discovering and then checking if the plan had worked out. The OT and the client modified the plan together if the goal was not achieved. The aim was to enable clients to become their own problem-solvers and encourage them to discover new strategies by themselves. The OT guided the client in this active exploration and did not solve the problems for them.

6. To give a structure to the implementation of the problem-solving strategy in everyday life, a training diary was used during the intervention process. The client should be encouraged to keep a training diary in order to resume responsibility for his/her goals and the training. The diary was also used as a tool to document the training (related to the goals of the intervention) and to inform others about the training.

7. To involve others, e.g. significant others and other health care professionals in the intervention, the OT supported the client in communicating his/her goals and planned strategies for the intervention. They used the Goal-Plan-Do-Check or the training diary to inform others in order to support the client in using the strategies in daily activities.

8. By using the problem-solving strategy as a structure for doing activities in a new way, the OTs enabled the clients to practice it and integrate it in daily activities. The client practiced the activities he/she had chosen and the OT used the strategies to enable significant experiences thus working toward making the change visible to the client. For the training to be successful, the OT needed to adjust the training to the needs of the client. By having repeated experiences of performing different daily activities, the clients were to integrate the new strategies in the everyday life after stroke.

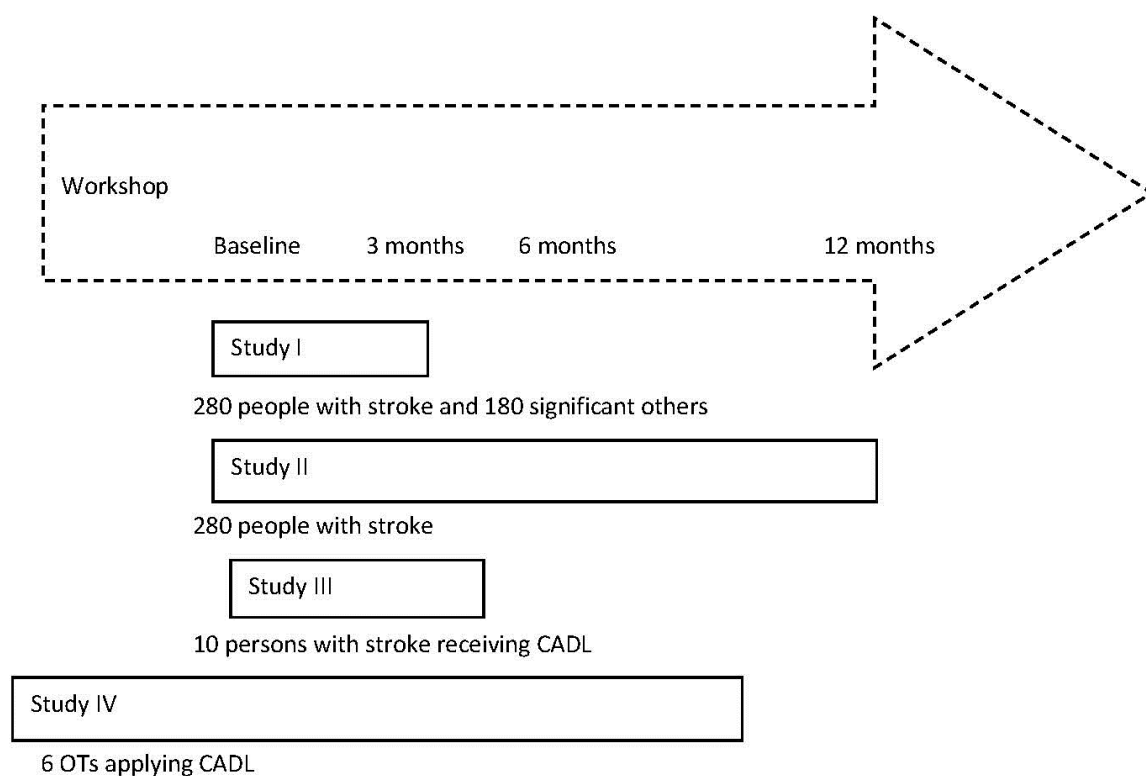
9. When the goals, formulated in the COPM, had been reached, the client and the OT discussed and evaluated the strategies that were implemented. Thereafter, they formulated new goals and strategies together. The challenges in performing daily activities could be adjusted when a concrete structure of doing things was integrated. Hopefully, the client gradually took over the responsibility for implementing the global problem-solving strategy in everyday life.

The UADL interventions varied in extent and methods according to the knowledge and clinical experience of the individual OT and according to the routines and praxis of the participating rehabilitation units.

3.3 PROCEDURE AND DATA COLLECTION

An overview of Studies I-IV and how they were performed in time, in relation to each other, see Figure I.

Figure I. Overview of Studies I-IV



3.3.1 A multicentre randomized controlled trial

In order to evaluate the effects of the CADL, an RCT was conducted in line with the recommendations in the CONSORT (90) - Study I and II. An RCT is the most rigorous way of determining whether a cause-effect relation exists between the treatment and the outcome.

3.3.2 Data collection - measurements and questionnaires

Before starting the data collection, the data collectors had regular meetings to ensure consistency in using the protocols. Manuals were developed in order to clarify the data collectors' agreement in using the different instruments. Regular meetings were held with the researchers and the data collectors throughout the data collection period, in order to ensure inter-rater-reliability and to manage the procedure of data collection. In Study I and II, data collection was performed in the form of interviews, using the protocols of questions and instruments, with the people with stroke and in Study I as well, with significant others of the people with stroke. Data collectors were blinded to the content of the intervention and to which were the CADL units and which were the UADL units. The persons with stroke decided where data collection was to take place, at the rehabilitation units and/or in the home of the person with stroke.

The researchers contacted the OTs on a regular basis in both the CADL and the UADL group in order to maintain their participation in the LAS-II and to monitor the fidelity of the CADL.

In both Studies I and II, the medical history was obtained from the medical records of the people with stroke. For people with stroke, demographic data and outcome variables were collected at baseline, 3, 6 and 12 months. In Study I, data collected at baseline and 3 months was used and in Study II, data collected at all time-points was used. In Study I, demographic data and different outcomes for significant others were collected at 3 months.

An overview of the instruments used in Study I and II is presented in Table II.

Table II. An overview of measurements and instruments applied in Study I and II.

Instruments	People with stroke				Significant others
	Baseline	3 months	6 months	12months	3 months
Mini Mental State Examination (MMSE)	x				
Scandinavian stroke scale					
- Speech production	x				
- Gait	x	x			
Stroke Impact Scale (SIS)		x	x	x	
Perceived recovery scale (SIS)	x	x	x	x	
Frenchay Activities Index (FAI)	x			x	
Occupational Gaps Questionnaire (OGQ)		x		x	x
Impact of Participation and Autonomy (IPA)				x	
Katz Extended ADL Index (KE)	x	x	x	x	
Barthel Index (BI)	x	x	x	x	
Stroke Severity	x				
Life Satisfaction Scale (LiSat-11)		x		x	x
Home-help service		x			
Satisfaction with training		x			
Falls		x	x	x	
Caregiver Burden Scale (CBS)					x
Informal care					x

3.3.2.1 Measurements for people with stroke

Cognitive. The Mini-Mental State Examination (MMSE) (91) was used to screen cognitive impairment at baseline.(91)

Communication. The Scandinavian Stroke Scale (92) was used to categorize the participants' speech production at baseline. The categorization was: no aphasia, limited vocabulary, more than yes/no, only yes/no or less.

