Rehabilitation in place

Experiences of daily occupations after acquired brain injury

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ABSTRACT

The general aim of this thesis was to better understand and describe the experiences of occupations in the context of daily life and the meaning of actions in different places (training apartment, rehabilitation setting, home and workplace) for persons of working age with acquired brain injury (ABI) during a rehabilitation process.

The aim of the study I was to investigate how persons with acquired brain injury experienced their 1-week stay in an apartment fitted with electronic aids to daily living (EADL). Eleven participants with acquired brain injury (of working age) were interviewed on the last day of their stay. A phenomenological method was used during analysis. The findings are presented in a meaning structure comprising 4 main characteristics: Plunging into the EADL-equipped environment, landing and feeling comfortable with the new environment, incorporating the "new" in daily activities, and taking off for the future.

The aim of study II was to identify what characterized the lived experience of memory impairment in daily occupations during the first year after acquired brain injury. Four participants, aged 22-61, were interviewed over four occasions during the first year after acquiring a brain injury. A phenomenological method was used during analysis. The findings are presented in a meaning structure comprising 4 main characteristics that reflects the temporal process of rehabilitation over a year: 1) A chaotic life-world, 2) struggling for a coherent doing in new contexts, 3) conscious strategies in new contexts, and 4) achieving new habits.

The aim of study III was to describe the meaning of actions in different places during one year of rehabilitation after stroke. Qualitative interviews with seven persons, aged 42-61, done over the course of a year were analyzed using a grounded theory method. Seven categories emerged and were presented in overlapping phases as: 1) Workplace in mind, 2) experiences at home enabling reflection, 3) rehabilitation setting creates uncertainty, 4) retrieving inspiration from familiar places, 5) matching the complexity of tasks across places, 6) understanding the reality by confrontation, and 7) on the way to place integration. From these themes, a core category as the main finding in this study emerged: The desire for place integration inspires engagement in rehabilitation.

The aim of study IV was to examine the meaning of acting with others in different places over the course of one year post-stroke. Qualitative interviews with nine persons, aged 42-61, done over the course of a year were analyzed using a grounded theory method. Four categories were identified from the analysis of the participants’ experiences during the year of rehabilitation and were presented in the sequence that they emerged: (1) Not recognized as the person I am, (2) the burden of burden, (3) connection with others through daily life activities, and (4) inspiration from engaging with others. From these themes a core category as the main finding in this study emerged: A process of belonging for integration.

A main conclusion of the findings in the four studies is that the meaning of actions in different places was experienced as a desire for place integration which inspired engagement in rehabilitation. Findings suggest that the following implications can be implemented in clinical practice in order to support rehabilitation after ABI: 1) Connecting activities across places in rehabilitation, 2) integrating familiar activities and places into rehabilitation, 3) creating places that inspire, and 4) supporting acting with others for belonging.
This doctoral thesis is based on the following four papers, which will be referred to by the Roman numerals assigned below:


IV. Erikson, A., Park, M., & Tham, K. Belonging: The mattering of acting with others for persons with stroke during the first year of rehabilitation (submitted for publication).

The editors of the different journals where the papers were published, in press or submitted have been informed that the papers will be printed in this doctoral thesis.
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INTRODUCTION

The objective of this thesis was to better understand and describe the experiences of occupations in the context of daily life and the meaning of actions in different places (training apartment, rehabilitation setting, home and workplace) for persons of working age with acquired brain injury (ABI) during a rehabilitation process.

Acquiring a brain injury commonly means a sudden life-course disruption and an altered situation in daily life, both for the persons with ABI and for their families. Daily life situations become chaotic and can no longer be taken for granted. According to phenomenology, the life world is taken for granted (Husserl, 1970). For example, persons do not need to reflect on how to do activities they are used to doing such as waking up in the morning, taking a shower, getting dressed, eating breakfast or going to work. They do them without consciously thinking of what they do. Phenomenological research has shown that after acquiring a brain injury there is a dramatic change and that persons need to reflect on how to do previously taken-for-granted activities while the contexts for action (home and workplace) are experienced in new ways.

Based on this research, these are some of the questions that I have been struggling with during my research work: How do persons with acquired brain injury (ABI) experience a context equipped with electronic aids to daily living (EADL) during one week stay? How do persons with memory impairment experience doing activities in different settings during one year of rehabilitation? More specifically, what are their experiences of the physical and social aspects of the different settings when doing activities during a year of rehabilitation? Is it even possible to understand the shifting meanings of the experiences of doing activities in different settings for persons with ABI? These questions are based on the assumption that understanding the experiences of an individual person’s “new” life after acquiring a brain injury can be used to help identify the most effective interventions for rehabilitation, in general, and occupational therapy, in specific.

Phenomenological knowledge of how individuals experience ABI would provide useful information for occupational therapy in light of the client-centered paradigm of occupational therapy, which requires identifying each individual’s desires and goals to guide intervention. Since Swedish law requires rehabilitation interventions to be client-centered, there is the added mandate for understanding particular person in context. In order to better understand and make explicit persons’ experiences and the meaning of doing activities in different contexts across time, phenomenological and grounded theory methods enabled me to
enter into such an understanding of the experiences of doing activities in different contexts during rehabilitation, based on the unique experiences of persons with ABI. In this process, further conceptual resources were used that can be thought of as the conceptual framework that guided this process.
CONCEPTUAL FRAMEWORK

The point of departure in this thesis was the experiences of persons of working age with ABI and the meaning of doing activities in different places during their rehabilitation process. Different theoretical perspectives have been used in order to achieve an understanding of the complexity of the meaning of actions in different places. There were three main perspectives taken that formed the conceptual framework of this thesis as follows. The phenomenological perspective used in this thesis was primarily based on how phenomenology is described by and integrated into Karlsson’s (1993) Empirical Phenomenological Psychological (EPP) method. The EPP is based upon Husserl’s (1970) philosophy and, to some extent, the philosophy of Heidegger (1993). This thesis also integrated Merleau Ponty’s (2002) concept of the lived body as “a fusion of soul and body” (p. 94). Additionally, Dewey’s transactional perspective as applied to and developed by Cutchin’s (2003, 2004) conceptualization of place integration and a sociohistorical and cultural perspective on sociality (Carrithers, 1992) as applied and developed in Lawlor’s (2003) conceptualization of socially occupied beings.

The perspectives are, in different ways, interrelated and were more or less present during the research process. For example, the occupational perspective was present during the entire research process, but shifted in accordance with the integration of the phenomenological perspective in occupational therapy (Kielhofner, Tham, Baz, & Hutson, 2002b; Rowles, 1991). Although present during the entire process, the phenomenological perspective (Husserl, 1970; Karlsson, 1993) receded during the last period of research when an occupational science perspective of transaction, focusing on place integration (Cutchin, 2003, 2004), and the conceptualization of socially-occupied beings (Lawlor, 2003) were integrated into the research process.

The occupational perspective focuses on human occupation as described in different theoretical models in which the Model of Human Occupation (MOHO) (Kielhofner, 2008) has been one of the most dominant. This model has, like other models of practice in occupational therapy, been criticized (Dickie, Cutchin, & Humphry, 2006) for having a dualistic view of the person and the environment as separate parts. This view can be problematic when trying to understand human occupation as a dynamic and ongoing process between the person and the context (Dickie et al., 2006). Therefore, a transactional perspective, as used in the concept of place integration (Cutchin, 2003, 2004), was adopted in order to apply a more dynamic view on human occupation. In addition, Lawlor’s (2003)
conceptualization of the human as a “social occupied being” reflected the need to understand how the meaning of doing activities cannot be separated from the social context. This deepens the complexity of understanding how rehabilitation processes must take into account that humans do not just “do” things in isolation, but are “socially-occupied.” The understanding that illness and disability does not just influence individuals, but also their families and others in their social shifts the client-centred perspective to one of the family’s perspective (Lawlor & Mattingly, 2009).

The Occupational Perspective

In this thesis, the term *occupation* has been used as an overarching concept while the term *daily activities* has been used when referring to or describing how individual participants actually did occupations in the different places during rehabilitation. The term action has also been used, based on how John Dewey’s (1980) transactionalism is interpreted and used in the concept of place integration (Cutchin, Aldrich, Bailliard, & Coppola, 2008; Dickie et al., 2006). This will be presented in more detail in the section on place and place-integration.

The occupational perspective applied in this thesis emphasizes the importance of understanding the meaning of doing activities in each individual’s unique life situation (C. H. Christiansen & Townsend, 2004; Davis & Polatajko, 2004; Fisher, 1998; Hasselkus & Rosa, 1997; Kielhofner, 2008; Law, Polatajko, Baptiste, & Townsend, 1997; Yerxa, 1998). According to the MOHO (Kielhofner, 2008), human occupation refers to “…the doing of work, play, or activities of daily living within a temporal, physical, and socio cultural context that characterizes much of human life” (p. 5). The occupational perspective used in this thesis, however, is more in accordance with Christiansen & Townsend’s (2004) view that the concept of occupation is very complex and cannot be defined by just translating the Latin word *occupare* into types of employment. Instead, the concept of occupation includes a complexity of interrelated areas, such as: time use concerning both individual and cultural characteristics, biological and psychological factors, as well as the social conditions that influence how individuals choose what they do. The different and sometimes competing definitions of occupation in the field of occupational science reflect the field’s continued efforts to reach a definition of the concept of occupation. Whether or not that is either beneficial or useful, it is clear that an understanding of occupation requires, according to
Polatajko (2004), “careful examination of the doing, the doer, the context of the situation in which the occupation is found, and the relationships among these elements” (p. 58).

Study I used the concept of occupational adaptation (Schkade & Schultz, 1992). The concept of occupational adaptation is a process involving the person and the occupational environment, or the interaction between them. This process of adaptation focuses on the person’s (internal) adaptation to his or her environment in the context of daily activities. This focus on adaptation to the environment within occupational therapy literature has been criticized as being too dualistic (separating out person and environment) and static (linear, unidirectional change of person adapting to environment) (Cutchin, 2004).

Both studies I and II used the term occupational performance (Baum & Law, 1997). Occupational performance has been a concept in occupational therapy for a long time and describes as a core domain of the practice profession (AOTA, 2002). Occupational performance refers to the “doing” of an occupational form, which is affected by the configuration of or aspects in the environment (Nelson, 1998). Actions making up occupational performance are referred to as skills (Kielhofner, 2008, see p. 102). Habits are a related aspect of occupational performance in the MOHO and defined as “acquired tendencies to automatically respond and perform in certain consistent ways in familiar environments or situations” (Kielhofner, 2002, p. 53). However, this thesis, particularly in studies I and II, takes a phenomenological perspective of habits as it relates to the habit body (Merleau-Ponty, 2002/1945), which is more fully described in the section on phenomenological perspective.

Studies III and IV did not use the concepts of occupational adaptation, occupational performance or habits. Instead, both of these longitudinal studies used the concept of place integration, which builds on Dewey’s (1980) transactional perspective to foreground the dynamic and inter-relational of nature of doing activities in particular places over time (Cutchin et al., 2008). In addition, study IV drew upon a sociohistorical and cultural perspective that foregrounded humans as socially-occupied beings (Lawlor, 2003) to draw out the complexity of the social aspects of experience of ABI across the research settings.

The Concepts of Place and Place Integration

During the research process, the concept of place, as it is applied and developed in the concept of place integration using Dewey’s (1980) transactional perspective, was integrated into the perspective of this thesis. The transactional perspective emphasizes the temporal
dimension of a constantly changing, dynamic, relational and mutual interaction between person and places. Through action, the person and environment are connected and twined together into dynamic and complex unit. Thus, place integration fore grounded the experiences of persons when acquired brain injuries suddenly disrupted the meanings of their actions and in particular settings.

The concept of place links the meaning of experiences to the particular environments in which actions occur (Hamilton, 2004; Rowles, 1991, 2009). According to Rowles (1991, 2009) one can never fully understand a person without taking into consideration; “the place where the person dwells” (p. 81). In Cutchin’s (2004) description of place integration, he refers to the phenomenological roots of Grahame Rowles description of place as “a center of lived meaning, where social, cultural, and physical elements of a person’s environment become one’s place by being woven into being and selfhood” (p. 309). Yet, the concept of place-integration extends this concept of place, by using transactional perspective to focus attention on the process by which meaning is created in a constantly ongoing, dynamic transaction between persons and environment over time (Dickie et al., 2006).

