LONG-TERM OUTCOME AFTER BRAIN INJURY

with a focus on return to work, life satisfaction and participation

Ulla Johansson

Umeå 2004
To my family
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ABSTRACT

Rehabilitation after brain injury is often a process which is spread over several years and runs through different phases. After subacute in-patient rehabilitation a community based postacute rehabilitation can follow. In this late phase after injury the rehabilitation focuses on reintegration into the community through a return to work and participation in other occupations in society. The overall aim of this dissertation was to study the long-term outcome of brain injury, with a special emphasis on the return to everyday domestic and productive occupations and the connection these have to life satisfaction. The aim was also to describe and understand the lived experience of the consequences of brain injury in these areas.

This dissertation comprises four studies on different aspects of the long-term outcome of those who have had a brain injury. In a sample of 56 people, the value of occupational therapy assessments as predictors of an eventual return to work was investigated. In a longitudinal follow-up study, the life satisfaction of the participants (n 36) was reported and its correlation to a return to work was evaluated. Interviews were conducted (n 10) to explore the main characteristics of the meaning of work after brain injury in ten respondents. And, finally, in the fourth study, 157 people reported their participation in community activities. The extent of the correspondence between the level of participation and life satisfaction was calculated.

The findings showed that occupational therapy assessments were useful in predicting a return to work in the late phase of the recovery after brain injury. A combination of assessments on the level of body function with assessments on activity level appeared to comprise the best predictive model. In two different studies the reported life satisfaction was found to be significantly lower than the level of life satisfaction in a sample of healthy Swedes for almost all domains. When comparing life satisfaction at two points in time with an interval of three years between them in the longitudinal study, no significant improvement was found. There was no difference reported by the participants for their overall life satisfaction regardless of whether they were back at work or in education, or not. On the other hand, participation in daily occupations in a wider perspective was found to have a positive impact on satisfaction with life as a whole. However, half or more than half of the participants claimed that their participation was restricted except for the items self-care and mobility, where a higher degree of participation was reported. The meaning of work after the brain injury had changed: Work had taken on a new place in life and the importance of work had decreased. In contrast, the social dimension of work had expanded in importance. After the brain injury, the perception of the participants’ own competence and work identity had changed and the respondents described their striving to return to normality.

To conclude, brain injury has a lasting effect on a person’s life, even many years after the injury; consequently there is need for rehabilitation in this late phase. Life satisfaction, which is often used as an overriding goal for rehabilitation, did not improve over time. This finding raises the question of whether life satisfaction is too broad a concept and/or insufficiently sensitive to improvements. There is need for further research in this area to clarify the factors that have an impact on life satisfaction.

Key words: Activities of daily living, brain injury, community integration, lived experience, life satisfaction, longitudinal, occupational therapy, participation, phenomenology, prediction, return to work, rehabilitation.
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<td>Assessment of Motor and Process Skills</td>
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<td>Brain injury</td>
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<td>Empirical Phenomenological Psychological method</td>
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ORIGINAL PAPERS

This dissertation is based on the following papers, which will be referred to by the Roman numerals assigned below.


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INTRODUCTION

Through the years that I have spent as an occupational therapist in clinical practice engaged in brain injury rehabilitation, many thoughts have occurred to me and many questions have come up. In particular, one episode in the beginning of the 1990s had an influence on the start of the present dissertation. This was meeting two clients who were involved simultaneously in the out-reach rehabilitation programme. They were of the same age, both recovering from a stroke, but the journey that their rehabilitation took turned out to be quite different. One of the clients, who had been working as a bank clerk before the stroke was really eager to go back to work. The other one, who had been an entrepreneur, also intended to start working again. Both had several obstacles to overcome to achieve their goal. They also had a completely different attitude to the work-related tasks that they considered to be acceptable. While the bank clerk thought that the nature of the work undertaken did not matter at all, the important thing was to have some work to do, the work tasks themselves were very important to the entrepreneur. The latter could not find the strength to struggle with his disabilities if the work-related tasks did not give him just the right kind of challenge. This insight into two people’s lives caused me to ponder on many questions related to rehabilitation in a late phase after brain injury. What is the most crucial factor for success in achieving the rehabilitation goal of returning to work? Does the individuals’ perception of the meaning of work have an impact on the rehabilitation process? These questions gave me the drive to find out more about life after brain injury. When I searched for answers in the literature, I realized that there was a need for further knowledge about the long-term outcome after brain injury. Thus, this thesis addresses the issues mentioned above and others that are connected to them.

Brain injury

In this dissertation, the term brain injury is used as a generic term for brain damage caused by stroke, traumatic brain injury (TBI) or other acquired brain injuries. This expression term is found in the literature in studies that include people with brain damage derived from these different causes. Many studies differentiate between traumatic brain injury and stroke, as the main clusters of brain injuries, while others use a generic term. Sometimes the focus of the studies is on a specific diagnostic group, in others it is on a specific life situation as the means of re-entry into an occupational life.
Some differences in the rehabilitation outcome between those with a traumatic and vascular brain injury have been described in the literature. For example, Mazaux and Richer (1998) reported that a greater improvement can be seen in those recovering from TBI compared to those with stroke, but Rice-Oxley and Turner-Stokes (1999) believed that making a distinction between brain injuries based on whether they were caused by a stroke or trauma was artificial since the brain injury itself causes highly diverse patterns of disability regardless of its origin.

One reason why I have chosen to use the term brain injury in my research is that this more generic grouping is representative of the patients who attend rehabilitation clinics (Turner-Stokes, Disler, Nair, & Wade, 2004). My focus of attention in this dissertation is a late phase of the recovery after injury, when the intervention is directed at issues related to living in society rather than medical outcome. Another reason for this choice is my background as an occupational therapist in clinical practice: My focus is occupational performance. The studies included in this dissertation are not about the effects of specific types of intervention or issues related to diagnoses, but rather, the aim was to explore the everyday situation of people with brain injury in a long-term perspective. The intention was to contribute to the growing but incomplete understanding of the needs of this group of people, and to emphasise the importance of adopting a variety of perspectives when a rehabilitation team draws up plans for intervention.

**Incidence of brain injury in Sweden**

People with brain injury are one of the major patient groups at rehabilitation clinics in Sweden. About 250 people per 100,000 inhabitants are inflicted with a traumatic brain injury every year (Socialstyrelsen, 1999) which gives an incidence of 25,000 new cases each year. Among these young men predominate. Traumatic brain injury is also the most common cause of death after accidents in younger people (Socialstyrelsen, 1999). Among those with a traumatic brain injury, it is estimated that rehabilitation is needed in about 6-20 per 100,000 inhabitants.

In addition, about 30,000 people have a stroke each year in Sweden (Socialstyrelsen, 1997), 20,000 of these are first-time strokes. It is estimated that about one third of those who have a stroke will have residual symptoms that will influence their lives (Sundberg, Bagust, & Terént, 2003). The average age in this group is higher than in those with a traumatic brain injury: only about 20 percent are of working age and about 5% are younger than 45 years (Grimby & Stibrant Sunnerhagen, 1999). There is a tendency, however, for stroke to occur increasingly frequently at a younger age in Sweden. Two recent
studies have found an increased incidence rate of stroke in people of working age (Johansson, Norrving, & Lindgren, 2000; Medin, Nordlund, & Ekberg, 2004).

Rehabilitation after brain injury

Rehabilitation is often used as an umbrella term for different kinds of interventions (medical, psychological, social and vocational) (Höök & Grimby, 2001). In the area of health care there are many different forms of rehabilitation programme. Rehabilitation has been described as “a reiterative, active, educational, problem solving process focused on a patient’s behaviour (disability)” (Wade & de Jong, 2000). Consequently, it is a continuous process that involves the identification of problems and needs, interpretation of cause, implementation of adequate intervention and evaluation of outcome (Stucki, Ewert, & Cieza, 2002; Wade & de Jong, 2000). When the need for rehabilitation has been brought about by a brain injury, the rehabilitation will often need to be extended over several years (Corrigan, Smith-Knapp, & Granger, 1998; Das-Gupta & Turner-Stokes, 2002; Hoofien, Gilboa, Vakil, & Donovick, 2001; Ponsford, Olver, & Curran, 1995) and has been described as consisting of different phases. During the first and acute phase, the focus is on survival, with rehabilitation efforts being concentrated on reducing complications that could occur as a result of the injury (e.g., contracture prevention), (Mazaux & Richer, 1998; Turner-Stokes, 2002) and early intervention such as sensory stimulation (Mazaux & Richer, 1998), and behaviour management (Malec & Basford, 1996).

When the patient is medically stable, a subacute inpatient rehabilitation phase often follows. The focus of the intervention during this period is on addressing impairments and activity limitations (Turner-Stokes et al., 2004), aiming to regain skills required for independent living, such as self-care and mobility, as well as achieving an adequate level of psychological competence (Bullinger et al., 2002; Turner-Stokes, 2002). Intervention can be concentrated on stimulating recovery and/or identifying a means of compensating for any disability (Mazaux & Richer, 1998). The objective in this rehabilitation period is to prepare for a transition from the hospital back into the community, enabling to patient to achieve a way of living as independently as possible.

In a late, postacute phase after injury, when the client has returned back home, a community based rehabilitation phase follows. The aim of the services during this phase is to improve participation in activities in the community (Turner-Stokes et al., 2004) and to assist the patient to learn how to live under the new conditions that prevail in his or her life. Different community re-entry
programs focus on physical, domestic and social obstacles to participation (Bullinger et al., 2002; Mazaux et al., 2002), work or leisure activities and community mobility (Turner-Stokes et al., 2004).

Sometimes there is a need for continuous support for the disabled person and his or her family for a long period of time after the more formalized rehabilitation programme has ended (Das-Gupta & Turner-Stokes, 2002; Mazaux & Richer, 1998; Turner-Stokes, 2002). At times, this support can be found in the natural social net-work, but at other times there is a need for specialist contribution in different respects.

The focus of rehabilitation after brain injury has shifted during the last few decades (Lindberg, 1995; Mazaux & Richer, 1998). From intervention that was concentrated on the restoration of body functions (Ostwald, 1989; Pentland, 1987), originally with a focus on physical dysfunctions, but then later on also including cognitive ones (Mazaux & Richer, 1998), the scope of rehabilitation has expanded to include community based interventions as well, concentrating on long-term consequences like restrictions on participation (Powell, Machamer, Temkin, & Dikmen, 2001). The common experience, that those with brain injury experience problems in generalising what they have learnt in one environment to another, has underscored the advantage of rehabilitation undertaken in the context of the clients’ normal environment (Mazaux & Richer, 1998; Rice-Oxley & Turner-Stokes, 1999).

Teamwork in rehabilitation

The intention of performing an evaluation at a rehabilitation clinic is to get a comprehensive picture of a client’s resources and limitations (Höök & Grimby, 2001), and then to assist the therapist in meeting the various goals of the client. To achieve this, rehabilitation is founded on team-work. Wade and DeJong (2000) define the structure of the rehabilitation service as a multidisciplinary team that works together towards common goals for each patient, while McGrath and Davis (1992) present a model based on an interdisciplinary team work as the ideal structure for rehabilitation. The competence of the team as a whole is applied to solve the problem in the best manner possible in collaboration with the patient and his or her family.

The occupational therapist is usually a member of the brain injury rehabilitation team (Rice-Oxley & Turner-Stokes, 1999). The occupational therapist focuses on the doing of those everyday activities a person finds meaningful and wants or needs to do (Fisher, 1998; Kielhofner, 2002). The
occupational therapy intervention aims to resume the ability to perform these activities or, when this is impossible, to learn alternative ways to carry them out. As the performance of these activities is also dependent on an interaction between the person and the environment, occupational therapy intervention is often concerned with bringing about changes in the environment to enable the individual to participate in his or her preferred life situations.

Brain injury rehabilitation in Sweden

The Swedish health care system

The Swedish health care system is founded on a social insurance system that gives everyone access to the public medical service. Brain injury rehabilitation in a subacute phase is generally located in hospital clinics, but it is organized according to different models in different places, sometimes as inpatient care and sometimes as out-patient attendance at a hospital clinic. This hospital care is often provided in specific departments, such as rehabilitation medicine or geriatric clinics. Clients of working age are treated in rehabilitation clinics and rehabilitation for those who are retired is given in geriatric clinics.