Mobility. The Scandinavian Stroke Scale (92) was used to categorize gait capacity at baseline and at 3 months. A modified item was used and the categorization was: unable to walk, walks with aid and help of another person, walks with aid, or walks 5 meters without aid.

Perceived participation. The Stroke Impact Scale (SIS) 3.0 (87) was used to assess perceived participation and the perceived impact of stroke at 3, 6 and 12 months. The SIS consists of

eight domains: strengths, memory and thinking, emotions, communication, ADL/IADL, mobility, hand function and participation. Domain eight, participation, was chosen as the primary outcome. The SIS is made up of 59 items and the scores range from 0 to 100; the greater the score the smaller the impact. The SIS also consists of a recovery scale, ranging from 0 (no recovery) to 100 (full recovery). Perceived recovery was measured at every data-collection point. The SIS has shown to be reliable, valid and sensitive to change (87) and has been frequently used (93). A proxy version (94) was used when possible when the participants with stroke were unable to answer.

The Frenchay Activities Index (FAI) (95) was used to assess participation in performing social activities and everyday activities in the areas of domestic chores, leisure/work and outdoor activities at baseline and at 12 months. The FAI consist of 15 items; the score is based on the frequency with which an activity has been performed during the previous 3 or 6 months and ranges from 0 (inactive) to 45 (very active).

The Occupational Gaps Questionnaire (OGQ) (96) was used to assess perceived participation in everyday occupation at 3 and 12 months. The OGQ covers the areas: instrumental ADL, work or work-related activities, and leisure and social activities. The OGQ comprises a checklist of 28 activities. For each activity, there are two questions: (i) whether the person performs the activity (yes/no) and (ii) whether the person wants to perform the same activity (yes/no). An occupational gap is considered to be present when there is a discrepancy between the response to the two questions and the optimal outcome is a lack of gap.

The Impact of Participation and Autonomy (IPA) (97) was used to assess perceived participation and autonomy at 12 months. The IPA consists of 32 items pertaining to the domains of autonomy indoors, family role, autonomy outdoors, social relations and work and education. The score on each item is graded on a 5-point rating scale, ranging from 0 (very good) to 4 (very poor). For each domain, the participation score is calculated by summing the item scores. Higher scores denote more restrictions in participation for the specific domain.

Independence in ADL. The Katz Extended ADL Index (KE) (86) was used to assess independence and dependence of assistance in ADL before stroke, at baseline and at 3, 6 and 12 months. The KE contains six personal ADL (P-ADL) and four instrumental ADL (I-ADL) items. The KE was trichotomized into “dependent in both”, “independent in P-ADL or I-ADL” and “independent in both”.

The Barthel Index (BI) (98) was used to assess independence and dependence in ADL at baseline and at 3, 6 and 12 months. The BI comprises 10 self-care and mobility activities. Scores range from 0-100 and a lower score indicates greater dependency in ADL.

Stroke Severity: The BI scores (administrated at baseline) were used to determine stroke severity, where scores of < 15 represented a severe stroke, 15-49 a moderate stroke and 50-100 a mild stroke (99).

Life Satisfaction Scale: The Life Satisfaction Scale (LiSat-11) (100) was used to assess life satisfaction at 3 and 12 months for people with stroke. The LiSat-11 contains 11 items about overall and domain-specific life satisfaction, self-rated on an ordinal scale ranging from 6 (very satisfactory) to 1 (very dissatisfactory). One global question was used to assess the participants' overall satisfaction with life, "My life as a whole is". In order to analyze the LiSat-11, the scores were dichotomized into "satisfied = yes" (score 5-6) and "not satisfied = no" (score 1-4).

Home-help service: Information about home-help service (yes/no) was self-reported in the protocols and used in the analysis at 3 months.

Satisfaction with training: One statement from a questionnaire based on a taxonomy developed by Ware (101) was used to reflect met/unmet need for training at 3 months. "I have received the training that my condition has required" rated on an ordinal self-rating scale ranging from 1 (fully agree) to 5 (not agree at all). The scores were dichotomized into agree = met need (score 1-2) or do not agree = unmet need (score 3-5).

Falls: Self-reported information about falls (yes/no) since the last follow-up was collected at 3, 6 and 12 months to monitor the safety of the intervention.

3.3.2.2 *Measurements for significant others*

Caregiver Burden Scale: The Caregiver Burden Scale (CBS) (102), which consists of 22 items, was used to assess caregiver burden at 3 months. The items cover areas of the caregiver's health, feelings of psychological wellbeing, relations, social network, physical workload and environmental aspects. The items are scored on a scale of 1 to 4 and the higher the score the greater the burden.

Life Satisfaction Scale: The LiSat-11 (100) was used to assess the overall life satisfaction of the significant others at 3 months.

Perceived participation: The OGQ (96) was used to assess perceived participation in everyday occupations of the significant others at 3 months.

Informal Care: Information on unsalaried, informal care was collected (yes/no). The significant others were asked if there were any ADL in which people with stroke needed their assistance or supervision that, prior to the onset of stroke, had been performed without supervision or assistance.

3.3.3 Duration and content of intervention received

From the OTs' records, information the number of occupational therapy contacts during the CADL and the UADL was collected for all the 280 people with stroke. After the clients with stroke had been discharged from the rehabilitation units, the OTs printed out the OT records and the clients' personal data were omitted and replaced with the study participant code and further sent to the researchers. No instructions were given to the OTs in none of the groups on

how they should document their work in the records. The conceptual terminologies of the Swedish Association of Occupational Therapists (103), were used to review the OTs' records. The OT contacts were accounted for the number and content and each contact could contain one or several foci (e.g. activities in daily living and function).

3.3.4 Data collection – Interviews

In the context of LAS-II, data collection for Study III and IV was conducted through interviews.

Participants in Study III were people with stroke who received the CADL. OTs who conducted the CADL suggested the participants for Study III. The participants needed to be able to convey their lived experience of the phenomenon; i.e. participating in CADL and therefore only clients who were able to express their experiences of the rehabilitation and CADL were asked to participate in the study. Clients with mild speech and cognitive impairments were included. An overview of the participants' characteristics is presented in Table I (see Study III). Interviews with each participant were conducted on two occasions (20 interviews), the first approximately two to three weeks after the start of the CADL and the second approximately one to two weeks after being discharged from the CADL. The interview guide was developed and reviewed after the first interview with each participant. The length of the client's rehabilitation varied and thus the time period between the first and second interview varied from less than one month to about five months. Each interview lasted between 30 minutes and one hour. The initial interviews were performed at the rehabilitation units for those (eight) participants who were inpatients at that time and in the participants' home for two of them. The second interviews were all performed in the participants' home. The interview guide was developed and reviewed after the first interview for each participant.

Study IV had a longitudinal design and followed OTs who conducted the CADL in order to capture their experiences of applying the CADL. The OTs who were about to participate in the first workshop received an invitation to participate in Study IV; five of them agreed to participate and were interviewed before they participated in the CADL workshop and then at 3, 6 and 12 months after the workshop. One additional OT was included in the study later through theoretical sampling (104) and two interviews were conducted. All OTs were women and of varying ages. An overview of the participants in Study IV is shown in Table II (see Study IV). Written informed consent was obtained from each participant. The time and place for the interviews was decided in consultation with the participants. Each interview lasted approximately one hour and was conducted at the OT's workplace, a participating rehabilitation unit. A semi-structured interview guide was used during the interviews (104, 105) and questions were developed through theoretical sampling during the entire period of data collection (104). Interviews (n=22) lasted between 45 and 90 minutes. In agreement with the principles of theoretical sampling (104), data was collected and analyzed to complement unanswered questions during the study process. Theoretical saturation guided the data collection, which ended when no additional data was found that could further develop the properties of the upcoming categories (106).

