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UNIVERSITY OF COPENHAGEN

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PhD thesis

Astrid Henriette Aaby Svendsen

Long-term outcome following post-acute, neuropsychological rehabilitation: A controlled study.

Academic advisor: Thomas W Teasdale

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Foreword:

The three articles listed below and used as result chapters combined with a literature review, a method section, a chapter containing unpublished results as well as a summary and conclusion comprises this experimental PhD dissertation in psychology, submitted to the Faculty of Social Sciences at the University of Copenhagen.

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Svendsen, H.. Teasdale, T. & Humle, F.: The influence of neuropsychological rehabilitation on employment and leisure activities following brain injury: A controlled long-term follow-up. (submitted)

Svendsen, H. & Teasdale, T.: The influence of neuropsychological rehabilitation on symptomatology and quality of life following brain injury: A controlled long-term follow-up. (submitted)

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Glossary

Acquired brain injury: As opposed to congenital brain injury, acquired brain injury is the type of injury (e.g. TBI, CVA, tumour, infections, anoxia, Alzheimer's disease) that hits people, who have lived with a normal non-affected brain until they are afflicted. However, some forms of acquired brain injury are degenerative e.g. Alzheimer's disease, where a continues progression of the disease is expected, whereas when used in this dissertation, the term acquired brain injury alludes to conditions of a non-progressive nature i.e. the injury was sustained at a specific time and, apart from the secondary effect (e.g. swelling of the brain) of the initial physical trauma, further deterioration is not expected.

CVA: Cerebro Vascular Accident: Covers several aetiologies SAH, IS, HS.

CRBI: Centre for Rehabilitation of Brain Injury, University of Copenhagen.

EBIQ: European Brain Injury Questionnaire, measures brain injury symptoms on nine sub scales.

Flex-job means a job where the salary is paid partly by the employer and partly by the government. The state of Denmark decided to create this kind of job during the 90's as a way to keep people with disability of any kind attached to the labour market.

GSE: Generalised Self-efficacy scale. It gives one measure (out of many) of self-efficacy i.e. the power or capacity to produce a desired effect. (http://wik.ed.uiuc.edu/index.php/Self-efficacy).

HADS: Hospital Anxiety and Depression Scale, measures anxiety and depression on two scales.

Holistic, Post-acute, Neuropsychological Rehabilitation: Is based on the idea of a therapeutic community, were survivors of brain injury work intensively on making progress in a group, and the significant others are involved as well acknowledging the fact that brain injury not only affects the person with the brain injury but also the family. The term comprehensive day treatment program has also been used to denote essentially the same kind of treatment.

HS: Hemorrhagic Stroke or bleeding of intracranial blood vessels.

IS: Ischaemic Stroke.

LoC: Locus of Control Belief can be internal or external. People with an *internal* locus of control believe that they control their own destiny. A way of characterising to what extent a person believes they can control subsequent events.
(Http://wik.ed.uiuc.edu/index.php/Locus_of_control)

PCRS: Patient Competency Rating Scale, a questionnaire primarily used to measure awareness but can also be used to get a measure of competency and can be divided in 4 subscales.

SAH: Subarachnoid Haemorrhage.

SO: Significant Other, in this dissertation it covers family, important friends or carers of those taking part in the.

TBI: Traumatic brain injury: covers several degrees of severity e.g. cranial fracture, cerebral lesion or contusion, concussion. In this dissertation any potential participant with either an isolated cranial fracture or concussion was excluded, and thus the abbreviation TBI is used to denote participants with more severe traumatic head injuries.

WHO: World Health Organisation. Their brief Quality of Life questionnaire is used as an outcome measure and their conceptualisation of health in three levels of functioning has been an inspiration.

WHO-QoL-Bref: Brief Quality of Life Questionnaire: measures quality of life on four different subscales.

Table of contents

List of Tables

List of Figures

Abstract in Danish

Denne ph.d. afhandling startede som et projekt initieret af Mugge Pinner, tidligere direktør for Center for Hjerneskade (CRBI) og lektor doktor phil. Tom Teasdale på en bevilling fra social ministeriet. Projektet forsatte under min tid som ph.d. studerende ved Institut for Psykologi, Københavns Universitet. Afhandlingen beskriver resultaterne fra en langtids- opfølgningsundersøgelse af tidligere deltagere i CRBIs program.

Tidligere undersøgelser af post-akut, holistisk, neuropsykologisk genoptræning har generelt vist positive resultater, men relativt få har inkluderet en kontrol gruppe og ingen af disse undersøgelser har undersøgt psykologiske og sociale faktorer for genoptræningsdeltagerne længere end 11 år efter genoptræningens afslutning.

Det primære formål var at se om en positiv effekt af genoptræningen kunne spores 12-17 år efter genoptræningen indenfor områderne arbejde, fritid, socialt netværk så vel som mental veltilpashed. Endvidere blev der fokuseret på deltagernes opfattelse af CRBIs genoptræningsprogram.

Et retrospektivt undersøgelses design blev anvendt. Designet inkluderede 37 konsekutivt genoptrænede deltagere med enten TBI eller CVA samt en kontrolgruppe. Denne kontrolgruppe bestod af 13 deltagere med sammenlignelige hjerneskader og som ikke havde modtaget samme post-akutte intervention. Undersøgelsen bestod af et spørgeskema og et semi-struktureret interview. Deltagerne og deres pårørende fik tilsendt og udfyldte spørgeskemaerne forud for interviewet, der foregik i deltagernes hjem.

Resultaterne viste en positiv effekt af genoptræning. Deltagerne i genoptræningsprogrammet havde en højere grad af arbejdsmæssig aktivitet, livskvalitet, kompetence, self-efficacy og internt 'locus of control' samt en mindre frekvens af symptomer på hjerneskade og lavere grad af angst og depression. Resultaterne viste endvidere en positiv effekt for pårørende til de genoptrænede deltagere i form af højere livskvalitet, mindre grad af angst og depression samt generelt mindre påvirkning af hjerneskadens følger. Indenfor områderne fritidsaktiviteter, socialt netværk og sygdomsindsigt sås dog ingen effekt af genoptræningen.

Det overordnede resultat tyder på at post-akut, holistisk, neuropsykologisk genoptræning har en positiv, vedvarende effekt, trods de metodiske begrænsninger der ligger i det retrospektive design

Abstract in English

This dissertation started as a project initiated by former director of the Centre for Rehabilitation of Brain Injury (CRBI) Mugge Pinner and Dr. Tom Teasdale funded by the ministry of social affairs. My tenure as a Ph.D. student at Department of Psychology, University of Copenhagen, continued and completed the project. This thesis describes the results of a long-term follow-up study of former participants in the CRBI-program.

Prior studies of post-acute, holistic, neuropsychological rehabilitation have generally reported positive results, however few have included a control group and none of the studies have looked at outcome beyond 12 years after rehabilitation.
The primary objective was to see whether a beneficial effect of rehabilitation could be seen 12-17 years after rehabilitation within the areas of work, leisure and social networks, as well

as in terms of mental well-being, and also whether the participants had found the CRBI program beneficial, and if so, what aspects thereof.

A retrospective design including 37 consecutively treated rehabilitation participants with TBI or CVA as well as a control group consisting of 13 participants with similar injury characteristics and not having received similar post-acute rehabilitation was conducted. The participants took part in a questionnaire and interview study. The questionnaires were filled out by participants and their significant others before the interviews, which primarily took place in their homes.

The results demonstrated a positive ongoing effect of rehabilitation status in terms of higher productivity, quality of life, competency, self-efficacy, and internal locus of control and of lower frequency of brain injury symptoms and of anxiety and depression for the participants with brain injury. The results further demonstrated a positive effect of rehabilitation for the significant others in terms of higher quality of life and lower levels of anxiety and depression as well as less current impact of the brain injury on their lives. The study found no effect of rehabilitation status in terms of leisure activities, social network or awareness of deficits.

Within the limitations of a retrospective design, the overall results suggest that post-acute, holistic, neuropsychological rehabilitation does indeed have an enduring beneficial effect.

Chapter 1. Literature review

Persons living with an acquired brain injury comprise a substantial group in Denmark as well as in other countries around the world. This chapter presents the incidence of the two different types of acquired brain injury studied in this dissertation (cerebro-vascular accidents and traumatic brain injury). Typical effects of brain injury are described. These can be conceptualised according to the general model of health presented by the World Health Organisation, WHO. Different types of rehabilitation are described to give an impression of which subgroups of individuals with acquired brain injury are the target for holistic rehabilitation. The salient features of holistic rehabilitation and vocational results from 37 studies of holistic rehabilitation are presented. Other outcome areas of brain injury research are presented, such as symptoms, competency, awareness, locus of control, self-efficacy, anxiety and depression, and quality of life, to contextualise the hypotheses of this dissertation given at the end of this chapter.

1.1 Aetiology of brain injury and incidence in Denmark in general and for CVA and TBI in particular

Denmark is a country with 5.4 million inhabitants (www.dst.dk). It is estimated that about 60.000 people in Denmark live with acquired brain injury, which corresponds to a prevalence of about 1111 per 100.000 inhabitants or about 1% of the population. Taking into consideration that the injury also affects the family, about 250.000 people in Denmark are affected by acquired brain injury, that is, about 5% of the total population.

The most prevalent causes of acquired brain injury in Denmark are cerebrovascular accidents (CVA) and traumatic brain injury (TBI). Other common causes for brain injury include inflammation (e.g. meningitis), tumors and hypoxic brain injury (e.g. after suffocation, drowning, heart attack or surgery).

Due to methodological constraints, this dissertation has a particular focus on CVA and TBI. Approximately 10000 people acquire CVA every year in Denmark. It is the third most frequent cause of death and the most frequent cause of disability. Mortality is below 20%, and approximately 70% are discharged to their own home (www.vfhj.dk). In Sweden, a somewhat similar society, it is estimated that about two thirds of all strokes are first time strokes (Asplund & Olsson, 1997) and that 20% of stroke victims are of working age. Among these 5% are under the age of 45 at time of stroke (Grimby & Sunnerhagen, 1999) and a third of those who have a stroke will experience residual symptoms (Sundberg, Bagust, & Terent, 2003).

About 12-15000 people suffer a traumatic brain injury (of all severities) every year in Denmark. Males are at higher risk than females. Tagliaferri et al. (2006) reviewed epidemiological studies across Europe and found that males had one and a half to three times the risk of females. The majority of the 12-15,000 injuries are concussions with predominantly good recovery (leaving a fraction with post-concussional syndrome (Lyon & Svendsen, 1999). In 1993, the Department of Health estimated that 693 persons per year survived after severe traumatic brain injury (Sundhedsstyrelsen, 1997) and in addition a group with moderate or mild brain injury were also in need of social support, education or rehabilitation. Of the 693 with severe injury, 49 were under the age of 15, 441 were under 60 at time of injury and 203 were older than 60. Young males (averaging 24 years) had the highest representation among those with severe traumatic brain injury. This illustrates the need for a long-term perspective, where disability management and societal intervention are concerned, given that TBI is usually seen in otherwise healthy people who can expect a normal lifespan of several decades after the injury. Engberg estimated that in 1989, 317 per 100,000 inhabitants were suffering TBI sequalae preventing them from working (Engberg, 1995).

Both causes of acquired brain injury (CVA and TBI) contribute annually to a considerable number of individuals of working age with impairments and disabilities indicating a substantial need for treatment.

1.2 Impairments caused by acquired brain injury

It is well known that acquired brain injury can result in a wide range of physical, cognitive and neurobehavioral symptoms, as well as emotional reactions to the trauma and resulting impairments (Livingston, Brooks, & Bond, 1985; Thomsen, 1974; Lezak & Obrien, 1988). Trexler (2000) described how physical impairments of motor functions can manifest in the areas of initiation, dexterity, coordination/balance, dysarthria, motor-programming, praxis of limbs and face, strength, range of motion, endurance and speed. Impairments of sensory functions can be visual, tactile, auditory and proprioceptive in nature. Cognitively, there can be impairments of alertness, vigilance, attention and concentration, memory, language and visual functions, as well as executive functions such as initiation, planning, organising, self-monitoring. Neuro-behaviourally, the brain injury can result in confabulation, perseveration, tangentiality, disinhibition (verbally, affective or motor) and unawareness of deficit on an intellectual, emergent or anticipatory level. In combination with the cognitive and affective deficits, the person with acquired brain injury can sometimes be diagnosed as having an organic personality disorder or appear to have changed his or her personality (Mathiesen & Weinryb, 2004). Emotional reactions can take the form of a loss of identity, depression, anxiety or catastrophic reaction, all potentially leading to a spiral of deterioration. Family and friends are also significantly affected by the brain injury, often having to take a more active caretaking role towards the brain injured person, adjusting to changes in behaviour and personality or reacting with anxiety and depression (Livingston et al., 1985; Lezak, 1988; Oddy, Humphrey, & Uttley, 1978a).

The specific deficits depend on the site of lesion or stroke. Strokes often occur at the middle cerebral artery, resulting in hemianopia, neglect, hemiparalysis, aphasia and anosognosia (or unawareness) of aphasia or paralysis (Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1996). Since ischaemic stroke or infarct often has a more specific lesion site, deficits tend to be more circumscribed than after traumatic brain injury. However, in principle all cognitive and neurobehavioural deficits can be seen after brain injury caused by cerebrovascular insults, depending on the site and extent of the lesion(s).

Thus, I have chosen not to separate the two injury types when describing the possible consequences of either CVA or TBI, even though there may be some differences in outcome between CVA and TBI patients. For example, TBI patients are generally younger at time of injury and recovery may be faster. TBI patients may not have the lifestyle risks for a repeat of the same type of injury that the CVA group has). However, individual brain injuries cause a highly diverse range of symptoms, which makes the distinction between TBI and CVA rather arbitrary from a functional, rehabilitation point of view.Irrespective of the aetiology, the individual with acquired brain injury can experience significant impairment from the neurological and psychological trauma. The psychological trauma consists of sudden change of life-style, roles and identity and the experience of being mortal. Individuals with acquired brain injury must re-evaluate their roles and identity and relate to the reactions from their surroundings. In rehabilitation, it can be hard to separate the neurological from the psychological trauma, and this needs to be taken into account when treating the individual (Mateer, Sira, & O'Connell, 2005).

Initially, the person with acquired brain injury experiences a period of spontaneous recovery, and patients who after acquired brain injury have symptoms of dysfunction can therefore have very different prognoses depending on the amount of spontaneous recovery. Most of the spontaneous recovery occurs in the first year after injury. It can be easy to mistake spontaneous recovery as an effect of rehabilitation (Forchhammer, 2004).

Because the effects of brain injury persist beyond the period of spontaneous recovery, efforts at rehabilitation have long been made. Treatment of head injury was described as early as 2500-3000 years ago in an Egyptian document discovered in Luxor by Smith in 1862 (Wilson, workshop in Copenhagen, 2001). In modern times, two early contributors are German neurologist and psychiatrist Kurt Goldstein and the Russian psychologist Alexander Romanovich Luria.

Goldstein is known for his humane approach to rehabilitation. He emphasised how it was important to observe and relate the symptoms of a brain injured patient to a theory of brain function in order to understand the adjustment problems of patients with brain injury. In addition, he coined the term *catastrophic reaction* used to describe some of the adjustment problems brain injured patients can experience. Patients with brain injury can due to their cognitive deficits be overwhelmed by environmental situations and demands. In such circumstances they can exibit compensatory and protective behaviour as a reaction to failure in coping with the environment.

Luria pointed out the importance of a detailed neuropsychological examination in order to determine the nature of the cerebral dysfunction in brain injured patients and how extensive practice was needed during the rehabilitation process. Furthermore he and other contributors to the field stressed motivation, individual coping style and premorbid personality characteristics as important outcome predictors in addition to lesion site and injury severity. Both Goldstein and Luria have been instrumental in defining the field of neuropsychological rehabilitation and inspired the founders of holistic rehabilitation, Yehuda Ben-Yishay and Leonard Diller. Ben-Yishay and Diller applied the concepts from neuropsychology, clinical and experimental psychology to the rehabilitation of patients with acquired brain injury. For a comprehensive history, see Prigatano (1986).

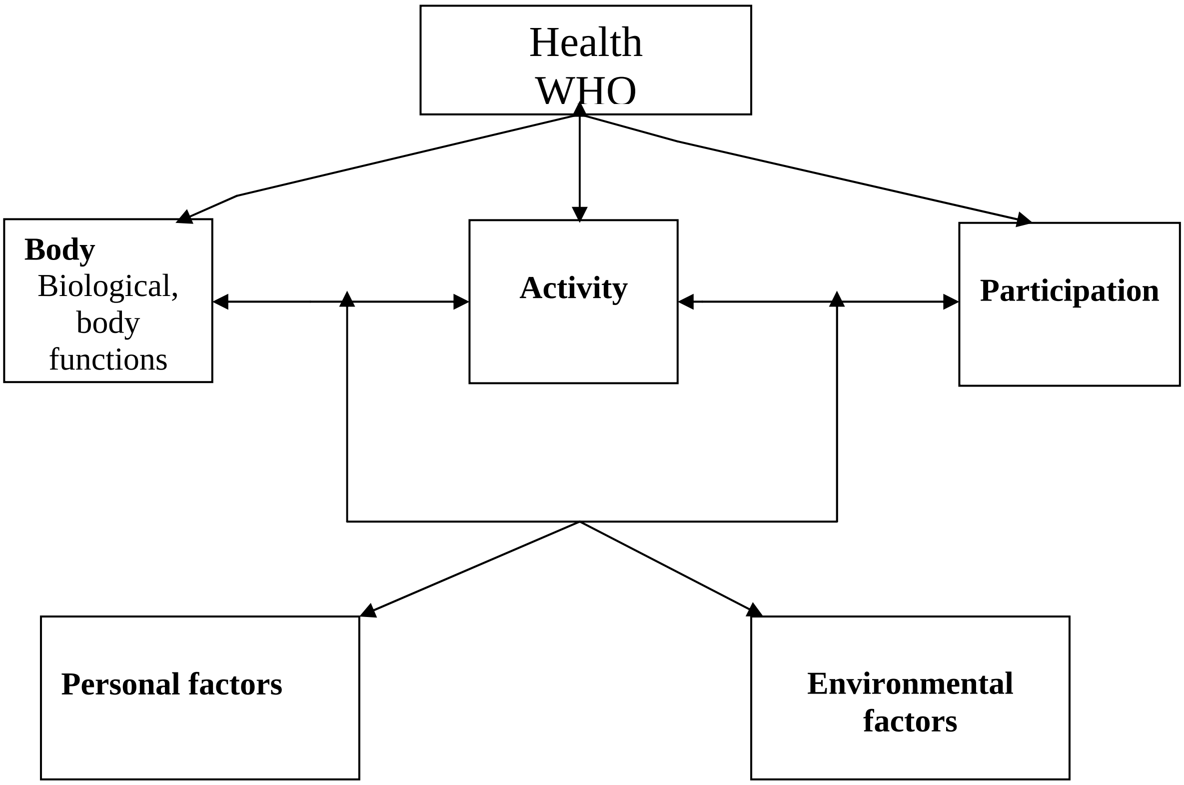
1.3 The WHO model of health

The World Health Organisation has provided a definition of rehabilitation within its general model of health and wellbeing. This model has become popular as a frame of reference for research in many areas, including brain injury.

The World Health Organisation (WHO) provides the following definition of rehabilitation:

> *Rehabilitation implies the restoration of patients to the highest level of physical, psychological and social adaptation attainable. It includes all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling disabled people to achieve optimal social integration.*

Figure 1.1 WHO model of health



The impairments caused by brain injury belong to the level of the body. According to the WHO model (Figure 1.1), health is not only the state of the body, but also how bodily impairments affect the individual’s ability to perform various functions, such as activities of daily living (self-care, grooming, dressing, cooking etc.) communication, or those related to work. Finally, health after brain injury is also defined as how the ability of the individual is affected with respect to participating in the community, filling important roles such as parenting or being a worker. Areas of activity and participation are often affected by brain injury. The impairment and emotional reaction to impairment often results in increased dependency in activities of daily living, and a lowered rate of participation characterised by social isolation and lowered ability to engage in competitive work or leisure activities.

Thompsen (1992; Thomsen, 1984), Oddy and colleges(1985) and Wood & Yurdakul (1997), have described the long-term persistency of symptoms after head injury as well as the effect on the family up to 20 years after injury. These findings were confirmed in a recent Danish long-term population-based follow-up study of stroke and TBI patients (Teasdale & Engberg, 2005a; Engberg & Teasdale, 2004). The participants experienced that symptoms (such as difficulties with concentration, memory and emotional control), maintenance of employment, leisure activities and social relations remained affected up to 15 years after injury. Wood (2006a) also found that cognitive impairment remained in 74 individuals with head injury 16 years after injury.

As the WHO model implies, there is no linear relationship between the amount of impairment and the effect on activity and participation, making it hard to infer from severity of injury precisely what the outcome will be for a given person. Thus a brain injury resulting in persistent aphasia might mean that one person cannot continue to work, if that work is dependent on intact speech functions, whereas it might not preclude work for another person working as, say, a carpenter. Not only can the effect of a brain injury vary according to lesion site and severity but the effects on the person's activities can be very varied according to the circumstances of the individual. Level of activity and participation as an indicator of psychosocial adjustment may mean more for emotional well-being than the severity of injury. Whitnall and colleagues (2006) studied a cohort of 457 survivors at one year and seven years post-injury. A level of disability above 50% was found at both one and seven years, and in the interim about a quarter had improved functioning and a similar proportion had deteriorated. The persistence of disability and development showed a stronger association with indices of depression, anxiety and low self-esteem than with initial severity of injury or enduring cognitive impairment. This last study together with others (Wood & Rutterford, 2006b;

Hillier, Sharpe, & Metzer, 1997) points towards a possibility of both improvement and deterioration even beyond the initial period of spontaneous recovery.

Two additional components are included in the WHO model of health: personal factors and environmental factors. The effect of impairment on activity and participation can be modified by personal factors such as pre-injury education, coping skills, substance abuse, genes, and psychiatric history. Rutterford & Wood(2006) found that coping strategies, cognitive appraisal and perceived self-efficacy contributed in predicting outcomes, such as community integration, in 131 persons with head injury more than 10 years after injury. Lubusko and co-workers (1994) found that nine head-injured individuals who returned to their previous level of employment after their injury had a higher degree of internal locus of control (LoC) and a lower degree of experienced hopelessness than a group of 10 head-injured individuals who did not return to pre-injury levels of employment. Moore and Stambrook (1992) found in a study of 53 males with TBI that a combination of more frequent use of self-controlling and positive reappraisal coping strategies and a lower external locus of control was associated with significantly less mood disturbance and physical difficulties, and a trend to be less depressed. The environment can also affect the individual’s psychosocial adjustment after brain injury in ways such as degree of family support, anti-discrimination or flexible workplace legislation, societal norms towards disability, handicap facilities, funding and accessibility of rehabilitation.

Rehabilitation can be divided into three phases.Acute rehabilitation takes place during coma and arousal states. Specific aims are to prevent orthopaedic and visceral complications, and to provide sensory stimulation with the hope of accelerating arousal. Secondly, sub-acute (generally inpatient) rehabilitation is designed to facilitate and accelerate recovery from impairments, and to compensate for disabilities. Motility, cognition, behaviour and affect are often simultaneously addressed. Physical and psychological independence and self-awareness are major goals. A third, post-acute rehabilitation phase includes outpatient therapy for achieving physical, domestic and social independence, reduction of handicaps and re-entry into the community. It is the effort towards improvements in this phase that is the focus of the present dissertation. In the post-acute phase, the individuals shift roles from a hospital context of being primarily patients to a societal context where they are citizens. During the hospital phase, health has predominantly been seen as a matter for medical science. Treatment and prevention are jobs for the medical expert, and the person with brain injury is a patient being treated; the goal is to be able to become more independent in carrying out activities of daily living. After discharge from hospital the social sector takes over and health is more the domain of the social sciences; how life can be organised after brain injury and how the person can handle the effects of the brain injury. The psychological and social problems come into focus, and the person with sequelae after brain injury is often expected to take a more active role in rehabilitation in order to achieve health in these areas.

1.4 Different kinds of post-acute rehabilitation

Since the heterogeneity of brain injury can result in a wide and variable range of behavioural deficits, no one type of post-acute intervention can serve all the multiple needs. Several different types of post-acute rehabilitation programs have been developed accordingly.

Table 1.1 Different types of post-acute rehabilitation (Trexler, 2000; Malec & Basford, 1996)

Type	Severity of injury	Patient characteristics	Goal	Program component
Outpatient Community Re-entry	Mild to moderately injured	Sufficient awareness to participate in realistic goal setting	Self-care, independent living, return to work	Community based therapies with vocational emphasis
Holistic	**Mild to severely injured, impaired awareness**	**Safe in outpatient setting**	**Psychosocial adjustment, compensation for cognitive impairments, return to work**	**Therapeutic milieu, neuropsychological orientation and integration of staff**
Residential community reintegration	Moderately to severely injured Impaired self-awareness	Unsafe without supervision	ADL and independent living	Functional skills training in residential environment
Neuro-behavioural	Moderately to severely injured impaired self-awareness	Unsafe without supervision, severe behaviour problems	Behavioural control, stability and quality of life	Behavioural modification in structured environment

Table 1.1 is adapted from Trexler (2000) and Malec & Basford (1996) and shows different types of post-acute rehabilitation programs according to different needs of participants. A growing number of studies document outcome for different types of post-acute rehabilitation programs (Malec et al., 1996). In addition, extensive research has been carried out within remediation of specific deficits in the areas of attention, memory, language, communication, visuospatial ability, apraxia, executive functioning and awareness (Cicerone et al., 2005) as well as in specific aids and techniques (Wilson, Emslie, Quirk, Evans, & Watson, 2005; Wilson, 2000; O'Connell, Mateer, & Kerns, 2003). This dissertation will primarily focus on the findings of holistic neuropsychological rehabilitation programmes. The

terms rehabilitation, holistic rehabilitation and comprehensive day treatment program will from now on all refer to holistic neuropsychological rehabilitation, to be defined in the following section.

1.5 Holistic rehabilitation at the CRBI in Copenhagen

In addition to the older tradition of providing rehabilitation to people in the acute phase of the injury , several centres have been established to address the long-term consequences, by offering rehabilitation in the post-acute phase, after the individual with brain injury has been discharged from hospital and is no longer a patient in a formal sense. Yehuda Ben-Yishay and Leonard Diller were the first to establish such centres in Israel and New York (Prigatano, 1986). The Centre for Rehabilitation of Brain Injury at the University of Copenhagen (CRBI) was established by Anne-Lise Christensen in 1985 as the first of its kind in Denmark, followed closely by Vejlefjord. Today, this kind of treatment is offered at several centres in Denmark (Odense, Roskilde, Sønderjylland, Vejle, Aalborg, Århus) and around the world (Australia, England, Finland, Germany, Holland, and the United States).

