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Recapturing self-care after stroke or spinal cord injury

Exploration of experiences and
evaluation of a client-centred
intervention

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ABSTRACT

After stroke or spinal cord injury a person's lived body and life-world commonly change, and suddenly taken-for-granted occupations such as self-care become difficult to perform. This can be a great challenge to living an independent everyday life. In order to enable performance of self-care, occupational therapists commonly initiate self-care training in the early phase of rehabilitation. However there is a lack of well-defined self-care interventions evaluated in research.

The general aim of this thesis was to describe the occupational therapists' experiences of self-care training and the clients' experiences of recapturing self-care after a stroke or a spinal cord injury as well as in close collaboration with occupational therapists to develop a new client-centred self-care intervention for evaluating the effect of this intervention in a randomized control trial (RCT) pilot study.

This research project comprises four studies concerning the recapturing of self-care in a rehabilitation setting during the early phase of rehabilitation (the first week to three months) after a stroke or a spinal cord injury. The project used both qualitative methods (Study I-III) and quantitative methods (Study IV). Study I described what characterized the phenomenon of self-care training from 12 occupational therapists' viewpoints. Study II identified the lived experiences of recapturing self-care, and Study III the meaning of context in the recapturing processes of 11 persons with stroke or spinal cord injury. Studies I-III are based on interviews and analyzed using the Empirical Phenomenological Psychological (EPP) method, aimed at describing the essence, structure and character of the studied phenomenon based on the participants' lived experiences. In Pilot Study IV the aim was to evaluate the effect of client-centred self-care intervention (CCSCI) on (i) activities of daily living (ADL) and life satisfaction in persons with stroke, (ii) caregiver burden, use of informal care and home-help services, and (iii) the feasibility of the RCT study design. Forty persons with stroke were included (Intervention Group (IG) n=19, Control Group (CG) n=21), as well as their significant others (n=16).

Study I identified eight therapeutic strategies used by all the occupational therapists to support their clients in taking control of their self-care and their lives again. Study II identified four main characteristics that were presented in all the participants' lived experiences: a) becoming familiar with the new body, b) recapturing self-care through trying, c) reclaiming control, and d) feeling uncertainty in the continued process of recapturing self-care. Study III identified six main characteristics of the meaning of context in recapturing self-care: a) support from others, b) expectations in the air, c) extended time, d) new daily structure, e) therapeutic relationship enabling possibility, and f) gradual change in challenge. The main characteristics described in Studies II and III seemed to be prerequisites for the recapture of self-care after stroke or spinal cord injury. Study IV did not show any statistically significant differences between the two groups in outcomes at the three-month follow-up. Comparing clinically significant improvements in ADL on an individual level, 13 out of 14 (93%) participants improved in ADL in the IG, and 12 out of 19 participants (63%) in the CG. The CCSCI appears promising for the recapture of self-care. The feasibility of study design and methods were, in general, favourable for a larger RCT.

In conclusion, this research project identified the lived experience and the meaning of recapturing self-care after stroke or spinal cord injury. It can increase the understanding of these phenomena among rehabilitation professionals such as occupational therapists. A well-defined and research-based self-care intervention was developed and evaluated in collaboration between the researcher and occupational therapists. The findings from Studies I-III were integrated in the new CCSCI, evaluated in Study IV. This approach of integrating qualitative studies in a new and well-defined intervention can be viewed as a model for how to implement research into practice, which has been shown to be a challenge in the area of health care.

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
AOTA	American Occupational Therapy Association
BI	Barthel Index
CAOT	Canadian Association of Occupational Therapists
CCSCI	Client-Centred Self-Care Intervention
CG	Control Group
COPM	Canadian Occupational Performance Measure
EPP method	Empirical Phenomenological Psychological method
FAI	Frenchay Activities Index
FIM	Functional Independence Measure
I-ADL	Instrumental-ADL
ICF	International Classification of Functioning, disability and health
IG	Intervention Group
LiSat-11	Life Satisfaction scale 11
MMSE	Mini Mental State Examination
MoHO	Model of Human Occupation
MU	Meaning Units
OT	Occupational Therapist
P-ADL	Personal-ADL
RCT	Randomised Controlled Trial
SCI	Spinal Cord Injury
SIS	Stoke Impact Scale
WHO	World Health Organization

LIST OF PUBLICATIONS

This thesis is based on following papers, which will be referred to the text by their Roman numerals:

- I. Guidetti, S., & Tham, K. (2002). Therapeutic strategies used by occupational therapists in self-care training: A qualitative study. *Occupational Therapy International*, 9, 4, 257-276.
- II. Guidetti, S., Asaba, E., & Tham, K. (2007). The Lived Experiences of Recapturing Self-Care. *American Journal of Occupational Therapy*, 61, 303-310.
- III. Guidetti, S., Asaba, E., & Tham, K. The meaning of context in recapturing self-care after stroke or spinal cord injury. Submitted.
- IV. Guidetti, S., Andersson, K., Andersson, M., Tham, K., & von Koch, L. Client-centred self-care intervention after stroke - a randomised, controlled pilot study. Submitted.

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PROLOGUE

Self-care first caught my interest in 1980, when I started working as an occupational therapist at a medical unit in Karolinska University Hospital in Stockholm. Stroke patients over 65 years old came to the medical wards and I was expected to do self-care assessments. I saw the need of training and could sometimes begin, but I felt that the treatment plans were inadequate, primarily due to a lack of time. During this time I had the opportunity to carry out a study evaluating the effect of personal-care training (Söderback & Guidetti, 1992). I searched for descriptions of self-care programmes, but most of the research I found described assessment of self-care or training with only vague descriptions of what kind, or of how it was done. In my eagerness to carry out the study by training 20 patients, I left out my descriptions of what I actually did. One of the patients was a man with post-polio syndrome. He helped me to understand that self-care training was not the most important or most healing for him. In conducting this study we met every morning to train with a sock puller to give him more independence in his self-care. After two weeks he said:

“Susanne, I know how important this study is to you and I would really like to help you to do this. But every morning after our struggle with the sock puller, I’m so exhausted that I have no energy to do anything else. I must go to bed again instead of doing what I really would like to do, which is to wheel myself in my wheelchair to the hospital library.”

At that point I had a change in thinking. Even though I still was convinced of the importance of self-care activity, the interaction with this man changed my perspective.

Some years later, I was involved in another ADL project, assessing persons with wheelchairs and adapted clothing (Kratz et al., 1997). This project gave me an understanding of the meaning of choosing activities, and of the ability to wear the right clothes. Then my Masters project in Kenya, planned in line with my first study but in quite a different context, gave me an additional perspective on self-care when confronting the reality that there were 70 patients in each ward sharing one shower. This plan ended up at the outpatient clinic with a lot of children in need of training and of developing independence. I met a lot of scepticism from colleagues and others about whether the children really found this fun. I obtained a deeper knowledge of the phenomenon of self-care and its meaning. The children appreciated being given some attention. They started to pull on their clothes as soon as we met; it seemed as they wanted to show how talented they were. We often worked without a spoken language, but the self-care activity seemed to be so obvious for the children who had seen their parents and siblings doing these things. This case study (Guidetti & Söderback 2001) convinced me that self-care was an important activity for personal development and for self-confidence. Some children did not develop their dressing abilities, but one little girl started to stand without support; there the training may have led to her daring to test her body more. All of these interactions and experiences increased my interest in what occupational therapists do when conducting self-care training, and in what is important in self-care from a client-centred perspective. My journey in self-care ended up as the inspiration for this research project.

INTRODUCTION

This thesis will focus on the lived experiences of recapturing self-care after stroke or spinal cord injury, and the meaning of context during this process. The intention has also been to develop and evaluate a new client-centred self-care intervention (CCSCI) (Study IV) in close collaboration with occupational therapists, based on the qualitative studies (Studies I, II, III). After a major life-course disruption like having a stroke or spinal cord injury, there is often a need to regain the occupations previously taken for granted, such as self-care. Some persons have the neurological capacity to improve their reduced ability, while other clients will need to learn new strategies in order to compensate for their neurological impairments. Furthermore, the physical and social environments often need to be modified to further support the person's performance of self-care activities (Gray, 1998; Fisher, 1998; Trombly, 1995). The self-care intervention is considered to be essential for the clients' "way back" to an active life (Chiou & Burnett, 1985; Giles, Ridley, Dill & Frye, 1997; Law, 1993).

The term recapturing denotes a process of engaging and regaining abilities in order to participate in self-care activities; in the case of this thesis, the recapture of self-care was a central concern. In order to study recapturing self-care in a rehabilitation context, two main perspectives were used in this research project. First, based on an occupational perspective, occupation is viewed as a basic human need and as something that gives personal meaning to everyday experiences (Meyer, 1922; Kielhofner, 2008). Self-care is an example of occupation (Townsend & Polatajko, 2007). The person's experiences and values of the different activities included in self-care (Canadian Association of Occupational Therapists (CAOT), 1997; Law, 2002; Wilcock, 2006) are important and restrictions on occupational participation influence the person and his/her significant others in their daily lives (Laliberte Rudman, Herbert & Reid, 2006). Self-care occurs in a context of time, space, society and culture (Kielhofner, 2008). The second perspective, critical to this thesis, is based in phenomenology, aiming to describe how a phenomenon (i.e. recapturing self-care) is presented in the experiences of the occupational therapists conducting self-care training (Study I), as well as the lived experiences of persons living with stroke or spinal cord injury (Studies II and III).

In the following chapter, I will try to clarify how occupation and self-care are conceptualised in the literature and how these concepts relate to the different studies in this research project. Moreover, I will place these concepts in relation to phenomenology and other relevant theoretical frame of references.

Self-care as occupation

My work as an occupational therapist has been influenced by the Model of Human Occupation (MoHO) (Kielhofner, 1995, 2002, 2008). Kielhofner defines the concept of human occupation as the doing of work, play and activities of daily living within a temporal, physical and social context that characterises much of human life. Occupational therapists use the term occupation to systematise and characterise the profession's area of concern. Many of the activities that a person performs every day fall into the "taken-for-granted" activities (Husserl 1970/1936). When something new and unexpected occurs in life, for example after stroke or a spinal cord injury, the person starts to reflect on the performance of daily activities commonly performed autonomously. The life-world (Husserl 1970/1936) has suddenly changed and cannot be taken for granted anymore (Bengtsson, 2001). Wilcock's (1998) description of occupation situates self-care activities as a "natural human phenomenon" that is taken for granted because it forms "the fabric of everyday lives", while Crepeau (2003) asserts that occupations are daily activities providing structure to daily living and meaning for people. These two descriptions of occupation linked to self-care make it explicit that self-care can be viewed both as activities taken for granted and as activities that give structure and meaning to people, something which is a prerequisite for life itself (Kielhofner, 2008).

Whereas health and illness are often viewed in terms of damage to mind and/or body, an occupational perspective on illness shifts the focus from mind and body to the person's ability to carry out and engage in daily occupations (Molineux, 2004). Occupation is, however, not a singular concept, but rather something that can be better understood when viewed from a few different theoretical and philosophical traditions, albeit with unifying characteristics. Occupational therapists working with clients to promote engagement in occupation arguably take into account different types of activities that might engage the client. According to the literature, these activities are categorised and defined in different ways (Fisher, 2003; Townsend & Polatajko, 2007; Kielhofner, 2008).

Occupation can be defined as: "*groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)*" (CAOT, 1997, p. 34)

The above CAOT definition of occupation places an emphasis on a client-centred perspective, which has been an important perspective in this research project. For instance, within the

CAOT definition of occupation, self-care is defined as an activity given meaning and value by the person. This is in keeping with the focus that has been placed on the individual's lived experiences in this research project. However, within the aforementioned definition of occupation, the concept of context is weakly addressed. Another definition has, therefore, also been drawn upon: "*Occupation is understood as culturally defined and individually valued activities that humans performed on a daily basis over the course of their lives in such environments as home, work, and school, as well as leisure venues.*"

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(www.ki.se/ki/jsp/polopoly.jsp?d=7994&a=15087&l=sv)

According to these definitions, self-care can be viewed as occupation. Polatajko (2004) and Zimmerman and colleagues (2006) have developed the taxonomic Code of Occupational Performance (TCOP) (Townsend & Polatajko, 2007 p.19), which is thought to be applicable in this research project. The TCOP defines an *occupation* as "*an activity or a set of activities that is performed with some consistency and regularity that brings structure and is given values and meaning by individuals and a culture.*" In the taxonomy, *Activity* is defined as, "*a set of tasks, with a specific end point or outcome that is greater than that of any constituent task,*" and *Task* as, "*a set of actions having an end point or a specific outcome.*" From the TCOP perspective, self-care is an occupation including activities such as dressing, including tasks such as putting on socks. In fact, according to the CAOT, self-care has been characterised as occupations of looking after oneself, including personal-care, personal responsibilities, functional mobility and the organisation of personal space and time (CAOT, 1997). Thus self-care is commonly used to refer to the basic activities performed on a daily basis (Christiansen, 1994; Christiansen & Ottenbacher, 1998), in other words Activities of Daily Living (ADL). ADL are commonly divided into personal-ADL (P-ADL) and instrumental-ADL (I-ADL) (Fisher, 1998; Törnquist, 1995). In occupational therapy, the term ADL commonly refers to P-ADL including toileting, bathing, dressing, eating and grooming, which is in line with how the TCOP (Townsend & Polatajko, 2007) defines the activities included in self-care, viewed as an occupation, the definition referred to in this thesis.

Self-care and occupational performance

In this thesis, the focus is on the performance of self-care activities and the terms doing and performing are used throughout. A basic assumption in occupational therapy and occupational science is that experiences from doing occupations may contribute to development. Wilcock

(2006) concluded that to participate in everyday life is a vital part of the person's lived experiences and development (Wilcock, 2006). Kielhofner, Tham, Baz and Hutson (2008) stated: "*Learning to do something means that we must grasp the experience – learn how it feels,*" (p 73) which is in line with Merleau-Ponty (2002/1945), who stressed that we learn new things by having bodily experiences of doing. Law (2002) adds that, by participating in occupations, persons acquire skills and competency; connect with others as well as find purpose and meaning in life.

Another assumption shared by several theorists in occupational therapy and occupational science is that people derive meaning from what they do (Hasselkus, 2002; Kielhofner, 2008; Law, 2002; Wilcock, 2006) such as getting dressed, in the clothes that they want to wear, and that might give meaning to the doing or performance. Occupational performance can be viewed as a complex set of interactions between the person and his/her environment (Kielhofner, 2008). In self-care situations, the environment provides the context for the performance and can give opportunities, limits, challenges and important physical and social support (Fisher, 2003). The definition of occupational performance used here is:

"Occupational performance refers to the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age-appropriate for looking after oneself, enjoying life and contributing to the social and economic fabric of a community" (CAOT, 2002, p.30)

When performing occupations, a person's engagement is not only related to the doing of, for example, self-care; engagement also implies choices, motivations, and meanings (AOTA, 2002). Engagement in occupation as the focus of occupational therapy intervention involves both subjective experiences and objective (physically observable and mental components) aspects of performance (AOTA, 2002; Kielhofner et al., 2008). According to Kielhofner and colleagues (2008), the person's lived experiences might offer a unique way of conceptualising subjective experiences and by giving attention to these subjective experiences may lead to an understanding of the person's performance capacity.