In this view, place is not an easy concept to define because it does not merely describe a physical space. The person and environment are not two different entities that impact on one another. Rather, it is through action that a unifying meaning is created of experiences of doing in particular places. Thus, the concept of place integration provided a broader way to conceptualize how a person, through his or her actions, is integrated into particular places through actions in constantly changing and relational process (Cutchin, 2004; Cutchin et al., 2008; Dickie et al., 2006).

**The concepts of place and place integration in relation to occupational therapy**

The definitions and nature of the environment and the interaction between person and environment differs thou among models. For example MoHO (Kielhofner, 2008) describes the environment as influencing occupational behavior by affording opportunities for performance and/or providing “press” for or influence on specific behaviors. In this description, the environment impacts on how occupations are performed (Kielhofner, 2008; Kielhofner, Tham, Baz, & Hutson, 2002a). In the Canadian Model of Occupational Performance, the environment is an entity outside the person that responds to the actions of a person (CAOT, 1997). While the Person-Environment-Occupational performance model (PEO, Christiansen & Baum, 1997) and the Model of Competent Occupational Performance
in the environment (Hagedorn, 2000) view the environment as something that creates demands on or expectations for occupational behavior. Even though these models provide a view on the interactions between the person and the environment, the way in how these models describe the person-environment interactions differs.

The transactional perspective, as it is integrated in the concept of place and place-integration (Cutchin, 2004), is not explicitly incorporated in the models in occupational therapy and occupational science mentioned above. However, the concept of place integration does build from the concept of place, which has been incorporated into the theory of occupational therapy and occupational science. The concept of place illuminates the various meanings individuals attach to different contexts of action and how those meanings, in turn, affect what individuals do. For example, the onset of an illness or disability may alter the meaning of where one does something, as for example, from a place imbued with meaning and full of opportunities and resources into a place which is demanding and constraining (Kielhofner, 2008). By further drawing from transactionalism, the concept of place shows how “occupation” or what persons do in particular places is “…a type of relational action through which habits, context, and creativity are interplaying toward a provisional yet particular meaningful outcome that is always in process; the type of occupation is defined by the particular combination of habits, context, creativity and provisional outcome” (Cutchin et al., 2008, p. 164).

The physical aspect of a place

Contextual or physical aspects such as, landscapes, built environments, objects, tools, furniture and equipment are necessary when persons are doing their daily activities in different places and colors their experiences and functioning in daily life (C. H. Christiansen & Townsend, 2004; Hamilton, 2004; Kielhofner, 2008). The physical aspects of place are imbued with meaning (Rowles, 1991, 2009) and, according to Hamilton (2004), are connected with memories of experiences that can connect past to the future and give a sense of continuity and energy. These physical characteristics of place were fore grounded in study I (the training apartment equipped with EADL) and in study III (the physical aspects of places in rehabilitation).
The social aspect of doing with others

The conceptual framework of this thesis also used a sociohistorical and cultural perspective on human sociality as developed in occupational science. Since human experiences exist through our interrelatedness with others, the concept of humans as “socially occupied beings” (Lawlor, 2003, p. 426) adopted for this thesis, provided a way to see how the meaning of actions is intrinsically interrelated with whom one is “doing-with.” According to Lawlor (2003), engagement in daily activities isn’t just the doing rather “it is by doing something with someone else that matters” (p. 432). Since long-term rehabilitation involves many different rehabilitation professionals and many family members are also affected by the ABI, family centered care (as opposed to client-centered care) is a “complex social arena” where “…health care encounters involving family members are sites of intense boundary crossing where families and practitioners create, negotiate, contest, and/or modify perceptions, perspectives, and care giving and treatment practices” (Lawlor & Mattingly, 2009, p. 34). Thus, examination of the meaning of acting with others in the rehabilitation process would help support the complex “interpretive acts” that practitioners must make based on their understanding of the meaning of interventions and disability in persons and their families lives from their perspectives (Lawlor & Mattingly, 2009). This perspective was specifically adopted in study IV examining the meaning of acting with others in different places during rehabilitation after ABI.

The Phenomenological Perspective

The following section introduces the philosophical base of the phenomenological perspective used in this thesis (Husserl, 1970). The phenomenological perspective was integrated into the data analysis in studies I and II through the use of the EPP-method (Karlsson, 1993) and throughout the general focus of all the studies on the experiences of persons with acquired a brain injury.

Phenomenology specifically aims to investigate how a phenomenon presents itself through lived experiences in the life world (Husserl, 1970). I chose to use a phenomenological perspective in studies I and II in this thesis to focus on describing the meaning structure of specific phenomena expressed in the participants’ described life-world experiences in different contexts, such as the training apartment (study I) and across rehabilitation, home and workplace contexts (study II). This focus on the meanings of lived experiences in different
contexts aligns with the concept of place that foregrounds the meaning of particular settings as they are experienced. The concept of place is, then, used as a theoretical tool to also bring in a phenomenological perspective in studies III and IV.

Phenomenology, which originates in the philosophy of Edmund Husserl (1859-1938), is intended to analyze the essence of the phenomenon studied. The word “phenomenology” is made up to two elements: “phenomenon” (from the Greek *phainomenon*) which means, “as it appears” or “as it shows itself” and “logy” (from the Greek *logos*) which means “structure” or “essence” (Karlsson, 2004). In phenomenology, “things” are considered as phenomena or things as they present themselves to us. So, in contrast to being led by principle, researchers in phenomenological research are guided by things as they show themselves (Husserl, 1970).

Scientific theories are not to be taken for granted. Rather, the researcher must seek to do full justice to the things/phenomena studied. Phenomenology may be described as an experience-based philosophy (Bengtsson, 2001). By our access to things, we acquire experience of something as manifested via our natural attitude in the world. From those experiences, the phenomena studied must be rendered explicit or identified and described in a way that gives a fair picture of the phenomena studied (Bengtsson, 1998). Thus, in order to describe the phenomena studied, the researcher must be as open as possible to the original and immediate experience of the things (phenomena studied) to be considered by bracketing (temporarily putting aside) theoretical knowledge (Karlsson, 1993).

The life-world

Studies I and II examined the *life-world* of the persons with acquired brain injury. In particular, study I focused on lived experiences of persons with ABI doing activities in the training apartment during one week and study II focused on the lived experiences of persons with memory impairment doing activities in different places during a year of rehabilitation. The life-world is the world we live in, and to study the life-world is to examine the particularities of daily life (Husserl, 1970), including, for example, emotional and *felt* experiences as well as those that are directly observable (Karlsson, 2004).

To understand changes in the experience of the life-world for individuals who have acquired a brain injury, it is essential to understand the historical trajectory of life-worlds. The life-world is also social and cultural. There are many life-worlds. For example, our world is not the same as the world in the Stone Age. The life-world is always taken for granted, without any questioning of its existence. However, the occurrence of something new and
unexpected -for example, when a person is confronted with major life events such as acquired brain injury-triggers reflection on everyday life, particularly those activities that were done automatically or without conscious reflection. The life-world has then suddenly changed and comes into consciousness and can no longer be taken for granted (Bengtsson, 2001).

According to Husserl (1970), the life world is conditional, depending on a particular person’s actions and experiences. The most important concept in phenomenology is intentionality, in which a subject bestows meaning on objects in the world. As a result, things are always experienced as “something”: They have a meaning. Intentions to do certain things, then, that give meaning to the objects used. For example, my intention to cook a dinner for friends gives meaning to the saucepan, other objects used, and my actual kitchen. Without my past experiences using these objects for similar intentions, it would be difficult for me to cook. For Heidegger (1993/1927), the life-world could be explained by being-in-the-world, in which the meaning of objects as equipment appears through their use. Each object, then, belongs to a totality of equipment (Karlsson, 1993, p. 33), which also defines its value. For example, saucepans, potatoes, stoves belongs to the context of cooking, where the totality of equipment suggests the meaning of having a nice meal.

The world is experienced in the present or the here and now. However, because of previous experience, persons can also experience a world beyond direct/immediate experience. Husserl (1970) describes this as an inner horizon. Thus, the world experienced does not only show physical characteristics but also, in each specific situation, a multiplicity of variable characteristics including values and meanings of how things were used. Thus, the experiences of the physical quality of a given environment, such as the home environment or an EADL-equipped training apartment are linked to the meaning of how those objects in an environment could be used (Bengtsson, 1998).

The lived body and the habit body

The philosopher Merleau-Ponty took his starting-point in the life-world and then further developed the phenomenology of Husserl and Heidegger. Merleau-Ponty’s understanding of the life-world identifies meaning in terms of how we relate to and interact with the world in our daily life (Dahlberg, Drew, & Nyström, 2001); that is, how we access the world through bodily experience: “I am conscious of the world through the medium of my body” (Merleau-Ponty, 2002, p. 94). In Merleau-Ponty’s view, the body is not seen as an object, but as “a fusion of soul and body” that is “intervolved” with the environment by identifying oneself
with “certain projects and be[ing] continually committed to them” (p. 94-95). He also said that a person “is” the body and does not “have” the body. In the sense that a person cannot step outside his or her body, the body is always experienced from an internal perspective--hence the fusion of body and soul (the subjective body).

According to this perspective of the lived body, we are usually not consciously aware of doing activities. We do not reflect on how we do those activities. Our life world is expanded through the use of instruments, such as a stick for a person who is blind, when they become incorporated into the body with use. To incorporate a thing with the body means to create a habit, such as when a child learns to cycle and the bicycle is integrated as a part of the body. Only when something unexpected occurs and the person cannot take the habit body (Merleau-Ponty, 2002) for granted any more, does a person start to reflect on the doing. We become aware of the habit body through limitations when doing activities or, as expressed by Merleau-Ponty (2002), “I am conscious of the body via the world” (p. 94). The concept of the lived body has been incorporated into the Model of Human Occupation in order to provide a perspective on how the meaning of experiences, both unifies the mind and body as one entity and influences, in turn, the performance (Kielhofner, 2008; Kielhofner et al., 2002a).

**Acquired Brain Injury**

The term acquired brain injury (ABI) refers to the diagnosis of both stroke and traumatic brain injury (TBI). All the participants in this thesis had acquired brain injury, due to stroke (studies I, II, III and IV) or TBI (studies I-II). Stroke is a generic term for cerebral infarction (about 85% of persons having stroke), cerebral haemorrhage (about 10%), and subarachnoidal haemorrhage (about 5%) (Socialstyrelsen, 2001 and 2002; 2005 and 2009). Various types of accidents are the most common causes of TBI (Socialstyrelsen, 2001 and 2002).

About 30,000 people in Sweden experience a stroke every year. Of these, about 10,000 are less than 65 years of age (Medin, Barajas, & Ekberg, 2006) as are the persons with stroke in this research project. One third of those who have a stroke will have residual symptoms that will influence their lives (Sundberg, Bagust, & Terént, 2003). Each year, around 25,000 individuals in Sweden are hospitalized due to traumatic brain injury (TBI) as were three persons in this research project. The majority of the persons with TBI are younger men and the vast majority of those have had mild TBIs (Kleiven, Peloso, & von Holst, 2003; Peloso, von Holst, & Borg, 2004).
The disabilities following vary according to the type, localization and severity of injury (Socialstyrelsen, 2005 and 2009). Consequences after stroke are complex and relate to body function, activity and participation. Limitations to body functions range from cognitive impairments such as impaired memory, attention, and/or executive functions to fatigue and mood changes such as depression or aggression (Hart et al., 2003; M. Lindberg, 1995; Olver, Ponsford, & Curran, 1996; Socialstyrelsen, 2005 and 2009). These impairments, changes in affect and overall well-being impact on daily life functioning, participation in activities, and satisfaction (Carod-Artal, Egido, Gonzales, & Varela De Seijas, 2000; Eriksson, Tham, & Fugl-Meyer, 2004).

Cognitive impairment

Most of the participants in studies I and II, III, and IV experienced cognitive impairments. The most common cognitive consequence of acquired brain injury is memory impairment (Fish, Manly, Emslie, Evans, & Wilson, 2007). Study II focused specifically on the lived experience of memory impairment in daily activities and some of those participants with memory impairment also participated in studies III and IV. According to a Cochrane literature reviews, studies evaluating strategies for memory training in cognitive rehabilitation (i.e. either coping strategies or strategies to increase memory function by means of practice and/or internal mnemonics) did not identify any evidence to support or refute the effectiveness of such interventions (das Nair & Lincoln, 2007; Majid, Lincoln, & Weyman, 2000). Although the study of Boman, Lindstedt, Hemmingsson & Bartfai (2004) demonstrated improvement in cognitive functions, functioning in daily activities or perceived participation did not improve. Memory is traditionally defined in biomedical and neuropsychological terms, and most studies on ABI do not use phenomenological methods to understand the experiences of persons with memory impairment.