Rehabilitation in a postacute phase is arranged as an outreach service from hospital clinics, or as primary health care. This service, which is often called community rehabilitation, is based on joint action between the medical care services and resources in the community. The competence available within the health care service is combined with that in the employment, social insurance or social welfare-offices in this expanded team. The various public services aimed at helping the individual's rehabilitation are coordinated by the Social Insurance Office. This office also provides individuals who are unable to work owing to illness or injury with economic compensation. This collaboration between the health care service and the community is necessary for the success of community based rehabilitation.

The Swedish government has adopted an ideology called the “working line”, which means that every citizen who is able to work is expected to work to earn a living (Furåker, 1997). In consequence with this, the ambition is to support services that help people who are outside the labour market for some reason to get back to work. Instead of giving passive economic benefits, the ambition is to provide activating services. This emphasis on activity has also influenced the role of occupational therapists in Sweden as the demand for occupational therapy has increased (Evertsson, 2002).

One of the goals for the late rehabilitation phase after brain injury is to evaluate the possibilities of making return to work or of undertaking some
form of education. During inpatient or day care, work skills are often addressed in “work-hardening” programmes (Söderback, Pekkanen, Ekholm, & Schüldt, 1993). In a later phase, most work related rehabilitation includes a trial period of work for which financial compensation is provided to the clients by the social insurance system. As far as possible, the trial is held in the former workplace, but when this proves impossible, arrangements are made for it to be held elsewhere. This period often involves adaptation of work tasks and a reorientation in working life, which is important both for the employer and the employee. It is intended that this trial period will provide an evaluation of the individual’s capacity to work and it is concluded either by the client returning to the labour market or by the allocation of a disability allowance. The return to work can also be supported financially by giving a subsidized wage when the work capacity of the person in question has been reduced below the norm for a healthy employee.

Research in Sweden

Few studies have been conducted of long-term outcome after brain injury in people of working age in Sweden. Most of the research found on brain injury deals with stroke samples where the majority of those afflicted are retired. For example, studies have been conducted that address the effectiveness of stroke rehabilitation units (Glader, Stegmayr, Johansson, Hulter-Åsberg, & Wester, 2001; Grimby & Stibrant Sunnerhagen, 1999; Stibrant Sunnerhagen, 2003), and the cost benefit of stroke rehabilitation (Sundberg et al., 2003). In other investigations, life satisfaction in a long-term perspective after stroke has been reported on (Ahlsjö, Britton, & Murray, 1984; Viitanen, Fugl-Meyer, & Bernspång, 1988; Åström, Asplund, & Åström, 1992), whilst Söderback and Ekholm (1992) described the consequences of brain injury in a sample where half of the group were younger than 65 years and Lindberg (1995) studied long-term outcome after subarachnoid haemorrhage in a sample of mixed ages.

In two investigations of people of working age (Schalen, Hansson, Nordström, & Nordström, 1994; Schalen, Nordström, & Nordström, 1994) psychosocial and economic aspects of outcome after severe traumatic brain injury were investigated and, in a recent study, Vestling and co writers (2003) studied indicators for a return to work in young stroke survivors. A qualitative approach was used by Röding and co workers (2003) when they described young stroke patients’ experience of the rehabilitation process. The results from these studies will be discussed in the following parts of this dissertation.
**Participation**

When adopting a rehabilitation perspective, the focus is not primarily on the underlying pathology, but on the ability of the client to function in his or her life situation. The emphasis, therefore, is on helping individuals with the limitations they experience when trying to perform an activity and in their participation, to enable them to become as active participants in life as possible, enabling them to take part in family life, working life and leisure activities (Höök & Grimby, 2001). The overall goal is commonly expressed as reintegration into the community (Sander et al., 1999; Seale, Caroselli, Becker, Neese, & Scheibel, 2002; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993).

**ICF**

The change of emphasis in rehabilitation from a medically and physically oriented process to a comprehensive, more socially driven service (Wade & de Jong, 2000) has been facilitated by the development of the International Classification of Functioning, Disability and Health (ICF), (WHO, 2001). The ICF attempts to achieve a synthesis between different perspectives of health from a biological, individual and social perspective (Stucki et al., 2002).

The ICF is a classification of human functioning and disability that describes health and health-related conditions. It has recently replaced the former classification, the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980). The ICF has redefined the negative concept of handicap, which was used in the ICIDH, in a more positive way as ‘participation’. In that way, the classification has altered from being a classification of the consequences of disease to a classification of health-related components.

In the ICF the information about health and health-related conditions is organized in two components: 1) body function and body structure and 2) activity and participation. Body function refers to the functions of the body systems, while body structure refers to anatomical parts of the body. Activity means the individual’s performance of a task or activity, and participation denotes the engagement of a person in the social activities that he or she wants or needs to engage in. The consequences of injury or illness are described as impairment of body functions and deviation in body structure. Disturbances on the activity and participation level are denoted as limitations in activity performance and restriction of participation in community activities. The
different classification levels will be referred to in the following description of long term sequel after brain injury in this dissertation

The ICF includes contextual factors in the classification which can enhance or restrict human functioning and the experience of health. An individual’s functional status is considered to be a consequence of an interaction between health conditions and contextual factors (i.e., environmental and personal qualities). The environmental factors in the ICF embrace the physical and social issues that can be decisive for a person’s functioning. Personal qualities, in contrast, consist of the aspects of an individual’s background that might have an influence on their rehabilitation, such as the habits, education, age, experience or gender of the person in question. Personal qualities are not classified in the ICF, but are widely considered to be important for health.

Occupation

Participation in social life includes engagement in different occupations. This dissertation focuses on people’s occupation in different areas of life. One of the core assumptions in occupational therapy is that well-being is promoted when an individual engages in a varied repertoire of occupations combined with appropriate periods of rest (Fearing & Clark, 2000; Meyer, 1977; Reilly, 1962; Wilcock, 1998). Occupation is viewed as having an inbuilt power to enable health and well-being and is, therefore, central both as a goal for and a means of bringing about a successful rehabilitation.

Work

One occupation that has a prominent position in the everyday life of healthy adults of working age is work. In our western society, work is considered as meaningful doing for the individual (Wilcock, 1998) and it has an important role in people’s lives. It shapes persons’ identities. Kielhofner (2002) states that when we work, play and perform ADL tasks, we shape our capacities and our patterns of doing. We identify ourselves with our profession, e.g., we present ourselves as teacher or technician. Another function of work is that it structures time into work-time and time for leisure, thereby giving life its rhythm and meaning (Meyer, 1977). The human being has a need for such structure over the day, with a balance between working time and leisure time (Jahoda, 1979; Kohn & Schooler, 1983; Wilcock, 1998).

Work also has a social dimension, meaning that work fulfils social needs. But we also develop our interactions with others and with our life-world through
the performance of occupations of all types. The feeling of belonging to a group where one is implicated in the values of the group is important for a person (Kohn & Schooler, 1983). In modern society, professional pride is often replaced by identity in a group membership, amongst colleagues, for example, or the identity of being employed at a specific company.

The role that work is believed to have in society as a whole has shifted during the years, and is different from one culture to another. In an analysis of six different theories on the meaning of work, Grenholm (1988) concluded that none of them described work as having a value of its own. The value of work, in the perspective that Grenholm found it being evaluated, consisted of being the means of attaining specific goals like economic independence or achievements that are valuable for another person. In contrast, in their research, Rice, Near and Hunt (1980) stated that work is beneficial in itself, but that work can also be harmful for health if there is an imbalance with the demands of the work not corresponding to the individual’s capacity (Wilcock, 1998). People can feel stress because they have too much to do or because they are being deprived of experience through having too little to do.

**Life satisfaction**

An optimal level of life satisfaction has been described as the desired outcome for the rehabilitation process (A. Fugl-Meyer, Brännholm, & Fugl-Meyer, 1991). Quality of life and life satisfaction are considered to be related to attaining a healthy and productive life-style (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001); they are increasingly being used as the ultimate goals of rehabilitation (Hinckley, 2002; Powell, Heslin, & Greenwood, 2002). The concept quality of life is broad and there are many different definitions in the literature. Flanagan, for example (1982), grouped components of quality of life in five different areas: a) physical and material wellbeing, b) relations with other people, c) social, community and civic activities, d) personal development and e) fulfilment and recreation.

There is confusion between the concepts of quality of life and life satisfaction (Melin, 2003). Meeberg (1993) believed that quality of life has both subjective and objective aspects to it, while life satisfaction is purely subjective and refers to a person’s feelings of happiness in his or her life. A frequently used operationalization of life satisfaction is that an individual is satisfied with a domain of life or with life as a whole when the person’s aspirations and achievements are met (Brännholm, 1992). The quality of life that is focused on as a rehabilitation goal in health care concerns the individual’s wellbeing (Nordenfelt, 1992), and more specifically, how an individual’s quality of life is
affected by their illness, which is called their health-related quality of life (Hariz, 2002; Murphy, Baker, & Ma, 1999).

Campbell (1976) underlines that satisfaction also includes a cognitive aspect, when the individual assesses the current situation against external standards, such as the corresponding situations of relatives or friends, or private levels of aspiration. Corrigan and co workers (2001) describe life satisfaction as a cognitively oriented, subjective judgement of one’s current life situation in relation to one’s own expectations. However, the use of a life satisfaction assessment as a clinical measure requires the respondents to have a certain level of cognitive ability.

There are many different measures of quality of life and life satisfaction. They can be grouped in objective measures (which are outsider-defined, where somebody assesses somebody else’s quality of life) and subjective measures (which are insider-defined, i.e., self reported). Subjective measures are often defined as being life satisfaction instruments. These are used more frequently than objective measures in rehabilitation programmes. Brown and co workers (2000), believed that objective measures tell little about how people with impairments or disability experience their life situation and, therefore, are not useful in rehabilitation planning and evaluation.

**Outcome in brain injury rehabilitation**

Brain injury is associated with numerous impairments, activity limitations and barriers to participation. The injury can result in a broad range of disabilities, which serves to confound the application of standard measures of outcome. Because of this, the measurement of outcome after brain injury is complex (Das-Gupta & Turner-Stokes, 2002). It also differs according to the actual phase of rehabilitation. Measures on the level of body function are mostly appropriate in the acute phase when intervention is focused on body function, and when rehabilitation addresses this. In a postacute phase, in contrast, more emphasis is put on measures on the level of activities, while measures of the level of participation are most useful in the late, community-based rehabilitation phase (Turner-Stokes, 2002).

Outcome varies among other things on the severity of the injury and the localization of the damage (Rice-Oxley & Turner-Stokes, 1999). One criterion often used for inclusion in outcome studies is diagnosis, but this is a blunt instrument for describing the severity of injury. Coma duration and post traumatic amnesia (PTA) are both measures used to give supplementary information about the severity of injury (Rice-Oxley & Turner-Stokes, 1999;
Tate, Perdices, Pfaff, & Jurjevic, 2001), but they are not very specific. Sometimes it is difficult to compare the results from different studies for the reason that limited information is available about the severity of the injury in the samples (Turner-Stokes, 2002), but also because different instruments have been used for the evaluation. Differences in the health care systems between countries are also factors that contribute to these difficulties, as are differences in the social benefits available.

The expected outcome also varies depending on the age of the person afflicted. The important goals for an individual of a younger age are very likely different from those of a person close to retirement. This is partly because the occupational roles in terms of family life, working life and leisure alter throughout one’s life (Kielhofner, 2002). Factors distinguishing younger people from the older people, for example, are differences relating to social issues such as marital stress and child-care (Rice-Oxley & Turner-Stokes, 1999).

In addition to this, different perspectives are taken of recovery after brain injury, as mentioned, with the “outsider” perspective being that taken when recovery is measured by others and the “insider” perspective being when the outcome is that experienced and reported by the person afflicted with the brain injury (Powell et al., 2001). In recent years, interest in the individual’s own experience has grown. Studies aiming to capture the insider perspective have been conducted more frequently, using self-reporting methods such as interviews or questionnaires for data collection.

In Sweden, the community has a responsibility for its inhabitants both to provide medical care and to ensure that sickness compensation is available. In this respect, an “objective” outsider-defined perspective is of more interest than an insider one. For example, the Social Insurance Office, which has the responsibility of coordinating services for rehabilitation and for employability assessment, will base its assessment of a person’s needs on the professional opinions it receives rather than on an insider’s perspective. From this economic perspective, it is imperative that “objective” criteria be put in place to evaluate people’s ability to work and to evaluate cost-benefit aspects of embarking on different rehabilitation programs.