Trexler and Helmke (1996) describe the characteristics of holistic neuropsychological rehabilitation programs. Defining features are: individualised goal setting, holistic rehabilitation planning, neuropsychological orientation, therapeutic milieu, outcome oriented rehabilitation planning, intensity of rehabilitation program and brain injury rehabilitation expertise. *Individualised goal setting* means the involvement of participants and families directly in finding and setting short and long-term rehabilitation goals, and that type and intensity of specific therapies are tailored to the individual. *Holistic rehabilitation planning* includes a ‘primary therapist’ who works individually with the participant to facilitate understanding of the purpose of the program and the relevance of specific therapies.

Furthermore, joint staff plan and make decisions about transdiciplinary treatment and the involvement of the family in the rehabilitation process. *Neuropsychological orientation* means that the treatment focuses on neuropsychological impairments such as awareness, cognitive deficits and emotional reactions to injury and disability, and addresses these directly. *The therapeutic milieu* is formed by group therapies to address awareness, social skills and acceptance. All aspects of the program incorporate feedback from peers and staff. *Outcome-oriented rehabilitation planning* covers therapies provided at home, in the community, and in vocationally relevant situations, in order to promote generalisation to supplement clinic-based therapies. A follow-up is also scheduled after discharge to monitor maintenance of rehabilitation gains. *Intensity of rehabilitation program:* the program must be of a duration and intensity sufficient to promote transfer of learning. The *brain injury rehabilitation expertise* includes a locale with staff dedicated to brain injury rehabilitation and a patient-to-staff ratio no greater than 2:1. The staff must be experienced and include at least one neuropsychologist.

The CRBI offers intensive holistic neuropsychological rehabilitation to adults with acquired brain injury. It is inspired by the principles of group based rehabilitation as proposed by the programs founded by Ben-Yishay and Prigatano; the individual, qualitative approach of Luria; and Goldstein’s concepts of adjustment and seeing the individual behind the brain injury (Caetano & Christensen, 1997). Further details of the program will be presented in Table 1.2 and in the following methodological chapter (chapter 2) as well as in the article concerning the participants’ satisfaction with rehabilitation at CRBI (chapter 6).

1.6 Findings from studies of holistic rehabilitation

Studies concerned with holistic rehabilitation have mainly reported outcome and possible predictors of outcome within the areas of employment, neuropsychological test-results and health related results. The reviewed studies show differences in their focus; some studies are concerned with general outcomes such as participation and other studies have reported results from more specific measures such as physical fitness. The present section describes primarily results in the area of employment since this has been the most prevalent outcome measure. Other outcome areas of importance will be described in the following section, 1.7. For detailed information about the reviewed studies Table 1.2, Table 1.3 and Table 1.4 show subject characteristics, treatment intervention and results from 37 studies of holistic rehabilitation (beginning at page 31).

General findings:

Most studies have looked at pre-program to post-program changes (16, 22, 25, 27, 31, 32, 36) with one additional follow-up (1, 2, 4, 5, 7-9, 11 -15, 17 - 20, 23, 24, 28- 30, 32, 33, 35, 37) Four studies have looked at maintenance of gains either in terms of finances (6) productivity (3, 10, 21) marriage (10) or leisure (10) and the disability rating scale (21). Productivity decreases from pre-injury to program and increases after program, generally maintaining gains from one to three years post-rehabilitation. Leisure activities and the proportion in a marriage also increased during the program and gains were maintained. One study (21) showed that scores on the Disability Rating Scale were dynamic, since some declined in function from post-program to follow-up on this scale. Financially, it was seen that costs of the rehabilitation program in Denmark was almost recouped after 3 years due to savings on financial support, public services and treatment, and that the municipalities would have earned a small surplus after an estimated 5 years (6).

Productivity is a term used in the study to cover any employment related activity including full- or part-time competitive work or education as well as any kind of supported, sheltered and volunteer work. Productivity at follow-up after holistic rehabilitation programs has been 31%-90% in the 29 studies. The productivity in control groups (study 30, and 32 to 37) has ranged from 17% to 94%. A previous review of post-acute brain injury rehabilitation (Malec et al., 1996) found that 71% of 856 subjects who had received some kind of post-acute rehabilitation were employed after this kind of rehabilitation compared with only 53% of 796 subjects that had received no, little or only inpatient rehabilitation.

When looking at employment over the long-term after brain injury in general there has been a tendency for vocational status to decrease over time (Olver, Ponsford, & Curran, 1996; Ashley, Persel, Clark, & Krych, 1997). Looking at the results (in Table 1.4) after holistic rehabilitation, however, there does not seem to be this pattern. At post-program 36-68% were employed (16, 36), at 3 to 9 months after program 52% to 83% were employed (1, 31, 14, 37), at 1 year the productivity rate was 31% to 90% (2,8,9,20,37) and at 1 to 5 years the productivity rate was 60-89% (3,7,13,15,29, 33, 35). Those studying outcome from 1-11 years post-rehabilitation report a productivity rate ranging from 47% to 88 % (4, 18, 19, 24, 28). No decline in productivity post-program was seen in the long-term follow-up studies by Klonoff and colleagues (18, 19, 28). These findings support those studies demonstrating maintenance of vocational gains 1 to 3 years after rehabilitation (3, 10, 21).

With one exception, the holistic programs report of higher productivity compared to control groups and the gains have been seen to be maintaned over as long a period as 11 years after rehabilitation.

In addition to increased productivity, the reported studies also present other areas of potential outcome after holistic rehabilitation. These areas are: goals met in rehabilitation (20), reduction in symptoms of brain injury or disability (20, 25, 27, 32, 36) return to or increase of leisure activities (7, 8,10), marriage (7, 8,10, 28), independent living (2, 8, 9, 14, 21), increase in social life (2, 20, 21) improved intra- and interpersonal factors (such as self-esteem, self-awareness, social cooperation, ability to display empathy, decreased stress) (1, 11, 20, 30, 31, 37), improved cognitive measures (1, 27, 30, 34,13, 2, 20, 31), physical improvement (2, 29), decrease in need for health services (8), and driving safely (27,28).

There are some limitations and biases in interpreting and comparing results. One area of potential bias is participation rate. The studies have included from 12 to 164 participants and there has been a participation percentage ranging from 40-100%. The British Medical Journal makes a general recommendation of no lower than 80% participation rate in order to avoid misrepresentation. About half the studies that inform the reader of participation rates are above this criterion. Some studies have not reported attrition at all, but most of the studies reporting participation rate have found some but not many differences between those who participated and those who did not.

Another area in which the studies differ is that of included injury types. It can be seen that the studies differ in terms of including only TBI (1, 5, 12, 15, 17, 21, 22, 27, 30, 31, 32, 34, 35 and 37) or a mix of brain injury aetiology. Study 8 compared outcomes of participants with CVA to outcomes of participants with TBI. This study found similar patterns of psychosocial decline from pre-injury to pre-program and improvement during and after rehabilitation in terms of marriage, independent living, use of health services, employment and leisure activities. Four studies found no difference in employment between CVA and TBI patients (10, 13, 16 and 24). Study 25 found that those with CVA reported lesser somatic, cognitive, impulsivity and isolation symptoms of brain injury than the TBI group.

The studies also differ considerably in how they categorise injury severity, and in the reported injury severities. Some use GCS, others provide length of coma or length of hospitalisation and others give neuroimaging details. Injury severity was found to have a negative impact on employment outcome in two studies (5, 15) and no effect in others (9, 10, 13, 24 and 35). One study showed better adjustment in the more severely injured (16). This latter study made adjustments for injury severity upon admission. Possible explanations for the variance in how injury severity relates to outcome could be the use of different measures, restricted range of injury severity included and retrospective assessment of GCS or PTA which may be subject to bias.

Rehabilitation related predictors of outcome

Chronicity of injury means the time from injury to rehabilitation or point of measurement. Chronicity has been debated as important for outcome. Malec & Basford (1996) reported several studies all indicating that early intervention (or short chronicity) was better than late. The studies reviewed in Table 1.2 show that the chronicity at rehabilitation varies in subjects from 1 month to 25 years. Studies 9 and 22 found that beginning rehabilitation within the first year has a positive effect on employment, but study 22 did not find a significant effect of chronicity on social and home-integration, study 4 found that those beginning within 5 years of injury have better employment outcome than those beginning later. Seven studies including three controlled studies found no effect of chronicity (10, 13, 15, 20, 30, 33 and 35).

In the reviewed studies, cognitive status or functioning has been measured by neuropsychological tests as well as rating scales. Two of the reviewed studies found no relationship between cognitive gains during rehabilitation and vocational status (32 and 13), but one controlled study (30) and one study of mild head injuries did so (12). Two studies found that better cognitive status pre-rehabilitation (13, 15) was related to better outcome. One study (16) found the opposite. Neuropsychological measures and intelligence have generally been found to correlate with employment (Wozniak & Kittner, 2002; Johnston, Sherer, & Whyte, 2006).

Process measures means here characteristics of the participant in rehabilitation as well as the cooperation between participant, significant other and staff. Several studies have found process measures of importance for outcome. Productivity was positively correlated with individual acceptance of disabilities and rehabilitation program (5), compliance with staff recommendation (3, 29), self-awareness (5, 15) and working alliance (16, 19, 29 and 33). Compliance was also linked to physical outcome and improvement in an attention test, but not to subjectively experienced symptoms (29).

Intensity of treatment describes not only how long the rehabilitation period lasted but also how many hours of therapy the individual received. The intensity of studies presented in Table 1.2 shows that length of rehabilitation varied from 8 weeks to one year, and hours provided ranged from 52 to more than 600. On the one hand, the two prospective controlled studies that show no effect of rehabilitation (31, 37) have programs lasting only 8 weeks. On the other hand, another controlled study (35) lasting only 6 weeks showed significant improvement in terms of employment, and a program (2) lasting 30 weeks showed an unemployment rate of 69% at follow-up (substance abuse and low education may influence results in this study). However, study 37 is based on a military population including a large proportion of persons with fairly mild injury severity. In a subset analysis of 75 individuals with more severe injuries (unconsciousness for more than 1 hour) there was a beneficial effect of the rehabilitation program. Malec and Degiorgio (2002) studied outcome in 114 residents of Minnesota after three different rehabilitation regimes (one of them a holistic/comprehensive day treatment program, the other two less intensive) one year after treatment and found similar percentages of participants in employment (77-85%). Those in the holistic program had less education, longer chronicity, more disabilities and lower self-awareness compared to the other two less intense interventions. The authors concluded that rehabilitation had to be matched to levels of disability and chronicity of injury. This is perhaps why there is no consistent relationship between length and intensity of intervention and outcome (Malec et al., 1996).

It seems like process measures such as compliance, working alliance and awareness are generally positively correlated to outcome. Even though some of the studies also found a positive association between shorter chronicity, greater intensity of rehabilitation and better cognitive status prior to rehabilitation, there was not as clear an association between these rehabilitation related predictors and outcome.

Demographic predictors of outcome encompass the role of age, education, gender and genetic markers.

Age: In Malec & Basford's (1996) comprehensive review of post-acute brain injury rehabilitation, they state that several studies of natural recovery after brain injury have reported an inverse relationship between age and outcome, and those studies that did not find a correlation between age and outcome tended not to include more elderly people. Even though the ages of participants range from 15 to 60 years in the studies reviewed here, the average age either at injury or at the time of rehabilitation is between 20 and 40 in 34 of the studies. Only three studies report an average age above 40 (25, 26, 29), seemingly dependent on injury type, because in one study all subjects have CVA (26) and in the two other studies less than half of the subjects have TBI. Ten of the studies have looked into the importance of age for (different) outcome (4, 10, 13, 19, 24, 25, 26, 28, 30 and 35). Those studies reporting a beneficial effect of young age (13, 19, 24, 28) all studied groups with average ages above 30, whereas two studies (10 and 30) finding no effect of age on productivity studied comparatively younger groups. However, two studies (4, 35) in which no effect of age on productivity was found had average ages of 30-31, and in two studies (25,26) the average age was above 40, only one of them (26) looking at productivity, the other (25) at self-reported symptoms. The controlled study found no effect of age on outcome two years after rehabilitation.

Education: Most of the studies listed in Table 1.1 report an average length of education ranging from 10 to15 years. Some studies, however, only report vocational training, making comparison difficult. Those studies (5, 9, 19, 28, 30, and 33) that investigated the importance of education for vocational outcome provided mixed results, and these had an average length of education of 12 to14 years. Four studies with follow-up times ranging from six months up to 11 years (5, 9, 19, and 30) found no effect, and two studies (28 and 33) with follow-up one to seven years after rehabilitation found a positive association between higher education and productivity. However two of the studies found a connection between productivity outcomes and premorbid intellectual capacity as measured by neuropsychological tests (study 9 reading ability, study 5 verbal aptitude). A recent review (Johnston et al., 2006) concluded that there is a positive association between employment and education found in studies of the TBI population.

Gender: Apart from a sub-sample of CVA participants, the male percentage ranges from 50% to 96%. In the general literature there is no clear effect of gender on productivity outcome after TBI and CVA (Johnston et al., 2006; Wozniak et al., 2002). Four of the presented studies have likewise reported of no effect of gender (10, 13, 28 and 35) and a positive effect of male gender on vocational outcome was found in three studies (19, 24, 26). In study 25, the males showed a greater decrease in symptoms from pre to post-program.

Study number 8 is included to demonstrate the possible genetic influence on outcome after rehabilitation. Those who carried a possible genetic marker for Alzheimer's disease showed a significant increase in brain injury symptoms according to the European Brain Injury Questionnaire as answered by themselves and their significant others, whereas those who did not carry this marker showed improvement in the same time period from six months to three years post-injury.

It is difficult to draw a clear conclusion, but in some studies younger age, male gender, higher education and genetic markers did have some bearing on a positive outcome.

This section has presented outcome mainly on the participatory level, considering such measurables as productivity, leisure activities and marriage. The next part of this chapter will be devoted to rehabilitation outcomes on a more subjective level, primarily concerning personal factors, level of activity and impairment and subjective well-being.

Table1.2 Subjects Level III – non-controlled	n	Total population	Age at injury (I)/program (P) (SD and or range) in years	Education (years)	Gender M/F %	Pre-injury empl/ edu %	Injury type (%)	Chronicity in years (SD and or range)	Severity of injury (SD and or range)
1. Ben-Yishay et al. (1985) (6 year clinical study	90 90%	100 (10 with-drew)	Average age mid-twenties	?	67/33	?	100% TBI	?	Coma from several days up to three months
2. Scherzer (1986) 3 consecutively treated groups	32	?	I: 22 (9-37) P: 27 (19-44)	12 (7-15)	78/22	~54	94% Closed head injury 3% multiple emboli, 3% open head injury	5 (1-20)	46 (0-180) days 19% were drugabusers prior to injury
3. Ben-Yishay et al. (1987)	94 93%	101	I: 27 (10,15-60)	14 (3, 8-20)	76/24	?	97% TBI 3% Other	3 (2½, ⅓-17¼)	Coma 34 (34, 1-120) days Behavioural competency Index 6.6 (1.5) 52% unsuccessful return to work/study 26% unsuccessfully involved with vocational agencies
4. Hoofien et al., (1990) (consecutively treated patients from 1976-85)	85 93%	91 6 drop-outs	P: 30 (20-52)	?	89/11	?	7% CVA 16% Gunshot 60% Car accidents 7% neurosurgery 11% Other (blast injury, suffocation)	>= 1 (1-11)	All considered failures by referring agencies 21% Right, 25% Left 54% Diffuse/bilateral
5. Ezrachi et al. (1991) (4 year period)	59	?	P: 27 (10)	14 (2)	?	?	100% TBI	2¾ (2⅓)	Coma 26 (31) days, Moderate to severe injuries
6. Larsen et al. (1991) (Those treated in 1987)	20 100%	20	P: 27 (16-48)	45% 9 years 55% 10-12	50/50	?	55 % TBI 30 % CVA 15 % Other	3 (2, ⅔- 9)	Coma (n=14) 18 (12, 1-42) days Hospitalisation 153 (137, 21-395) days
7. Christensen et al. (1992) (85-87) 2½ years of consecutively treated)	46 97%	47	P: 30 (11, 16-58)	10 (2, 7-12)	?	96	48 % TBI 30 % CVA 22 % Other	2.9 (2, ½-14)	Coma (days): 0 = 22%; <1 20%; <7 15%; >= 7 41%, unknown 2% 15% Hospitalisation 191(15-798) days 28% had hemiparesis 22% Psychiatric treatment prior to program 35% Unsuccessful vocational return

Table 1.2 page 2 Subjects level III – non controlled	n	Total population	Age at injury (I)/program (P) (SD and or range) years	Education (years)	Gender M/F %	Pre-injury empl/ edu %	Injury type (%)	Chronicity/years (SD and or range)	Severity of injury (SD and or range)
8. Teasdale et al. (1993) All treated 85-87	36	?				?			
TBI	22		P: 27 (9)	10 (2)	73/27	95	61 % TBI	3 (3)	Coma: No 5%, <7 days 36%, >=7 days 59% Hospitalised. 138 days (96)
CVA	14		P: 36 (12)	11 (2)	43/57	100	39 % CVA	3 (2)	Coma: No 57%, <7 days 36%, >=7 days 7% Hospitalised 60 days (49)
9. Malec et al. (1993)	29 78%	37 (8 drop-out lwr educat.)	P: 33 (12, 18-60)	7% < highschool = 52% < 41%	69/31	?	69 % TBI 14 % CVA 17 % Other	4 (6, 0.1 - 25)	Loss of consciousness 13 days (15, 0-60) Mild to moderate (DRS scaled)
10. Teasdale et al. (1994) Consecutively treated 1985-88	67 100%	67	I: Median 24 (8-55) P: Median 27 (range 16-59)	54% 9 yrs 46% 10-12	61/39	100	54 % TBI 30 % CVA 16 % Other	2 (⅔-14)	Coma in days 8 (4-21) Hospitalisation in days 75 (1-395)
11. Teasdale et al. (1995) Consecutively treated 1989-91	30 43%	71 (41 incompl data)	I: 32 (14)	?	73/27	?	37 % TBI 37 % CVA 36 % Other	3 (4)	Coma in days 6 (6) Hospitalisation in days 67 (47)
12. Cicerone et al. (1996)	20	?					100 % Mild traumatic brain injury	Months	Mild (GCS 13-15, LOC < 30 min, PTA <24 hours) About half had failed in returning to work
Good outcome	10		P: 35	15	?	?		7	
Poor out come	10		P: 39	15	?	?		8	
13. Teasdale et al. (1997b) Consecutively treated 1989-92	55 66%	83 14 un-traceable 12 with aphasia	I: 31 (13) P: 34 (12)	49% 9-10 years 51% 1-3 years more	60/40	?	40 % TBI 34 % CVA 26 % Other	3 (50% within 1½ year)	Coma in days 7 (7) Hospitalisation in days 78 (68) According to Glasgow Outcome Scale moderately disabled, some severely disabled
14. Sherer et al. (1997)	13	?	I: 34 (10)	15 (2)	61/39	100	100% Brain tumor survivors	6¼ (7⅓)	? (moderate to severe) ?
15. Sherer et al. (1998a)	66	?	P: 32 (12, 17-67)	13 (3, 6-21)	76/24	?	100% TBI	¾ (1⅔)	67% severe, 12% moderate, 17% mild, complicated, 5% mild 97% unaware of deficits according to clinician

Table 1.2 page 3 Subjects level III non-controlled	n	Total population	Age at injury (I)/program (P) (SD and or range) in years	Education (years)	Gender M/F %	Pre-injury empl/ edu %	Injury type (%)	Chronicity/ years (SD and or range)	Severity of injury (SD and or range)
16. Klonoff et al. (1998), consecutively treated from 1992-1996	64	?	35 (14-64)	14 (8-20)	69/31	?	58 % TBI 30 % CVA 12 % Other	Median 2 (½-80) months	TBI (n=24): GCS 9 (4) Judged: 48% severe 17% moderate 35% mild
17. Klonoff et al. (2000)	112 79%	142	31 (14-62)	14 (8-21)	69/31	97	100 % TBI	¾ (0.1-1½)	GCS (n=76) = 8 59 % severe 17 % moderate 24 % mild
18. Teasdale et al. (2000) 1993-1996	39 72%	54	33 (16-56)	2 (on scale from 0 none to 5 academic)	64/36	?	49 % TBI 46 % CVA 5 % Other	2 (2)	Coma 6 (10) days Hospitalisation 69 (62) days 26% with genetic marker
19. Klonoff et al. (2001) Successful discharge 1986-98	164 74%	207	34 (14-64)	14 (8-21)	66/34	94	69 % TBI 23 % CVA 8 % Other	1.2 (0.1-1½)	GCS (n=74) 61 % severe, 18 % moderate, 21 % mild reflecting total sample
20. Malec et al. (2001), consecutive adm. 88-98	96 85%	113 (drop-outs less chronic.)	34 (12)	<12: 16 % 12-15: 62 % > 15: 22 %	73/27	?	72 % TBI 19 % CVA 9 % Other	5 (7)	TBI 82 % severe 7 % moderate 7 % mild 4% undetermined
21. Sander et al. (2001) Enrolled 93-96	36 40%	86 50 miss data, +chronic	31 (2)	18% < highschool = 24% < 58%	68/32	94	100 % TBI	¼ (0.2)	50% Severe 50% mild to moderate
22. Seale et al. (2002	71 82%	87					100% Closed head injury		92% severe
< 1 year post injury	32		I: 29	12	75/25	78		0.6	GCS in ER = 7 Pre-injury: Psychiatric treatment 28% Alcohol abuse 59% Drug abuse 44%
> 1 year post injury	39		I : 27	12	67/33	84		2.4	GCS in ER = 5 Pre-injury: Psychiatric treatment 15% Alcohol abuse 44% Drug abuse 28%

Table 1.2 page 4 Subjects level III – non controlled	n	Total popula-tion	Age at injury (I)/program (P) (SD and or range) in years	Education (years)	Gender M/F %	Pre-inj. Employ / educ. %	Injury type (%)	Chronici-ty/years (SD and or range)	Severity of injury (SD and or range)
23. Ponsford et al. (2003) Consecutively enrolled	143 65%	220 compare-able	I: 34 (14)	11 (2)	?	?	Relatives of TBI participants, 39% mothers, 34% spouses, 11% sibling, 4% children	0.1 (0.1)	GCS: 72% severe, 15% moderate, 13% mild PTA: 29% <7 days, 32% 8-28 days, 39% PTA>28 days
24. Johansen et al. (2004) Consecutively admitted from 1992-2002	150 70%	215	I: 38 (12)	28% none 5% special worker 44% skilled worker 16% longer 7% academic	60/40	~ 90%	41 % TBI 45 % CVA 14 % Other	2⅓ (3.8)	Days in coma: 8 (9) Hospitalisation 112 (96) days Mild to moderately severe
25. Svendsen et al. (2004) Enrolled for treatment 1997-2001	143 70%	204 (longer chronicity and m TBI)	I: 41 (12)	4 (scale from 0 none-5 academic)	58/42	?	27 % TBI 60 % CVA 13 % Other	1 (2)	Days in coma: 2 (4) Hospitalisation 71 (75) days
26 Adams et al. (2004) Enrolled for treatment 1991-1999	127 69%	183	I: 48 (25 percentile=38, 75 percentile =54)	7% less than 28% high school, 23% some college 42% college	61/39	100	100% CVA	0.2	Hospitalisation in days 113 30% Right, 38% Left, 24%subcortical, 7% bilateral
27. Leon-Carrion et al. (2005)	17	?	I: 23 (7)	14 (8-21)	60/40	?	100 % TBI	0.9 (1⅓)	Severe TBI: GCS = 6 (3) All had drivers licence
28. Klonoff et al. (2006) Successful dis-charge last 7 y	93 47%	206	I: 37 (15-65)	14 (8-21)	67/33	99	54% TBI 26% CVA 20 % Other	1.8 (0.04-34)	GCS (n = 38) 66 % Severe 13% moderate 21% mild
29. Schoenberger et al. (2006)	98 95%	103	I: 42 (12) P: 44 (12)	?	57/43	?	27 % TBI 59 % CVA 14 % Other	55% < 1 y 90%<2 ½ years	Hospitalisation days 93 (97)

Table 1.2 page 5 Subjects from controlled studies	n	Total popula-tion	Age at injury (I)/program (P) (SD) in years	Education (years)	Gender M/F %	Pre-injury empl/ edu %	Injury type (%)	Chronici-ty/ years (SD)	Severity of injury Mean (SD and or range)
30. Prigatano et al. (1984)									Loss of consciousness
Rehab	18	?	I : 26	13	83/17	100	100% TBI	1.8	Between 1 and 21 days, One > several wks
Control	17	?	I : 23	12	88/12	100	100% TBI	1⅓	Between 1 and 14 days, One > two weeks
31. Ruff & Niehman (1990)	Prospective					?			
Holistic	12		31 (10)	13 (2)	67/33		Head injured	4⅓ (1.6)	Coma 48 days (28)* GOAT, DRS, RLT
Cognitive rehab.	12		28 (9)	13 (1)	75/25		Head injured	3⅔ (2⅛)	Coma 26 days (16)*GOAT, DRS, RLT
32. Rattok et al. (1992)		?				?	95% TBI 5 % Other		
Mix I Holistic	23		27	14	65/35			2⅔	Coma 34 days, BCI 6
Mix II	18		27	14	89/11			2¾	Coma 39 days, BCI 7
Mix III	18		28	15	61/39			3	Coma 37 days, BCI 7
33. Prigatano et al. (1994)	93%								
Holistic	38	41	I : 30	14	68/32	100	100 % TBI	3.6	GCS: 8.1
Control	38	?	I : 29	12	71/29	100?	100 % TBI	2.8	GCS: 8.0
34. Cicerone et al. (2004)	Prospective (1997-98) 100%								
Holistic	27	56	38	13	63/37	96	100 % TBI	2.8 (0.4)	89% severe
'Standard'	29		37	13	79/21	96	100 % TBI	0.4 (0.8)	89% severe
35. Saarajuuri et al. (2005)									In both groups approximately 30% had attempted work before referral.
Holistic	19	?	I : 31		84/16	84	100 % TBI	3½	GCS: 7.9 (3-14), contusion 79%, DAI 42%, ICP 37%, craniotomy 21%
'Standard'	20	213	I : 30		85/15	85	100 % TBI	3.9	GCS: 8.0 (3-14), contusion 80%, DAI 25%, ICP 25%, craniotomy 25%

