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# **Occupational gaps after acquired brain injury:**

An exploration of participation in everyday occupations and the  
relation to life satisfaction

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## ABSTRACT

Participation in everyday occupations and life satisfaction is often reduced after acquiring a brain injury. The everyday life situation is altered and life satisfaction is also decreased for persons who are close to those who have acquired a brain injury, for instance partners. The overall aim of this dissertation was to explore and identify what people do and want to do in everyday life over time after acquiring a brain injury, with focus on their perceptions of gaps in their everyday occupations and the relation to their perceived functioning and life satisfaction. The joint life satisfaction among couples, where one person has had an acquired brain injury, and the relation to their perceived functioning and participation in everyday occupations were also explored. Furthermore, the aim was to initiate the development of methodology capturing the perceived occupational gaps, and to understand how occupational gaps were characterised in the lived experiences of performing everyday occupations.

This dissertation comprises four studies that focus on the participants' perceptions of everyday occupations. The joint life satisfaction among 55 couples and the influence the perceived functioning and disability had on their life satisfaction was explored (Study I). The concept of occupational gaps was identified; an occupational gap is defined as the gap that occurs between what an individual wants and needs to do and what he or she actually does. The Occupational Gaps Questionnaire was developed, which is considered to measure to what extent an individual does/does not what he or she wants to/wants not to do. Perceived occupational gaps before and after injury and the relation to impairments and time lapse since injury were explored among 187 participants who had acquired their brain injury 1-4 years earlier (Study II). The relation between perceived occupational gaps and life satisfaction in a subsample (n=116) of the previous study sample was also explored (Study III). Finally, the phenomenon of occupational gaps was explored by identifying how the occupational gaps were characterised in the participants' (n=4) lived experiences of performing everyday occupations the first year after stroke (Study IV).

The findings showed that the majority of the couples in which one person had acquired a brain injury perceived a low joint life satisfaction that was mainly influenced by their restricted participation in everyday occupations. The studies of occupational gaps showed that the participants that perceived occupational gaps increased by 25% after acquiring a brain injury, and the extent of perceived occupational gaps was mostly related to the participants' perceived executive and motor impairments. In addition, the time that had elapsed since injury, i.e. whether one year or four years had passed since onset, had no effect on the extent of gaps. Furthermore, the extent of occupational gaps was shown to have a definite relation to life satisfaction, where low extent of occupational gaps related significantly to a high life satisfaction. The phenomenological study identified five main characteristics that described participants' experiences in their everyday doings. They strove to narrow gaps in symbolic occupations; experienced themselves as being the persons they were before or modified their sense of self through doing; encountered occupational gaps in former taken-for-granted activities; created strategies enabling doing; and had a sense of being competent despite the disruption.

In conclusion, participation in everyday occupations is often restricted in the long term for persons who live with an acquired brain injury as well as for their partners. Consequently, access to client-centred and occupation-based rehabilitation interventions, even in the long-term, is required for clients with acquired brain injuries and persons close to them who have unmet needs. Life satisfaction had a definite relationship with participation in everyday occupations (Study I) and perceived occupational gaps (Study III), which implies that by enabling persons or couples to do what they want to do in everyday life their satisfaction with life might be enhanced.

**Keywords:** Activities of daily living, brain injury, participation, life satisfaction, rehabilitation, occupational therapy, phenomenology, adaptation psychological

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## **ABBREVIATIONS**

ADL	Activities of Daily Living
ABI	Acquired Brain Injury
AOTA	American Occupational Therapy Association
CI	Confidence Intervals
EPP	Empirical Phenomenological Psychological (method)
HADS	Hospital Anxiety and Depression Scale
ICF	International Classification of Functioning, Disability and Health
LEAIQ	Late Effects of Accidental Injury Questionnaire
LiSat	Life Satisfaction (checklist)
OGQ	Occupational Gaps Questionnaire
OR	Odds ratio
RLS	Reaction Level Scale
SAH	Subarachnoid haemorrhage
TBI	Traumatic Brain Injury
WHO	World Health Organization

## LIST OF PUBLICATIONS

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

- I. Eriksson, G., Tham, K. & Fugl-Meyer, A.R. (2005). Couples happiness and its relationship to functioning in everyday life after brain injury. *Scandinavian Journal of Occupational Therapy*, 12, 40-48.
- II Eriksson, G., Tham, K. & Borg, J. (2006). Occupational gaps in everyday life 1-4 years after acquired brain injury. *Journal of Rehabilitation Medicine*, 38, 159-165.
- III Eriksson, G., Kottorp, A., Borg, J. & Tham, K. The relationship between occupational gaps and life satisfaction after acquired brain injury. *Submitted*.
- IV Eriksson, G. & Tham, K. The meaning of occupational gaps in everyday life after stroke. *Submitted*.

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## **BACKGROUND**

In my clinical work as an occupational therapist I have had the opportunity to meet many young and middle-aged persons in the process of getting to know their new selves in their altered life situations after brain injury. Their efforts to regain their everyday occupations and all their various ways of handling their challenges aroused my interest and curiosity. I have had the great advantage of getting to know my clients over a long period of time and collaborating with them to find ways of dealing with demanding situations while preparing dinners for their children as well as finding new structures in the work situation in order to retain part-time work. The conversations I have had with these persons and persons close to them, both in the clinic and in their own environments, taught me the importance of taking the clients' views into account to be better able to support them in their recreating of their everyday lives. The everyday life situations had also been changed for the persons close to the clients who had acquired a brain injury, as they had to take on greater responsibilities than before for their shared everyday lives. Meeting all these persons evoked my interest in gaining more in-depth knowledge about how persons with brain injury and those close to them perceived their everyday occupations.

The need for developing client-centred rehabilitation strategies has been emphasised to enhance the participation in everyday occupations in the long term (Mazaux & Richer, 1998). However, there is limited knowledge on how everyday occupations are perceived after acquiring a brain injury, and an enhanced knowledge in this area might be seen as a prerequisite for developing client-centred interventions. What is known is that everyday occupations are often more challenging for the persons with brain injury (Hahn & Baum, 2004), and the partners or spouses perceive reduced possibilities to participate in some of their occupations due to the need to provide assistance (Palmer & Glass, 2003). It has not, however, been explored how a couple perceives their joint everyday life and how satisfied they are with life. Furthermore, there is limited knowledge on what persons do and want to do after acquiring a brain injury and how to assess their perceived gaps in everyday occupations, and the relation between persons' perceptions of their everyday doings and their perceived life satisfaction is also unexplored. This thesis explores the perceptions of the persons with ABI on their participation in everyday occupations in the long term, as well as the perceptions of the partners of some of those persons. The objective is also to develop a way to assess what people do and want to do and to explore how their perceptions on everyday doings relate to

their perceived functioning and their life satisfaction. The four studies in this thesis might contribute empirical support for the development of the theoretical base for client-centred rehabilitation and an enhanced understanding among rehabilitation professionals of how the persons perceive and experience their everyday occupations.

## INTRODUCTION

### *Occupation and its importance for health and well-being*

The main focus of this thesis is on how persons with acquired brain injury (ABI) perceive their engagement in everyday occupations in the long term after injury and how some of the partners of these persons perceive their everyday occupations.

*Occupation* is the term used in occupational therapy and in occupational science to frame and describe the area of concern for practice, theory development, and for research. Occupation has been defined in various ways and the focus for occupational therapy has been debated and changed throughout the last four decades. In this thesis, I have chosen the definition of Law and co-workers (2002),

*“Occupation refers to groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture.*

*Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)” (p. 34).*

This definition emphasizes the individual meaning and value in a person’s everyday occupations and recognises the importance of cultural and environmental aspects on doing. These aspects harmonize with the perspective of being client-centred in occupational therapy practice (Townsend, 2002) and in rehabilitation.

From the perspective of an occupational therapy practitioner, occupation has its focus on clients’ actual doing. Primarily occupation relates to the ability of an individual to perform the daily life tasks that he or she wants and needs to perform, or that the person is expected to perform by society (Fisher, 2003). For the purpose of this research project the concept of occupational gaps was identified, to capture the perceived gaps in everyday occupations after ABI. An occupational gap is defined as the gap that occurs between what an individual wants and needs to do and what he or she actually does.

Being occupied refers to being engaged in something, in an actual process of doing something (Fisher, 2003), e.g. writing your thesis or preparing dinner for your loved ones.



Occupational performance, accordingly, refers to a meaningful sequence of actions in which the person enacts and completes a specified task that is relevant to his or her culture and daily life roles (Fisher, 2003). The performance of occupations is seen as the result of a dynamic relationship between person, environment, and occupation over a person's lifespan (Law et al., 2002).

The basic assumptions for occupational therapy, that being engaged in occupation is an integral part of human nature and that all people have a basic need and drive to be occupied, was first stated by Meyer (1922). Participation in occupations shapes our minds and bodies and influences people's health and well-being (Law, 2002; Willcock, 2001; Yerxa, 1998) and is also seen as the primary source of meaning in human life (Christiansen, 1999; Hasselkus, 2002). These assumptions are regarded as important to explore empirically by scholars in occupational science in order to understand the nature, meaning and the constitution of occupation (Jarman, 2004; Willcock, 2005; Christiansen & Townsend, 2004; Miller Polgar & Landry, 2004; Clark, 1993). The assertion that participation in occupation is a determinant of health and well-being has been shown empirically (Morgan & Bath, 1998; Charmaz, 1994; Law, Steinwender & Leclair, 1998; Clark, Azen, Zemke, Jackson, Carlson, Mandel, et al., 1997). However, further studies are emphasized to clarify the interaction between occupation, health and well-being (Willcock, 2005) and in Study III in this thesis the objective is to explore the relation between what persons with brain injury do and want to do and how that relates to life satisfaction.

For *participation* in everyday *occupations* two different perspectives are referred to in this thesis. I draw from both WHO's definition in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and from the definition of *occupational participation* as suggested by Kielhofner (2007). Participation, according to ICF, is defined as a person's involvement in a life situation, or as the lived experience of people in the actual context in which they live. This objective view of participation, i.e. the observed participation, has been criticised, and the addition of a more subjective dimension on participation in ICF has been emphasized (Ueda & Okawa, 2003; Hemmingsson & Jonsson, 2005). This subjective dimension, as well as a more pronounced focus on occupation, is included within the definition of "occupational participation", i.e. "engagement in work, play, or activities of daily living that are part of one's socio-cultural context and that are desired and/or necessary to one's well-being" (Kielhofner, 2007). According to Kielhofner (2007) engagement in

occupations is seen not only as the actual doing but also the subjective experience, which underlines the personal and social significance of the doing.

According to Hasselkus (2002), the involvement in occupations is about doing, but is also a source of meaning in life, as mentioned earlier. By engaging in occupations persons experience subjective meaning derived from the actual doing as well as from how the occupation persons chose to take part in was performed. The experience of performing occupations tells us about who we are, and has implications for future choices of occupations to take part in and how our life will be orchestrated (Hasselkus, 2002).

### *The international classification of functioning, disability and health*

The International Classification of Functioning, disability and health (ICF) provides an international and inter-professional basis for the understanding and description of health and health-related states. It is widely used as a frame of reference for outcome research, and for describing health-related states as well as the opposite, e.g. consequences of illness (WHO, 2001). In the ICF (WHO, 2001) the information is organized into a) Functioning and Disability and b) Contextual factors. Functioning and Disability are divided into two components: 1) body function and body structure and 2) activity and participation. Each component can be expressed in the positive term “functioning” as well as in the negative term “disability” (i.e. impairment, activity limitation, participation restriction). Body functions are defined as the physiological functions of body systems. Body structures are defined as the anatomical parts of the body, such as organs and limbs. Activity is defined as the execution of a task or action by an individual. Participation is defined as involvement in life situations. Involvement incorporates taking part, being included or engaged in an area of life, being accepted, or having access to needed resources. Participation has been operationalised into nine domains, focused on observable performance (WHO, 2001). Although the definition “involvement in life situations” emphasizes an interest in people’s subjective experiences, it is not possible, when using ICF’s classification, to take into account or code anything but the external observations of performance (Hemmingsson & Jonsson, 2005). In contrast, three of the studies in this thesis will focus on the perceptions of persons with ABI, and on what they do and want to do in their everyday life. The contextual factors in ICF include the environmental and the personal components. The classification of Functioning and Disability in ICF will be used as an overall model for categorizing consequences after ABI in this thesis.

## *Acquired brain injury*

The main focus in this research project is persons' perceptions of their everyday life situations one month to five years after ABI. The participants had been afflicted by different types of ABI with various consequences on their perceived functioning and disability, which are explored in relation to their perceived participation in everyday occupations (Study I) or perceptions of occupational gaps (Study II) and time since onset (Study II) and to life satisfaction (Study I). The term "acquired brain injury" (ABI) is used as a generic term for brain damage caused by stroke (Studies I-IV), traumatic brain injury (TBI) (Studies I-III) or other causes (Study I). In these later phases after injury a distinction between ABI by diagnoses might have low significance since the ABI and the consequences of the injuries are very varied, regardless of their origins (Rice-Oakley & Turner-Stokes, 1999). In Sweden, clients with various types of ABI are referred to the same rehabilitation units and the clients attending rehabilitation receive interventions based on the observed and perceived disabilities rather than interventions based on the etiological diagnosis. ABI is one of the leading causes of disability in most industrialised populations and people with ABI are one of the largest groups of clients receiving rehabilitation in rehabilitation clinics in Sweden (Borg, Gerdle, Stibrandt Sunnerhagen, 2006).

The incidence of stroke in Sweden is about 30,000 per year, and in the acute stage the majority are treated in stroke units. The incidence in persons younger than 65 years, which the participants were in this research project, is currently around 10,000 per year (Medin, Nordlund & Ekberg, 2004). In the age group between 30-65 years of age, which includes the majority of those individuals that receive brain injury rehabilitation in Sweden, the incidence increased between 1998 and 2000 (Medin et al., 2004).

Stroke is a generic term for disturbances of cerebral function that have a vascular origin and includes cerebral infarction (about 85%), cerebral haemorrhage (about 10%) and subarachnoid haemorrhage (about 5%) (Socialstyrelsen, 2005). In Studies II and III more than half of the participants had had a subarachnoid haemorrhage (SAH). About one-third of those afflicted by stroke will have long-lasting consequences of their injuries that will affect their everyday lives (Sundberg, Bagust & Terent, 2003). Each year 25,000 persons are hospitalized due to TBI in Sweden, and the majority of these are younger men, although the vast majority have had mild TBIs. (Kleiven, Peloso & von Holst, 2003; Peloso, von Holst & Borg, 2004).