Long term sequel after brain injury

The long-term outcome of patients with brain injury has been studied more frequently during the last decade. The time taken for the follow-up to be conducted in the studies found in the literature survey conducted for this dissertation varies from one year after the injury to 20 years after it. Some
longitudinal studies have focused on the changes in the recovery over time. From a general point of view, there are more studies on stroke than traumatic brain injury (Das-Gupta & Turner-Stokes, 2002). Some samples contain both stroke patients and those with traumatic brain injury. However, there has been little attention paid to long term outcome, in terms of, for example, the rate of return to work in young stroke survivors. Among studies of people of working age, there are considerably more follow-ups on traumatic brain injury.

The overall goal for brain injury rehabilitation in a late phase has been expressed as achieving an acceptable level of life satisfaction (Bethoux, Calmels, & Gautheron, 1999; Bullinger et al., 2002; Mazaux et al., 2002). This is a very widely formulated goal, and one which is difficult to evaluate. Re-entry into the community is often used as a more distinctly formulated final goal (Bullinger et al., 2002; Mazaux & Richer, 1998; Powell et al., 2001; Turner-Stokes et al., 2004), and is taken to be, for example, reintegration into family life and working life (Das-Gupta & Turner-Stokes, 2002; Ponsford, Olver, & Curran, 1995; Willer et al., 1993). The measures of outcome most commonly reported are functional and psychosocial status, living status, vocational status and life satisfaction (Malec & Basford, 1996).

Body function

Outcome data on the level of body function in the late phase of recovery is used to explore the population. In some studies of long-term outcome, measures of the level of the body function are used to evaluate indicators for a return to work and life satisfaction (Malec & Basford, 1996; Vestling et al., 2003).

In a review of the literature on rehabilitation after traumatic brain injury in adults, Mazaux and Richer (1998) summarize that about 40% of people with severe TBI still had persisting motor disabilities at the end of postacute rehabilitation. Fifty percent of these suffered from cognitive impairment and 60% from psychological impairment. In a 10–20 year long-term follow-up of people with moderate to severe brain injury, Hoofien and co-workers (2001) found severe long-term psychiatric problems, psychomotor slowness and difficulty in information processing to be the main problems.

It is generally agreed that physical impairments have less limiting influences on outcome, e.g. on a return to work, than cognitive and behavioural impairments (Ponsford, Olver, Curran, & Ng, 1995), even if the impact of physical impairments can not be neglected (Hillier, Sharpe, & Metzer, 1997). This is even more evident in longitudinal studies. In a study of the subjective
perception of recovery after brain injury for example, Powell and co workers (2001), found, that even if physical concerns were dominant during the first year after injury, they decreased over time, while the awareness of cognitively related concerns increased with time. A similar result is presented by Olver and co writers (1996), who reported a small increase in complaints of cognitive, behaviour and emotional difficulties between 3 and 5 years post-injury.

Activity and participation

Outcome related to the level of activity is mostly reported as independence in daily activities (Malec & Basford, 1996). On a relatively short perspective, one year after stroke, Clarke, Black and co workers (1999) found that dependency in day-to-day physical functioning (such as self-care, mobility and locomotion) imposed restrictions on the participants’ valued life activities. A more positive outcome was presented by Kersten and co writers (2002), who found that 60% of a group of young stroke survivors reported good mobility.

Recovery over time has been described by Olver and co workers (1996) in a longitudinal follow-up study where they found a significant increase in independence in performing domestic and community activities between 2 and 5 years after injury. This outcome showing relative independence being achieved in a very long-term perspective is supported by some authors (Hoofien et al., 2001; Mazaux, De Seze, Joseph, & Barat, 2001), but is contradicted by Dawson and Chipman (1995) who found, in a Canadian follow-up study conducted 13 years after brain injury, that more than half (66%) of the sample still needed assistance with some activities of daily living.

The outcome in terms of the level of participation reported in the literature represents a return to work, integration in social life and participation in domestic life (Turner-Stokes, 2002). A return to work is estimated to be one of the most important factors for re-entry into the community (Mazaux & Richer, 1998; Teasell, McRae, & Finestone, 2000; Wagner, Hammond, Sasser, & Wierciszewski, 2002). The rates of return to work reported vary between samples, largely depending on the severity of the injury, the time after injury at which the follow-up took place (Mazaux & Richer, 1998; Wozniak & Kittner, 2002), and variations in the way in which work was defined, for example, whether part time work was included (Teasell et al., 2000; Wagner et al., 2002; Wozniak & Kittner, 2002).

One explanation for this diversity in work re-entry rates could be that a return to work will represent different things to different people: e.g focusing on independence in the work situation, the financial side of employment, financial support other than salary, and full-time or part-time work (Malec & Basford,
Furthermore, in some studies a return to work is taken quite simply to be equivalent to the person with the brain injury being estimated to be able to perform work, which is not the same as having demonstrated that he can make a successful return to work, and in other investigations, performing domestic work is equated with having made a return to work. Cultural differences between countries are probably another factor behind the varying results. For example, in countries where voluntary occupations are common, it is easier to find meaningful occupations. And in addition to the above, variations in the social insurance systems from one country to another, including health care provision and the labour market will have a great impact on the vocational outcome.

Returning to work
The use of return to work as an outcome measure is dependent on age, but as most studies found in the literature review on stroke conducted in conjunction with the work being presented here relate to older people, most of whom have retired, few studies on stroke survivors returning to work were identified.

In a review of outcome after brain injury (Malec & Basford, 1996) found that, when the studies are averaged, more than half of the people included returned to work, however from one study to another there was tremendous variation (9-79%). Furthermore, in the same review, the authors noticed a tendency for the re-entry rates to decline over the years, which they suggest could depend on higher demands in society and fewer suitable jobs being available for people with residual symptoms after brain injury. In combination with this, the development of acute medical care has resulted in a greater number of more severely injured persons surviving nowadays. One of the studies included in the review which is of particular interest to the research reported here was a Swedish study of traumatic brain injury, (Schalen, Nordström et al., 1994), in which it was reported that 70% of those who had received such an injury had gone back to work or education at the time the investigation took place, which was 5 – 8 years after the injury had occurred.

A common finding was that a considerable proportion of those who had returned to work had had to change the tasks they performed and/or reduce their working hours. For example, Neau and co writers (1998) found that, of those back in work one year or more after their injury, 26% needed their work tasks to be modified. Similarly, in a Swedish study, Vestling and co workers, (2003), reported that about 50% of those back at work had changed their work assignments and/or changed their working hours. The corresponding figures from an earlier study (Söderback, Ekholm, & Caneman, 1991) were 20%. In an investigation taking a very long-term perspective, Hoofien and co workers
(2001) found that many of those who were back at work 10-20 years after their injury were performing unskilled work tasks. In their review article referred to previously, Mazaux and Richer (1998) found that several authors also describe how the participants experience difficulty learning a new job after being inflicted with brain injury.

Accomplishing a successful transfer between an education and a work has also proved to be difficult after brain injury (Olver et al., 1996). Few of those who had been studying at the time of their injury were able to get a job after they had completed their studies.

Besides experiencing marked difficulties returning to the labour market after a brain injury, there is the issue of stability in employment. In this respect, several studies have reported obstacles to people keeping their employment after brain injury (Hoofien et al., 2001; Olver et al., 1996).

Social integration

The social life of the injured person was often reduced as a consequence of the injury, and the choice of leisure occupations had changed, to involve more passive occupations than before the injury (Conneeley, 2002; Dawson & Chipman, 1995; Finset, Dyrnes, Krogstad, & Berstad, 1995; Hoofien et al., 2001; Mazaux & Richer, 1998; Ponsford, Olver, & Curran, 1995). A low level of social functioning was found in young patients one year after the onset of stroke (Clarke et al., 1999; Kersten et al., 2002) and in a long-term perspective, Corrigan and co workers (1998) found a stable, but low, level of societal functioning in the first five years following brain injury. This result is in line with other long-term follow-ups (Mazaux et al., 2002; Olver et al., 1996). In a study conducted in Sweden, Schalen and co writers (1994) reported that 40% still had a problem with their intra personal relationships and 20-30% had problems related to their leisure activities five to eight years after receiving their injury.

Domestic life

In their review, Mazaux & Richer (1998) found that family life was disturbed after brain injury. This is supported by Finset and co workers (1995) who described how family members experienced considerable changes in their lives after the injury. A significant improvement over time was found (Corrigan et al., 1998), however, when home integration was compared at about 3 and 5 years post brain injury. However, Hoofien and co writers (2001) described how, in a very long-term perspective (14 years after injury), domestic life still was affected.
Quality of life or life satisfaction

The quality of life dimension has been included as a measure of outcome after brain injury and an increasing amount of attention has been put on quality of life or life satisfaction as an overriding outcome in a late phase by (Bullinger et al., 2002; Das-Gupta & Turner-Stokes, 2002; Mazaux & Richer, 1998; Neau et al., 1998; Vestling et al., 2003; Wozniak & Kittner, 2002). Brown and Vandergoot (1998) reported a tendency for more severely injured people to estimate their life satisfaction as being good or unaffected, while people with mild injury seemed to have the experience of a more negative influence on their life satisfaction after brain injury. This is in accordance with Koskinen (1998), who found that those who had more grave damage had a rather high quality of life despite the severe brain injury. A Swedish study of brain injured people has shown a decreased satisfaction with life after injury. All domains but those of financial situation and contact with friends were significantly lower than for a non-disabled sample (Bränholm, Lundmark, Månsson, & Fugl-Meyer, 1996). Schalen and co workers (1994) reported that 15% of a sample inflicted with a brain injury 5-8 years earlier, considered their quality of life so low that the situation was difficult to handle. From their study of stroke victims, Neau and co workers (1998) reported that quality of life was poor in 40% of the sample. One year or more after the onset of the stroke, one third of the participants complained of problems with psychosocial implications.

Predicting outcome after brain injury

It is of a great interest in clinical practice to find tools for rehabilitation planning that are based on knowledge of the rehabilitation process after brain injury. As a result, there is a longstanding tradition of research trying to find predictors of outcomes. Pre-injury variables as well as data related to the injury and from the subacute rehabilitation phase have been examined to determine their ability to predict long-term outcome in terms of work re-entry and life satisfaction. In their review of the literature on postacute brain injury rehabilitation, Malec and Basford (1996) found that functional measures were more predictive of occupational outcome than cognitive measures. For example, independence in ADL has shown to be a robust predictor of return to work (Malec & Basford, 1996; Wozniak & Kittner, 2002).

There is no full consensus among researchers about the predictive value of different variables, even if there is a tendency that the severity of the injury, the age at the time of injury, pre-injury work-related skills and some specific cognitive impairment resulting from the injury, such as memory problems are often reported as being significant for a successful work re-entry or a failure to
return to work. Difficulties comparing the results from different studies as has been mentioned above, in combination with methodological limitations underlie this lack of knowledge. The fact that every person is a unique human being with specific resources and limitations and that no two brain injuries are alike does not make research in this area particularly straightforward.

When a person is inflicted with such a serious illness as a brain injury, it does not only affect the individual’s own life but also the family and other people. Support from significant others very likely is of great importance, for the person inflicted with a brain injury, during the rehabilitation process. Likewise, support from the team to the significant others is one of the big needs in rehabilitation. In this dissertation, however, this aspect of brain injury rehabilitation will not be addressed.
AIMS OF THE DISSERTATION

The general purpose of this dissertation was to study the long-term outcome after brain injury with a special emphasis being placed on everyday domestic and productive occupations and their connection to life satisfaction. The aim was also to describe and attempt to understand the lived experience of the consequences of brain injury in these respects.

The specific aims were:

- To evaluate the value of occupational therapy assessments to predict a return to work after brain injury (Study I).

- To describe the experienced life satisfaction of a person after brain injury in a long term perspective and to study the significance of a return to work on life satisfaction (Study II).

- To explore the meaning of work for people with brain injury (Study III).

- To describe participation in everyday occupations in a late phase of the recovery after brain injury and to evaluate the influence of participation on life satisfaction (Study IV).
SUBJECTS AND METHODS

Subjects

The subjects involved in the studies included in this dissertation were people with acquired brain injury who had been referred to the Department of Rehabilitation Medicine at Gävle-Sandviken Hospital, Sandviken, Sweden.