Table 1.2 page 6 Subjects from controlled studies	**n**	**Total populat.**	**Age: Injury (I)/ Program(P) (SD)**	**Education (years)**	**Gender M/F %**	**Pre-injury employ /edu %**	**Injury type (%)**	**Chronici-ty/ years (SD)**	**Severity of injury (SD and or range)**
36. Hashimoto et al. (2006)	Prospective			?					
Holistic	25	?	P : 27 (10)		72/28	96	88% TBI 12% Other	1.4 (1.4)	76% Severe, 20% Moderate, 4% unknown FIM motor at program 88 (8) FAM cognitive at program 30 (4)
'Standard'	12	?	P : 29 (11)		?	?	At least 83% TBI	1⅓ (⅓)	83% Severe; FIM motor at program 89 (4) FAM cognitive at program 30 (4)
37. Salazar et al. (2000)	Military (1992-97)								
Holistic	67	167 (72%)	I/P: 25 (7)	41% College	93/7	100	100 % TBI	0.1 (0.1)	Coma > 1 hour: 53%, Coma > 24 h: 30% GCS 9.4 (3.7), PTA > 7 days: 41%, MRI 51%
Home program	53		I/P: 26 (6)	44% College	96/4	100	100 % TBI	0.1 (0.1)	Coma > 1 hour: 76%, Coma > 24 h: 38% GCS 9.5 (3.4), PTA > 7 days: 42%, MRI 54%

Table 1.3 **Intervention**	**Treatment**			
	Duration	**Intensity**	**Estimated Treatment hours**	**Type**
Studies 1, 3, 5, 32 New York 1. Ben-Yishay et al.(85) 3. Ben-Yishay et al.(87) 5. Ezrachi et al. (91)	20 weeks	5 hrs/day 4 days/week	Approximately 400 in first phase	Three phases I Intensive, holistic remedial intervention II Individualised, guided occupational trials culminating in placement III Follow-up
32. Rattock et al. (1992)	20 weeks	5 hrs/day 4 days/week	MI: All elements 400 hrs MII: No cognitive more interpersonal 400hrs MIII: No interpersonal more cognitive 400 hrs	Three phases: I Intensive, holistic remedial intervention II Individualised, guided occupational trials culminating in placement III Follow-up Program elements: attention training, cognitive remediation, group interpersonal exercises, community activities, personal counselling.
2. Canada Scherzer (1986) 3 consecutively treated groups	Approximately 30 weeks 3 modules of 10 weeks	?	First year 336 hours Following 386	Based on the New York model and adapted Cognitive training, community activities, personal counselling, physical activity, social skills and pre-vocational training as well as job trials and reintegration into the work force
4. Israel Hoofien et al., (1990)	1 year rehabilitation ~2 year work trial	Daily		Intensive, multidisciplinary, individual and group: psychotherapeutic, cognitive, social and vocational interventions Two phases I intensive rehabilitation II supervised work-trial
Copenhagen Study 6, 7, 8, 10, 11, 13, 18, 25, 29 6. Larsen et al. (1991) 7.Christensen et al(92) 8. Teasdale et al. (93) 10. Teasdale et al. (94) 11. Teasdale et al. (95) 13. Teasdale et al(97b) 18. Teasdale et al. (00) 25. Svendsen et al.(04) 29. Schoenberger et al.	4-5 months in the program	4 days/week 6 hours a day	468 hours in the intensive program	Objective: Achieve independence in home and community and to return to productive work. Program based on Luria and BenYishay & coworkers and Prigatano and associates. Group and individual therapies. Focus on awareness, acceptance and psychosocial adjustments and cognitive remediation Follow-up: 6 monthly group meetings, and individual contact and help to vocational trial according to need

Table 1.3 page 2 **Intervention**	**Treatment**			
	Duration	**Intensity**	**Estimated Treatment hours**	**Type**
9. + 20 Minnesota Malec et al. (1993)	On average 28.2 weeks	+/- 4hours per day 5 days a week	568 Hours	Focus on group therapy; increasing insight into disabilities and compensation, emotional and behavioural self-management; specific group and individual treatment provided as needed, each patient has a team leader Daily group sessions to build behavioural and cognitive skills through a transdisciplinary approach, supportive feedback and a variety of therapeutic modalities. Aim to improve:1) self-awareness, compensational skills, personal organisation, social skills and organisation, emotional and behavioural self-management, health maintenance and social, vocational and leisure participation.
20. Minnesota Malec et al. (2001), consecutively admitted from 1988-1998	On average 27 weeks	+/- 4hours per day 5 days a week	540 hours	
Texas Challenge Program 14. Sherer et al. (1997)	2.6 months (SD = 1.9) of stay	5 hrs/day 20 (12.9) days of treatment	~100 hours on average	1) Individualised transdisciplinary treatment in groups or individually, designed to decrease the impact of impairments on daily functioning in home and community. Patient and relatives received education and counselling 2) Treatment and volunteer work trial 3) Assistance, feedback and follow-up in return to desired vocational position. Focus: teaching patients compensatory strategies, arranging environmental support to maximise functioning, counsel and educate to further personal and family adjustment and awareness.
15. Sherer et al. (1998)	?	5 hrs/day	?	
21.Sander et al. (2001)	4.2 months (+-1.8) (1 to 7.6 months)	?	?	
26. Adams et al. (2004)	Median 4.7 months	?	?	
Phoenix AZ 32. Prigatano et al. (1994)	often 6 months	4-6 hours a day, 4-5 days a week	(~585 hours) + 4 months protected work trail 15-20hrs week	Systematic intensive interdisciplinary day treatment model, individual and group psychotherapy, cognitive, physical, occupational, recreational and speech/language therapies. Aim to help pts cope with the effects of brain injury and promote return to meaningful productive lives. Focus: increasing awareness and acceptance of injury and deficits, developing compensatory strategies, increase understanding of emotional and motivational responses. Family education and support is integral to the process, individual family meetings, program observation and weekly family group.
16. Klonoff et al. (1998)		5 days a week 8.15 to 14.30 6.15	Based on study 31 Approximately 500-600 on average	
17. Klonoff et al. (00)	6.2 months	4-5 days a week		
19. Klonoff et al. (01)	6 months (0.8-18)	4-5 days a week		
28. Klonoff et al. (06)	5.7 months (0.8-15.5)	4-5 days a week		

Table 1.3 page 3 Intervention	Treatment			
	Duration	Intensity	Estimated Treatment hours	Type
22. Texas Seale et al. (2002) < 1 year post-injury > 1 year post-injury	On average 146 days.Rehabilitation for at least 45 days;	?	?	Multiple program type rehabilitation system – maybe more broad spectrum than ‘holistic’: Individuals usually residing at the facility. Treatment given: medical, case management, physical, occupational and speech therapy, residential services, therapeutic recreation, vocational services and neuropsychology.
23. Melbourne Ponsford et al. (2003)	?	?	?	?
24. Aarhus, Denmark Johansen et al. (2004)	4 months	6 hrs/day 4 days a week,	~408 hours plus additional follow-up and work trial support	Objective: Achieve independence in home and community and to return to productive work. Program based on Luria and BenYishay & co-workers and Prigatano and associates. Group and individual therapies. Focus on awareness, acceptance and psychosocial adjustments and cognitive remediation
27. Spain Leon-Carrion et al. (2005)	On average10.5 (sd = 6.2) months	?	?	Intensive, multidisciplinary, holistic, neuro-rehabilitation program
30. Oaklahoma Prigatano et al. (1984)	6 months	6 hr/day 4 days a week	(~624 hours)	Group and individual Aim: increasing awareness and acceptance, development of compensational strategies, increase understanding of emotional and motivational responses to injury
31. San Diego CA Ruff & Niemann (1990)	8 weeks	4 days / week ~18 hrs/week	140-144 hrs total	Day treatment program Cognitive remediation including group psychotherapy and daily wrap up
35. Finland Saarajuuri (2005)	6 weeks	7½ hour daily	Approximately 195 hours	Modelled over New York, Phoenix and Copenhagen program Post-acute, intensive, interdisciplinary focus on neuropsychological rehabilitation and psychotherapy with vocational intervention and follow-up support.

Table 1.3 page 4 **Intervention**	**Treatment**			
	Duration	**Intensity**	**Estimated Treatment hours**	**Type**
Edison NJ 12. Cicerone et al. (1996)	?	?	?	Various components of a neuro-rehabilitation program according to need: neuropsychological and cognitive remediation, psychotherapy, functional skills training neuromedical management and neurosensory training and work trial
Good out come				
Poor out come				
Edison NJ 34.Cicerone (2004) Holistic	4 months	4 dys/week 5 hours/day 1 day/wk vocational	ca 340 hours	Individual and group cognitive remediation program with emphasis on feedback and interpersonal group process. Emphasis on increasing awareness and developing compensations for cognitive deficits, small group treatment for interpersonal and pragmatic communication skills, individual and/or group psychotherapy, family support and therapeutic work trials and placements to facilitate educational or vocational readiness.
'Conventional'	4 months	Between 12-14 hrs/wk	ca 306 hours	Individual physical and occupational therapy + speech and neuro-psych treatment
36. Japan Hashimoto et al (2006)	grp 1: 6 mdr grp 2-4: 3-4 mths, Controls ?	grp 1: 4 hours /day 5 days/ week grp 2-4: 2 hrs, twice a week Controls ?	grp 1: 520 hours total grp 2-4: 52-68 hours total Controls?	Modelled over New York program Case management, explanation of disorder, psychological/speech, recreational, occupational, vocational, physical, welfare therapies, coordination with families.
Washington, DC 37. Salazar et al. (2000) Holistic	8 weeks	5 days a week	?	Modelled on Phoenix program Hospital cognitive rehabilitation program modelled over Holistic and neurobehavioural rehabilitation with individual and group therapy (but in an in-patient setting) including work placement
Home program	8 weeks	½ hour telephone contact / week	4 hours of telephone contact ~20 hours self-training	Limited home rehabilitation program (encouragement to engage in activities) with weekly ½ hour telephone support from a psychiatric nurse

Table 1.4 Results	Areas of outcome /Measures	Time of measure	Results, sometimes combined in one large section		
			Employment	Other	
1. Ben-Yishay et al. (1985)	Employability Actual employment Cognitive tests Staff ratings of interpersonal measures	3 and 9 months after beginning work trial	3 mo ratings: 76% employable in open market (50% competitively, 25% subsidised or part time work) 11% sheltered 13% unemployable 9 mo: Actually employed: 65% in open market, 15% sheltered work shops 20% unemployed.	Improvement on self-esteem self-appraisal (self-awareness) ability to display empathy social cooperation	Significant improvement on cognitive measures Failures in work integration due to inadequate follow-up, maintenance, support systems, involving primarily those who came from distant places
2. Scherzer (1986)	Neuropsycholgical tests Employment Independence at home	5 time points last time 1 year after program	9% employed or independent homemaking 22% supported work 69% unemployed	Major improvement in several areas of activities 75% improves in intellectual, social and interpersonal lives,	Physical improvement (n=10) : endurance, grip strength and spinal flexibility 14 cognitive tests shows no improvement 75% relatives (65% participants) saw improvement in home life
3. Ben-Yishay et al. (1987)	Employment	pre program, post-program, ½, 1,1½,2,2½,3 years after rehabilitation,	Productivity at program completion: 84%, ½ year 80% 1 year 78% 1½ year 70% 2 year 76% 2½ year 77% 3 year 70% Competitive Employability rate (n = 36 who completed all 3 years): program completion 64% 1 year 62% 2 years 59% 3 years 50% Loss of work productivity related to: social isolation, forgetting rehabilitation strategies & financial disincentives Pts willingness to adopt compensatory strategies was related to stable employment		
4. Hoofien et al. (1990)	Full or part time employment (most of the time since rehab): 4) competitive position 3) sheltered position 2) remain unemployed 1) no data available	Pre-program status compared 2-10 years after rehabilitation	64% of the participants improved compared to pre-rehabilitation status : 33% employed competitively, 31% sheltered employment, 28% showed no improvement, (no valid data for 8%) No effect of: age at rehabilitation, or laterality of lesion Effect of shorter chronicity (1-5 years better outcome than those admitted later)		

Table 1.4 Results p.2	**Areas of outcome /Measures**	**Time of measure**	**Results, sometimes combined in one large section**	
			Employment	Other
5. Ezrachi et al. (1991)	Employability Actual employment Cognitive tests Behavioural Competency Index (BCI) Staff ratings of process measures	Pre-program Post-program ½ year after program end	Predictors of actual employment (step wise multiple regression: Pre-program measures: adaptation to community, verbal aptitude, length of coma and self-appraisal Post-program measures: acceptance of program, verbal aptitude, length of coma, involvement with others, dexterity and self-appraisal (self awareness) Acceptance (of program and problems of head injury) was single strongest predictor of both potential and actual outcome; post- program measures better than pre-program measures in both prediction potential and actual employment. The ability to know in advance who will benefit is modest. Is employability more pure measure (due to potential job availability and transportation)? Verbal aptitude (WAIS comprehension, vocabulary, similarities and Info) suggesting pre-injury intellectual capacity is important, but education did not appear as an important factor.	
6. Larsen et al. (1991)	Financial burden on society. Information acquired from municipalities. Pre-program costs based on the 3 months prior to program.	Pre-rehabilitation Post-rehabilitation 1 year, 3 year + Estimated 5 year follow-up	Program cost 35200$ Savings on financial support, public services and treatments on 3½ year 32667$ After 5 years the cost of the CRBI program was earned and the public sector saved 11500$ Largest savings on: speech therapy, support person, psychologist counselling, institution, outpatient hospital visits Increased spending on vocational training and foster families. Large variability in data.	
7. Christensen et al. (1992)	Questionnaire for occupation Leisure Marriage Received help Health visits	pre-injury, pre-program, post-program 1 to 2½ yrs post-program	70% work, education or voluntary work at follow-up ~ 20% to pre-injury levels Significant decline in hours from pre-injury to follow-up Significant increase from preprogram to post-program, continued but non-significant increase to follow-up	Other : Leisure activities returned to pre-injury level in terms of hours and social involvement Continuing functional improvement in family life and living conditions, dependence on health services declined Marriage/cohabitation: significant fall from pre injury to program (41% ->26%) significant increase from program to follow-up (26% -> 40%)
8. Teasdale et al. (1993)	Questionnaire for occupation, leisure Marriage/cohabiting use of health service	pre-injury, pre-program, post-program 1 year follow-up	Pre-program no one was able to work or undergo education, 1/3 had tried failed return to work or education. 65% in employment or education at 1 year follow up. Similar patterns of psychosocial decline post-injury and improvement following rehabilitation for TBI and CVA in terms of marriage, independent living, use of health service, employment and leisure activities	

Table 1.4 Results p.3	Areas of outcome /Measures	Time of measure	Results, sometimes combined in one large section		
			Employment	Other	
9. Malec et al. (1993)	Portland Adaptability Inventory (PAI) Goal Attainment Scaling (GAS) Employment	Pre-program Post-program 1 year follow-up	From pre-program to post-program: 7%->59% i transitional or competitive work, 76%->31% unemployed 1 year: 59% in competitive work, 1% in transitional work, 29% unemployed. Employment increases from discharge to 1 year. No effect of coma, education or neuropscyh tests except but reading ability	pre-post: 59%->93% living w/o supervision Increased goal attainment 86% PAI fall from 19->12 1 year: 86% living w/o supervision (no change from discharge to fllw-up)	Extra gains for those with chronicity < 1 year at program
10. Teasdale et al. (1994)	Employment Marriage Leisure	Pre-injury Pre-program Post-program 1-year follow-up 3-year follow-up	All employed 15 % in jobs often pending on rehab 30 % in jobs/education 63 % in jobs/education 65 % in jobs/education No effect of gender, injury-type, age at injury, chronicity at rehab, coma length or hospitalisation	Marriage 45 % 30 % 25 % 50 % 41 %	% engaged in leisure activities 85 % 50 % 65 % 85 % 81 % % engaged solely in leisure activities carried out alone increases from 15 % prior to 30 % at 1 yr and is 23 % at 3 yr
11. Teasdale & Caetano (1995)	SCL-90 (10 scales) American norms	Pre-program Post-program 1 year follow-up	Subjectively perceived stress is diminished during the rehabilitation program and this reduction is sustained at 1 year follow-up. Pre-program: Slight to moderate elevation on all 10 scales. Post-program significant or near significant reduction on 8/10 scales. Small and non significant reductions from post-program to follow-up		
12. Cicerone (1996)	Neuropsychological tests (attention, memory, higher cognitive functions) MTBI Symptom checklist	Pre-program Post-program 1-6 months after program (self-report)	Good outcome group all productive	75% improves on self-reported post-concussive symptom	Significant improvement on 46% of cognitive tests
			Poor outcome group not productive	No gains	Sign. improvement on 7% (1) cognitive test
13. Teasdale et al. (1997b)	Cognitive test battery (attention, visual scanning, memory, word fluency) Employment	Tests pre and post-program (tester not in program) Employment at 1½-5 years f-up	60% actively employed or pursuing education at follow-up 38% at pre-injury level Younger age at injury, but not Injury type, coma, chronicity or gender were related to positive outcome	Significant but small improvements in test scores during program. No evidence that improvements in test scores from pre- to post-program were associated with a positive later outcome. 3/10 test scores pre-program were related to outcome after controlling for age	

Table 1.4 Results p.4	**Areas of outcome /Measures**	**Time of measure**	**Results, sometimes combined in one large section**	
			Employment	Other
14. Sherer et al. (1997)	Independence Productivity	Pre-program Post-program 8 mths follow-up	Unempl comp training volu Pre: 69% 31% Post: 25% 33% 25% 17% F-up: 8% 42% 25% 25%	Frequent monitoring selected monit. Independent Pre 46% 46% 8% Post 38% 24% 38% F_up 33% 17% 50%
15. Sherer et al. (1998a)	Awareness Questionnaire (pt-SO difference) AQ Clinicians rating Rancho Los Amigos levels of cognitive functioning	On average 17 months after rehabilitation (30 months after injury)	67% competitively employed (45% competitively employed, 5% modified position,17% school) 33% (7% volunteer work, 26% unemployed) Predictors: Explaining 31% of the variance: Clinicians rating (odds ratio 7.4) and Patient-SO difference on AQ (odds-ratio 0.26) Full model explaining 41% including: pre injury: employment, abuse; injury severity + chronicity and Cognitive functioning on admission	
16. Klonoff et al. (1998)	Adjusted outcome, adjusted for severity on admission (0-10); Patient attitude, Working alliance (ptt+SO); Work eagerness + readiness, Cognitive test	Pre program Post- program	62% gainfully employed or full time students (16% at pre-injury level), 83% productive at discharge 90% good adjusted outcome Good adjusted patients had more severe injury and longer rehabilitation, better working alliance, Seeking compensation meant lower work eagerness ratings. Better neuropsychological test scores related to poorer outcome. No significant difference between TBI versus non-TBI in terms of outcome	
17. Teasdale et al. (2000)	Apolipoprotien (APOE) e4-carrier, Brain injury symptoms (EBIQ) (ptt-SO), Tests of attention+memory	pre- & post-program; ½-3 years post-program(EBIQ)	EBIQ pre-program to follow-up (patient & SO): non-e4 carriers significant improvements e4 carriers: significant deterioration No effect of e4 from pre to post-program on neuropsychological tests of attention and memory	
18. Klonoff et al. (2000) TBI only	Employment collected by independent rater	3 months, 1,3,5,7,9,11 years after program	88 % were productive up to 11 years after discharge , 77% competitive employment or in school either full or part time (50% full time paid employment) 11% volunteer (8%) or homemaker (3%) 12% retired or not productive in any capacity No decline in productivity or competitive activity seen over time from discharge	
19. Klonoff et al. (2001)	Employment collected by independent rater Working alliance	3 months, 1,3,5,7,9,11 years after program	84% were productive up to 11 years after discharge, (33% at pre-injury level) 67% competitive employment or in school either full or part time (46% full time paid employment) 17% volunteers (12%) or homemakers (5%) 16% retired or not productive in any capacity No decline in productivity or competitive activity seen over time from discharge Better vocational outcome was associated with male gender, younger age, and higher staff working alliance ratings of patients and families, but not education.	

Table 1.4 Results p. 5	Areas of outcome /Measures	Time of measure	Results, sometimes combined in one large section	
			Employment	Other
20. Malec et al. (2001)	Portland Adaptability Inventory (PAI + MPAI) Goal Attainment Scaling (GAS) Vocational Independence scale (VIS) Independent Living Scale (ILS)	Pre-program Post-program 1 year Follow-up	Pre-program 84% unemployed, At 1 year follow-up 57% community employment 39% working independently, 10% in transitional placements and 18% in supported or volunteer work No significant effect of chronicity, even though most dramatic gains in rehab were seen within 1 year of injury 88% drop outs remain unemployed (drop outs had shorter chronicity)	1 year follow-up: GAS: 81% of goals met MPAI/PAI improvements: especially reduction of physical disability, increased self-awareness, emotional self-regulation and increased societal participation. Cognitive functions of memory, attention and problem solving were perceived by staff to improve least Pre program 47% lived independently post-program 69% lived independently 1 year follow-up 72% lived independently
21. Sander et al. (2001)	Disability Rating Scale (DRS) (n = 34) Community Integration Questionnaire (CIQ) (n = 24)	Admission Discharge F-up I: ca. 1 yr F-up II: > 2-5 yr	10% 68% 63% 63%	Significant progress from admission to discharge on DRS & CIQ. Gains generally maintained at follow-up, but dynamic since some individuals declined. 47% worsened on DRS and 9% on CIQ at follow-up. Some may need long-term service.
22. Seale et al. (2002	CIQ	Admission Post-discharge L1Year : 47 days G1Year : 38 days	Those with a chronicity shorter than 1 year at rehabilitation show greater improvement on the productivity scale	No significant different social and home-integration between those starting rehabilitation within 1 year after injury and those commencing rehabilitation later. But larger percentages of participants (less than 1 year post-injury) with positive changes.
23. Ponsford et al. (2003)	Family Assessm. Device FAD Leeds scales of anxiety and depression Outcome questionnaire Anger Control Questionnaire CHART SIP	2-5 years post-injury		Families were on average functioning within the normal range on FAD. Anxiety and depression more likely seen in those actually responsible for care. No spouse-parent difference. Cognitive, behavioural and emotional changes strongest predictors of anxiety and depression in relatives and of unhealthy family functioning

Table 1.4 Results p. 6	**Areas of outcome /Measures**	**Time of measure**	**Results, sometimes combined in one large section**	
			Employment	Other
24. Johansen et al. (2004)	Employment, social network Emotional measures HADS, KATZ, PCRS, WHO-QoL-BREF, Generalised Self-efficacy Scale (GSE), Locus of Control (LoC)	1-10 years after rehabilitation	47% in productive activity on average 25 (11) hours/week Younger males, non-right hemisphere injured, non-frontal lobe injury have higher productivity. No effect of chronicity or injury severity 42% married at F-up (20% divorced between injury and F-up) 53% home owners	Lower Quality of life and competency and more anxiety and depression 'caseness' compared to Danish non-brain injured control group. KATZ: Depression index as well as disorientation and withdrawal index higher compared to American norms. Patients felt the program especially had increased their: awareness of deficits, compensational as well as communication skills and self-confidence
25. Svendsen et al. (2004)	EBIQ	Pre-program Post-program		Higher levels of symptoms compared to non-brain injured control group. Pre to post-program: Significant reduction in levels of experienced symptoms and in levels of current impact of brain injury on SOs. Only few differences between patients and SOs. No effect of age, frontal-non-frontal injury location or kind of SO.
26. Adams et al. (2004)	Independence and productivity	Admission Discharge ~1 year F-up (n=90)	Productive / Non-productive 4% / 96% 81% / 19% 76% / 24% Male gender and higher independence on admission related to positive work outcome.	Maximally Independent / Selective monitoring / Frequent monitoring / Institution 8% / 27% / 40% / 25% 62% / 29% / 7% / 2% 64% / 28% / 7% / 1% Levels of independence and employment improved during rehabilitation and gains were maintained
27. Leon-Carrion et al. (2005)	FIM+FAM, physical examination and cognitive test	Pre-program Post-program	Driving: Pre-injury all had drivers licenses – post-injury those with sufficient physical function returned to driving in spite of emotional or cognitive problems or medical advice Pre-program 35% drove against advice, 50% had incidences (cause: disorientation, confusion and confrontations Post-program 71% could return to driving safely. None sought re-evaluation of driving skills Significant gains in rehabilitation in self-care, sphincter control, mobility, communication, cognitive functions and psychosocial adjustment.	