### *Consequences of ABI on body function, activity and participation*

The classification of functioning and disability in ICF is used in this framework and in Studies I and II to categorize consequences after ABI in the post-acute phase after onset, though it is not unproblematic (Björkdahl, 2007). The way body functions, activity and participation are classified in ICF differs sometimes from how consequences after ABI are traditionally measured (Björkdahl, 2007) and reported in the literature. The rule applied in this section is to categorize prevalence of impairment under body functions, though the impairment might be described in the literature as limited ability in performing activity. Consequences such as limitations and restrictions on activity/participation are categorized as activity/participation when the objectives in the studies are to evaluate performance and participation in everyday occupations. Activity and participation have not been separated in the current review, though in the long term after ABI it is reasonable to expect that most of the consequences for activity and participation are actually perceived as restrictions in participation (Turner-Stokes, 2002).

### *Body function*

It is common that people perceive a variety of impairments due to their ABI which may have consequences on their everyday life situations. In this research project the relation between perceived impairment and joint life satisfaction among couples was explored in Study I. In Studies II and III the relation between perceived impairments and perceived occupational gaps was investigated. The impairments seen in persons after ABI are heterogeneous. The variation is due to type, localization and to the severity of the injury (Socialstyrelsen, 2005). Common impairments that might last long after acquiring brain injury are impaired motor and cognitive functions, including executive functions. Physical impairments are quite common in the early phases after severe damage, but often diminish over time. Cognitive impairments are frequently perceived in early as well as late phases after ABI, and are, together with decreased process skills, considered to have greater influence on independence in the performance of everyday occupations than do physical impairment (Bernspång & Fisher, 1995; Ponsford, Olver, Curran & Ng, 1995).

The prevalence of impairments after ABI differs between studies, which probably reflect differences in study samples, study settings, time after injury, diagnostic criteria and instruments used. Motor impairments persisted for almost half of the clients after TBI (Mazaux & Richer, 1998) at the end of post-acute rehabilitation, while 75% reported perceived motor impairments in a long-term follow-up (Dawson & Chipman, 1995). In a

Danish study on prediction of ability to walk after stroke (Wandel, Jørgensen, Nakayama, Raaschou & Olsen, 2000) the prognosis generally was good for those persons having a mild or moderate stroke but was not good after severe stroke.

Cognitive impairments were perceived by a majority of a group of people two years after TBI (Ponsford, Olver & Curran, 1995). Memory impairment was most prevalent, followed by difficulties with concentration and a low speed of thinking, and about half of the sample had executive problems in, for example, planning, organization and taking initiative. Memory impairment as well as depressive mood increase with injury severity (Masson, Maurette, Salmi, Dartigues, Vecsey, Destailats et al., 1996). Decreased awareness of the impairment or disability after ABI is also common. Awareness of disability is of importance for being motivated to deal with the consequences of ABI in the everyday doings (Tham, Borell & Gustavsson, 2000). However, although we knew the importance of awareness, it has not been taken into account in this research project, as most of the studies (I-III) relied on self-reported data on postal questionnaires.

Depression and fatigue are also commonly perceived after ABI. Depressed mood or anxiety was perceived by more than half of the individuals in the long term after TBI (Ponsford, Olver & Curran, 1995; Masson et al., 1996). Fatigue was also reported by more than half of the individuals after TBI (Ponsford, Olver & Curran, 1995) as well as after mild stroke (Carlsson, Möller & Blomstrand, 2003). The depression rate among people post-stroke in Sweden has been shown to be about 15% (Eriksson, Asplund, Glader, Norrving, Stegmayr, Terent et al., 2004).

### *Activity and Participation*

It is common that people perceive restrictions in self-care, productivity and leisure in everyday life after ABI even in the long term. There is, however, an agreement in the literature that most people are independent in self-care one to two years after TBI (Ponsford, Olver & Curran, 1995; Hoofien, Gilboa, Vakil & Donovan, 2001). Regarding performing household activities, the results from empirical studies are somewhat contradictory. Hoofien and colleagues (2001) and Ponsford and colleagues (1995) reported limitations in household activities as less prominent, while Dawson and Chipman (1995) found that more than half of their sample still needed assistance with their performance of these activities ten years or more after TBI. Instrumental ADL activities outside the home, such as using public transport or driving, as well as those activities which are more demanding of cognitive function, such

as administrating household economy, were difficult to perform in the long term (Masson et al., 1996; Ponsford et al., 1995).

Participation in leisure activities in the long term is commonly more restricted than participation in any activity of daily living. Persons may no longer be able to participate in leisure activities, or may need assistance or have to perform activities in alternative ways (Ponsford et al., 1995). Especially participation in leisure activities together with others or outside the home are decreased (Dawson & Chipman, 1995; Hoofien et al., 2001; Ponsford et al., 1995; Mazaux & Richer, 1998).

Usually half of the persons with TBI have returned to work a couple of years after injury (Malec & Basford, 1996), and a recent study on people with mild to moderate TBI revealed that more than half of them began to work within six months (Boake, McCauley, Pedroza, Levin, Brown & Brudage, 2005). The persons that returned to work frequently had to reduce their working hours or modify their work tasks (Neau, Ingrand, Moille-Brachet, Rosier, Couderq, Alvarez et al., 1998; Vestling, Tufvesson & Iwarsson, 2003), while some had difficulties in keeping their employment after ABI (Hoofien et al., 2001). In a follow-up after TBI half of those who were qualifying themselves for a profession returned to their educations (Ponsford et al., 1995). There is limited knowledge of persons' perceptions of their participation in everyday occupations after having an ABI. In Studies II and III the participants' perceptions of whether they do the activities they want to do in their everyday life is explored.

### *Consequences for spouses of individuals afflicted by ABI, in their activities and their participation in everyday life*

The everyday life situation is also altered for significant others of persons who have ABI. Their perceived health may decline and often they perceive a burden due to the need for assistance that they have to provide to make everyday life work. Usually consequences after ABI are explored separately for people with ABI and for their spouses or families. There is limited knowledge on how the couple or the family as a unit perceives the changed situation in everyday life after ABI. What is known is that an ABI frequently changes everyday life including activities, roles and habits in the family (Clark & Smith, 1999). The literature on consequences for spouses or significant others after ABI are focused on perceived burden and on participation. Two Swedish studies have shown that perceived burden relates to the ability to respond to stress (Forsberg-Wärleby, Möller & Blomstrand, 2002) and counselling about

stroke and its consequences tends to lower the burden (Björkdahl, Lundgren Nilsson & Stibrant Sunnerhagen, 2007).

Responsibility for the everyday life situation rests much more heavily on the spouse after an ABI, and it was shown in a Swedish study that one-fifth of the persons living at home after stroke needed assistance with self-care and more than a third had assistance with instrumental ADL activities (Glader, Stegmaeyer, Johansson, Hultér-Åsberg, Staaf & Wester, 2001). These obligations might result in decreased opportunities to maintain friendships and recreational activities (Palmer & Glass, 2003) as well as to continue to work as before (Hall, Karzmark, Stevens, Englander, O'Hare & Wright, 1994).

### *Life satisfaction*

There is an assertion in the literature that engaging in everyday occupations which a person wants to perform influences life satisfaction. This relationship has to the best of my knowledge not been explored empirically, and therefore it is explored for persons with ABI in Study III.

Life satisfaction might be considered the main goal of the rehabilitation process (Fugl-Meyer, Bränholm & Fugl-Meyer, 1991). In this research project life satisfaction is viewed as the way it was introduced by Fugl-Meyer et al. in 1991, i.e. a person's experience of life satisfaction reflects the extent to which the person achieves his/her vital goals. Later on, being satisfied with life was operationalised by Bränholm (1992) as the individuals' subjective experience of satisfaction or contentment, with a domain of life or with life as a whole, when the aspirations and achievements are met. Thus, satisfaction with life is believed to be achieved when a goal or a need is fulfilled (Michalos, 1980). The perceived level of life satisfaction is identified by the individuals' own cognitive assessments of their perception of the current situation (Campbell, Converse & Rodgers, 1976). Overall life satisfaction is considered to be synonymous with degree of happiness (Veenhoven, 1984). In Western societies the majority of individuals rate themselves as being satisfied with life (Diener & Diener, 1996). Life satisfaction is seen as a purely subjective aspect of how people perceive their lives.

In the literature there is a confusion between the concept of life satisfaction and the concept of quality of life and the concepts are used interchangeably (Melin, 2003). The concept of quality of life, though defined in various ways, has a much broader focus and incorporates both objective views, such as economy and housing, and a subjective perspective on life (Meeberg, 1993).

Neither quality of life nor life satisfaction are classified or defined in ICF. In the ICF there is a “grey zone” between the health domains of well-being that are classified, for example seeing and remembering, and other domains of well-being that are not primarily seen as health domains, and where the responsibility does not lie with the health care system (WHO, 2001). Both quality of life and life satisfaction might be viewed as belonging to that “grey zone” of concepts of health-related elements in ICF, and thus may be seen as indicators of health.

*Perception of life satisfaction after ABI among people with ABI and among spouses of individuals afflicted by ABI*

Low life satisfaction has been reported among persons experiencing stroke (Neau et al., 1998) as well as after TBI in reviews by Johnston and Miklos (2002) and Dijkers (2004). Life satisfaction does not increase over time after TBI (Johnston & Miklos, 2002). In other diagnostic groups life satisfaction correlates with severity of injury, but for individuals with mild or moderate TBI life satisfaction has been reported to be lower than for those with a more severe TBI (Johnston & Miklos, 2004). Factors that significantly associate with higher life satisfaction after ABI are those of being employed and socially integrated (Corrigan, Bogner, Mysiw, Clinchot & Fugate, 2001) as well as participating in leisure activities (Steadman-Pare, Colantonio, Ratcliff, Chase & Vernich, 2001). The availability of emotional and social support have also been shown to be important for the perception of life satisfaction (Steadman-Pare et al., 2001) and Kreuter and co-workers (1998) found that the satisfaction with life as a whole was significantly higher for those living in a partner relationship than for those who were single.

Life satisfaction has been explored separately, for individuals with ABI and for their significant others, i.e. mostly for their partners or spouses. There is limited knowledge of how ABI affects life satisfaction for couples seen as social units, which is the focus of Study I. However, a very recent Swedish study (Carlsson, Forsberg-Wärleby, Möller & Blomstrand, 2007) showed that the domains in life with which the couples were least satisfied were leisure time, sex life and vocational life. Only 30% of the couples agreed upon being satisfied with life as a whole.

Life satisfaction among partners of individuals affected by ABI diminishes (Segal & Shall, 1996; Tennant, Macdermott & Neary, 1995; Forsberg-Wärleby, 2004) and their reduced life satisfaction is mainly related to problems with the brain-injured partners' restricted functioning in everyday life and amount of assistance required, as well as to the perceived



stress due to the need for caregiving (Segal & Shall, 1996). The most pronounced areas affected for those spouses who care for a person who have restricted participation are lack of energy, social isolation and emotional and sleeping problems. The younger spouses seem to live under greater stress (Tennant et al., 1995). In a Swedish study a year after stroke the spouses were less satisfied with life as a whole, the leisure situation, daily occupations, sexual and partner relationships and with their social lives than they had been previously (Forsberg-Wärleby, 2004).

### *The life-world and lived experiences after ABI*

In medical sciences there is a tradition of studying the body and human doings from an outside perspective. Motor and cognitive functioning and performance of everyday occupations are observed and assessed from a professional, objective perspective. The need for more knowledge on how people themselves experience something like acquiring a brain injury or having to deal with long-term disabilities in everyday occupations has been underlined (Kielhofner, Tham, Baz & Hutson, 2007). A way to reach such an understanding is to use a phenomenological approach (Dahlberg, Drew & Nyström, 2001; Karlsson, 1995; Kielhofner et al., 2007). In phenomenology, the interest is in the natural attitude in the world we live in, i.e. the way we subjectively experience and take for granted everyday life and doings in the life-world. The life-world (Husserl, 1970/1936) is as we perceive it. We do not critically reflect on our perceptions and what we do, we just do and we just are. Our natural attitude in the life-world means that we commonly do not consciously analyse what we are doing and experiencing (Dahlberg et al., 2001; Husserl, 1970/1936; Merleau-Ponty, 2002/1945). Familiar things are there for us to be used, and by the way they are linked to each other in series of activities (Erikson et al., 2007) they generate meanings (Heidegger, 1993/1927). When doing something like going skating, you literally just fly away on the ice and you feel the wind cooling your face. You do not reflect on where your feet are. Your skating is automatic. Your body in a way disappears in the doing (Kielhofner, 2007; Merleau-Ponty, 2002/1945), until you observe cracks in the ice. Then suddenly you have to concentrate for a while on the actual skating and on which way to turn to avoid the cracks.

This everyday world we live in is called the life-world in phenomenology and it is individual and commonly taken for granted (Husserl, 1970/1936). But when something new and unexpected occurs, as when a person has to face a changed everyday life due to acquiring a brain injury, then he or she start to reflect on how to perform the most basic everyday tasks that were previously carried out automatically. This has been described in studies by Erikson

and colleagues (2007) and Guidetti and colleagues (2007). The life-world for persons with ABI may change and cannot be taken for granted anymore. To better understand the experiences in these changed life-worlds there is a need for research focusing on the meaning of everyday occupations in the changed life situations after ABI. This understanding can guide rehabilitation professionals when assisting their clients in their processes of recapturing their everyday occupations. The theme throughout this research project is the participants' perceptions of everyday occupations, and in Study IV their life-world experiences are in focus.

### *Adaptation and continuity*

When studying aspects of significance for rehabilitation after ABI it is important to use concepts related to the process of change. One concept that is widely used is adaptation. According to New Webster's Dictionary (1992) adaptation is defined as "the act or process of adapting". To "adapt" is defined as "to put (oneself) in harmony with changed circumstances". Adaptation in its broader sense is a characteristic of all living beings and implies a change over time in interaction with the environment. Adaptive resources among human beings are built up over different time spans; the long-term or evolutionary adaptation, the adaptation due to growth and maturation during one's lifetime, and the more short-term corresponding to immediate change and learning (Coelho, Hamburg & Adams, 1974). In this research project the focus is on adaptation in everyday occupations over a longer period of time.

In occupational therapy adaptation has been a central concept since the beginning of the profession (Meyer, 1922). It is commonly used as describing an attitude, i.e. an internal factor, of adapting or adjusting in a situation of occupational challenges when the customary response to the challenge is no longer adequate to master the situation (Schkade & Schultz, 1992; Christiansen & Baum, 1997; Kielhofner, 2007). Others emphasize both internal and external factors, e.g. changes in the environment, as contributing to adaptation (Unsworth, 1999; Neistadt & Crepeau, 1998). The time perspective on adaptation differs between the occupational therapy scholars, where Schkade and Schultz (1992) have a more short-term performance perspective while Kielhofner and Forsyth (2004) view adaptation as a dynamic and unfolding process of being and becoming that develops from a transaction between the person and the environment. Kielhofner (2007) identifies two important interrelated components for adaptation, identity and competence, which are seen as developing over time

in a close interplay with one's environment while participating in everyday occupations. A successful adaptation is seen as contributing to life satisfaction.