The catchment area for the department is the county of Gävleborg. One cause of brain injury was trauma, from, for example, traffic accidents, falls or horse-riding accidents. Another major cause of injury was vascular incidents. In addition, a smaller group had brain injuries brought about by some other reason, such as anoxia or infection. All participants were in a late phase of their recovery after injury, and were living in the community at the time of the research. Information about the diagnosis and the participants’ age at the time of their inclusion in the studies are given in Table 1.

Study I

The sample in Studies I and II consisted of people who had been consecutively admitted to an outpatient rehabilitation programme over a two year period. The admission criteria for the programme were that they needed community based rehabilitation after suffering from a brain injury and that they were of working age or of an age at which one would normally participate in full-time education in compulsory education or at Upper Secondary School. Some of the participants had received subacute rehabilitation as inpatients after injury, while others had not received any rehabilitation services before their admission to this rehabilitation programme. They were all living in the community and their rehabilitation goals were integration in domestic life, work and social activities. Additionally, there was a need for support to their families and/or other significant persons.

The data collection for Study I was carried out a minimum of two years after the injury had occurred. The sample was heterogeneous in terms of the time post injury, with the range being from 2 to 12 years after the injury. Descriptive data relating to the participants and their injuries is shown in Table 1.
Table 1. Basic characteristics of participants in Studies I-IV

<table>
<thead>
<tr>
<th>Study No.:</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
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<tr>
<td>N</td>
<td>54</td>
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<td>10</td>
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<td>-vascular</td>
<td>10</td>
<td>9</td>
<td>6</td>
<td>109</td>
</tr>
<tr>
<td>-other</td>
<td>6</td>
<td>3</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Sex:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male/Female</td>
<td>35/19</td>
<td>22/14</td>
<td>5/5</td>
<td>94/63</td>
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<tr>
<td>Age at follow-up in years: mean (range)</td>
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</tr>
<tr>
<td>Follow-up 1</td>
<td>35 (17-56)</td>
<td>37 (18-56)</td>
<td>39 (33-60)</td>
<td>51 (22-65)</td>
</tr>
<tr>
<td>Time of follow-up in years: mean (range)</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Follow-up 1</td>
<td>5,7 (2-12)</td>
<td>3,1 (2,2-3,9)</td>
<td>3,2 (1,5-5,5)</td>
<td>5,4 (2-19)</td>
</tr>
<tr>
<td>Data collection methods:</td>
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<td>- questionnaire</td>
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<tr>
<td>- interview</td>
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<td>x</td>
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</table>

Study II

In Study II, the subjects included in Study I were followed-up using a longitudinal design. The time span used in Study II describes the average time between admittance to the rehabilitation programme and the follow-up. The data used for Study II were collected at two points of time, the first at an average of three years after admittance to the programme and the second at an average of six years after admittance. The sample consists of a heterogeneous group as far as time after injury is concerned, but it represents an ordinary set of clients at an outpatient rehabilitation programme. The selection for this sample is not based on a specific time after injury, but on a common need for rehabilitation. In this longitudinal study, 13 subjects were excluded at the first follow-up and an additional seven subjects at the second follow-up. Therefore the sample was comprised of 36 people. There were more men than woman and more people with traumatic injuries than vascular injuries found in the non respondent group (Table 1). PTA did not differ between groups. Likewise, when we examined the work status for respondents and non respondents, no predominance was found in the non respondent group for failure to return to work.
Study III

The respondents in Study III were all patients in the outreach rehabilitation programme of Gävle-Sandviken Hospital. The criteria for participation were that all participants had some experience of being back in work for a period of work trial after injury and that they had the verbal ability required to participate in an interview.

Study IV

The subjects in Study IV had been consecutively admitted to the Department of Rehabilitation Medicine after a brain injury. They had been patients in inpatient, day-care and/or outpatient rehabilitation programmes. The criterion for participating in this study was that more than two years had passed after the injury had occurred. Slightly more than 70% of those who had got the mailed questionnaire answered. Among those who did not answer a predominance of traumatic brain injury was found. A higher percentage of men were also found in the group of non respondents compared to those who did answer.

Data collection methods

An overview of the main data collection methods used in the studies included in this dissertation is presented in Table 1.

Medical records

The demographic data required for Studies I, II and IV were collected from medical records. In these studies, the diagnoses and the extent of post-traumatic amnesia (PTA), (Russell, 1932) were used to describe the severity of the traumatic brain injury. The information relating to the patients’ post-traumatic amnesia used in Studies I and II was collected from the patients’ files, while in Study IV the participants were asked whether they had had a period of amnesia after their injury and, if so, the length of time that this had endured. The self-report format used for the PTA information has been used in other studies when data from medical records were not available (Hellawell, Tayor, & Pentland, 1999). McMillian (1996) found a high level of agreement between prospective and retrospective reports of PTA and concluded that retrospective measurement of PTA is a valid method. However, it should be noted that in their study they used a more structured questionnaire than the one used in this follow-up.
In Study I, data from the occupational therapy assessments were collected retrospectively from the medical records. The data originated from the assessments used by the two occupational therapists at the initial evaluation of the client at the time when the client was admitted to the rehabilitation programme. The assessments included were:

**The Rivermead Behavioural Memory Test (RBMT)**, (Wilson, Cockburn, Baddeley, & Hiorns, 1988) was used to assess memory. The RBMT has proven to be an ecologically valid test for everyday memory problems (Towle & Lincoln, 1991). A Swedish version, translated by Christer Larsson, an Umeå-based occupational therapist, was used. This translation was made in cooperation with the publisher. The original version of this assessment is valid and reliable (Wilson et al., 1988).

**The Rivermead Perceptual Assessment Battery (RPAB)** (Edmans, 1987) was used to assess visual perception and attention. This assessment battery was designed for use by occupational therapists. The validity and reliability of this test has been demonstrated (Whiting, Lincoln, Bhavani, & Cockburn, 1985). This assessment was translated into Swedish by occupational therapists at the Department of Rehabilitation Medicine, Gävle-Sandviken Hospital and is used with the consent of the publisher.

“Sunnaas’ test for apraxia” was used to test for apraxia (Björneby & Reinvang, 1985). This assessment consists of a selected set of items testing for apraxia taken from conventional neuropsychological tests. The test was compiled at Sunnaas Hospital, Oslo, Norway. It has not been specifically tested for validity and reliability.

IADL was assessed using the **Assessment of Motor and Process Skills (AMPS)** (Fisher, 1997). The AMPS is an observational assessment of the motor and process skills underlying occupational performance. The instrument contains 16 motor and 20 process skill items that are evaluated when a person performs ADL tasks that he or she has chosen from among the standardized tasks available in the AMPS. The motor skills are the observable actions the client uses to move either him- or herself or to move objects during the performance of ADL tasks. The process skills are the observable actions used by the client to select appropriate tools and materials for the task in hand and to organise his or her performance logically over time to complete the task effectively, thus, process skills relate to the many small units involved in occupational performance. The performance is scored according to a 4-point scale. The AMPS raw scores are transformed to ‘person ability measures’ using many-faceted Rasch analysis, which makes it possible to adjust for the
Subjects and methods

difficulty of the item, the challenge a task poses and rater severity. The AMPS has proven to be valid and reliable (Fisher, 1997). It has also been validated for use in a Swedish population (Bernspång & Fisher, 1995).

The Functional Independence Measure (FIM) was used to measure PADL. The FIM is an instrument which is valid and reliable (Granger, Cotter, Hamilton, & Fiedler, 1993; Hamilton, Laughlin, Fiedler, & Granger, 1994) and that was designed to assess a person’s level of activity limitation in terms of the need that the person has for assistance. It contains two subsets of items, each comprising a scale, with one set of items relating to motor abilities (13-items) and the other to cognitive abilities (5-items). The motor scale assesses self-care, sphincter control, mobility and locomotion, and the cognitive scale assesses communication and social cognition. Each item is rated according to a seven-point scale, where total dependency has a score of 1 and complete independence a score of 7. The answers can be dichotomised into independence (6 and 7 on the rating scale), or dependence on personal assistance (1 to 5 on the rating scale) in accordance with the manual. The Swedish version of the FIM has been introduced and evaluated (Grimby et al., 1996). In Study I, the FIM was used as a questionnaire. The use of FIM as a questionnaire has been described by Greenspan and co workers (1996).

In Study IV, data on dependence in ADL activities measured by the FIM were taken as descriptive information about the severity of injury. The FIM data used in this study had been collected in the traditional way by the rehabilitation team as a whole.

Questionnaire

In Studies I, II and IV a mailed questionnaire was used for the data collection. In Study I, a minor part of the data was gathered from a questionnaire, while in the other two studies this formed the main means of data collection. The use of questionnaires in a population of people with acquired brain injuries has been the subject of some discussion (Hellawell et al., 1999; Sbordone, Seyranian, & Ruff, 1999). The result of this discussion is that although the use of questionnaires is valid for brain injured people, particular caution must be taken when developing a questionnaire to ensure that it is adapted to the common disabilities following brain injury, e.g., memory problems and concentration. Thus, the questions have to be clear and easy to follow and the scoring/response system should not be too complicated. A balance between the wish to obtain comprehensive information from a questionnaire and the difficulty of presenting respondents with too extensive a questionnaire must be attained. With this in mind we chose to design relatively short questionnaires
that included questions from different instruments or checklists, which were considered to be suitable for this population. An expanded version of the LiSat-11 instrument (A. Fugl-Meyer, Melin, & Fugl-Meyer, 2002) was used in Studies II and IV for the questions about life satisfaction. The LiSat-11, which is an expansion of the LiSat-9 (A. Fugl-Meyer et al., 1991), has been used in comprehensive studies of public health in Sweden (K. Fugl-Meyer, 1996). The checklist consists of eleven items, one characterising life as a whole and the others characterising different domains of life. It uses a six-point scale ranging from 1 (very dissatisfied) to 6 (very satisfied). In some of the analyses a dichotomy is used where 1-4 is classified as not being satisfied and 5-6 as being satisfied. The version used in Studies II and IV in this dissertation consists of 12 items, including one item about instrumental ADL (Hariz, Lindberg, Hariz, & Bergenheim, 2003). Good validity and reliability have been reported for the original (LiSat-9) version (A. Fugl-Meyer et al., 1991).

A checklist about job satisfaction (Simovici, 1976) was used in Study II. The items in this checklist represent both intrinsic and extrinsic work satisfiers. Intrinsic work satisfiers are those that are inherent in the job itself, such as achievement, recognition, work-status and responsibility. Extrinsic work factors are, e.g., company policy, supervision, working conditions and salary.

The mailed questionnaire in Study II also included an inventory of subjective symptoms after brain injury. This inventory has been developed through the clinical practice at the Department of Rehabilitation Medicine and is based on common complaints from clients with brain injury.

The Reintegration to Normal Living (RNL) Index (Wood-Dauphinee & Williams, 1987) was used in Study IV. The RNL Index consists of 11 statements addressing mobility, ADL, leisure and social activities, family role and perception of self. The participants were asked to score each item according to a four-grade scale where 1 represents “does not describe my situation” and 4 “does fully describe my situation”. The items form two subscales: “daily functioning”, consisting of eight items, and “perception of self”, consisting of three items. The subscales have been found to be more sensitive to change than using overall scores. The RNL Index has also proved to have good psychometric properties (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988) and has been found to be suitable for the self-report format (Carter & Buckley, 2000). A translation has been made in a forward-backward translation procedure by Maria Larsson Lund, Boden, Sweden, in cooperation with professional translators to develop a Swedish version equivalent to the original Canadian version.
The questionnaires included questions about the work or educational status (working or not, full-time or part-time job, type of economical compensation) and the civil status of the individual participants at the time of the follow-up. The questionnaire used in Study IV also included a question about amnesia after injury.

Interview

In study III, all the participants were interviewed about the meaning of work. The interviews were guided by a few open-ended questions. An interview guide was prepared in which each respondent was asked to recount in a narrative manner his or her experience of the meaning of work after brain injury (Kvale, 1997). Attendant questions were used to get a more detailed narrative. The focus of the questions was the respondent’s experience of the content of work before and after the brain injury, the experience of having a decreased work capacity after injury and the meaning of work in general. They were also asked about how they perceived their future prospects of working life. Each interview took about one hour to carry out.