Another aspect of performing occupations such as self-care is that doing tells us who we are and, thus, has implications for future choices of occupations to participate in and how our life will be orchestrated (Hasselkus, 2002). Especially in the Western cultures, persons frequently identify themselves and each other by what they do (Asaba, 2005). Doing self-care activities

is a part of life, as self-care activities are closely linked to the self and the body. It is through occupations that people demonstrate who they are or what they hope to be (Asaba, 2005; Wilcock, 1998) and through doing the person will be and becoming (Wilcock, 2006).

Phenomenology

It might be difficult to understand the lived experience of disability and the loss of activity that is often the case after a stroke or spinal cord injury. In a rehabilitation setting, occupational therapists need to meet their clients in their changing life-worlds and the findings of research using a phenomenological approach can guide the occupational therapist's understanding of the lived experience of disability (Kvigne, Gjengedal & Kirkevold, 2002; Tham, Borell & Gustavsson, 2000). Barber (2004) states that phenomenology is useful in understanding occupation because it is common for persons to take things and activities for granted when engaging in daily activities and in these activities they do not reflect much on the meaning of occupation. The researcher goes beyond the situation described by the person in order to reveal the underlying meaning of the experiences (Karlsson, 1993). This is in accordance with the perspective used in this thesis. Three of the studies in this thesis (Studies I, II, III) use the Empirical Phenomenological Psychological method (EPP method) (Karlsson, 1993) and focus on recapturing self-care from a life-world perspective. In phenomenological research, descriptions of a person's spontaneous experiences are systematically analysed in order to identify the meaning structure, i.e. the essential characteristics of a certain phenomenon such as recapturing self-care (Studies II, III). The phenomenological perspective used in this thesis is mainly based on the philosophies of Husserl (1970/1936) and Merleau-Ponty (2002/1945).

In the following, I will present Husserl's and Merleau-Ponty's definitions of life-world and the lived body to clarify my phenomenological perspective and the justification for using this approach in this research project. *Imaging*

- Getting out of bed this morning, maybe in a hurry, just running into the bathroom and within the next five minutes you are on your bike.

During this sequence, a lot of self-care activities are performed without reflecting on how and what to do and usually the body disappears in the doing (Kielhofner et al., 2008). Before an event like a stroke, the self-care activities were just there, performed without reflection, automatically, but after a stroke the whole life-world has changed. The body feels different

and doesn't work properly and the self-care activities cannot be taken for granted anymore (Kielhofner et al., 2008). It is not until something unexpected occurs that the person starts to reflect on the doing and to be aware of his/her body. Merleau-Ponty (2002/1945, pp 94-95) says: "*I'm conscious of the body through the world*". Keeping in mind these activities as being taken for granted may make it easier to understand aspects of human occupation such as self-care (Kielhofner et al., 2008).

Phenomenology, which originates from the philosopher Edmund Husserl (1859-1938), intends to analyse the essence of the studied phenomenon. The word "*phenomenon*" comes from Greek and means: "*that which appears*" (Barber, 2004). Husserl clarifies the importance of exploring "*things as they present themselves to us*" instead of setting principles where the reality is already set (Husserl, 1970/1936). The "*things*" are the studied objects and could be logical objects, feelings, cultural objects or social institutions (Bengtsson, 2001) or, as in this thesis, the recapturing of self-care. The person's experiences give access to the "*thing*." In order to be able to examine the clients' perspective of recapturing self-care, Studies II and III needed to start in the person's lived experiences of performing activities. By using a phenomenological approach in occupational therapy research, one can describe how actors (in this research project, the person who had had a stroke or a spinal cord injury and the occupational therapists) experience an action and what that action means to the actor (Barber, 2004). Therefore, by studying the person's lived experiences, the researcher gains access to the phenomenon itself (i.e., how the phenomenon presents itself in the lived experiences).

The concept of life-world

Husserl (1970/1936) developed the concept of life-world and, according to him, the individualised life-world is obvious and concrete, subjective and taken for granted in our daily lives without its existence being questioned. The life-world is a social world, in which people live, communicate with and understand each other. The life-world, according to Husserl, focuses on the person's experiences in daily life. Therefore, the understanding and the awareness of the world might be viewed differently by different persons. But the life-world is also an historical (Husserl, 1970/1936) world due to experiences, where new experience is compared with the old experiences and connected to the future and, by that, the experiences are intertwined with historical time. Husserl (1970/1936) states that each experience has its own horizons and people experience their worlds upon these horizons. The horizons are not

static; instead the horizons develop and move in relation to the people's experiences.

Merleau-Ponty (2002/1945) links these horizons to the person's experiences of time and space: "*I am neither in space nor time, nor do I conceive space or time. I belong to them and my body combines with them and includes them.*" (p.162)

Merleau-Ponty (2002/1945) states that time is an ongoing movement of past, present and future as "*the past is the former future and a recent present; the present an impending past and recent future; the future a present and even a past to come*" (p 488). Hammel (2007 b) outlined the importance of reconnecting past and future lives together with past and present lives, such as after a spinal cord injury. This view is in line with the occupational perspective as the way persons occupy their time is related to the concept of occupation (Christiansen & Townsend, 2004; Kielhofner, 2008). To understand how persons with stroke or spinal cord injury experience the meaning of context, time and space cannot be overlooked.

Intentionality is a central concept in Husserl's phenomenology and refers to the relationship between the subject and the object, or the event of the person's experiences (Husserl, 1970/1936). According to Dahlberg, Drew and Nyström (2001), there is always an intentional relationship with the things that make up daily lives, when the persons (i.e., subjects) perceive and understand the meaning of things they relate to activities and places that belong to and signify their worlds (Dahlberg et al., 2001). Merleau-Ponty (2002/1945) states that the subjects' consciousness is consciousness of something and is always directed toward an object. The thing is always experienced as something – things have a meaning for the persons and, without a meaning, things would not be what they actually are. For example, the bike for me is a meaningful thing because I use the bike to transport myself. But without knowing how to ride a bike, this thing would probably be a "meaningless" object for me.

The concept of the lived body

Maurice Merleau-Ponty (2002/1945) built on Husserl's life-world concept and introduced a new dimension of the "*lived body*." The life-world for Merleau-Ponty is also the lived world which people have access to through their bodies (Dahlberg et al., 2001). According to Merleau-Ponty (2002/1945), the body itself is the ground for a person's life world and it is through the body that a person perceives the world. He stated that the person "is" the body and one cannot separate the life-world from the body; he emphasises the importance of the lived body as a point of departure for the life-world. The body is viewed as the intentional subject

that is always present in a person's everyday occupations and that is also the starting point from which people act and grasp their life worlds. The body is not usually seen as a separate object; instead, the body is lived or experienced in immediate connection with the environment.

Knowing is created by experiences linked to each other and the body in everyday occupation (Kielhofner et al., 2008) and when persons develop understanding and knowledge, the knowledge is embodied (Dahlberg et al., 2001). The body as a whole is the point of departure for how people apprehend and know how to do things. "*The body is the existential medium of knowing*" (Kielhofner et al., 2008, p. 72). For example, when learning how to ride a bike, you have to take into consideration every movement and even the environment; using maximum concentration is necessary. Then suddenly the knowing of how to ride the bike is there, the act of riding it has become so incorporated in the body that there is no need to think about how to do it anymore. The activities are needed to learn and the experiences are so integrated with the body and have become a part of the "*habit-body*". The body gives access to the world which means that each change in the body leads to a change in the world (Doolittle, 1992, 1994; Ellis-Hill, Payne & Ward, 2000; Kvigne & Kirkevold, 2003; Merleau-Ponty, 2002/1945). In the biomedical sciences, the body is traditionally studied from an outside perspective, the objective body (Kielhofner et al., 2008). But when studying the process of recapturing self-care, there is also a need to study the body from an inside perspective, the subjective body (Kielhofner et al., 2008).

Phenomenology and self-care

Self-care activities such as eating, dressing, and walking are necessary activities that are taken for granted, activities that are closely linked to a person's body and self. The person's lived body inhabits space and time (Merleau-Ponty, 2002/1945) when performing self-care. According to Seymour (1998), from a biomedical perspective, the body is often seen as predictable, measurable, universal and constant, collections of moving parts and processes which could be fixed by medical interventions if they faltered. Examination of a person's lived experiences of, for example, self-care may increase the understanding of what the activity means to the person him/herself (Barber, 2004), which can guide the intervention planning process. Furthermore, a critical examination of the occupational therapist's and client's "lived experience" of recapturing self-care, in this research project (Studies I, II &

III), can increase the understanding of how to define and further develop self-care intervention in the rehabilitation context.

Self-care is traditionally viewed as basic to humans and as goal-directed with the aim of maintaining, restoring or improving health and well-being (Söderhamn, 2000). The ability to carry out self-care is not, in itself, an essential means to sustain, restore or improve health and well-being but rather the potentiality for self-care activity as an integral part of the lived body. When searching the literature for this project I found that during the last few years there has been a growing interest in studying the lived experience of persons living with disabilities from a phenomenological point of view. When the first studies (Studies I and II) were conducted, the studies were mostly from the field of caring science. One phenomenological study has been found where the studied phenomenon had to do with the lived experiences of recapturing self-care (Clark & Rugg, 2005). There are many books and articles describing the lived experience of disability and there are examples of experiences of situations in daily activities, such as self-care, and of how these activities are taken for granted. There is, however, little or no literature using an occupational perspective which focuses on the process of recapturing self-care.

In two meta-analyses of qualitative studies in the area of spinal cord injury (Hammell, 2007a, b) it is argued that rehabilitation should not merely be about person's bodies. In this thesis, the lived body is seen as the point of departure for performing self-care (Merleau-Ponty, 2002/1945). The body is always there and is not something you can run away from; it is something you always take with you. There is little research on the nature of the experience of the body in the context of daily occupation (Kielhofner, 2008). Some studies have focused on the lived experience of daily occupation after stroke (Erikson, Karlsson, Borell & Tham, 2007; Tham et al., 2000).

There are a numbers of studies that illuminate the person's experiences after stroke (Kvigne & Kirkevold, 2003; McKevitt, Redfern, Mold & Wolfe 2004; Röding, Lindström, Malm & Öhman, 2003; Sisson, 1998) or spinal cord injury (Hammell, 2007b; Isaksson, Josephsson, Lexell & Skär, 2007; Sand, Karlberg & Kreuter, 2006) without a specific focus on occupation. In order for rehabilitation professionals to understand processes experienced by persons after a disability, studies such as those occupations put forth are needed. Cant (1997, p. 304) describing his experiences after stroke and after one year concludes, *"I now feel I am a*

modified version of the “me” that I used to know. Enforced change is frequently an unpleasant experience but, in my situation, I think I can learn to live with the new me”. In Cole’s (2004) book of narratives of living with spinal cord injury, one man described the necessity of caring for the self: *“Each person needs to explore his limits physically, with his new body as well as his mental need of support.... I am constantly finding new things and ways my body works.”* (Cole, 2004, p 265)

For the occupational therapist, there is also a need to understand the rehabilitation process from an occupational perspective. Within this field, the phenomenological studies have increased during recent years. Some of these studies have an occupational perspective, describing how daily activities are experienced by persons with acquired brain injury (Eriksson, 2007) or stroke (Kvigne & Kirkevold, 2003). Others describe some unfolding experiences by persons with specific impairment such as memory impairment (Erikson et al., 2007), unilateral neglect (Tham et al., 2000; Tham & Kielhofner, 2003) and visuospatial agnosia (Lampinen & Tham, 2003). In these studies there are some common patterns such as, for example, how the life-world is experienced as chaotic in the beginning after onset and that the body and daily activities are no longer taken for granted, which implies that these persons need to reflect on their bodies in their daily activities. A common pattern is also that, by having significant occupational experiences, these persons begin to discover and handle their daily activities

Autonomy, choice, control and independence

After a stroke or spinal cord injury, a person may feel a sense of loss with regard to both autonomy and control over the life situation. Even the sense of having choices and the opportunities of being able to act on the choices could be lost (Hammell, 2006). To have the chance to make choices seems to be closely linked to the feeling of control. When a person is challenged by disability, there is a sudden need to reflect on the performance of taken-for-granted activities such as self-care (Kielhofner et al., 2008). This need for reflection is not only a matter of practical necessity, but also representative of a process in which autonomy, independence, and choice must be considered. Cardol, De Jong and Ward (2002) stressed that the rehabilitation strategies should increase individual autonomy and participation in daily life in order to enable the ability to make decisions and act as one wishes. For instance, dressing

oneself is not only a mechanical set of actions, but is also imbued with choice and autonomy in acting upon one's choices.

Söder (1989) defined autonomy as the opportunity to be able to influence, choose, and make decisions that concern one's existence, even if each person's need for assistance might vary in accomplishing these choices and decisions. Cardol and colleagues (2002) note that autonomy is not a state of being, but is rather something individuals develop in the course of their lives. The concept of autonomy is often used to distinguish a person's independence in self-care activities from the person's opportunity to choose and make decisions concerning his/her own existence (Tamaru, McColl & Yamaski, 2007). Rogers (1982) outlined earlier that the requirements for independence are competence and autonomy, and that autonomy is reflected in the ability to make choices and have control over one's environment.

Söder's and Roger's views on autonomy are in agreement with occupational therapy principles, suggesting that rehabilitation should be more sensitive to the individual's experienced values of certain activities (Chiou & Burnett, 1985; Gray, 1998; Jongbloed, 1994; Law, 1993). Nilsson and colleagues (1997) explain it by saying that losing one's autonomy as a result of a stroke could inevitably mean becoming powerless in one's own body and powerless in relation to the surrounding world to a greater or lesser extent, thus becoming dependent on other people. After almost a lifetime of control of oneself and one's situation, it certainly feels unbearable to lose one's self-control and independence (Duggan & Dijkers, 1999). Frank and Elliott (1989) found that persons with spinal cord injuries who perceive themselves as having control over their lives, experience less psychological distress and less depression than persons who do not experience that they have a sense of control over their lives. The context for the studies included in this thesis is the first period of recapturing self-care after a stroke (Studies I, II, III & IV) or a spinal cord injury (Studies I, II & III). The facility to emphasise control over one's life with perceived quality of life supports a client-centred approach within occupational therapy (Law, Baptiste, & Mills, 1995), an approach that has been integrated into this research project.

In everyday life, most people are independent with regard to self-care. Within other domains of everyday life, most people are also interdependent, i.e. commuting to work using public transportation requires the indirect help of others. According to the *Oxford Advanced Learners Dictionary*, independence means "*the freedom to organise your own life, make your*

own decisions, etc., without needing help from other people” (2005). Being independent in self-care activities is an indicator for having a greater chance to live more or less independently in one’s own home, which is of importance for many persons (Wressle, Öberg & Henriksson, 1999). To become independent regarding self-care is also of importance for a person’s self-perceived sense of agency (i.e., the sense that they are the owner of their own actions and choices). In this way, the person needs to make a connection between his/her sense of independence and his/her ability to make choices, express intentions, and thereby affect his/her own situation through doing.