The continuity theory (Atchley, 1999), which is often used in gerontology, is also referred to in this research project, although the study samples are of working age. Continuity theory is a theory of continuous development, including adaptation to changing situations. Continuity, e.g. maintaining life style patterns and activity profiles, and change, e.g. the onset of a disability or retirement, are seen as existing simultaneously in people's lives. There is an assumption in the theory that the primary goal of adult development is adaptive change, which means that the thinking of how best to adapt to change continues to develop through the individuals' learning throughout their lifetimes. Thereby, people will be well prepared to adapt to life course changes when they occur. Atchley (1999) defines adaptation as a process of adapting to fit a situation or environment, e.g. dealing with changes encountered in everyday life and doings. His definition is in line with those of occupational therapy scholars revealed above, though he does not stress the interaction between the person and the environment and the reconstruction of the new situation. The reason for referring to continuity theory in the current thinking of adaptation in a changed life situation after ABI in this thesis is that it stresses the importance of the co-existence of continuity and adaptation in a way that is not apparent in occupational therapy and occupational science.

The overall perspective on adaptation in this thesis is that it is a process of change, within the context of everyday occupations, where experiences in the past and present everyday life situations are involved in the rebuilding and coordination of the future lives. In Study IV experiences in everyday life situations contributing to the process of change are explored. In Studies II and III an instrument trying to capture where the participants are in the process of reconstructing the life situation is used.

In rehabilitation medicine coping is a more frequently used concept, sometimes used synonymously with adaptation. To clarify, coping contributes to adaptation and adaptation is hence seen as a general concept (White, 1974). Coping is commonly defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person" (Lazarus & Folkman, 1984). The studies in this thesis do not explore how people manage psychological stress after ABI.

## *Rehabilitation of persons with ABI*

This research project is planned and carried out in a context of rehabilitation of persons with ABI. The persons in study samples I and IV received rehabilitation interventions and in study samples II and III aspects of long-term outcome after ABI was explored, whether the participants had received rehabilitation interventions or not. The goal for rehabilitation was stated by Wade (1992) as being

“to maximise the patient’s role fulfilment and his independence in his environment, all within the limitations imposed by the underlying pathology and impairments and by the availability of resources; help the person to make the best adaptation possible to any difference between roles achieved and roles desired”.

This is in line with the general goal for rehabilitation in Sweden, which is expressed as life satisfaction and experience of health in a changed life situation brought about by long-term disabilities (Borg, Gerdle, Grimby & Stibrant Sunnerhagen, 2006). The concept of rehabilitation is used with various meanings and rehabilitation interventions can be medical, psychological, social and vocational (Höök & Grimby, 2001). In Sweden, people who have disabilities due to ABI are usually treated at specialised brain injury rehabilitation units. Rehabilitation is based on team work in such units. The rehabilitation starts early after onset of ABI and the interventions vary depending on in which phase after onset they are carried out (Lexell, 2007), i.e. acute, sub-acute, post-acute or community-based (which refers to longer-term interventions). Participation in everyday occupations is the main focus for occupational therapy interventions in rehabilitation units in the post-acute phase when the clients live in the community (Johansson, 2004), which also is the focus of this thesis. Rehabilitation in the client’s own environment has proven to be advantageous due to the common problem of generalising knowledge or experience from one context to another (Mazaux & Richer, 1998). Rehabilitation given in the community setting might also be directed at family functioning. There is, however, a lack of knowledge on how couples in which one person had acquired a brain injury perceive their joint everyday lives after ABI. There is some evidence that team interventions in the post-acute phase are effective, e.g. for maintaining and improving self-care (The Cochrane Collaboration, 2003), and many authors emphasize the importance of long-term support after ABI (Lexell, 2007; Dikmen, Machamer, Powell & Temkin, 2003; Hoofien et al., 2001; Johansson, 2004), but further studies are needed to know how team rehabilitation can best be organised.

## *Occupational therapy for persons who have acquired a brain injury*

In occupational therapy the focus is on enabling clients to engage in their desired occupations (Fisher, 1998, Kielhofner, 2007, Townsend, 2002), which is the profession's unique contribution to health care. Occupational therapists develop, together with the client, a plan for change in the clients' participation in occupations and provide opportunities to engage in occupation, modify the task or the environment where the performance takes place, or assist with counselling (Kielhofner, 2004). Though the emphasis in occupational therapy is to provide occupation-based practice, the impairments are also considered. There are two different approaches to the clients' occupations. The top-down approach focuses on the client's perspective on his or her everyday occupations and on which occupations are important for the client to recapture. In contrast, the bottom-up approach considers the impairment which might have an influence on the ability to perform valued occupations (Fisher, 2003). The latter approach was and is prevalent in biomedically-oriented rehabilitation contexts. In today's occupational therapy literature, when the profession has rediscovered the importance of enabling everyday occupations (Kielhofner, 2004), the emphasis is on top-down or client-centred approaches (Fisher, 1998; Baum & Christiansen, 2005; Kielhofner, 2004; Townsend, 2002).

In occupational therapy for people who have ABI, the interventions have developed from two different traditions that have points in common with these previously described approaches. The remedial approach, which focuses on interventions for improving body functions, such as cognitive, neurobehavioral or motor functions that are needed for occupational performance is somewhat in line with the bottom-up approach (Neistadt, 1990). In the functional or adaptive approach the occupation itself is in focus and interventions are targeted at incorporating or modifying skills or habits, changing the way the activity is performed or changing the environment in which it is performed (Katz, 2005; Neistadt, 1990). In the more recent occupational therapy literature, at least in cognitive rehabilitation (Katz, 2005), the need and use of both approaches is underscored. Severity of impairments, their underlying causes, age of the injured person as well as in which environment the rehabilitation takes place is of importance for which approach to choose (Katz, 2005). This thesis intends to generate knowledge to further develop occupation-based practice according to the top-down approach. However, a thorough knowledge of brain functioning and impairments due to various brain damages is seen as a prerequisite for planning the intervention and grading the challenge in the activities the clients want to resume.

### *Evidence for the effectiveness of occupational therapy interventions*

The basic assumption in occupational therapy, that there is a relation between health and performance of occupations, has been supported by empirical studies. A systematic review shows that using a task-oriented approach in rehabilitation, where clients choose activities and perform them in familiar environments, i.e. a top-down approach, increases their perceived participation in everyday occupations after stroke (Trombly & Ma, 2002). There is also evidence from systematic reviews that impaired functions after stroke (Ma & Trombly, 2002), ability to perform self-care (Legg, Drummond, Leonardi-Bee, Gladman, Corr, Donkervoort et al., 2007) and household activities as well as social participation (Warlow, 1998; Steultjens, Dekker, Bouter, van de Nes, Cup & van den Ende, 2003; Walker, Leonardi-Bee, Bath, Langhorne, Dewey, Corr et al., 2004) are improved by interventions focusing on everyday occupations. Findings in another systematic review also reveals the importance of environmental factors for interventions after stroke, and it is shown that the ADL ability is scored higher when the interventions was conducted in the clients' homes (Langhorne et al., 2005). The systematic reviews mentioned above all lend support to occupation-based practice and to top-down or client-centred approaches in occupational therapy.

### *A client-centred approach in occupational therapy*

The point of departure for the questions raised in this thesis is the need to know more about and understand the clients' own perspectives, including their perceptions and experiences of everyday occupations after ABI, and their satisfaction with everyday life. In occupational therapy the client-centered approach was first incorporated in an occupational therapy framework by the Canadian association and is now a basic assumption for practice in most occupational therapy models (Townsend, 2002; Kielhofner, 2007; Fisher, 1998, Baum & Christiansen, 2005). Client-centeredness in occupational therapy today is based on ideas of empowerment and justice and embraces respect for clients and recognition of their experience and knowledge. The clients, who also can be spouses, close relatives or whole families, are involved in decision-making and the therapist advocates with and for the clients' needs (Townsend, 2002).

Studies on the long-term outcome after brain injury rehabilitation stress the need for developing client-centred rehabilitation strategies in the home environment to enhance the participation in everyday occupations (Ponsford, Olver & Curran, 1995; Mazaux & Richer, 1998). The four studies in this thesis may contribute further empirical support for developing the theoretical basis for client-centred occupational therapy practice.

To sum up, there is evidence that occupation-based occupational therapy for persons with ABI is effective, but there is still insufficient knowledge on how the persons themselves perceive their everyday occupations after ABI. If and how much people participate in activities and the lived experience of performing everyday occupations after ABI with various impairments has previously been explored, but there is a need for more knowledge on how persons with ABI perceive their participation in everyday occupations. Such knowledge would constitute an important theoretical basis for developing client-centred occupational therapy practice and brain injury rehabilitation.

There are several studies identifying how life satisfaction relates to impairments and activity/activity limitations and participation/participation restrictions among individuals with brain injury, and the studies reveal that the relation between life satisfaction and activity and participation are more pronounced than the relation with impairments. Furthermore, it has been assumed in the literature that possibility of engaging in wanted everyday occupations will influence the perceived life satisfaction, but that has not been explored empirically, to the best of my knowledge.

There is research pinpointing the need for access to rehabilitation interventions in the long term after ABI, but little is known about how these interventions would best be implemented in a client-centred context. To develop these interventions there is, however, a need of knowledge of how the persons perceive the gaps in their everyday occupations.

Previous studies have discussed the importance of viewing the couple or family as a unit in the rehabilitation after ABI. To develop the family-focused interventions there is a need of knowledge of the couples' shared perceptions in the new everyday life situation after ABI.

Finally, in occupational science there is a need for empirical support for the basic assumption of the relation between occupation and life satisfaction.

## AIM

### *General aim*

To explore and identify what people do and want to do in everyday life over time after acquiring a brain injury, with a focus on their perceptions of gaps in their everyday occupations and the relation to their perceived functioning and life satisfaction. The joint life satisfaction among couples, where one person has had an ABI, and the relation to their perceived functioning and participation in everyday occupations were also explored. Furthermore, the aim was to initiate the development of methodology capturing the perceived occupational gaps, and to understand how occupational gaps were characterised in the lived experiences of performing everyday occupations.

### *Specific aims*

- To identify couples' joint perceptions of overall life satisfaction when one of the persons in the couple had acquired a brain injury between one and five years earlier. The main interest was the influence that functioning and disability in everyday life had on the couple's joint life satisfaction after brain injury (Study I).
- To explore one aspect of adaptation, by examining the occupational gaps occurring between what individuals want to do and what they actually do in terms of their everyday activities before and after brain injury. In addition, the relationships between occupational gaps and impairments/activity limitations and the time lapse since the brain injury were explored (Study II).
- To explore the relationship between occupational gaps and life satisfaction for a group of people one year or more after they acquired a brain injury (Study III).
- To explore the phenomenon of occupational gaps with the aim of identifying how occupational gaps were characterised in the lived experiences of performing everyday occupations during the first year after stroke (Study IV).



## METHODS

The research questions in this thesis concern persons' perceptions of their everyday occupations after ABI in the post-acute phase and how that relates to perceived functioning and life satisfaction. All four studies are intended to capture the participants' perceptions but with different methods. The first study (Study I) focused on the relationship between functioning in everyday life and the joint perception of life satisfaction among couples where one in the couple had had a brain injury. The couples were asked to report their perceptions in a mailed survey questionnaire, sent to them on one specific occasion that was between one to five years after acquiring the brain injury.

The focus and design of Studies II and III were based on the results from Study I. These studies focused on what people wanted and needed to do in everyday life and what they actually did after an ABI, and how it related to functioning (Study II) and life satisfaction (Study III). The definition of the concept of occupational gaps (i.e. the gap that occurs between what an individual wants and needs to do and what he or she actually does) was operationalised into the Occupational Gaps Questionnaire, developed and used in Studies II and III. The data for these studies were collected by using a mailed survey questionnaire. In order to deepen the understanding of the lived experiences of performing everyday occupations after brain injury a qualitative phenomenological approach was used in Study IV. An overview of the studies and methods used are given in Table 1.

**Table 1:** Overview of the four studies: Design, study context, methods of data collection and data analysis and perspective on collected data.

	Study I	Study II	Study III	Study IV
<b>Design/ research approach</b>	Cross-sectional, quantitative explorative	Cross-sectional, quantitative explorative	Cross-sectional, quantitative explorative	Longitudinal, qualitative, phenomenological
<b>Study context</b>	Community living	Community living	Community living	Rehabilitation clinic, community living
<b>Methods of data collection and instruments</b>	Mailed survey  Questionnaire to both in the couple:  Questions on perceived impairment, activity, and participation, and parts of the instruments: ADL-taxonomy, LEAIQ, LiSat-11	Mailed survey  Questionnaire:  Questions on perceived impairment.  Occupational Gaps Questionnaire (OGQ)	Mailed survey  Questionnaire:  Occupational Gaps Questionnaire (OGQ), LiSat-11, HADS	Open-ended in-depth interviews with interview guide and field notes at 1, 3, 6 and 12 months after onset
<b>Perspective of collected data</b>	Subjective, self- reported (Persons with ABI and their partners)	Subjective, self- reported (Persons with ABI)	Subjective, self- reported (Persons with ABI)	Subjective life-world perspective (Persons with ABI)
<b>Data analysis methods</b>	Descriptive statistics, regression analyses	Descriptive statistics, factor analysis, regression analyses	Rasch analyses, descriptive statistics, regression analyses	Empirical, phenomenological psychological method (EPP)

## *Participants*

The participants with ABI in this thesis ranged in age from 20-65 years. The participants in Studies I and IV were recruited because they had contacts with and received interventions from a brain injury rehabilitation unit, and the sample in Study I received rehabilitation interventions more than a year after injury. The participants included in Studies II and III (same sample) were treated at a neurosurgery intensive care unit in the acute phase, and it is uncertain whether they were referred to rehabilitation or not, though obvious needs for rehabilitation were identified in the studies for part of the sample. Those in the sample in Studies II and III are quite heterogeneous regarding injury severity, i.e. about half of them had returned to work, and were also people who needed a lot of assistance. The participants were

living in the community, as were all the participants in Study IV at the end of data collection. Demographic characteristic of the study samples are presented in Table 2.