Data Analyses and Designs

Statistical Analyses

The choice of the type of statistics applied was dependent on the size of the sample and ordinal data. In almost all instances the calculations were made by the statistical software SPSS for Windows NT. The statistical methods used are presented in Table 2. In all analyses the level of statistical significance was set to $p \leq 0.05$.

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study IV</th>
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<tbody>
<tr>
<td>t-test</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Chi2</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Logistic regression</td>
<td>X</td>
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<tr>
<td>Marginal homogeneity test</td>
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<td>X</td>
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</table>

The population in Study I was divided into two groups according to work-related status of the individuals, i.e., whether they were back at work or in education or not back at work or engaged in education. The two groups were compared with reference to the different variables and the difference between the groups was assessed by conducting either a two-tailed t-test or Chi2 test.
Logistic regression was used in Study I to identify the variables that, when taken together, formed the best model for predicting a return to work or full-time education after brain injury. This method was also used in Study IV to analyse the association between life satisfaction and the RNL subscales “daily functioning” and “perception of self”. The association were expressed as odds ratios and 95% confidence intervals. Logistic regression is used when the outcome variable is dichotomous and the independent variables include both numerical and nominal data.

In Study II a non parametric test for two related samples, the Marginal Homogeneity Test, was used to compare data collected at two different points in time from the same sample. The test is an extension of the McNemar test and is used when data is multinomial, i.e., it has more than two categories of response. The sample was divided into two groups according to the reported satisfaction with life as a whole to calculate any differences between the groups in terms of demographic data and subjective symptoms. Another grouping was made according to the work status of the individuals, meaning whether they were working, including undertaking education, or not, in order to calculate differences between the groups in terms of life satisfaction. In both cases a Chi-Square test was used.

**Empirical, phenomenological, psychological method, EPP**

A phenomenological approach was used in the third study in order to describe and understand the experience of the meaning of work after brain injury. The transcribed interviews were analyzed using a modified form of the EPP-method in which the psychological perspective was replaced with an occupational therapy perspective, that being a focus on the participants’ occupational experiences in their daily lives. The aim of the analysis was to discover the essential (dimensions concerning the) characteristics of the phenomenon i.e., the meaning of work after brain injury based on data reflecting the participants’ life-world experiences. The EPP method attempts to be as open and presupposition-free as possible; the researchers’ pre-existing theoretical understanding, such as bio-medical knowledge about brain injury, was, therefore, bracketed.

The data were analyzed in five steps. In the first step the interviews were read with the intention of gaining a better understanding of the participants’ original experience and getting a good grasp of the material. In the second step, each protocol (i.e, interview) was divided into smaller units of meaning each time a shift was found in the meaning of the data.
In the third step, the meaning units thereby obtained were interpreted and transformed into the researcher’s language. The purpose of this step was to move from the specific facts to the meaning embedded in them. The analysis continued in the fourth step by synthesizing the transformed meaning units into a summary for each protocol (Karlsson, 1993). In the fifth step all the summaries were compared with the intention of identifying a general meaning structure for all protocols, i.e., the main characteristics that, when taken together, represented the phenomenon. Throughout these last two steps of the analysis the researchers repeatedly returned to the original protocols to validate their interpretations. During the analysis the authors also continuously discussed several possible interpretations before the final interpretation was established.

The validity of the findings, in terms of the “horizontal consistency of the interpretations” (Karlsson, 1993), was examined by exploring whether the interpretation of each of the interviews was consistent with the meaning uncovered “across” all interviews. And finally, to examine the trustworthiness of the interpretation, this was also subject to peer examination by a group of experienced researchers and clinicians.

**Ethical considerations**

Approval was granted by the director of the clinic for Study I, and by Gävle-Dala Ethical Committee for Studies II and III (dnr 98133-47 and 2000339-47). The Ethical Committee, Uppsala University (dnr 02-297) approved Study IV. The subjects who participated in Study I, II and VI were offered written information about the study and the participants in Study III were given verbal information. Informed consent was sought from the subjects in all studies.
RESULTS

Occupational therapy assessments as predictors of return to work after brain injury

The results presented in Study I showed that the occupational therapy assessments used in this study were valuable in predicting a return to work or return to education after brain injury. A statistically significant difference was found between those who were back at work or in education and those who were not back for specific aspects, these being: memory as measured by the RBMT ($t = 6.529, p < 0.0001, df 50$), visual perception as measured by the RPAB ($t = 3.416, p = 0.001, df 50$) and praxis function measured by the Sunnaas test for apraxia ($t = 3.428, p = 0.001, df 50$). It was also found that those in need of assistance with PADL as measured by the FIM were significantly less likely to have returned to work or become a student ($\chi^2 = 5.650, p = 0.017, df 1$). The scores on all of the above mentioned items were higher for those who were back at work or studying.

The variables for which a significant difference was found were tested in different combinations using logistic regression with the intention of identifying the best prediction model. We found that measures relating to body function in combination with those concerning the level of activity provided the best prediction model for return to work after brain injury. Memory dysfunction (RBMT) in combination with a reduced ability to perform PADL (FIM) explained 58% of the variance of the outcome in the sample. This calculation is based on 47 valid observations (due to missing data). The predictive value was even more apparent in a sub-sample ($n = 21$), where a model that included RBMT, FIM and AMPS motor ability scores explained 79% of the variance of the outcome. The antithesis — that persons with no such limitation returned to work or education — was not as reliable.

Furthermore, data relating to the type of disorder as the diagnosis and PTA were tested for their ability to predict the likelihood of the participant making a successful return to work but they could not distinguish between those who were successful in returning to work or education and those who were not in this study.

Life satisfaction

The reported life satisfaction in Studies II and IV for life as a whole and for the different domains of life was low in comparison to that for a healthy
population of adult Swedes. A significant difference was found in the level of satisfaction between the two groups of brain injured people and the healthy reference group, with the exception of the domain “Financial situation”, where the level of satisfaction was almost the same for all groups (Table 3). Data on the domains: IADL, and physical and mental health was not available for the reference group.

Table 3. Life satisfaction for the participants in Studies II and IV all of whom have suffered a brain injury some time before and data for comparison from a reference group of healthy Swedes (K. Fugl-Meyer, 1996).

<table>
<thead>
<tr>
<th></th>
<th>Reference group</th>
<th>Study II</th>
<th>Study II</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Satisfied %</td>
<td>Satisfied %</td>
<td>Satisfied %</td>
<td>Satisfied %</td>
</tr>
<tr>
<td></td>
<td>(p value)</td>
<td>(p value)</td>
<td>(p value)</td>
<td>(p value)</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>70</td>
<td>31</td>
<td>50</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>(0.000)</td>
<td>(0.010)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>96</td>
<td>75</td>
<td>78</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>(0.000)</td>
<td>(0.000)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td>58</td>
<td>33</td>
<td>42</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>(0.003)</td>
<td>(0.049)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Vocational situation</td>
<td>53</td>
<td>23</td>
<td>30</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>(0.001)</td>
<td>(0.012)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Financial situation</td>
<td>39</td>
<td>31</td>
<td>28</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Sexual life</td>
<td>56</td>
<td>23</td>
<td>36</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>(0.000)</td>
<td>(0.017)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Partnership relations</td>
<td>79</td>
<td>32</td>
<td>42</td>
<td>53</td>
</tr>
<tr>
<td></td>
<td>(0.000)</td>
<td>(0.000)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Family life</td>
<td>81</td>
<td>56</td>
<td>48</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>(0.000)</td>
<td>(0.016)</td>
<td>(0.000)</td>
<td></td>
</tr>
<tr>
<td>Contact with friends</td>
<td>67</td>
<td>42</td>
<td>49</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>(0.001)</td>
<td>(0.022)</td>
<td>(0.000)</td>
<td></td>
</tr>
</tbody>
</table>

No significant difference was found in Study II between those who were satisfied with life as a whole and those who were not for the demographic
variables age, gender, civil status, type of occupation and diagnosis. However, in Study IV, age was found to be a significant confounder for life satisfaction (OR 1.051, CI 1.015 – 1.089, p = 0.006).

The second follow-up, conducted for Study II included an inventory of subjective symptoms. From this, it was found that those who were not satisfied with life as a whole reported having a greater number of subjective symptoms than those who were satisfied. A Chi2 test revealed a significant difference between groups for the subjective symptoms reported, such as problems with using one’s initiative (p = 0.019, Chi2 = 9.952, df = 3), depression (p = 0.027, Chi2 = 9.180, df = 3), concentration (p = 0.048, Chi2 = 9.517, df = 4), dizziness (p = 0.010, Chi2 = 9.128, df = 2), sleep (p = 0.040, Chi2 = 10.024, df = 4), sensitivity to cold (p = 0.040, Chi2 = 8.292, df = 3) and reading (p = 0.034, Chi2 = 8.698, df = 3).

Life satisfaction over time

In Study II the reported life satisfaction at two different points in time, three and six years after admittance to an outreach rehabilitation programme, was compared. No significant difference was found between the first and the second follow-up for satisfaction with life as a whole, tested with the Marginal Homogeneity test. However, the domain instrumental or domestic activities of daily living (IADL), such as cleaning, cooking, shopping, revealed a significant difference (Std MH Statistic –2.400, p = 0.001) between one follow-up and the next, with more people being satisfied at the first follow-up than the second.

Life satisfaction and work

To assess whether life-satisfaction differed for those who were working or studying and those who were not, the subjects in Study II were divided into two groups: those who were active in this respect and those who had neither returned to work, nor taken up studying. The dichotomized LiSat scale was used to assess the magnitude of any differences. No significant difference was found between the groups concerning the overall life satisfaction, either at the first or at the second follow-up. Neither was there a difference between those who were employed full and part-time in terms of the satisfaction the participants reported with life as a whole.

At the first follow-up, a significant difference was found between groups for the domains mental health (p = 0.042, Chi2 = 4.117, df = 1), contact with friends (p = 0.037, Chi2 = 4.359, df = 1) and financial situation (p = 0.015,
Chi2 = 5.981, df = 1), with more subjects being satisfied with these domains of life in the group that had returned to work or education than in the other group. At the second follow-up a significant difference was found for the domain IADL ($p = 0.037$, Chi2 = 4.359, df = 1), with more people in the group comprised of those who were active in the job market or of studying, being satisfied. No significant difference was found for the other domains at the second follow-up.

Life satisfaction and participation

The RNL Index was used in Study IV to measure the subjectively rated level of participation in different life situations. In separate analyses of the variables, we found that the RNL subscales, “daily functioning” and “perception of self”, had a significant influence on satisfaction with life as a whole. Furthermore, the impact of one of the two variables was modified by the level of the other (the interaction term was statistically significant, $p=0.002$). Changes in the participants’ “perception of self” were estimated to have a great positive effect on their level of life satisfaction, irrespective of their level of “daily functioning”, but changes in “daily functioning” had a reverse effect on life satisfaction except for those situations where the participant had the highest level of “perception of self”. The interaction should be interpreted as the effect of one of the variables being modified by the level of the other, (Table 4).

Table 4. Interpretations of odds ratios of being satisfied with life as a whole for the case of interaction between daily functioning and perception of self.

<table>
<thead>
<tr>
<th>Level of perception of self</th>
<th>Odds ratios</th>
<th>Level of daily functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>One unit difference in daily functioning</td>
<td>One unit difference in perception of self</td>
</tr>
<tr>
<td>1</td>
<td>0.129</td>
<td>0.975</td>
</tr>
<tr>
<td>2</td>
<td>0.317</td>
<td>2.392</td>
</tr>
<tr>
<td>3</td>
<td>0.778</td>
<td>5.865</td>
</tr>
<tr>
<td>4</td>
<td>1.908</td>
<td>14.382</td>
</tr>
</tbody>
</table>

The meaning of work after acquired brain injury

Thus, Study III revealed that the meaning of work after suffering a brain injury is described by four main characteristics, each of which consists of two or more sub-characteristics as shown in Figure 1.
Figure 1. Main characteristics and sub-characteristics of the meaning of work.