There is little research exploring how occupational therapists interpret the terms independence and dependence, and how these terms are used in relation to self-care within the rehabilitation settings. Brillhart and Johnson (1997) explored motivating factors for returning to an active life among persons with spinal cord injuries. Findings showed that independence and education were important factors contributing to motivation during the rehabilitation process. The individualised training for self-care agencies means that the abilities for performing self-care can enable clients to participate in and direct their own care. This supports the clients in becoming experts and advocates in their own self-care. The therapist’s vision of independence also influences how and what is planned during rehabilitation (Hammell 2006). Cole (2004), who discussed the perceptions of autonomy among people with spinal cord injury, stated: *“I’m independent. What does that mean?... We are all dependent. Those with spinal cord injury are no different to others. The concept of independence, meaning doing for your self, is misguided and simplistic and does enormous harm.... We are all mutually dependent, and we are some of us physically dependent on others and others are emotionally dependent on us.”* (Cole, p. 227)

In everyday life, people commonly are both independent and interdependent, which means dependent on others. Although interdependence literally means that all persons are dependent on one another, the concept is part of a more complex one. For instance, interdependence includes a notion of relationship between people that is fluid and based on changing contexts (Asaba, 2005; Kielhofner, 2008; Townsend & Polatajko, 2007). There have been some critical discussions on the concept of independence (Josephsson, 1994; Lilja, 2000). According to Lilja (2000), one could argue that it might be more valuable for a disabled person to be able to perform recreational and social activities rather than self-care activities. Rehabilitation should

be more sensitive to the individual's experienced evaluation of certain activities (Chiou & Burnett, 1985; Gray, 1998; Jongbloed, 1994; Law, 1993; Moulton, 1997).

Occupational choices are defined as decisions on commitments to enter an occupational role, acquire a new habit, or undertake a personal project (Kielhofner, 2008). In everyday life, persons make a lot of activity choices, such as choosing to drink a cup of coffee or to take a shower. Simply, people's choices of activities shape their present and future everyday lives. A stroke or a spinal cord injury can interfere with performance in such a way that extra time is required to do things. Alternatively, a person might need to make a series of choices to find new ways of performing self-care activities. People have choices and can exercise control over their lives, when they have opportunities to decide what they will do, to initiate activities at the time that suits the person in question and in the manner that the person has chosen is the essence of independence.

Contextual factors in self-care

Self-care activities are performed in close interactions between the person and his/her environment, and to understand the recapturing process of self-care there is a need to identify the meaning of context (Study III). Context refers to a variety of interrelated conditions within and surrounding a person that may influence the person's doing. Sometimes the context can provide performance and sometimes it can hinder performance. The persons' ways of understanding a new situation are not just about their own perceptions about what occurred for example after a stroke or spinal cord injury; they are also about the ideas and perceptions that are part of the social contexts in which people's everyday lives are carried out (Asaba, 2005). These contexts might be cultural, physical, social, personal, spiritual and temporal. Context may also include a time dimension and represents more than merely a generic social milieu or physical environment. In this research project, the term context refers to physical and social environments in a rehabilitation setting as well as the experienced life-world that the person inhabits one to three months after a stroke or a spinal cord injury. The context in Study IV includes the acute stroke unit, rehabilitation clinics and homes for the elderly. It is important for occupational therapists to understand all the factors that make up the total dynamics that affect the client's doing, thinking, and feeling in for example self-care intervention. In this thesis, the notion of context does not separate the person and the environment with regard to performing self-care. The notion of context is closely aligned with

concepts from the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as well as a phenomenological life-world perspective, which adds an important dimension needed to understand the complex and many-faceted meaning of context (i.e., the person's living space in which she/he acts). According to Rowles (1991) the experienced environment actually is the life-world.

The phenomenological perspective used in this thesis (Studies I, II and III) does not separate the person and the context. The life-world is conditional on the existence of a subject, who experiences, lives and acts in this life-world. The person's engagement within a life-world provides a culturally defined spatiotemporal setting or a horizon for daily lives (Rowles, 1991). By critically examining the person's life-world experiences in daily activities, the meaning of context can be identified and described (Tham & Kielhofner, 2003). The life-world is inter-subjective, which means that, basing our understanding on our own perceptions and experiences, we can understand the experience of other people (Merleau-Ponty 2002/1945). To enable occupational performance, it is often necessary to consider changes within the person's context (Kielhofner, 2008) by, for example, providing technical devices in the home setting or supporting significant others in how to handle the new situation in daily activities. Johansson (2003) concluded that an enriched environment for persons with stroke influences their rehabilitation and that an enriched environment may vary according to personality and earlier life experiences. Research has also shown that it may be more realistic to expect independence in daily activities to be achieved in a familiar environment (Erikson et al., 2007; Socialstyrelsen, 2005; von Koch, Widen Holmqvist, Wohlin Wottrich, Tham & de Pedro-Cuesta, 2000).

According to the ICF (WHO, 2001), a person's functioning and disability is understood as a dynamic interaction between health conditions (injuries, traumas, etc) and contextual factors. The contextual factors in a person's life situation comprise environmental factors (physical, social, attitudinal) and personal factors (an individual's background). Hammell (2007 a,b) noted the interrelationship between the resources of the environment and the ability both to engage in meaningful occupations and assume responsibility and control over one's life. There are barriers or facilitators (WHO, 2001). Participation involves the life situation and the lived experiences. In rehabilitation and for professionals working with persons after stroke or spinal cord injury, there is a need to understand the contextual aspects and incorporate them into the rehabilitation strategies (Wohlin Wottrich, 2006, 2007).

Occupational therapy interventions

In rehabilitation and in occupational therapy, there have been and still are different approaches for interventions such as self-care intervention. Christiansen (2000) described the remediation approach focusing on improving impaired functions, such as cognition or motor functions in contrast to the compensatory approach identifying new ways of performing activities with the remaining performance capacity by using compensatory strategies. The critique is that restoration of impaired functions itself is not necessary when enabling participation or occupational engagement, which is essential when using a client-centred approach (Fisher, 2003; Townsend & Polatajko 2007). This research project has an occupational perspective and is closely linked to a client-centred approach, focusing on recapturing self-care rather than on improving underlying functions (Townsend & Polatajko, 2007). The occupational perspective has been the guiding principle for developing the new client-centred self-care intervention utilised in Study IV.

Therapeutic use of occupation

Several theorists in occupational therapy describe how activities can be used as a therapeutic medium to enable the performance and engagement in occupations that the clients want and need to do in their everyday lives (Eriksson, 2007; Fisher, 1998; Kielhofner, 2008; Nelson, 1996; Trombly, 1995). It is emphasized that activities vary in importance according to how the individual chooses to form his/her life and the ability to perform activities is viewed as a multidimensional concept (Law, 1993). Activities that are relevant/ purposeful and meaningful for the person can be used as strategies or as goals in the intervention (Trombly, 1995; Rexroth, Fisher, Merritt & Gliner, 2005). How a person values his/her living after a spinal cord injury has been shown to be significant for the commitment to engage in personal meaningful occupation (Hammell, 2007a), which according to Law (2002) is vital for all humans. When using occupations in therapy the occupational therapists should understand the client's ability to perform the activity as well as evaluate and conduct the intervention on the basis of the client's volition and motivation to do and perform the activity (Fisher, 2003). In order to plan how occupations can be used in therapy, the first step in the evaluation procedure is to understand the client. The intervention should be tailored to fit the person's resources and goals, and provide specific training in the activities in which the person wants and needs to be engaged (Ma & Trombly, 2002; Trombly & Ma, 2002).

Law and colleagues (1991) concluded that the key concepts in client-centred practice were: individual autonomy and choice, partnership, the therapist's and the client's responsibility, enablement, contextual congruence, accessibility and respect for diversity. Clapton and Kendall (2002) added that rehabilitation providers need to create opportunities based on trust and informed relationship with their clients and gradually assist the clients to assume autonomous decision-making and action.

Studies have shown that occupational therapists use different therapeutic strategies (Booth Davidson, Winstanley, & Waters, 2001; Tham, Ginsburg, Fisher & Tegnér, 2001) such as, for example, giving structured instructions or feedback on specific client-identified activities or initiating adaptations within a familiar context to enable occupational performance (Trombly & Ma, 2002). Trombly, Randski, Trexel & Burnet-Smith (2002) noted that participation in goal-specific occupational therapy was associated with reaching self-identified goals and reducing disability. However, there are only a few phenomenological studies identifying the therapists' strategies (Gahnström-Strandqvist, Tham, Josephsson & Borell, 2000; Wohlin Wottrich, von Koch & Tham, 2007) and there is a lack of studies identifying the therapeutic strategies used by therapists in self-care intervention. One study by Booth and colleagues (2001) observed training of washing and dressing skills among clients with stroke, and identified strategies such as prompting, instructing and facilitating techniques. Mattingly (1994) concluded that therapeutic usefulness depends not on what the occupational therapist does to the client; it is rather about what the therapist and the clients are able to accomplish together. *"If the client does not view the therapy as valuable-it will not be valuable"* (p.814). In this research (Study IV), enabling refers to the processes of facilitating, guiding, coaching, educating, prompting, listening, reflecting, encouraging, or otherwise collaborating with the clients so that the persons have the means and opportunity to participate in occupations such as self-care (Law, Polatajko, Baptist & Townsend, 2002). More studies focusing on both the therapist as well as the client's experiences of the intervention are needed and can give valuable information for intervention planning (Brillhart & Johnson, 1997; Burton, 2000; Doolittle, 1992; Tham et al., 2000; Wohlin Wottrich et al., 2006).

Self-care in occupational therapy

Self-care as a concept is well known in occupational therapy and self-care training is one of the most frequent interventions used in rehabilitation (De Wit et al, 2006; Moulton, 1997;

Neistadt & Seymore, 1995; Taylor & Manguno, 1991). As early as 1958, techniques to facilitate dressing for quadriplegics' lower bodies were tried out for the first time, and when the occupational therapists saw that they were feasible goals, they started to develop and refine these techniques by trial and error in clinical observations. A study of dressing-training with 34 quadriplegic patients and 26 paraplegic patients in an intensive treatment program showed that all patients who met the criteria and completed the training achieved either total or upper extremity dressing independence (Runge, 1967).

Self-care intervention is a dynamic and multidimensional phenomenon, which can be described as a process involving interaction and collaboration between the therapist and the client (Mosey, 1986). The aim of the self-care intervention is mainly to contribute to independence in self-care (Guidetti & Söderback, 2001; Neistadt & Seymore, 1995; Söderback & Guidetti, 1992), which in turn is expected to contribute to increased autonomy (Rogers, 1992) and experiences of life satisfaction (Fugl-Meyer, Melin & Fugl-Meyer, 2002). Different professionals such as occupational therapists, nurses and physiotherapists may be involved in self-care training and the intervention exists in different areas (Christiansen, 1994). Usually the occupational therapists are responsible for self-care assessment, planning and starting the intervention. Despite the evidence of the beneficial effects of occupational therapy on independence in self-care after stroke, the rationale and strategies for the interventions are often vaguely defined and sparsely described (Legg et al., 2007; Steultjens et al., 2003) and consequently it might be hard for rehabilitation professionals to integrate these interventions into clinical practice (Craik, 2003). Research in this area has mainly aimed at developing methods for assessment of ability or independence (Fisher, 1998; Törnquist, 1995).

Rehabilitation after Stroke

The annual incidence of persons with stroke in Sweden is approximately 25,000 per year and about six percent of the total amount of inpatient hospital care is devoted to the care and rehabilitation of patients with stroke. The increase of the elderly in the population is expected to lead to a 30% increase in stroke incidence by 2010 (Socialstyrelsen, 2005). Stroke is the second leading cause of death in the world; and about half of those who survive are dependent on others for assistance with self-care activities six months after stroke (Legg, Drummond & Langhorn, 2006). There is international consensus for care in stroke units leading to an

increase in survival, independence in ADL and a decrease in need of care in nursing homes (Socialstyrelsen, 2005; The stroke unit trialists Collaboration, 1997). McKeivitt, Redfern, Mold and Wolfe's review (2004) addresses the fact that relatively few studies have sought to document the experienced view of the acute care described by persons with stroke. One study reported that in the first week after stroke, the patients' feelings of unreality and awareness of their changed role might lead to a psychological crisis (Backe, Larsson & Fridlund, 1996). Bernspång and colleagues (1987) concluded that the two most important aspects of function/dysfunction to explain ADL for persons with stroke were motor function and "construction" perception. The first three to six months are acknowledged as the time when most of the recovery will occur (Chang & Hasselkus, 1998) and the spontaneous recovery explained 16% to 42% (out of 101 persons) of the observed improvements of body functions and ADL in the first few weeks after stroke (Kwakkel, Kollen & Twisk, 2006).

According to the Swedish national guidelines for stroke care (Socialstyrelsen, 2005) evidence of the effect of rehabilitation interventions is weak, especially concerning training of motor function. Studies have shown that the content and amount of rehabilitation as well as the intensity of intervention have an impact on the outcomes in ADL (Bode, Heinemann, Semik & Mallison, 2004). A recent Swedish study of the life situation two years after stroke (Socialstyrelsen, 2004; Hulter-Åsberg, Johnsson, Staaf, Stegmayr & Wester, 2005) showed that 37% percent of the persons with stroke (n=4729) perceived unmet rehabilitation needs and the amount of informal care was high, which is in accordance with international studies (Palmer & Glass, 2003). Grant, Glandon, Elliott, Giger Newman and Weaver (2004) found that one of the three most common problems experienced by caregivers during the first months after stroke was difficulty in managing their relatives' ADL. Laliberte and colleagues (2006) established that, both persons with stroke and their caregivers were living in a restricted occupational world and described that a large amount of time was spent in completing self-care with assistance. One way to decrease the caregiver burden and dependence might be to focus rehabilitation interventions on improving the ADL functioning of clients with stroke, which was a point of departure for Study IV.

Occupational therapy focused on improving the ability to perform self-care activities after stroke has shown significant effects on the clients' self-care performance (Unsworth & Cunningham, 2002) and a reduced risk of deterioration in ADL ability (Legg et al., 2007; Steultjens et al., 2003). Haslam and Beaulie (2007) compared two types of ADL

interventions, a) functional intervention (i.e. the repetitive practice of particular tasks, usually activities of daily living), and b) remedial intervention, and found that functional intervention was more effective. There is evidence that a task-oriented approach is an effective strategy in order to improve self-care (Steultjens et al., 2003; Trombly & Ma, 2002; Teasell & Kalra, 2003). Clients participating in collaborative, goal-focused therapy demonstrated significantly better performance in upper-body dressing (Gagne & Hoppes, 2003).

Rehabilitation after spinal cord injury

Spinal cord injury involves a dramatic transformation in life and the person affected often needs to engage in a long rehabilitation process. The exact numbers of persons affected by spinal cord injury is unspecified but in Sweden the number is estimated at 10-15 persons per million, (compared to USA's 40 persons) and about 120 persons per year sustain a traumatic acute spinal cord injury. The prevalence suggests a total of 5000 persons living with a spinal cord injury in Sweden today. This may vary from year to year but has been relatively stable in recent years. Approximately the same number, at least, have a spinal cord injury resulting from other causes than trauma (Holtz & Levi, 2006). The most common cause of spinal cord injuries is traffic accidents and most of the persons with spinal cord injuries are men under 30 years of age. Tetraparesis (30%) and tetraplegia (21%) are more common than paraparesis (21%) and paraplegia (28%) (Holtz & Levi, 2006). The top three problems identified by persons with spinal cord injury were mobility, dressing and grooming (Donnelly et al., 2004).