Table 2. Demographic characteristics on the participants in the research project

	Study I	Study II	Study III	Study IV
No of participants in study samples	n=55 couples	n=87	n=116	n=4
Gender F/M	*19 /36	96/91	60/56	1 / 3
Age, years Mean, (range)	*53 (27-64)	47 (20-65)	46 (20-65)	56 (50-61)
Married/cohabiting	100%	61%	57%	1 out of 4
Working/studying after injury	-	54%	47%	3 out of 4 a year after onset
Diagnoses	TBI n=10 * Stroke n=39 * **Other n=6 *	TBI n=67 SAH n=120	TBI n=45 SAH n=71	Stroke n=4
Time since injury Mean time lapse range	1-5 years	26 months 11-47 months	26 months 11-47 months	Included at 1 month after onset

\* Information concerns the brain-injured individual in the couple

\*\* Other diagnoses are consequences of brain tumour or infectious diseases

### *Study I*

The participants in Study I were selected from a survey study of individuals with ABI and persons close to these individuals, with the aim of capturing long-term outcome. The sample in Study I consists of a sub-sample from this larger survey, and included all those persons where a partner had answered the questionnaire addressed to a close person, i.e. 55 couples. “Partners” were defined here as those who were married to or cohabiting with the brain-injured person. Inclusion criteria in the survey for persons with ABI were: (a) age 18-65, (b) the brain injury had been required after 16 years of age and one to five years before the data-collection commenced, and (c) in contact with the brain injury rehabilitation unit in a hospital in central Sweden the year before the survey was conducted.

### *Study II*

The participants in Studies II and III were in some parts the same, i.e. all participants in Study III also participated in Study II. Numbers of participants included in the two studies differed

due to different requirements in the analyses. The sample in Study II consisted of 187 persons, which were those who answered the mailed questionnaire sent to a total of 217 persons (response rate 89%). The inclusion criteria were: (a) admission to intensive care for TBI or SAH one to four years earlier, (b) aged 20-65 years at the time of the survey, and (c) having been assessed in the acute stages by a rehabilitation physician. A physician assessed the injury severity of the sample in the acute stages by using the Swedish Reaction Level Scale (RLS) (Starmark, Stålhammar & Holmgren, 1988). Of the participants included, 50% were rated as alert (RLS level 1), 34 % were rated as being drowsy, very drowsy or confused (RLS level 2-3), and 16% were rated as unconscious (RLS level 4-8).

### *Study III*

The sample in Study III consisted of 116 of the 187 participants included in Study II. The participants that perceived no occupational gaps were excluded from the sample used in Study II. Injury severity in this sample was approximately the same as in the sample in Study II, i.e. 44% rated as alert, 38% rated as drowsy, very drowsy or confused, and 18% rated as unconscious.

### *Study IV*

The sample in Study IV consisted of four participants, three men and one woman with stroke. They were recruited in a consecutive series, together with 12 other persons, in a research project that aimed at capturing the lived experience of everyday occupations in persons having four varied types of cognitive impairments that are common after stroke (memory impairment, visuo-spatial impairment, impaired attention and impaired body image). For this study participants were chosen specifically to get a variation of impairments, and each of the four participants in Study IV represented one of the four impairment groups. Informants that could provide rich data representing the phenomenon were chosen (Dahlberg, 2001). The inclusion criteria were: (a) first-ever stroke less than one month earlier, (b) working age, (c) limitations in the performance of daily activities according to their occupational therapist at the clinic, and (d) ability to understand interview questions and to be able to recall and share daily experiences during the year. The participants were inpatients at a brain injury rehabilitation unit at the initiation of the study.

## *Data collection*

### *Survey questionnaires*

In Studies I-III two mailed survey questionnaires were used for data collection. The questionnaires consisted of common instruments or parts of instruments used in evaluating outcome in rehabilitation, i.e. the LiSat-11 (Fugl-Meyer, Melin & Fugl-Meyer, 2002) (Studies I and III), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (Study III), and the Late Effects of Accidental Injury Questionnaire (Malt, Blikra & Hovik, 1989) (Study I). They were all considered to be easy to understand and had previously been used among people with ABI. An instrument developed within the research project, the Occupational Gaps Questionnaire, was included in one of the survey questionnaires (Studies II and III).

Considering common consequences after ABI, such as memory impairment, fatigue and language problems, an effort was made to develop clear questions that were easy to comprehend and to score. With the intention of capturing perceived impairments, a number of questions were developed based on clinical experience of how clients with ABI perceive and describe common problems in the context of everyday life due to specific impairments (Studies I and II). In Study I these questions on impairment was posed to both the persons with ABI and to their partners. The partners were asked how they perceived the brain-injured partners' impairments. In addition, questions on demographic variables were included in the questionnaires. In Study I questions based on the ADL-taxonomy (Törnquist & Sonn, 1994) were used to measure perceived ability in personal activities of daily living (ADL) and instrumental ADL. These items were rephrased into a problem/no problem dichotomy. In Study I these questions, when posed to the partners, referred to the assistance provided by them with personal and instrumental ADL activities.

### *The Late Effects of Accidental Injury Questionnaire (LEAIQ)*

The LEAIQ is a self-report questionnaire developed for assessing the biological, psychological and social effects of traumatic injuries (Malt, Blikra & Hovik, 1989). The questionnaire has been used in people who had experienced trauma, for example traffic accidents, and the instrument has proven to be valid and reliable for screening late effects of trauma. From LEAIQ five questions (problems with physical and psychological health, perceived changes in leisure, social contacts and relations with the family) were used in the survey (Study I) and when these questions were posed to the partners they referred to the partners' own life situations.

### *The Hospital Anxiety and Depression Scale (HADS)*

The HADS is a self-report questionnaire that assesses anxiety (seven questions) and depression (seven questions), and in Study III the seven questions assessing depression were used. The HADS is developed for use in somatic and primary care (Zigmond & Snaith, 1983) and it is used extensively. It was chosen to be included in this project instead of other self-report questionnaires on depression, because all symptoms of depression relating to physical symptoms often reported after ABI, such as fatigue, dizziness and headache, were excluded in the questions (Bjelland, Dahl, Haug & Neckelmann, 2002). The HADS ranges from 0 to 21, and a participant was regarded as being depressed if he/she scored above 10, which is considered a depressive state when used clinically. The questions have been found to function well in assessing symptom severity of anxiety disorders and depression in both somatic, psychiatric and primary care clients as well as in the general population (Bjelland et al., 2002).

### *The LiSat-11 checklist*

The LiSat-11 was used in Studies I and III to measure life satisfaction. The LiSat-11 has been used for various populations in Scandinavia (Fugl-Meyer et al., 2002) and in studies of public health in Sweden (Fugl-Meyer, 1997). The original version (LiSat-9), developed by Fugl-Meyer and co-workers and published in 1991 (Fugl-Meyer, Bränholm & Fugl-Meyer, 1991), has proven to have good reliability and validity (Fugl-Meyer et al., 1991). The LiSat-11 checklist encompasses eleven items. One item assesses overall life satisfaction, and that question was used to assess the couples' joint life satisfaction in Study I. The remaining ten questions assess domain-specific life satisfaction. It uses a six-step ordinal self-rating scale, from (6) "very satisfying" to (1) "very dissatisfying". The LiSat-11 was used in its entirety in Study III. In the analyses in Studies I and III a dichotomy is used to report the participants' perceived life satisfaction, where the raw scores 1-4 are regarded as not being satisfied and the raw scores 5-6 are regarded as being satisfied with life. In Study I this dichotomy was used when classifying the couples into three different groups (happy couples, not happy couples and discordant couples) according to their joint life satisfaction. This dichotomy is viewed as a valid scale reduction (Fugl-Meyer et al., 2002).

### *The Occupational Gaps Questionnaire (OGQ)*

The OGQ was used in Studies II and III to measure perceived occupational gaps, i.e. to which extent an individual does/does not what he or she wants to do/wants not to do. The instrument

was also used in a pilot study in a sample of people who very likely were healthy and were recruited while going through Central Station in Stockholm. This pilot study is not part of any of the studies in the thesis but was included in order to compare the perceived occupational gaps between different samples. The result of the pilot study will be presented in the Result section.

The OGQ has been developed for this research project and the operationalisation of occupational gaps emanate from the definition of occupational gaps, i.e. the gap that occurs between what an individual wants and needs to do and what he or she actually does. The items (activities) chosen and the wordings in the questions posed for each item were developed after a thorough review of existing instruments in the same area. However, the development of the OGQ is primarily based on a Swedish activity profile developed by Wallgren (2007), which originated in the Activity profile developed by Baum (1993) together with the ADL taxonomy (Törnquist & Sonn, 1994). <sup>1</sup>Most of the items in the OGQ were provided with examples on activities that could be considered to be covered by each specific item. The questionnaires reviewed, besides the Activity Profile developed by Baum (1993), were the Interest Checklist and the Role Checklist (Bränholm & Fugl-Meyer, 1994), the NPS Interest Checklist (Pettersson & Selander, 1996), and The Interest Checklist developed by Matsutsuyu (1969) and later modified by Kielhofner and co-workers (2007). The other reviewed questionnaires were used as a frame of reference to make sure that culturally relevant activities had not been missed, as separate items as well as examples of activities. Both items and examples were added due to that procedure.

The wordings in the two questions that are posed in connection with each item in the OGQ (see Table 3) were inspired by the questions in the NPS Interest Checklist (Pettersson & Selander, 1996) and the Interest Checklist modified by Kielhofner and co-workers (2007). Question 2 refers to whether the respondents “want to” do the activity. According to the definition, an occupational gap refers to the discrepancy between what an individual “wants and needs to do” and what he/she actually does. While developing the questionnaire the wordings of the two questions were discussed with occupational therapy practitioners and researchers. The conclusions drawn from these discussions were that Question 2 would be

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<sup>1</sup> To fit in a Swedish context, culturally irrelevant items in the American activity profile were excluded and some closely related items were collapsed. The instrumental ADL items from the ADL taxonomy were added, together with two other I-ADL items that are usually challenging for persons after stroke. The instrument was used in a 98-item version, which later on was grouped into a 24-item version, on I-ADL, leisure and social activities, used clinically and in a research project. In the OGQ 16 of these items were used as framed by Wallgren (2007), while two were excluded, two were collapsed, three were split into six separate items and one was rephrased. Four items were added, of which three were classified as work or work-related activities.

more comprehensible if the respondents would be asked if they “want to” do activities and therefore the “need to” do activities was not included in the question. The OGQ is presented in Table 3.

Table 3: Activities examined in the Occupational Gaps Questionnaire and the questions posed in connection with each item

<b>Instrumental ADL</b>	<b>Leisure activities</b>
Shopping	Sports
Cooking	Outdoor life
Washing clothes	Hobbies
Cleaning	Cultural activities
Performing light maintenance (of home, garden, or car)	TV/video/radio
Performing heavy-duty maintenance	Reading newspaper
Administering economy	Reading periodicals/literature
Transportation (e.g. driving, public transport)	Writing
	Playing games, or playing the lottery, crosswords, etc.
	Playing computer games & surfing the Internet
<b>Social activities</b>	<b>Work or work-related activities</b>
Seeing partner and children	Working, full or part-time
Seeing relatives, friends & neighbours	Studying, full or part-time
Engaging in activities in societies, clubs or unions	Taking care of and raising children
Participating in religious activities	Performing voluntary work
Visiting restaurants & bars	
Travelling for pleasure	
<b>Question 1:</b> Do you perform the activity now?	Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>Question 2:</b> Do you want to perform the activity now?	Yes <input type="checkbox"/> No <input type="checkbox"/>

An occupational gap is considered to be present if the participants answered yes to one question and no to the other question on the item. In Studies II and III the two kinds of gaps that could be present, i.e. “does, but does not want” and “does not, but wants to do”, were treated equally. This approach in analyses was chosen though it might be considered that a gap due to not doing an occupation that you want to do could be perceived differently from doing something that you do not want to do.

### *Interview*

In Study IV, four extended interviews were conducted with each participant at 1, 3, 6 and 12 months after the stroke onset. Researchers experienced in phenomenology conducted the interviews, of which the main supervisor conducted the majority. The interviews at one month after stroke took place in the rehabilitation clinic, but after becoming outpatients most of the participants chose to have the interviews in their homes. Each interview lasted 1 to 1½ hours.



The questions were informal and open-ended. The focus was the participants' experiences of everyday occupations now, compared to before stroke or since the last interview, and their difficulties in performing their wanted and needed occupations. The interview guide was developed between each interview with each participant in order to follow up questions about what had come up during the former interviews. All interviews were audiotaped and transcribed verbatim.

## *Data analyses*

### *Statistical analyses*

In the following, the statistical analyses in Studies I-III will be described. Many statistical methods are used (see Table 4) in this research project, and the choice of method applied was dependent on sample size, whether data was normally distributed or not, and the level of data (nominal, ordinal or interval). The calculations were made with the STATISTICA statistical software and in Studies I and II STATISTICA was used in conjunction with the SAS system to perform the regression analyses. Furthermore, the WINSTEPS software program was used to perform the Rasch analyses in Study III. The level of significance was set at  $p < 0.05$  in all analyses except for the analyses in Study I, where it was set at  $< 0.01$ .

Table 4. Statistical methods used in Studies I-III

Statistical methods	Study I	Study II	Study III
Rasch analysis			X
t-test			X
Kappa Coefficient of Agreement	X		
Chi-square	X	X	X
Wilcoxon signed-rank test		X	
Wilcoxon matched pairs test		X	
Spearman's rho		X	X
Mann-Whitney U-test	X	X	X
Logistic multiple regression for proportional odds	X		
Univariate logistic regression	X		
Multiple linear regression		X	X
Univariate linear regression			X
Factor analysis		X	

### *Raw scores versus measures*

The perceived occupational gaps were calculated both by using sums of the raw scores obtained from the OGQ (Study II) and by using Rasch-generated measures (Study III). In Study II the numbers of gaps perceived were used as a variable (i.e. extent of perceived occupational gaps). In order to take the perceptions of the gaps into consideration, i.e. that they may have different challenges, in Study III, raw scores from the OGQ were converted into a linear measure (i.e. extent of perceived occupational gaps) using a Rasch measurement model (Bond & Fox, 2001) before further analyses. In Study III, LiSat-11 was used to measure life satisfaction. The raw scores obtained from the LiSat-11 and the OGQ was evaluated using Rasch measurement models (Bond & Fox, 2001) to ensure that they could generate valid measures (one for the LiSat-11 and one for the OGQ). Criteria for goodness-of-fit were initially set for the items and for the sample (Bond & Fox, 2001; Wright & Linacre, 1994; Wilson, 2005), as well as for unidimensionality (Linacre, 1991-2006) and sensitivity in the instruments (Fisher, 1992). If all of these criteria were met the measures generated from the Rasch analyses were considered to be valid estimations of occupational gaps and life satisfaction for further statistical calculations.