<table>
<thead>
<tr>
<th>Work had taken on a new place in life</th>
</tr>
</thead>
<tbody>
<tr>
<td>- The importance of work had decreased</td>
</tr>
<tr>
<td>- Work caused the stroke</td>
</tr>
<tr>
<td>- Work tasks had become less meaningful</td>
</tr>
<tr>
<td>- Work gave a more significant structure to everyday life</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The social dimension of work took on an expanded meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Colleagues had come to play a more important role in life</td>
</tr>
<tr>
<td>- Working life had an influence on social life outside work</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The perceived competence and work identity had been altered</th>
</tr>
</thead>
<tbody>
<tr>
<td>- The old work identity had been threatened</td>
</tr>
<tr>
<td>- Uncertainty in the assessment of one’s own competence</td>
</tr>
<tr>
<td>- On the way to finding a new identity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Striving for normality</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Symbol of success</td>
</tr>
<tr>
<td>- Work as means of rehabilitation</td>
</tr>
</tbody>
</table>

Work has taken on a new place in life

Work had taken on a new position in life in comparison to the one it had had prior to the injury. Immediately after the injury, work had not been foremost in the minds of the participants; questions relating to survival and recovery from impairments were more prominent. The experience of having a brain injury had resulted in reflections on a more existential level. Participants expressed how their work no longer gave their lives its primary meaning. Even those who had considered their work to be the most important thing in their lives before their injury had revised their opinion. One element of this for those who had had a stroke was the concern about whether it was the workload that had caused the stroke.

Work had also taken on a new role in the sense that the participants no longer faced the same situation when it came to choosing between tasks. The tasks that were available after brain injury did not give the same pleasure as the work undertaken before the injury and some questioned whether the reward was worth the effort. Nevertheless, there were some benefits to be obtained from working: it had become obvious to the participants that one quality intrinsic to a working person’s day was that the work gave better structure to everyday life. This improved structure followed through into the leisure time, and seemed to be significant for the participants’ experience of satisfaction with their everyday life.
The social dimension of work had taken on an expanded meaning. The interviews revealed that the social dimension of work had become more apparent. During the rehabilitation process, the participants felt that colleagues played an important role in their motivation to conduct a work trial. Colleagues were described as being more important for the sense of belonging to the work-place than supervisors. However another side of the expanded meaning of the social dimension of work was that the participants were more aware of the fact that work had an impact on their social life, even in their spare time.

Perceived work identity and competence had been altered. The participants felt that they were no longer attractive in the labour market, which influenced their sense of identity. Their occupational role had changed, as had their opportunities for personal development and the possibility of getting credit because of their work. Participants also described a feeling that their personal value, their value as an individual, was not the same as it had been. The participants had been familiar with their own competence prior to the injury, but now they sometimes experienced a fear that something was different. They described how they hesitated if there was a discrepancy between their own apprehension and that of other people, where their capacity to work was concerned. During the long period of rehabilitation, an adaptation process had started during which the participants tried to adjust to their new circumstances. A new sense of identity was emerging.

Striving for normality. The immediate goal of the rehabilitation was not to return to work specifically, but rather, to get back to what was perceived to be a normal way of life. Being “normal” again or getting back to a “normal” existence was repeatedly mentioned by the respondents as being the most fundamental issue, and working was considered to provide evidence of such a return normality. Another aspect of this perceived normality was to regain the familiar feeling of mastering one’s own body and of being able to use the same repertoire of skills as before. During the endeavour to reach that goal, work had been experienced as a motivating factor. Being a “normal” person again was also described as being like everyone else. The participants discussed whether limitations on their activity were consistent with being “normal” because, at some point in life, every person encounters situations in which he or she experiences limitations.

Activity and participation after brain injury. Information on the participants’ level of activity and the extent of their participation was collected in Studies I and IV. In Study IV one of the aims
was to describe the outcome in terms of the extent of the respondents’ participation in everyday occupations related to self-care, home maintenance, work and leisure. The data in Study I originated from the FIM used to interview the subjects about their independence in performing ADL activities. Nine persons (16%) reported having a need of assistance on the items in the FIM motor scale and twenty-nine persons (53%) reported a need of assistance with the cognitive items. Data from the FIM was collected in Study IV as well, but in this study data from the evaluation made by the rehabilitation team was used. In the sample used in Study IV, 18% were considered to depend upon assistance with the motor scale items while 47% needed assistance with the cognitive items.

Table 5. Participation (RNL Index) reported as a percentage.

<table>
<thead>
<tr>
<th>RNL item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move around in my living quarters as I feel is necessary</td>
<td>25</td>
<td>5</td>
<td>9</td>
<td>61</td>
</tr>
<tr>
<td>Move around in the community as I feel is necessary</td>
<td>22</td>
<td>11</td>
<td>11</td>
<td>56</td>
</tr>
<tr>
<td>Able to take trips out of town as I feel is necessary</td>
<td>18</td>
<td>10</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Comfortable with how self-care needs are met</td>
<td>15</td>
<td>2</td>
<td>15</td>
<td>68</td>
</tr>
<tr>
<td>Occupied in work activity</td>
<td>25</td>
<td>14</td>
<td>21</td>
<td>40</td>
</tr>
<tr>
<td>Participates in recreational activities as wanted</td>
<td>12</td>
<td>18</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td>Participates in desired social activities</td>
<td>10</td>
<td>20</td>
<td>17</td>
<td>53</td>
</tr>
<tr>
<td>Assumes a role in family as wanted</td>
<td>7</td>
<td>16</td>
<td>22</td>
<td>55</td>
</tr>
<tr>
<td>Comfortable with personal relationships</td>
<td>7</td>
<td>15</td>
<td>30</td>
<td>48</td>
</tr>
<tr>
<td>Comfortable with myself in company of others</td>
<td>9</td>
<td>17</td>
<td>33</td>
<td>41</td>
</tr>
<tr>
<td>Deals with life events as they happen</td>
<td>9</td>
<td>20</td>
<td>33</td>
<td>38</td>
</tr>
</tbody>
</table>

1 = Does not describe my situation
2 = Describes my situation partly
3 = Describes my situation mostly
4 = Fully describes my situation
Another aspect of participation was obtained by the RNL Index used in Study IV where the subjects reported the extent to which they experienced that they were able to participate in activities in different life situations. Somewhat more than half of the group (56 – 61%) reported that they were able to move around in their living quarters, community and outside in the town as much as they felt necessary, while 68% expressed that they were comfortable with how their ADL needs were met (Table 5).

The re-entry rate of the participants in Study I to work or education was 51 %, (Table 6). Most of those who had returned to work had had to change their working conditions in some way. Fifty seven percent now worked part–time (in comparison with less than one percent before the injury occurred) and 36 % of those working received a state-subsidised wage, reflecting some limitations in their capacity to work.

Table 6. Occupational status and employment at the time of the follow-up in Study I.

<table>
<thead>
<tr>
<th>Occupational status at follow-up</th>
<th>Employment at follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student</td>
<td>Working for former employer</td>
</tr>
<tr>
<td>Working fulltime</td>
<td>Working for a new employer</td>
</tr>
<tr>
<td>Working part-time</td>
<td>Receiving a subsidised wage</td>
</tr>
<tr>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>16</td>
<td>10</td>
</tr>
</tbody>
</table>

Meaningful occupation is a wider concept than work. In this dissertation, the main focus has been on work, including education, but in Study IV, the concept of occupation is used in its wider meaning. In this study, the data relating to the work status of the individuals was not collected specifically to examine the working status of the participants. Rather, the respondents were asked if they were occupied in meaningful work activity. In this specific question, “work activity” included work in the home and voluntary work, as well as more conventional paid work. Forty percent reported that they were engaged in a work-related activity as much as they wanted or needed to be, while 25% did not feel that such a description represented their situation at all. Half of the group participated in recreational and social activities in the community as much as they wanted and occupied their desired role in the home (Table 5).


DISCUSSION

In this dissertation the long-term outcome after brain injury has been studied with a special emphasis being placed on everyday occupations like self-care, social and productive occupations and the influence of these occupations on life satisfaction. A further aim was to describe and understand the lived experience of the meaning of work after brain injury. The main findings from this research will be discussed here.

Activity and participation

Data describing the participants’ independence in performing daily life activities showed that few people experienced difficulties that could be connected to motor impairments in this phase of rehabilitation. However, about half the people in the sample needed help from another person because of cognitive impairments. This profile was found in two different samples and is in line with the results of other studies e.g., (Ponsford, Olver, & Curran, 1995; Powell et al., 2001). It is generally considered to be more difficult to compensate for an inability to perform daily life activities arising from cognitive impairments than to compensate for limitations caused by physical impairments (Rice-Oxley & Turner-Stokes, 1999).

In Study IV, participation in everyday occupations was reported from an “insider” perspective with the participants expressing their own opinion about what they wanted and needed to do. The level of participation was felt to be low. On average, full agreement with the assertions that claimed that the participants participated in different activities as much as they wanted or needed to was only obtained in about half the sample. The reported ‘relatively high’ level of participation in self-care was in accordance with the “outsider” observation (made using the FIM motor scale) of a high level of independence in ADL. The lowest level of participation reported on the “Daily functioning” subscale was for the item work activity (RNL index), indicating that the participants experienced restrictions in the productive side of life. These results have implications for rehabilitation indicating that more effort should be put into enabling participation in meaningful occupations.

Since most of the studies identified in the literature report on daily occupations adopting a more quantitative approach, the results are not easily compared with our findings. We found two studies (Carter & Buckley, 2000; Harker, Dawson, Boschen, & Stuss, 2002) in which the RNL index had been used and
in both of these, more than half of the samples had been reintegrated into society.

Life satisfaction after brain injury

Life satisfaction and quality of life have been focused on as the overriding measures of outcome in rehabilitation. A limitation when using such a broad concept is the failure to identify a generally accepted definition (Campbell et al., 1976). There is, however, a consensus about the importance of giving attention to such qualities in health care; however, the many varied attempts to describe the nature of quality of life and life satisfaction have yet not resulted in full agreement about the best definition of these concepts.

In Studies II and IV we found that the general level of life satisfaction was low in the study sample compared to a reference group of healthy Swedes (K. Fugl-Meyer, 1996). The participants in our study reported having a significantly lower level of satisfaction with life as a whole and in all the different domains except the one concerning their financial situation. This finding is in line with that of some other Swedish studies on stroke (Ahlsjö et al., 1984; Brännholm et al., 1996; Viitanen et al., 1988). On the other hand, in a Swedish long-term follow-up of people with subarachnoid haemorrhage (Lindberg, 1995) 62% reported having an unaltered or increased quality of life compared to the situation before their injury, while Schalen and co workers (1994) found that only 15% reported major changes in life satisfaction after traumatic brain injury. This difference between findings could, however, be due to disparity in the samples. It is likely that this is the case, but another explanation could be differences in assessments used.

In both study II and IV a predominance of men was found in the non response group. As no difference has been found for satisfaction with life as a whole between men and women (A. Fugl-Meyer et al., 2002) it is not likely that this difference influences our results. There was no significant difference between respondents and non respondents for age at follow-up or PTA. The meaning for the interpretation of the results, of more traumatic brain injured people than vascular injured among the non respondents, is difficult to estimate.

Study II also showed that life satisfaction did not change significantly over a period of three years in a late phase of the recovery after injury, with the exception of satisfaction with IADL, which decreased. In this aspect, time did not heal all wounds. The relationship between attaining different rehabilitation goals and the level of life satisfaction has not yet been elucidated. No studies
have been identified in the literature that reports the effect of rehabilitation on life satisfaction. The participants in our study had all been subject to community based rehabilitation services, but the impact of the specific intervention on life satisfaction was not addressed in this research. Our results, however, indicates that life satisfaction is not easily increased after brain injury. Several authors (Bays, 2001; Heinemann & Whiteneck, 1995; Vestling et al., 2003) define factors, such as social support and productivity, associated with a higher level of life satisfaction. Some authors have also suggested specific areas, such as social relationships, leisure and vocational activities, that should form the focus of rehabilitation efforts with the goal of increasing life satisfaction (Bays, 2001; Mazaux et al., 2001), but despite this interest, there has been a lack of research evaluating these kinds of interventions.

Our findings, that life satisfaction was low and did not change greatly over a long period of time, except satisfaction with IADL, which decreased over time, gave rise to questions about whether the utilisation of an increase in life satisfaction as a goal for rehabilitation is predetermined to failure. This is too wide a concept to be used as an outcome of brain injury. Still, there is not yet enough knowledge on this issue, to determine what would be a more precise measure. There is a need for further research on the relationship between life satisfaction and the outcome of rehabilitation. As there are differences between countries in terms of the life satisfaction (Melin, 2003) it is important that research in this area is conducted in Sweden.