In Study IV, observations were conducted with three OTs before their last interviews at 12 months. Observations were conducted in order to observe the OTs in a clinical session with a client. The observations served as a basis for questions in the upcoming interviews.

3.4 DATA ANALYSIS

3.4.1 Statistical analysis

The outcomes in Study I and II for people with stroke were perceived participation, independence in ADL and life satisfaction. In Study I, use of home help service and satisfaction with training were also used as outcomes measures for people with stroke and for the significant others, the outcomes were caregiver burden, life satisfaction and provision of informal care.

In Study I and II, intention-to-treat analysis was performed. In Study I, univariate analyses of variance and multinomial/binomial logistic regression analysis was performed to compare the outcome of the CADL group with the UADL group at three months. The imputation method of last value carried forward or the worst value of the study population was applied for missing values. In Study II, ordinal regression analysis was used to compare the CADL and the UADL groups and in order to investigate if there were any differences in change over one year between the groups, a linear mixed-effect model and generalized estimating equations (GEE) analyses were performed. For the instrument SIS (domain eight), separate GEE analyses were performed for “a positive clinically meaningful change” and “a negative clinically meaningful change” i.e. change of 15 points between 3 and 6 months compared with changes between 6 and 12 months.

In both Study I and II, covariates were included in the statistical analyses to adjust for factors that could influence the outcome. The analyses were conducted using SAS (Science Analysis System) and SPSS (Statistical Package for the Social Science).

3.4.2 Qualitative analysis guided by the principles of Empirical Phenomenological Psychological method

In order to describe and understand what characterized the meaning of CADL from the clients' perspective, the Empirical Phenomenological Psychological method (EPP method) (107) was used in Study III. The method was modified during the data analysis where the psychological perspective of the method was replaced with an occupational perspective focusing on the participants' experiences of doing activities. This modified form has also been used in several previous studies in occupational therapy (8-10, 25, 31, 46, 66, 67).

The EPP method is a qualitative method with a descriptive approach aiming to answer questions regarding what and how something is rather than why. The aim of using the EPP method was to describe the meaning structure of the studied phenomenon based upon the participants' description of their experiences (107). The phenomenon studied in Study III was the experiences of participating in CADL from the perspective of people with stroke. The

method aims to elucidate the essence of the studied phenomenon presenting itself in the life-world experiences (4).

The data and analysis were interpreted in five steps. In the first step, the participants' interviews were read with an empathic understanding and to get a "good grasp" of each interview i.e. to understand the participants' lived experiences. In the second step, the interview transcript was reread to identify and divide the text into smaller units called meaning units. The process of identifying meaning units helped the first author to focus on the meaning structure of the phenomenon. In the third step, the meaning units were interpreted and understood in relation to the whole text and the phenomenon. The focus was on the meaning hidden in the facts and the participant's everyday language was rendered into the first author's own words. In the fourth step, a synthesis of the transformed meaning units was performed into a "situated structure of meaning" for each interview. This step involved returning to the original interview text to ensure that the best interpretations were found. In the fifth step, the situated structure from all the participants were used to create a general meaning structure based on the characteristics that ran across all the interviews describing the participants' experiences of the meaning of CADL.

The guiding principle during the data analysis was to discover the phenomenon and to identify the meaning embedded in the participants' lifeworld experiences in their daily activities. The analysis started after all the interviews were completed.

3.4.3 Qualitative analysis guided by the principles of Grounded Theory

In Study IV, a Grounded theory (GT) approach (104, 106) was used to gain a deeper understanding of the process of how the OTs applied the CADL in their clinical practice during one year. The researchers studied the OTs' experiences and reflections concerning their interaction with the clients with stroke. A constructivist approach in grounded theory was used (104), which focuses on the phenomena studied and considers both the data and analysis as created from shared experiences and relationships with participants. In the present study, the aim was not to develop a theory rather generate an "abstract theoretical understanding" (104) (p.4).

Three levels of coding were performed during the analysis (104). In the first *initial* coding, transcripts were read line-by-line and incidences coded e.g. "listening to the client". Further, in *focused* coding, the most significant codes were used to synthesize and explain the data and the core category emerged: "A process of sharing for enabling a sense of agency in daily activities". Through *axial* coding, categories were linked to subcategories and the question, how they were related to each other, was asked. The metaphor "enabling the client to transfer over to the driver's seat – shifting place" was used throughout the analysis to help the authors to describe and characterize the participants' clinical reasoning and strategies used in the CADL. In the construct of the GT approach, a constant comparative method was used to identify and systematically compare similarities and differences in the data. The analysis

started after the first interview was conducted and the constant comparative method and memo writing continued alongside the whole data collection and analysis.

4 SUMMARY OF RESULTS

In this section, the results from the empirical studies will be presented.