Table 1.4 Results p. 6	Areas of outcome /Measures	Time of measure	Results, sometimes combined in one large section		
			Employment	Other	
28. Klonoff et al. (2006)	Driving Living Employment Marriage Income	1-7 years post-rehabilitation	86 % productive at F-up 74 % competitively Positive work status related to: younger age, higher education, non-right hemisphere injury and ability to drive post-injury but not to gender	40% income fall from pre injury (42500$) to F-up (25550$) Marriage did not differ from pre-injury: 81% remained or engaged in stable relationship at F-up 94% drove pre-injury, 73% drove at F-up; 34% involved in accidents Driving was related to: return to work, higher education, non-right hemisphere injury and shorter treatment length.	
29. Schoenberger et al. (2006)	Employment at F-up Retrospective awareness and compliance ratings (scales from study 29 and 5) Pre-post-program: Attention test D-2 Physical fitness EBIQ	Pre program Post-program 1½-4 years post-rehabilitation	13 % competitive 20 % Vocational training 33 % Supported employment 5 % Volunteer 28% Unemployment Working alliance and compliance correlated significantly with employment	Physical training at follow-up 37 % at least weekly 23 % infrequent/ leisure 39 % no training No correlation with alliance, but with compliance	Improved physical fitness and D-2 and decreased cognitive, somatic and general symptoms. No difference between patients and SOs on EBIQ Compliance ratings correlate with awareness ratings, physical fitness and D-2 improvement but not with subjectively experienced symptoms
Controlled studies					
30. Prigatano et al., (1984) Holistic	Productivity WAIS, WMQ KATZ	⅔year btwn tests	Employment related to gains on KATZ and cognitive tests, not to education, age or chronicity. 50% productive	Positive but non-significant changes on KATZ	WAIS PIQ, Block design, WMQ better for those in holistic rehabilitation.
Control		1 year btwn tests	36% productive		
31. Ruff & Nieman (1990)	KATZ Cognitive tests (previous study)	Pre-program and post-program		No differences in terms of psychosocial adjustment. No differences on KATZ	Both groups experience gains on cognitive tests, the cognitive group more so than the holistic group in terms of memory and learning
Holistic					
Cognitive rehab					
33. Prigatano et al. (1994)	Working alliance Employment			Working alliance w. patient and SO significantly related to outcome As well as successfully completed work trial in rehab and education >12 years. No effect of chronicity	
Holistic		3.6 years after injry	87% (49% full time) in work		
Controls		2.8 years after injry	55% (36% full time) in work		

Table 1.4 Results p.8 Controlled	Areas of outcome /Measures	Time of measure	Results, sometimes combined in one large section		
			Employment	Other	
32. Rattock et al. (1992)	Employability (10 point scale)	3 months after work trial begins 9 months after	No difference between groups Open Sheltered Unempl	All treatments demonstrated near and far transfer of remedial training in certain circumscribed areas of cognition. The more intensive cognitive group had additional cognitive effects. All programs worked in terms of improving independence and intra/interpersonal functioning: Holistic (I) superior in some aspects of functional independence Interpersonal group (II) better on Intra and interpersonal measures compared to cognitive group (III)	
I Holistic	Cognitive –test battery Behavioural Competency Index (BCI)		3 m: 70% 17% 13% 9 m: 52% 17% 31%		
II More interpersonal			3 m: 78% 11% 11% 9 m: 78% 11% 11%		
III More cognitive	Ratings of self-esteem, self-awareness, empathy, cooperation		3 m: 83% 6% 11% 9 m: 61% 17% 22%		
34. Cicerone et al. (2004)	CIQ productivity scale Satisfaction with community and cognitive functioning Neuropsychological tests	Pre-treatment Post-treatment	Progress in CIQ-productivity scale	Holistic group significant improvement on cognitive tests. Test-results not related to satisfaction with cognitive functioning. Holistic twice as likely to improve on CIQ even though both groups show significant improvement on the CIQ. CIQ predicted by treatment and satisfaction w. cognitive functioning. Satisfaction with community functioning was higher in the standard grup	
Holistic			1.4 -> 3.1		
'Standard'			3.4 -> 3.6		
35.Sarajuuri et al. (2005)	Employment	Post-injury	Work/study/volunteering	Odds Ratio 6.96 of being productive after holistic rehabilitation compared to standard. Productivity not related to gender, age, injury severity (GCS) or chronicity, only rehabilitation and pre-injury employment (Odds-rtio 11.9)	
Holistic		3.5 (1.5) years, (2 yrs post-rehab)	89 %		
'Standard'		3.9 (1.7)	55 %		
36. Hashimoto et al. (2006)	CIQ social integration Employment	Pre- and post-treatments	Post-treatment Full-time work/study or welfare institution	Significantly more improvement on FIM+FAM, speech intelligibility, problem solving, memory, attention, social integration on CIQ (92% improves versus only 42% of controls) in the holistic group.	
Holistic			36% (100% have a plan to do so)		
'Standard'			17% (58% have a plan to do so)		
Randomised controlled trial					
37. Salazar et al. 00	Gainful employment Fit for military duty Multidisciplinary test	Pre-program Post-program ½ year 1 year 2 year	1 year after		
Holistic			90% gainful employed 80% was fit for military duty of those with loss of consciousness > 1 hour)	Cost 51840$	No difference on KATZ
Home-program			94% gainful employed 58% was fit for military duty of those with loss of consciousness > 1 hour	Cost 504 $	

1.7 Specific areas of outcome

Some of the specific studies will be presented here that demonstrate the relevance of the outcome areas and various domains chosen to be evaluated in this follow-up study.

1.7.1 Symptoms of brain injury and competency

Symptoms of brain injury and competency in everyday life, as perceived by the survivors and their significant other, represent the reality of their shared life experience after acquired brain injury (Ponsford, Sloan, & Snow, 1995) and can be seen as outcome measures that are both ecologically valid and meaningful to the survivor and his or her family. Improvement is indicated by a reduction in dependency and thereby a reduction in the personal burden and burden on the significant other or society (Diller & Ben-Yishay, 2003). Symptoms and level of competency in activities of everyday life are therefore central measures in evaluating outcome after rehabilitation.

Participating in rehabilitation is one factor that may influence the extent and nature of symptoms reported after a brain injury (Port, Willmott, & Charlton, 2002; Ownsworth, McFarland, & Young, 2000) and a number of studies have shown that subjective symptoms of brain injury decrease after rehabilitation (Fordyce & Roueche, 1986; Stilwell, Stilwell, Hawley, & Davies, 1999; Svendsen, Teasdale, & Pinner, 2004).

A related issue is the fact that brain injury has a significant impact on close relatives of the survivor (Wood & Yurdakul, 1997; Allen, Linn, Gutierrez, & Willer, 1994;

Lezak, 1988; Gosling & Oddy, 1999). The neurobehavioural symptoms following brain injury correlate with the family's appraisal of the injury's impact on them. A particularly frequent finding has been that problems in the areas of emotion, behaviour and awareness, rather than physical disability, are associated with the relatives experiencing higher amounts of stress (Hillier & Metzer, 1997; Peters, Stambrook, Moore, & Esses, 1990; Thomsen, 1992) and at least one follow-up study found that chronic sequelae after acquired brain injury are an ongoing burden for the relative (Thomsen, 1984, 1992). Willer, Flaherty and Coallier (2001) point out that the greatest needs of patients' significant others are for information, social and emotional support, and assurance that the patient is receiving the best possible treatment. These needs are largely addressed at the Centre for Rehabilitation of Brain Injury in Copenhagen, as in other holistic post-acute rehabilitation programmes and many other brain injury rehabilitation settings. In an earlier study using the EBIQ it was shown that rehabilitation can achieve a reduction in symptoms in patients with acquired brain injury albeit not to the levels of a non-brain injured control group, and a consequent lessening of the burden on their relatives (Svendsen, Teasdale and Pinner, 2004).

1.7.2 Awareness

Disturbance in the patients' ability to acknowledge (certain) changes in his or her behaviour and ability to function occur frequently after acquired brain injury. This unawareness of deficit is also called anosognosia when it is a direct consequence of the organic brain injury as opposed to psychogenic denial of anxiety provoking facts (Prigatano & Schacter, 1991), even though the psychogenic component can often occur alongside the organic.

After a brain injury, lack of awareness of deficits such as memory loss can affect willingness to engage in therapy, outcome of hospitalisation (Pedersen et al., 1996), ability to function in society (Wise, Ownsworth, & Fleming, 2005), emotional adjustment (Sawchyn, Mateer, & Suffield, 2005), subjective wellbeing (Evans, Sherer, Nick, Nakase-Richardson, & Yablon, 2005) and burden on significant others (Prigatano, Borgaro, Baker, & Wethe, 2005). These deficits of awareness may also influence the self-perception of the extent and nature of experienced problems after brain injury, calling into question the validity of self-reporting. A (conservative) estimate of prevalence of unawareness of deficits is 20 to 30% for traumatic brain injury and stroke survivors in the acute phase (Pedersen et al., 1996; Prigatano et al., 1998; Prigatano, 2005). A number of studies have found patients to either under-report their symptoms or over-report their competency compared to the ratings given by family member or clinician. Furthermore, patients tend to underestimate emotional and behavioural changes in particular(Oddy, Coughlan, Tyerman, & Jenkins, 1985; Prigatano, Altman, & O'Brian, 1990). Other studies have, however, found reasonable concordance between the self-report of patients with brain injury and the report of their significant others (Oddy, Humphrey, & Uttley, 1978b; Ponsford, Olver, & Curran, 1995; Svendsen et al., 2004; Lannoo et al., 1998).

One focus of holistic rehabilitation is to increase awareness (Malec et al., 1996). Acquiring awareness is seen as a pre-requisite for becoming motivated to change, for learning compensational strategies, and to continue using these in everyday life (Ben-Yishay & Diller, 1993). Increased awareness is thought to lead to a more realistic appraisal of competency and therefore to safer behaviour and independence, which in turn can affect family life positively by lessening the burden on significant others. Previous studies have shown that rehabilitation can increase awareness (Ezrachi, Ben-Yishay, Kay, Diller, & et al., 1991; Fleming, Lucas, & Lightbody, 2006; Ownsworth et al., 2000).

Apart from rehabilitation, other factors are said to influence the level of awareness after acquired brain injury. Cultural factors have been shown to play a role in the extent and nature of symptoms and level of competency that are reported (Prigatano, Ogano, & Amakusa, 1997; Prigatano & Leathem, 1993). Earlier studies have also found that the aetiology of the brain injury (Teasdale et al., 1997a), executive dysfunction (Port et al. 2002), time since injury (Godfrey, Partridge, Knight, & Bishara, 1993) and severity of brain injury (Leathem, Murphy, & Flett, 1998) can influence the level of insight as well as consistency between raters. In the study to be presented here, the two groups are comparable in terms of aetiology of brain injury, time since injury, and more or less as regards severity of brain injury (equal degree of hospitalisation, but higher injury severity score (ISS) in the control group). It has not been possible to compare location of injury in the two groups.

1.7.3 Locus of control and self-efficacy

Locus of control and self-efficacy are two related concepts. The concept of locus of control was developed by Julian Rotter in the 1950s. People with an internal locus of control see themselves as capable of influencing future events, responsible for their own actions, and that their efforts can determine the outcome of future events more than sheer luck or fate. The concept of self-efficacy introduced by Albert Bandura (1986) stands for the belief that one has the capabilities to execute the courses of action required to manage prospective situations. In terms of rehabilitation the difference between the two concepts is important. Even though a person may believe that the effort they put into rehabilitation will make a difference (locus of control; by training, they can make it better) they may or may not believe that they are capable of behaving in a way that will produce the desired result. You may have an internal locus of control if you believe that if you train really hard in rehabilitation you can control or overcome your difficulties, but at the same time you can have a low sense of self-efficacy, if you do not think that you are capable of training that hard. If training in rehabilitation brings success, a sense of self-efficacy will increase and self-esteem will also improve if rehabilitation is important to you. People with a high sense of self-efficacy will be more inclined to take on new tasks and spend more effort and time trying to succeed – i.e. they will not give up as easily as people with low self-efficacy.

According to the definition of self-efficacy, the event of acquiring a brain injury is connected with a potential risk of lowering self-efficacy and changing locus of control. Moore and Stambrook (1995) have proposed a model that hypothesises that long-lasting cognitive, behavioural, emotional, psychiatric, and interpersonal after-effects of traumatic brain injury may create a real life "learned helplessness" with deficits in coping and altered locus of control beliefs. In one study of 19 traumatically brain injured individuals (Lubusko, Moore, Stambrook, & Gill, 1994) those who did not return to their pre-injury level of employment had lower internal locus of control beliefs. Dumont, Gervais, Fougeyrollas & Bertrand (2004) found that perceived self-efficacy explained 40% of the variance in social participation among 53 adults with TBI living in their homes. In a controlled study of comprehensive holistic rehabilitation compared to 'standard' rehabilitation (Cicerone, Mott, Azulay, & Friel, 2004), perceived self-efficacy was found to have a potential impact on functional outcomes after TBI. Rutterford and Wood (2006) evaluated a model including self-efficacy as a psychosocial predictor in psychosocial adjustment on 131 subjects, all of whom were more than 10 years post-injury. Self-efficacy contributed significantly to the predictions of community integration, satisfaction with life, anxiety and depression, but not to quality of life. Ben-Yishay and Diller (1993) have described self-efficacy among concepts central to the process of cognitive remediation, and that holistic rehabilitation could be a way of supporting self-efficacy.

Goldstein and Ben-Yishay (Ben-Yishay & Daniels-Zide, 2000) have described the catastrophic reaction and negative spiral that characterises the period following the brain injury. People try things they were used to and experience failure, which makes them panic and be afraid of new challenges and thus less inclined to try again, which then makes them less likely to re-master the old skills or new skills needed. Intensive post-acute rehabilitation provides a tight secure structure and support that counteract the catastrophic reaction and helps people gain awareness and practice. The fruit of the practice is mastery, which in turn increases self-efficacy. Focussing on internal locus of control has been recommended in rehabilitation of traumatic brain injury, especially in connection with pain management (Branca & Lake, 2004).

1.7.4 Anxiety and Depression

Anxiety and depression are two important markers of poor emotional well-being on the part of the person with acquired brain injury, as well as caregivers and relatives. Both have been described as frequent sequelae to brain injury, though depression has received more attention. In a recent review of depression after brain injury, Fleminger, Oliver, Williams & Evans (2003) found that problems with concentrating were more prevalent than feelings of guilt in patients with brain injury compared to non-brain injured patients. In general, however, the findings were that symptoms of depression following brain injury are non-specific and not clearly distinguishable from depression in people without brain injury. The prevalence of depression in patients with stroke and TBI are similar. In the first year about 20 to 40% suffer an episode of depression, and about 50% experience depression at some stage post-injury. Lesion location and hemisphere association are not strong predictors of depression. It can occur for many different reasons pertaining to factors pre- peri- and post-injury, and be understood as reactions to the loss or sudden life change or crisis, or the confusion and frustration over not being able to live up to expectations towards oneself. Depression has especially been seen in the wake of improved self-awareness.

On a long-term basis the elevated risk of suffering depression or anxiety does not seem to diminish. In a 30 year follow-up of 60 people with TBI, Koponen and colleagues (2002) found that 26.7 % had had a DSM-IV axis I disorder of major depression with onset after the brain injury. Hoofien, Gilboa, Vakil & Donovick (2001) followed up 76 individuals with severe TBI (mean length of coma 14 days) at 10 to 20 years post-injury. The injuries were caused by vehicle and work accidents, as well as during combat. The participants had been referred to the National Institute for the Rehabilitation of the Brain Injured in Israel. This is a public community-based neuropsychological rehabilitation centre. Most of the participants had received some kind of post-acute rehabilitation. At follow-up more than 40% expressed anxiety and depression on the SCL-90 compared to a normal population. Contrary to the previous studies, Wood and Rutterford (Wood et al., 2006b) found no serious emotional problems (mild anxiety score on the HADS (mean 8.5) and a depression score within normal range (mean 6.1) in 80 participants with severe traumatic brain injury (mean length of PTA 19 days) at 10 to 32 years post-injury.

It is not yet fully understood who is at risk. The association between neuro-psychiatric disorders and severity of injury is weak. Socioeconomic status prior to injury seems to have an influence on long-term outcome (Fleminger & Ponsford, 2005). Curran and colleagues (2000) found that maladaptive coping strategies such as worry, wishful thinking and self-blame were linked more strongly than injury severity to the presence of higher levels of anxiety or depression. Anson and Ponsford (2006) found that coping characterised by avoidance, worry, wishful thinking, self-blame, and using drugs and alcohol were associated with higher levels of anxiety and depression in 32 persons with TBI.

One study has shown that level of emotional stress in the participants fell during rehabilitation and that the lowered level of emotional stress measured at post-programme was maintained at a one year follow-up (Teasdale & Caetano, 1995). Ponsford, Olver, Ponsford & Nelms (2003) studied anxiety and depression in relatives and carers of individuals who had accessed a comprehensive rehabilitation services at two to five years post-injury. Anxiety and depression were more likely to be found in those responsible for care of their injured relatives. The presence of cognitive, behavioural, and emotional changes in the injured person was the strongest predictors of anxiety and depression in caregivers.

1.7.5 Quality of Life

The literature has provided a wealth of definitions of 'Quality of Life' (QoL) and many different measures thereof (Dijkers, 2004). The concept of QoL has evolved over the last 40 years. Initially it was limited to political and economic aspects of life in the absence of illness. With the advent of the WHO model of health, the concept of QoL became related to handicaps and participation: autonomy, work, income, and social activities (Tazopoulou, Truelle, North, & Montreuil, 2005). Over the last 20 years, the concept has moved from handicaps to the individual’s subjective ‘well-being’, leading to an appraisal of the individual’s feelings about his or her own life. WHO defines Quality of Life as “an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”. It is a broad-ranging concept affected in complex ways by the person's physical health, psychological state, social relationships and their relationships to salient features of their environment. (http://www.who.int/evidence/assessment-instruments/qol/ql1.htm). Thus QoL according to the WHO is a subjective psychological feeling of well-being that is not equivalent to lack of symptoms or illness. An individual's QoL can not as such be estimated from severity of symptoms or objective factors such as employment or marital status but only by a subjective evaluation.

The field of brain injury has only relatively recently taken an interest in measuring QoL. In general, the studies undertaken have shown a decrease in QoL or life satisfaction after brain injury and one which persists in long-term follow-up studies, including after rehabilitation (Johansen, Pedersen, & Lauersen, 2004; Wood et al., 2006b). In a previous study using the WHO-QoL-Bref questionnaire in a follow-up study one to ten years after rehabilitation, a group of 150 people with brain injury had a mean QoL score lower than a Danish healthy non-brain injured norm group, but comparable to a group consisting of individuals with insulin dependent diabetes, and higher than a group of subjects with more serious chronic illness (such as arthritis, hearth disease, hypertension and amputations).

As a result of a consensus meeting, Bullinger et al.(Bullinger, 2002) recommended repeated measuring of QoL in the acute and post-acute phase of recovery after TBI. There have both been recommendations to develop instruments specific to brain injury that reflect the characteristics and needs of this population, and to validate some generic instruments for use in the brain-injured population. Bullinger and colleagues thus recommended that assessment of the patient's quality of life should include both a generic and a disease-specific instrument. Among the generic instruments, the SF-36, the EuroQol and the WHO-QoL could be considered, even though cognitive impairment and existential dimensions were not sufficiently considered in most of the reviewed instruments. The literature about specific instruments for patients with TBI is scarce, and the group could not give any empirically based recommendations.

1.8 Objective

Follow-up studies from the CRBI and other centres have generally shown positive results (e.g. Prigatano et al.; 1984, Ben-Yishay et al., 1987; Prigatano et al. 1994; Christensen et al., 1992; Malec et al., 1993; Teasdale et al. 1993). Improvements have been shown within the domains of social life, family, and work. So far, however, follow-up studies have suffered from two limitations. Firstly, most have been carried out within the first few years after rehabilitation – typically within five years. This limits the conclusions that can be drawn concerning whether the improvements shown in the studies will hold over time or subside. Secondly, so far follow-up studies have been very limited as regards the inclusion of a control group. Very few studies have compared the outcomes of a group who received rehabilitation with a group who did not, despite the same kind of injury. This means that improvements measured following rehabilitation could be due in principle to factors other than rehabilitation and that would have occurred regardless.

The overall objective of this experimental study is to see whether post-acute, holistic rehabilitation of people with acquired brain injury has a lasting effect on these individuals' psychosocial situation and well-being. Specifically, this study will investigate the current psychological and social status of a group of participants 12-17 years after receiving intensive post-acute holistic neuropsychological rehabilitation at the Centre for Rehabilitation of Brain Injury, University of Copenhagen (CRBI). The follow-up study is conducted on 37 participants, 12-17 years after they received rehabilitation at the CRBI. This is a substantially longer follow-up period than most previous studies. The collected psychosocial data from these individuals will be compared to similar data collected from a control group consisting of 17 subjects, who sustained similar injuries and never received intensive post-acute rehabilitation.

The pioneer of post-acute rehabilitation in Denmark, and founder of CRBI, Anne-Lise Christensen (2000) states:

> *"The goal… is to provide a rehabilitation program that ensures prospects for life after brain injury composed of elements that encourage personal growth, responsibility, attachment to others and to work and enjoyment: to support brain-injured individuals in gaining the ability to live their lives to the fullest and to master the constant changes that are part of human life.(pp.151)*

This is a very broad statement of purpose, which also pertains to the nature of holistic rehabilitation, i.e. aiming to encompass as many aspects of the individual as possible. Outcomes have traditionally been measured within the following domains (Pedersen, 1999): Independence (ADL), cognitive function, awareness, emotional wellbeing, societal reintegration, user satisfaction and goal obtainment in rehabilitation. All the results to be presented in this dissertation stem from the same study of 37 participants who had received rehabilitation at the CRBI and a group of 13 individuals also with brain injury who did not receive similar post-acute rehabilitation. I have selected three domains of outcome that will be presented in three chapters in the form of articles: 1) work and leisure activities; 2) mental health and well-being; 3) satisfaction with rehabilitation; and 4) an additional chapter of non-published results.

1.8.1. Chapter 3, article 1: Long-term outcome: participation in the form of productivity and leisure activity.

Article 1 concerns mainly outcomes as defined by the World Health Organisation (WHO) as health on a participatory level and the two aspects of psychosocial functioning of productivity and leisure activity.

The hypotheses regarding productivity are:

1. We expect that members of the rehabilitation group to a larger extent will be engaged in more productive or competitive work.
2. We expect them to be better remunerated.
3. We expect them to be more satisfied and accepting of their job placement, be it of a lesser status than before the injury.

Leisure hypotheses:

1. We expect that the rehabilitation group spend more hours weekly involved in leisure activities.

1.8.2 Chapter 4, article 2: long-term outcome within the domain of mental health

Mental health outcomes can be seen as measuring health on the impairment and personal activity level according to WHO and to include measures of subjective well-being not included directly in the WHO model of health.

Symptoms of brain injury:

1. We expect that those who received rehabilitation and their significant others (SOs) to experience the symptoms of brain injury as well as the impact of the injury on the SOs less than the control group.

Competency

2. We expect the participants who received rehabilitation to have a higher degree of competence within activities of daily living (ADL) and social and cognitive skills, as reported by themselves and their SOs.

Awareness

3. We expect a greater level of agreement between the participants and the significant others as regards symptoms and competency, among the rehabilitation group versus the control group.

Well-being

4. We expect the participants in the rehabilitation group to have a higher degree of self-efficacy and internal locus of control compared to the participants in the control group, according to their own self-ratings.
5. We expect lower levels of anxiety and depression in the rehabilitation group compared to the control group.
6. We expect members of the rehabilitation group to score more highly on general measures of quality of life.

1.8.3 Chapter 6, article 3: long-term outcome regarding satisfaction with rehabilitation

Outcome in this article concerns user satisfaction and evaluation and is explorative in nature. These results stem from the rehabilitated group only. Participants were asked open-ended questions concerning the rehabilitation at the CRBI. They were also asked to rate which program-elements they had found most beneficial as well as how important the CRBI had been for different areas of outcome.

1.8.4 Chapter 5: additional outcome

Further areas of outcome are explored in chapter 5. The comparability of the rehabilitation and control group is explored in terms of additional injury data, current health behaviour, brain injury related complaints, adaptation to life after brain injury, and current use of as well as experienced need for public services. Comparisons are made between the rehabilitation and control groups on the participatory level in terms of social network and additional aspects of productivity and leisure activities.

Additional productivity hypotheses:

1. We expect the rehabilitation group to be capable of working a greater number of hours each week.
2. We expect the rehabilitation group to have been in their current productive situation longer due to better placements before they found the work they have today.

Additional leisure hypothesis:

1. We hypothesise that the survivors in the rehabilitation group, to a higher degree will have leisure activities that involve interaction with other people (and not as many passive entertainment activities like watching tv).

Hypotheses regarding social relationships:

1. The rehabilitation group is hypothesised to have more social connections (partner, family and friends) (quantity of social network).
2. The rehabilitation group is expected to be more satisfied with connections to partner, family and friends (the quality of their network).
3. The rehabilitation group is expected to receive more social/practical support from family, friends or neighbours.

Adaptation to life after brain injury:

1. The rehabilitation group is expected to show more signs of a better psychological adaptation to life after brain injury.

The following chapter will present the methods employed as well as methodological considerations.

Chapter 2. Method

The study was designed as a cross-sectional questionnaire and interview follow-up twelve to seventeen years after rehabilitation, with a retrospectively matched control group. This chapter presents the methodological choices employed in the project by presenting the design in terms of the control group, outcome measures, choice of non-blind study, setting and statistical methods. Characteristics such as selection and attrition are described for the subjects who participated in the rehabilitation and control groups. The first phase of this study was the selection and matching of subjects in the rehabilitation and control groups by a retrospective review of hospital files. The type of injury characteristics and demographic variables collected from the hospital files are described. The two groups are *post-hoc* matched on the basis of injury related characteristics. These results are presented along with the reliability analysis of the chosen matching variables. This chapter will also describe the specific questionnaires and the interview guide, and finally address the strengths and weaknesses of the chosen methods.

2.1 Design considerations

2.1.1 Inclusion of a control group

Evidence based medicine requires that the efficacy of a given treatment be documented by scientific studies. Cicerone, Dahlberg, Kalmer et al. (2000) have proposed graded guidelines for how strong a recommendation any given treatment should be given for persons with acquired neuro-cognitive impairments and disabilities. This recommendation is made on the basis of the quantity and quality of studies of treatment efficacy. The short version of the guidelines from Cicerone, Dahlberg, Kalmer et al. (2000) are presented here in Table 2.1:

Table 2.1 Graded levels of recommendation for clinical practice based on current research

Practice standards	**Practice guidelines**	**Practice options**
Based on at least one well-designed Class 1 study with an adequate sample, or overwhelming Class II evidence, that directly addresses the effectiveness of the treatment in question, providing good evidence to support a recommendation	Based on well-designed Class II studies with adequate samples that directly address the effectiveness of the treatment in question, providing fair evidence to support a recommendation	Based on Class II or Class III studies, with additional grounds to support a recommendation, but with unclear clinical certainty.

How strongly any given practice is recommended thus depends on the methodological strength of the studies that support that treatment. The strongest level of support comes from class I studies. Class I studies are defined as prospective randomised controlled trials, which could be considered ideal in initially establishing the efficacy of a given treatment. Class II studies include prospective cohort studies, retrospective case-controlled studies, or clinical series with well-designed controls. Class III studies consist of clinical series without concurrent controls or studies with appropriate single-subject methodology.

Prospective randomised double blind longitudinal methodology is regarded as the gold standard within drug trials, and is also proposed as the strongest level of evidence within rehabilitation research as indicated above (Cicerone et al., 2005; Gordon et al., 2006; Chesnut et al., 1999). If applied, a Class I study would minimise potential biases such as 1) possible individual differences between groups 2) external influences besides the rehabilitation which could potentially affect the outcome measures chosen and 3) any bias that may be due to the identity of the rater. However, randomised controlled trials of the clinical effectiveness of rehabilitation with non-treated controls are often difficult if not impossible to establish in a clinical setting. Nor could this methodology be applied within the limited timeframe of this ph.-d., both for ethical reasons as well as the time and cost. Instead of the randomised controlled trial with a non-treated comparison group it has been a recommended option that controlled studies of the effectiveness of treatment can attempt to see whether it offers any specific benefits compared to a different treatment, and ideally comparing it with the 'best available' treatment of known efficacy (Gordon et al., 2006). This kind of comparison has the benefit of minimizing the effect of non-specific therapeutic factors that are part of most treatments, e.g. ascertainment bias, attention or placebo effect.