Return to work and other forms of productive activity related to life satisfaction

Return to work after brain injury is the focus of this dissertation. Different aspects of this commonly used rehabilitation goal have been addressed here. The question raised in Study II of whether a return to work had an impact on the satisfaction with life as a whole was answered by those in this sample: with a “No”. This is in line with an earlier Swedish long-term follow-up after SAH (Lindberg, 1995) in which no correspondence was found between work and life satisfaction. However other studies (O’Neill, Hibbard, & Brown, 1998; Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001), have presented contradictory results. Most of these studies have been conducted in other countries, but in a recent Swedish study of stroke survivors, Vestling and co workers (2003) found a positive relationship between a return to work and subjective wellbeing and life satisfaction. However, there are some methodological differences between their study and our’s which make it difficult to compare the results.
In a Swedish sample of vocationally disabled people who had been subject to work rehabilitation, an increased level of life satisfaction was found after they had made a successful return to work except for satisfaction with life as a whole and with ADL (Bränholm, Eklund, Fugl-Meyer, & Fugl-Meyer, 1991). In another follow-up of vocationally disabled (Melin, 2003) the only domain that showed adequate responsivity in relation to outcome was satisfaction with the vocational situation. The subjects included in these studies were disabled due to somatic impairment other than brain injury but these results are of interest for the understanding of the impact of work-related rehabilitation on life satisfaction.

There is a commonly occurring discussion in the literature about the difficulty of comparing the results from different studies of brain injured people. One of the problems associated with making comparisons is to describe the severity of the injury and another is to identify methodological differences. Cultural differences and different definitions of the concept of “work” could be other sources of divergent results.

A return to work after brain injury is often accompanied by different obstacles. The individual often needs to have his or her former work tasks adapted or to be given new work tasks that are simpler than the work he or she performed prior to the injury. In Swedish society today there are few of these simple work tasks, i.e., repetitive, routine work. This situation makes it difficult for a person with a limited working capacity to re-enter the labour market. Likewise, in a time of relatively high unemployment it is difficult for a person with a brain injury to compete with a healthy person for a job.

Based on the results from Study II where no significant relationship was found between work and life satisfaction, the focus in Study IV was broadened from work, specifically, to encompass the wider concept of daily occupation. In Study IV work was evaluated as an integral part of the item work activity, which is included in the subscale “daily functioning” in the RNL Index. As mentioned above, two other studies were found in which this index had been used, (Carter & Buckley, 2000; Harker et al., 2002) but these studies did not address the impact of participation in daily occupation on life satisfaction. Work activity in this instrument includes house work and voluntary work, as well as paid work. The results from the subscale “daily functioning” were found to have a significant impact on life satisfaction. It is especially difficult to estimate the impact of work from the data in this study and conclusions about the relationship between work and life satisfaction can not be drawn. The subscale “daily functioning” can be considered to provide a summary of everyday occupations.
The importance of meaningful daily occupation on life satisfaction is underlined by these results. Furthermore, according to the results, the focus should be expanded from the commonly used outcome “work re-entry” to include other forms of productive activity in brain injury rehabilitation. One reason why paid work has been assigned this superior position in rehabilitation could be the economic aspect of work, but this is certainly combined with a deep founded opinion in society that work is the most valuable occupation mankind has found.

The meaning of work

Knowledge about the meaning that work holds for people with brain injury could give a better understanding generally of the clients participating in work rehabilitation programmes. More specifically, it can give information about what motivates the individual to participate in a period of strenuous work rehabilitation. The characteristics identified in Study III demonstrate that the meaning of the participants’ working life had changed after the injury. The central place that work had had in the life’s of the participants before the injury had changed. To some of them, this represented an opportunity to change their lifestyle. Work had dominated their life and their families had complained that they had felt slighted by this. One woman also expressed a feeling of gratitude over the chance she had been given: thanks to the injury, she had been forced to give her family higher priority.

A more negative impact on life after brain injury was the experience that there was a limited repertoire of jobs available. Those who had aimed high to obtain better positions and make a career for themselves, had had their hopes dashed. There was no longer a place for them in the top positions and their identity as a worker was threatened by this. They described their insecurity about their own capacity, which probably had an impact on the process of adaptation, i.e., it made their adaptation to the new situation more difficult. After the brain injury they needed external feedback to confirm their capacity. This is also fundamental for intervention in this phase which mostly deals with the clients’ psychosocial environment, teaching their colleagues and their family to give them support and feed-back in a concrete and positive manner.

If we intend to develop the skills of the rehabilitation team at designing effective intervention strategies, there is a need for more research which focuses the experience of the individual living with a brain injury. This type of research could also increase the client-centeredness of brain injury rehabilitation through gaining a better understanding of the clients.
Occupational therapy assessments as predictors of a return to work after brain injury

In Study I, certain assessments were identified that were able to predict a likely return to work or education after being inflicted with a brain injury. These assessments reflected capacities that would be needed in a work situation, specifically memory function and the ability to perform activities of daily living independently. This finding demonstrated the usefulness of ADL assessments particularly when made in combination with assessments on assessments of body function to predict the long-term outcome of brain injury. Other authors (Malec & Basford, 1996; Wozniak & Kittner, 2002) go even further and claim that functional ability, e.g., ADL performance is the most reliable predictor of outcome. The implication is that the same skills and abilities are required for the performance of ADL activities as for the ability to work independently.

Setting realistic goals for rehabilitation after brain injury is one of the greatest challenges for the rehabilitation team. Our findings emphasise that the occupational therapist has significant information about the client, information that could be useful for the prediction of the outcome as well as being vital for planning any intervention. It is important that the occupational therapists are aware of the value of their unique perspective. Likewise it is imperative that the rest of the team is made aware of this competence and, thereby, able to benefit from it.

Subjects

The inclusion criteria for the samples studied in this dissertation were having acquired brain injury, being of working age and having a need for rehabilitation owing to the brain injury. The selection of the sample corresponds to the clinical sample of patients attending a department for rehabilitation medicine. The samples in our studies probably consist of clients with more residual problems than would be typical for a study of general outcome after brain injury (Malec & Basford, 1996). In rehabilitation medicine departments there is a heterogeneous group with a wide range of ages and time spans since the injuries occurred. The range of time to have elapsed since the injury indicates that many people need rehabilitation services a long time after receiving their injury. The participants in these studies all lived in the same county, which limits the variation in the environmental factors that could have impacted on their outcome (Powell, Temkin, Machamer, & Dikmen, 2002). No distinction has been made between stroke and TBI as this was not considered to be important in this late phase of recovery, as was discussed in the introductory part of this dissertation. Very limited research has been identified on stroke
patients of working age in comparison to the body of research on TBI. The specific situation of the small group of younger stroke victims is often lost in the big cluster of stroke survivors, the majority of whom have already retired (Röding et al., 2003).

Methodological considerations

The studies included in this dissertation have been conducted during a period of time when there have been a large number of changes in society. As the aim of this research has not been to evaluate the effectiveness of rehabilitation programmes, it is not my intention to map the changes that have taken place in the rehabilitation area during these years. However, the outcome in terms of a return to work rate has probably been affected by the difficult labour market, and the figures might be different if Study I were to be repeated today. It is also possible that there is a growing interest in Swedish society in occupations other than paid work, e.g., in voluntary work, which can give new opportunities for meaningful occupation for those with a limitation in vocational capacity.

The research methods adopted in this work have been chosen with the research questions in mind and because of what was practicable. The rather small sample in Studies I and II affects the ability to make generalisations from the results. Some of the studies need to be replicated, and in this respect, it would be of interest, for example, to further control for the ability of the AMPS to predict a return to work.

A longitudinal study design is valuable in that it gives a wide range of information, but it has a disadvantage in terms of the greater drop out. In the discussions about the need of and the difficulty to conduct controlled randomised studies in this area, attention has been called to longitudinal design as an alternative where the subjects constitute their own controls (Rice-Oxley & Turner-Stokes, 1999). Using this design, the ethical dilemmas of using control groups that are offered fewer rehabilitation services than the intervention group can be avoided.

A disadvantage of qualitative studies is the limited ability one has to generalize them to populations other than those included in the study. On the other hand, they have clear advantages in terms of gathering information from the “experts” themselves. The purpose of qualitative studies is to describe and understand a phenomenon and not necessarily to generalize the findings. The phenomenological approach can be regarded as a form of basic research (Karlsson, 1993). The method aims to explore what a phenomenon is and what
qualities it has in order to clarify and understand different life-world experiences.

Mailed questionnaires have been used with satisfying results in other studies of brain injured people (Sbordone et al., 1999). The questionnaires used in our studies, have been designed with special consideration being taken of the specific cognitive impairments that are commonly found after brain injury. The intention has been to formulate distinct questions and to restrict the size of the questionnaire to limit difficulties in answering caused by cognitive impairments. On the other hand, this can also limit the information obtained by the questionnaire.

A relatively high percentage of answers were obtained in the studies despite the presence of, e.g., memory dysfunction. It is difficult to estimate how many of the non responses depended on memory dysfunction and how many were caused by the fact that people actively chose not to participate. There was an overrepresentation of traumatically injured people among the non respondents in Studies II and IV, but it is difficult to estimate whether they had more memory problems than those who did answer or whether they were not prepared to answer the questionnaire for some other reason. Common for the non respondents groups in these two studies was also a higher percentage of men than women. The possible impact of the non responses for the interpretation of the results is discussed with the results.

Area of research

This dissertation addresses issues related to a return to work and the taking up of other productive activities long after having acquired brain injury. The starting point for this research was many years of clinical practice in brain injury rehabilitation focused on reintegration into the community. The intention of the studies included has been to keep the focus on matters of importance for clinical practice. The research found in the literature at the time that this work was initiated was dominated by the endeavour to find out which neuropsychological or other body function provided the best predictor of a successful return to work along with an enthusiasm for the development of cognitive rehabilitation programmes. The long-term outcome of those who had had a brain injury was not yet the main concern.

Lately, however, the trend has been to pay increased attention to participation in the community as a long-term outcome of rehabilitation. One manifestation of this shift is the development of the new WHO classification of functioning, disability and health, ICF (WHO, 2001), in which participation is considered to
be one aspect of health. Another concept that has received much attention in the last few years is quality of life or life satisfaction. This is frequently mentioned as being the overriding goal and there is an increasing interest in conducting research to analyze the nature of this concept (Hinckley, 2002; Powell, Heslin et al., 2002).

Most research conducted in Sweden, in the area of brain injury rehabilitation, has addressed new findings in acute hospital care and different models of subacute care, e.g., stroke units. Few studies have been published on the long-term outcome of brain injury for people of working age and, consequently, the body of knowledge in this area is mainly founded on studies conducted in other countries. As the outcome could be influenced by cultural differences and disparity in social security systems, it is evident that brain injury rehabilitation in Sweden needs to be related to studies conducted here. In a situation when a growing emphasis is placed on participation and life satisfaction as the overall measures of rehabilitation outcome, there is a need for increased knowledge about these issues. The aims of this dissertation were to find some answers to the questions raised in the meetings with the clients described in the introduction and, thereby, to contribute to this body of knowledge.

From the point of view of occupational therapy, the questions raised in this dissertation are of great interest. In the theory behind occupational therapy, occupation is viewed as something that is crucial for peoples’ well-being (Reilly, 1962; Wilcock, 1998) and, consequently, studies on the meaning of work and of other productive activities after suffering brain injury are of vital importance.

**Implications from the point of view of occupational therapy**

Linking back to the two clients who had very different outcomes described in the beginning of the introductory chapter, this research has given me a deeper understanding of their situation. As the picture has become clearer, it has become apparent that the individual’s reaction to and reflections on such a dramatic event as a brain injury is dependent on several factors. The reintegration into activities in the community can be enhanced by a strong motivation (which gives the drive to struggle, for example, back to work). However, it is not necessarily the case that the client’s evaluation will be the same as that of the environment so it is important to listen to the experience of the client. The studies have also demonstrated that there may be other occupations in life, besides work, that are as valuable in this situation and give satisfaction in life.
Life satisfaction in relation to occupation

Life satisfaction has been used as the overriding goal for rehabilitation after brain injury and it has also been addressed in two of the studies included in this dissertation. However, life satisfaction as a phenomenon has only marginally been mentioned in some passages in occupational therapy literature where it has been regarded as a function of meaningful occupation. Kielhofner (2002) proposed the idea that a balance between our volition and what we actually get done in our daily life contributes to life satisfaction. This description is in line with the definition of life satisfaction that we have used in these studies: an individual is satisfied with life when his or her aspirations and achievements are met (Brännholm, 1992).