### *Parametric and non-parametric statistical methods*

Several non-parametric statistical methods as well as one parametric method were used to describe and analyse differences and associations in the samples in the three studies. The non-parametric methods were used when describing and analysing data that concerned small samples (Study I), data that were not normally distributed (Study I-III) and data that were on a nominal or an ordinal level (Study I- II). Chi-square was used to describe the three samples, and Mann Whitney U-test was used to analyse differences between included and excluded participants in specific analyses in Studies I - III (Siegel & Castellan, 1988). In Study II the Wilcoxon sign-rank test was used to analyse differences in doing before and after injury, and the Wilcoxon matched pairs test was used to analyse differences in occupational gaps between before and after injury (Siegel & Castellan, 1988). The Spearman rho test was used to analyse the association between numbers of occupational gaps and injury severity as well as time since injury in Study II. The same test was also used to analyse the association between the measures of occupational gaps and life satisfaction in Study III, due to the fact that occupational gaps are not normally distributed (Siegel & Castellan, 1988). In Study I the within couple agreement concerning ratings of perceived functioning was analysed with the

Kappa Coefficient of Agreement, because the variables analysed were nominal (Siegel & Castellan, 1988).

A parametric t-test for independent samples was used to calculate if there was any difference in life satisfaction between those who were depressed and those who were not depressed in Study III. A parametric method was used because the generated measure of life satisfaction was treated as linear (interval data).

### *Multivariate analyses*

In Study I the sample was divided into three groups, i.e. happy, not happy or discordant couples, according to their joint life satisfaction. Logistic regression was used to explore which impairments, activity limitations or participation restrictions/assistance with activity, when taken together that were most likely to predict each couple's belonging to one of the three classified groups. The method logistic regression for proportional odds is used when one wants to predict the effect of several independent variables (both numerical and nominal) on the dependent variable, which has more than two classified categories of outcome (i.e. three categories of couples according to their rated happiness) (Harrell, 2001).

In Study I logistic univariate regression was used, and in Study III linear univariate regression was used to analyse to what extent possible independent variables related to the dependent variable in the analyses, and if the relationship was significant the variable was included in the multiple regression analyses (Bland, 2000).

In Studies II and III linear multiple regression analyses was chosen, because the dependent variables were treated as continuous (Harrell, 2001). In Study II the multiple regression analysis was performed to explore the influences of impairments and time since injury, when taken together, on the extent of occupational gaps, i.e. calculated by numbers of gaps. In Study III the same analysis was used to explore the influence of the independent variables (extent of perceived occupational gaps, i.e. Rasch-generated measure, injury severity, depression, diagnosis, gender, whether the participants worked or not after injury and whether they were born in Sweden or not) when taken together, on the dependent variable life satisfaction.

Finally, in Study II an exploratory factor analysis was performed to examine if there were interpretable patterns in the items concerning impairments, and five factors emerged from the analysis, which later on were included as independent variables in the regression analysis (Polit, 1996).

*The empirical, phenomenological, psychological method (EPP).*

In Study IV a modified form of the EPP method (Karlsson, 1995) was used to analyse the data. A focus on experiences of everyday occupations replaced the psychological perspective. The EPP method aims at describing the meaning structure in the participants' lived experiences related to a specific phenomenon, which in Study IV was the phenomenon of occupational gaps (i.e. how the gaps were characterised in the participants' lived experience of everyday occupations during one year after stroke). The data were analysed in two phases. First (step 1-4 in the EPP method), the interviews were read through with the intention of gaining an understanding of and interpreting the explicit and implicit meanings expressed by each participant separately. In the second phase (step 5 in the EPP method), the analyses of all participants' interviews were compared and interpreted, with the aim of tracing out the general meaning structure of the phenomenon across participants, and to identify the main characteristics. Aspects, or sub-characteristics, of the main characteristics were also identified in this phase. The analyses were discussed and refined several times between the researchers until a "horizontally consistent interpretation" was reached. This means that the researchers made sure that each characteristic fit well with the other characteristics that were shown in the analysis, and in that way the most valid interpretation was clarified (Karlsson, 1995). The findings were also presented to, and discussed together with, experienced occupational therapists and researchers in the brain injury rehabilitation field in order to examine the trustworthiness of the interpretations (Polit & Beck, 2004).

## RESULTS

### *The joint life satisfaction among couples and the relation to functioning*

In Study I the aim was to identify couples' joint perceptions of overall life satisfaction when one of the persons in the couple had acquired a brain injury between one and five years earlier. The couple was viewed as a social unit, and the main interest was the influence that functioning and disability, i.e. impairment, activity limitations and participation restrictions, in everyday life had on the couple's joint life satisfaction after brain injury. The main result in this study was that only a minority, 16 couples out of 55, were jointly satisfied or very satisfied with life, which can be considered as synonymous with being happy. Of the remaining 39 couples, 22 couples reported low joint life satisfaction and the rest of them were discordant, i.e. the persons in the couple reported high and low life satisfaction, respectively.

About a half to three quarters of the couples reported impairments for half of the 19 variables. From 4 to 49% of the participants with ABI perceived limitations in activities and restrictions on participation. Lowest percentages concerned mainly problems with personal ADL, while prevalence of problems in instrumental ADL was reported by a third to about a half of the persons with ABI. Of the partners, a fifth to about a half reported that they assisted with various instrumental ADL activities. Both persons in the couples also perceived problems with their participation in leisure time and in social life, and the problems were more pronounced for the partners. The exploration of the relationship between perceived problems of impairments, activity limitations and participation restrictions and the couples' joint life satisfaction were first analysed separately for the person with ABI and for their partners. The five variables (three for the persons with ABI and two for the partners) that had come out of the two separate logistic regression analyses, were included in a new analysis which yielded, for the couples, a logistic regression model comprising the three variables "enjoying leisure time", "making contacts with others", and "washing clothes". These three variables were the most likely to predict the couples' belonging to one of the classified groups, i.e. happy, not happy and discordant couples.

Table 5: *Odds ratios (OR), p-values and confidence intervals for the variables included in the model predicting the couples' belonging to the "happy couples (1), discordant couples (2) or not happy couples groups (3)"*

	OR	p<	95 % CI
Washing clothes	9.5	0.003	2.2-48.2
Contact with others	6.3	0.02	1.4-31.1
Enjoying leisure time	5.1	0.04	1.1-25.5

All variables in the model concern the problems as rated by the brain-injured person

The odds ratios (OR) from the regression analysis indicate, for example, that the risk of being a couple having problems with contacts with others to be a not happy couple is 6.3 times greater than that of being a discordant or a happy couple.

### *Occupational gaps and the relationship to impairments, time lapse since injury and life satisfaction*

In Study II the extent of perceived occupational gaps (calculated by numbers of gaps) before and after ABI, and the relationship to impairment and time lapse since injury were explored. In Study III the extent of perceived occupational gaps (calculated by an estimated measure) and the relationship to life satisfaction, depression and a number of other independent variables reported in the methods section, was explored in people with ABI. Results from Study II show that the number of occupational gaps perceived by the participants after the brain injury was significantly higher than before injury. Almost half of the participants reported that they had occupational gaps before brain injury compared to more than two thirds of the sample after injury. After injury the participants also reported higher numbers of occupational gaps, shown in Figure 1.

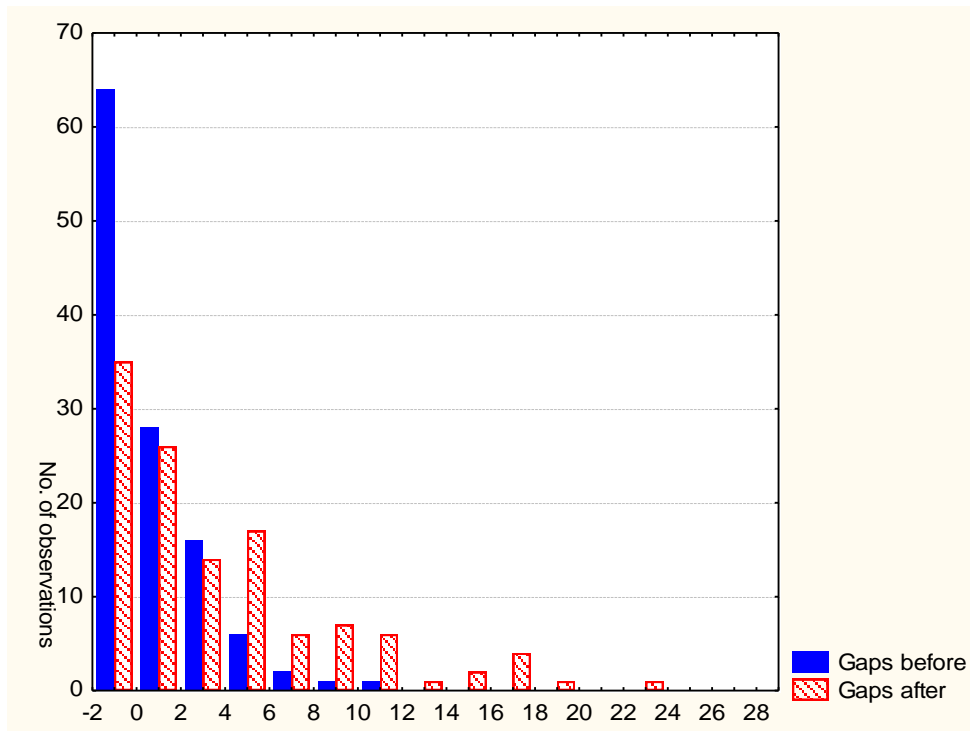


Figure 1. Numbers of participants having various numbers of occupational gaps (0-24) before and after ABI.

There was a variation in the perceived impairments after brain injury. Half of the sample in Study II reported that they perceived fatigue, difficulty in concentrating, and memory impairment. In some areas, such as motor impairment, the prevalence of impairments was reported to be much lower. The items capturing perceptions of impairment in the study questionnaire were factor-analysed in order to be able to explore their relationship to the extent of occupational gaps. Five factors were formed (cognitive and emotional, motor, communicative, executive, and other somatic impairments such as headache, dizziness). There were significant associations between all the five factors and numbers of occupational gaps when univariate analysis was performed, where higher extent (i.e. in this study higher numbers of occupational gaps) associated to more perceived impairments. More severe injury (i.e. RLS ratings), which also was included in the analysis as an explanatory variable, also associated significantly to higher numbers of occupational gaps. There was, however, no significant association between time elapsed since injury and number of occupational gaps. The multiple regression model that best described the relationship between numbers of occupational gaps and the participants' perceived impairments (Study II) is presented in Table 6.

**Table 6.** The relationship between number of occupational gaps after brain injury, factor-analysed perceived impairments and the Reaction Level Scale (RLS) ratings (n=120).

Variable	Parameter estimate	Standard error	95 % C I for parameter	<i>p</i>
Factor: Motor impairments	1.32	0.46	0.41-2.23	0.005
Factor: Executive impairments	2.07	0.51	1.06-3.09	<0.001
Factor: Other somatic impairments	0.79	0.34	0.12-1.47	0.022
RLS 1/ RLS 2-8 <sup>a</sup>	-1.56	0.81	-3.17-0.05	0.057

<sup>a</sup> RLS-ratings are dichotomised in RLS 1 vs. RLS 2-8 according to previous analyses

<sup>b</sup> The two-factor interaction between factor 2 and RLS implies that the RLS 1 group with motor impairment (factor 2) have a steeper increase in occupational gaps compared to RLS group 2-8 with motor impairment.

The model suggests that executive impairments have the greatest influence and that motor impairment, together with other somatic impairments also has an impact on the numbers of occupational gaps on a group level. This model explained 65% of the variance in perceived occupational gaps. The model indicates (reflected by parameter estimate) that executive impairments have more than twice as much influence on the number of occupational gaps than other somatic impairments.

In Study III the relationship between the extent of perceived occupational gaps (calculated by an estimated measure), life satisfaction, depression and a number of other independent variables was explored. Before conducting the analysis on the relationship between occupational gaps and life satisfaction, the raw score responses on the OGQ and LiSat-11 were analysed and transformed to valid interval measures using Rasch measurement models, one for OGQ and one for LiSat-11. The procedure is described in the Data analysis section and the result on OGQ is presented in Study III and in the following section. While the instruments were considered to be valid estimations of perceived occupational gaps and life satisfaction, respectively, in this sample, the measures derived from the Rasch analyses were used for further statistical analyses.

The multivariate regression analysis in Study III suggested that the extent of occupational gaps ( $p < 0.001$ ;  $b = -0.21$ ) and the presence of depression ( $p = 0.005$ ;  $b = 0.52$ ) were the most influential variables in predicting life satisfaction. Thus, a low extent of perceived occupational gaps, represented by a low measure for occupational gaps, was significantly related to a higher measure of life satisfaction. The absence of depression also contributed



significantly to greater life satisfaction. In this regression model, the measure of occupational gaps alone explained 32% of the total variance in life satisfaction, presence of depression explained 6% and the diagnosis explained an additional 2%. The participants who had had a SAH perceived significantly higher life satisfaction than those with TBI ( $p = 0.026$ ).

The distribution of the measure of occupational gaps is shown in Figure 2, where the measure demonstrates a clear ceiling effect in the sample.

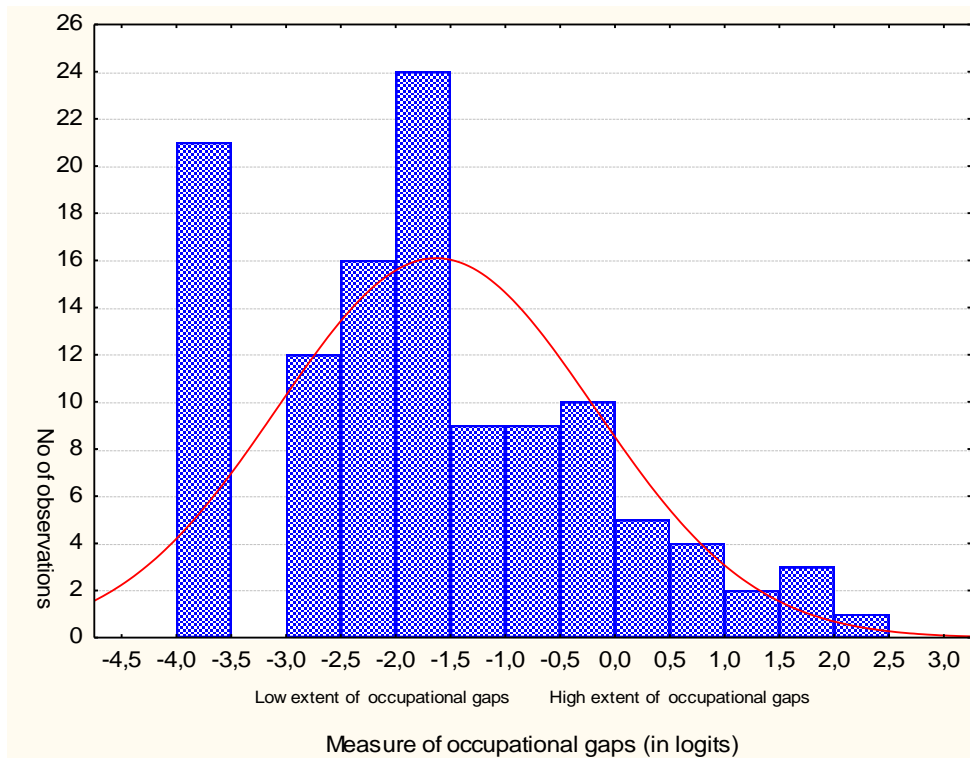


Figure 2. The distribution of measure of occupational gaps

The measures of occupational gaps and life satisfaction correlated significantly ( $r = -0.63$  ;  $p < 0.001$ ). See Figure 3.