Spinal cord injuries have consequences for the person's future life and, thus, the start of the rehabilitation process is of importance. In a Swedish follow-up of 160 persons, perceived problems primarily in activities related to family role, work and education but 23-33% of them also stated severe problems with mobility and self-care (Larsson-Lund, Nordlund, Nygård, Lexell & Bernspång, 2005). Being dependent on others in one's daily activities after a spinal cord injury has been described as demanding and frustrating when one's autonomy, formerly taken for granted, has suddenly disappeared (Lohne & Severinsson, 2003).

Information, participation in the planning of the rehabilitation and emotional support have been seen as important factors influencing the recovery process after spinal cord injury (Sand et al., 2006). For improving independence in daily activities, occupational therapy focusing on daily activities has been seen to be effective in comparison to neuro-motor training alone after a spinal cord injury (Pillastrini et al., 2007). The degree of injury has proved to influence the

effect of intervention (Mingaila & Krisciunas, 2005). Boss and colleagues (1995) found that persons with spinal cord injury were most competent regarding dressing, bladder management and bathing, following discharge from acute rehabilitation. Brillhart and Johnson (1997) found that motivation for returning to an active life after a spinal cord injury was related to the struggle for independence in self-care. The development of self-care and autonomy through decision-making has been seen as promoting a growing sense of independence (Lucke, 1999).

Research-based intervention

There are ongoing discussions among researchers (Kielhofner, 2005; Corcoran, 2006) as well as clinicians concerning how to implement research in practice and everyday work in, for example, occupational therapy. Most of the ongoing research does not reach those engaged in clinical activity and there is a gap between the clinicians and the researchers, which need to be reduced (Welch & Dawson, 2006). Today's clinicians often base their interventions on their clinical experience, not on research-based evidence, although they have an expressed desire to do so (Craik & Rappolt, 2006). Previous research offers diverse models, where intervention of different kinds is presented (Christiansen & Baum, 1997) but seldom implemented in clinical practice (Kielhofner, 2005). Instead, other types of knowledge are used when there are clinical decisions to be made, for example, clinical knowledge, lifelong learning and knowledge gleaned from colleagues (Bennet et al., 2003; Gervais, Poirier, Van Iterson & Egan, 2002; Philibert, Snyder, Judd & Windsor, 2003; Welch & Dawson, 2006). The main problem stated for involvement in research-related activities is the lack of time (Karlsson & Törnquist, 2007). In the field of occupational therapy, there has been a debate during recent years about the use of evidence-based occupational therapy. Taylor (2007) defined evidence-based occupational therapy as the client-centred enablement of occupation, based on client information and critical review of relevant research, expert consensus and former clinical experiences. RCT are seen as the golden standard for evidence of the effectiveness of an intervention by ensuring absence of bias, because randomisation ensures an equal likelihood of being allocated either to the intervention or to the control group (Taylor, 2007). But health care including occupational therapy constitute areas of human experience that do not always allow measurement and quantification (Dahlberg et al., 2001). Phenomena such as the recapturing of self-care require research methods and research techniques meeting the characteristics of human being data in order to meet the person's life-world (Dahlberg et al., 2001). A recent paper (Taylor & Braveman, 2004) highlighted the difficulties involved in

implementing research evidence into clinical practice. There are few studies examining how to implement knowledge based on research/evidence from research projects where the clinics are involved (Fänge, Rissner & Iwarsson, 2007). However, if clinicians can influence the development of new interventions in close collaboration with researchers, it is likely that the interventions will be more easily implemented (Kielhofner, 2005). There is a need of collaboration between the clinicians and the researcher in order to further develop occupational therapy (Bennett et al., 2003; Rappolt & Tassone, 2002; McKeivitt et al., 2004) and one way is to involve clinicians in the research (Kielhofner, 2005; Philibert et al., 2003).

One way of reducing the gap between research and clinical knowledge is also to enable the clinicians and the researchers to meet for shared reflection in, for example, workshops (Welch & Dawson, 2006; Dysart & Tomlin, 2002; Craik & Rappolt, 2006). In conclusion, there is support in the literature for research projects conducted in close collaboration between the clinicians and the researcher being of importance for implementing the research and research findings in clinical practice (Tse, Lloyd, Penman, King & Bassett, 2004). The projects feature a partnership of shared power and responsibility between the researcher and the clinicians, which was the point of departure for the development of the new self-care intervention evaluated in Study IV.

To Sum up there has been a tradition within the field of occupational therapy to focus on self-care intervention and to measure therapeutic outcomes by using ADL-instruments assessing independence in self-care. The research has mainly focused on developing new ADL-assessments. There is also some evidence from research showing that occupational therapy including task specific training is effective to improve functioning in daily activities such as self-care. However, the rationales for the interventions are often vaguely defined and the intervention sparsely described and consequently it might be hard for rehabilitation professionals, as occupational therapists, to implement these interventions into clinical practice. There is research and literature in the field of rehabilitation related to the concept of independence arguing that the rehabilitation strategies ought to enhance individual autonomy and participation in daily life in order to realize the ability to take control and make decisions. Occupation such self-care is not only a mechanical set of activities, but also imbued with choices and autonomy in the context of doing.

There is a growing body of research examining the lived experience after stroke or spinal cord injury, especially in the field of nursing. These studies mainly focus on psychological and emotional consequences but a few studies examine the nature of disability experiences after stroke or spinal cord injury using an occupational perspective. However, these studies examine the lived experience of daily occupations in general but are not specifically focusing on how participants experience self-care in the early phase of the rehabilitation (1-3 months after onset). Few studies identify therapeutic strategies based on the therapists' experiences from their clinical work, but no studies with the main focus on therapeutic strategies used in self-care training. Finally, in the fields of occupational therapy, there is a need of initiating research projects that are conducted in close collaboration between clinicians and researchers, which seem to be a prerequisite for implementing research based intervention in clinical practice.

AIM

General aim

To describe the occupational therapists' experiences of self-care training and the clients' experiences of recapturing self-care after a stroke or a spinal cord injury as well as in close collaboration with occupational therapists to develop a new client-centred self-care intervention (CCSCI) for evaluating the effect of this intervention in a RCT pilot study.

Specific aims

- To describe what characterizes the therapeutic strategies used by occupational therapists during self-care training. (Study I)

- To identify the characteristics of the lived experience of recapturing self-care after a stroke or spinal cord injury. (Study II)

- To identify the meaning of context in recapturing self-care after a stroke or spinal cord injury. (Study III)

- To evaluate the effect of a client-centred self-care intervention (CCSCI) on (i) activities of daily living (ADL) and life satisfaction in persons with stroke, (ii) care-giver burden, use of informal care and home help services, and (iii) feasibility of study design. (Study IV)

METHODS

The research questions in this thesis concern recapturing self-care in a rehabilitation setting during the early phase of rehabilitation (first week to three months) after a stroke or a spinal cord injury. The first study (Study I) describes what characterizes the phenomenon self-care training from the occupational therapists' view; Studies II and III describe the characteristics of recapturing self-care and identifying self-care from the person's perspective. The two diagnostic groups were selected because self-care training is a common intervention in their early phases of rehabilitation. The characteristics of the impairments and disabilities vary in persons belonging to these two groups and the aim was to gain rich and varied data representing different characteristics of the phenomenon (i.e., recapturing self-care) under investigation (Karlsson, 1993). These three qualitative studies are based on interviews and analysed using the Empirical, Phenomenological, Psychological (EPP) method (Karlsson, 1993). My pre-understanding was based on my clinical experience and previous research within the ADL-area, which coloured the occupational perspective used in the analyses. When using the EPP method, previous knowledge not in accordance with the phenomenological perspective is "bracketed" (Karlsson, 1993) during the analysis of data in order to being open to how the phenomenon is presented in the lived experiences described by the participants.

In the pilot study IV, with a RCT-design, a new client-centred self-care intervention (CCSCI) focusing on recapturing self-care was evaluated. The researchers made the choice to evaluate the CCSCI in the group of persons who had had a stroke in order to get a homogenous group of participants. Study II also indicated a special need of well-defined self-care interventions among the participants who had a stroke since they did not experience self-care as training (Study II). In This study is a part of a larger ongoing study with continuing follow-ups at six and twelve months after stroke. The intervention was based on the data from the three previous studies and other research and developed in collaboration with six occupational therapists who participated in a 5-day course (designed for this project by the researcher) and who were responsible for conducting the new CCSCI evaluated in the pilot study. The aim of the course was to integrate research-based knowledge (i.e., knowledge from qualitative and quantitative research) and the occupational therapists' clinical knowledge when developing the intervention as well as to integrate CCSCI into clinical practice through a close collaboration between the researcher and clinicians.

An overview of the studies and methods used are given in Table 1.

Table 1 Overview of Studies I-IV.

	Study I	Study II	Study III	Study IV
Study design	Qualitative, descriptive interview study, Phenomenological approach	Phenomenological, interpretative, interview study	Phenomenological, interpretative, interview study	RCT-pilot study, with 2 groups, intervention and control groups
Study context	Rehabilitation clinics	Rehabilitation clinics, 1-3 months post stroke	Rehabilitation clinics, 1-3 months post stroke	Stroke units (baseline), Rehabilitation clinics, short-term hospital, Elderly home, Home setting (3 months)
Participants	12 Occupational therapists with 5 or more years of experience	5 persons with stroke 6 persons with SCI	Same as Study II	40 persons with stroke. IG n=19 CG n=21 Significant others n=16
Data collection	Interviews, informal open-ended questions based on the therapeutic stories (12)	Interviews, informal open-ended questions based on a interview guide (11)	Interviews, informal open-ended questions based on a interview guide (11)	At baseline, 1 and 3 months; MMSE, Barthel Index, FIM, FAI, SIS, LiSat-11, Caregiver Burden Scale
Data analysis	Empirical Phenomenological Psychological method (EPP-method)	EPP method	EPP method	Descriptive statistics, Mann-Whitney U test (ordinal data), χ^2 (categorical data), T-test (continuous data), the Wilcoxon matched pairs test

Participants

Study I

The study group consisted of 12 occupational therapists with at least five years of clinical work experience. To study a wide variety of intervention strategies used by occupational therapists during self-care training, therapists were selected who were working with clients who had either had a stroke (n=6) or a spinal cord injury (n=6). The occupational therapists were working at geriatric or rehabilitation clinics in Stockholm, Sweden. A selective choice was made from persons who were recommended by colleagues as ‘good’ occupational therapists who were conducting self-care training several times a week in their daily clinical work.

Studies II and III

The study groups consisted of five participants who had had a stroke and six who had a spinal cord injury. Participants were consecutively recruited from one hospital in Stockholm,

Sweden where they received acute care. The criteria for selection were: (a) age ≤ 65 years, (b) inability to perform self-care activities and in need of self-care training in their continued rehabilitation, according to their occupational therapists' clinical assessment, and (c) ability to understand interview questions and to share their experiences according to their occupational therapists' clinical assessment. All the participants were employed (their vocations varied and included for example: a cook, construction worker, personal secretary, computer salesman, or student at the time of the injury). See Table II for the participants' demographics and clinical characteristics.

Table II. Participant Demographics.

Participant Diagnostic Group	Age	Gender	Living Conditions	Wheelchair	Location of Brain Lesion	Paraplegic or Tetraplegic
Stroke	40	Man	Married	No; crutches	Right hemisphere	--
Stroke	57	Woman	Married	No	Right hemisphere	--
Stroke	60	Woman	Married	No	Left hemisphere	--
Stroke	65	Man	Widower	No	Left hemisphere	--
Stroke	50	Man	Married	Yes	Right hemisphere	--
SCI	28	Man	Married	Yes	--	Paraplegic
SCI	65	Man	Married	Yes	--	Tetraplegic
SCI	53	Man	Married	Yes	--	Tetraplegic
SCI	30	Man	Living together	Yes	--	Paraplegic
SCI	21	Man	Single	Yes	---	Tetraplegic
SCI	38	Man	Living together	Yes	--	Tetraplegic

Note. SCI = spinal cord injury.

Study IV

The 40 participants with stroke were included in the study from October 16, 2006 to June 7, 2007. The participants were randomly assigned to the Intervention Group (IG), n=19 or to the Control Group (CG), n=21. The randomisations sequence was generated by the researcher (SG) and the senior researcher (LvK) by use of a random number table and stratified by rehabilitation clinic and stored in numbered, sealed, non-transparent envelopes by a secretary at the Karolinska Institutet. After baseline assessment (3-5 days after stroke) was conducted, a research assistant was contacted, who called the secretary. The secretary opened the

appropriate envelope and phoned the rehabilitation clinic to which the patient was referred, and informed them of the patient's group allocation.

The persons were asked to identify significant others, e.g., close relatives, to participate in the research project. At the three -month follow-up, five persons declined to participate and two had died. In total 33 persons participated in both baseline assessment and follow-up at three months, IG n=14 and CG n=19 and 16 significant others, eight in each group. The significant others were all living together with the persons with stroke, except one significant other in the CG who was the daughter of the client. See Table III for the participants' characteristics at baseline

Table III. Characteristics at baseline of the Intervention Group and the Control Group and their significant others.

Variable (<i>Range of scores</i>)	Intervention Group n=19	Control Group n=21
Persons with stroke		
Men/Women	8/11	9/12
Age in years, mean (SD)	66 (14)	69 (15)
Residential status: live together/ live alone	9/10	10/11
Localisation: left /right/ unspecified	10 / 8 / 1	10 / 9 / 2
Cerebral infarction / Haemorrhage / Infarction + Haemorrhage	12 / 6 / 1	17 / 4
Aphasia / dysphasia	1 / 5	4 / 7
Mini Mental State Exam, (0-30)	23 (22-28) *§	23.5 (22-27)*
Significant others	n=8	n=8
Men / Women	4 / 4	3 / 5
Age, number of years, mean	63.8	63

*median (interquartile range), §n=15, ||n=14

Client Centred Self-Care Intervention

In order to develop and evaluate CCSCI three different rehabilitation clinics in the Stockholm area were invited and agreed to participate in a five-day course (spread over a one-month period). Initially, the researcher informed the rehabilitation clinics closely linked to the acute hospital about the project and invited them to participate. The clinics agreed to participate and selected six occupational therapists to participate in the course and the pilot study (Study IV).

The content of the intervention course

The course was designed for this project by the researcher with the objectives to integrate research-based knowledge with the clinical knowledge and to develop a client-centred self-care intervention in collaboration with the therapists and thereafter conducted and evaluated in a RCT-pilot study (IV). The five-day course was planned with the following schedule:

Day 1

- a) An introduction about the research project by the researcher.
- b) In order to reflect on how they usually conducted self-care intervention in their clinical practices, the occupational therapists, two by two, were asked to tell each other about one specific self-care training session they had in mind.
- c) The researcher presented different concepts as phenomenology, self-care, client-centred practice, Goal-Plan-Check and Do (Polatajko et al., 2001), and the use of ADL-assessments in order to clarify the theoretical framework of the self-care intervention.
- d) The participants were given the three qualitative studies from this thesis (Studies I, II and III) to read and reflect upon critically before Day 2.