Consequences in daily activities

Since the participants in studies I, II, III, and IV with acquired brain injury during working age, there was a range of consequences on self-care in daily activities. Research has shown that most people are independent in self-care one to two years after ABI (Hoofien, Gilboa, Vakil, & Donovick, 2001), with less reported limitations in house hold activities (Ponsford, Olver, & Curran, 1995). According to Malec & Basford (1996) and Boake, McCauley,
Pedroza, Levin, Brown, & Brudage (2005) more than half the working age persons with mild to moderate ABI return to work between six months to a few years after injury. However, persons with ABI did need reduced working hours or modified work tasks (Vestling, Tufvesson, & Iwarsson, 2003), while some had difficulties in keeping their employments (Hoofien et al., 2001). Despite this research, there is limited knowledge about how working age persons with ABI experience their daily activities at home and work. Research within this area is therefore needed in order to develop guidelines for rehabilitation.

Experiences of daily activities

There are many studies on the experiences of stroke, for example: the experienced challenges to and actions perceived to be supportive of recovery (Jones, Mandy, & Partridge, 2008), experiences of appraisal and coping after stroke in rehabilitation (Rochette, Korner-Bitensky, & Desrosiers, 2007), and the experiences of managing an everyday life of uncertainty (Carlsson, Moller, & C., 2009). A few studies have also examined the experiences of individuals with specific types of cognitive impairments, such as unilateral neglect (Tham, Borell, & Gustavsson, 2000; Tham & Kielhofner, 2003) and visuospatial agnosia (Lampinen & Tham, 2003). In addition, a few studies have identified the lived experience of the consequences of memory impairments with dementia (L. Nygård, 2004; L. Nygård & Borell, 1998; L. Nygård, Borell, & Gustavsson, 1995). However, there is little research that focuses on the experiences of doing activities in the course of rehabilitation of persons of working age. This knowledge is essential for client-centered interventions in rehabilitation.

Rehabilitation after ABI

Rehabilitation interventions in Sweden for persons of working age with stroke can be medical, psychological, social and/or vocational, dependent on the nature of the person’s disability. ABI has a lasting effect on the person’s life many years and rehabilitation of persons with stroke takes place over a long period of time in many different phases (Borg, Gerdle, Grimby, & Stibrandt Sunnerhagen, 2006; Das-Gupta & Turner-Stokes, 2002; U. Johansson, 2004). All the participants in studies I, II, III, and IV demonstrated impaired body functions, activity limitations and/or participation restrictions according to the International Classification of Function, Disability and Health (WHO, 2001) and were in rehabilitation.
In Sweden, rehabilitation after stroke among persons of working age typically occurs at specialized brain injury rehabilitation units in hospitals early after onset. In post-stroke acute care, there is evidence that stroke units provide a better outcome than treatment in general medical wards in terms of: survival, discharge destination, dependency, and long-term effect of rehabilitation during the first year after stroke (Rice-Oxley & Turner-Stokes, 1999; Socialstyrelsen, 2005 and 2009). In post-stroke rehabilitation, interventions vary depending on which phase after onset they are carried out (Lexell, 2007). In the sub-acute phase, interventions primarily focus on improving impairments and reducing activity limitations (Turner-Stokes, Disler, Nair, & Wade, 2004) in order to achieve the goal of achieving independence in daily activities (Socialstyrelsen, 2005 and 2009).

The national guidelines of stroke care (Socialstyrelsen, 2005 and 2009) recommend early discharge from hospital (stroke units) in combination with multidisciplinary rehabilitation at home. If both inpatient and outpatient rehabilitation are commonly located in hospital rehabilitation settings in the sub-acute phase, the later phases of rehabilitation commonly consist of a period of community-based rehabilitation based on collaboration between medical services and resources in the community (U. Johansson, 2004).

**Rehabilitation at home**

In studies II, III and IV, home was one of the contexts of research. According to a Cochrane literature review, there is insufficient evidence to compare the outcome of rehabilitation in hospital environments, home-care like environments or own home environments for older, persons over the age of sixty (Ward, Drahota, Gal, Severs, & Dean, 2008). However, a meta analysis on the effect of stroke rehabilitation in general found strong evidence for successful outcomes for patients discharged early from an acute hospital unit and receiving interventions from an interdisciplinary stroke rehabilitation team in their homes (Teasell, Foley, Bhogal, & M., 2006). While a study of young persons with stroke showed that they were both frustrated and described feelings of being invisible due to the fact that the rehabilitation setting didn’t acknowledge the different needs of young persons with stroke compared with older patients (Röding, Lindström, Malm, & Öhman, 2003). Both quantitative and qualitative studies have generated support for the home environment influencing rehabilitation in a positive way. Rehabilitation in the home resulted in improved independence in personal activities of daily living (Trialists, 2003) and earlier improvement in activity (as compared to a day clinic) as well as reduced burden of care and costs (Björkdahl, Lundgren Nilsson, & Stibrant
Sunnerhagen, 2007). Studies of patients’ perspectives also showed how “coming home” was an important factor for their recovery and rehabilitation (Becker, 1993).

The National Board of Health and Welfare (Socialstyrelsen, 2005 and 2009) concluded from the positive evidence on rehabilitation at home that home rehabilitation decreases the risk for death and deterioration of abilities necessary for doing activities in daily life. Even though research demonstrates positive outcomes of home rehabilitation for persons with stroke, there is little understanding of why or how the meaning of home supports rehabilitation. Several studies have proven helpful in this regard. For example, a study by Lampinen & Tham (2003) showed how confusing and unfamiliar the physical environment can appear after stroke when attempting to do daily activities, while the study by Wohlin Wottrich, von Koch & Tham (2007) showed how the contextual factors in familiar environments, such as home, support rehabilitation by linking the \textit{habit body} to the “new body” experienced after stroke. In addition, a study of persons with physical disabilities showed that the meaning of home influenced the interactions between the individuals and the environment (Lund & Lexell, 2008) including their performance of household tasks (Darragh, Sample, & Fisher, 1998), suggesting that the familiarity of the environment supported how persons with stroke managed in their homes (Wohlin Wottrich et al., 2007). In order to develop intervention strategies more knowledge is needed to understand how persons become integrated in different places over time.

\textbf{Rehabilitation at work}

In studies II, III and IV most of the participants had been to their workplace or participated in training in their work places during rehabilitation. Even though the experience of ABI changed the meaning of the workplace, a successful return to work signified a return to normality for persons with ABI (U. Johansson & Tham, 2006). However, research on the experiences of the workplace for persons with ABI remain sparse and calls for a further understanding of the workplace, itself, in the rehabilitation of persons with ABI based upon their own experiences. Further, the workplace supported rehabilitation when colleagues facilitated this return to work with understanding, positive and supporting attitudes (Alaszewski, Alaszewski, Potter, & Penhale, 2007; Gilworth, Eyres, Carey, Bhakta, & Tennant, 2008; Medin et al., 2006) that points to the need to understand how social relatedness supports or hinders rehabilitation over time.
Social Aspects of Rehabilitation

Study IV in this thesis focuses on the social aspect of rehabilitation. The way back to life after ABI is complex and can be problematic for both persons with ABI and their significant others (family members, friends or colleagues). After acquiring a brain injury, persons with ABI and their families commonly experience social isolation (C. Murray & Harrison, 2004; Röding et al., 2003; Visser-Meily et al., 2009). For persons with stroke, long-term social and emotional consequences have shown to be the largest domain of problems in daily life (J. Murray, Ashworth, Forster, & Young, 2003). For example, life-satisfaction is low (Eriksson et al., 2004), major challenges in connectedness and withdrawal with others continue after discharge home (C. Murray & Harrison, 2004; Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007; Röding et al., 2003).

There are also consequences for other persons in the social network of persons with stroke, such as family members, other caregivers, friends and colleagues. Common problems influencing the well being of family members, partners and spouses were uncertainty (Hunt & Smith, 2004) and perceived burden of care (Wyller et al., 2003) where the emotional stress was often higher than the actual amount of care needed by the person with stroke (Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). The emotional stress on social relations had negative long-term consequences for partners (Visser-Meily et al., 2009). Even though family caregivers are often adversely affected (Palmer & Glass, 2003), there is some evidence for a positive outcomes when families involved in the rehabilitation of persons with stroke are given ongoing support in daily activities as well as routinely provided with information, education and counseling by professionals (Clark, Rubenach, & Winsor, 2003; Smith, Forster, & Young, 2009; Turner, Fleming, Ownsworth, & Cornwell, 2008).

Rehabilitation programs need to consider, support and enable social interaction during the rehabilitation process (Borg, Berdle, Grimby, & Stibrandt Sunnerhagen, 2006). There is, however, little research focusing on better understanding the meaning of acting and interacting with others (as rehabilitation professionals, family members, colleagues and friends) during the rehabilitation process after ABI. This is important because a few longitudinal studies of persons with stroke and their spouses/partners showed that the couples were interdependent in daily activities and should be viewed as a unit, while following their experiences over a year underlined how divergent approaches and values towards how to handle the changes in daily life after stroke impact on engagement in rehabilitation (Ekstam,
Despite understanding the interdependency of persons with stroke and their spouses/partners in the rehabilitation process, or the importance of support from colleagues for returning to work (Alaszewski et al., 2007; Gilworth et al., 2008) there is a continued need for more research examining how social aspects in different settings can be used to support social interaction in real life situations (U. Johansson, Högberg, & Bernspånå, 2007)

**Occupational Therapy after Acquired Brain Injury**

In general, rehabilitation for individuals with acquired brain injury has used a remedial approach, which aims at restoring underlying capacities as cognitive or motor functions (Trombly & Radomski, 2002; Unsworth, 2007) and/or a compensatory approach, which aims at enabling performance of daily activities by teaching compensatory strategies or providing adaptations or modifications to the physical environment (Toglia, 2005). However, empirical studies have failed to demonstrate generalization of cognitive training to daily activities in natural environments (Berg, Konning-Haanstra, & Deelman, 1991; Sohlberg & Raskin, 1996). Research has also shown that it may be more realistic to expect independence in daily activities to be achieved in such familiar environments as the home setting (Socialstyrelsen, 2005; von Koch, Widén Holmqvist, Wohlin Wottrich, Tham & de Pedro-Cuesta, 2000).

In contrast to the above approaches, occupational therapy interventions that promote a client-centered perspective aim to enable occupations that the person finds useful or meaningful in a given environment (Fisher, 1998; Kielhofner, 2008; Law et al., 1997) and emphasizes the importance of taking clients’ knowledge and experiences of their difficulties in daily activities into account for positive outcomes in the rehabilitation process (C.H. Christiansen, Baum, & Bass-Haugen, 2005). Recent occupational therapy research suggests that the implementation of a client-centered approach for persons with stroke is essential for understanding each unique person in rehabilitation. After an acute care phase, practitioners must shift from focusing on impairments to an approach based on understanding why occupational problems occur and how to solve them in order to support their clients in their return to a meaningful life (Guidetti, Asaba, & Tham, 2007, 2009). Thus, rehabilitation professionals play an important role in creating therapeutic contexts, as it was shown in a study where the context contributed to recapturing self-care (Guidetti et al., 2009). However, still little is known about how contextual aspects in different places can support doing activities in everyday life.
**Electronic aids to daily living (EADL)**

One common occupational therapy intervention is to modify the physical environment through the use of assistive technology (AT). AT is a broader concept that includes devices, equipment, instrument, technology and software (ISO9999, in Boman, Stenvall, Hemmingsson, & Bartfai, 2009). Electronic aids of daily living (EADL) are devices that are used to access, operate, and control electrical appliances for comfort, communication, leisure, and personal security (Lange & Smith, 2002). Study I examined the experiences of persons with stroke in a training apartment equipped with EADL.