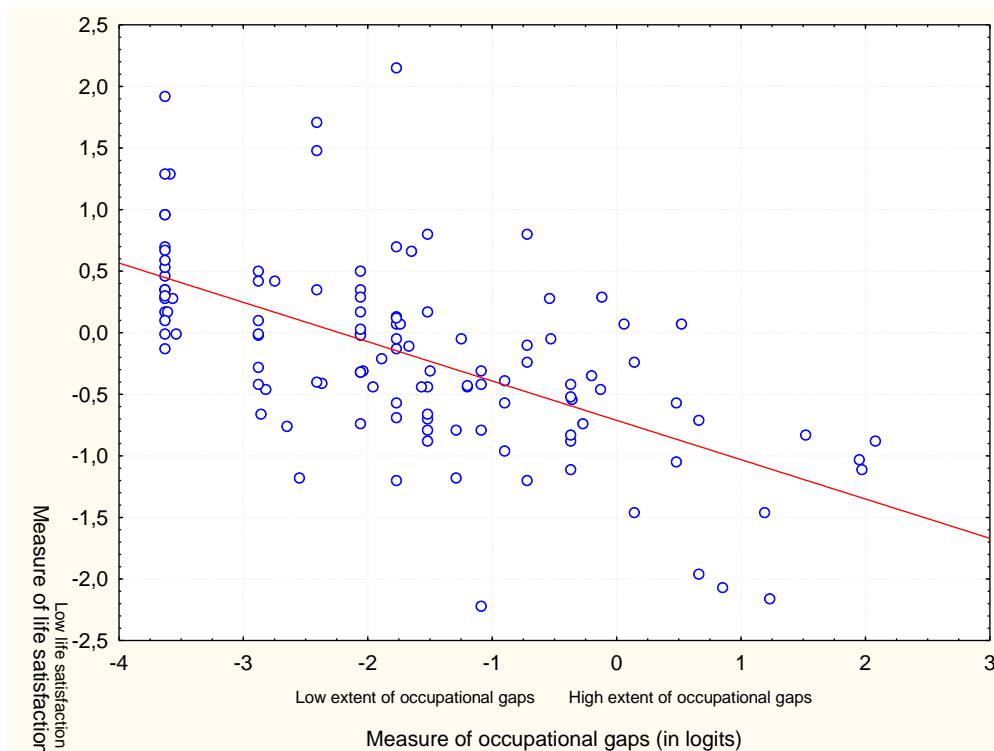


Figure 3. The association between the measures of occupational gaps and life satisfaction ( $r = -0.63$ ;  $p < 0.001$ )

### *The meaning of occupational gaps in everyday life*

In Study IV, the phenomenon of occupational gaps was explored with the aim of identifying how occupational gaps were characterised in the lived experiences of performing everyday occupations the first year after stroke. The findings from the phenomenological analysis identified essential characteristics of the participants' lived experiences of performing everyday occupations, which overlapped during the whole year. The findings are presented in a meaning structure comprising five main characteristics. One characteristic in the meaning structure describes how the participants were *striving for narrowing gaps in symbolic occupations*. Most of these symbolic occupations were closely linked to the participant's self and had grown from their experiences in life over a long period of time. When they had lost their ability after stroke to perform these occupations it meant that their opportunity to recognise and express themselves had diminished. The participants' overall intention and goal with all training during rehabilitation was to be able to participate in these occupations again and the prospect of resuming symbolic occupations generated a strong driving force. When he/she was able to narrow the gap, the participant once again could live his or her social role and be the persons they were before. The participants also expressed experiences of *being oneself or modifying the sense of self through doing* when performing their everyday occupations. They reflected on who they were after their stroke, and they related their

experiences of their abilities to do as before, and their diminished or lack of abilities to do specific occupations, to their views of themselves. At the same time they felt like the persons they had been before, as well as experiencing themselves as being strange or unfamiliar in their doings. The previous continuity in their doings now was partly broken. When they realised that they had to modify their previous way of performing occupations, and alter their doing or stop doing too demanding activities, they seemed to start to modify their sense of self as doers. The participants also expressed that they were *encountering occupational gaps in former taken-for-granted activities*. These activities that previously were performed without thinking were now harder and more tiring to perform, but still they could be accomplished. The meanings of these gaps differed from the meanings of gaps in symbolic occupations. These taken-for-granted activities were not activities that the participants desired to do, but they had to be performed to make everyday life work, for instance getting dressed or making phone calls. To handle this enhanced hardship in performing occupations the participants *created strategies enabling doing*. They developed conscious strategies that made doing easier and more satisfying. Three types of strategies were described; strategies built upon a new way of thinking, on a new way of doing and strategies where the environment was used. The strategies were often essential for their doings and were integrated in their habitual way of performing everyday occupations, but the participants used as few strategies as possible and preferred to do as they previously had done. The participants also expressed a *sense of being competent despite disruption* in their everyday life. They felt competent when they managed to perform certain occupations that were needed, but not necessarily wanted. A prerequisite for the sense of competence and the sense of recognising to appear seemed to be that the participant had the ability to perform at least parts of an activity, which for example formed a habit or routine at home, in the same way as previously. When a year had passed they still did not fully recognize themselves in their everyday doing and they went on searching for who they were, and challenged their limits, to get a clearer view of the future possibilities in their everyday occupations.

### *Preliminary evidence of validity and reliability for the OGQ*

All 28 items demonstrated acceptable goodness-of-fit to the Rasch model, supporting internal scale validity. When examining the 116 brain-injured participants in Study III, they all demonstrated acceptable goodness-of-fit in their responses, supporting person response validity. The items separated the sample into two distinct groups. The person separation index was 1.82 and the person reliability index was 0.77. The raw scores obtained from the OGQ in

a pilot study on a sample of persons who most likely were healthy, reported below, were added in a new Rasch analysis. The analysis on these two samples revealed that there was no significant difference regarding the extent of gaps between these samples.

In the analysis in Study III, the OGQ was close to meeting the criterion of explaining 60% of the total variance in the dataset to be considered being unidimensional, i.e. OGQ measures explained 56% of variance. However, measures derived from the OGQ were considered to be a valid estimation of occupational gaps in this sample, since no other factor explained more than 5% of the variance in the dataset.

A pilot study on the perception of occupational gaps was conducted using a small reference sample (n=53) of people of working ages that most likely were healthy, of which 60% were women (mean age = 42 years). The participants from all over Sweden were going through the Central Station in Stockholm one specific day in spring 2007 when they were asked to answer the OGQ. The raw score responses from the healthy sample together with the scores obtained from the sample in Study II (n=168) was analysed using Rasch (Bond & Fox, 2001). The sample size from Study II decreased from 187 to 168 due to missing data on the OGQ. The result of the analysis is presented in Table 7. Eight persons (15%) in the sample of healthy people and 44 persons (26%) in the sample from Study II perceived no occupational gap. The sample in Study III included people who had all perceived occupational gaps. There was no significant difference ( $p=0.79$ ) in the extent of occupational gaps between the healthy sample (n=53) and the brain-injured sample (n=168).

Table 7. Measure of occupational gaps in samples with people with ABI (n=169) and (n=116) and a sample of healthy people (n=55)

Samples	Range (Logits)	Mean (Logits)	Standard deviation (Logits)	Median (Logits)	Quartile (Logits)
People with ABI (n=116) Study III	2.08– -3.63	-1.65	1.43	-1.77	-0.72– -2.86
People with ABI (n=168) Parts of sample in Study II	2.09– -4.89	-2.42	1.90	-2.07	-1.09– -4.15
Healthy people (n=53)	2.46 – -4,89	-2.50	2.24	-2.42	-0.9– -4.89

## CONCLUSIONS

The results in Study I showed that less than one-third of the couples in which one person had had an ABI perceived a joint life satisfaction, i.e. in which both persons were satisfied with life as a whole. The joint life satisfaction was related to the couples' functioning in everyday life, and specifically to participation in leisure time, social life and instrumental ADL.

In Study II it was shown that the numbers of participants who perceived occupational gaps increased by 25% after being afflicted by ABI. The findings also demonstrated that perceiving executive, motor and other somatic impairments such as headache after injury had an impact on the perceived numbers of occupational gaps. The time elapsed since injury had, however, no effect on the perceived occupational gaps.

The results in Study III confirmed that there is a definite relationship between persons' perceived occupational gaps and their perceived life satisfaction after ABI. Suffering from depression also had an impact on the perceived life satisfaction.

In Study IV the characteristics of the phenomenon of occupational gaps were identified in the participants' experiences of performing everyday occupations during the first year after stroke. The five main characteristics described the participants' experiences of: striving for narrowing gaps in symbolic occupations; being oneself or modifying the sense of self through doing; encountering occupational gaps in former taken-for-granted activities, creating strategies enabling doing; and a sense of being competent despite the disruption.

## GENERAL DISCUSSION

The goal of this research project was to gain knowledge on how the persons themselves perceive their everyday occupations after ABI, and thus contribute to the development of the theoretical base for client-centred rehabilitation. The main focus was to explore people's perceptions on what they do and want to do in their everyday life over time, which according to the ICF (WHO, 2001) is closely connected to participation. Participation in everyday occupations is a complex phenomenon and many different aspects may interact with each other and influence how people perceive their everyday life situations. The intention with this project was not to explore all the aspects that may influence the everyday life situation after ABI. Important aspects that are not taken into consideration in this thesis could for example be accessibility in society and societal resources. In this section, a discussion on the main themes that the empirical studies resulted in will be presented. Initially, the perceptions of occupational gaps and the relation to life satisfaction will be discussed as well as the importance of motor and executive functioning for the performance of wanted occupations. In addition, the concept of occupational gaps and the relation to participation in everyday occupations will be considered, together with aspects of measuring occupational gaps. This will be followed by a discussion on limitations of the methods used. The Discussion section will be concluded with a discussion on the implementation of the results in rehabilitation. Suggestions for future studies will be integrated throughout the whole discussion section.

### *Everyday occupations and the relation to life satisfaction*

The participants' perceptions of their everyday occupations and how their perceptions were related to life satisfaction were in focus in Studies I and III. In Study I the participation in everyday occupations and the relation to the couples' joint life satisfaction was investigated, and in Study III the relation between perceived occupational gaps and life satisfaction was explored among the persons with ABI. These studies showed that there was a definite relationship between participation in everyday occupations (Study I) and perceived occupational gaps (Study III) and life satisfaction.

For the couples in Study I, the joint life satisfaction related mostly to participation in leisure, social activities and in one instrumental ADL activity. Variables concerning perceived impairment, personal and instrumental ADLs and the partners' perceived assistance with activities were included in the analyses. The joint life satisfaction was most influenced by the

their perceptions of participation in everyday occupations which is in line with the results from studies showing that impairments are less related to perceived life satisfaction (Johnston & Miklos, 2002) than activity and participation and injury severity (Johnston & Miklos, 2002; Dijkers, 2004; Cicerone, 2004).

The fact that only a minority of the couples in Study I were satisfied with life as a whole was well supported by a recent study conducted in Western Sweden in a slightly older sample of couples (Carlsson et al., 2007). These studies indicate the need for focusing on the couple as a social unit during rehabilitation and addressing their individual as well as their mutual needs in everyday life.

In Study III the analysis revealed that the extent of perceived occupational gaps explained the greatest variance in life satisfaction. Previous studies have shown that participation in occupations is a determinant of health and well-being (Law et al., 1998; Clark et al., 1997). In a recent Swedish study it was shown that persons with ABI perceive restricted participation in everyday occupations, and mostly in work activities, in the long term after ABI (Johansson, Högberg & Bernspång, 2007). This was, in agreement with Study III, related to life satisfaction. However, a review on participation as outcome of rehabilitation of people who have had ABI (Cicerone, 2004) reveals that relatively few studies have that focus. Several of the studies included in the review on social participation, i.e. integration in and productivity in occupations outside home, associate to life satisfaction. However, the relationship was quite modest in these studies. Furthermore, there is no evidence of a relationship between perceived participation and satisfaction with participation. Cicerone (2004) argues that this lack of relationship is due to the fact that current measures of community integration or social participation do not take the preferences of the persons with ABI into account. Nor do the measures reflect the perceived effectiveness in the performance of everyday occupations, which may influence the individuals' satisfaction with participation. Cicerone (2004) concludes that assessments measuring participation should pay attention to the individuals' preferences and values in doing. Based on this conclusion (Cicerone, 2004), one possible reason to the definite relationship between the low extent of occupational gaps and high perceived life satisfaction in Study III can be the use of a client-centred instrument (Brown, Gordon & Haddad, 2000).

#### *Adaptation within a changed life situation*

The results from Study III showed that perceived occupational gaps had a definite relationship to life satisfaction, and in Study I the joint life satisfaction was associated with participation in

some everyday occupations. Individuals may, through adaptation and by recreating ways of dealing with their everyday occupations, perceive that they are taking part in their new life situations. As previously recounted, a successful adaptation in the new everyday life situation is viewed as contributing to satisfaction with life (Kielhofner, 2007). However, it ought to be discussed whether the definite relationship between low extent of occupational gaps, which implies that the participants participated in their wanted everyday occupations, and high life satisfaction in Study III as well as the joint life satisfaction in Study I are due to a successful adaptation in everyday occupations or not.