Day 2

- a) The occupational therapists discussed in groups, as in a workshop setting, how they could use the findings from Studies I-III in relation to a case study (formulated by the researcher) in order to formulate an intervention that they presented to each other. The therapists were given an assignment to practice strategies out in their clinics in order to practice the discussed strategies that could be drawn from Studies I, II and III with one of their clients at their own clinic.

Day 3

The occupational therapist conducted the assignment at the clinic.

Day 4

- a) Each therapist presented their case study, with further discussions on their reflections according to difficulties and relevance for how to develop the new self-care intervention.
- b) A senior researcher presented other phenomenological studies (Tham et al., 2000; Tham & Kielhofner, 2003) in order to widen up the perspective and research base for the intervention under development. The senior researcher and therapists discussed how they could use the different strategies and dilemmas in the occupational therapists' clinical work when they conducted the self-care training.

Day 5

a) The researcher and the occupational therapists formulated together the intervention and the general aim of the CCSCI based on the research-based knowledge and the clinical knowledge. The general aim of the intervention was set to enable persons with stroke to resume responsibility for their self-care and to influence their own rehabilitation process.

The researcher was supporting the occupational therapist during the period for conducting Study IV and was available by telephone or visits. The researcher and the therapists were also meeting four times to further discuss, and support on-going interventions at each of the three rehabilitation clinics.

The content of the CCSCI

The nine steps of the CCSCI were developed in collaboration between the researcher and the occupational therapists participating in the course that became the base for Study IV:

- 1) On the first meeting with the client, the focus of the occupational therapist is to establish a relationship with the client (Studies I, II and III).
- 2) The occupational therapist observes the client in performing self-care in order to shape a picture of the client (Study I).
- 3) The occupational therapist fills in the Sunnaas ADL Index (Korpelainen, Niilekselä & Myllylä, 1997) together with the client and in this step discover and identify difficulties in performing the activity as well as how the client values the activities (Studies II and III).
- 4) The occupational therapist invites the client to formulate three goals for activities he/she wants and needs to perform (Studies I and III), based on the Canadian Occupational Performance Measure (COPM) (Law et al., 2005). COPM is an individualized, client-centred measure designed for use by occupational therapists to detect changes in a client's self-perception of occupational performance over time. The aim of COPM was to guide the intervention (Donnelly & Carswell, 2002) and to improve the clients' participation in the rehabilitation process (Wressle et al., 2002). Phipps & Richardson (2007) have found that the COPM process effectively assists clients with neurological impairment in identifying meaningful performance goals related to ADL-activities. They have also recommended the use of COPM for designing an occupation-based client-centred intervention programme and for evaluating the occupational therapy outcomes.

- 5) The client and the occupational therapist identify domain specific strategies that enable successful performance of the chosen activities (Studies I and III), and the client is introduced to use a global problem-solving strategy, *goal-plan-do-check* strategy, to handle his/her difficulties in self-care performance (Polatajko et al., 2001). The goal-plan-do-check strategy aims at providing a structure for the therapists and the clients to talk through the problems encountered in the performance of the self-care. The Goal requires self-interrogation, the Plan requires a self-monitoring, the Do demands self-observations, and the Check fuels self-evaluations (Polatajko et al., 2001). These are used in order to help the client to see how he/she can set goals, plan actions, do things and check the outcomes.
- 6) The client and the occupational therapist plan the self-care intervention, how and when the client should perform the chosen self-care activities (Studies I and III), and the client is introduced to use a training diary. The diary is used in order to resume responsibility for the client's own goals and training as well as to be used as a tool for others to be informed about and also to document training related to the goals for the self-care intervention.
- 7) The occupational therapist informs the other staff at the rehabilitation clinic and the significant others about the client's goals and the planned strategies for the self-care intervention (Study III).
- 8) The client is practicing the chosen self-care activities with the chosen strategies according to the intervention plan in order to recapture self-care (Studies I, II and III).
- 9) When reaching the goals, the client and the occupational therapist discuss and evaluate the strategies implemented and then formulated new goals (Study I).

The frame of reference of the CCSCI was introduced to the therapists in the course and was based on the following assumptions on which the researcher and therapists had an agreement to use when conducting the intervention within the RCT pilot study (IV).

The CCSCI should be conducted within a client-centred context (Law, Baptiste & Mills, 1995), i.e., the training should be adjusted to the individual's ability, motivation, perceptions and needs and in close collaboration between the patient and therapist, which is in line with findings from previous studies (Studies I-III). Close relatives (i.e., significant others) should be invited to collaborate. Different intervention strategies should be used such as enabling an awareness of ability/disability (Tham et al., 2000; Tham et al., 2001), finding new ways (compensation) to perform self-care and/or modifying the environmental demands to enable performance (Studies I-III).

Ordinary self-care training

The participants randomly assigned to the CG participated in ordinary ADL-training, which meant that the intervention varied in extent and methodology according to the routines and praxis at the rehabilitation clinic, but also with the knowledge and clinical experience of the individual occupational therapist. In the CG, the amount of rehabilitation was supposed to follow the ordinary rehabilitation programme at the clinic, which included all the rehabilitation needed except for the new CCSCI. The occupational therapists involved with the CG had not participated in course that developed the CCSCI.

Data collection

Interviews (Studies I-III)

In Study I the occupational therapists were interviewed once for about one hour by the researcher in their work settings. The occupational therapists were asked to describe, as concretely and with as many details as possible, their experiences of conducting self-care training with one particular client. They were informed that they could choose a case where the outcome from the training was either positive or negative.

All interview questions (Studies I, II and III) were informal and open-ended, albeit based on an interview guide. The interviews were audio-taped and transcribed verbatim.

In Studies II and III, the researcher contacted the persons who had had a stroke or a spinal cord injury through their occupational therapists. The interviews were conducted with each participant once for approximately one hour in his/her rehabilitation setting. The participants were asked to describe, as concretely and with as much detail as possible, their experiences in performing self-care activities; moreover, they were asked how they experienced these activities immediately after onset and at present (main focus).

Assessment instruments (Study IV)

Information regarding the participants' age, gender, and stroke diagnosis (localisation) was taken from the patients' medical records. Cognitive function at baseline was assessed by the *Mini-Mental State Examination* (Folstein, Folstein & McHugh, 1975).

Independence/dependence in ADL was assessed using the *Barthel Index* (Mahoney & Barthel, 1965). An increase in BI score of 30 or more either up to a maximum score was considered an individual clinically significant improvement. *Functional Independent Measure* (Grimby et

al., 1996) A-M scale was used to determine disability in terms of dependence or need of assistance in self-care, sphincter control, mobility, and locomotion. The higher the FIM (A-M) scores the lower the need of assistance. Frequency of social/lifestyle activities was assessed by the *Frenchay Activities Index* (Wade, Legh-Smith & Langton Hewer, 1985) in which the score is based on the frequency with which an activity has been performed in the previous three or six months and ranges from 0 (inactive) to 45 (very active). The participants' perceived impact of stroke was assessed using the *Stoke Impact Scale (SIS)*, subscale 5 regarding perceived difficulties in ADL, and *SIS self-assessed recovery* (Duncan et al., 1999). To assess the participants' perceived satisfaction with life three months after stroke, one global question of the *Life Satisfaction Scale 11 (LiSat-11)* was used. The participants rated their life satisfaction on a scale from 1 (very dissatisfying) to 6 (very satisfying). Participants with a score of 5–6 on the LiSat-11 global question were considered to be satisfied with life as a whole, and participants with a score of 1-4 were dissatisfied with life as a whole.

Caregiver burden perceived by the significant others was assessed at the three months' follow-up using the *Caregiver Burden Scale* (Elmståhl, Malmberg & Annerstedt, 1996), which consists of 22 items for different types of subjective caregiver burden covering areas of caregiver's health, feelings of psychological well-being, relations, social network, physical workload, and environmental aspects. The items are scored on a scale from one to four and the higher the score the greater the burden.

Information regarding length of stay, i.e., number of days at the stroke units and in the rehabilitation clinic, number and type of outpatient rehabilitation contacts received after discharge from the rehabilitation clinics up to three months was collected from the computerized register of the Stockholm County Council. The participants' number of occupational therapist contacts and their content in occupational therapy sessions were collected from the occupational therapists' medical records. Number of hours of home help service was either reported in interview by the participants or calculated based on number of visits reported by the participants, in which case one visit was set to 0.5 hour. Information regarding residential status, home help service and informal care was collected by interview. Data was also collected at six and twelve months after stroke, but that data will be presented in a future study.

Data analyses

Studies I, II and III, The Empirical, Phenomenological, Psychological method (EPP)

The EPP method is a qualitative, descriptive and interpretative method and by “descriptive” is meant an approach that aims to answer the questions *what* and *how* rather than *why*.

In order to understand the participants’ life-world experiences and how the phenomenon presents itself in their experiences (Karlsson, 1993), any theory outside phenomenology or knowledge derived from clinical practice within a medical context, that explained or accounted for the phenomenon under investigation, was bracketed during the analysis.

The data in Studies I, II and III were analysed and interpreted in five steps. Steps 1-4 were completed separately for each participant during the analysis, in order to discover how the characteristics of the phenomenon were presented and expressed within each participant’s life-world experiences described in the interviews. In step 5 the characteristics that ran across all participants (i.e., general characteristics) were identified and interpreted in order to describe the meaning structure of the phenomenon comprising main and sub-characteristics.

In the first step of the analysis, the interviews were read through until an understanding of the original experiences described by each participant was reached. In the second step, the participants’ interview protocols were divided into smaller units, meaning units (MU). The text was divided each time there was a discerned a shift of meaning in the data (i.e., when the participants described a new aspect or experience). In the third step, each MU was understood and interpreted in light of all data from the interview protocol and the phenomenon under study, and the MU was translated into the researchers’ language. In the fourth step, the interpretations from step three were synthesized, summarized and arranged in a way that described the features of the phenomenon (i.e., characteristics). In the fifth step, the researchers moved from how the phenomenon was characterized within each participant’s interview (described in the summary format) to a general meaning structure that ran across all the participant interviews. Examples and quotations were used to illustrate the characteristics as well as the variations in individual experiences. Analyses were discussed and refined several times by using a “horizontally consistent interpretation” between the authors, making sure that each characteristic fitted well with the other characteristics from the analyses, and in that way clarified the most valid interpretation (Karlsson, 1993). The results were also

presented to and discussed together with (peer-review) experienced occupational therapists and researchers in the neurological rehabilitation field as a method of validating the findings.

Study IV

The feasibility of design and method of the pilot study regarding patient recruitment, methods and procedures were analysed in order to adjust the protocol for a larger RCT. Data were analysed from all participants who completed the study at three months. Descriptive statistics were used to present the level of functioning. For analysis of differences between the groups the Mann-Whitney U test was applied for ordinal data, and χ^2 for categorical data and the T-test for independent samples for continuous data. The Wilcoxon matched pairs test was applied to evaluate changes within the groups. A p-value < 0.05 was accepted as statistically significant. Also the participant's individual change was calculated. All analyses were conducted using STATISTICA (StatSoft, Inc.) (Version 7).

RESULTS

In **Study I**, the aim of this qualitative study was to describe what characterizes the therapeutic strategies used by occupational therapists during self-care training. Twelve occupational therapists working with clients who had a stroke and a spinal cord injury were interviewed and asked to tell about their therapeutic stories focusing on the self-care training process.

The findings showed that the occupational therapists' strategies focused primarily on how to *establish a relationship with trust* with their clients and the need for an atmosphere of empathy and understanding toward the client in order to establish this meaningful relationship. To have a connection to occur for starting the self-care training, the occupational therapist needed to understand the client to be able to gain the client's cooperation and to meet the client where he/she needed to be met. The first challenge for the occupational therapist was *to find the right way to motivate the client*, where the therapist first had to understand the client's ability to perform activities and then create an understanding of the client's need to participate in self-care training. The occupational therapists expressed how they created a "seeing-situation" for the clients to have them to realize the value of self-care training and to be able *to support the setting of goals* in collaboration with their occupational therapist. The clients needed to understand the expectations and goals in the self-care training to prepare them for participation. The occupational therapists used several strategies to

enabling occupational experiences as making the competence visible for the clients, facilitating the discovery of disability and finding new solutions in problems in becoming independent. For the training in self-care to be successful, the therapists expressed how they *adjust training to the needs of the client*. By withdrawing their presence during the self-care training, they could give the clients an adequate challenge. The occupational therapist had to balance time to meet the client's needs as to give time to the clients to practice and perform self-care, but also to use the time in a competitive way as a measure outcome, which could also be feedback. During the self-care training, the occupational therapists described their use of some strategies that were integrated in all the different phases of the therapists as *being a chameleon by shifting therapeutic roles, maintaining their therapeutic alliance* and *using varied ways of communication*. The general aim for using the strategies was to support the clients in taking control over their lives again.

Some implications discussed in Study I were that a prerequisite for being able to discover and take control over one's new life is the relationship and collaboration between the therapists and their clients, which is based on mutual trust, and also that the therapists view their clients as experts about their own situation during the whole self-care intervention process. The clients also needed experiences from doing and from practice in self-care, to improve their competence and sense of control. These seem to be the keys for development.

Studies II and III are based on interviews from five persons who had had a stroke and six persons who had a spinal cord injury. All of the participants were in the beginning of their rehabilitation process and in their midst of self-care training. All interviews were analysed using the EPP method. In Study II the aim was to identify the characteristics of the lived experiences of recapturing self-care after a stroke or a spinal cord injury.

In Study III the aim was to identify the meaning of context in recapturing self-care after a stroke or spinal cord injury. The term "*meaning*" is used to denote the different roles that context played in the process of recapturing self-care.

The findings from Study II identified four main characteristics among all of the 11 participants' lived experiences of self-care during the beginning of their rehabilitation process. The participants who had had a stroke or a spinal cord injury shared common experiences with regard to self-care while also attributing different meaning to this process. They described their life-world as unfamiliar and their body as feeling different, so during this

period they needed to gradually *become familiar with their new bodies*. By experiences from different daily activities, all participants expressed *recapturing self-care through trying*. By trying and feeling that they were able to do something with their bodies, the participants expressed a possible development. For the participants who had a spinal cord injury, they described the activities as “everything you do is training” compared to the participants with a stroke as seeing “self-care as not training—it was something you must do”. All participants described how they sought to *reclaim control* over their bodies and their lives. For the persons with a spinal cord injury, they talked about control in terms of taking control over their new bodies, but for the persons with a stroke they focused on reclaiming a body part such as an arm or a leg as well as taking control over activities linked to their old identities. All of the participants *felt uncertainty in the continued recapturing process* when the process did not end at the time for these interviews. These findings in Study II showed that more extensive social support was needed during self-care training in the “transit” phase (i.e., in the beginning). When starting to practice self-care activities, it was important to allow for time during which clients could try to feel their bodies in the activity. If clients’ did not feel comfortable performing self-care, they could start with something purposeful but less meaningful and therefore not threatening. Moreover, the rehabilitation interventions should enable bodily experiences, such as the integration of affected body parts in the performance of self-care, to enable recapturing and perceptions of autonomy.