Access to computers has increased dramatically over the last two decades and recent advances in new technology opened up new possibilities for persons with cognitive impairment (Orpwood, 2008). Dilani (2001) pointed out the importance of integrating a human perspective with the latest developments in technology to advance health care in the future, which is in line with the concept of “design for all” (Tahkokallio, 1998) that aims to design environments that can be used by everyone. Memory impairments, however, can make it more difficult to learn how to use electronic aids. Further, there is a lack of knowledge on how to relate the concept of “design for all” and the increased complexity of technical aids in the home environment, particularly in relation to family (Boman, Tham, Granqvist, Bartfai, & Hemmingsson, 2007). There are only a few studies that examine the outcomes of using EADL in training apartments for persons with ABI. Despite studies showing that EADL may play an important role for persons with memory impairment in facilitating daily activities (Boman et al., 2007) and that persons with memory impairments who stayed in a training apartment during one week showed significant improvements in learning how to use the electronic memory aids (Boman et al., 2009), it is not clear how EADL-equipped training apartments contribute to rehabilitation from the perspective of persons with ABI.

In previous research little attention has been paid to the meaning of places in rehabilitation or the different meanings of acting with others during the rehabilitation process in these different places. Knowledge on how different places and acting with others in those places could guide the development of strategies for how to support the rehabilitation process in order to achieve a better life situation for both the person with ABI and his/her family members, colleagues and others.
RESEARCH AIMS

The general aim of this thesis was to understand and describe the experiences of occupations in the context of daily life and the meaning of actions in different places (rehabilitation setting, home and work-place) for persons of working age with acquired brain injury (ABI) during a rehabilitation process.

The specific aims

- To describe the nature of the phenomenon of occupational adaptation during a 1-week stay in an EADL-equipped training apartment for persons with acquired brain injury (study I).
- To identify what characterizes the lived experience of memory impairment in daily occupations during the first year after acquired brain injury (study II).
- To describe the meaning of actions in different places during one year of rehabilitation after stroke (study III)
- To describe the meaning of acting with others, in different places during one year of rehabilitation after stroke (study IV).
METHODS

In order to understand the lived experiences of daily occupations in different places during the year of rehabilitation I chose to use qualitative methods in all the four studies. Two different methodological approaches were used. In studies I and II, the Empirical Phenomenological Psychological method (EPP) was used (Karlsson, 1993). In studies III and IV, a grounded theory approach (Glaser & Strauss, 1967) based upon Charmaz (2006) guidelines was used. Using different qualitative methods enriches studies by providing complementary perspectives on similar phenomena (Molineux & Whiteford, 2005). The aim of using a phenomenological approach (studies I and II) was to describe the lived experiences of participants that focused on the meaning of performing activities in different places. The grounded theory approach (studies III and IV) was used to investigate how the participants’ actions related to the social processes during rehabilitation. These qualitative, descriptive and interpretative methods were used during the collection, analysis and interpretation of the interview data. In addition, the longitudinal design of studies II, III, and IV fore grounded the process of rehabilitation over the course of a year. There was one key difference to these approaches. For example, studies I and II used a phenomenological approach to examine the meaning of the participants’ lived experiences by bracketing (or consciously reflecting on and removing from analysis) theories outside of phenomenology. Whereas studies III and IV used a grounded theory approach that brought in theoretical resources in order to examine and refine emerging categories.

Study I examined the meaning of performing activities for persons with ABI in a training apartment equipped with electronic aids to daily living (EADL) that included daily schedule, address book, control panels to remind persons to close windows, lock the doors, or turn off the television and warning systems to turn off the stove, running water and the like. Study II examined the meaning of performing activities for persons with memory impairment during the year of rehabilitation. To enrich understanding of the meaning of these experiences, the grounded theory approach employed in studies III and IV used theory on action and social processes in order to fore ground how these phenomena were related during the course of rehabilitation. Although the grounded theory method “…consists of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves” (Charmaz, 2006, p. 2), the intention in studies III and IV was not to construct a theory. Rather, the intent of these longitudinal studies was to use
current theory on place integration to generate “...abstract theoretical understanding” (Charmaz, 2006, p. 4) of the dynamic relationship between the participants and the physical and social aspects of places during a year of rehabilitation.

There is a lack of qualitative, longitudinal studies on persons of working age with acquired brain injury. In prospective longitudinal studies, it is possible to compare data from different time points in a process and thereby identify a process of change (Saldana, 2003). Thus, the grounded theory approach used in studies III and IV focused on “nuances of meaning and action” (Charmaz, 2006, p. 184), while the transactional view of place integration (Dickie et al., 2006) heightened attention to the interactions between persons and the places or processual nature of rehabilitation emphasized by the longitudinal design. Conducting several interviews during the participants’ rehabilitation process also strengthened the participant-researcher relationship and enriched understanding of the participants’ experiences relating to the studied phenomena (Kvale, 1996). Participants in studies II, III, and IV had the opportunity to choose place for the interviews with the intent to further strengthen the quality of data collected.

Participants

Study I

In study I, the eleven participants were recruited from the Facile short term project (C. Lindberg, Bartfai, Granqvist, & Söderström, 2000) in which nineteen participants stayed in a training apartment equipped with EADL at the end of their rehabilitation. The criteria for the participants in study I were the same as those for the Facile project, namely that the participants were: a) older then eighteen years old, b) had no known psychological diagnosis or drug problems, c) were motivated for participation in the study, d) living independently in their homes, e) understood the Swedish language, f) had acquired the disability secondary to brain trauma during adulthood, and g) had no other major cognitive impairments, such as aphasia, apraxia, spatial or visual disturbance. Of the six men and five women selected, nine were rehabilitation inpatients at the time of the study and two had already been discharged to their homes. Eight of the participants had vascular brain injury and three of the participants had traumatic brain injury. Nine of the participants had acquired their brain injury one to five months prior to participating in the study.
Studies II, III, IV

A new sample was established for studies II, III, and IV. The participants in studies II, III, and IV were recruited from inpatients at a rehabilitation setting in Stockholm, Sweden. The aim of these studies was to capture the experiences of daily activities of persons who represented four types of cognitive impairments that are common after stroke: a) memory impairment, b) visuo-spatial impairment, c) impaired attention, and d) impaired body image. The criteria for all of these participants was: a) first-time acquired brain injury, less than one month earlier; b) working age; c) restrictions due to cognitive impairments in the performance of daily activities according to the treating occupational therapist; d) sufficient memory to retell events that had occurred during the past 24 hours; e) sufficient verbal ability to understand the interview questions and to be able to recount daily experiences during the year.

A total of 19 persons participated in these three studies in the following numbers: a) four persons in study II, b) seven persons in study III, and c) nine persons in study IV. Two of the participants participated in all three studies. All the participants had acquired brain injury (stroke or traumatic brain injury) and were experiencing consequences in the form of impaired function, activities limitations and/or participation restrictions with additional criteria for the following studies as follows. In study II, the participants experienced poor to moderate memory impairment, according to the Rivermead Behavioural Memory Test (Wade, 1992; Wilson, Cockburn, Baddeley, & Hiorns, 1989) for a total of four persons (three men and one woman). In studies III and IV, theoretical sampling was used to develop the properties of emerging categories until saturation was reached (Charmaz, 2006, see p. 96). The participants for both studies III and IV were selected because of the richness of their descriptions of how they experienced places during rehabilitation. Due to the richness of data, a choice was made during the course of analysis to divide the data into two different studies, in order to more closely examine the physical and social aspects of actions in different places. The initial sampling consisted of four participants in study III, with a final sample of seven (four men and three women). The initial sampling in study IV consisted of seven participants with a final sample of nine (six men and three women).

In study I, the participants were doing different types of work: two worked with economy, two did office work, three did data/technical work, and four did other kinds of practical work. In studies II, III and IV three did technical work, two ran their own company,
one did work in rehabilitation, one did work as a dental hygienist, and one did work in transportation.

Table 1. Type of brain injury, gender, age and FIM of participants in studies I, II, III, IV

<table>
<thead>
<tr>
<th>Type of brain injury:</th>
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</tr>
</thead>
<tbody>
<tr>
<td>-traumatic</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-vascular</td>
<td>8</td>
<td>3</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Man/Women</td>
<td>6/5</td>
<td>3/1</td>
<td>4/3</td>
<td>6/3</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Man</td>
<td>25-63</td>
<td>22-61</td>
<td>42-61</td>
<td>42-61</td>
</tr>
<tr>
<td>Women</td>
<td>34-76</td>
<td>51</td>
<td>51-55</td>
<td>51-55</td>
</tr>
<tr>
<td>FIM*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-motor</td>
<td>87,3 (75-91)</td>
<td>82 (69-90)</td>
<td>75,6 (67-90)</td>
<td>76,8 (56-90)</td>
</tr>
<tr>
<td>-cognitive</td>
<td>29,6 (26-32)</td>
<td>13 (5-28)</td>
<td>21,1 (5-28)</td>
<td>19,8 (5-28)</td>
</tr>
</tbody>
</table>

*Functional Independence Measure (motor max score 91, min score 13; cognitive max score 35, min score 5), < 78 in motor scores: in need of assistance for personal care.

Study Contexts

The study contexts in this thesis consisted of the rehabilitation setting, the training apartment equipped with EADL, and the participants’ homes and workplaces.

Study I

The study context in study I was a training apartment in a Swedish rehabilitation setting. The training apartment was equipped with EADL. The training apartment was intended to give individuals with disabilities and the elderly the experience of living in a comfortable, aesthetically pleasing, functional, and safe environment that simulated a home before returning to their actual homes. As opposed to an impersonal rehabilitation setting, the aesthetics of the training apartment was designed to inspire the individuals to engage in the activities and social life they would have had in their daily lives prior to their injury. As a transition from rehabilitation to home setting, each participant stayed alone during the night for a week (Monday to Friday) in this training apartment.

The individualized occupational therapy interventions in the training apartment comprised one to three hours each day. The goal of these interventions was to improve the performance of daily activities deemed relevant by the individuals by minimizing the demands of a home setting using electronic aids. In addition to performing the daily activities
using electronic aids in the training apartment, each individual also had individualized conventional rehabilitation interventions, such as one to two hours of occupational therapy, one to two hours of physical therapy, as well as medical, psychological, speech therapy if needed.

**Studies II, III and IV**

The study context in studies II, III, and IV consisted of the different contexts where the participants were doing their activities during the year. In general, the study contexts consisted of the rehabilitation setting, home and work in the following sequence. At one month post-stroke, all of the participants were inpatients at a rehabilitation clinic, which included individualized occupational therapy and physiotherapy on a daily basis and sessions with social workers, psychologists and/or speech & language pathologists. Most weekends were spent in their homes. At three months and during the rest of the year, most of the participants were day-care patients at the rehabilitation setting and were spending nights and weekends in their homes. Early in rehabilitation, many of the participants had been in contact with their work places. By three months post-stroke, most of the participants had been in contact with or had visited their work settings.

**Data Collection**

Following the description, Table 2 below gives an overview of the method design, data collection and data analysis used in studies I, II, III, and IV.

**Study I**

In study I, an extended interview was conducted with the participants on the last day of their week-long (Monday to Friday) rehabilitation in the training apartment. The aim was to obtain rich descriptions of their experiences in this specific context. Prior to the interviews, the primary occupational therapists also provided an image of their perspective of the participants’ experiences, such as how they had managed to perform activities during the week and/or if something special had happened. Each interview lasted 50-90 minutes. In order to focus on the participants’ lived experiences of performing daily activities in this EADL-equipped apartment, questions were informal and open-ended (Kvale, 1996). Field notes were taken after the interviews and the interviews were taped and transcribed verbatim.
Study II, III, IV

In studies II, III, and IV the interview data were longitudinal in approach (Saldana, 2003), collected on four occasions during the first year after stroke (month one, three, six, and twelve). Participants determined the location of the interviews based on convenience (home, work, the researcher’s workplaces, rehabilitation setting). The interview guides were developed between each interview in order to follow up on the participants’ answers to previous interview questions (Kvale, 1996). There were two general areas of questions. The first area concerned the participants’ experiences of performing daily activities compared to those experiences performing daily activities prior to acquiring a stroke. A second area concerned the participants’ experiences of daily life with stroke, such as how they managed difficulties that arose when doing activities. Prior to the interviews that took place in the rehabilitation setting, the participants’ primary occupational therapists were also interviewed when available in order to get their perspective of the participants’ current situation. Field notes of researcher’s reflections were taken directly after each interview. All interviews were tape-recorded and transcribed verbatim.