In the American Guide to Occupational Therapy Practice (Moyers, 1999), quality of life is mentioned as an outcome for occupational therapy. Kielhofner (2002), however, has emphasized that there is a risk of using life satisfaction as an outcome evaluation in occupational therapy since life satisfaction is a global assessment that may not be able to capture the impact of occupational therapy. On the other hand, Fearing and Clark (2000) emphasised that the outcome of intervention is more a matter of a client’s personal satisfaction than of whether the plan laid down for the rehabilitation has been fulfilled exactly. This dissertation does not address the issue of the impact of intervention on life satisfaction.

A central concept in occupational therapy is that it is important for the individual to perform meaningful occupations in everyday life. When we work, play and perform ADL tasks we shape our capacities and our patterns of doing (Wilcock, 1998). We also develop our interaction with other people and our life-world during occupation. A cornerstone in occupational therapy is that well-being is promoted when an individual engages in a varied repertoire of occupations combined with appropriate periods of rest (Fearing & Clark, 2000; Wilcock, 1998). We do things because they make us feel good (Hagedorn, 2000; Kielhofner, 2002).

If occupation has this inbuilt power to promote health and well-being, the inability or limited ability to perform everyday occupations will inevitably have considerable consequences. Our finding that satisfaction with life as a whole was not correlated to a successful return to work could be explained by the fact that the participants’ work situation had been markedly changed, even for many of the participants who had returned to work after the brain injury. The change included a shift in work-tasks and moving from a full-time to a part-
time job. The participants’ work task repertoire had been restricted through the loss of highly valued occupations, presenting a challenge to the individuals. Hagedorn (2000) emphasizes that the meaning of an occupation to the individual is dependent on the situation and on the participant’s personal motivations and experiences. The situation for the participants had changed in several ways and the meaning of work had been altered after the brain injury. Work tasks, in particular, were not as enjoyable as they had been. Kielhofner (2002) claims that we want to feel competent in what we do and consequently we tend to find those things enjoyable that we do well, and the opposite; that if we do not feel competent the occupation does not give us as much joy.

In an investigation adopting a longitudinal perspective, we found that overall life satisfaction did not increase significantly over a period of three years. Normally overall life satisfaction is considered to be rather consistent over time in spite of intermediate life events, even if people readjust to base level more quickly after positive life events than after negative ones (Lazarus & Lannier, 1979). The lasting effect of the brain injury on occupation and the difficulty of adapting to the challenges the injury imposes could be partial explanations of our findings.

Occupational adaptation

Occupational adaptation is a description of a process that all human beings are believed to undergo throughout their lives. It allows individuals to respond in a masterful and adaptive way to the various occupational challenges that they encounter (Schkade & McClung, 2001). Kielhofner (2002) describes occupational adaptation as the consequence of one’s history of participating in occupations. Over time we construct our occupational identity and develop our competence through our ongoing occupational participation. This is a rewarding process as adaptive responses contribute to feelings of wellbeing as Hagedorn (1996) has pointed out when she argues that it is through occupational adaptation that individuals experience increased life satisfaction.

The demand for occupational adaptation is greatest when the individual, for example a person inflicted with a brain injury, must change his or her role in life. This is also the point in a person’s life at which the adaptation process is most at risk of disruption because one of the greatest challenges faced by people with brain injury is to find an appropriate balance between the activities they wish and need to perform and the activity associated with this and their new requirements for increased rest. When the level of performance demanded is below the capacity of the person, it can result in boredom, but, on the other hand, when the demands are far too high, it can introduce feelings of anxiety.
Discussion

or hopelessness (Wilcock, 1998). There is no specific template for an activity level that suits all people. Rather, adjustment must be tailored to the conditions of each individual.

Identity

One of the components of occupational adaptation is identity (Kielhofner, 2002). Personal identity is described by Christiansen (1999) as who the person thinks he or she is. Kielhofner (2002) adds “and wishes to become”. In saying this, he means that building an occupational identity starts with self-knowledge of our own capacities. Fearing and Clark (2000) have stressed the importance of occupation for one’s sense of identity. In one way or another, individuals expresses who they are through what they do (Christiansen, 1999; Kielhofner, 2002; Wilcock, 1998). In western society, we tell others who we are by giving ourselves occupational titles.

Consequently, any disability that limits our occupational performance is a threat to our identity. The loss of productive roles can erode a person’s sense of self-worth (Christiansen, 1999; Fearing & Clark, 2000). The results from the present studies show that there are limitations on the activities and restrictions on the participation of those afflicted with brain injuries, which probably had an impact on the participants’ experience of themselves as productive individuals. From the interviews conducted for Study III, we found that not being able to go back to work or experiencing great changes in their work-situation had had an impact on the identity of the respondents: They had experienced a threat to their old identity.

Competence

Another characteristic of the experience of the meaning of work after brain injury was the uncertainty each person had about his or her present competence. Some of the respondents described experiencing feelings of insecurity related to whether their understanding of their own competence was adequate or whether they had misjudged the situation. They did not have the basic information needed to adapt to their changed circumstances. Awareness of the need to change one’s response pattern is the most crucial factor for adaptation (Schkade & McClung, 2001). In line with this, the respondents in our study described their need for external feedback if their performance was not competent.

Competence is described in the occupational therapy literature as putting one’s identity into action (Kielhofner, 2002), that is not to say that it is equivalent to perfection, rather, the concept is intended to describe a consistent and adequate level of performance that gets the job done (Hagedorn, 2000).
Schkade and McClung (2001) use another concept when they describe the clients’ self-assessment of competence: the experience of relative mastery. This is affected by the person’s internal expectations and the expectations of the environment. The respondents in Study III described how they tried to interpret other people’s apprehension of their capacity pondering over what had been commented and what had not been said about the work they had done.

Kielhofner (2002) stated that there are more pronounced effects from disability on the competence of a person than on the person’s sense of identity. The participants in our study, however, experienced a loss of competence, but they also felt that their identity was threatened. The focus of occupational therapy theory is occupation and aspects of occupational dysfunction. Thus, intervention addresses processes of adaptation in a person’s life following injury or disease. In this respect, occupational therapy research may contribute to the knowledge of what conditions have an impact on life satisfaction.

Implications for clinical practice

This research originated from issues brought up during clinical work as an occupational therapy practitioner. Some of the findings in this dissertation that have implications for clinical practice are summarized below:

- Occupational therapy assessments conducted in a late phase of a recovery can predict the failure to return to work after brain injury and would provide valuable information for the rehabilitation team. This knowledge can help to direct interventions towards goals that are achievable for the client.

- The focus on a return to work as the eventual goal for the outcome after brain injury needs to be widened to incorporate meaningful occupation in general, as this is important for the client’s sense of well-being. Occupations that are meaningful to the client should be focused on in line with the desired implementation of a client-centred approach.

- Providing clients with external feedback about their occupational performance gives them a better chance to determine their own capacity after a brain injury. This would enhance their adaptation of their performance to correspond to the conditions prevailing at that time.
• Intervention should also be directed to give information and support to colleagues of the brain injured person, as they constitute an important source for to motivate him or her to carry through a laborious period of returning to work.

• The importance of determining distinct, measurable goals for intervention needs to be stressed — even more than it is at present. Overall goals like aiming to increase life satisfaction may be too broad to be evaluated meaningfully.

Future research

The results from these studies have led to several new questions that need to be answered. The following are examples of interesting areas for future research.

The AMPS as a measure of IADL seems to be a valuable predictor for an eventual return to work. As our study was only comprised of a small sample, the value of the AMPS as a predictor in this respect needs to be examined further in a bigger sample. The AMPS is a commonly used assessment by occupational therapists in Sweden and it is important to find out whether it could reliably be used to predict a successful return to work after suffering a brain injury.

The findings that occupational therapy assessments could predict a return to work are valid for clients in a late phase of their recovery. It would be of interest to evaluate whether these results are transferable to clients in a subacute phase after brain injury.

There is a need for further research on life satisfaction in relation to the outcome of rehabilitation. As the concept of life satisfaction is often used as a goal for rehabilitation, it is vital that the factors contributing to an increased life satisfaction be determined and elucidated. Moreover, the impact of rehabilitation services on life satisfaction needs to be studied.

Research has been published on the relationship between life satisfaction and, primarily, a return to work. The focus needs to be widened to encompass other occupations that are meaningful to the individual. A return to work is one part of reintegration into the community, but there is a need for more comprehensive studies that address other aspects of community reintegration.
The occupational adaptation process includes finding a balance between everyday occupations and the limitations of the individual. In sociological studies of healthy people, a “spill-over” effect from working life to leisure time has been demonstrated, by which it is seen that those who had a satisfying work situation also were more active during their leisure time. The question, therefore, still remains of whether and how a return to work has an impact on the participation of the individuals concerned in other activities that relate to their everyday lives after they have suffered a brain injury.

There is also a need for more research focusing on the experiences of the individual living with brain injury. The findings in Study III stressed the long-term perspective that is required of work directed towards rehabilitation of those with a brain injury. It would be valuable if future studies were to address the experience of working after being afflicted with a brain injury over an extended period of time. This study, like many before it, reveals that the adaptation process continues over several years. However one question of interest here is how the meaning of work evolves over time.

Another area for research is deepening the understanding of the social dimension of work because this took on an expanding meaning after brain injury; paying more attention to this aspect of reintegration into the community. Ideally, in such a study, the client, his or her relatives and colleagues would be involved.

And finally, it would be of interest to determine whether our findings about the changed meaning of work after receiving a brain injury are applicable to people participating in work rehabilitation as a consequence of being afflicted with diseases or injuries other than brain injury.
SAMMANFATTNING (SUMMARY IN SWEDISH)

Konsekvenser av hjärnskada i ett långtidsperspektiv – med fokus på arbetsåtergång, livstillfredställelse och delaktighet

Rehabilitering efter hjärnskada är en process som ofta sträcker sig över en lång tidsperiod och som består av olika faser. En subakut sjukhusbaserad rehabiliteringsfas kan ibland följas av en postakut fas då rehabiliteringssanställdena förläggs till personens hemmiljö och till olika platser i samhället. I den senare fasen fokuseras rehabiliteringen på reintegrering i samhället genom återgång till arbete och till andra aktiviteter i samhället. Det övergripande målet för den här avhandlingen var att studera konsekvenser av hjärnskada i ett långtidsperspektiv med speciell betoning på återgång till vardagliga sysslor som hushållsarbete, lönearbete och fritidsaktiviteter och det samband som finns mellan dem och livstillfredställelse. Syftet var också att beskriva och förstå upplevelsen av att leva med konsekvenserna av en hjärnskada.


Resultaten visade att arbetsterapeutens bedömningsinstrument var användbara för att predicera återgång till arbete i en sen fas efter hjärnskada. En kombination av bedömningar på kroppsnivå tillsammans med bedömningar på aktivitetsnivå visade sig utgöra den bästa prediktionsmodellen. Livstillfredställelsen, mått i två olika studier, visade sig vara signifikant lägre på nästan alla områden jämfört med en svensk normalpopulation. Ingen signifikant förbättring över tid återfanns när livstillfredställelse, mått vid två olika tillfällen med en intervall av tre år mellan tillfällena, jämfördes. Det fanns inte heller någon skillnad vad gäller tillfredställelse med livet i stort mellan dem som var tillbaka till arbete eller studier och dem som inte var tillbaka. Däremot visade sig delaktighet i aktiviteter i samhället i ett vidare perspektiv ha positiv inverkan på livstillfredställelse. Många rapporterade
begränsningar i sin delaktighet. Halva eller drygt halva gruppen beskrev begränsningar på alla områden förutom inom områdena personlig vård och att förflytta sig i samhället, inom vilka högre delaktighet rapporterades. Arbetets mening hade förändrats efter hjärnskadan; arbetet hade fått en ny plats i livet och vikten av arbete hade minskat, däremot hade den sociala delen av arbete ökat i betydelse. Uppfattningen om den egna kompetensen och arbetsidentiteten hade förändrats och respondenterna beskrev en strävan att komma tillbaka till det normala.

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