The findings from Study III identified six main characteristics. The participants expressed that immediately following their stroke or spinal cord injury that they experienced a need for *support from others* due to fatigue and feeling challenged by performing tasks. In the beginning, the support was about having someone else perform the self-care for them; gradually this shifted to wanting support in order to perform self-care more independently. They also described an aspect of context in which a culture of assuming responsibility for one’s own self-care emerged. These *expectations in the air* were considered intangible, as if there was an unspoken anticipation for the individuals to act in particular ways even though the particularities were often perceived to be unclear. There were even implicit, tangible expectations that occurred by the participants being asked questions. The participants mentioned the being in a context of *extended time* (i.e., a feeling of increased amount of time) as important in the recapturing of self-care in the beginning to have time to rest. During the early rehabilitation phase, they expressed a need for more time in order to catch up with their new situations and new bodies. Time and the use of time were necessary as tools for enabling

the self-care activities, and sometimes for just doing nothing. Furthermore, they needed what they described as “downtime”, time not filled with something, but time to think about their bodies and about what they were doing. Participants also felt that they needed extended time, to have taken the time it takes, in order to perform activities such as self-care. The participants also described the need to perform the activities at the right point in time.

Prior to the stroke or spinal cord injury, self-care had been a part of everyday life that was taken for granted by the participants in this study. They described a need for help to organize their day and to obtain routines and structure in their daily activities. The characteristics of a *new daily structure* were needed. By giving concrete structures for doing things, the challenge was formed to meet the participant’s present ability. Participants described the therapeutic relation with the occupational therapist as a *therapeutic relationship as an enabling possibility* in the recapturing of self-care. Participants who had a stroke or a spinal cord injury shared common experiences with regard to the therapeutic relationship, while also attributing different meanings in their relation with the therapists. The participants with a spinal cord injury felt close to their occupational therapist, and often referred to their relationship using the term, “*We*,” as if they had become a union. The participants recovering from stroke described their relationship with the occupational therapist as a non-present organizer and advisor. The therapist supported them and was seen as expecting the participant to perform an activity on his/her own. The support by others changed from maximal to minimal over time. A *gradual change in challenge* was important for developing the performance of self-care activities. These findings in Study III showed that rehabilitation professionals have an important task in creating a context for self-care by enabling extended time, as well as by enabling clients to see possibilities and create expectations about doing things on their own. The therapeutic relationship with the occupational therapist, the social interactions with others, and being in a supportive context seemed to be a prerequisite for recapturing self-care.

In the pilot Study IV, a new CCSCI focusing on recapturing self-care was evaluated. The intervention was based on previous research and was developed in close collaboration between the researchers and occupational therapists. The aim in this study was to evaluate the effect of CCSCI on (i) ADL, life satisfaction in persons with stroke, (ii) caregiver burden, use of informal care and home-help services, and (iii) the feasibility of the study design.

There were no statistically significant differences in outcomes for Barthel Index, FIM, SIS, FAI, LiSat-11 and Caregiver Burden Scale between the groups. Within group comparisons showed that there were statistically significant improvements in self-care between baseline and three months in both groups according to FIM (A-M). Comparing clinically significant improvements in ADL on an individual level, 13 out of 14 (93%) participants improved in ADL in the IG, and 12 out of 19 participants (63%) in the CG. The total amount of occupational therapy received at the rehabilitation clinic was similar in the groups but the content of the occupational therapy sessions differed. The participants in the IG received on average almost twice as much P-ADL training than the CG, who had more leisure activities, e.g. painting, gardening, etc. One person in the CG had 18 sessions of motor-function training, while another had 21 leisure sessions. There was no difference in the use of health care according to home rehabilitation, home help services changes of living, and outpatients' contacts after discharge from the rehabilitation clinics. The CCSCI appears to be promising for the recapturing of self-care after a stroke, and a large randomised controlled trial is warranted, in which the present design and methods with some modification will be suitable.

GENERAL DISCUSSION

From the inception of this project, my goal has been to gain a deeper understanding about self-care intervention. More specifically, my interest has been in the strategies that occupational therapists use to support clients in performing self-care and the client's experiences of recapturing self-care after a stroke or a spinal cord injury. Through the process of learning from the lived experiences of the participants in this project, there emerged a need to develop a new self-care intervention for occupational therapy based on Studies I-III as well as knowledge derived from other research studies. Self-care has been part of occupational therapy from an early period (Runge, 1967; Törnquist, 1995). During recent years there have been fewer articles focusing on self-care training than before, but rather an increasing number of studies focusing on social participation within the occupational therapy literature. It could be debated whether occupational therapists are abandoning self-care as an area of less importance.

In the following the importance of recapturing self-care after a stroke or a spinal cord injury will be discussed based on the findings of the studies included in this thesis as well as literature supporting my reasoning. Firstly, I will give a summary of the process of recapturing self-care.

The process of recapturing self-care

The findings from Studies II and III made explicit some characteristics of the process of recapturing self-care in the early phase of the rehabilitation process after a stroke or a spinal cord injury. In the beginning of the process, the participants described experiences of chaos and experiences of a different body and an unfamiliar life-world. Their bodies had previously been taken for granted in their daily activities as, for example, self-care activities. During this period they needed to become familiar with the “new” to recapture self-care. These findings are in accordance with the writings of Merleau-Ponty (2002/1945) and supported in previous research (Tham & Kielhofner, 2003; Erikson et al., 2007; Kvigne & Kirkevold, 2003; Hammell, 2007a). The experience of chaos after a sudden life-course disruption such as a stroke or a spinal cord injury has been described in many previous studies (Tham & Kielhofner, 2003; Erikson et al., 2007; Hammell, 2007a). According to Merleau-Ponty (2002/1945), the body is the point of departure in the life-world and a disability often leads to a damaged body and by then a changed life-world. Backe, Larsson and Fridlund (1996) found that in the first week after a stroke, patients felt a changed perception in their bodies and a loss of capability in their daily lives. Kvigne and Kirkevold (2003) also found that stroke survivors experienced their bodies as the unpredictable body, the demanding body, and the extended body during their process of recovery. They expressed that they became strangers to themselves, where their lives just continued, albeit with a feeling of bodily tiredness. In a study by Carpenter (1994), the participants with a spinal cord injury experienced an overall sense of loss in the beginning after their injury.

In the beginning of the process the participants in Studies II and III also described their chaotic situation as a feeling of being in transit, which was characterised by passive acceptance of assistance by others in self-care. The support was changing from others actually doing the self-care for them to gradually wanting support in order to perform self-care more independently.

Later in the process, support meant having someone else in proximity that could provide support just by being nearby. This finding was also supported by the occupational therapists in Study I when they gradually withdrew their support in self-care training, as well as the study by Tham and Kielhofner (2003) who found that others began to step aside in order to allow the person with a stroke to practice managing their daily activities on their own (Tham & Kielhofner, 2003). In a study describing the impact of support (Hammell, 2007b), the

importance of professional support, and support from peers are delineated but not described in the specific context of recapturing self-care. In contrast to immediately after the stroke or the spinal cord injury, when participants just felt the need to rest during the early rehabilitation phase, they expressed a need for more time in order to catch up in order to become familiar with their new situations and new bodies. Kvigne and Kirkevold (2003) described this as the time consuming body.

By practicing and developing new ways of doing the self-care activities, the participants acquired significant experiences through which they gradually became more familiar with their new bodies and abilities (Study II), which is in accordance with previous phenomenological studies (Erikson et al, 2007; Kvigne & Kirkevold, 2003; Tham et al, 2000). In a study by Carpenters (1994, p. 619), one participant described the process of becoming as *“Everything about your body has to be relearned, just like a child, only a thousand times more difficult”*. All participants in Study II expressed the desire to become less dependent on others and to have more opportunities to make choices for their actions in daily life at the clinic. They sought to reclaim control of their bodies and doing in their daily life. In particular, to become independent in self-care was important for one’s self-perceived sense of agency (i.e., the sense that they are the owner of their own actions). It seems as if they made a connection between their sense of independence and their ability to make choices, a relationship that has previously been discussed in the literature (see the introduction part of this thesis) and, which according to Kielhofner (2008), is closely linked to how persons express their intentions in their present and future life.

The description of the characteristics of the complex process of recapturing self-care discussed above can increase the understanding of the importance of enabling clients to become familiar with their changed bodies and life-worlds since self-care activities are basic activities closely linked to the body. This assumption is in line with the reasoning of Merleau-Ponty (2002/1945), who stated that the body is experienced as a whole and the way people apprehend and know how to do activities are through the body. An increased understanding of the lived experience of recapturing self-care can also be integrated in the self-care intervention conducted by occupational therapists (as in Study IV) and rehabilitation professionals in general.

Becoming through the doing of self-care

The context for this research project was the early phase of rehabilitation and in the former section the process of recapturing self-care during this early phase was discussed with the focus on the lived experience of the body and the recapture of self-care. However, the findings in Studies I-III indicated the importance of doing self-care to become familiar with the new body and life-world but also to connect past life with future life, which is in accordance with what Wilcock (1998) described as *doing, being and becoming*. This section will discuss how recapturing self-care in the early phase of rehabilitation may be related to *becoming* in a more long-term perspective. Wilcock (2006) stated that life is a process and that everything that happens in our life is an integral part of our becoming. We can infer from this that the experiences of recapturing self-care after a stroke or a spinal cord injury are integral parts of becoming. Wilcock (2006) added that awareness of every part of our self allows us to become who we are and that *becoming* is intimately related to the concept of self.

The participants in Studies II and III were in the midst of recapturing self-care and felt like strangers to themselves in their new life situations (Study II). The participants who had a stroke expressed how closely self-care was linked with their former identities, which they desired to resume. For one woman, self-care activities such as dressing were closely related to her identity as a personal secretary for a prominent company, and she expressed a lack of opportunity to practice activities of personal significance, wearing high heels or applying makeup. The performance of these activities had not been assessed by the occupational therapists, and the woman was judged to be independent in self-care. This finding was in line with Clark (1993), who highlighted the importance of using (in therapy) activities linked to the clients' former identities and social roles. According to Seymore (1998), activities as self-care are integrated in a social context and influence how people look at you and how you look at yourself. Many previous studies have identified experiences of a loss of identity among persons living with the consequences of a stroke (Ellis-Hill & Horn, 2000; McKevitt, et al., 2004) and a spinal cord injury (Hammell, 2007a, b). However, the participants in Studies II and III had just started to discover and become familiar with their new bodies and life-worlds in order to know how to handle their daily activities, as self-care, which also has been described in a study by Tham and colleagues (2000).

The phenomenological studies in this thesis illustrate the lived experience of the early period of *doing, being and becoming* (Wilcock, 1998) after a stroke or a spinal cord injury. By doing self-care activities, the participants in Study II linked to the former taken for granted body (i.e., habit-body), and for a few participants these experiences had probably begun to be incorporated in their new habits which also have been shown in previous phenomenological studies (Tham et al., 2000; Erikson et al., 2007). According to Merleau-Ponty (2002/1945) and Dahlberg and colleagues (2001), knowing is characterised by when the persons' understanding and knowledge, based on their experiences, become embodied. For the participants in this research project, the understanding and knowledge had probably not yet been embodied, but the recapturing self-care can be viewed as an important platform for their continued process of *becoming*.

For the participants in Studies II and III, the recapture of self-care did not end at the time for the interviews; rather they expressed their future horizons as uncertain yet filled with desires and hope. One clinical implication based on the reasoning above is that occupational therapists need to be aware of the importance of recapturing self-care for the clients' continued process of *becoming* and for connecting their past lives with their future lives. As self-care is closely linked to their former habit-body, enabling experiences from doing self-care may help the clients connecting to the former body and life but also to the future *becoming*.

Aspects enabling the recapturing of self-care

Studies I, II and III elucidated some important aspects that contributed to the recapturing of self-care during the early phase of a rehabilitation process, in particular 1-3 months after a stroke or a spinal cord injury. In the following section, I will discuss these aspects.

Recapturing occurs in social interaction

The findings in Studies I-III indicate that recapturing of self-care occurs in different types of social interactions that also were changing during the rehabilitation process. In other words, the recapture of self-care was not accomplished in isolation from others. These findings were verified by both the therapists (Study I) and the clients (Studies II-III) and have been integrated as an important part in the development of the CCSCI evaluated in Study IV. The participants in Studies II and III expressed that immediately following a stroke or a spinal cord injury they needed social support and assistance in performing certain activities, which

later in the process changed to a need of more emotional support (Study III). In both Studies II and III, the participants described themselves as going from passive receivers to more actively performing activities, and that their need for support gradually changed during their development of becoming more active.

In Study I, the occupational therapists tried to understand the client in order to establish a meaningful relationship with the client and by then building the self-care training. During the self-care training process, the therapists described themselves as chameleons since they felt that they needed to change themselves according to the clients' needs for support in different self-care situations. Understanding the client in order to establish a meaningful relationship is in line with a client-centred approach (Law, 1998) adopted in Study IV and in agreement with Gahnström-Strandqvist and colleagues (2000), who identified therapeutic strategies emphasizing the importance of creating a relationship based on mutual trust. Therefore, in the CCSCI evaluated in Study IV, the first step of the intervention was to create a relationship with the clients.

Based on the findings in Study I, the therapists seem to play a crucial role in adjusting their support in therapeutic situations with different challenges, which is in accordance with the findings of Gahnström-Strandqvist and colleagues (2000), as well as Wohlin Wottrich and colleagues (2007). Another main finding in Study III was that the participants with a stroke or a spinal cord injury differed in how they attributed their relationship with their occupational therapists. In this study there were powerful experiences regarding to the interaction with the therapist, a "WE" symbiosis, when the participants became very close to the therapists and talked about "we" in most of the sentences. The "we" are viewed in Gahnström-Strandqvist and colleagues' (2000) study as a necessary partnership between the client and the occupational therapists. It seemed to be a connecting link in the shared work in the doing context, i.e., the rehabilitation process, where both the partners need to be active in the performance as well as in a dialogue. A clinical implication is that the professionals need to be aware of the influences that the relationship could have in a self-care intervention.

Experiences contributing to change and development

The findings from Studies I-III indicated that enabling significant experiences through trying and practicing self-care activities was a prerequisite for recapturing self-care. This conclusion is in accordance with Kielhofner (2008) and Merleau-Ponty (2002/1945), who asserted that

persons develop skills and knowledge by having experiences that link to past experiences. Mattingly (1998) outlined how therapists work to create significant experiences for their clients “*because if therapy is to be effective, therapists must find a way to make the therapeutic process matter to the client, to make it meaningful to the client*” (p. 82). In Study I, the occupational therapists described how they enabled significant experiences through practice, by using different strategies, in order to make the competence visible for their clients, which was in accordance with how the persons who had had a stroke and a spinal cord injury expressed the importance of recapturing self-care through trying (Study II). By doing self-care activities, the participants in Study II regained a sense of control, which according to Hammel (2007) is important to be able to do things to envision a future engagement in meaningful activities.