Following the principles of theoretical sampling and constant comparison (Charmaz, 2006; Glaser & Strauss, 1967), the second, third, and fourth interviews at three, six and twelve months respectively provided emergent topical areas to explore and elaborate on in subsequent interviews. Broad questions about the home or rehabilitation settings led to more specific questions. The main purpose of using theoretical sampling was to elaborate and refine the categories constituting emerging conceptualizations. Thus, the broad question of how participants experienced doing activities across all three studies led to the following, more specific, questions in each study. For example, study II raised questions on how the participants with memory impairment, managed or developed strategies for doing activities in different places, while studies III and IV raised questions on how the physical and social aspects of the study contexts was related to doing activities. In specific, study III more closely examined the meanings of objects or particular physical aspects of those places were related to doing activities, while study IV more closely examined the meaning of acting with others in these different places. Thus, the participants’ narratives of their experiences during the year of data collection led to new questions relevant for theoretical sampling, while the emerging categories were incorporated into and shaped the interview guide for each subsequent interview.
Table 2. Study design, methods of data collection, methods of data analysis and study contexts in studies I and II

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Methods of Data collection</th>
<th>Methods of data analysis</th>
<th>Study contexts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>Phenomenological approach Interview study</td>
<td>1 interview with each participant the last day of a one week stay in a training apartment, n=11, app. 330 pages text</td>
<td>The Empirical Phenomenological Psychological (EPP) method</td>
<td>A training apartment fitted with electronic aids to daily living</td>
</tr>
<tr>
<td>Study II</td>
<td>Phenomenological approach Interview study Longitudinal design</td>
<td>4 interviews with each participant during one year of rehabilitation, n=16, app. 480 pages text</td>
<td>The Empirical Phenomenological Psychological (EPP) method</td>
<td>A rehabilitation setting Home Work place</td>
</tr>
<tr>
<td>Study III</td>
<td>A grounded theory method, longitudinal in design</td>
<td>4 interviews with each participant during one year of rehabilitation, n=28, app.840 pages text</td>
<td>A grounded theory method based on Charmaz (2006) guidelines</td>
<td>A rehabilitation setting Home Work place</td>
</tr>
<tr>
<td>Study IV</td>
<td>A grounded theory method, longitudinal in design</td>
<td>4 interviews with each participant during one year of rehabilitation, n=36, app. 1080 pages text</td>
<td>A grounded theory method, based on Charmaz (2006) guidelines</td>
<td>A rehabilitation setting Home Work place</td>
</tr>
</tbody>
</table>

The phenomenological approach

In studies I and II, Karlsson’s (1993) Empirical Phenomenological Psychological (EPP) method was modified during data analysis. In these studies, an occupational perspective focusing on the participants’ experiences of doing activities replaced the psychological perspective. The EPP method aims to understand the meaning structure of a phenomenon based on the participants’ descriptions of their experiences. The method aims to make explicit the essence of the studied phenomenon presenting itself in the life-world experiences (Husserl, 1970). The phenomena being studied were the experiences of participants with ABI in the EADL-equipped training apartment in study I and the experiences of the participants with memory impairment doing activities in different contexts during the year long rehabilitation process in study II. The guiding principle during data analysis of both studies was to discover the intentionality of consciousness. In other words, the researcher attempted
to identify the meaning embedded in the participants’ life-world experiences in their daily activities.

The EPP method focuses on the meanings persons give to experiences as opposed to what happens over time, and during the analysis the researcher abstains from making hypotheses or proposing theories to explain the phenomenon; that is, theories outside of phenomenology were bracketed during analysis. In order to describe the meaning structure of the studied phenomenon as faithfully as possible, the researcher strives to be as open as possible to the participants’ lived experiences. The participants’ descriptions are on a phenomenal level, but the aim for the researcher is to trace out the essential characteristics of the participant’s experiences.

The EPP-analysis is divided into five steps. **Step 1** includes examining the interviews conducted with each participant to gain an understanding of the participant’s original experiences through the researcher’s empathetic understanding. The empathetic understanding is to understand the lived experiences without any interpretation. **Step 2** consists of discriminating meaning units (MUs) in the interviews; that is, unique ideas, themes, topics, or experiences. The transcripts are divided into MUs is done by noting when shifts in meaning, or significance of what is being said, occur in the interviews. **Step 3**, includes analysis through using the use of eidetic induction through interpretation during analysis; that is, meaning moving from a particular fact towards examining its implicit and explicit meaning in relation to the studied phenomenon. As applied to both studies I and II, first the MUs in each participant’s interview transcripts were interpreted in relation to the all of the interviews. Then themes were identified by moving back and forth between what happened over time and the meanings that permeated what happened from the participants’ perspective. In **step 4**, a summary is made of the interpreted MUs (from step 3) into a “situated structure of meanings” (Karlsson, 1993, p. 106). A situated structure of meaning describes, in a phenomenological significant way, the structure of the phenomenon and how the process of the phenomenon is lived through.

Finally, in **step 5**, the researcher moves from the situated structure of meaning to an overall structure; that is, an analyses of all participants’ experiences that incorporates the characteristics of a phenomenon running across all situated structures. The intention of study I was to trace out the overall meaning structure of doing activities in the training apartment across the general characteristics of the participants. The intention of study II was to trace out the overall meaning structure of how the participants’ with memory impairment experienced
doing activities in different settings during the year of rehabilitation across the general characteristics of the participants. During this step, the researcher also identified aspects of dimensions of the overall meaning structure in each study, in order to gain a deeper understanding on variations of the studied phenomenon. For example, in study I, *mastering the EADL-equipped environment* was an aspect of the experience of *landing* or feeling comfortable with the new setting as a dimension of the overall meaning structure of doing activities in the training apartment. In study II, *coherence in doing disrupted by unfamiliar situations* was an aspect of the experience of *struggling for coherent doing in new contexts* as a dimension of the overall meaning structure of doing activities in different settings across a year of rehabilitation for persons’ with memory impairments.

During data analyses in each study, the researchers discussed and refined these aspects and their dimensions of the overall meaning structures by applying a “horizontally consistent interpretation” (Karlsson, 1993, p. 131) in order to make sure that each aspect was consistent with the other aspects revealed in the analysis. Ensuring a horizontally consistent interpretation was done from the experiences of each participant, first, and then across all of participants to strengthen the findings. The findings were also presented to and discussed with researchers and experienced occupational therapists in the field of neurological rehabilitation.

**The grounded theory approach**

In studies III and IV, a grounded theory approach (Glaser & Strauss, 1967) using Charmaz’ (2006) guidelines was used during analysis. In order to identify and systematically compare similarities and differences in the data, a constant comparative method using three levels of coding (initial, focused, and axial) was used to “define what is happening in the data” (Charmaz, 2006, p. 46). As mentioned in the introduction of methods, the intention in studies III and IV was not to construct a theory. Rather the intent was to generate an “abstract theoretical understanding” (p. 4), which is represented as the core categories found in each of the studies.

Both studies III and IV began after all the interviews had been completed. Thus, the cyclic process in grounded theory of collecting and coding data that usually begins after the first interview was not relevant in these studies. Instead, initial line-by-line coding began with the interviews across the year of rehabilitation (16 interviews, app. 480 pages) of four participants drawn from the sample of studies II, III, and IV. The data analysis of study III 28
focused on the physical aspects of the study contexts, while the data analysis of study IV focused on the social aspects of the study contexts. This initial coding led to theoretical sampling that focused on elaborating and refining the emerging core categories (Charmaz, 2006; Glaser & Strauss, 1967). The theoretical sampling is as follows. In study III, three more participants (12 interviews, app. 360 pages) were selected. These combined seven participants (28 interviews (app. 840 pages) from study III established the starting point for study IV. Finally, two more participants (eight interviews, app. 240 pages) were selected for study IV until saturation emerged in the data. The additional three participants in study III and two participants in study IV provided more detailed descriptions of the experiences of doing activities and doing/acting with others in different study contexts during the year of rehabilitation.

The coding process formed the basis for the analysis by using a combination of initial, focused and axial coding. During initial coding the data were analyzed line-by-line. This is, according to Charmaz (2006, see p. 50), an appropriate method to apply when the data is about empirical problems and processes such as in these studies examining a rehabilitation processes over a one-year period. The initial codes emerged from the first coding of broad areas, for example from the participants’ experiences of doing activities in particular places (study III) and doing activities with others (study IV). A central task during this phase was to be critical, where raising questions further helped to identify significant processes (Charmaz, 2006, see p. 51). Questions raised during this stage of analysis in both studies concerned the changes in the rehabilitation process during the year. For example, the questions in study III concerned: the meaning of performing activities in different places during the year, the physical aspects of the familiar settings of home, work and rehabilitation setting, and the problem solving processes of individuals when doing activities with a particular focus on the meanings or importance of engaging in particular activities in different places. The questions guiding analysis study IV concerned, for example, what it meant for the participants to do activities with significant others (rehabilitation staff, family, friends and colleagues) in different places during the year (the rehabilitation setting, home and work).

The most significant and frequent codes found during initial coding are then used during focused coding to shift through large amounts of data. Comparing data clarifies and further sharpens the definitions of the categories (Charmaz, 2006, see pp. 91-92). For example, focused coding began to distinguish a difference between doing activities in new as opposed to familiar places. In study IV, the category inspiration from engaging with others
emerged from the initial codes for how participants experienced doing activities with others (such as family members and friends) as both energizing and inspiring. By closely examining these descriptions of doing with others, focused coding also began to distinguish a contrasting experience. For example, participants also felt that doing with others created burdens for others, leading to a new category of burden of burden.

Finally, in the last stage of analysis, axial coding refines the dimensions of categories by relating them to subcategories (Charmaz, 2006, see p. 60). For example, the category retrieving inspiration from familiar places was related to the subcategories of discoveries at the workplace and discoveries at home (study III). While the category inspiration from engaging with others was related to the subcategories of the mattering of acting together with others and getting a measure through doing with others (study IV). When the data no longer sparked new theoretical insights nor revealed new properties of the core categories, no further analysis of data was required (Charmaz, 2006, see p. 113). The interrelationships between categories emerging from the data during these initial, focused and axial coding formed the core categories the desire for place integration inspires engagement in rehabilitation (study III) and a process of belonging for integration (study IV). During the entire process, analysis and refinement of categories was ongoing between the first, second and third authors until agreement was reached in order to enhance reliability. These findings were also discussed with an experienced research group as a form of informal triangulation.
FINDINGS

All four studies are about processes in rehabilitation. However, the findings are presented differently which reflects the methods used. In studies I and II, which used Karlsson’s (1993) Empirical Psychological Phenomenological method, the findings are presented as meaning structures. According to Charmaz’ (2006) guidelines to grounded theory, a process “…consists of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between. The temporal sequences are linked in a process and lead to change” (p. 10). Thus, the findings of the studies III and IV present the findings to emphasize the processual nature of rehabilitation over a year as demarcated by the interviews which took place at months three, six, nine and twelve. The core categories in both studies III and IV are sequenced to represent the loose temporal sequence in which they emerged during the year. Study IV additionally emphasizes the temporal process of each emerging categories within each individual category.

Study I

There is, as yet, little documentation on the outcomes of using electronic aids to daily living (EADL) and little research has been found in the literature on how persons with acquired brain injury experience EADL-equipped training apartments. The phenomenon analyzed in study I was how individuals with acquired brain injury experienced the performance of activities in the training apartment equipped with electronic aids to daily living. The Empirical Psychological Phenomenological (EPP) method was used to find the main characteristics of the phenomenon as it was experienced through the participants’ week-long Monday through Friday stay. The meaning structure common to all the participants’ experiences transitioning to the EADL-equipped apartment during their one week stay emerged in overlapping phases that could be clustered around four main characteristics. These characteristics of the meaning structure are presented in the order in which they emerged during analysis.

Initially, the participants’ experiences were characterized plunging into the EADL-equipped environment. In that phase, the participants found the EADL-equipped training apartment challenging, felt insecure about their own ability to use the alarm system, and were concerned about whether they would fail in using this new equipment. In the next phase, the experienced landing, for example, as they gradually began to feel that they could handle the
technology, a sense of security seemed to emerge that also made them feel at home. They grew more confident in their ability to manage doing activities during the week-long stay. The alarm system and the computer began to become the “core” objects that provided feelings of safety and security. In the next phase, the participants experienced incorporating “the new” in daily activities by adapting how they did things. Doing household activities seemed to provide the starting point for adapting to using the equipment that gradually progressed over the week, leading to an experience of increasing sense of competence characterized taking off for the future. In the last phase, the participants’ experiences of learning to and handling the electronic aids during the week inspired the sense that they could handle their lives at home outside of the rehabilitation setting. According to the participants’ descriptions, their experiences in the training apartment contributed to a sense of freedom, inspiration, dignity, as well as positive experiences of social interaction.