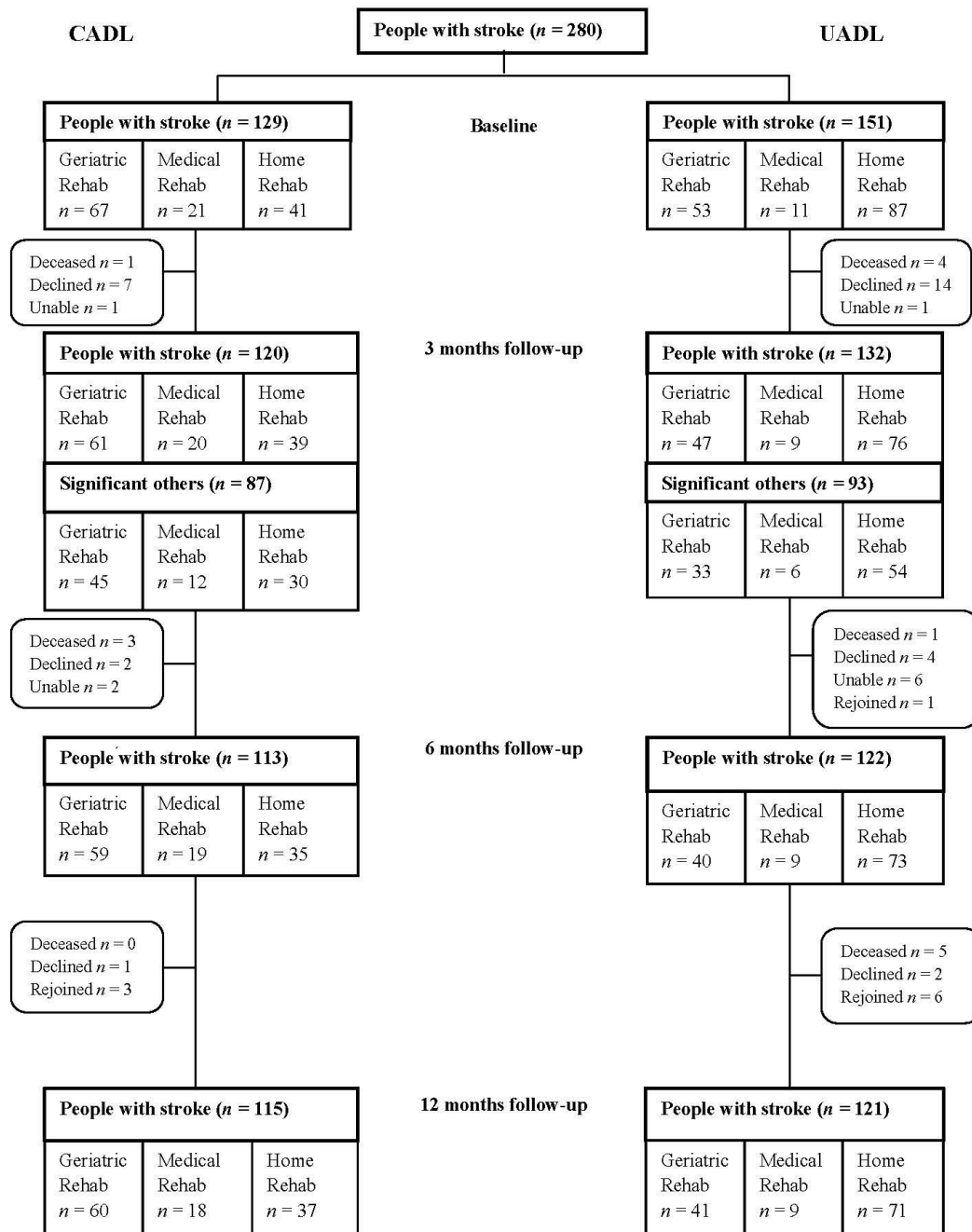
4.1 EFFECTS OF CADL COMPARED TO UADL

In Study I and II, the aim was to study the effects of CADL compared to UADL in people with stroke during one year and their significant others at 3 months in Study I.

4.1.1 Participant flow and characteristics in LAS-II

A sample of 280 people with stroke was included in the multicentre study of LAS-II. Additional participants in Study I were 180 significant others included at the 3-month follow-up. The participants with stroke in LAS-II were recruited between October 6, 2009 and September 7, 2011 and followed up until September 2012. Only half as many participants were deceased and had declined to participate at 12 months in the CADL group compared to the UADL group. The participant flow for Study I and II is presented in a flowchart, Figure II.

Figure II. Flowchart



The CADL group consisted of 129 people with stroke and the UADL group of 151 people with stroke at baseline. The mean age in the CADL group was 74 and 71 in the UADL group and more people were dependent in P-ADL and I-ADL before stroke in the CADL than in the UADL group. The CADL group had more severe and moderate stroke and at baseline/inclusion, more people were dependent in ADL in the CADL group than in the UADL group (BI). An overview of people with stroke and their significant others is presented in Table III.

Table III. People with stroke at baseline and 12 months, significant others at 3 months.

Measure, range	People with stroke				Significant others	
	Baseline		12 months		3 months	
	CADL <i>n</i> = 129	UADL <i>n</i> = 151	CADL <i>n</i> = 115	UADL <i>n</i> = 121	CADL <i>n</i> = 87	UADL <i>n</i> = 93
Age, year mean (SD)	74 (10)	71 (11)			60 (15)	64 (13)
Men/ women, <i>n</i> (%)	73/56 (57/43)	95/56 (63/37)			31/56 (36/64)	23/70 (25/75)
Cohabiting, <i>n</i> (%)	68 (53)	91 (60)			51(59)	63 (68)
Level of education, <i>n</i> (%)						
Elementary school/High school	94 (73)	113 (75)				
University	35 (27)	37 (24)				
No formal education	0 (0)	1 (1)				
	Before stroke:					
Frenchay Activities Index (FAI), 0-45, mean	29	31	18	22		
Katz Extended ADL Index (KE), <i>n</i> (%)						
Dependent in both	16 (12)	6 (4)	61 (53)	42 (35)		
Independent in P-ADL or I-ADL	34 (27)	42 (28)	31 (27)	46 (38)		
Independent in both	79 (61)	103 (68)	23 (20)	33 (27)		
	At inclusion:					
Stroke severity, <i>n</i> (%)						
Mild (<i>BI</i> = 50–100)	94 (73)	129 (86)	104 (90)	113 (93)		
Moderate (<i>BI</i> = 15-49)	31 (24)	20 (13)	9 (8)	6 (5)		
Severe (<i>BI</i> = <15)	4 (3)	2 (1)	2 (2)	2 (2)		
Barthel Index (BI), 0-100, median (range)	65 (5–100)	80 (10–100)	82 (0-100)	88 (0-100)		

Note. FAI ranges from 0 (inactive) to 45 (very active); BI ranges from 0 to 100; a lower score indicates greater dependency.

4.1.2 Outcomes for people with stroke

There were no statistically significant differences in the primary outcome SIS domain eight “participation” at 3 months or in change over 12 months between the CADL group (*n*=129) and the UADL group (*n*=151). No significant differences were found between the groups in

the other secondary outcomes at 3, 6 or 12 months except at 3 months in the SIS domain “emotion” in favor of CADL ($p=0.04$). In Study II (see Table IV in Study II), the raw scores regarding perceived participation, independence in ADL and life satisfaction at 3, 6 and 12 months are presented. The clinically meaningful change in the primary outcome “participation” (SIS domain eight) is shown in Table IV. The odds for a positive clinically meaningful change between 3 and 12 months were 1.53 for the CADL group compared with the UADL group (CI 0.93-2.51, $p=0.098$). The odds for a negative meaningful change between 3 and 12 months were 0.67 for the CADL group compared with the UADL group (CI 0.38-1.19, $p=0.168$).

Table IV. Clinically significant changes in the participation domain of the Stroke Impact Scale for the CADL and the UADL groups at 6 months (3 to 6) and at 12 months (6 to 12)

	3–6 months		6–12 months	
	CADL <i>n</i> = 110	UADL <i>n</i> = 122	CADL <i>n</i> = 110	UADL <i>n</i> = 114
Positive change, <i>n</i> (%)	26 (24)	25 (21)	24 (22)	14 (12)
No change, <i>n</i> (%)	76 (69)	82 (67)	66 (60)	83 (73)
Negative change, <i>n</i> (%)	8 (7)	15 (12)	20 (18)	17 (15)

Note. A positive clinically meaningful change = +15 points or more,
 No change = difference between -14 and +14 points,
 A negative clinically meaningful change = -15 or more.

Information from the OTs’ records concerning the number of OT contacts during the CADL and the UADL intervention in both Study I and II are shown in Table V. The mean duration of rehabilitation for people admitted to the participating rehabilitation units was 40 days (range 7-120 days).

Table V. Number of OT contacts in Study I and II.

	3 months		12 months	
	CADL n=129 mean	UADL n=151 mean	CADL n=129 mean	UADL n=151 mean
Treatment period, days	54	45	71	59
Occasions/contacts* <i>OT and participant, n</i>	19	13	21	15
OT Administration, <i>n</i>	4	3	4	4
Occasions total*, <i>n</i>	22	16	24	18
<u>Focus of contacts:</u>				
Goal setting, planning and evaluation*, <i>n</i>	3	1	3	1
ADL* leisure and work included, <i>n</i>	20	13	22	15
Training of function*, <i>n</i>	9	7	10	7
Environment* environmental investigation, technical aids and home modifications, <i>n</i>	5	3	5	4
Family* contact with significant other, <i>n</i>	1.3	1.3	1.4	1.5
Other* information about home care and rehabilitation, <i>n</i>	0.1	0.2	0.2	0.2

Note. *Face-to-face, in group, or by telephone.