The participants in Study II also described that experiences from doing “harmless activities” that were less threatening than, for example, self-care activities aroused feelings of being able to do something with the body; these experiences seemed to be helpful when trying out activities as self-care. Experiences from “harmless activities” have not been mentioned before in relation to recapturing self-care. The participants with a stroke and a spinal cord injury differed in how they viewed the training situation (Studies II-III). However, through their experiences of doing activities such as self-care it seemed as if they became familiar with these activities and started to handle them better. To have these significant self-care experiences contributing to change and development have not been described before in empirical studies, but they are in line with previous phenomenological studies (Eriksson, 2007; Erikson et al., 2007; Lampinen & Tham, 2003; Tham et al., 2000; Tham & Kielhofner, 2003) describing how experiences from doing may contribute to development in the rehabilitation process. One clinical implication is that therapists can facilitate recapturing of self-care by enabling their clients to practice self-care and to use trial and error, experiences that may help the clients to find new solutions to do their self-care. These findings from Studies I-III served as a base for using the Goal-Plan-Do-and Check-strategy (Polatajko et al., 2001) included in the CCSCI evaluated in Study IV.

Enabling a sense of control and autonomy

The findings in Study II showed that gaining a sense of control and independence seemed to enable further development in the recapturing of self-care as well as development in the

rehabilitation process. The participants (Study II) expressed that they recaptured self-care through the doing of activities. Both the participants in Study II and the occupational therapists in Study I described the importance of taking control in self-care and the therapists described how they tried to create a seeing situation in order to support their clients to take control in self-care. By gaining control and independence seemed to be closely linked to perceptions of autonomy and agency, which seemed to be the point of departure for making activity choices.

Independence has, during the history of occupational therapy, been an important goal for intervention. Rogers (1982) outlined that the requirements for independence are competence and autonomy, and that autonomy is reflected in the ability to make choices and have control over one's environment. Studies I-III focused on recapturing self-care in the early period of rehabilitation after a stroke or a spinal cord injury, and the participants (Study II) had just started to feel control, make choices and to feel a sense of being actors and less dependent on others, which is in line with the reasoning of Söder (1989) who defined autonomy as the opportunity to be able to influence, choose, and make decisions that concern one's existence, even if each person's need for assistance might vary in accomplishing these choices and decisions. In the prologue of this thesis, I presented the story of a man who needed two weeks of intense practice of self-care activities to realize that donning socks was something that he could choose to have someone else to do instead of doing it himself. The extra energy that he gained from having someone else assisting him with this task allowed him to perform activities that were more important to him such as visiting the library at the hospital. By having these experiences through doing, he discovered what he actually wanted to do and could formulate and make his own decisions. The story also makes explicit the importance of discovering disabilities to gain a sense of control (Tham et al., 2000) and to be aware of what choices one should make. Previous studies have also shown a correlation between stated importance of self-care and independence in daily activities (Sivaraman Nair & Wade, 2003; Hammell, 2007a), which is in line with the story presented in the prologue.

Since independence is a phenomenon closely linked to occupational therapy, both in assessments and interventions, it is of importance to better understand its characteristics. Based on the findings of Studies I-III and the reasoning above, I argue that focusing rehabilitation on recapturing self-care (i.e., self-care intervention) in the beginning of rehabilitation will enable a sense of control and independence, which can serve as a platform

for the continued long-term rehabilitation, enabling engagement and participation in valued everyday occupations as recreational activities and work (Eriksson, 2007).

Creating an enabling context

The meaning of context in recapturing self-care has not been explored earlier using a phenomenological approach. Study III has highlighted some contextual aspects that appeared to play a crucial role in the recapturing of self-care. These findings were integrated in the course as overall strategies to take in consideration and to use by the occupational therapists conducting the CCSCI in study IV. This section will further discuss and focus on some aspects of importance for creating an enabling context.

The use of expectations in the air

The findings in Study III showed that the participants experienced “expectations in the air,” which seemed to contribute to change and development in self-care. “Expectations in the air” has, according to my knowledge, not been mentioned before in the occupational therapy literature. The nature of the experiences of expectations in the air was described in Study III as a sense or a feeling of intangible and unspoken expectations of how to act, as, for example, to increasingly perform self-care activities. The expectations were implicit and integrated in the environment and in the attitudes of others coloured by values and norms. In the literature, concepts as expectations according to values and norms are very much related to the concept of independence (Cole, 2004; Hammel, 2006), but in this literature these concepts are discussed from a long-term perspective on disability, not in the early period of rehabilitation as in this research project where the participants in Study III experienced expectations that sometimes could be explicit verbal expressions as in asked questions. To have an understanding of these different types of expectations and how they might enable the recapturing of self-care could be useful in the clinical everyday work at the rehabilitation clinics. By discussing and reframing the specific self-care goals as in the CCSCI the use of the relevant expectations in the rehabilitation team-members might lead to a more explicit understanding of the expectations for the therapists but also for their clients.

The importance of Time

In this research project there are several aspects in the findings related to time and how time may contribute to the recapturing of self-care (Studies I-III). I also found aspects of time that

were related to the development and implementation of the new intervention CCSCI. The occupational therapists in Study I used strategies such as giving their clients time and balancing the time in accordance to the clients' needs and at the right point in time mentioned as timing. According to Mattingly (1998), the person's narrative time differs from the biomedical time because it is actor-centred rather than disease-centred. Time in Study I had a close affinity to the recapturing of self-care; as a therapist, the use of time was seen as a useful therapeutic medium. Time used in different ways seems to be a prerequisite to recapturing self-care. As an occupational therapist as well as others in the near of the clients may need to be informed in order to give the right support, which also has been stressed in other studies (Tham & Kielhofner, 2003). Gahnström-Strandqvist and colleagues (2000) identified time as one consideration in the decision-making process of the occupational therapist, but also that the occupational therapists should be attentive to the clients' time rhythm in their therapeutic process.

In Studies II and III, the persons depicted a body tiredness that influenced both what they actually did in self-care but also how they saw the content of their rehabilitation. The participants also expressed their needs of down time. Findings indicated that the persons after a stroke or a spinal cord injury need time for reflecting and doing nothing as well as a need of taking the time it takes to do their self-care activities in the beginning of the rehabilitation process. The self-care activities were no longer taken for granted and the body did not disappear in doing (Kielhofner et al., 2008), which seem to result in that the participants needed to use much more energy and time (Study III) which also has been found in other qualitative studies (Hjelmblink & Holmström, 2006; Kvigne & Kirkevold, 2003). Hammell (2007a) used the term biographical disruption comprising three dimensions—the body, conceptions of self, and time suggesting that an injury leading to an inability to perform valued occupations of daily life may lead to a sense of loss in these domains. Hammell's (2007a) findings also supported the linkage between engagement in valued occupations and the use of time in personally meaningful ways.

In the context of Study IV, one challenge was to develop a new intervention by integrating the knowledge from research in the knowing of the occupational therapists responsible for conducting the CCSCI in Study IV. This process may take some time. According to Wilding and Whiteford (2006), it takes time to change the role of occupational therapists and their ways of working in clinical practice, which was shown in an action research study of

everyday occupational practice (Wilding & Whiteford, 2006). Taylor (2007) emphasised the necessity of having the possibility to read research as well as time to reflect and discuss in collaboration, if possible, with the researcher but also in workshops with colleagues. To change a routine and a way of doing activities need to be incorporated in the life-world as well as the lived body, even for the occupational therapists. The health care system needs to take this into consideration when they at the same time are asking for faster and more effective rehabilitation programmes (Dysart & Tomlin, 2002; Karlsson & Törnquist, 2007). One clinical implication is that rehabilitation settings and contexts need to take into reflection a person's need for time and use of time when, for example, planning the intervention. Taking into concern that time at rehabilitation clinics is becoming shorter, one dilemma is that there is not enough time for the clients to experience the process of recapturing self-care as well as for the occupational therapists to take part in and implement the new upcoming research in their daily practice.

Developing and implementing a new self-care intervention

To develop and evaluate a new self-care intervention was one part of the general aim of this thesis. When searching for research on self-care intervention, a knowledge gap was found. There was a lack of studies concerning the lived experiences of recapturing self-care as well as studies evaluating the effects of well-defined self-care interventions. In line with current described "*scholarship of practice*" (Kielhofner, 2005), the CCSCI was developed in close collaboration between the researcher and occupational therapists working in rehabilitation settings.

The aim of this new CCSCI was to enable persons with a stroke to resume responsibility for their self-care, as well as to influence their own rehabilitation process. However, the results of Study IV did not show any statistically significant differences between the two groups in outcomes regarding dependence/independence in ADL, life satisfaction, caregiver burden or use of services at the three-month follow up. When comparing clinically significant improvements in ADL between onset and at three months on an individual level. These results indicate a difference in effect between the CCSCI and the ordinary self-care training, in favour of the CCSCI. However, considering the limited sample size of the study, the results should be interpreted with caution. Many different aspects may have interfered with the outcomes of Study IV.

For example, it might be expected that the improvement in the intervention group (CCSCI) would continue after three months since the participants, as a part of the CCSCI, have learned to apply the *goal-plan-do-check* strategy (Polatajko et al, 2001) that can be applied to any new self-care problems encountered, but since the follow-up presented in this study was conducted at three months, this plausible effect was not investigated. However, outcomes at six and twelve months will be analysed and presented in a future study.

Another aspect that might have interfered with the results of Study IV that it is complicated to isolate the influence of the CCSCI, due to the use of other health care services, e.g., home rehabilitation, day-care rehabilitation, etc., which both the IG and the CG received (see Table III in Study IV). Previous studies (Legg et al., 2007; Steultjens et al., 2003) have highlighted that it can be difficult to compare occupational therapy interventions since occupational therapy is a complex intervention, which was shown in Study IV, Table IV, describing the content of the occupational therapy interventions received in the IG as well as the CG.

The complicated process of developing the CCSCI needs to be further discussed. For example, to be able to conduct the CCSCI, the occupational therapists needed to develop an understanding of the lived experience of recapturing self-care as presented in Studies II and III. They also needed to gain and integrate knowledge of the theories and concepts that were presented as a theoretical frame of reference in the course, as, for example, client-centred practice. Several authors have stressed the importance of involving the clients more (Röding et al., 2003) and to clarify the rationale of the intervention (Grant et al., 2004; Röding et al., 2003). When comparing how the occupational therapists in Study I viewed their client-centred perspective with how the participants in Studies II-III gave examples of not being part of the intervention and not understanding the rationale behind the intervention, there were discrepancies. One example was that participants with a stroke in Study II saw self-care as something they just needed to do and that training was picking pegs. At the same time they were upset when they did not understand why they were picking these pegs. These findings were taken in consideration when developing the CCSCI.

The collaborative interaction (Study III) between clients and occupational therapists (Craik, Davis & Polatajko, 2007) as well as between the researcher and the therapists (Study IV), seem to be essential for the occupational changing process to occur (Kielhofner, 2005; Taylor, 2007). One reason why the client-centred practice could be difficult to implement in the

clinical work could be that the rehabilitation clinics still might be influenced and steered by the biomedical perspective (Wilding & Whiteford, 2007). The occupational therapists conducting the CCSCI in this Study IV were all working in rehabilitation clinics where the biomedical perspective often is the dominating paradigm, which according to Wilding and Whiteford (2006) may hinder the occupational therapists to clarify and use their own paradigm focusing on enabling occupations. To be in a context using this “mixed paradigm” could be even more frustrating and confusing for the clients when trying to sense the “expectations in the air” (Study III). This reasoning supported the need for developing a well-structured self-care intervention, as the CCSCI evaluated in Study IV, highlighting the setting of occupation-based goals in collaboration between the clients and occupational therapists.

Evidence-Based Practice as the golden standard

This thesis contains three qualitative studies and one RCT-pilot study where the findings from the qualitative studies served as a base for developing a well-defined self-care intervention in collaboration between the researcher and the occupational therapists. A RCT design was used in a pilot study to evaluate the CCSCI, which is seen to be a good design according to principles for Evidence-Based Practice (Taylor, 2007). However, the use of qualitative research awakens thoughts and criticism in the ongoing debate of Evidence-Based Practice classification, using the RCT-design, as the golden standard (Taylor, 2007). Despite the evidence of the beneficial effects of occupational therapy in improving personal-ADL after stroke, the rationale and strategies for the self-care interventions are often vaguely defined and sparsely described in RCT-studies (Legg et al., 2007, Steultjens et al, 2003) and consequently it might be hard for rehabilitation professionals to implement these interventions into clinical practice. Based on experiences from this research project (Studies I-IV), I argue that in order to develop new interventions there is also a need of knowledge derived from qualitative studies that may generate an understanding among occupational therapists and other rehabilitation professionals. By understanding the nature of the lived experience (Karlsson, 1993) of recapturing self-care and how experience may change (Kielhofner, 2008) in the recapturing process, therapists can integrate this understanding into their clinical work and transfer the understanding to new contexts (Dahlberg et al., 2001). However, this type of understanding-based knowledge is difficult to use as evidence in Evidence Based Practice (Taylor, 2007).

I purport that in order to develop a new intervention, the research-based intervention should be based on both 1) evidence derived from quantitative studies, and 2) knowledge based on qualitative studies aiming to describe the characteristics of experience based phenomena as well as to generate an understanding that can be generalised (Dahlberg et al., 2001). To be able to develop new interventions and assessment instruments, the clients' lived experiences as well as the occupational therapists' clinical knowledge and experiences are important to integrate in research-based knowledge. This research project could be used as a model for developing a new intervention, in collaboration between the researcher and therapists, by integrating a series of systematic qualitative studies. The intervention may then be evaluated in a RCT-study to evaluate the effect of the intervention, but first there is a need of conducting a pilot study (Study IV) to evaluate the feasibility of design and methods in order to plan the RCT. This model for developing and evaluating a new intervention is in line with how action/participatory research are conducted (Kielhofner, 2005). Action/participatory research may be useful when the rehabilitation clinics have valuable data, practical knowledge and capacity, and when the researchers have the methods and theories with knowledge to supervise, for example, the occupational therapists (Kielhofner, 2005).

Methodological considerations

This research project contributes with new knowledge on the experiences of conducting self-care training from the occupational therapist's point of view (Study I) as well as the lived experiences of recapturing self-care after a stroke or a spinal cord injury (Studies II and III). In the following some methodological challenges in these studies will be discussed.

The design

In this thesis the phenomenon of recapturing self-care was studied from diverse perspectives with altered design and methods. A phenomenological approach as well as an experimental (RCT) design was used in this research project. Studies I-III were based on data from single interviews with occupational therapists (Study I) and persons with a stroke or a spinal cord injury (Studies II and III) in their early phase of rehabilitation (1-3 months after onset). The context for the RCT pilot study (Study IV) was conducted in the early period of rehabilitation after a stroke. Both qualitative and quantitative designs and methods may give complementary data and thereby the weaknesses of a single approach could be diminished (Polit & Beck, 2004). This pluralistic design using complementary methods and perspectives

is useful in occupational therapy research when studying complex phenomena as recapturing self-care, which can strengthen the validity of the findings from this research project (Molineux & Whiteford, 2005). Barker and Pistrang (2005) stated that no single research approach is best overall; rather what is important is that the methods are appropriate for answering the research questions. A phenomenological approach is appropriate to use when studying how phenomena are presented in persons' lived experiences (Studies I-III) (Karlsson, 1993) and an RCT-pilot design is appropriate when evaluating the effect of, intervention in and the feasibility of methods used (Polit & Beck, 2004).