Study II

There is little research on how persons with memory impairment following ABI experience doing daily activities. Study II analyzed the phenomenon of how individuals with memory impairment after acquired brain injury experienced doing activities in different contexts over one year of rehabilitation. The EPP analysis found that there were clear differences in how the participants with memory impairment experienced doing daily activities at the beginning and at the end of the year of rehabilitation. The findings are presented in a meaning structure comprising four main characteristics that are presented in the order as they emerged during the year. The description of the year-long process reflects the nature of the participants’ experiences in the performance of daily activities in different contexts.

Initially, the participants experienced a chaotic life-world, which had changed from a familiar, taken-for-granted world to an unfamiliar, confusing and frightening one. They could not do activities in a coherent flow, and they were often disrupted when doing activities because they had to stop and try to remember how they used to do the activities. In their uncertain orientation in time, they sought out links to experiences in their once familiar past lives prior to their illness, which gave them a sense of security and control in the present. In turn, their experiences in their past life prior to injury provided the standard for how they would see themselves in the future. The next characteristic in the year long process was the experience of struggling for coherent doing in new contexts. The participants were confronted
with the challenge of doing new activities that had not been integrated into their habit body (Merleau-Ponty, 2002). In new contexts, their experiences in automaticity in doing activities broke down, which in turn disrupted the coherence in doing in a series of activities. Now, their daily life after injury was filled with a constant struggle for achieving coherence in doing and they needed conscious strategies to create a structure to establish new habits in what they experienced as new settings. This was described by the characteristic, conscious strategies in new contexts. The fourth characteristic of the meaning structure emerged in their home settings, where achieving new habits, described how familiar settings—like home—supported regaining the automaticity and coherence of doing activities they did in daily life in the same settings before injury. These experiences of doing daily activities contributed to participants’ self-image based on their new life situation and view of the future.

**Study III**

There is little research on the meaning of actions in particular places across time for persons with ABI. To gain a deeper understanding of the complex relationship between place, person and action during a year-long rehabilitation process, a grounded theory approach was used. The findings in study III are presented in a loosely defined temporal pattern where the first category, workplace in mind, appeared in the beginning of the rehabilitation and the last category, on their way to place integration, appeared in the end of the year. In total seven categories were linked together and characterized a core category: The desire for place integration inspires engagement in rehabilitation and are presented in order below.

The first category, workplace in mind emerged early in rehabilitation and continued to be present during the year. The strong desire to be integrated into their workplaces inspired participants to choose training material and activities representative of the challenges they needed for returning to work. The category experiences at home enabling reflection showed that, once back at home, they had to reflect upon their own abilities when performing activities, which contributed to their desire to engage in and complete the rehabilitation process. In contrast to their experiences at home, the next category that emerged showed that the rehabilitation setting creates uncertainty. Despite initial experiences of feeling supportive and secure, the participants began describing feeling uncertainty in an environment that was perceived as unfamiliar. Their experiences of uncertainty reflected doubts about whether or
not they would be able integrate into a new environment, where doing activities could not be taken for granted.

The next category, retrieving inspiration from familiar places, showed that their work places and homes provided the participants with opportunities to both experience and reflect on their current abilities that simultaneously challenged and inspired them to engage in the rehabilitation. The desire to integrate into their workplaces also inspired them to find activities in their homes and rehabilitation settings that would approximate the activities significant to their working lives. This experience was described as matching the complexity of tasks across places. The category, understanding the reality by confrontation, describes how the actual circumstances of daily life forced the participants to understand what they would need to be able to do in order to return to work. By the end of the year, the last category showed that the participants were on the way to achieving place integration in their home and work and was described as on the way to place integration.

Study IV

The social aspect in the rehabilitation process is complex and can continue to be problematic for persons with stroke after the transition back to their homes. The grounded theory approach was used to conceptualize the relationship between the meanings of acting with others in different places during the first year of rehabilitation after stroke. The findings are presented in four characteristics in a temporal process that occurred over the 12 months. The temporality is neither linear nor rigid across all participants. Rather it captures a general image of the process of belonging for place integration. Within each of the categories there was also a temporal process.

The first category, not recognized as the person I am, showed that the participants did not consistently feel recognized as capable and fully autonomous persons. During different periods, the participants felt that they were perceived as incompetent, misunderstood or no longer recognized as persons. The category, the burden of burden, captures the participants’ experience that their new situation after stroke was a burden for their children, spouses and partners. This perception of being a burden was, in turn, experienced as a burden by the participants themselves. This burden, in turn, made it difficult for them to feel a sense belonging to a social world. Yet, the participants also felt connected with family and friends when doing activities with others in familiar places as described in the category, connection.
with others through daily activities. Similarly, doing activities with their colleagues in the workplace—also described as a social meeting place—eased them into feeling a sense of belonging and also a sense of being valued and recognized. The last category, *inspiration from engaging with others*, describes how doing something that had meaning to the participants with others gave them energy, and provided a way to measure their own changes during the year.
CONCLUSION OF FINDINGS

The findings of study I showed that the combination of the electronic aids to daily living (EADL) in an training apartment that the participants considered aesthetically pleasing and beautiful (compared to the rehabilitation setting) and feelings that this was a place they could invite friends, spouses and others, gave the participants the experiences that seemed to help establish a “taking off” for their future life within a relatively short time.

The findings of study II showed that the participants’ life-worlds had, after the ABI, changed from a taken-for-granted existence to a chaotic world that was difficult to understand. The routine of doing daily activities and, thus also, their automaticity and coherence of doing had broken down. Doing familiar activities (already integrated in the habit body) in familiar contexts supported coherent doing in daily life during the year.

The findings of study III showed that the participants’ desire for place integration into their familiar places, such as home and workplace, was a constant inspiration for their engagement in rehabilitation and for finding activities on their own that matched the task demands at their workplaces.

The findings of study IV showed that the participants felt connected with others, family, colleagues and friends when doing daily activities, even though it was complex social relations with family at home. The doing with others gave them energy and inspiration and the colleagues at workplace (a meeting place), easing them into feelings of belonging. The rehabilitation was expressed as a process of belonging for place integration.
DISCUSSION

The general aim of this thesis was to describe and understand the experiences of occupations in the context of daily life and the meaning of actions in different places (rehabilitation setting, home and work-place) for persons of working age with ABI during a rehabilitation process.

Based on the participants’ described experiences of daily occupations in the training apartment, rehabilitation setting, home and workplace, the findings suggested the meaning of actions in different places was experienced as a desire for place integration which inspired engagement in rehabilitation. A phenomenological (Karlsson, 1993) and a grounded theory (Charmaz, 2006) approach were used to identify and describe the characteristics of the participants’ experiences of the rehabilitation process. Knowledge of the meaning of actions in different places during the rehabilitation process could be integrated in the development of rehabilitation interventions for persons of working age with ABI. First I will present a general discussion of the main findings of the studies, followed by their implications to occupational therapy practice. Then, I will consider some methodological and ethical issues. Finally, I will discuss some ideas for future research.

The findings in this thesis showed that the experiences of occupations dramatically changed after the onset of brain injury, which altered the meaning of doing activities in different places during the rehabilitation process. All studies (I, II, III, and IV) showed that the participants could not take their life-world (Husserl, 1970) for granted in the beginning of the rehabilitation process after acquired brain injury. Rather, they had to deal with a new, chaotic and unfamiliar world. These findings are in agreement with previous research concerning the lived experiences in daily activities after stroke (Guidetti et al., 2007; Patomella, 2008; Tham et al., 2000).

The concept of place integration (Cutchin, 2003, 2004) provided a way to see how the meanings of participants’ actions over time were related to particular places during rehabilitation in a constantly changing and relational process. All four studies demonstrated that acting in different places (EADL-equipped training apartment, rehabilitation setting, home, and workplace) had specific meanings to the participants during rehabilitation. This is in line with the concept of place linking experiences in different places to individual meaning (Hamilton, 2010/2004; Husserl, 1970; Rowles, 2009). The four studies also demonstrated that the participants found inspiration that supported rehabilitation through doing activities that
mattered with others in particular places. This will be more closely examined from the
different perspectives used in this thesis of the meanings of place, activities and acting with
others below.

The Meaning of Different Places in the Rehabilitation Process

The findings in this thesis showed that actions in different places (rehabilitation setting, home
and workplace) had significant meanings in the rehabilitation process after acquired brain
injury. The characteristics of the different contexts were central to how the meaning of place
was reflected in the studies (I, II, III, and IV). The findings indicated that the meaning of
actions in different places altered over the course of rehabilitation. Experiences from different
places during rehabilitation were linked to individual. In the following, I will discuss the
findings with focus on the relationship between individual meaning of actions and the
characteristics of the different places where most participants were doing their activities
during the rehabilitation process.

The rehabilitation setting

All participants initially described their experiences of feeling secure with the support of
others while doing activities in the rehabilitation context in the beginning, which is in line
with previous studies describing the importance of support from others in the early phases of
rehabilitation after stroke (Guidetti et al., 2007; Kielhofner et al., 2002b; Tham et al., 2000).
However, in study I when the participants compared their positive experiences in the EADL-
equipped training apartment before transitioning to home with their latter experiences in the,
the rehabilitation ward, the ward was described as unfamiliar and challenging. In studies II
and III, the participants expressed that the rehabilitation setting, which was a new and
unfamiliar place to them, was challenging when they tried to do activities that previously had
been taken for granted and integrated into their habit-body (Merleau-Ponty, 2002). According
to Rowles (2003), argued that taking interventions out of person’s places, there is a risk since
activities become more challenging to handle, which also was expressed in the findings of this
thesis.
The training apartment

Despite the novelty and unfamiliarity of the EADL equipped training apartment, the participants seemed to go through a process of place integration within a relatively short time (five days). Even without being able to build their actions from a habit-body, the participants could, in different ways handle doing, even new activities, by the end of the week. One possible interpretation is that the electronic aids supported their activities, which is in agreement with recent studies showing that EADL in a training apartment played an important role for persons with memory impairment in facilitating daily activities (Boman et al., 2009; Boman et al., 2007). The participants’ descriptions of their experiences in study I also provide some additional interpretations. The participants described the EADL-equipped training apartment as challenging, but also as aesthetically attractive. These characteristics combined gave feelings of inspiration and freedom for actions then also characterized the training apartment as a social meeting place.

The home

The findings in this thesis showed that actions at home had specific meanings in the rehabilitation process after acquired brain injury. Home was a place characterized by experiences of familiarity, support from significant others and linkages to previous ways of doing things. The familiarity of doing daily activities at home held particular importance for the participants with memory impairment in study II. In contrast to participants’ experiences in the EADL-equipped training apartment in study I, home was experienced as a familiar place. Through doing activities they were used to doing at home (e.g. cooking favorite recipes), the participants of study II linked their habit-body (actions of the body done before stroke) to the doing activities after stroke. The finding that experiences at home supported a level of automaticity in doing activities in persons with memory impairments has not previously been described. The conclusion that the home context supports a linkage to previous habits, however, is supported by several studies that found that unfamiliar contexts can be confusing when doing daily activities after stroke (Lampinen & Tham, 2003), while familiar ones support rehabilitation (Wohlin Wottrich et al., 2007).

Although the findings of this thesis support the findings of the few qualitative studies exploring the meaning of rehabilitation at home after stroke (von Koch, Widén Holmqvist, Wohlin Wottrich, Tham, & de Pedro-Cuesta, 2000; Wohlin Wottrich et al., 2007), this thesis
also adds some important characteristics to better understand the meaning of actions at home for rehabilitation. For example, study I showed the importance of a home-like training apartment for successful completion of new activities in an unfamiliar context among persons with memory impairment. In addition, those previous studies (von Koch et al., 2000; Wohlin Wottrich et al., 2007) mainly focused on older persons with stroke who had retired from work. Both studies III and IV showed how participants of working age got inspiration in their homes for doing activities in other places, such as the rehabilitation setting or workplace. Using the concept of place integration (Cutchin, 2003, 2004) showed how activities in the home inspired the participants to create other possible future horizons that supported their investment in the rehabilitation process. Memories in places connect past to the future (Hamilton, 2010/2004) and experiences at home seemed to give the participants a sense of continuity and energy that was also connected them to their workplaces.