4.1.3 Outcomes for significant others

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

4.2 EXPERIENCES OF PARTICIPATING IN CADL

In Study III, people with stroke described their lived experiences and the meaning of participating in the CADL. Three main characteristics were identified, with two to four sub-categories, which seemed to enable agency in the therapeutic process. The first main-characteristic *Transparency* was defined as the participants' experience of being able to see (visualize) and follow, which helped them to understand and participate in their own CADL intervention. The participants described how they experienced their intervention as transparent, which contributed to awareness and enabled them to enact agency in everyday life. The second main-characteristic *Mutual trust and responsibility* described the clients' experiences of feeling safe when participating in the interaction with the OTs. Continuity of the therapeutic process and practicing together with the OTs seemed to be necessary to build the mutual trust and responsibility the clients experienced. The third main characteristic was *Learning by doing*, which described the clients' experiences of learning new strategies, which they could integrate and connect to new contexts. The main categories were connected to each other and overlapped. A meaning structure of the lived experience of the phenomenon, participating in CADL, is presented in table II in Study III.

4.3 THE PROCESS OF SHARING TO ENABLE AGENCY IN DAILY ACTIVITIES

The findings from Study IV identified three categories with the core category *The process of sharing for enabling agency in daily activities*. The core category described how the OTs guided their clients to enable agency in daily activities through *sharing*, which seemed to be a necessary condition throughout the intervention process. The relationship between the OTs and the clients turned out to be the foundation of the intervention process where *Sharing an understanding as the point of departure* existed. Furthermore, the OTs described how they continued to use *Sharing through experiences* with the clients where they took turns being the receiver or the transmitter of sharing. The OTs expressed how these two categories enabled change in the intervention process but also how the different *Challenges in applying the CADL* affected the OTs in applying the CADL.

5 DISCUSSION

From the inception of this thesis, my aim has been to gain a deeper understanding about client-centredness in the context of rehabilitation. More specifically, my interest has been in the strategies that occupational therapists use in a client-centred ADL intervention and how a client-centred ADL intervention can support clients to participate and engage in activities they want and need to perform. My interest has also been on evaluating the effect of CADL as regards the impact of client-centredness on the perceived participation and everyday life of people with stroke. In the following, the findings from the four studies included in the thesis will be discussed and related to the research field of client-centred practice and other relevant areas of theory and research.

5.1 EVALUATING COMPLEX INTERVENTIONS

The four studies in this thesis evaluate a complex intervention through different perspectives and methods. The various studies, taken together with other studies in this research project (31, 71, 88, 108, 109), provide new knowledge in the context of a client-centred ADL intervention. In this thesis, two of the studies (Study I and II) were designed to compare the effects of the CADL to those of the UADL in the primary outcome “participation” (SIS domain eight) and secondary outcomes during one year. According to the results in Study I and II, we could not confirm our research hypothesis that a client-centred ADL intervention would have a greater effect on participation to that of usual ADL intervention during the first year after stroke. No significant differences were found in the statistical analysis between the two groups regarding the primary outcome, perceived participation in everyday life. The lack of differences in outcome aligns with the conclusions of a systematic review of RCTs examining the patient-centred interventions. The systematic review has shown that the beneficial effects in favour of the patient-centred care of rehabilitation were reported mainly in the areas of patient satisfaction and perceived quality of care (72). The results of no significant differences (in change) between the CADL group and the UADL group are also in line with a cluster RCT on the efficacy of client-centred occupational therapy for people with multiple sclerosis, showing no significant difference compared to usual occupational therapy on disability, participation and autonomy outcomes (110).

Furthermore, the project LAS-II was a carefully planned and a rigorous RCT design, following the structure of CONSORT (90) and was chosen to evaluate the CADL. However, the rehabilitation process after stroke is multifaceted and the CADL is a complex intervention where different aspects may influence the outcome of participation (83). The results of Study II show a trend towards a clinically positive and meaningful change in participation, which might indicate that perhaps there were differences in the changes between the groups. There are some plausible explanations as to why there was no difference in effect between the groups: 1) the OTs performing the UADL also used a client-centred approach, 2) the OTs using the CADL did not use a client-centred approach throughout the project 3) the rehabilitation consisted of interventions from other health-care disciplines that affected the

outcome and 4) the outcome measures did not capture the core aspects of the CADL and/or were not sufficiently sensitive to change.

The first two explanations mentioned above were whether the differences between the CADL and the UADL might have been too small to give a significant difference in effect on the outcomes. The first explanation was if the OTs performing the usual ADL intervention included client-centred approaches in their clinical practice. This cannot be ruled out since the client-centred perspective has been much taught and discussed among OTs in the past decades (52). However, more OT-contacts with the foci of goal setting in the CADL group than in the UADL group were found. This is in line with another study (88) conducted in the context of LAS-II, which shows that in the medical records, the OTs in the CADL group documented significantly more on all aspects related to goal setting and on client engagement/motivation for rehabilitation than OTs in the UADL group. This is of interest because no instructions on how to document in the clients' medical records had been given to the OTs participating in the LAS-II. The differences in the documentation indicate that the OTs in the CADL group seemed to have a more client-centred approach than the OTs in the UADL group, since participation in goal setting is perceived as an important aspect of improving client outcomes in stroke rehabilitation (74, 111), though not confirmed of the findings of the studies in this thesis. These results of good process and poor outcome are similar to another RCT study (110) evaluating a client-centred intervention in patients with multiple sclerosis.

The next plausible explanation was that the OTs in the CADL group did not fully implement the intervention throughout the project. We cannot be sure of that even if all OTs in the project, both in the CADL and the UADL group, were contacted on a regular basis by the researchers of the CADL group in order to monitor fidelity to the intervention. The finding in Study IV showed how the OTs found it challenging to perform the client-centred approach throughout the whole intervention and with all the clients. Performing the client-centred approach varied in extent between the participating OTs participating in Study IV and was also time consuming. This finding is supported in Eriksson et al's study (108), in which it was reported that therapists provide intervention in a research context might find it challenging and might have a lack of time and experience to apply the research as intended.

Another possible explanation was that the rehabilitation consisted of the interventions from other health-care disciplines. Training in the client-centred approach only included the OTs, not the other members of the rehabilitation team. What approach the other team members used on the participating clients and what effect that could have on the outcome is unknown. It is important in the future to consider the development of a client-centred approach that includes and educates all the members of the rehabilitation team.

Furthermore, another plausible explanation might be that the outcome measures did not capture the aspects of the main focus of a client-centred ADL intervention and was not sufficiently sensitive to change. However, in the analysis in Study II, the CADL group nevertheless demonstrated a trend towards a positive clinically meaningful change in

participation that was more pronounced than that observed in the UADL group during the 12 months. One understanding, with the support from the findings in Study III, is that the persons with stroke in the CADL group had developed generic skills for solving problems in daily activities, long after a stroke onset that might have influenced their perceived participation in everyday life. Even though there were no differences on a group level a small change might be of importance for the individual. Furthermore, all measures used in the present project were self-reported instruments, but it might be that the instruments did not capture the satisfaction the individual attached to the different outcomes or the magnitude of the change. However, the findings in Study III and IV captured how the CADL contributed to a positive change for the participants. Using qualitative studies alongside complex interventions in order to better understand the effects of the intervention (85) is considered important to capture the whole picture.