From reviewing the international literature it can be seen that the first generation of studies that looked into the potential efficacy of holistic rehabilitation programmes in the western world lacked the incorporation of a control group (with a few important exceptions (Prigatano et al., 1984; Prigatano et al., 1994; Rattock et al., 1992)) and thus had no way of showing whether the positive outcomes could be due to confounding variables such as spontaneous remission or other individual characteristics. Later on a few prospective studies have also included a control group (Cicerone et al., 2004; Sarajuuri et al., 2005; Hashimoto, Okamoto, Watanabe, & Ohashi, 2006). The longitudinal and observational studies of Klonoff, Lamb & Henderson (2001)and Johansen, Pedersen & Lauersen (2004) included groups that were 10-11 years post-rehabilitation, but otherwise most studies have been undertaken within the first five years after rehabilitation and there has been no known attempt to include a control group when looking at the impact of rehabilitation longer than ten years after the treatment.

In an updated review of the evidence for comprehensive holistic rehabilitation Cicerone (2005) conclude that so far this kind of treatment, as offered at the CRBI programme, can be recommended at the level of a practice guideline in treating persons with moderate to severe acquired brain injury. However, there is still a need to confirm the positive findings from the many class III studies with controlled trials and to examine a broad range of relevant health outcomes.

The opportunity for a control group in this study emerged as a consequence of a large, comprehensive long-term population based follow-up study undertaken by Teasdale and Engberg (Teasdale & Engberg, 2001; Engberg & Teasdale, 2001; Teasdale & Engberg, 2000; Teasdale & Engberg, 2002; Engberg et al., 2004; Teasdale et al., 2005a; Teasdale & Engberg, 2005b). This control group does not consist of historic controls who sustained their injuries and had treatment prior to the existence of the rehabilitation programme (like in the studies by Prigatano, 1984, 1994) but consists of controls who lacked access to treatment, because of the limited capacity and knowledge of the two Danish post-acute rehabilitation centres which existed at that time (The Centre for Rehabilitation of Brain Injury in Copenhagen and Vejlefjord in Jutland). They form a geographic control group. Thus the two groups whose outcomes are to be statistically compared stem from two sources: a) a group of persons with acquired brain injury who had completed the post-acute, intensive, neuropsychological rehabilitation at the Centre for Rehabilitation of Brain Injury in Copenhagen (CRBI) and b) a group with comparable injuries who had not received any such post-acute rehabilitation.

2.1.2 Outcome measures

Even though a quantitative approach as employed in this study lacks some nuances of the individual which a more qualitative approach would have provided, the results will be measurable and suitable for group comparisons and comparison to other studies of the efficacy of rehabilitation.

Malec & Basford (1996) stated that outcome measures in the field of post-acute rehabilitation typically falls into three categories: vocational status, living status as well as functional and psychosocial adjustment. Recent years have witnessed a growing recognition that the evaluation of outcome following brain injury rehabilitation should involve measures which are ecologically valid and meaningful to the patient (Fleminger & Powell, 1999). Thus, Ponsford, Sloan & Snow (1995) have described how research has increasingly emphasised the use of outcome measures which relate directly to the daily life of the patient, such as health and employment, rather than solely psychometric measures such as neuropsychological test results, which are otherwise very important e.g. in planning treatment but according to Carney et al.(1999) can be considered more intermediate measures of improvement and according to some studies appear to bear only modest relationship to functional outcomes(Malec, Smigielski, DePompolo, & Thompson, 1993; Teasdale, Hansen, Gade, & Christensen, 1997b). Questionnaires were chosen to cover health and employment, and it was thus decided not to include neuropsychological tests since these are time consuming, can be confrontational, and have not proven to be the most sensitive measure of efficacy in the context of rehabilitation at the CRBI (Teasdale et al., 1997b). The intention of the CRBI programme is to improve awareness and emotional acceptance of the changed life situation in particular after a brain injury, to a higher extent than actual cognitive retraining. It is thought that the CRBI helps the individual by a demystification and generalisation of the current situation, and also by introducing alternative, more appropriate coping strategies for a person with a brain injury in the Danish society rather than idiosyncratic ways of coping developed prior to the injury better suited to a lifestyle with a non-injured brain.

2.1.3 Procedures

It would have been impossible to make the study double blind since the participants know they were getting treatment and because part of the effects are dependent on the trainee's awareness of the procedures and goals of the intervention. It could have been made single blind, with the data collector blind to the group-status of the individual. This is an approach recommended by Wilson (Presentation in methodology at the ReCBIR symposium, May 2006 in Copenhagen) among others, but time and secretarial resources did not allow it here, and the interview also asked the persons who had received rehabilitation at the CRBI program to evaluate the programme at the end of the interview.

However, the information supplied in the letters of invitation to the possible participants only informed that the purpose was to register long-term effects of acquired brain injury, and thus did not reveal the comparative aspect of the study, nor did it mention the rehabilitation program. After the participants had sent their letter of consent back to the researcher, they were contacted by telephone or email in order to inform them further about the procedure and that they would receive a questionnaire, one part for themselves to fill out and one part for their significant others to fill out, and that they were to do this separately and hand it over at the time of the interview or send it back. They were instructed that if they had any difficulties filling out the questionnaire, they could get help at the time of the interview. In all but two cases (both participants with aphasia) the questionnaires were filled out prior to the interview, thus not biasing the answers in the questionnaires due to the interaction with the interviewer and the evaluation of the CRBI program that took place at the end of the interview. The interview was conducted in the participant's home or in an office at the Department of Psychology, University of Copenhagen, located on a different floor from the CRBI to minimise any chance of associating the interview with rehabilitation programmes. Only three out of sixty-one participants chose to have the interview at the university.

Given the desire to cover a broad range of outcome measures within the domains of employment and leisure, emotional wellbeing and satisfaction with rehabilitation, it was decided to split data collection into a questionnaire and an interview study – in order not to make the questionnaire too long and thus lower the chances of getting complete returns. A preliminary test version of the interview took about 1.5 hours to complete, so it was not possible to perform it by telephone, as has been used as a means of obtaining follow-up data by e.g. Klonoff, Lamb & Henderson (2001).

Financially it was also not possible to compensate all participants for their travel expenses. Thus the interview was to be offered in the participants home as already mentioned. Some potential advantages and disadvantages of this approach apart from the possibility to observe how the person lived include:

1) Providing a safe, comfortable setting, which could promote more honesty in reporting how their life was affected by the brain injury – although it could be argued that a more objective setting such as an office could facilitate more attention and might be more stimulating given that it is different from the everyday environment. It was hoped that the comfortable home setting might allow more people with aphasia to participate, given the possibility of using significant others to facilitate communication or the use of body language, unavailable in a telephone interview. However in one study it has been argued that face-to-

face interviews have been shown to elicit less accurate, more ‘socially desirable’ responses than e.g. telephone surveys (Ashley et al., 1997).

2) Minimizing any hassle involved in participating, even though some might feel that it would be intrusive to have somebody come to their home, regarding it as too personal or too annoying to have to tidy up.

3) Compared to a telephone interview, a face-to-face interview would allow more follow-up or clarifying questions.

At some point it was considered if the observation of how people lived and organised their household should be included, but it was decided not to go beyond registering whom they lived with (e.g. spouse, alone or at an institution) since the rehabilitation group at time of rehabilitation already was fairly independent in living and since the primary focus of this study was psychosocial outcome and not activities of daily living. The relative high degree of independence at time of rehabilitation was also a reason for not using a measure such as the Community Integration Questionnaire CIQ (Willer, Ottenbacher, & Coad, 1994). The CIQ can be used as a measure of participation measuring independence in living, social network and employment activities. It has the huge advantage of standardizing outcomes such as employment, which is often measured differently from study to study and thus the CIQ makes comparison between studies easier (Cicerone, 2004). However in this study it was considered that the two groups would have a loft effect on the scale of independency in living. Therefore this measure was not included.

2.1.4 Statistical methods employed

In order to get a well-matched control group, the original plan was to match on an individual level – case-control matching. Other studies have shown that the following factors can have an influence on outcome:

- age (at injury)
- gender
- length of education
- pre-injury employment/educational status
- injury type
- severity of head injury
- geographical location (rural/urban)
- marital status

The reason injury location was not chosen as a potential matching variable was due to the knowledge that this information would not be available or very valid for the participants with TBI given the often diffuse nature of the injury.

Given a fairly limited possible control group size it was only possible to do a pre-participation group screening based on age and the ability to return to work after discharge from hospital. It was not deemed likely to be able to obtain length of education from the hospital files and only pre-injury employment status and socioeconomic status was rated.

Data from hospital files were coded by two different persons for each group. However data for 15 individuals were double scored in order to check for any bias due to the rater. Inter-rater reliability was estimated using Kendall's Tau b correlation coefficient since it is appropriate for small samples with possible ties (Field, 2005) and t-test or Mann Whitney to test for possible differences.

The comparison of outcome measures in the two groups will not be controlled for injury type partly because of the small number in the control group, partly because a distinction between the injury types might be considered artificial given the highly diverse patterns of disability caused by brain injury regardless of origin (Rice-Oxley & Turner-Stokes, 1999) the mixed population is more representative for the subjects receiving rehabilitation at the CRBI and in part because outcome measures relate to living in society and responding to psychological intervention rather than strictly medical outcome or issues related to diagnosis.

All statistical analyses were performed using SPSS 13.0 setting alpha to 0.05. The statistical group comparison regarding interview data employed chi-square analyses and non-parametric or parametric independent samples tests, as appropriate. Odd-ratio and a 95% confidence interval were calculated for the employment situation.

Scale scores for all six questionnaires proved to be approximately normally distributed. Therefore, repeated-measure analyses of variance as well as independent samples t-tests were employed to test the hypotheses. However, in some of the repeated measure analyses, the assumption of sphericity was not met. In such cases the Greenhouse-Geisser epsilon correction was applied to the appropriate degrees of freedom. Effect sizes are provided, when possible, as estimates of the magnitude of the significant results; this includes the F-statistics with one degree of freedom (Field, 2005).

When testing directional hypotheses, one-tailed significance levels are used. This is also the case with the F-test with one degree of freedom for the numerator. Because it derives from a null hypothesis with only one restriction, i.e. the difference between two coefficients, the F-statistic in this case has one degree of freedom for numerator and corresponds to a squared t-statistic. Thus, the p-value can be obtained for a one-tailed test using this relationship and the symmetry of the t-distribution (http://www.stata.com/statalist/archive/2004-08/msg00898.html).

Reliability of the questionnaire regarding locus of control that was made for the occasion was calculated using Chronbach's Alpha. This is a model of internal consistency, based on the average inter-item correlation.

A general principle of statistical power is that the more subjects and the fewer variables, the finer the differences that can be detected i.e. the statistical power gets stronger. In medical research it is often a part of the design to perform power calculations as to how many subjects a study should include to detect a difference or effect of a certain size. Large sample sizes are also desirable in the field of rehabilitation. However, it is a bit harder to forecast differences of a certain size within the field of holistic rehabilitation, and since it was not possible to choose the potential size of the control group, a calculation of power was not performed as a part of the design process. The control group ended up consisting of only 13 members for different reasons explained in detail below. This is a very small sample size and affects the statistical analyses by demanding larger effects or differences between the rehabilitation and control group in order for these differences or effects to be significant. Potentially, this means overlooking clinically significant differences that will not be reported because the level of statistical significance will not be reached due to the relatively small sample size. Calculating several statistical analyses comes with the risk of type I and II errors, meaning to either reject a true hypothesis (a difference between the rehabilitation and control group that in fact exists, but does not reach the level of statistical significance) or accept a false hypothesis (a difference between the rehabilitation group and control group that in reality does not represent anything but mere coincidence, but reaches an accepted level of statistical significance). However, given the small sample size there is more of a bias to overlook clinical differences due to the statistical analysis than to over report differences.

2.2 Subjects

First, the rehabilitation group will be described in terms of data collected and participation rate. Second, the participation rate in the control group will be described followed by the comparability of the two groups along with the inter-rater reliability of the injury severity data.

2.2.1 The rehabilitation group: Collecting injury related data.

In the years 1987 to 1992 a total of 126 individuals received comprehensive post-acute neuropsychological rehabilitation at the CRBI. Around that period of time about 57% of all those referred were accepted for treatment at the CRBI (Larsen, Mehlbye, & Gørtz, 1991). Of these, 45 were registered at the CRBI with a diagnosis of CVA and 58 with a diagnosis of TBI.

In order to be able to match the CRBI group with the control group regarding the initial injury severity and hospital stay, it was necessary to collect this data from their hospital records which were not all available at the CRBI. Thus, an application was sent to the Ethics Committee for Copenhagen and Frederiksberg and the Danish Data Protection Agency in order to be able to review hospital journals and record data without personal consent from the time that the 103 participants were in hospital with the brain injury that caused them to come to CRBI for rehabilitation. Normally one would need written consent from a person in order to read their hospital files, but if it is part of a register-based study, the Ethics Committee can grant permission.

The 103 possible participants had had a total of 303 admissions (other than emergency wards; these were not included since they were often missing) in 37 different Danish hospitals (it was not feasible to pursue 10 admissions into hospitals abroad) on 69 different wards in 10 different counties. The MDs in charge of the different wards were contacted and asked for permission to review the files and with his or her permission the hospital archives were contacted and the files reviewed. Files from 294 admissions were reviewed; files from 9 admissions were missing since one of the hospitals had ceased functioning, and due to a change in hospital law some hospitals were not saving journals more than ten years old. The data recorded from the hospital files concerned the following areas (see Appendix A):

1) Hospitalisation: Length of stay, type of ward (acute, surgery, medicinal, rehabilitation etc.), discharge diagnosis, types of surgical procedures, post-traumatic epilepsia, control visits regarding physical and psychological sequelae and if referred to a post-acute rehabilitation centre.

2) Demographic data before injury (and two years later for relevant data): year of injury, sex, age at injury, employment or education situation before injury, social status group (based on education and income), any brain injury before current, physical or psychological health (mainly chronic diseases or substance abuse), living conditions, and need for help/supervision in the home.

3) Functional status before injury, seven days after onset or latest CNS operation, at transfer to local hospital, at transfer to rehabilitation hospital, at discharge with regards to: a) Cranial nerve paralysis (only at discharge), b) musculoskeletal system; locomotor system; motor apparatus; mobility, speech, cognitive function, behaviour, mental function (as an overall assessment), activities of daily living (ADL) and Glasgow Outcome Scale.

4) Injury related characteristics: During the time period of 1982-1992, the International Classification of Diseases (ICD) 8th Edition codes were used for coding the main diagnosis of both cerebrovascular accidents and traumatic brain injury. Cerebro-vascular accidents were for purposes of recording hospital data dichotomised in two groups a) and b) and these two groups consisted of:

    a. Subarachnoidal haemorrhage defined as ICD-8 diagnosis 430: verification of bleeding (lumbar puncture/CT-scan, angiography), localisation of aneurysm or vascular malformation (localised to the main bleeding artery (the carotid or vertebralis or communicans posterior), treatment, findings on latest CT/MR scan, known resting malformations/aneurysms, level of consciousness before injury, seven days after onset or latest CNS operation, at transfer to local hospital, at transfer to rehabilitation hospital and at discharge.

b. Main stroke category consisting of the diagnoses: Intracerebral haemorrhage ICD-8 431, Other and unspecified intracranial haemorrhage ICD-8 432, Occlusion and stenosis of pre-cerebral arteries ICD-8 433, Occlusion of cerebral arteries ICD-8 434, Acute but ill-defined cerebrovascular disease ICD-8 436, characteristics recorded were: background of diagnosis, CT/MR findings (location, secondary injuries (such as oedema and other), and atrophy) and level of consciousness before injury, seven days after onset or latest CNS operation, at transfer to local hospital, at transfer to rehabilitation hospital and at discharge.

c. Traumatic brain injury (TBI) defined as cerebral lesions, i.e. cerebral contusions/ traumatic intra-cranial haemorrhage, with or without diagnosed cranial fractures (ICD-8 851-854). The following variables were recorded: additional cranial fracture, clinical verification of lesion (among others time until Glasgow Coma Scale score was nine or the ability to follow a command, and duration of post-traumatic amnesia), radiological verification and findings on CT/MR (secondary injuries, haemorrhage, atrophy), cause of injury (e.g. traffic accident) and total trauma severity score as indicated by the Injury Severity Score (ISS) (Association for the Advancement of Automotive Medicine, 1990).

2.2.2 The rehabilitation group: Attrition and participation.

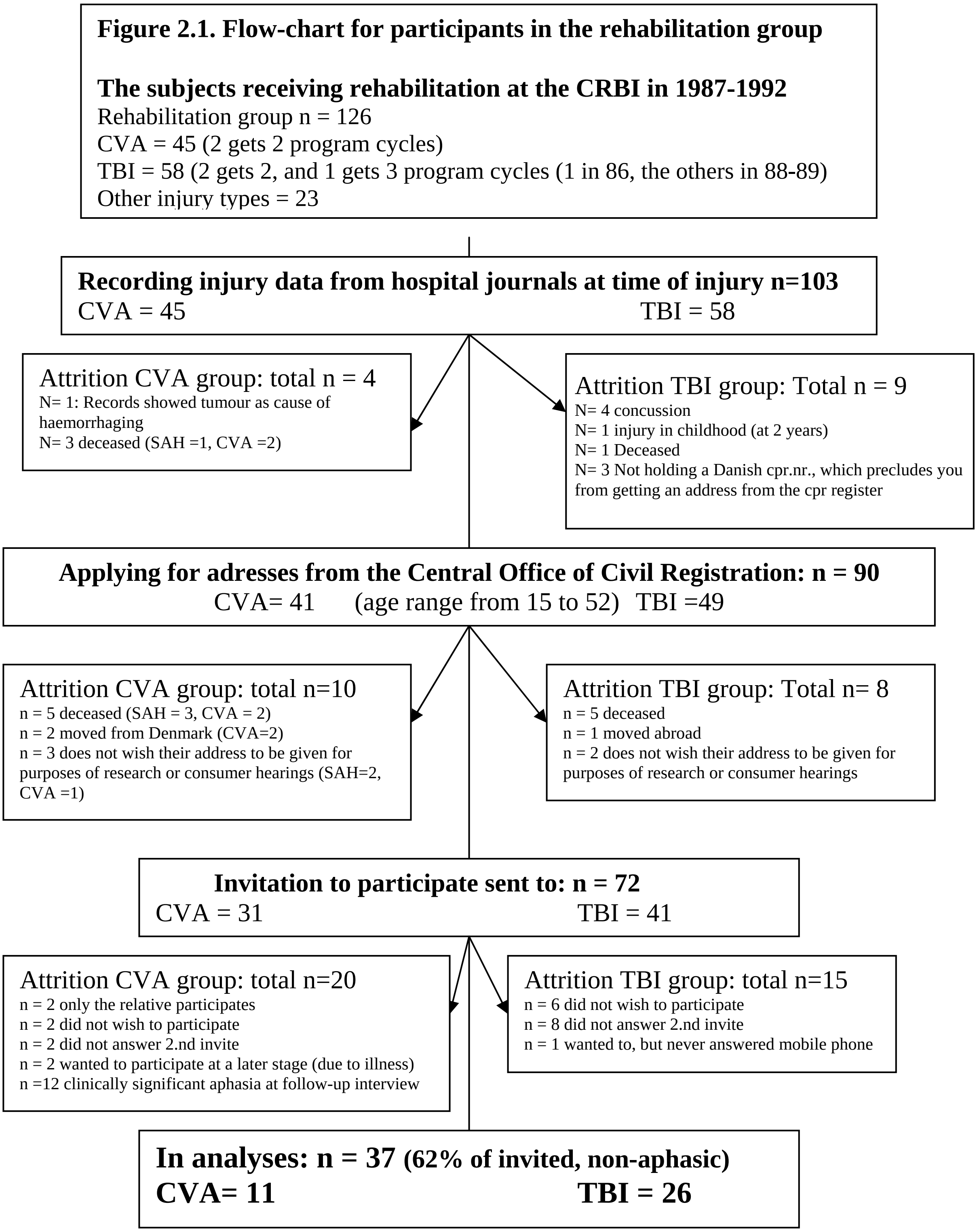
Figure 2.1 shows the attrition and level of participation in the rehabilitation group. According to the hospital data, three from the CVA and one from the TBI group were deceased; in one case a tumour had been the cause of the stroke, four had only had very mild TBI, one had sustained his injury as a child, and three did not have a Danish personal identification number, which precludes finding their address via the Danish Central Office of Civil Registration (CPR). Due to the constraints of the epidemiologically pooled potential control group, those with concussion and the person with childhood injury and the person for whom a tumour resection had caused the stroke were all excluded, leaving 90. Their addresses were applied for (together with those of the control group) via the Central Office of Civil Registration at the end of 2003. Five (two from the TBI group and three from the CVA group) had wished not to have their addresses given for any commercial or research purpose, a further ten were deceased (five from the TBI and five from the CVA group, giving a total mortality of 14% of the original group) and three had emigrated from Denmark (two with a diagnosis of CVA and one with a diagnosis of TBI).

Addresses were obtained for 72 persons (70% of those originally in the program) and invitations, including information about the study and a letter of consent to be signed and returned upon acceptance to participate, were sent out in batches of about 20 at a time (See Appendix B). A total of eight declined the invitation and ten did not answer the second invitation, which was sent a month later if an answer was not received. Three participants wanted to participate but could only do so at a later stage and they were not contacted again. A total of 49 participants (68% of those invited) and 43 significant others participated in the questionnaire and interview study. Two of the significant others participated without the brain injured person: one potential participant with a diagnosis of

CVA had Alzheimer's disease at the time of follow-up, and only her husband participated; one participant also with a diagnosis of CVA refused but her daughter participated. However, later it was decided that the two cases where only the significant others answered were to be excluded. Due to the small number of possible controls, aphasia at time of discharge was not a selection criterion in the initial selection of the controls. Since it proved impossible to find matching controls for the twelve participants with clinically significant aphasia at time of follow-up they were also excluded, leaving data from 37 participants and 32 significant others to be analysed. The percentage of participation ended up being 62% (37/60).

Figure 2.1 Flow-chart for participants in the rehabilitation group

Figure 2.1. Flow-chart for participants in the rehabilitation group



The subjects receiving rehabilitation at the CRBI in 1987-1992
Rehabilitation group n = 126
CVA = 45 (2 gets 2 program cycles)
TBI = 58 (2 gets 2, and 1 gets 3 program cycles (1 in 86, the others in 88-89)
Other injury types = 23

Recording injury data from hospital journals at time of injury n=103
CVA = 45 TBI = 58

Attrition CVA group: total n = 4
N= 1: Records showed tumour as cause of haemorrhaging
N= 3 deceased (SAH =1, CVA =2)

Attrition TBI group: Total n = 9
N= 4 concussion
N= 1 injury in childhood (at 2 years)
N= 1 Deceased
N= 3 Not holding a Danish cpr.nr., which precludes you from getting an address from the cpr register

Applying for adresses from the Central Office of Civil Registration: n = 90
CVA= 41 (age range from 15 to 52) TBI =49

Attrition CVA group: total n=10
n = 5 deceased (SAH = 3, CVA = 2)
n = 2 moved from Denmark (CVA=2)
n = 3 does not wish their address to be given for purposes of research or consumer hearings (SAH=2, CVA =1)

Attrition TBI group: Total n= 8
n = 5 deceased
n = 1 moved abroad
n = 2 does not wish their address to be given for purposes of research or consumer hearings

Invitation to participate sent to: n = 72
CVA = 31 TBI = 41

Attrition CVA group: total n=20
n = 2 only the relative participates
n = 2 did not wish to participate
n = 2 did not answer 2.nd invite
n = 2 wanted to participate at a later stage (due to illness)
n =12 clinically significant aphasia at follow-up interview

Attrition TBI group: total n=15
n = 6 did not wish to participate
n = 8 did not answer 2.nd invite
n = 1 wanted to, but never answered mobile phone

In analyses: n = 37 (62% of invited, non-aphasic)
CVA= 11 TBI = 26

Summary of attrition: (from n = 103 to n = 37)

	CVA group (from n = 45 to n = 11)	TBI-group (from n=58 to n=26)
Wrong injury registration	1	4
Injury as child	0	1
Deceased	8	6
No Danish cpr.nr	0	3
Moved abroad	2	1
No address from cpr	3	2
Only the relative participates	2	0
Did not answer invitation	2	8
Did not wish to participate	2	6
Wanted to participate at later stage	2	1
Aphasia at follow-up	12	0

Table 2.2 Comparison within the rehabilitation group	Rehab Interviewed		Rehab not interviewed		Probability
	n = 37		n = 23		
Sex	n	(%)	n	(%)	
Male (%)	26	(70)	14	(61)	n.s. †
Female (%)	11	(30)	9	(39)	
Pre injury employment					
Work/education on normal terms	34	(92)	22	(96)	n.s. †
With support	3	(8)	1	(4)	
Education					
Academic (5 years plus)	1	(3)	2	(9)	
Middle long (about four years)	3	(6)	0	(0)	n.s. +
Skilled workers (or about three years)	11	(31)	6	(29)	
Specialised worker (or about 1 to 2 years)	11	(31)	7	(33)	
No education	10	(29)	6	(29)	
Injury type					
TBI	26	(70)	15	(65)	n.s. †
CVA	11	(30)	8	(35)	
PTA (TBI subjects)	25		13		
< One week	0	(0)	2	(15)	
< Two weeks	4	(16)	1	(8)	
< One month	10	(40)	1	(8)	n.s. +
>= One month	11	(44)	9	(69)	
Level of wakefulness seven days after trauma (CVA only)					
Clear and awake	6	(55)	10	(63)	n.s. +
Somnolent, confused	3	(27)	2	(25)	
Uncontactable	2	(18)	1	(12)	
Glasgow outcome scale at discharge	36				
Severe disability	1	(3)	0	(0)	n.s. +
Moderate to severe disability	10	(28)	14	(61)	
Moderate disability	19	(53)	7	(31)	
Moderate disability to good recovery	6	(16)	1	(4)	
Good recovery	0	(0)	1	(4)	

* = t-test, † = X^2 test, + = Mann Whitney

Table 2.3 Comparison within the rehabilitation group	Rehab Interviewed n = 37		Rehab not interviewed n = 23		Probability
Variables	Mean	(SD)	Mean	(SD)	
Hospitalisation (total days including inpatient rehabilitation)	167	(153)	207	(164)	n.s. *
Days on life support (respirator)	6	(8)	8	(9)	n.s. *
Duration of coma in days (TBI only)	13	(10)	13	(9)	n.s. *
Injury Severity Score (TBI only)	18	(7)	22	(9)	n.s. *
Mean Age at time of injury (years)	26	(9)	28	(11)	n.s. *
Time from injury to rehabilitation (years)	2.6	(1.5)	2.6	(2.7)	n.s.*
Chronicity of injury in 2004 (years)	17	(2)	18	(4)	n.s. *

* = t-test, † = X^2 test, + = Mann Whitney

From Table 2.2 and Table 2.3. it can be seen that the interviewed and non-interviewed rehabilitation participants from the CRBI program are comparable on demographic and injury related data. Geographic residence has not been investigated since we had no assumption that there would be any difference.