However, despite getting inspiration in their homes for doing activities in other places (studies II and III), specific experiences of the participants at home also showed the complexity of social demands that are also rooted in experiences before acquiring brain injury. Feelings of belonging also continued to be disrupted, which was shown in study IV, when the participants experienced a burden of the burden of their family members of ABI.

The workplace

One of the main findings in this thesis was the meaning that the workplace played in the rehabilitation process after acquired brain injury. During the duration of the rehabilitation process, participants expressed that their workplace was present in their minds and that their desire to return to work guided a lot of their choices. The meaning of work after acquired brain injury has been explored in previous research that showed that persons with acquired brain injury (ABI) strived to return to work in order to achieve a sense of normality (U. Johansson & Tham, 2006). This could be one reason to why the participants in studies II, III and IV, early on and during the entire year of rehabilitation, expressed desire to return to their workplaces. However, the findings of study IV also draw out another significance of the workplace has not been previously described in rehabilitation research. In this study, the experience of doing familiar and “harmless” (Guidetti et al., 2007) activities in the workplace as a social meeting place seemed to contributed to feelings of belonging that supported the rehabilitation process.
Place as a Source of Inspiration for Rehabilitation

Using place integration as a theoretical resource, the findings in this thesis showed that the different places (rehabilitation setting, home and workplace) inspired the participants’ engagement in activities and in their own rehabilitation process. The importance of experiences-in-places in inspiring rehabilitation after acquired brain injury is sparsely described in previous research. I will first consider the general characteristics of places that inspired participants’ rehabilitation process, followed by more detailed descriptions.

Some general characteristics of places, which supported a “right challenge” in activities, were experiences of places being aesthetically attractive (study I) and/or gave space for actions of freedom (studies I, II, III, and IV) and meeting others (studies I and IV). Furthermore, familiar places that supported activities linked to the participants’ habit-bodies (Merleau-Ponty, 2002) seemed to also support engagement in the process of rehabilitation (studies II, III, and IV). One reason could be that familiar activities are integrated into a habit body and thereby easier to do than unfamiliar activities. Places that gave possibilities of seeing each person’s unique qualities (studies I, II, III, and IV) and acting with others (family, colleagues and friends) also led a sense of belonging (study IV) that was related to persons being able to see possible futures (studies I, II, III, IV). One important question is if the places for rehabilitation within health care fulfill these conditions that seemed to, based on the participants experiences, inspire engagement in their own rehabilitation process after acquired brain injury.

The places in the studies inspired participants in different ways. In study I, learning how to handle the assistive technology in the, what participants described as being aesthetically attractive, EADL-equipped training apartment provided them with a feeling of dignity and also a place to invite others to meet. The inspiration in that environment might have been the combination of the aesthetic attractiveness in combination with EADL. Even if the environment was unfamiliar and initially experienced as stressful (handling the alarm system), it provided a challenge that, for these participants, seemed to be “right” (Yerxa, 1998). The experiences of “aesthetically pleasing” and dignity may have helped facilitate the feeling of challenges being inspiring, without being threatening. The EADL-training apartment, like the workplace in study IV, also seemed to inspire participants to engage in rehabilitation by creating a sense of belonging when family, friends, staff and other patients came and visited to share coffee or a dinner.
Thus, not only were the physical aspects of place imbued with meaning through aesthetics, but also—since places are socially constructed—through providing spaces for meeting others or “places of experiences” (Hamilton, 2010/2004). It seemed that the participants felt a freedom of acting together with others the EADL-equipped training apartment or being able to experience, as expressed by Lawlor (2003), “doing something with someone that matters” (p. 432). Experiences of doing things that mattered with someone also linked to the participants’ descriptions of home and workplace. Additionally, the sense of belonging derived from their colleagues’ support in their workplaces also seemed to inspire the participants to engage in the rehabilitation process. According to Lawlor (2003, see p. 426) sociality and action are intrinsically interrelated. Doing familiar activities, such as having coffee, with colleagues gave the participants a sense of belonging without the feeling of the burden of being a burden. This desire to belong was related to, and thus interpreted as important, inspiring participants to transfer to import activities linked to the meanings they had for doing-with others at home and the workplace into the rehabilitation setting.

The Meaning of Connecting between Activities and Places

One interesting finding in this thesis was that the participants imported activities experienced at home and work to the rehabilitation setting, but did not export activities from the rehabilitation setting to their homes or workplaces. Their strong desire to belong at home and especially at their workplaces seemed to inspire the participants to find activities that would connect across different places that ultimately supported their engagement in their own rehabilitation process. Participants’ initiative in connecting activities from familiar places to the rehabilitation setting has been sparsely described in previous research. However, one previous study of therapists who followed their patients from the stroke unit at hospital to the home rehabilitation programs showed the importance of providing continuity to treatment by finding associations or links to former activities performed at home (Wohlin Wottrich et al., 2007), while an ethnographic study by Becker (1993), also showed the importance of continuity in activities in daily life after stroke.

The participants connected activities across places in different ways. For example, they brought objects from home connected to familiar activities that provided a more homelike atmosphere in the training apartment. For example, the participants who were musicians brought music records. The participants also brought in familiar activities they felt
to be fun and which also supported training. For example, one participant brought a model boat to build and another participant baked a cake she used to bake at home. Such activities linked to the participants’ habit bodies (Merleau-Ponty, 2002) also connected past to possible future horizons (Husserl, 1970).

Participants also used activities from familiar places to provide meaning to their experience of rehabilitation. For example, one participant who was a dental hygienist described how she began rehabilitation trying to imagine which activities at the rehabilitation setting were most similar or matched the demands of her workplaces, such as working with clay, wood and such things (study III). Then, she began to think of which objects she could bring into the rehabilitation setting that would support the activities of her workplace, such as a phantom model, in order to have as realistic training as possible. This can be related to Heidegger’s (1993) description of how objects belong to a meaning context. She also linked activities across places when training her arm, such as working at her kitchen sink or cleaning her home. Connecting activities across places seemed to be a way for her to create training at home that matched the complexity of her tasks at work.

Another example of how participants used activities to provide connections across places was the person with memory impairment who placed objects on his kitchen table at home that related to the activities at the rehabilitation setting and workplace as a kind of mnemonic device (study II). This strategy can also be used in rehabilitation. Since the challenge in cognitive rehabilitation has been to transfer the skills learned in remedial training tasks to daily activities (Berg et al., 1991; Majid et al., 2000; Sohlberg & Raskin, 1996), the occupational therapists ought to, following a client-centered approach, support persons with ABI in rehabilitation by identifying the activities that connect across a person’s actual places. As supported by the experiences of persons with ABI in this thesis, the importance of using objects from and/or familiar activities that are meaningful to persons is in the sense of connections across places that this provides.

**Belonging through Acting with Others in Different Places**

The findings in this thesis indicated that supporting experiences of belonging is a crucial aspect in the rehabilitation process after acquired brain injury (studies I, II, III, and IV). In the beginning of the rehabilitation process, participants experienced a sense of being disconnected from others compared to prior to ABI. During the rehabilitation process, participants
gradually felt a sense of belong through acting with others in different places (study IV). Yet, belonging, per se, is sparsely explored in previous research in the area of rehabilitation after ABI. In the following section, I will discuss aspects of belonging through acting with others in more detail.

Study I indicated that when participants invited family members, other patients, friends or colleagues, the training apartment was transformed into a “meeting place” that facilitated experiences of belonging. They experienced a freedom to interact with others in a place where they felt dignity and inspiration. In line with this, a recent study showed that acting with others (cooking with other patients) or doing activities rooted in a past repertoire in a training kitchen was experienced as less threatening then other activities, or “harmless” (Guidetti, Asaba & Tham, 2007).

Study IV focused specifically on the participants as “socially-occupied,” or the meaning of acting with others in different places. In this study, the work place was the place where the participants described the feelings of being recognized as a critical aspect of feeling a sense of belonging (studies III and IV). Hammell’s (2004) suggestion, then, that belonging is a key dimension of meaning in doing activities may be related to recent findings that a successful return to work for persons with stroke signified an achievement of “normality” (U. Johansson & Tham, 2006). Being recognized as the persons they actually were (study IV) during the whole rehabilitation process can be understood from a social science perspective that views the “…transformation from a place of relative invisibility to one in which one receives recognition and regard as a human being” as a “healing of belonging” (Park, 2008, p. 236).

The process of belonging described in study IV was closely related to the experience by doing activities together with others that is in line with occupational scientist Lawlor’s (2003) writings about “the shared nature of human experience” (p. 426). The participants described doing things with their colleagues as important for creating a sense of belonging. For example, the participants in studies III and IV described how they could come to their workplace and just sit and talk and feel recognized. Experienced as the support and friendship that comprise a “social world of engagement” (Wyller et al., 2003), the focus on the acting with others (having coffee, conversations) characterized this experience as a social meeting place that is in line with Josephsson’s (1994) conceptualization of “occupations as meeting places.” Previous research in the field has, in line with these findings, shown that social support at work is of importance for reintegration to work (Alaszewski et al., 2007; Gilworth
et al., 2008; Medin et al., 2006). Experiences of belonging at the workplace, like in the training apartment, could be supported when activities are less threatening or “harmless” (Guidetti et al., 2007), such as sharing a coffee or conversation.

The sense of belonging at home seemed to be more complex, probably due to the more complex interrelations of multiple social actors (Lawlor & Mattingly, 2009). Even though the participants felt supported at home, it seemed to be hard to be recognized as the persons they felt themselves to be. One reason could be due to the great deal of stress and uncertainty (Hunt & Smith, 2004) placed on family members after stroke that negatively affects family life (J. Murray et al., 2003; Röding et al., 2003), which can lead to breakdown of familiar relationship and withdrawal from friends (C. Murray & Harrison, 2004; Visser-Meily et al., 2009). An additional finding of this thesis provides an additional dimension to the social consequences of ABI. For example, persons with ABI also experienced the burden placed on family members as a burden.

In conclusion, the findings of this thesis point to the crucial role that rehabilitation professionals have in supporting families to find new and satisfying ways of doing together which might ease the burden for both the persons with acquired brain injury and their families in the rehabilitation process after stroke.

Clinical Implications

Based upon the participants described experiences, the findings showed that different places (rehabilitation setting, home and workplace) had different meaning for each participant during the year of rehabilitation. An overall clinical implication for professionals in rehabilitation, based upon these findings, is the importance of understanding the meaning of actions in the client’s actual places. The concepts of place integration (Cutchin, 2003, 2004) and socially-occupied beings (Lawlor, 2003, In press) may be helpful concepts for the development of interventions by highlighting how the meaning of activities is created in a dynamic process between person-place and particular others. Using these theoretical resources in this thesis underlined how the desire to belong in different places can be used to inspire engagement in rehabilitation.

In the following I will summarize some important clinical implications that can be drawn upon the findings in this thesis.
Connecting activities across places in rehabilitation

Findings indicate the importance of using the meaning of objects and activities to connect activities across places in rehabilitation in order to inspire engagement in rehabilitation. By working with clients and others (family members, colleagues, friends) to identify and connect activities between different places through, for example, conducting early visits at home or workplace, rehabilitation professionals may also incorporate activities that link to the habit bodies of persons with ABI as well as past and future horizons.

Integrating familiar activities and places in rehabilitation

Findings show the importance of integrating familiar activities into rehabilitation interventions that enable coherence and automaticity in doing activities already incorporated in the client’s habit-body. This is of particular importance for clients having memory impairment as shown in study II. The meaning of activities was also linked to the desire to for place integration (studies III and IV) and, more specifically, to acting with others for a sense of belonging (study IV). By focusing rehabilitation interventions on supporting the clients to do familiar and meaningful activities with others, occupational therapists can support engagement in occupations.