5.2 TRAINING AND PRACTICE ENHANCED A CLIENT-CENTRED APPROACH

The findings in this thesis indicate that the OTs participation in the workshop and by practicing the CADL seem to gain knowledge how to apply the CADL. The findings in Study III and IV showed how OTs participation in the workshop supported them to develop and work with a more client-centred approach. The findings suggest that the OTs made an effort to understand the client's lived experiences and have that as a point of departure for the intervention. Understanding is the point of departure in the CADL and in line with how the Swedish health-care legislation (14) has stated that rehabilitation should be based on respect for the client's autonomy and integrity. The findings suggest also that the OTs invited the clients to participate in their intervention, e.g. in the goal setting process which was also confirmed in Flink et al's study (88).

However, the client-centred approach used in the CADL was taught for occupational therapists who already consider themselves working client-centred (52). Despite this, the findings in Study IV show how implementing a new intervention into clinical practice can be a challenging process. This is in line with previous research (18, 112), and with the focus group interviews showing that the OTs delivering the CADL experienced a need to have access to the clients and use the intervention as soon as possible after ending the workshop in order to integrate the intervention in their clinical work (108). In the course of the 5-day workshop during a month, the therapists could practice the CADL in clinical practice. However, how well prepared the therapists were to use the intervention in clinical practice before the clients were included in the RCT is unknown.

Moreover, the results in Study I and II found no differences in the outcome measures. However, findings from Study III and IV in agreement with Flink et al (88), indicate that there is potential for improvement to increase client-centredness in order to develop a client-centred practice. Having a client-centred approach is in line with how both the national guidelines for stroke (14) and the international reports (113) emphasize care, that the patient has the right to be involved and make decisions about their own health and health care. The findings indicate that a workshop including both training and practice supports the

implementation of a client-centred approach in clinical praxis. However, the findings also suggest that practicing the intervention should be spread out over a longer period of time in order to truly integrate the intervention into practice, also to ensure that the clients receive the new intervention in the right way.

5.3 PARTICIPATION AS A COMPLEX CONCEPT

Perceived participation was the outcome on which the effect of the CADL was evaluated. The aim of the CADL was to enable agency in daily activities and participation in everyday life among people with stroke, since people with stroke often perceive restrictions in participation (114). Participation, according to Desrosiers (115), is considered as a central outcome of successful rehabilitation and a goal for rehabilitation of people with stroke. However, participation has been defined as a complex and multidimensional concept covering both the observed performance of an activity and the subjective experience of participation (30, 116-118). Measuring participation can be challenging and complex since participation occurs in the interaction between the domains, person, environment and occupation and the measurement must be performed during this interaction (23). The different dimensions influencing participation in occupation have been described by Law (23) as "the person's preferences and interests; what he or she does, where and with whom; and how much enjoyment and satisfaction he or she finds". Fallahpour et al (25) describes how participation reflects the person's unique experience and therefore differs among people.

Lack of significance in the primary outcome of participation in the findings of Study I and II might indicate that the variation in the participants' experiences might not have been reflected in the chosen and used instruments. According to Magasi et al (119), there are a myriad of instruments designed to measure participation from different perspectives. The instruments chosen in the present project were perhaps not sensitive enough to capture changes over time. Appropriate outcome measures should be applied in order to ascertain the effectiveness of interventions that target participation but there is no consensus concerning what measures to use, although the SIS and the FAI have been used frequently (93). However, all instruments used for measuring the perceived participation and other outcomes in the RCT were self-reported capturing the client's subjective experience (116). The client's own experience of participation after stroke came forth in Study III, which was the foundation of the CADL and the phenomenological perspective where the client's experiences are central.

No significant differences were found in the primary outcome of participation in Study I and II, however on the other hand, findings in both Study III and IV suggest that the CADL enabled the clients' to act as agents in their daily activities and to participate in everyday life. The client-centred approach, shared by the OTs and the clients were experienced as transparent and increased the clients' awareness and discovery of their situation. The process of discovery (8) seems to enable the clients in being their own agents in daily activities and the findings show furthermore how the phenomenon of agency and participation is intertwined in the context of everyday life (30, 31, 35).

5.4 THE SHARED AND TRANSPARENT THERAPEUTIC PROCESS

The qualitative studies (Study III and IV) showed that a shared and transparent intervention process seemed to enable agency in daily activities and participation in everyday life among people with stroke. Sharing and transparency seem to be the essence and meaning in CADL and a necessary condition for client-centredness in rehabilitation after stroke. The findings in this thesis on how sharing and transparency facilitate each other and seem to create change, from both the client's and the therapist's perspective, have not previously been described in the context of rehabilitation after stroke. In previous research, sharing has been described as being important in both the therapeutic relationship and the therapeutic process (1, 120, 121), which is in agreement with the empirical findings in this thesis. Transparency has been described as a strategy of giving feedback in different ways in order to increase the client's awareness (36, 122-124).

5.4.1 Therapeutic components in client-centred ADL intervention after stroke

The findings in Study III and IV suggest different therapeutic components that are relevant for a client-centred approach in a client-centred ADL intervention after stroke. In CADL, the therapist's understanding of the client's lifeworld experiences (lived experience) was meant to be the point of departure for creating the therapeutic process. This was confirmed in the two qualitative studies, which together reflected the importance of building the intervention on the experiences of the clients but also the shared experiences of the therapist and client, which were co-created during the therapeutic process.

The suggested therapeutic components found in Study III and IV were: *creating a shared therapeutic alliance, inviting clients in shared goal setting, collaboration by practicing together and the client as the owner of the therapeutic process*. These components are expressed in the content of CADL and described in other words, by occupational therapy scholars (1, 18, 121) as therapeutic strategies. The concurrence of the findings of therapeutic components and how previous research has emphasized the therapeutic process confirms that the therapists performing the CADL used a client-centred approach. However, in the findings, the connection of sharing and transparency contribute to new empirical knowledge from both the client's and the therapist's perspective. Moreover, these findings can be seen as generic, which could support clinicians in different health care professions in implementing strategies in their clinical practice and for the development of theory.

5.4.1.1 *Creating a shared therapeutic alliance*

One therapeutic component found in Study III and IV, from both the clients' and the therapists' perspective was the importance of creating a shared therapeutic alliance. The therapeutic alliance represented constant sharing of experiences, which appeared to be the underlying mechanism that contributed to transparency. Transparency on the other hand seemed to make the therapeutic alliance visible where the client and the therapist shared their understanding of the situation and provided continuity and maintenance in the therapeutic

process. This is in line with the description the participants in the Guidetti et al study (10) provided on becoming a “we” as a unit with the therapist.

Furthermore, the empirical findings of the therapeutic alliance, including sharing and transparency appeared to be the foundation in the CADL and as Price (120) has described, a “catalyst for change”. Creating a therapeutic alliance, partnership or a relationship is described as a crucial strategy in the therapeutic process (1, 120, 121). In order to create a shared therapeutic alliance and enter the client’s lifeworld has, in previous research (1, 46, 48, 120, 121), shown that therapists need to use their empathetic understanding, show professional expertise and meet the clients in their changing lifeworld over time. This is in accordance with the findings in Study III and IV. However, the findings also suggest that the strategies for sharing and transparency in the therapeutic alliance are necessary in order to bring about a change in the therapeutic process.