In continuity theory, Atchley (1999) argues that maintaining patterns of activities and life style as well as a continuity of the self co-exist with changes in these aspects due to onset of a disability, in the process of adapting to the new life situation. It cannot be concluded from Study III whether the lower extent of occupational gaps that relates significantly to life satisfaction is due to successful adaptive processes in the new life situation or not, even if one can assume that some adaptation has occurred in their everyday lives (Kielhofner, 2007). Nor can it be stated that the couples with high joint life satisfaction in Study I are those that have a more successful adaptation. In the findings in Study IV there are, however, descriptions of adaptive processes. Many of these recounted episodes on new ways of dealing with difficulties in doings not previously encountered, as well as preserved ways of handling everyday doings, might be seen as descriptions of adaptation in a new life situation. These experiences seemed to assist the participants in Study IV in the process of adaptation in their changed situations in everyday life and helped them in preserving or modifying their sense of self as doers. These findings are consistent with findings from other studies on stroke (Becker, 1993), TBI (Klinger, 2005) and other chronic illnesses (Charmaz, 2002). The findings in the studies by Becker (1993), Klinger (2005) and Charmaz (2002) as well as the findings in Study IV challenge what was proposed by Kielhofner (2007), that identity is suggested to be less affected than competence when adapting in a new situation brought about by a disability. The experience of how the identity is affected might differ depending on the cause to the disability. It seems that having a reduced ability in managing self-care generated different experiences of the possibility to express oneself depending on whether the participants had a stroke or a spinal cord injury (Guidetti, Asaba & Tham, 2007).

The participants in Study IV created strategies enabling doing, stopped doing occupations that were too demanding or tiring for them or let others carry out the actual doing while instructing how the occupation should be performed. All these various ways of dealing with doings reflected adaptation within a new situation and the participants felt better when they



had changed their doings, which was also reported by Becker (1993). It is likely that the participants in Studies I and III also experienced and dealt with their new situations in everyday life in similar ways. However, this was not the focus for these studies.

*The importance of motor and executive functioning and the time elapsed since injury for everyday occupations*

The results from Study II showed that 71% of the sample perceived one or more occupational gaps after injury, which can be considered to be a considerably reduced participation in their wanted everyday occupations. One of the factors most associated with the extent of occupational gaps was perceived motor functioning. Motor functioning was also important for the couples' joint life satisfaction in Study I. One specific instrumental ADL activity, namely washing clothes, related significantly to the couples' joint life satisfaction after ABI. An analysis of problems with washing clothes showed a strong association with motor impairment, although this was not reported in the study. This is in line with reports in a review by Johnston and Miklos (2002) that being independent in occupations that require motor function a year or more after brain injury correlate with higher life satisfaction. In a Canadian study on predictors for participation in the long term after stroke (Desrosiers, Noreau, Rochette, Bourbonnais, Bravo & Bourget, 2006) motor functioning together with affect, age and comorbidity were shown to be the best predictors two to four years after onset, which also support the findings in both Studies I and II. Other studies agree on the importance of motor functioning for participation in everyday occupations but also underline the role of behavioural and cognitive functioning (Masson et al., 1996).

Executive functioning, which is seen as a higher level of cognitive functioning (Katz, 2005), was the most associated factor for the extent of perceived occupational gaps in Study II. This is supported by a study on executive functioning after stroke where there was a clear relationship between decreased executive functioning and reduced ability in ADL (Pohjasvaara, Leskela, Vataja, Kalska, Ylikoski, Hietanen et al., 2002). Difficulties in solving problems, planning, initiating and organising the performance of everyday occupations might be viewed as a self-evident cause of a diminished ability to carry out occupations. However, the research on executive impairments and their implications for everyday functioning is still limited (Cicerone, Dahlberg, Malec, Langenbahn, Feliceti, Kneipp et al., 2005). A further development of interventions aiming to improve problem-solving, self-regulation and the use of external strategies in the context of everyday occupations is recommended, together with studies on their effectiveness (Cicerone et al., 2005). An occupation-based occupational

therapy practice is considered to be a base for developing such interventions as well as for assessing executive functioning and participation in everyday occupations in the client's own environment (Katz & Hartman-Maeir, 2005), which the results in Study II also indicate.

The fact that motor and executive functioning is related to gaps in everyday occupations after ABI is supported in a study by Bernspång and Fisher (1995), where difficulties in motor and process skills were related to functioning in everyday occupations. It was shown in the study that persons with decreased motor skills could live independently as long as they had process skills needed to compensate for their reduced motor functioning. Process skills are defined as the observable actions of performance a person enacts to logically sequence the action of the ADL task performance over time, select and use appropriate tools and materials, and adapt his or her performance when problems are encountered (Fisher, 2003).

Study II showed that the time that had elapsed since ABI, and specifically the time ranging from one to four years after onset had no effect on the participants' perceived occupational gaps. This result is consistent with what is shown in several outcome studies on participation in everyday occupations in the long term after ABI (Hoofien et al., 2001; Ponsford et al., 1995; Masson et al., 1996). The importance of long-term support after ABI and access to rehabilitation has previously been emphasized (Lexell, 2007; Dikmen et al, 2003; Johansson, 2004) and the results in Study II support that. They also indicate that the interventions should be client-centred to enable an enhanced participation in everyday occupations.

### *The concept of occupational gaps and the relation to participation in everyday occupations*

The main theme in this thesis is perceptions of occupational gaps in everyday occupations. The operationalisation of the concept of occupational gaps and the instrument that intends to measure occupational gaps have been developed and tested in Studies II and III. During this process it became clear that the concept or phenomenon of occupational gaps seems to be closely linked to participation in everyday occupations which will be discussed in the following.

The definition of occupational gaps might be seen as the opposite (negative aspect) of participation in everyday occupations, as defined by Kielhofner (2007), i.e. occupational participation, but with the addition of the social dimension of participation defined by WHO (2001). A suggested definition of participation in everyday occupations (negative aspect), which is supposed to be equivalent to the definition of occupational gaps, could then be:

*the experience of not engaging in (Kielhofner, 2007) or being involved in (WHO, 2001) occupations that are part of one's socio-cultural context and that are desired or necessary for one's well-being" (Kielhofner, 2007).* According to this reasoning, the negative aspect of participation in everyday occupations would be consistent with perceptions of "an occupational gap between what one wants and need to do and what one actually does" (Study II), which needs to be further explored in future studies.

If the reasoning above could be accepted as valid, one might argue that one of the main contributions of this thesis is to initiate development of a tool measuring participation in everyday occupations. Enhancing participation is the focus in occupational therapy, and a development of participation measures is needed (Law, 2002). There are some empirical findings from this thesis concerning occupational gaps that ought to be discussed to develop and substantiate this reasoning.

#### *The lived experience of occupational gaps*

The findings in Study IV added new dimensions to the concept of occupational gaps used in Studies II and III. In the phenomenological analysis in Study IV, several characteristics of the meaning of occupational gaps in everyday doings were identified. The participants experienced occupational gaps of different kinds in the performance of everyday occupations; there were "gaps in occupations with a symbolic meaning" and "gaps in former taken-for-granted activities". In the following, these two types of gaps will be discussed and linked to how occupational gaps could be viewed in connection with participation in everyday occupations.

A "symbolic occupation" was an occupation that was closely linked to the participants' sense of self. They had, through gaps in occupations that seemed to be an integral part of who they were as persons, diminished their possibility of recognising and expressing themselves in doing. The experience of not being able to participate in an occupation with symbolic meaning and the strong wish to narrow this gap was the driving force and the overall intention of their rehabilitation. The participants expressed a strong desire to participate in these symbolic occupations again and thereby recognise themselves. Some aspects of the concept of "engaging occupations" in the context of retirement (Jonsson, Josephsson & Kielhofner, 2001) partly connect to symbolic occupations. One common theme in these two concepts is the long-term involvement in "engaging" as well as in "symbolic occupations" during a lifetime and these occupations both constitute some kind of commitment or responsibility to others.

The integration of specific occupations with a sense of who one is as a person is an aspect that has previously been touched upon in occupational therapy, in occupational science and in sociological literature. In the Model of Human Occupation the concept of volition is seen as a pattern of thoughts and feelings about oneself as an actor that occurs as one anticipates, chooses, experiences and interprets what one does (Kielhofner, 2007). Furthermore, Kielhofner (2007) proposes that identity and competence in the context of occupations are the components that are important in the dynamic process of adaptation throughout life. The occupational identity is one's sense of present and future self, based on one's history as an occupational being. Christiansen (2004) adds to this reasoning that with each occupational choice individuals define who they are. Based on social psychology, Christiansen delineates the relationship between occupation and identity. Everyday occupations are named, chosen and performed in a social context, and thus choosing and being engaged in occupations within our social worlds are essential for developing the self. With reference to symbolic interactionism (Mead, 1934), Christiansen argues that people develop and maintain their sense of self mostly through interactions with others and that social acceptance is fundamental to human well-being. Laliberte-Rudman (2002) reports that a number of qualitative studies support the ideas that occupation is used to express identity and is central in reconstruction processes after onset of disability. Kaufmann (1988) found that an important strategy for persons who had experienced stroke was to use activities with a symbolic meaning, to integrate experiences that life and everyday doings had been very much altered into their identity. In summary, the importance of recognition of oneself in everyday occupations after onset of disability is well supported in the literature. To this body of knowledge Study IV adds knowledge of the significance of focusing on symbolic occupations as essential for incorporating the changes in doing into the new sense of self, in a rehabilitation context.

Encountering "gaps in former taken-for-granted activities" concerned experiencing difficulties in performing the ordinary activities that were previously performed without thinking. These gaps seemed to disturb the flow of everyday life. The ordinary activities were a part of the recognisable everyday routine that had to be done to make things work, and these activities in a way also confirmed the persons they were. However, symbolic occupational gaps differed from these former taken-for-granted activities by seeming to be of greater importance for the participant's sense of self. The gap in former taken-for-granted activities implied that the activities were harder to carry out, but that they still could be accomplished with considerable effort. These familiar activities, carried out in a consistent way from day to

day, are according to Kielhofner (2007) the basis for our habits and roles in everyday life and they constitute what is referred to as habituation in Model of Human Occupation. There are several studies confirming the experience of loss of or enhanced hardship performing these taken-for-granted activities after stroke, and the significance the loss had for individuals' sense of self and stability in life (Becker, 1993; Clark, 1993; Guidetti et al., 2007)

To summarise the findings from Study IV on occupational gaps, one might say that "occupational gaps in symbolic occupations" concerns what individuals want to do and that "gaps in former taken-for-granted activities" relate to occupations that are needed. In that sense the participants' lived experiences in Study IV seem to be in agreement with the definition of occupational gaps (Studies II and III).

#### *Occupational gaps as a measure of participation in everyday occupations*

Participation and its relation to occupation have recently been explored in both qualitative and quantitative studies in people with chronic pain (Borell, Asaba, Rosenberg & Schult, 2006) and among people who are very old (Haak, 2006). Haak (2006) found in her studies that for very old people participation had two main dimensions, i.e. performance-oriented participation and togetherness-oriented participation. Performance-oriented participation was experienced when engaging in performance of occupations for others, while the dimension of togetherness was experienced when sharing experiences with others, such as meeting friends and family. Borell and colleagues (2006) advanced that understanding when they found that participation for individuals experiencing chronic pain has to do with agency, being active and being social. For these individuals participation also had to do with doing something for others.

The dimensions of being active and doing things for others encompass an active "engagement" in occupations, and these dimensions might be considered to be partly covered in the OGQ, as for example in the items "sports" and "taking care of and raising children". The dimension of "being together with others" could include doing with others, but also being in the context of others' doing and sharing experiences with others. This dimension of participation might be seen more as "being involved in" (not engaged in) (WHO, 2001) occupations that are part of one's socio-cultural context". The dimension of being together with others is, however, covered by only a few items in the OGQ, such as "seeing partner and children". This dimension of being together with others (Borell et al., 2006; Haak, 2006) as well as doing for others (Borell et al., 2006) are dimensions of participation that are not included in the concept of occupational participation (Kielhofner, 2007) but they do seem to

add important aspects. Occupational therapy would gain from exploring the concept of participation in everyday occupations further, and thereby deepening the knowledge on aspects both relating to doing and to being social in the context of doing.

To conclude this reasoning on the connection between perceived occupational gaps and participation in everyday occupation, the empirical findings discussed above support the suggestion that there seems to be a close linkage between these concepts and that the OGQ might generate a measure on participation in everyday occupations concerning the areas covered by the instrument. Further development of the OGQ and subsequent measurement of occupational gaps in various populations might therefore generate knowledge on participation in everyday occupations useful for occupational therapy and occupational science as well as for planning and evaluation of client-centred rehabilitation. In addition, exploration of participation in everyday occupations might also contribute to the emerging body of knowledge on the subjective experience of participation, which ought to be included in the ICF (Hemmingsson & Jonsson, 2005), to substantiate the description of participation as “the lived experience of people in the context where they live” (WHO, 2001).

#### *Assessing occupational gaps*

The OGQ instrument has been developed and tested in this research project as an operationalisation of the definition of occupational gaps. There are some aspects of the definition as well as of the operationalisation that need to be discussed here.

#### *Defining occupational gaps*

The concept of occupational gaps has been defined “as the gap that occurs between what the individual wants and needs to do and what he or she actually does”. The findings in Study IV have contributed to a more nuanced understanding of the phenomenon of occupational gaps. The participants’ descriptions of their experiences of performing everyday occupations made explicit that the gaps perceived were very individually coloured. Gaps changed in importance over time, and were for some of the participants not thought of as gaps later on, due to a changed meaning of being able to perform that occupation. Furthermore, gaps disappeared when participants regained functioning. However, an occupation that participants had taken up again could still be seen as an occupation in which they experienced an occupational gap, due to *dissatisfaction with the performance*. Participants also experienced that they were dissatisfied with the effort that the performance of even very ordinary everyday occupations demanded of them, i.e. they experienced *gaps in performance*.

All these various ways of viewing the phenomenon of occupational gaps (Study IV) have been considered in the process of revising the definition. It seems that the importance of doing specific wanted occupations is covered in the definition, while dissatisfaction with performance is not. Information on satisfaction with the performance of specific occupations might be seen as an important aspect for participation in everyday occupations and for well-being, and could be added to the instrument in order to give more complex information on participation in everyday occupations. These concerns might be covered by adding a few words into a proposed new definition: “An occupational gap is the gap that occurs between what the individual wants and needs to do and what he or she actually does *and is satisfied with in the context of doing*”.

A revision of the definition calls for a revision of the OGQ. One way to add the dimension of being satisfied with doings into the instrument would be to add one more question, i.e. 1 a) “do you perform the activity now?” and 1b) “if you perform the activity; *are you satisfied with your performance?*” which also would be answered with “yes” or “no”. A suggestion for analysing no presence of gaps (positive aspect) would then be that both Question 1 a) and 1 b) should be answered with “yes” and Question 2 should also be answered with “yes”, i.e. “want to perform the activity”.