2.2.3 Control Group: Attrition and participation

A non-rehabilitated brain injury group was recruited from two earlier extensive epidemiological studies by Teasdale and Engberg involving a randomised and nationally representative selection of subjects with either traumatic brain injury (TBI) (Engberg et al., 2004) or Cerebro-Vascular Accident (CVA) (Teasdale et al., 2005a), as recorded in a Danish Central Register of hospitalisations. Both of these studies involved a postal questionnaire including an item asking whether the subjects had been able to return to employment after their injury. Table 2.4. and 2.5. show how the possible controls were selected from the population group that Engberg and Teasdale studied on the basis of three characteristics. The primary selection criterion was their ability to return to employment following discharge from their head injury hospitalisation. From the available pool we selected 90 subjects with a diagnosis of CVA and 19 subjects with a diagnosis of TBI who had indicated that they had been unable to return to employment following their injury. The second selection criterion was that the subjects must not have a known record of receiving similar post-acute rehabilitation (this excluded a further nine from the CVA group and five from the TBI group). The rehabilitation group had an age range from 15 to 52 years at the time of injury (see figure 2.1) and it was decided to exclude all those from the possible control group who were older than 55 at time of injury in order to get a somewhat comparable control group. The control group sample sent to the Danish Central Office of Civil Registration thus consisted of 35 with a diagnosis of CVA and 19 with a diagnosis of TBI. Figure 2.2. shows the attrition within the control group. After completing data collection on the 18 subjects, only a single subject from the control group proved to have clinically significant aphasia. Since this made it impossible to match the two groups for aphasia, the subject was excluded along with the 12 mentioned above from the rehabilitation programme. This lowered the age range in the rehabilitation group, with no one in the rehabilitation group older than 44 years at time of injury. As a consequence it was decided that the four subjects in the control group who were older than 44 years at time of injury were to be excluded from the analyses in this dissertation. Of the 24 control subjects who had no other post-acute rehabilitation similar to the CRBI programme and had no aphasia as well as were 44 years at time of injury or younger, 13 (54%) took part in the study. This is lower than the participation rate in the rehabilitation group which amounted to 62%.

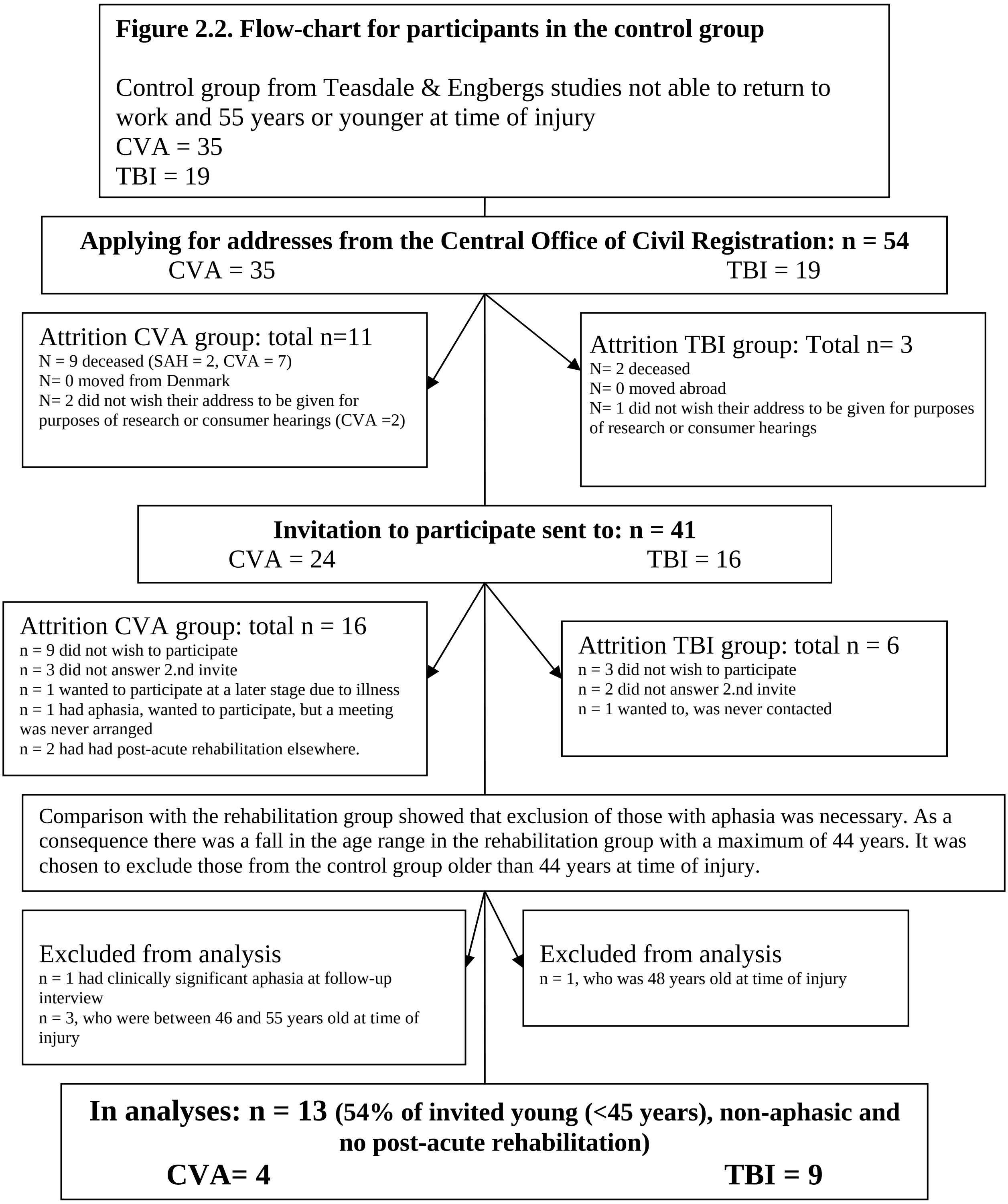
Table 2.6 and 2.7 are comparisons of non-participants and participants from the invited possible controls. Since the participating control-group members over 44 years at time of injury were excluded from the comparison with the rehabilitation group, they have also been excluded from this comparison. There were no significant differences between non-participants and participants in the invited control group. It was not possible to include educational status, since this measure was not included in data obtained from the hospital files.

Table 2.4 Control group: Cerebro-vascular accident (CVA) sample selection	
Initial sample (Teasdale & Engberg, 2005)	4892
Alive at beginning of 1997 follow-up	3010
Randomised sample of people injured in 1982, or 1987, or1992) and alive in 1997	694
Omitted after review of hospital records	106
Records not available	16
Incorrect year of admission	11
Other Coding error	13
Diagnosis not verified	67
Not contacted due to review	58
Co-diagnosis	24
Severe progression	18
Address unavailable, etc	16
Died 1997-1998	80
Questionnaire sent (Teasdale & Engberg, 2005)	449
Not returned	105 (23%)
Returned	344 (77%)
Answer regarding ability to work immediately after their hospitalisation	321
1. Returned to conditions as usual	50
2. Returned to work with limitations	55
3. Not at all able to return to work	**89**
4. Not working at time of injury	126
Not included in control sample	255
Those who were able to return to conditions at work as usual	50
Those who returned to work with limitations	55
Those who had no work at time of injury	126
Received post-acute rehabilitation similar to the CRBI program elsewhere	**9**
Age 56 or older at time of injury	**45**
Possible controls	**35**

Table 2.5 Control group: Cerebral lesion sample selection	
Initial sample of people injured in 1982, or 1987, or1992) and alive in 1997 (both cranial fractures and cerebral lesions)(Teasdale & Engberg, 2005)	958
Randomised sample	456 (47.5%)
Hospital records reviewed	389 (85.3%)
Omitted during review of hospital records	67 (14.7%)
Records not available	12
Diagnosis of TBI not justified	32
Died over the period during which the records were retrieved	13
Under age 15 when injured	10
Not contacted	52
Severe co-diagnosis of cancer	14
Severe chronic alcohol or drug abuse	16
Pre-injury dementia	11
Addresses unavailable	11
Questionnaire sent (Teasdale & Engberg, 2005)	337
Not returned	80 (23.7%)
Returned	257 (76.3%)
Sub-dural haematoma	17
Cranial fracture (where of some have contusions as well? Tom)	114
Included Cerebral lesion	126
Answer regarding ability to work immediately after their hospitalisation	120
1. Returned to conditions as usual	31
2. Returned to work with limitations	44
3. Not at all able to return to work	**29**
4. Not working at time of injury	16
Not included in control sample	64
Those who were able to return to conditions at work as usual	31
Those who returned to work with some limitations	44
Those who had no work at time of injury	16
Received post-acute rehabilitation similar to the CRBI program elsewhere	**5**
Age 56 or older at time of injury	**5**
Possible Controls	**19**

Figure 2.2 Flow-chart for participants in the control group

Figure 2.2. Flow-chart for participants in the control group



Control group from Teasdale & Engbergs studies not able to return to work and 55 years or younger at time of injury
CVA = 35
TBI = 19

Applying for addresses from the Central Office of Civil Registration: n = 54
CVA = 35 TBI = 19

Attrition CVA group: total n=11
N = 9 deceased (SAH = 2, CVA = 7)
N= 0 moved from Denmark
N= 2 did not wish their address to be given for purposes of research or consumer hearings (CVA =2)

Attrition TBI group: Total n= 3
N= 2 deceased
N= 0 moved abroad
N= 1 did not wish their address to be given for purposes of research or consumer hearings

Invitation to participate sent to: n = 41
CVA = 24 TBI = 16

Attrition CVA group: total n = 16
n = 9 did not wish to participate
n = 3 did not answer 2.nd invite
n = 1 wanted to participate at a later stage due to illness
n = 1 had aphasia, wanted to participate, but a meeting was never arranged
n = 2 had had post-acute rehabilitation elsewhere.

Attrition TBI group: total n = 6
n = 3 did not wish to participate
n = 2 did not answer 2.nd invite
n = 1 wanted to, was never contacted

Comparison with the rehabilitation group showed that exclusion of those with aphasia was necessary. As a consequence there was a fall in the age range in the rehabilitation group with a maximum of 44 years. It was chosen to exclude those from the control group older than 44 years at time of injury.

Excluded from analysis
n = 1 had clinically significant aphasia at follow-up interview
n = 3, who were between 46 and 55 years old at time of injury

Excluded from analysis
n = 1, who was 48 years old at time of injury

In analyses: n = 13 (54% of invited young (<45 years), non-aphasic and no post-acute rehabilitation)
CVA= 4 TBI = 9

Summary of attrition: (from n = 54 to n = 13)

	CVA group (from n = 35 to 4)	TBI-group (from n= 19 to n = 9)
Deceased	9	2
No address from cpr	2	1
Did not answer invitation	3	2
Did not wish to participate	9	3
Wanted to participate at later stage or was not contacted (1 had aphasia)	2	1
Excluded		
Aphasia at follow-up	1	0
Older than 44 years at time of injury	3	1
Received post-acute rehabilitation elsewhere	2	0

Table 2.6 Comparison among the controls Variables	Control Interviewed		Control not Interviewed		Probability
	n = 13		n = 11		
Sex	n	(%)	n	(%)	
Male (%)	7	(54)	8	(73)	n.s. †
Female (%)	6	(46)	3	(27)	
Pre injury employment					
Work-education on normal terms	12	(92)	8	(89)	n.s. †
With support	1	(8)	1	(11)	
Injury type					
TBI	9	(69)	5	(45)	n.s. †
CVA	4	(31)	6	(55)	
PTA (TBI subjects)	8		4		
	0	(0)	1	(25)	
< One week	2	(25)	0	(0)	
< Two weeks	0	(0)	1	(25)	n.s. +
< One month	2	(25)	1	(25)	
>= One month	4	(50)	1	(25)	
Level of wakefulness seven days after trauma (CVA only)					
Clear and awake	2	(50)	3	(60)	n.s. +
Somnolent, confused	2	(50)	2	(40	
Uncontactable	0	0			
Glasgow outcome scale at discharge	13		11		
Severe disability	1	(8)	1	(9)	n.s. +
Moderate to severe disability	4	(30)	2	(18)	
Moderate disability	7	(54)	8	(73)	
Moderate disability to good recovery	0	(0)	0	(0)	
Good recovery	1	(8)	0	(0)	

* = t-test, † = χ^2 test, + = Mann Whitney

Table 2.7 Comparison among the controls Variable	Control Interviewed		Control not Interviewed		Probability
	n = 13		n = 11		
	Mean	(SD)	Mean	(SD)	
Hospitalisation (total days including inpatient rehabilitation)	144	(151)	104	(47)	n.s. *
Days on life support (respirator)	6	(6)	4	(5)	n.s. *
Duration of coma in days (TBI only)	14	(13)	11	(12)	n.s. *
Injury Severity Score (TBI only)	29	(11)	33	(8)	n.s.*
Mean Age at time of injury (years)	31	(8)	31	(9)	n.s. *
Chronicity of injury in 2004 (years)	15	(4)	17	(4)	n.s. *

* = t-test, † = χ^2 test, + = Mann Whitney

2.2.4 Comparability

Table 2.8 and 2.9 show a comparison of the participating Rehabilitation and Control subjects on the matching demographic and injury severity variables.

The two groups are comparable in all demographic and medical injury characteristics, with the exception of geographical distribution and injury severity score. The catchment area for the CRBI programme was largely confined to the Easterly island of Zealand, whereas the control group was drawn from two epidemiological studies (Engberg et al., 2004; Teasdale et al., 2005a) which covered a wider range of Danish counties from East to West. In consequence, as shown in Table 2.8, there is a significant difference between the two groups with regard to geographical distribution.

It can be seen from Table 2.9 that the only other significant difference (t(33) = -3.5, p = 0.001) between the two groups is the injury severity score, where the control group have a higher score compared to the rehabilitation group. The injury severity score summarises all injuries to the head as well as the body, including loss of consciousness, broken bones, loss of limbs etc.

The rehabilitation group seems slightly younger at time of injury than the control group. The correlations between injury severity score, age at injury and the different questionnaire results all proved to be very small and to explain less than 10% of the variance on all Scale scores. Due to the limited participants and the negligibly small effect of age or injury severity, these factors have not been controlled for in the analyses.

Spontaneous recovery is a factor that can influence outcome after rehabilitation, especially during the first year post-injury (Seale et al., 2002). The majority from the rehabilitation group were beyond the initial phase of spontaneous recovery. Only 1 participant or 3% was entering the rehabilitation program less than one year after their injury (10.9 months post-injury). On average the group was 2.6 years post-injury (SD = 1.5) ranging from 10.9 months to 7.4 years post-injury.

Table 2.8 Comparision of rehabilitation and control group on injury and demographic data.

Table 2. 8 Variable	Rehab Group n = 37		Control Group n = 13		Probability
Sex	n	(%)	n	(%)	
Male (%)	26	(70)	7	(54)	n.s. †
Female (%)	11	(30)	6	(46)	
Pre injury employment					
Work-education on normal terms	91.9%		92.3%		n.s. †
With support	8.1%		7.7%		
Education					
Academic (5 years plus)	2	(5)	1	(8)	
Middle long (about four years)	1	(3)	1	(8)	n.s. †
Skilled workers (or about three years)	5	(14)	1	(8)	
Specialised worker (or about 1 to 2 years)	10	(27)	7	(53)	
No education	19	(51)	3	(23)	
Injury type					
TBI	26	(70)	9	(69)	n.s. †
CVA	11	(30)	4	(31)	
PTA (TBI subjects)	25		8		
< One week	0	(0)	2	(25)	
< Two weeks	4	(16)	0	(0)	
< One month	10	(40)	2	(25)	n.s. +
>= One month	11	(44)	4	(50)	
Level of wakefulness seven days after trauma (CVA only)					
Clear and awake	6	(55)	2	(50)	n.s. +
Somnolent, confused	3	(27)	2	(50)	
Uncontactable	2	(18)	0	0	
Glasgow outcome scale at discharge	36		13		
Severe disability	1	(3)	1	(8)	n.s. +
Moderate to severe disability	10	(28)	4	(30)	
Moderate disability	19	(53)	7	(54)	
Moderate disability to good recovery	6	(16)	0	(0)	
Good recovery	0	(0)	1	(8)	
Geographic residence at time of injury					
Island of Zealand	33	(89)	6	(46)	p = 0.001 †
Elsewhere in Denmark	4	(11)	7	(54)	

* = t-test, † = X^2 test, + = Mann Whitney

Table 2.9 Comparision of rehabilitation and control group on injury and demographic data.

Table 2.9 Variable	Rehab Group		Control Group		Probability
	n = 37		n = 13		
	Mean	(SD)	Mean	(SD)	
Hospitalisation (total days including inpatient rehabilitation)	167	(153)	144	(151)	n.s. *
Days on life support (respirator)	6	(8)	6	(6)	n.s. *
Duration of coma in days (TBI only)	13	(10)	14	(13)	n.s. *
Injury Severity Score (TBI only)	18	(7)	29	(11)	p = 0.001 *
Mean Age at time of injury (years)	26	(9)	31	(8)	n.s. *
Time from injury to rehabilitation (years)	2.6	(1.5)	n.a.	n.a.	n.a.
Chronicity of injury in 2004 (years)	17	(2)	15	(4)	n.s. *

* = t-test, † = X^2 test, + = Mann Whitney

From Table 2.10 it can be seen that the significant others in the two groups are comparable in terms of participation rate (even though it is a little lower in the rehabilitation group), gender (the majority being women), whether they knew the participant before the injury (the majority did), what relationship they have to the participant (even though there are non-significantly more spouses in the control group), age (albeit the controls seem a bit younger concurring with there being fewer parents, more spouses and more children compared with the significant others in the rehabilitation group) and formal education.

Table 2.10 Characteristics of significant others	Rehabilitation group n = 32/37	Control group n = 13/13	p
Significant others participating	86 %	100 %	n.s. †
Gender			
Male	31.2 %	23.1 %	n.s. †
Female	68.8 %	76.9 %	
Did they know the participant before the injury?	78.1 %	83.3 %	n.s. †
Yes	21.9 %	16.7 %	
No			
Relation to the participant			
Spouse or defacto	37.5 %	53.8 %	
Parent	31.3 %	15.4 %	
Sibling	9.4 %	7.7 %	n.s. +
Friend	6.3 %	7.7 %	
Child	6.3 %	15.4 %	
Other (e.g. support person)	9.4 %	0 %	
Age in years (SD)	51(14)	44(14)	n.s. *
Years of school	10 (1.6)	11 (1.3)	n.s. *

* = t-test, † = X^2 test, + = Mann Whitney

2.2.5 Reliability of injury severity data.

Table 2.11 Reliability data		n	Control group rater		Rehabilitation group rater		t-test/ Mann Whitney	Kendall Tau-b	p (1- tailed)
			Mean	SD	Mean	SD			
All	Total no. of days in hospital (acute plus eventual rehab)	15	67.1	110.7	59.9	101.9	t(14) = 1.15, p = 0.3	0.99	.000
	No. of days in acute treatment	15	52.4	65.8	46.6	55.6	t(14) = .93, p = 0.4	0.98	.000
	GOS	15	39.7	4.0	41.7	3.6	U = 83.5, p = 0.2	0.47	.026
CVA	Level of consciousness seven days after episode	5	13.8	2.5	11.3	2.5	t(3) = 1.73, p = 0.2	0.41	.248
TBI incl.	Days in coma	5	14.6	21.8	9.5	11.3	t(3) = 0.96, p = 0.2	1.00	.002
	PTA-group	6	3.8	1.3	3.5	1.2	U = 15.5, p = 0.67	0.55	.070
	ISS	10	20.2	9.5	16.7	7.2	t(9) = 1.42, p = 0.1	0.42	.035

As can be seen from Table 2.11, the person who rated the rehabilitation group rates more mildly measures of severity of injury, and rates the GOS higher than the control rater, potentially biasing the comparability towards underestimating the severity of injury on part of the rehabilitation group. However, there is no significant group difference between the two raters on any of the measures. The correlation between the two different ratings was significant on all measures except two: length of PTA as a grouped variable for those who had sustained a TBI, and level of consciousness for those who suffered a CVA. Length of hospitalisation and days in coma showed the strongest correlations from 0.98 to 1.0, whereas Glasgow Outcome Scale (GOS), level of consciousness for participants with CVA and Injury Severity Score (ISS) showed weaker albeit acceptable correlations ranging from 0.41 to 0.55.

Since there were no significant differences in ratings, these factors have not been controlled for in the analyses to be presented.

2.3 Constitution of questionnaire and interview

The first of the two following sections describes the questionnaires used. The second section describes the content of the interview.

2.3.1 Questionnaires

Questionnaires used to address six Hypotheses of emotional well being in the dissertation were:

1) The European Brain Injury Questionnaire (EBIQ). It was selected to give a subjective rating of brain injury symptoms and the impact of these consequences on the significant other in order to test the first hypothesis. This stated: it is expected that those who received rehabilitation and their significant others will experience the symptoms of brain injury and the impact of the brain injury on the significant other less disturbing than the control group.

2) The Patient Competency Rating Scale (PCRS) was chosen in order to assess perceived levels of competency according to the second hypothesis of emotional well-being. It is expected that the participants who had received rehabilitation would have a higher degree of total competency both reported by themselves and their significant others.

3) The EBIQ and the PCRS were analysed with attention to level of awareness of deficit in the two groups. The third hypothesis was that there would be more agreement between participant and significant other in the rehabilitation group. Level of agreement was measured in three different ways: the magnitude of difference between self and significant other; the

typical answer-style or kind of agreement between self and significant other; and the strength of correlation between self and significant other.

4) The Generalized Self-efficacy scale as well as questionnaire regarding locus of control (LoC) consisting of six items (constructed for the purpose of this study) were employed in order to test the fourth hypothesis stating that self-efficacy would be higher and locus of control more internal in the rehabilitation group.

5) The Hospital Anxiety and Depression Scale (HADS) was selected to test the fifth hypothesis regarding levels of anxiety and depression in participants and their significant others, since there is no general consensus on which measure of anxiety and depression to be used with the brain injured population. The rehabilitation group was thought to have lower levels of anxiety and depression.

6) The WHO-QoL-Bref was chosen in order to assess subjectively experienced quality of life in participants as well as their significant others. Level of quality of life was thought to be higher in the rehabilitation group.

The significant others received a similar questionnaire; however the Generalized Self-efficacy scale and the locus of control scale was not included. Instead they received additional demographic questions. The questionnaire took about an hour to an hour-and-a-half to complete.

European Brain Injury Questionnaire (EBIQ)

The EBIQ has been specifically designed in two parallel versions: a 'self' version for use on individuals with brain injury, and a 'significant other' version to be completed by their close significant others (Teasdale et al., 1997a). It contains 62 questions relating to ’problems or difficulties that people sometimes experience in their lives’, as well as three questions regarding what impact the injury has had on the significant other. Subjects with brain injury complete the 'self' version in which they are asked to indicate ‘how much (they) have experienced any of these within the last month’. Their responses were coded on a three-point scale: ‘not at all’ (1), ‘a little’ (2) or ‘a lot’ (3). Correspondingly, significant others completed the 'significant other' version in which they give their perceptions of the person with brain injury. From both the subjects′ and the significant others′ questionnaires, eight scales were calculated corresponding to complaints categorised as: somatisation, cognition, motivation, impulsivity, depression, social isolation, physical symptoms, and communication. An additional 'core’ scale summarised complaints globally.

The scores on these scales were computed as the simple average of the scores (1, 2 or 3) for the questionnaire items pertaining to each scale. The scale scores can thus also range from 1.0 to 3.0. Further psychometric details are presented elsewhere(Teasdale et al., 1997a).

Additionally, the EBIQ included three questions concerning the impact of the brain injury on the significant other, as judged by the persons with brain injury and the significant others themselves.

Patient Competency Rating Scale (PCRS)

The PCRS (Prigatano et al., 1990) comprises twenty-six items measuring competency on a 5-point Likert scale. The tasks and activities of daily living assessed are thought to be easily manageable by non-brain injured individuals. It has been translated into Danish by Hjerneskadecentret (Johansen et al., 2004). The questionnaire is typically used for a comparison of ratings made by the patient and a close significant other or clinician. Results can be presented as an average score, total score on a scale from 26 to 130, and subscales related to ADL (eight items), cognition (eight items), interpersonal (seven items) and emotion (seven items). These scales can be converted into a 1-100 scale (Leathem et al., 1998). Missing items on the scale scores are substituted by the average of the other items in cases missing no more than two out of eight on the ADL and Cognitive scales and no more than one out of seven on the interpersonal and emotion scales. If more items are missing the scale score is not calculated. Prigatano, Altman and O'Brien (1990) found good overall test and retest reliability for patients (r = 0.97) and their significant others (r = 0.92).

Generalised Self-Efficacy Scale (GSEC)

The GSEC is a ten-item psychometric scale that is designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life (Schwarzer & Jerusalem, 1995). Unlike other scales that were designed to assess optimism, this one explicitly refers to personal agency, i.e. the belief that one's actions are responsible for successful outcomes. The scale was originally developed in Germany by Matthias Jerusalem and Ralf Schwarzer in 1981 (1995) and has been translated into several languages and been completed by tens of thousands of participants.

The items are rated on a 4-point Likert scale with a total score ranging from 10 to 40. 30 has been suggested as a possible cut-off score but the authors recommend that the scale be primarily used for comparison.