5.4.1.2 Inviting clients in shared goal setting

Another therapeutic component found in this thesis was that the clients receiving the CADL were invited in shared goal setting that contributed to transparency in their intervention process. Goal setting and follow-up of goals were integrated in the CADL components and were corroborated in the findings of Study I and II and in the Flink et al study (88) showing that the foci in the CADL group consisted of more goal setting than the UADL group. Involving the clients in goal setting is supported by many scholars (21, 45, 120, 121), who have described how the person’s subjective experience is important to pay attention to when starting therapy. However, according to the findings in Study III and IV, the shared goal setting not only showed the importance of the clients being able to express their desires but also a strategy that contributed to transparency where both the clients and the therapists could follow the therapeutic process. The shared goal setting seemed also to increase the client’s understanding of their own situation, which is in line with another empirical study (75) showing how goal setting was a way of helping the clients stay motivated and on task. Furthermore, from the findings, transparency seemed to be essential for the client’s discovery of their new ability and situation. The awareness the clients gained through seeing and understanding the therapeutic process through their goals seemed to help them feel safe when “making things happen through their own actions”, which has been identified as a characteristic of agency (125).

5.4.1.3 Collaboration by practicing together

The third therapeutic component found in the findings of Study III and IV suggests that the CADL facilitates collaboration by enabling the therapist and the client to perform activities together. The findings showed how during the activities, both the clients and the therapists shared their experiences and the situation became transparent, which seemed to increase the clients’ understanding of their progress in the intervention. Performing activities seemed to be a prerequisite to integrating strategies in everyday life and a central aspect of the integration process in which the clients interact, have bodily experiences and reflect on their actions (8,

9, 67, 126). The findings indicate that performing activities together with the therapist seems to enable the clients to act as agents in daily activities and contribute to change. This is in accordance with Nyman et al (35) describing how occupations that are undertaken together with others have the power to enable change. An essential step for change is exploring doing things with altered performance capacity where the client is trying new ways of doing and examining the possibilities for occupational participation in one's context (1). The findings showed how the strategies of sharing and transparency during the activities created collaboration between the clients and the therapists and enabled the clients to explore and gain experience, which increased the awareness of disability. Using activities supports rediscovering the body and its potentially different capabilities, which is also a prerequisite to learning how to solve problems (8, 127). The findings indicate that performing activities together with the therapist is a necessary component in a client-centred ADL intervention and the collaboration during these activities should represent the strategies sharing and transparency in order to contribute to a positive change.

5.4.1.4 The client as the owner of the therapeutic process

The findings of Study III and IV indicate that the CADL enables a sense of agency in clients and makes them feel as the owners of the therapeutic process. Previous research (1, 18, 120, 128-130) has highlighted the importance of applying a client-centred approach and inviting clients as active partners in the rehabilitation. However, previous research has also described challenges in handing over the power to the clients, which is in accordance with the findings of Study III and IV. In the findings, constant sharing and transparency during the intervention seemed to enable the clients to understand the importance of their own achievement and positive attitude for creating a change in the CADL and for enacting agency in daily activities and participation in everyday life. According to Kielhofner (1), it is through experiences that people generate images of how effective they are in using their capacities. The shared and transparent therapeutic process represented a constant sharing of experiences, which suggests increasing the clients' awareness and understanding of their situation and seemed to be very important for their attitude.

The clients acting as agents has also shown to influence the significant others where a transfer of learning from the CADL to everyday life situations was shared with the significant others (71). A possible gain would be that the significant other would experience a lower caregiver burden if the client experienced the ownership of his/her daily activities and therapeutic process. This was an underlying assumption in the RCT in which the new client-centred ADL intervention was evaluated in both Study I and in Bertilsson et al's study (109).

5.5 METHODOLOGICAL CONSIDERATIONS

Recommendations when evaluating complex interventions (83) are to conduct both quantitative and qualitative studies, and according to the CONSORT (90), non-pharmacological intervention studies should include qualitative investigations along with clinical trials. Quantitative and qualitative methods complement each, offering a form of

triangulation (131), which is in accordance with the applied methods of this thesis. The use of different methods provided unique knowledge of a client-centred ADL intervention from different perspectives; effect-evaluation of the intervention, an understanding of clients' experiences of participating in the intervention and OTs' experiences of applying the intervention in clinical practice.

5.5.1 Methodological considerations in Study I and II

The overall strength of the project (LAS-II) the RCT design, performed as recommended in the CONSORT statement (90). The RCT is a rigorous trial design and considered the gold standard when evaluating interventions (132). A power calculation on the primary outcome for Study I and II was performed, which is a strength. Other strengths in the present project were that the intervention was conducted in both in-patient and outpatient rehabilitation units, urban versus rural and in three different counties. The units were randomized to provide CADL or UADL, instead of individual randomization. Randomization of units was a conscious choice in order to avoid the risk of contamination (132) and based on the findings in a preceding pilot study (16) where individuals in the same unit were randomized to receive different interventions. Blinding of the data collectors and statisticians on the kind of intervention a particular rehabilitation unit provided or the intervention that the individuals received were also the strengths of the present RCT (132). In addition, the data collectors did their utmost to collect data from the same participant over time in order to provide continuity in follow-up with the participants.

Self-reported instruments with a patient-perspective were used. This is a strength in a client-centred ADL intervention where the clients' experiences are the point of departure. Another consideration of using self-reported instruments could be that the person will have increased awareness of his/her situation when answering the questions. On the other hand, the use of self-reported instruments for people with stroke can also be seen as a limitation if the person lacks awareness. Furthermore, the instruments are frequently used in research; their reliability and validity have been tested which is a strength. There is a limitation concerning inter-rater and test-retest for the data collectors in Study I and II; no test was performed but regular meetings including practice on how to measure and the discussions between the data collectors and researchers were carried out (132).

In an RCT, the choice of outcomes could be a limitation if they do not capture the effects of the intervention. Evaluation of a complex intervention is complicated. When evaluating complex interventions, it is preferable to have a single primary outcome and a small number of secondary outcomes (83). In complex interventions, there are several variable components within the intervention, which possibly result in a number of outcomes, thus making it difficult to use an RCT with a single primary outcome (133). It might be that a complex intervention affects several outcomes of small magnitude. The use of RCT designs for the evaluation of complex interventions has been questioned; Redfern et al (134) advocate instead the use of observational and quasi-experimental studies.

In Study I and II, an intention-to-treat analysis was employed, which is a forte (135); the aim was to avoid various misleading artefacts that can arise over time in a longitudinal design, such as attrition (132, 136). All statistical analyses (Study I and II) included covariates in order to accommodate for factors that could affect the outcome.

5.5.2 Study sample

In complex interventions, there is a need to gain knowledge for whom the intervention will work for. Eligible to participate in the CADL were persons with stroke who were dependent in at least two daily activities and who were referred to a rehabilitation unit no more than 3 months after injury. The significant others were included in order to gain knowledge of how the intervention affected them, and not increase their burden.

The OTs recruited people with stroke to the RCT and we cannot completely eliminate the possibility that some OTs did not strictly select all consecutive eligible clients. Therefore, the recruitment bias could not be entirely excluded, however using an RCT design it would be the same for both groups. One strong point though was that the researchers contacted both the CADL and the UADL OTs on a regular basis to remind them of the inclusion criteria and to monitor the fidelity to the CADL manual for OTs who provided CADL.