There might be various suggestions of how to define the scale for analysis depending on what the intended use will be. If the OGQ will be used in populations with brain injury, this proposed dimension with satisfaction seems important. Thereby, the scale might be developed differently from the way it will be developed if the OGQ’s intended use is that of a generic instrument. Future studies are needed to evaluate the proposed definition, its operationalisation, various ways of developing the scale for analysis, and whether the OGQ demonstrates differential item functioning (DIF) (Bond & Fox, 2001) for specific groups.

Two aspects in the current instrument will be discussed; these are the wordings in the questions posed in connection to each item and the present items and possible addition of items.

#### *The wordings in the questions in the OGQ*

In the OGQ the respondents are asked if they want to perform activities. There is not much knowledge about what “want to perform activities” means to people, which complicates the interpretation of the data obtained from the instrument. Which occupations individuals perceive as significant in everyday life emanates from a complex process including previous experiences and the actual life situation. This thinking is disclosed by the theory of response

shift (Sprangers & Schwartz, 1999), where it is shown that people change their values, internal standards and requirements of life and adapt in new life situations that had been altered by negative consequences of chronic illness or injury. By prioritising differently and rethinking what is important in the new situation people seem to be satisfied with a life situation that previously had been considered unacceptable (Sprangers & Schwartz, 1999). Qualitative research on people's experiences of everyday life after TBI has confirmed this rethinking (Nochi, 2000).

The findings in Study IV show that the participants' experiences of meaning differed in their various occupations. Some of the occupations, such as the symbolic occupations, were more "wanted" by the participants than others. However, the activities that were ordinary in character (i.e. making a phone call) and perhaps experienced as more needed for everyday life functioning, could anyhow be experienced as wanted for the participants, because these activities made them feel competent and recognise themselves in the daily rhythm. What people want to do in everyday life is according to Kielhofner (2007) influenced by the perceived competence in doing, which often is affected after ABI, and thus, the perceived competence might change. Therefore, there is need for exploring what meaning "want to do" has for people and if and how life course disruptions may change this meaning, in order to be able to capture the nuances revealed in Study IV.

As previously mentioned in the Methods section, two kinds of gaps can be apparent in the OGQ depending on how the respondent perceives the wording of "wants to do". The gaps can be due to the fact that you do not do activities but want to do them, or gaps due to the fact that you do activities that you do not want to do. In the sample in Study II, the majority of the occupational gaps perceived by the participants were due to not doing what they wanted to do. A hypothesis, with reference to the theory of response shift (Sprangers & Schwartz, 1999), is that the distribution of gaps might differ in samples, as for example in a sample of healthy people or among people experiencing stress-related disorders.

#### *The present items and possible additions of items*

From the results in Study III it became obvious that the OGQ has a ceiling effect in a sample of people with ABI. More challenging items need to be included to make the instrument more sensitive to changes (Rosenberg, Nygård & Kottorp, 2007). In Study II the results showed that impaired executive functioning had the greatest association to numbers of occupational gaps perceived. Items incorporating demands on organisation and planning skills, such as arranging dinner parties or planning and carrying out a journey, might therefore be added.



There are only two items capturing work and studies in the instrument, though people of working age use most of their time on these contracted occupations (Harvey & Pentland, 2004) together with more committed occupations such as those categorised as instrumental ADLs in the OGQ. Work and studies have shown to be demanding for people after acquiring a brain injury (Ponsford et al., 1995; Hoofien et al., 2001) and other illnesses. Adding some more specified items on work and studies would therefore reasonably capture what people do or not do in everyday life and also increase the challenge in the instrument, if its main use is to be among adults.

### *Methodological considerations*

The studies contribute new knowledge on perceived occupational gaps and the relation to life satisfaction after ABI. The Occupational Gaps Questionnaire has been developed and some tests of reliability and validity are performed. The generalisability of the results may be questioned, and the different methodological limitations that may interfere with validity and generalisation will be discussed in the following paragraphs.

### *Samples, sample size and representativeness*

The samples in Studies I-IV consist mainly of people in working ages with various kinds of acquired brain injuries. The specific diagnoses has not been considered to be important in this late phase after onset and no distinctions have been made due to diagnoses in the analyses in Studies I-III (Rice-Oakley & Turner-Stokes, 1999).

The relatively small sample in Study I was in need of rehabilitation interventions years after onset, and might therefore consist of persons with more residual problems in everyday life than would typically be the case a longer period of time after the injury (Malec & Basford, 1996) and are therefore not a representative group of persons receiving rehabilitation. Therefore, the results from the study are not generalisable to other populations and conclusions should be drawn with caution. However, the study contributes important new knowledge on the couples' joint perspective, which underlines the importance of further studies on the joint life satisfaction and their experiences in everyday life after ABI over time using both quantitative as well as qualitative approaches.

The sample in Study II, of which the sample in Study III is a smaller part, encompassed the majority of the clients in working ages that were treated due to TBI or SAH at an intensive care unit at a neurosurgical department and were assessed by a rehabilitation physician in the acute stage. The sample, people from all over Sweden, seems to be representative with regard

to previously reported data on Swedish people with TBI (Kleiven, Peloso & von Holst, 2003) and people with SAH in Scandinavia (Pakarinen, 1967). The response rate on the survey questionnaire was very high. However, in order to generalise these results this study ought to be replicated and more studies in this relatively unexplored area are needed for the development of the body of knowledge needed in occupational therapy and rehabilitation practices (Cicerone, 2004).

Concerning qualitative studies the reasoning concerning sample size differs from what is commonly used in quantitative studies. The sample in Study IV consisted of four persons, and they were chosen because they could provide varied and rich data on the phenomenon studied (Dahlberg et al., 2001). The findings cannot be generalised due to the limited number of participants. However, the aim of phenomenological research is not to generalise findings, but to identify the essential characteristics of a specific phenomenon that are general for all study participants (Karlsson, 1995), and also to contribute to a better understanding of the participants' experiences that might be transferred to other persons or contexts (Dahlberg, 2001).

### *The design chosen*

Studies I-III all had a cross-sectional design due to the specific research questions, but also because it was feasible. With this design important knowledge on participation and life satisfaction in the samples at one point in time were gained, which points to new questions that warrant exploration. A longitudinal study design with several measuring points would have provided valuable information on stability in participation on if, and then how, participation in everyday occupations differs over time where the participants constitute their own controls (Rice-Oakley & Turner-Stokes, 1999). Future prospective research is recommended to further explore participation in everyday occupation over time. In Study IV, a prospective longitudinal design was used, making it possible to identify some aspects of change in the meaning of occupational gaps during the first year after stroke.

### *The validity and reliability of using postal questionnaires*

The data in Studies I-III were collected with postal questionnaires. There can be a question of whether this was the most reliable way of collecting data on the perceptions of everyday occupations, but it has been shown that using postal questionnaires is as reliable and valid as conducting face-to-face interviews with people who have ABI (Carter, Mant, Mant, Wade & Winner, 1997). Furthermore, the questionnaires in Studies I and II were designed so that these

studies met the special needs of people with brain injury, i.e. simply formulated questions of which the majority could be replied by a “yes” or a “no”. There is, however, a risk of recall bias on the retrospective data in the questionnaire used in Study II. Memory difficulties, how much time had passed since onset and a tendency to remember everyday life before onset as better than it was could all be reasons for bias and thereby a less reliable response to the questionnaire. A lack of awareness might also have influenced how the participation in everyday occupation was perceived as well as the consequences of the brain injury (Prigatano, 1991). However, the inclusion in the survey questionnaires of standardised and evaluated instruments commonly used in research strengthens the reliability of the result.

### *The use of a new assessment instrument*

Rasch analysis of the data obtained from the OGQ has shown that it has acceptable internal scale validity as well as person response validity (Study III). The instrument served to capture perceived occupational gaps in Studies II and III but the study might be seen as providing limited evidence, due to the use of the newly developed instrument. This is important to consider, when inferring from the results in Studies II and III. The OGQ is in its early stages of development. The next step would be to develop the conceptual model of the instrument and to add items and revise the instrument according to the proposed dimension of satisfaction based on the discussion in this thesis. Thereafter, various methods and designs need to be applied to obtain further evidence for validity, reliability and sensitivity to change in the new version of OGQ based on data from a larger sample representing varied groups of people experiencing different levels of ability (Polit & Beck, 2004; American Educational Research Association, 2002).

### *The qualitative approach used*

The EPP method was used in the collection and analysis of the interview data, and the method made it possible to identify and describe the phenomenon (i.e. occupational gaps) as it presented itself (Karlsson, 1995) in the life-world experiences described by the participants. In order to identify change in experiences over the course of rehabilitation, the participants were interviewed four times each during a year, which made it possible to follow up aspects that had come up during previous interviews. This design made it possible to establish a relationship based on trust between the researcher and the participant (Kvale, 1996), which generated rich descriptions of the participants’ life-world experiences and thereby strengthened the trustworthiness of the data and analysis (Dahlberg et al., 2001). One

methodological issue is how to ensure that the interpretations of the data are valid. In every step of the analysis the researchers were open and sensitive to the meanings of the phenomenon of occupational gaps and the interpretations of the data were carefully discussed between the researchers until a “horizontally consistent interpretation” was reached (Karlsson, 1995). The researchers tried to ascertain that the interpretations had an inner logic, that it was possible to follow the researcher’s reasoning in the descriptions throughout the study, and that the findings in the study constituted a consistent whole, i.e. the coherence criterion of validity was applied (Dahlberg et al., 2001).

### *Ethical considerations*

Persons who have ABI might be viewed as being a vulnerable group where special considerations are necessary when performing research (Polit & Beck, 2004). Several ethical dilemmas might pose difficulties in comprehending the information given on the research project and on the voluntary participation, which makes it difficult to make an informed decision on whether to participate. When using postal questionnaires the written information as well as the survey questionnaire must use simple language because oral explanation is not possible. If this is not taken into consideration it might imply that relatives take a more active part than the person with brain injury in responding to questions. Another dilemma might be that people with limited cognitive ability and awareness of disability may experience it as a violation of their integrity when being asked about disabilities they do not perceive. It might also be viewed as an intrusion to ask personal questions on changes in everyday life. These possible ethical dilemmas have been taken into consideration in this research project.

Studies I-III were approved by the Research Ethics Committee of Uppsala University and Study IV was approved by the Ethical Committee at Karolinska Institutet.

The participants in Studies I-III received written information regarding the aim of the investigation and their participation in the study together with the postal questionnaires sent to them. In the introductory letter the participants were informed that participation was voluntary. By answering the questionnaire the participants were regarded as giving their consent to participate, which is regarded as optional (Polit & Beck, 2004). In Study I, the persons with brain injury were instructed to ask for help with answering the questionnaire if necessary, and one-third of the sample in the study required help. By this procedure, even persons who could not answer by themselves at least had a say from the couples’ perspective.

In Study IV, the participants received written as well as verbal information about their participation, and all the participants consented to participate in the study verbally and in writing.

The participants in Studies I-III were promised confidentiality, and the questionnaires were assigned with a code number to prevent identification. For the small sample in Study IV, an ethical dilemma was that it was difficult to ensure their confidentiality. Information that could reveal who they were was therefore used sparingly and fictitious descriptions of aspects in their everyday life situations were used in the manuscript. Another ethical dilemma in Study IV was that when giving their consent to participate shortly after onset, participants might not have comprehended how they might experience this later in the rehabilitation process. However, none of the participants indicated any negative experiences of participating in the study during the four interviews.

### *Implementation of results in rehabilitation*

The results of this thesis provide knowledge that can be implemented directly in occupational therapy as well as in brain injury rehabilitation. Couples' joint life satisfaction in everyday life after ABI was identified. A new approach to study the consequences after ABI in everyday occupations has been developed by defining the concept of occupational gaps and by creating a way to assess occupational gaps. Knowledge was also generated on the meaning of occupational gaps in the course of rehabilitation. In the following, the implementation of this new knowledge in rehabilitation will be discussed. Primarily the discussion will concern the long-term rehabilitation of people who have acquired a brain injury.

- The results from Studies I and III give a clear indication on the definite relationship between participation in everyday occupations (Study I) or gaps in everyday occupations (Study III) and life satisfaction, for people with ABI (Study III) as well as for couples (Study I) where one person in the couple had acquired a brain injury. This finding has two main implications for rehabilitation that might enhance the possibility of reaching the overall goal of securing life satisfaction for the individuals with brain injury and those close to them. The results lend support for further development of: A) an occupation-based occupational therapy practice, and, B) a client-centred brain injury rehabilitation concerning all professions involved.

- A. Occupation-based occupational therapy is quite well established in brain injury rehabilitation. Clients train to increase functions by means of performing various everyday occupations. The objective of interventions can also be to recapture an occupation that is important for the client in his/her everyday life. The results in this thesis emphasize a more marked focus on the latter approach in occupational therapy. Occupational therapists can more advantageously address the clients' future participation in everyday occupations in their own environments, 1) by being sensitive to each client's experiences (Study IV) of which occupations that are important, 2) by enabling experiences in occupations that make them recognise themselves (Study IV), 3) by using the client-centred OGQ instrument as a basis for planning the interventions in collaboration with the client and thereby enabling the client to do what he/she wants and needs to do in everyday life (Studies II- IV), 4) and by involving the client in setting goals for the intervention, as for example goals related to their occupations with symbolic meaning (Study IV).
- B. In this thesis the participants' perceptions of their everyday occupations were captured in all the studies. This knowledge can be used when supporting clients in their reconstruction of their various new everyday life situations. The results in Study III showed a definite relationship between perceived occupational gaps and life satisfaction, which lends support to the importance of enabling the clients to do what they want and need to do after ABI. The findings from Study I, where the majority of the couples were not satisfied with life, indicate that brain injury rehabilitation should involve the partners to a greater extent in the rehabilitation process. It should be the perspective of the couple, (or the family as a social unit, i.e. the client) on what is important, and what is difficult to deal with for them in their everyday life, that should be the guide when developing a client-driven plan for rehabilitation.
- The results from Studies I – III showed that the participants' participation in everyday occupations was restricted and that they perceived occupational gaps and reduced life satisfaction a year or more after ABI. This indicates a need for follow up and access to rehabilitation interventions in the long term. Furthermore, in Study II the time lapse since the injury had no significant effect on the number of perceived occupational gaps, which also lends support to the need of follow up interventions.

- The OGQ, as used in this thesis, seems to be sensitive enough to capture occupational gaps in a sample of persons with ABI. The instrument has been used clinically to a very limited extent though it seems to have a clinical relevance. A suggestion based on the results in Studies II and III will therefore be to use the OGQ in occupational therapy practice 1) to identify the perceived occupational gaps as a basis for planning interventions aiming to narrow the perceived gaps (Study IV), and 2) to be used as an instrument for evaluating the client-centred occupation-based intervention aiming at enhancing participation in everyday occupations.

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