However, there are also some limitations regarding the study designs used. For example, by using a longitudinal design the process of recapturing self-care could have been studied in a more rigorous way. However, a choice was made to study the phenomenon when the participants were in the midst of recapturing self-care. Also the design used in Study IV could be viewed as limited since it was a pilot study and that the results due to the small sample could not be generalised. In Study IV, qualitative data from the experiences of clients, significant others and therapists (from both intervention groups) could have given complementary information of the process of recapturing self-care, from different perspectives. However, the RCT design is the most widely accepted research design for testing the efficacy of health care intervention; it could be argued that occupational therapy is a complex intervention that is difficult to compare with more plain drug-studies (Nelson & Mathiowetz, 2004).

Inclusion of participants

The aim of phenomenological studies (Karlsson, 1993) is not to generalise findings, but to identify the meaning-structure of a phenomenon and to generate an understanding of the lived experience related to a specific phenomenon (i.e., recapturing self-care). It is recommended to select participants that can describe a variety of experiences related to the phenomenon, which can provide a richness of varied data representing different characteristics of the phenomenon under study (Dahlberg et al., 2001; Karlsson, 1993). Therefore, a choice was made to include participants that commonly participate in self-care training in the early period of rehabilitation but that are known to experience a wide range of impairments and disabilities, i.e., participants with a stroke and participants with a spinal cord injury (Studies II and III). The participants in Studies II and III (same participants in both studies) were selected

consecutively due to the limited number of clients with a spinal cord injury at the hospital, i.e., all clients were consecutively selected to participate in the study. The most common sampling method used in qualitative studies is theoretical or purposeful sampling (Polit & Beck, 2004). The selection method used in Studies II and III resulted in a limited number of women (2/11) which could have interfered with the findings. In order to gain a homogenous sample concerning their daily activities (i.e., work), only persons <65 years of age were selected.

The occupational therapists in Study I were all selected through recommendations by colleagues as generally considered to be “good “occupational therapists, who were conducting self-care training several times a week in their clinical work with clients who had suffered a stroke or a spinal cord injury, all of them with at least five years of clinical experience. This method for selection was inspired by the work of Gahnström-Strandqvist and colleagues (2000). The fact that the therapists had many years of clinical experience might have influenced how they described their experiences of conducting self-care training. Some strategies they used were probably taken for granted and integrated in their tacit knowing (Polanyi, 1966) and therefore difficult to describe in the interviews.

In Study IV, 40 persons with a stroke and their significant others (n=16) were included, which is a limited sample concerning the possibility to generalise findings. The aim of this pilot study was to evaluate the effect of the CCSCI and the feasibility of design and method for an RCT-study. One limitation is that small samples are sensitive for dropouts and at the three-month follow-up there were seven dropouts in Study IV. The time for inclusion might be questioned as some of the participants improved while waiting to come to the rehabilitation clinic and were no longer in need of self-care intervention. This information was important to take in consideration when designing a future RCT. This finding was supported by Kwakkel, Kollen and Twisk (2006) who found that the spontaneous recoveries explained 16% to 42% of the observed improvements of body functions and activities in the first weeks after stroke.

Data collection

Studies I, II and III are based on interviews and Kvale (1996, p.9) stated “*If you would like to know how people understand their world and life why not talk to them*”. In order to get rich and varied data (Dahlberg et al., 2001; Karlsson, 1993), the occupational therapists in Study I were asked to describe their experiences of conducting self-care training (therapeutic story) with one particular client with a positive or negative outcome. However, most occupational therapists spontaneously described successful self-care training, which may have influenced the “positive” picture of their therapeutic strategies presented in the findings. Maybe written protocols would have been a better method to use to obtain data representing negative outcomes of self-care intervention. According to Karlsson (1993), it is of importance to get varied data representing different characteristics of the phenomenon under study.

In order to gain the experiences from the persons in Studies II and III, when they were in the midst of their recapture of self-care, the interviews were conducted 1-3 months after a stroke and a spinal cord injury, at one occasion. One single interview is viewed to be a limitation in qualitative research since the possibility to create a thorough relation based on trust, between the researcher and the informant, is restricted when meeting once, which also may limit the data’s richness and credibility (Dahlberg et al., 2001). However, despite this limitation, the participants in Studies II and III generously shared their experiences from doing self-care activities. Interview questions were informal and open-ended and focused on how they experienced and handled concrete self-care situations, which generated rich data. In fact, the data was rich and interesting enough to make up the basis for two studies (I and II). Kvigne and colleagues (2002) concluded that in phenomenological research an openness, on the part of the researcher, is a prerequisite for gaining access to the informants’ life-world and, if it is true to the sense, there is a question of how well all the statements agree with one another (Karlsson, 1993).

The use of the assessments in Study IV

To find assessment instruments to evaluate the changes in ADL independence in Study IV was difficult. The most frequently used instruments did not seem to be sensitive enough to the small changes of importance for the person or to be of clinical significance; according to Studies I-III there were activities such as putting on make-up that might be of importance for the person’s experiences of being independent. Instruments such as the FIM (Grimby et al.,

1996) and the Barthel Index (Mahoney & Barthel, 1965) are well known and standardised, but do not include these activities. Another way of measuring ADL ability could be to use an observation-based instrument as the Assessment of Motor and Process Skills (AMPS) (Fisher, 2003), which includes more challenging activities, which are sensitive to changes but could be more complicated and time-consuming to use. Donnelly and Carswell (2002) stated that clinicians and researchers must be aware of the strengths and the weaknesses of each individualised outcome measure and ensure that the use of a measure is compatible with a client-centred approach. Study IV had the intention to use client-centred assessments, as Stroke Impact Scale (Duncan et al., 1999), assessing the clients' perceived difficulties in for example ADL. The reliability of the data collected in Study IV was strengthened by the fact that the same research assistant (experienced occupational therapist), who was blinded to the group allocation, collected all data at baseline, one and three months after a stroke.

Data analysis

In Studies I-III, the EPP method (Karlsson, 1993) was used for data analysis, which was a sufficient method to identify how the studied phenomenon, recapturing self-care, was characterised in the lived experiences of the participants. The major challenge during the analysis was for the researcher to be open to how the phenomenon presented itself in the lived experiences, which is crucial in the phenomenological analysis in order to discover the essence, structure and character of the phenomenon (Karlsson, 1993). Since my pre-understanding was coloured by my clinical knowledge but also my taken for granted and embodied knowledge (Dahlberg et al., 2001) as a clinician in the field of neurology, I needed to be aware of this knowledge and bracket (Karlsson, 1993) it in order to be open to the life-worlds of the participants. In order to handle the pre-understanding (Dahlberg et al., 2001), the analyses were discussed and refined several times by using a "horizontally consistent interpretation" between the researchers, making sure that each characteristic fit well with the other characteristics from analyses and at the same time clarifying the most valid interpretation (Karlsson, 1993). Another challenge was that the main supervisor had been involved in a series of previous phenomenological studies within the same area of research, which might have influenced the analyses and findings since it was easier for the senior researcher to see how the phenomenon presented itself in the lived experiences. However, in the later process of analyses in Studies II and III, the co-supervisor had a more active role in discussing and putting critical questions to the interpretations made. With a conscious

awareness of this problem, the findings that appeared as new and unexpected characteristics were presented and discussed with experienced occupational therapists and researchers in the neurological rehabilitation field (peer-review) to further validate the interpretations and findings.

The statistical analyses of data in Study IV could not identify any statistical significant differences between the two groups three months after a stroke. However, when comparing clinically significant improvements in ADL on an individual level, 93% of the participants in the CCSCI group improved in comparison with 63% of the participants in the CG who received ordinary self-care intervention. In small samples it could be valuable to evaluate changes on an individual level, which is also in line with the main methodological approach used in this thesis.

CCSCI

To use the model of developing a new self-care intervention in collaboration between the researcher and occupational therapists was challenging and needs to be discussed. One strength, in this approach was that the new intervention was evaluated in a pilot study before it will be applied in an RCT, which gives place for further developments of the intervention. One limitation was that the occupational therapists were invited to participate in a “course” which might have raised expectations for a passive learning situation instead of using what Kielhofner (2005) calls a knowledge-creating sharing model. Implementation takes time and this model requires the occupational therapists to change their therapeutic relationships with their clients, which might not have been possible for the therapists within such a short time since to integrate new knowledge takes some time. The researcher followed and supported the occupational therapists during the implementation process, which is in line with the principles for participatory research (Crist & Kielhofner, 2005). It seemed as if the planning and content of the course, especially working with the cases, worked out fine but to develop the research-based self-care intervention put demands on an openness and flexibility amongst the occupational therapists for them to be able to change their procedures and to work more client-centred, also discussed in the general discussion.

In conclusion, the CCSCI is now defined and has a clear structure to follow, which has not been the case in previous studies evaluating self-care intervention (Legg et al., 2007; Steultjens et al., 2003). However, the CCSCI needs to be further developed to be used in a

future RCT, and the course would preferably be named a workshop and be extended over a longer period of time in order to make it possible for occupational therapists to integrate and implement the research-based knowledge and understanding.

Generalisation of findings

The aim of phenomenological research is not to generalise findings, but to make visible the meaning structure of the participants' life-world experiences related to the studied phenomenon in order to gain a deeper understanding of the meaning of recapturing of self-care. General characteristics were found (Studies I-III), and there were some characteristics in agreement with other phenomenological studies (Erikson et al., 2007; Hammell, 2007a,b; Kvigne & Kirkevold, 2003; Tham & Kielhofner, 2003) but also some new characteristics that were discovered. The knowledge from Studies I-III served as a base in the development of the CCSCI. In Study IV the RCT design was tested in a pilot study in order to integrate the results when planning a larger RCT study. In a future RCT study, the CCSCI, if implemented in a later phase of the rehabilitation process, does not necessarily have to be limited to recapture self-care activities after a stroke since the intervention approach can be applied into domains of other occupations and groups of clients. The new RCT can probably be seen as an application of the results to a new context (Dahlberg et al., 2001).

Ethical Issues

Persons who have had a stroke or a spinal cord injury and their significant others could be described as exposed and vulnerable in the early phase of rehabilitation. They commonly perceive their bodies as changed and their life-worlds as unfamiliar and chaotic, as seen in Studies II and III. All of these experiences must be taken into consideration when conducting research in rehabilitation settings, and there are several ethical issues that can be raised. First of all, the studies in this thesis were approved by the Ethical Committee at Karolinska Institutet. All participants in the studies (Studies I-IV) were given both written and oral information regarding the project's aims, research methods and procedures as well as methods of ensuring confidentiality. They were also given options of terminating their participation in the studies at any time. All study participants gave their informed consent to participate, so that we could obtain the voluntary participation of occupational therapists (Study I), clients (Studies II-IV) and significant others (Study IV). In Studies II-III a choice was made to avoid presenting data on the participants' impairments or disabilities as it would have been easy for

the readers of the scientific reports, considering the limited sample size, to recognise a particular client. This choice was also based on the nature of the research questions focusing on the lived experiences of recapturing self-care in contrast to the lived experiences of impairment or disability, which have been the focus of a few previous phenomenological studies (Tham et al, 2000; Erikson, 2007).

The fact that all data were collected by occupational therapists who had long clinical experience in the field of rehabilitation after stroke or spinal cord injury (Studies I-IV) probably minimised the risk of violating the participants integrity, as the researcher (Studies I-III) and research assistant (Study IV) were used to handling situations demanding their sensitivity to the participants' possible emotional reactions. When conducting the interviews the researcher strived to be as sensitive and attentive as possible. She repeated the aim and purpose of the interview before the interview started, always being aware that any signs of discomfort and/or embarrassment would terminate the interview. The qualitative interviews conducted in Studies I-III could have aroused emotional reactions and feelings of embarrassment, but since the interviews focused on the participants' experiences from concrete daily activities and situations it seemed that they appreciated telling about their experiences. This has also been seen in previous phenomenological studies.

Another ethical dilemma for the participants in Study IV might have been that they felt obliged to participate in the study due to their dependency on others, as they were asked to participate in the project very early after stroke onset (Days 3-5). At that stage patients commonly experience psychological stress and may not yet be aware of the consequences of stroke (Tham et al., 2000). It should be noted that in Study IV there was no exclusion of participants with aphasia, which is common within this area of stroke research.

The randomization procedure used in Study IV could also have aroused feelings of uncertainty, as there was a risk of being selected for the control group receiving ordinary self-care training. However, the participants were informed that ordinary self-care training is a reliable intervention and that there was still no documented effect of the new CCSCI.

CONCLUSIONS

The findings from Studies II and III indicate that the participants, who were in an early phase of rehabilitation, experienced their bodies as different and their life-worlds as unfamiliar and chaotic. They expressed a need and desire to recapture their self-care activities in order to become familiar with their new bodies and lives as well as becoming less dependent on others.

The findings from Studies I-III indicate that the persons with stroke or spinal cord injury recaptured their self-care through having experiences from doing and practicing self-care. By doing self-care it seemed as if they became familiar with their new bodies and life-worlds but also connected their past life with future life, which seemed to be of importance as a base for their continued rehabilitation process.

The findings from Study II indicate that gaining a sense of control and independence in self-care is closely linked to perceptions of self, autonomy and agency, which may be the point of departure for making activity and occupational choices.

The findings from Studies I-IV indicate that recapturing of self-care is a process that occurs in different types of social interactions that may change in character during the process. The occupational therapists seem to play a crucial role in establishing a meaningful relationship with the client and in adjusting their support in therapeutic situations in order to enable the recapture of self-care.

The findings from Studies I-III indicate that there are several aspects that together may enable the recapturing of self-care after a stroke or spinal cord injury, as for example having significant experiences contributing to change and being in a context enabling recapture; comprising aspects as expectations in the air and therapeutic use of time.

The results from Study IV did not show any statistically significant differences between the two groups (IG, CG), but when comparing the groups on an individual level the results appears promising concerning the effect of the CCSCI on independence in self-care after stroke, and a large RCT is warranted.

The design of this research project could be used as a model for developing a new intervention in collaboration between researchers and clinicians and by integrating a series of qualitative studies. The intervention can then be evaluated in a RCT pilot study in order to evaluate the feasibility of design and methods for planning a larger RCT.

Future studies

During this research process, several new research issues have emerge that could be the subject for future studies. The most important study would be to further develop the intervention and to accomplish a larger RCT-study. Based on the results of the pilot study (study IV), the future RCT should preferably be conducted in a later phase of rehabilitation after stroke in order to avoid the influence of spontaneous recovery and other rehabilitation services. The client-centred intervention can be applicable in other occupational domains such as recreational activities or productivity which may be of importance for the individual client in a later phase of rehabilitation. The intervention should be developed and implemented in close collaboration between the researchers and occupational therapists that should be followed in their implementation process by using an action-participatory research design. In order to know more about the process of recapturing occupation from different perspectives, qualitative longitudinal data should be collected in a sub-group of clients and their significant others. In this project the relationship and collaboration between the clients and their occupational therapists would be interesting to study and the questions of what happens when the symbiosis between the clients and their occupational therapists ends is of particular interest. Finally, there is a need of more phenomenological studies that can serve as a basis for developing an individualized therapeutic core.

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