Creating places that inspire in rehabilitation

Findings also indicate the importance of creating inspiring and challenging places linked to familiar activities in order to support engagement in rehabilitation in persons’ actual places. This can be done in different ways, as for example, when designing new rehabilitation settings one should understand and take into consideration the importance of creating an aesthetically attractive place with a homelike atmosphere that enable meeting-places for socialization. With small modifications to the rehabilitation setting, these conditions can be fulfilled, as for example through giving the possibilities of playing music and watching television, having a computer, having homelike furniture’s, beautiful textiles and other inspiring objects, flowers, together creating a home like atmosphere. This combination seems to facilitate the challenge of integrating even new technologies in daily activities (study I), in line with Yerxa’s (1998) call for just right challenges in occupational therapy.

Creating aesthetically pleasing places that inspired freedom of actions and experiences of dignity, in line with promoting agency from a client-centered perspective, enabled the
clients to take initiative in socializing with others (studies II and IV). Rehabilitation places should preferably inspire initiatives to invite others for coffee or meals, which may be of importance for experiences of belonging in both new and familiar places. Thus, findings indicate the importance of understanding the importance of creating social meeting places, even in rehabilitation settings. Using familiar activities from such familiar places as the home and workplace can be used to support clients to connect with family members, colleagues and friends. The occupational therapists can, by initiating home visits and visits at workplace, support the creation of meeting places by using familiar activities in those places or by importing those familiar activities into the rehabilitation setting.

Supporting action with others for belonging
The findings indicated the importance of understanding the clients’ needs of belonging through acting with others during rehabilitation. Rehabilitation professionals could play a crucial role in enabling the clients to be recognized as the persons they actually are by, for example, using the familiar activities that participants identify as meaningful in their daily lives in the rehabilitation setting. Although this is not a novel idea in occupational therapy practice frameworks, this thesis additionally showed how supporting familiar activities done with others outside of rehabilitation can also support persons with ABI to feel recognized as the persons.

In conclusion, an overall clinical implication for professionals in rehabilitation, based upon these findings is the importance of understanding the meaning of actions in the client’s actual and familiar places (the rehabilitation setting, home and workplace). Using the meaning of familiar activities is key to connecting rehabilitation experiences across places (the rehabilitation setting, home, workplace) that plays a critical role for the experience of continuity critical for persons with ABI. Finally, supporting acting with others (family, colleagues, friends) for belonging needs to be further stressed in rehabilitation programs.

Methodological Considerations
The design and methods used in this thesis were well suited to fulfill the goals and aims of this thesis. The different methodological approaches and frames of references complemented each other by bringing different perspectives on the experiences of persons with ABI who were of working age. The aim was not to generalize the findings to a larger group of people.
Rather the aim was to increase understanding of the meaning of acting in different places in rehabilitation with others that could be integrated in the development and implementation of strategies for occupational therapy interventions in specific and rehabilitation in general.

The process of complex phenomena, such as the concept of occupation (Molineux & Whiteford, 2005), was highlighted using longitudinal design (studies II, III, and IV), complementary methodological approaches (phenomenology and grounded theory), and a conceptual framework (occupation, place integration and socially-occupied beings). As noted by Saldana (2003), longitudinal data is valuable when studying processes. While study II had a longitudinal design to examine the meaning of the phenomenon studied within a rehabilitation process during one year, the longitudinal design of studies III and IV also used the theoretical resource of place integration to further highlight the examination of processes over time when using a grounded theory approach. The next section will be used to discuss the implications of two different methodological approaches and the use of interviews for studying processes. Finally, more general issues of validity, reliability and generalization in qualitative research will be discussed.

The use of the phenomenological approach

A phenomenological approach was used in studies I and II, which influenced the study designs. In study I, interviews were conducted with several individuals (n=11) in order to establish general patterns of their lived experience over a one-week stay in the training apartment. Since the researcher did not have the opportunity to build a relationship based on trust with the participants and was unable to follow up the answers from the previous interview, the richness and trustworthiness of data was limited. In contrast, the year long process of study II increased the richness and trustworthiness of data even though there was a limited number of participants (n=4). Due to the time limitations of study I and the small sample size of study II, the findings cannot be generalized in a traditional (positivistic) scientific way. However, the aim of phenomenological studies is not to generalize findings to other populations and contexts, but rather to contribute to a better understanding that may, in turn, be transferred to other persons or contexts (Dahlberg et al., 2001).

The EPP method (Karlsson, 1993) made it possible to identify the things (phenomena) as they presented themselves in the participants’ descriptions of their life-world experiences (Husserl, 1970). However, the researcher must understand and integrate the philosophy of phenomenology during analysis and this process of analysis takes a long time. One issue is...
how to be sure that the results in the studies are valid. Karlsson (1993) suggested three validation criteria in the EPP method. In this study two criteria relevant for the analysis of data were used. The first criterion applied in this thesis, stated as “The degree of success in the implementation of the partial phenomenological psychological reduction” (Karlsson, 1993, p. 131), is a challenging process when bracketing the theories that attempt to explain phenomena that are part of our natural attitude to the world. This criterion requires that “…the researcher does not impose biases and prejudices on his/her understanding of the protocol” (p. 131) in order to do the things (the phenomena) full justice. Instead, the researcher must trust in her/his ability to do the phenomena full justice. The second criterion to make the studies as valid as possible or “the horizontal consistency of interpretations” (p. 131) required that the researcher made sure that an interpretation of one part of the data (a characteristic) was consistent (fitted with) with other interpretations of the text. Thus, in order to achieve trustworthiness and minimize bias, the researcher went back and forth between interpretations of the participants’ descriptions of their experiences in the interviews (raw data) during the entire analytic process. Each stage of analysis in each study was also subject to peer examination by experienced researchers and practitioners.

The use of the grounded theory approach

The design of studies III and IV followed Charmaz (2006) guidelines for grounded theory (Glaser & Strauss 1967). This approach proved valuable when studying the process of actions across time in different places with others since, as opposed to the phenomenological approach that asks researchers to bracket theories, grounded theory can make use of other theories in order to ground or conceptualize emerging phenomena during the coding process. Initially, in studies III and IV, the focus of analysis was on processes over time. The concept of place integration (study III) to further conceptualize processes of change over time was use. Combined with the additional lens of socially occupied beings (Lawlor, 2003; In press) (study IV), the following main categories emerged: The desire for place integration inspires engagement in rehabilitation (study III) and A process of belonging for integration (study IV). When attempting to understand the meanings of particular places and actions with others over time, this combination of theoretical resources proved helpful when using grounded theory to understand process.

The use of the grounded theory approach might be an example of how a method can take use of theoretical concepts (place-integration and socially occupied beings) and vice
versa. Since the data had already been collected prior to analysis, the flexible guidelines in Charmaz’ (2006) guidelines also worked well. For example, even though the researchers could not do theoretical sampling through new interviews, the theoretical sampling occurred through analyzing more interviews until saturation were reached. However, this can be a limitation since nuances in meaning might be lost when the researcher does not have the possibility to follow up interesting threads in the data in the next interview with a person.

**Using interviews in qualitative studies**

The value of interview data is to have rich data, which was made possible, as shown in the studies, with the two researchers interviewing the participants four times during the year of rehabilitation. The longitudinal design of interviewing across one year meant that the researchers learned to know the participants well during data collection. However, interviewing persons with ABI can be challenging due to the memory impairment or fatigue common after injury. Especially in the first month after acquiring brain injury (interview 1), these challenges could have negatively influenced the answers. Yet, the interviews also seemed to also provide the participants with the opportunity to tell about their experiences that some felt inspiring. Several participants also expressed that the interviews situation was like a therapeutic, allowing them to reflect on the experiences of a new and chaotic world after injury. This is not unexpected for, as Charmaz (2006) pointed out, the interviewer asks participants to describe and reflect upon experiences in ways that seldom occur in ordinary life through listening, observing with sensitivity and encouragement to respond. One conclusion might be that the interviews conducted in this research process could be viewed as contributing to the participants’ rehabilitation processes.

The richness of the data collected might also be due to several concrete protocols. For example, developing the interview guide required refining them to follow up on the answers to important questions between each of the participant’s interviews. In addition, the researchers made every effort to make the interviews convenient for the participants by having them choose the places for the interviews (the rehabilitation setting, their homes, the researcher’s workplace). Allowing the participants to choose the place of the interview incorporated the importance of the interview context as stressed by Kvale (1996) into the research design. In this light, providing coffee or tea together if wanted, also provided an additional social context for the interviews. The combination of all these aspects discussed above could account for the reason why many of the participants expressed the value of being
interviewed and their interest in participating in a follow-up study in the future. This would be of great interest since there is a lack of longitudinal research within this area.

**Studying processes**

In occupational therapy research it is of interest to study different processes since the aim of occupational therapy intervention is commonly to enable or support change over time. The concept of place integration (studies III and IV)—in addition to the longitudinal design—put into the fore ground how the meaning of actions in different places changed over time. The use of qualitative methodologies to study processes has been sparsely described and discussed in research literature. According to Charmaz (2006), process “…consists of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between” (p. 10). In this thesis, there was a distinct advantage in having a longitudinal design in studies II, III, and IV, which made it possible to compare data from different times and places over a year and thereby begin to understand the meaning of actions during the process of rehabilitation. In each of these studies a choice was made to make visible the process of the different studied phenomena by presenting the findings in the overlapping phases in which they emerged.

**Generalizability and validity**

All four studies in this thesis are qualitative in approach, building on open-ended interviews with certain guidelines with persons with ABI. The aim was not to generalize the findings to a larger group of people but, rather, to increase an understanding of the meaning of acting in different places in rehabilitation. All of the interviews were conducted by the first author of study I and II, while the interviews were conducted by both the first and last authors of studies III and IV. Having two researchers conduct interviews could be a weakness. Even with the same protocol, researchers have different approaches to interviewing, including when and how to ask follow up questions, which is crucial for achieving nuanced and rich data (Kvale, 1996). In addition, not all the participants were interviewed—and thus more personally known—by all of the researchers. However, having two different researchers conducting interviews could also be viewed as a methodological strength in terms of the validity of the analysis. For example, divergent research experiences based on different understanding and insights led to constructive discussions about alternative interpretations of interview data that
was consistent with qualitative methods for ensuring validity (Patton, 2002). In addition, the results of study II were also presented to experienced occupational therapists and researchers in the field of neurological rehabilitation, while the analysis and coding at all levels in all of the studies I, II, III, and IV—including emergent characteristics, categories and/or conceptualizations—were grounded in the participants’ described experiences in order to strengthen the credibility of the findings (Chiovitti & Piran, 2003).

**Ethical considerations**

The studies were approved by the Ethical Committees at Karolinska Institutet. The participants received written and verbal information previous to their participation in the studies, and all the participants consented verbally and in writing to participation.

One ethical dilemma in Study I was that the researcher did not know the participants, which may have violated their integrity during the interview. However, the interview questions were informal and focused on concrete experiences of daily activities, which seemed to counteract any perceived violation of integrity. A dilemma in studies II, III and IV was the small number of participants, which made it difficult to ensure anonymity. Therefore, any information that could betray their anonymity was changed or deleted. In contrast to study I, the researcher was able to follow the participants over a year in studies II, III, and IV, introduces another possible ethical dilemma. Although the interviews in these longitudinal studies contributed to the detailed descriptions of their life-world experiences, the persons with ABI agreed to participate in the study at the start of their rehabilitation without knowing how they might experience their participation in the research process by the end of the year. However, none of the participants gave any indications of negative experiences from the interviews during the year and also expressed interest in continuing with additional follow-up research projects. This seemed to indicate that instead of being detrimental, the long term process enabled the researchers and participants to establish relationships built on trust, which may have been reflected in the participants’ expressing that the interviews felt therapeutic in that they helped them to reflect on their experiences of ABI.

**Future studies**

During the research process, several new research issues emerged that could be the subject of future studies in the field of occupational therapy. For example, one interesting future study
would be to do a follow-up of the participants in studies II, III and IV to examine how the meaning of actions with others in different places continues to shift over time—and to reflect on which findings of these studies hold over time. Another suggested area of study would be to develop a new intervention program based on the findings from study I of the experiences in the EADL-equipped training apartment and evaluate its effects in a group of individuals with memory impairment. It would also be of importance to develop, based on the findings from the studies included in this thesis, an instrument to assess if and how the criteria of places that support engagement in the rehabilitation process are being used in current interventions. Finally, it would be of interest to develop and then evaluate the effect of an intervention program based on the clinical implications of this thesis in which the meaning of familiar activities that could be done with others in actual places supported engagement in rehabilitation.
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