Locus of Control (LoC)

The LoC scale was constructed for the purposes of the present study. It consists of six questions pertaining to how great a sense of control a subject feels towards life. The items are rated on a four-point Likert scale similar to the above-mentioned self-efficacy scale and items are added to yield a total score ranging from 6 to 24 – the higher the score the higher degree of internal locus of control. The LoC score proved to be normally distributed, showed homogeneity of variance and had a satisfactory reliability (Cronbach’s Alpha = 0.81).

Hospital Anxiety and Depression Scale (HADS)

The HADS, was designed to provide a simple yet reliable general instrument to measure emotional distress on two scales, namely anxiety and depression (Zigmond & Snaith, 1983). It consists of fourteen items, seven items that reflect depression and seven that reflect anxiety. The scales have been created on the basis of factor analysis. The items are rated by the patient on a 4-point (0 to 3) ordinal scale, so possible both the depression and anxiety scale scores range from 0 to 21. A score of 0 to 7 for either subscale could be regarded as being in the normal range, a score of 11 or higher indicating probable presence ('caseness') of the mood disorder and a score of 8 to 10 being just suggestive of the presence of borderline symptomatology. The internal reliability is considered good and Chronbach's Alpha has generally been reported as high and on average 0.83.

There is one question ("I can enjoy a good book or a good TV-programme") which is sensitive to brain injury symptoms, and not necessarily sensitive to depression in this population. It has been suggested as a precaution to screen this item. The mean for this item was comparable to the other depression item means and was therefore not adjusted for in the analyses.

World Health Organization Quality of Life questionnaire (WHO-QoL)

The WHO-QoL (BREF = brief version) is a widely used general questionnaire that measures subjective quality of life. The Danish translation (Norholm & Bech, 2001) was used. It is a twenty-six-item version of the original hundred-item version, WHO-QoL-100. It covers four domains related to physical and psychological health (seven and six items respectively), social relations (three items) and environmental safety (eight items) as well as two items concerning quality of life and health in general. Each item is rated on a 5-point Likert scale.

Domain scores are scaled to range from 0 to 100 (in order to make it comparable to the hundred-item version). The higher the domain score, the higher the quality of life and health within the domain. Cronbach's Alpha values have in different studies varied from 0.66 to 0.83 for the four scales.

2.3.2 Interview

The interview was intended to broadly cover areas of outcome, mainly in terms of participation (employment, leisure and social network). Also examined were environmental factors such as therapy supplied by the Danish social system, which was not covered by the questionnaires, as well as factors that potentially could affect outcome such as recent life stressors, additional brain injury pathology, or other illnesses. The interview covered:

a) Life stressors within the last year such as divorce, in order to be able to analyse whether this factor could have any influence on current outcome (fifteen items). Items were taken from ‘The Social Readjustment Rating Scale’(Holmes & Rahe, 1967).

b) Health: hospitalisations since brain injury; additional brain injuries; illnesses and if these affect their current life; what medication they were taking (fifteen items).

c) To what extent the brain injury affected current life (three items).

d) Physical (thirteen items), cognitive (eleven items), emotional (ten items), interpersonal (seven items) and practical (ten items) symptoms of brain injury: the participant was asked to state if he or she experienced common symptoms of brain injury and to evaluate how much a given symptom affected their activities on a 5-point Likert scale.

e) Use of compensation strategies (eight items).

f) Received help from the social services due to the consequences of the brain injury at the time of the interview (twenty-four items): home-nurse, support person, home-aid, physiotherapy, occupational therapy, psychology-visits, special education, social counsellor, visits to MD or hospital. They were asked if they felt the amount of help was sufficient.

g) In terms of employment, the subjects were asked what position they currently held, for how long they had been in that situation (be it a job, pension or unemployment), number of hours per week, and financial situation as well as if they were satisfied with this employment situation (nineteen items).

h) Leisure covered if what leisure activities they had and if these activities were carried out alone or with others and frequency of any given activity and which if any activities they would like to have in the future (fifteen items).

i) Social network: how many friends and family members they had, and if they were in regular contact with them and how satisfied they were with this contact (fifty-three items).

j) Satisfaction with their own adjustment after brain injury (six items) taken from a study of identity after brain injury (Ben-Yishay & Daniels-Zide, 2000).

k) Satisfaction with current and past treatment in connection with the brain injury (four items for the control group and twenty for the rehabilitation group). Participants from the rehabilitation group were asked questions pertaining to how much they felt the rehabilitation at the CRBI had benefited different aspects of their life, such as employment, self confidence, communicative abilities etc. This was adapted from the follow-up study undertaken by Johansen, Pedersen & Lauersen (2004) They were also asked which of the programme elements they had found most important.

The interview consisted of a total of 209 to 226 items and took about two hours to complete.

The interview and questionnaire were tested on three pilot participants and their significant other in order to evaluate if the questions posed were understandable and easy to answer or if there were any other detectable biases or if the interview was experienced as too long. The three pilot participants had all been through the CRBI program within 2 years of the test. A few instructions were altered and a few questions taken out of the interview however it was not found necessary to make major changes and thus a second pilot was not conducted.

2.4 A discussion of strengths and limitations of the methodology

This chapter has presented the design, statistical methods, subjects and outcome measures employed in the follow-up study.

Methodologically, this study includes a fairly well-matched control group and compares outcome twelve to seventeen years after rehabilitation and twelve to twenty-two years after injury. A broad range of outcome measures is included covering employment, emotional well-being and the evaluation of rehabilitation by the participant. Thus, it is a fairly strong study that offers a unique scope within the field of rehabilitation. The retrospective matching is an attempt to control for potential confounders or variables known to be of importance for outcome. This is a way to limit the alternative explanations for potentially different outcomes between the rehabilitation and control groups. However, it can be argued that the retrospective design does not provide convincing evidence for any causal relationship between rehabilitation and outcome. One bias is that of ascertainment. Various factors could mean that those who received rehabilitation were more likely to do well, regardless of any effect of rehabilitation itself and in spite of matching for injury severity etc. For instance since the CRBI program was not widely known it was often resourceful significant others who found this offer and made the GP make a referral. One could argue that having a strong resourceful significant other reflects on the person with brain injury. On the other hand it could be argued that being referred were in some instances coincidental and given that there were only a few places offering holistic rehabilitation at that time not as many that would benefit from the rehabilitation were referred, making the potential ascertainment smaller. Unfortunately it has not been possible to calculate the proportion of patients referred for post-acute rehabilitation and how many who took the offer. This could have given some indication of the potential for selection bias. However even before referral various selection factors might have been in play such as only those, whom the referrer thought would do well, would be referred and only those who were going to do well would accept being referred. Another potential matching bias is that the employment status for the control group is only known at time of discharge from hospital and not at the same time as the rehabilitation group was referred to post-acute rehabilitation. Potentially this means that the control group might not have been eligible for recruitment at the same time the rehabilitation participants were. However not being eligible for referral would have meant the control participants would have been in employment, thus seemingly less affected by the injury and therefore not diminishing the potential effect of rehabilitation seen in this study.

The design further imposes certain limitations on the generalisation of the findings to be presented. The retrospective nature of the injury-related characteristics used to match the two groups, and the fact that the rating was done by two different raters, increases the uncertainty of the measures and is a limiting factor for the validity of the results of the matching. Detailed and timed information about key events can be more easily obtained from a prospective study. The retrieval of medical data from hospital journals would have been more accurate had it been done prospectively, given the opportunity to observe and control the way length of coma and PTA were measured. A prospective study could also control the amount of treatment given, whereas one of the limitations of this study is that it only can give a rough sense that rehabilitation has been provided in the hospital phase for both groups, and that the factor that differs between the two groups is that only the rehabilitation group underwent an intensive neuropsychological programme in the post-acute phase.

In terms of reliability it could be argued there is a slight tendency for the rater of the rehabilitation group to underestimate severity of the injury. This bias means that the rehabilitation group might have been more severely injured than assumed in comparison to the control group and thus there might be less of a difference between the two groups than initially expected.

The matching of the control group could only be done on a limited number of variables. This, in combination with the relatively limited number of subjects, means that both groups may be very heterogeneous, which can make it difficult to judge whether overall group differences are due to the rehabilitation itself or the different characteristics of the different brain injuries or other unknown systematic biases. However, those individuals in both groups who have suffered a traumatic brain injury (TBI) may be presumed to have very diffuse injuries, thus diminishing the factor of localization. In terms of those participants who had cerebro-vascular accidents (CVA), having excluded persons with present-day aphasia will have made the two groups more comparable in terms of which problems they are facing. The *post-hoc* exclusion of the aphasics was necessary because it was only possible at first to match for age and thus not aphasia at discharge from acute care. That is why the exclusion was made on the presence of current clinically significant aphasia. It is also possible that there could be participants so good at compensating that the interviewer did not detect their aphasia.

Not following the two groups and measuring at intervals also increases chances that group differences may result from factors other than the difference in the rehabilitation received. Ideally, pre-injury personality characteristics should have been recorded prior to injury, and only having access to employment and socioeconomic categories is weakness.

The selection of the control group and the criteria of CRBI programme show that the population included are far from a broad selection of the brain injury population and that the severity of the brain injury far from covers the broad spectrum of brain injury severities within the diagnosis groups of TBI and stroke.

The participation rate of 54 to 62 % is lower than the 80% which is considered a favourable participation rate in order to minimise responder bias. The responders who participated may have been those making the best personal adjustment. Given the comparative nature of the analyses such a bias would favour the control group given that this group has the lowest response rate, thus not adding to a potential effect of rehabilitation. However no significant differences were found between participants and non-participants from neither the rehabilitation nor the control group, which minimises this potential bias.

Comparability of the rehabilitation and control groups was suboptimal in the categories of geographical location at time of injury and total injury severity score. The geographical difference should not be seen as a rural-urban difference, which could have meant different levels of initial care and access to help from society, potentially influencing outcome (Fleminger et al., 2005). It is more of an East-West difference, and Denmark being a homogeneous country with socialised medicine and minimal disparities in terms of education or income, this difference is thought to be a minor bias. A higher total injury severity score in the control group indicated additional physical injuries (because injury severity scores such as PTA and length of coma were not significantly different in the two groups) which could potentially influence the current situation in the control group negatively. In a recent prospective study of centralised acute rehabilitation, the total injury severity was significantly correlated to the length of hospitalisation but not to Glasgow Outcome Scale (GOS) thus perhaps indicating this measure to be of less importance in a long-term follow-up study (Engberg, Liebach, & Nordenbo, 2006).

The interviewer was not blind to the status of the participants as belonging either to the rehabilitation or control groups. This could bias the way results were collected. To minimise it, questionnaires were filled out prior to meeting the interviewer, the interview was structured and the evaluation of rehabilitation was undertaken at the end of the interview, to make the data collection in the rehabilitation and control groups as comparable as possible. Inherent in the questionnaire method are difficulties related to the validity of the chosen questions and concepts. How well are questions understood? This is less a problem with the previously used questionnaires such as the EBIQ, PCRS, GSE, HADS and WHO-QoL-Bref, which have been validated in previous studies, although some of them (GSE, HADS and WHO-QoL-Bref) not on a brain injured population. The locus of control scale generated for the purpose of this study proved to have a good reliability, but it may be considered to have less validity compared to the 'established' questionnaires. There were only few questions in the interviews which could be considered an indicator of whether the subject generally understood the questions, though this is not unequivocal. The reliability of persons with brain injury as informants is an additional factor in terms of the reliability of the results of the outcome measures. Two questionnaires (EBIQ and PCRS) were also filled out by the significant other. Results indicated no difference in awareness of brain injury symptoms or competency in the two groups, but did show a general tendency for the participants with brain injury to underestimate symptoms and overestimate competency. Given the subjective nature of QoL, it has been emphasised (Bullinger, 2002) that the individual with brain injury must endorse their own opinion. There have also been indicators that a person with brain injury will tend to report internal feelings such as depression and anxiety more strongly than their significant other, thus minimising the chance of underestimations on the HADS.

Significant others are to a greater extent spouses/partners in the control group compared to the rehabilitation group. However in the earlier study of the EBIQ at the CRBI (Svendsen, Teasdale and Pinner, 2004) no systematic differences were found between the mean scale scores for significant others who were partners and those who were not. Likewise in the recent follow-up study of significant others and carers by Ponsford and her coworkers (2003) there was no difference between partners and other significant others with respect to levels of anxiety and depression. This could suggest that the different composition of significant others among the rehabilitation and control group was not a major bias also given the fact that most participants lived independently at time of interview with none or minimal supervision in activities of daily living.

Any information given in the interview on part of the participants about past events is bound to be prone to errors in recall (e.g. number of work trials after the injury, or the rating of the usefulness of different programme elements by the participants in the rehabilitation group).

The outcome measures used in this study are only a limited range of possible measures. Questions from the interview regarding employment leisure and social life may have been more comparable to other studies and more valid if a formal questionnaire such as the Community Integration Questionnaire (Cicerone, 2004) had been used, thus maybe offering a more integrated measure of participation. It would also have been interesting to include measures of coping strategies.

Basically these limitations mean that any positive results from this study can at most be said to indicate that intensive, post-acute, neuropsychological treatment is better than no treatment at all, but due to the design the results can not say that intensive post-acute neuropsychological rehabilitation is better than other treatment. Of course the design bears neither the ability to infer which aspects of the holistic programme work, nor why they work.

Chapter 3. Results regarding work and leisure activities

This chapter has the form of the article submitted for publication.

THE INFLUENCE OF NEUROPSYCHOLOGICAL REHABILITATION ON EMPLOYMENT AND LEISURE ACTIVITIES FOLLOWING BRAIN INJURY: A CONTROLLED LONG-TERM FOLLOW-UP.

Henriette Aaby Svendsen

Centre for Rehabilitation of Brain Injury and Department of Psychology, University of Copenhagen, Denmark

Thomas William Teasdale

Department of Psychology, University of Copenhagen, Denmark

Frank Humle

Centre for Rehabilitation of Brain Injury, University of Copenhagen, Denmark

Correspondence to Henriette Aa. Svendsen, Centre for Rehabilitation of Brain Injury and Department of Psychology, University of Copenhagen, Njalsgade 88, DK-2300 Copenhagen S. E-mail henriette.svendsen@psy.ku.dk, Telephone + 45 35 32 90 06, Fax + 45 35 32 48 02

3.1 Abstract

Objectives: To examine long-term employment status in a group of persons with brain injury, who had undergone intensive post-acute neuropsychological rehabilitation, compared to a similar group who had only received conventional care.

Design: Retrospective, controlled

Setting: Out-patient outcome after post-acute rehabilitation across Denmark

Participants: A group of 37 adults who had suffered cerebrovascular accidents (CVA) or traumatic brain injuries (TBI), and who had undergone a rehabilitation programme, were followed up 12-22 years post-injury, together with a non-rehabilitated control group of 13 adults, matched for brain-injury and demographics characteristics.

Interventions: Post-acute neuropsychological out-patient rehabilitation, carried out 12 to 17 years prior to follow-up, for a period of four months, 25 hours a week with a follow-up monitoring of at least eight months.

Main outcome measures: Employment status and leisure activities.

Results: The rehabilitation group showed significantly ($Z = -2.3$, $p = .02$) higher active employment status levels (n =31 or 83.8 % in some kind of employment) compared to the control group (n = 7 or 53.9 % in some kind of employment). The odds-ratio for employment after rehabilitation was 4.4 (95 % CI = 1.1 to 17.9). Among those in employment, the rehabilitation group was significantly ($X^2(1) = 8.7$, $p = .003$) more satisfied (n = 26/30 or 87 %) with their situation with regard to employment compared to the control group (n = 4/10 or 40 % were satisfied). There were no differences in terms of leisure activities.

Conclusions: Within methodological limitations this study suggests that post-acute neuropsychological rehabilitation following brain injury can have long-term beneficial effects on employment levels.

3.2 Introduction

Studies have repeatedly shown that adults are at risk of losing their employment capability after acquired brain injury and that this is viewed as one of its most serious and chronic consequences. Reported employment rates vary considerably in relation to degrees of injury severity, time since injury and precise definitions of employment circumstances. (Malec et al., 1996; Thomsen, 1984; Thomsen, 1984; Schalen, Nordstrom, & Nordstrom, 1994; Malec et al., 1996)

During the last 30 years numerous neuro-psychologically based comprehensive post-acute rehabilitation programmes have emerged worldwide in which particular emphasis is placed on vocational counselling (Malec et al., 1996). Generally, studies of these programmes have reported positive results (Ben-Yishay, Silver, Piasetsky, & Rattock, 1987; Klonoff, Lamb, & Henderson, 2001; Cicerone et al., 2004; Christensen, Pinner, Moller, Teasdale, & Trexler, 1992; Malec, 2001) suggesting that such rehabilitation can substantially improve levels of employability after brain injury. This evidence is, however, weakened by the fact that most studies have lacked non-rehabilitated control groups. Patients have thus often been used as their own controls by comparing employment prior to, and subsequent to, rehabilitation (Ben-Yishay et al., 1987; Malec et al., 1993; Teasdale, Christensen, & Pinner, 1993). But even where improvement is shown, a causal link cannot be inferred since this improvement may have been the result of other factors including spontaneous recovery.

The two earliest controlled studies showed improvement in employment using 'historic' controls (Prigatano et al., 1984; Prigatano et al., 1994) in which brain-injured patients undergoing post-acute rehabilitation at a given hospital were compared with matched patients who had been in the same hospital prior to the establishment of the programme.

Three recent controlled studies of rehabilitation programmes have also employed non-randomised non-rehabilitated (or less rehabilitated) control groups (Sarajuuri et al., 2005; Hashimoto et al., 2006; Cicerone et al., 2004) in all cases showing a better employment outcome for the rehabilitated groups. Two recent reviews of the brain injury rehabilitation literature have emphasised the continuing need for evidence of efficacy, necessarily involving controlled studies (Gordon et al., 2006; Cicerone et al., 2005). It might be added that there is a need for long-term follow-ups to verify the sustainability of any positive effects.

Although return to employment after brain injury is understandably a major rehabilitation objective, a concern for the promotion of positive leisure-time activities, which also often decline following injury, is being increasingly recognised (Teasdale & Siert, 1997; Ponsford, Olver, Curran, & Ng, 1995; Hall et al., 1994). This can be a particularly important consideration precisely where return to employment is absent or limited. In such cases the brain injured person could actually have more time to indulge in leisure activities and these activities could restore a degree of social interaction which might otherwise have been provided by the workplace.

In the present study we performed a retrospective, non-randomised follow-up of brain injured persons who had undergone a comprehensive post-acute rehabilitation programme and employing a non-rehabilitated control group derived from an epidemiological study undertaken by Teasdale & Engberg (2005a; Engberg et al., 2004). The follow-up period was longer than has hitherto been reported on and our study has incorporated, among other outcome measures, both employment and leisure-time activities.

3.3 Method

3.3.1 Subjects

Our data stem two sources: a) a group of persons with acquired brain injury who had completed the post-acute, intensive, neuropsychological rehabilitation at the Center for Rehabilitation of Brain Injury (CRBI) in Copenhagen and b) a group with comparable injuries who had not received any such post-acute rehabilitation.

The CRBI program adopts an interdisciplinary, comprehensive approach, which is tailored to the individual in the light of neuropsychological assessments. Patients are admitted a day program lasting four months with daily attendance of about 4-6 hours. This is followed by close contact and monitoring of progress in the community for at least a further eight months. Exclusion criteria include alcohol and drug abuse, together with psychiatric or progressive neuro-degenerative illness. A degree of motivation and independence (ability to travel, feed, groom etc.) is also required in order to participate. Details of the Copenhagen program are presented elsewhere (Christensen, Pinner, & Rosenberg, 1988). Persons with brain injury entering the program had been unable to return immediately to employment following their injury.

3.3.2 Rehabilitation Group.

For the purposes of the present study we selected all 85 non-aphasic subjects with either traumatic brain injury (TBI) or cerebro-vascular accident (CVA) who underwent the CRBI programme between January 1987 and December 1992. It had been necessary to exclude 12 aphasics since it proved impossible to find matching controls for them – see below. Not all 85 subjects were available for the study; 14 were deceased by the time of follow-up in 2004 and addresses could not be obtained for 11. Thus, 60 subjects were invited to participate in the study; 37 (62%) did so.

3.3.3 Control Group.

A non-rehabilitated brain injury group was recruited from two earlier extensive epidemiological studies by Teasdale and Engberg involving a randomised and nationally representative selection of subjects with either traumatic brain injury (TBI) (Engberg et al., 2004) or Cerebro-Vascular Accident (CVA) (Teasdale et al., 2005a), as recorded in a Danish central register of hospitalizations. These two studies both involved a postal questionnaire including an item indicating whether the subjects had been able to return to employment after their injury. From the available pool we selected 24 subjects who had indicated that they had been unable to return to employment following their injury and who matched the rehabilitation group for sex, age at injury, injury type, Injury Severity Scale (Association for the Advancement of Automotive Medicine, 1990), duration of coma (for TBI, days until Glasgow Coma Scale became 9), post-traumatic amnesia (for TBI), and hospitalization, as well as Glasgow Outcome Scale (Jennett, Snoek, Bond, & Brooks, 1981) at discharge. A single potential subject proved to have clinically significant aphasia. Since this made it impossible to match the two groups for aphasia, the subject was excluded along with the 12 mentioned above from the rehabilitation programme. Of the 24 control subjects, 13 (54%) took part in the study.

Table 3.1 shows a comparison of the participating Rehabilitation and Control subjects on the matching variables.

Table 3.1 Demographic and injury characteristics of rehabilitation and control groups.

Variable	Rehab Group		Control Group		Probability
	n = 37		n = 13		
Sex	n	(%)	n	(%)	
Male (%)	26	(70)	7	(54)	n.s. †
Female (%)	11	(30)	6	(46)	
Injury type					
TBI	26	(70)	9	(69)	n.s. †
CVA	11	(30)	4	(31)	
PTA (TBI subjects)	25		8		
< One week	0	(0)	2	(25)	
< Two weeks	4	(16)	0	(0)	
< One month	10	(40)	2	(25)	n.s. +
>= One month	11	(44)	4	(50)	
Level of wakefulness seven days after trauma (CVA only)					
Clear and awake	6	(55)	2	(50)	n.s. +
Somnolent, confused	3	(27)	2	(50)	
Uncontactable	2	(18)	0	0	
Glasgow outcome scale at discharge	36		13		
Severe disability	1	(3)	1	(8)	n.s. +
Moderate to severe disability	10	(28)	4	(30)	
Moderate disability	19	(53)	7	(54)	
Moderate disability to good recovery	6	(16)	0	(0)	
Good recovery	0	(0)	1	(8)	
Geographic residence at time of injury					
Island of Sjaelland	33	(89)	6	(46)	p = 0.001 †
Elsewhere in Denmark	4	(11)	7	(54)	
	Mean	(SD)	Mean	(SD)	
Hospitalisation (days)	167	(153)	144	(151)	n.s. *
Days on life support (respirator)	6	(8)	6	(6)	n.s. *
Duration of coma in days (TBI only)	13	(10)	14	(13)	n.s. *
Injury Severity Score (TBI only)	18	(7)	29	(11)	p = 0.001 *
Mean Age at time of injury (years)	26	(9)	31	(8)	n.s. *
Chronicity of injury in 2004 (years)	17	(2)	15	(4)	n.s. *

* = t-test, † = X^2 test, + = Mann Whitney

The two groups are comparable in all demographic and medical injury characteristics with the exception of geographical distribution and injury severity score.

The catchment area for the CRBI programme was largely confined to the eastern island of Sjaelland, whereas the control group was drawn from two epidemiological studies (Engberg et al., 2004; Teasdale et al., 2005a) which covered a wider range of Danish counties from east to west. In consequence, as shown in Table 1, there is a significant difference between the two groups with regard to geographical distribution.

It can be seen that the only other significant difference ($t(33) = -3.5$, $p = 0.001$) between the two groups is the injury severity score where the control group have a higher score compared to the rehabilitation group. The injury severity score summarises all injuries to the head as well as the body, including loss of consciousness, broken bones, loss of limbs etc.

3.3.4 Instruments

At the time of follow-up in 2004, participating subjects were sent a package of questionnaires to be completed prior to a comprehensive in-person interview, most often conducted in the subject’s home (findings from the questionnaires will be reported elsewhere).

The interview took about two hours to complete and covered health, employment, leisure, social network, quality of life and satisfaction with current and past treatment in connection with the brain injury.

For purposes of present analyses we have chosen the following variables: work pre-injury and at follow-up, income, satisfaction with current status in relation to employment and the importance of work for quality of life, as well as how many hours they spend weekly on leisure activities and if they were alone during the leisure activity. In terms of employment, the subjects were categorised in three groups:

a) Those engaged in normal employment with no state-support and those in normal employment where the salary is only partially paid by the employer and is supplemented by the state.

b) Those combining ‘sheltered’ employment, usually paid at a symbolic rate by an employer, with a disability pension.

c) Those that were solely in receipt of a disability pension, or unemployment benefits, with no form of employment.

We recorded the number of hours worked per week (if any) and total net monthly income from all sources, here calculated in Euros. Those subjects who had some form of employment (i.e. groups a, and b, above) were asked if they felt that that their current employment satisfied their own expectations towards themselves. Those not currently employed (group c) were asked whether they were satified with that situation. All were asked to rate on a visual analog scale from one to five, one being not very important to five being most important, how important they felt work was for their quality of life (irrespective of whether or not they actually did work).

During the interview, subjects were asked to state their leisure-time activities and to characterise whether these were carried out alone or together with others. A 10-item prompt list was used if no responses were forthcoming. This was broadly defined and included sport and exercise, reading, art and cultural activities, society activities and evening classes, housework and gardening, computer-use and television-watching. We have here combined all categories of activities with the exception of watching television which is treated separately. They were also asked how many hours they spent on any given activity per week.

We have employed chi-square analyses and non-parametric or parametric independent samples tests, as appropriate, using alpha set to 0.05 (two-tailed). All analyses were performed using SPSS 13.0.

5.4 Results

As can be seen from Table 3.2 the two groups were alike at time of injury in terms of employment with over 90 % in both groups being in competitive employment or education. There is a significant difference (Z= -2.3, p = 0.02) between the two groups in terms of current employment. Relatively more individuals from the rehabilitation group possess normal work and more from the control group have no work affiliation at all. The odds ratio for some kind of employment (categories 1 and 2 combined) after rehabilitation was 4.4 (95 % CI = 1.1 to 17.9).