5.5.3 Methodological considerations in Study III and IV

In this thesis, qualitative methods were used for two of the studies: Empirical Phenomenological Psychological method (107) and Grounded Theory (104, 106). Both the clients' (Study III) and the OTs' (Study IV) perspective on the experiences of the CADL were analysed through different methodological approaches and frames of references. In Study III, the EPP method (107) was chosen to understand the meaning of participating in the CADL, and in Study IV, GT (104) was chosen to understand the processes when applying the CADL in clinical practice. Charmaz (104) uses an interpretative approach intended to understand experiences, which means that the approach has some similarities with the phenomenological approach used in Study III.

The use of the phenomenological approach (107) was chosen to understand the clients' lived experiences and the meaning of participating in the CADL (Study III). Two interviews were conducted with all the participants/clients in order to build a relationship between the researchers and the clients and in turn, to be able to understand the clients' lived experiences. However, two researchers conducted the interviews, which could be considered as both a weakness and strength. Both the researchers used the same interview guide but they perhaps had different approaches on conducting interviews and following up with questions which could affect the findings (105). A strong point is that although there were two researchers involved, they were able to find general characteristics across the participants, which could have strengthened the validity. Another strength was that the same researcher conducted both the interviews for the same participant, which might contribute to a sphere of safety where the participant could share his/her experiences and feelings (105). In the EPP method, the

researcher is supposed to bracket all the theories and his/her pre-understanding during the analysis. The researcher should just focus on what is manifested in the data in order to understand the original lifeworld experience by using empathetic understanding, which can strengthen the validity of the interpretations. As the analysis of Study III was conducted after the analysis of Study IV, the author needed to be more aware of the recommendations concerning bracketing theories and pre-understanding. Another criterion to achieve trustworthiness was when the researcher went back and forth between the researcher's interpretations and the participants' original interview protocol (raw data) during the entire analytic process.

The use of the grounded theory approach (104, 106) was chosen to understand the OTs' processes of applying the CADL in clinical practice (Study IV). A longitudinal design was chosen in Study IV, which is a valuable design when studying processes (137). This approach has proved to be valuable when studying the actions across time in different places and people; this was useful in Study IV where six OTs were followed during one year. In GT, the researchers can employ other theories (e.g. the therapeutic use of self in Study IV), whereby they ground or conceptualize emerging categories during the coding process. Since the same researcher conducted all the interviews during the longitudinal design, it led to an environment where the participants felt safe to share their experiences and feelings (105). One possible limitation was that the Study IV was mainly based on the OTs' stories of their work which might have influenced their trustworthiness. Use the observations of all data collection sessions might have been one forte.

5.5.4 Generalizability of the findings from the studies

When evaluating complex interventions, it is important to combine a variety of methods (83), which in this thesis has resulted in new knowledge of the effects, experiences and the meaning of a client-centred ADL intervention.

The results can be generalized to people with stroke who need rehabilitation. In the qualitative studies (Study III and IV), the findings cannot be generalized to all clients with stroke who received the CADL and to all OTs who performed the CADL. In Study III, only clients from the CADL group were included, which means that we do not know if the characteristics of the studied phenomenon could have appeared without an enhanced client-centred approach. In Study IV, only the OTs who applied the CADL were included and we do not know if the phenomenon could occur even if they had not received special training in an enhanced client-centred approach. The aim was not to generalize the findings from the qualitative studies to a larger group of people rather the aim was to increase the understanding of the meaning of participating in the CADL and the process of applying CADL, which could be integrated in the development and implementation of strategies for occupational therapy interventions in specific and general rehabilitation.

An important point for consideration is that participating in interviews where participants are encouraged to express their experiences may influence their reflections of the studied

phenomenon. However, the participants themselves are the experts and can contribute in increasing the knowledge of a client-centred ADL intervention through a qualitative approach (131).

5.5.5 Ethical considerations

The four studies in the thesis were approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2009/727-31/1, 2010 2027-32, 2010 545-32). Registration of the RCT was made to announce that the trial started was performed in Clinical trial.gov identifier: NCT0 1417585.

Possible ethical dilemmas in conducting an RCT could be that the participants who did not receive the intervention they preferred, could feel that they did not get the best available intervention. However, the participants were given the same intervention as other participants at the same rehabilitation unit included in the study; only one intervention was conducted at each unit. During the data collection in the RCT, the participants might have felt sadness and anxiety when they were invited to answer and express their experience of the current life situation after stroke. Although, my own experience of data collection in RCT and experiences of collecting data for Study III and IV was that most participants expressed gratitude and appreciation for the opportunity to share their experience if they could be useful for others in similar situations. The possibility to reflect on their situation could facilitate their self-awareness and re-orientation to a new everyday life after stroke.

5.6 CONCLUSION AND CLINICAL IMPLICATIONS

The findings in this thesis confirm the importance of applying a client-centred approach in health care rehabilitation and rehabilitation after stroke, which is in accordance with the Swedish Health Care legislation and National guidelines for stroke. The results indicate that in order to develop and implement a client-centred approach where the client's lived experience is the basis in clinical practice, training and practice of the approach is needed. However, to truly integrate the intervention into daily work, the training and practice of the intervention should be spread out over a longer period of time.

The findings also indicate that the way in which the strategies of sharing and transparency are used to co-create is the necessary condition to develop an effective client-centred intervention/rehabilitation. The therapists should use their therapeutic use of self in order to constantly share experiences with the clients throughout the intervention. This process of constant sharing in turn leads to transparency to the clients, which increases their understanding and awareness of their situation. Included in the therapeutic process of sharing and transparency is a shared therapeutic alliance with the client, which is necessary to create in order to bring about a change in the therapeutic process.

Another clinical implication of the findings is that the therapist in clinical practice should invite the clients in a shared goal setting. The client's goals should be shared with the client;

the sharing of goals helps in making the intervention transparent and visible. Transparency benefits both the therapist and the clients to follow the therapeutic process.

The findings also highlight the importance of the therapists performing activities together with the clients. Collaboration was created by practicing activities together where the sharing of experiences contributed to transparency, which further led to a positive change in the therapeutic process.

5.7 FUTURE STUDIES

The findings in this thesis suggest that the strategies in the client-centred approach can be generic and can be used by different disciplines in health care rehabilitation. However, there is a need for further research regarding how a client-centred approach could work within an inter-professional team and how that could affect people with stroke and their significant others.

The aim of the CADL was to enable agency in daily activities and participation in everyday life. In the results, no significant differences in the primary outcome were present during one year. The outcome of participation is an outcome that we believe shows an effect over time. Therefore, a follow-up after five years from inclusion in the RCT can contribute to an increased knowledge of the effects of a client-centred ADL intervention.

In this thesis, both the qualitative studies were conducted in the CADL group. Study III was done with the clients with respect to their participation in the CADL and Study IV with the therapists performing CADL during a year. A possible qualitative study that is identified and needed to be conducted in the future is using a longitudinal approach to follow the clients in order to understand whether the CADL has been integrated into the client's everyday life after stroke. Another possible future study would be to complement the interviews in the data collection with the observations of the therapists who provided CADL, in order to follow how they work in clinical practice. Using both the interviews and observations, a clearer picture of the therapeutic strategies used could be provided. Other future qualitative studies are to follow the people with stroke receiving the UADL and the therapist performing the UADL in order to get a better understanding of the usual ADL intervention.

Furthermore, the combined findings of Study III and IV contribute to an increased understanding of a client-centred ADL intervention from both the client's and the therapist's perspective. To further enhance the understanding, a future study would be to follow both the therapists and the clients in their interactions with each other in order to get a different view of the same situation.

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