There is no significant difference between the rehabilitation and control groups in terms of average personal income after tax. Among those in employment, the rehabilitation group was significantly ($X^2(1)= 8.7$, p = .003) more satisfied (n = 26/30 or 87 %) with their situation with regard to employment compared to the control group (n = 4/10 or 40 % were satisfied). Those without employment were, with a single exception, dissatisfied with the situation.

Table 3.2 Employment and leisure **Variables**	Rehab group n = 37	Control group n = 13	p
Pre injury employment			n.s. †
Work-education on normal terms	91.9%	92.3%	
With support	8.1%	7.7%	
Employment form at follow-up			
1. Normal employment n (%)	11 (29.7)	1 (7.7)	p = .02 +
2. Sheltered employment + Disability pension n (%)	20 (54.1)	6 (46.2)	
3. Disability pension or unemployment benefits n (%)	6 (16.2)	6 (46.2)	
Total monthly personal income after tax in Euros Across the three work categories (SD)	1299 (489)	1412 (346)	n.s. *
% of sample for whom current work/pension situation satisfy own expectations towards self	86.3 %	40.0 %	p = .003 †
On a scale from one to five; the importance of work for quality of life (SD)	4.1 (1.1)	3.5 (1.5)	n.s. *
Average no. of hours per week of leisure activity (SD)	30 (24)	21 (12)	n.s. +
Average no. of hours of leisure activities per week spent with others (SD)	8 (14)	6 (6)	n.s. +
Average no. of hours of television watching per week (SD)	18 (15)	18 (10)	n.s. +

† = χ^2 test, + = Mann Whitney, * = t-test

As can be seen in Table 3.2, there were no significant differences between the rehabilitation group and the control group regarding the hours spent weekly on leisure-time activities, including watching television. There were no differences between the two groups in any of the other individual categories of activity nor were there differences in the number of hours spent in the company of others.

In view of the group differences with respect to ISS and (albeit non-significant) age we have performed some additional control analyses. There was no significant difference in ISS score, across the rehabilitation and control groups, between the participants who were employed (n = 29, M = 21, SD = 10) and those who were not employed (n = 6, M = 23, SD = 5) at follow-up (t(33) = -.6, p > .5). Age at injury did not prove to differ significantly (t(48) = -1.2, p > .2) between those in some kind of employment (M = 26 years, SD = 9 years) and those without employment (M = 30 years, SD = 8 years) at follow-up.

3.5 Discussion

3.5.1 Employment and leisure activities

In this study, the level of employment 12 to 22 years after injury was significantly higher in the group who had received rehabilitation. There was, however, no difference in income after tax between the two groups. This probably reflects the facts that, one the one hand, Denmark has comparatively generous disability pensions, and on the other hand, the salaries earned by persons with brain injury who work are not typically high. The average monthly income in both groups of 1300-1400 Euros is lower than for the total Danish working population who earned on average 1746 Euros in 2004 (Lauritsen & Brøndum, 2005).

Among those actually working, the level of satisfaction with their employment was significantly higher among the rehabilitation group than among the control group. This finding is consistent with a major explicit aim of the CRBI program, namely to help adjustment and being satisfied with a situation, albeit it more limited than the situation before the injury. This requires acceptance of the injury and its consequences. An earlier study about the CRBI program (Teasdale et al., 1995) showed that general stress decreased as a result of the program and remained at the reduced level at a one-year follow-up. Somewhat supportive of these results were also the higher (although not significant) average ratings in the rehabilitation group of the importance of work for quality of life. The relatively small number of subjects may have influenced this lack of significant difference.

There was no difference in number of hours spent weekly on leisure activities. The different findings within the two domains of employment and leisure activities may reflect a different focus of the rehabilitation, with a stronger emphasis on returning to work than on leisure activities.

3.5.2 Limitations

In considering the findings from this study, a number of limitations must be kept in mind. First, the matching of the control group could only be done on a limited number of variables. This, in combination with the relatively limited number of subjects, means that the two groups may differ on non-controlled injury-related characteristics. However, those subjects in both groups who have suffered a traumatic brain injury have typically sustained rather diffuse injuries, thus diminishing potential group differences with respect to localisation of injury. Similarly, for those who had cerebro-vascular accidents, having excluded persons with aphasia will have made the two groups more comparable in terms of which problems they are facing.

Second, injury severity score is significantly higher and age at injury is non-significantly higher in the control group albeit that the average age in the two groups only differs by 5 years at the time of injury. Two epidemiological studies (Teasdale et al., 2002; Teasdale et al., 2000) found that, for individuals with either stroke or traumatic brain injury, age was a major factor in relation to disability pension applications. Johansen et al. (2004), studied outcome one to ten years after a rehabilitation program, similar to that of the CRBI, and found the younger participants to a higher extent to be employed; two-third of participants under age 40 were employed, whereas only half of participants from age 40 to 49 years were in employment, and only a quarter of participants above the age of 50 were employed. However, disfavouring the younger rehabilitation group is that these people will have had less time to establish themselves, learning a trade or profession, thus making it harder to get into the workforce. As mentioned earlier there was no significant difference in terms of employment and either injury severity score or age at injury and they are therefore not thought to be a major bias.

Third, the study is limited by its retrospective, non-randomised design, which potentially overlooks differences between the two groups that could have caused the different allocation to treatment, and which could explain the present outcome differences. One such potential issue is geographical location. Relatively more people from the rehabilitation group came from the eastern island of Sjaelland, on which Copenhagen is situated, whereas the control group subjects had been proportionately distributed over other regions also, e.g. the islands of Bornholm and Fyn and the Jutland peninsula. This does not, however, correspond to a simple urban/rural environmental difference, and in general social and economic conditions are relatively homogeneous across the country.

Fourth, we acknowledge that responder bias could influence the results of this study, since those who participated may have been those who have made the best adjustment. However, if this were the case, then there would have been a greater overestimation of positive findings among the control group than among the rehabilitation group, since participation was lower in the former group.

3.5.3 Perspectives

The proportions of people in some form of employment are similar to findings from other controlled studies of outcome from post-acute rehabilitation centres with a general uptake. These studies have usually been conducted within the first one to five years after rehabilitation. To our knowledge this is the first controlled study looking at much longer-term employment rates after rehabilitation and the findings are similar to the results from the long-term non-controlled study of rehabilitation by Klonoff, Lamb & Henderson (2000). Klonoff and colleagues (2000) pointed out from their longitunal study that the level of employment did not decline with time after rehabilitation in their study. Some other studies of non-rehabilitated populations with acquired brain injury have otherwise indicated that this could be a risk after the first years post-injury (Ashley et al., 1997; Olver et al., 1996). Since our study was not longitudinal our results can not provide direct evidence to support the results of Klonoff and colleagues beyond the fact that levels of employment are comparable to studies conducted earlier after ended rehabilitation. The employment level in the control group is somewhat similar to, or a little lower than, the results of the 17 year follow-up study by Wood and Rutherford of a Welsh group of persons with acquired brain injury (2006b). In one prospective controlled randomised trial of US military personnel (Salazar et al., 2000), there was found no difference between those who received intensive in-patient cognitive rehabilitation and those who received a limited home based program, in both groups, 90 % or more were able to return to employment. The negative findings from this study might be thought to suggest that it is simply non-specific factors in post-acute rehabilitation that are effective, however the length of intervention (only eight weeks) and the special setting in the military makes a direct comparison with other studies of the efficacy of rehabilitation difficult. In another controlled study of post-acute intensive rehabilitation, where the control group received 'standard' rehabilitation there was a significant difference in terms of community functioning favouring the group who had received intensive rehabilitation (Cicerone et al., 2004).

In spite of the limitations of this study, we believe that our findings provide supportive evidence for the long-term benefits post-acute rehabilitation. This is particularly important in view of the generally long-life expectancy among persons with acquired brain injury of the types treated by such comprehensive rehabilitation programs. Further research is certainly still needed. It would, for instance, be helpful to make a finer analysis of which components of a comprehensive rehabilitation program are most effective for which aspects of outcomes.

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Competing interests

TWT is employed as a research consultant for the CRBI and FH is its director. HS has been reimbursed by the Centre for Rehabilitation of Brain Injury, University of Copenhagen, for postage and travel expenses in connection with the interview, and has had her data-entry paid for by the hospital.

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Chapter 4. Competency, brain injury symptoms and emotional well-being

This chapter has the form of the article submitted for publication.

The influence of neuropsychological rehabilitation on symptomatology and quality of life following brain injury: A controlled long-term follow-up.

Henriette Aaby Svendsen
Centre for Rehabilitation of Brain Injury and Department of Psychology, University of Copenhagen, Denmark

Thomas William Teasdale
Department of Psychology, University of Copenhagen, Denmark

Correspondence to Henriette Aa. Svendsen, Centre for Rehabilitation of Brain Injury and Department of Psychology, University of Copenhagen, Njalsgade 88, DK-2300 Copenhagen S. E-mail henriette.svendsen@psy.ku.dk, Telephone + 45 35 32 49 34, Fax +35 32 48 02

Keywords: Brain-injury; Rehabilitation; Follow-up

4.1 Abstract

Primary Objective: To establish whether, following acquired brain injury, intensive post-acute neuropsychological rehabilitation could have long-term beneficial effects.

Methods & Procedures: A group of 37 adults who had suffered cerebrovascular accidents or traumatic brain injuries, and who had undergone a rehabilitation programme, were followed up 12-22 years post-injury, together with a non-rehabilitated control group of 13 adults, matched for brain-injury and demographics characteristics. Both groups completed a set of questionnaires concerning broad aspects of psychological well-being. Significant others completed similar questionnaires.

Main Outcomes and Results: The rehabilitation group showed significantly lower levels of brain injury symptoms and higher levels of competency at follow-up. They also rated internal locus of control and general self-efficacy as significantly higher than the control group. Anxiety and depression levels were significantly lower and quality of life significantly higher in the rehabilitation group for both the subjects themselves and for their significant others.

Conclusions: Within methodological limitations this study suggests that post-acute neuropsychological rehabilitation can have long-term beneficial effects.

4.2 Introduction

Several studies of sequelae after brain injury indicate that improvement can continue well beyond the acute phase(Wood et al., 2006b; Ragnarsson, 2002; Sbordone, Liter, & Pettlerjennings, 1995; Thomsen, 1984). However, most long-term follow-up studies have shown that acquired brain injury in many cases is followed by persisting effects (Wood et al., 2006b; Hammond, Hart, Bushnik, Corrigan, & Sasser, 2004; Santos, Castro-Caldas, & De Sousa, 1998; Dikmen, Machamer, Powell, & Temkin, 2003)as well as by a burden on the significant others (Brooks, Campsie, Symington, Beattie, & Mckinlay, 1986; Ponsford, Olver, Ponsford, & Nelms, 2003). These effects can be seen in the areas of brain injury symptoms (Svendsen et al., 2004; Teasdale et al., 1997a), lowered competency in activities (Johansen et al., 2004) changes in beliefs about own capabilities (Moore & Stambrook, 1992) emotional symptoms (Hoofien, Gilboa, Vakil, & Donovick, 2001) and lowered quality of life (Dikmen et al., 2003; Koskinen, 1998; Klonoff, Snow, & Costa, 1986). Significant others may also experience a variety of difficulties in their role as carers (Blais & Boisvert, 2005).

Common to the many different models and theories about rehabilitation, is the basic aim of ameliorating, reducing or alleviating the patient’s complex symptoms (Wilson, 2002) and today the importance of reducing the burden on the significant others is also a prominent feature in many rehabilitation settings. During the last 30 years or so numerous neuro-psychologically based intensive post-acute rehabilitation centres have emerged worldwide and especially in the US and Europe (Ponsford et al., 2003; Cicerone et al., 2004; Sarajuuri et al., 2005; Trexler, 2000). These programmes aim to consider the combined cognitive, social and emotional effects of brain injury, as opposed to purely cognitive retraining. Generally, studies of these programmes have reported positive results (Ben-Yishay et al., 1987; Prigatano et al., 1984; Prigatano et al., 1994; Malec et al., 1993; Christensen et al., 1992;

Cicerone et al., 2004; Klonoff et al., 2001; Malec, 2001) suggesting that rehabilitation can markedly improve level of functioning and well-being after brain injury.

Methodologically, when addressing evidence for the positive effect of these rehabilitation programmes, most of these studies have been observational without control groups, usually involving the patients being used as their own controls by comparing performance prior to and subsequent to rehabilitation(Teasdale et al., 1997b; Teasdale et al., 1995; Teasdale et al., 1993; Malec, 2001; Sherer, Meyers, & Bergloff, 1997). Two studies have used historic controls (Prigatano et al., 1984; Prigatano et al., 1994) and two studies has implemented a non-randomised control group (Sarajuuri et al., 2005; Hashimoto et al., 2006) comparing outcome from a consecutive group of subjects with a group who received conventional clinical care and rehabilitation. A further, prospective, non-randomised study compared intensive, milieu-based neuropsychological rehabilitation with 'standard' post-acute rehabilitation (Cicerone et al., 2004). A recent review (Gordon et al., 2006) of the 'state of the science' of traumatic brain injury rehabilitation stated that, with regard to the evidence for rehabilitation, several factors are critical such as adequate sample size, the representativenes of the sample, appropriate comparison groups, random assignment to treatment and control conditions and outcome measures congruent with the expected effect. It would be difficult and time-consuming to engage in optimally large, prospective, randomised controlled trials with low attrition and no measurement biases which would be needed to provide conclusive evidence that these programmes are effective, but a NIH consensus conference concluded this is needed (Ragnarsson et al., 1999). In the present study we performed a retrospective, non-randomised follow-up using a non-rehabilitated control group derived from an epidemiological study undertaken by Teasdale & Engberg (Engberg et al., 2004; Teasdale et al., 2005a).

In terms of what outcomes to measure, the traditional neuropsychological test does not seem to be optimal when evaluating rehabilitation; for example, Carney et al.(1999) in their comprehensive review of cognitive rehabilitation, did not find a strong association between test scores and real life outcome such as employment. Teasdale, Skovdal, Gade & Christensen (1997b) found that test-scores improved from pre- to post-rehabilitation but, at one year after rehabilitation ended, the scores were back to pre-rehabilitation levels. In a case study of a densely amnestic patient there was no improvement on standardised tests over a 10 year period, however the individual showed immense improvements in independent living and employability largely due to good use of compensation strategies (Wilson & Evans, 2003). Wilson and Evans (2003) and Diller & Ben-Yishay (2003) thus recommend reduction in dependency, the return to premorbid social and work related roles and relief in personal burden by reduced disability as well as the burden on the family, as some of the meaningful outcomes to consider.

In this study we chose to look at perceived symptoms of brain injury and impact on significant others, experienced competency, awareness of these above-mentioned components as well as perceived self-efficacy and locus of control, anxiety, depression as well as quality of life in both the subjects and their significant other. The study has thus investigated a number of hypotheses.

First, we expected that those who received rehabilitation and their significant others would experience the symptoms of brain injury and impact of the brain injury on the significant others less than the control group. Second, we expected that persons who received rehabilitation would have a higher degree of competence within activities of daily living

(ADL), cognitive, interpersonal and emotional skills, as reported by themselves and their significant others. Third, in terms of awareness, we expected a greater level of agreement between the persons with brain injury and their significant others as regards symptoms and competency, among the rehabilitation group than among the control group. Fourth, we expected the rehabilitation group to have a higher degree of self-efficacy and internal locus of control as compared to the control group, according to their own self-ratings. Fifth, we expected lower levels of anxiety and depression in the rehabilitation group compared to the control group, and finally, we expected higher levels of self-reported quality of life in the rehabilitation group compared to the control group.

4.3. Method

4.3.1 Subjects

Our data stem partly from persons with acquired brain injury who had completed the post-acute, intensive, neuropsychological rehabilitation at the Centre for Rehabilitation of Brain Injury (CRBI) in Copenhagen and partly from persons with a moderate-to-severe acquired brain injury, who had not received any such post-acute rehabilitation.

The CRBI programme adopts an interdisciplinary, holistic approach, which is tailored to the individual in the light of neuropsychological assessments. Patients are admitted to the programme in groups of 12 to 16, and the programme runs for about three to four months with day attendance. This is followed by close contact and monitoring of progress in the community for at least a further eight months. Exclusion criteria include alcohol and drug abuse, together with psychiatric or progressive neuro-degenerative illness. A degree of motivation and independence (ability to travel, feed, groom etc.) is also required in order to participate. Details of the Copenhagen programme are presented elsewhere (Christensen et al., 1988). Persons entering the programme had been unable to return to employment following their injury.

Rehabilitation Group.

For the purposes of the present study we selected all 85 non-aphasic subjects with either traumatic brain injury or cerebro-vascular accident who underwent the CRBI programme between January 1987 and December 1992. It had been necessary to exclude 12 aphasics since it proved difficult to find matching controls for them – see below. Not all 85 subjects were available for the study; 14 were deceased by the time of follow-up in 2004 and addresses could not be obtained for 11. Thus 60 subjects were invited to participate in the study; 37 (62%) did so.

Control Group.

A non-rehabilitated brain injury group was recruited from earlier extensive randomised epidemiological studies by Teasdale and Engberg involving a randomised and nationally representative selection of subjects with either traumatic brain injury (Engberg et al., 2004) or stroke (Teasdale et al., 2005a), as recorded in a Danish central register of hospitalizations. These parallel studies involved a postal questionnaire including an item indicating whether the subjects had been able to return to employment after their injury. From the available pool we selected 24 subjects who had indicated that they had been unable to return to employment following their injury and who matched the rehabilitation group for sex, age at injury, injury type, Injury Severity Scale (Association for the Advancement of Automotive Medicine, 1990), duration of coma and post-traumatic amnesia (in the case of

TBI), duration of hospitalization, Glasgow Outcome Scale (Jennett et al., 1981) at discharge. A single potential subject proved to have clinically significant aphasia. Since this made it impossible to match for aphasia the subject was excluded along with the 12 mentioned above from the rehabilitation programme. Of the 24 control subjects, 13 (54%) took part in the study.

Table 4.1 shows a comparison of the participating Rehabilitation and Control subjects on the matching variables. The two groups are comparable in terms of age at injury, chronicity of injury at follow-up, gender, injury type, year of injury, hospitalisation, duration of coma and post-traumatic amnesia. The majority of subjects were traumatically brain injured males, on average they had spent 6 days on life support and about five months in hospital after their brain injury. The subjects with traumatic brain injury were on average in coma 10 days and more than half had post-traumatic amnesia for more than two weeks. Half of the subjects with stroke were at full consciousness seven days after their stroke or latest operation. At discharge the majority in both rehabilitation and control group were rated moderately or moderately to severely disabled on the Glasgow Outcome Scale. At time of injury, the average age in the rehabilitation group was 26 years and in the control group the average age was 31 years. At follow-up, the average age was in the mid-forties and subjects were on average 15 to 17 years post-injury.

The catchment area for the CRBI programme was largely confined to the eastern island of Sjaelland, whereas the control group were drawn from epidemiological studies which covered all of Denmark. In consequence, as shown in Table 4.1, there is a significant difference between the two groups with regard to geographical distribution.

It can be seen that the only other significant difference (t = -3.498, df = 33, p = 0.001) between the two groups is the injury severity score where the control group has a higher score (M = 29, SD = 11) compared to the rehabilitation group (M = 18, SD = 7). The injury severity score summarises all injuries to the head as well as the body, including loss of consciousness, broken bones, loss of limbs etc.

We looked at the correlations between the questionnaire results and either injury severity score or age at injury and they are all very small and on no scales do these two variables explain more than 10% of the variance. They are therefore not thought to constitute a major bias.

Table 4.1 Demographic and injury characteristics of rehabilitation and control groups.

Variable	Rehab Group		Control Group		Probability
	n = 37		N = 13		
Sex	n	(%)	N	(%)	
Male (%)	26	(70)	7	(54)	n.s. †
Female (%)	11	(30)	6	(46)	
Injury type					
TBI	26	(70)	9	(69)	n.s. †
CVA	11	(30)	4	(31)	
PTA (TBI subjects)	25		8		
< One week	0	(0)	2	(25)	
< Two weeks	4	(16)	0	(0)	
< One month	10	(40)	2	(25)	n.s. +
>= One month	11	(44)	4	(50)	
Level of wakefulness seven days after trauma (CVA only)					
Clear and awake	6	(55)	2	(50)	n.s. +
Somnolent, confused	3	(27)	2	(50)	
Uncontactable	2	(18)	0	0	
Glasgow outcome scale at discharge	36		13		
Severe disability	1	(3)	1	(8)	n.s. +
Moderate to severe disability	10	(28)	4	(30)	
Moderate disability	19	(53)	7	(54)	
Moderate disability to good recovery	6	(16)	0	(0)	
Good recovery	0	(0)	1	(8)	
Geographic residence at time of injury					
Island of Sjaelland	33	(89)	6	(46)	p = 0.001 †
Elsewhere in Denmark	4	(11)	7	(54)	
	Mean	(SD)	Mean	(SD)	
Hospitalisation (days)	167	(153)	144	(151)	n.s. *
Days on life support (respirator)	6	(8)	6	(6)	n.s. *
Duration of coma in days (TBI only)	13	(10)	14	(13)	n.s. *
Injury Severity Score (TBI only)	18	(7)	29	(11)	p = 0.001 *
Mean Age at time of injury (years)	26	(9)	31	(8)	n.s. *
Chronicity of injury in 2004 (years)	17	(2)	15	(4)	n.s. *

* = t-test, † = χ^2 test, + = Mann Whitney

4.3.2 Instruments

At the time of follow-up in 2004, participating subjects were sent a package of questionnaires to be completed prior to an in-person interview typically conducted in the subject's home (findings from the interview will be reported else where).

4.3.3 European Brain Injury Questionnaire (EBIQ)

The EBIQ has been specifically designed in two parallel versions: a 'self' version for use on individuals with brain injury, and a 'significant other' version to be completed by their close significant others (Teasdale et al., 1997a). It contains 62 questions relating to 'problems or difficulties that people sometimes experience in their lives', as well as three questions regarding what impact the injury has had on the significant other. Subjects with brain injury complete the 'self' version in which they are asked to indicate 'how much (they) have experienced any of these within the last month'. Their responses were coded on a three-point scale: 'not at all' (1), 'a little' (2) or 'a lot' (3). Correspondingly, significant others completed the 'significant other' version in which they give their perceptions of the person with brain injury. From both the subjects´ and the significant others´ questionnaires, eight scales were calculated corresponding to complaints categorised as: somatisation, cognition, motivation, impulsivity, depression, social isolation, physical symptoms, and communication. An additional 'core' scale, summarised complaints globally.

The scores on these scales were computed as the simple average of the scores (1, 2 or 3) for the questionnaire items pertaining to each scale. The scale scores can thus also range from 1.0 to 3.0. Further psychometric details are presented elsewhere (Teasdale et al., 1997a).

Additionally, the EBIQ included three questions concerning the impact of the brain injury on the significant other, as judged by the persons with brain injury and the significant others themselves.

4.3.4 Patient Competency Rating Scale (PCRS)

The PCRS comprises 26 items measuring competency on a five point Likert scale. The questionnaire is typically used for a comparison of ratings made by patient and a close significant other or clinician. Results can be presented as average score, total score on a scale from 26 to 130 and subscales related to ADL (eight items), cognition (eight items), interpersonal (seven items) and emotion (seven items), these scales can be converted into a 1-100 scale. Prigatano, Altman and O'Brien (1990) found good overall test and retest reliability (for patients (r = 0.97) and their significant others (r = 0.92).

4.3.5 Generalised Self-Efficacy Scale (GSEC)

The GSEC is a ten-item psychometric scale that is designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life (Schwarzer et al., 1995). In contrast to other scales that were designed to assess optimism, this one explicitly refers to personal agency, i.e., the belief that one's actions are responsible for successful outcomes. The items are rated on a four-point Likert scale with a total score ranging from 10 to 40.

4.3.6 Locus of Control (LoC)

The LoC scale was constructed for the purposes of the present study. It consists of six questions pertaining to how great a sense of control a subject feels towards life. The items are rated on a four-point Likert scale similar to the above-mentioned self-efficacy scale and items are added to yield a total score ranging from six to 24, the higher the score the higher degree of internal locus of control. The LoC score proved to have a satisfactory reliability (Cronbach's Alpha = 0.81).

4.3.7 Hospital Anxiety and Depression Scale (HADS)

The HADS, was designed to provide a simple yet reliable general instrument to measure emotional distress on two scales, namely anxiety and depression (Zigmond et al., 1983). It consists of fourteen items, seven items that reflect depression and seven that reflect anxiety. The scales have been created on the basis of factor analysis. The items are rated by the patient on a four-point (zero through three) ordinal scale, so possible depression as well as anxiety scale scores ranges from 0 to 21. A score of zero to seven for either subscale could be regarded as being in the normal range, a score of eleven or higher indicating probable presence ('caseness') of the mood disorder and a score of eight to ten being just suggestive of the presence of borderline symptomatology.

4.3.8 World Health Organization Quality of Life questionnaire (WHO-QoL)

The WHO-QoL (BREF = brief version) is a widely used general questionnaire that measures quality of life. We used the Danish translation (Norholm et al., 2001). It is a 26-item version of the original 100-item version, WHO-QoL-100. It covers four domains related to physical and psychological health (seven and six items respectively), social relations (three items) and environmental safety (eight items) as well as two items concerning quality of life and health in general. Each item is rated on a 5-point Likert scale. Domain scores are scaled to range from 0 to 100 (this is in order to make it comparable to the 100-item version). The higher domain score, the higher the quality of life and health within the domain.

Scale scores for all six questionnaires proved to be approximately normally distributed. We have therefore employed repeated-measure analyses of variance as well as independent samples t-tests to test our hypotheses. However, in some of the repeated measure analyses, the assumption of sphericity was not met. In such cases the Greenhouse-Geisser epsilon correction was applied to the appropriate degrees of freedom. Effect sizes are provided, when possible, as estimates of the magnitude of the significant results, this includes the F-statistics with one degree of freedom ((Field, 2005), p. 453). All analyses were performed using SPSS 13.0.

When testing directional hypotheses, one-tailed significance levels are used. This is also the case with the F-test with one degree of freedom for the numerator. Because it derives from a null hypothesis with only one restriction, i.e. the difference between two coefficients, the F-statistic in this case has one degree of freedom for numerator and corresponds to a squared t-statistic. Thus, the p-value can be obtained for a one-tailed test using this relationship and the symmetry of the t-distribution (http://www.stata.com/statalist/archive/2004-08/msg00898.html).

4.4 Results

4.4.1 EBIQ

Table 4.2 shows the mean scores for the rehabilitation group and the control group on each of the nine scales, for subjects and their significant others (SO). As can be seen, self-rated means are higher in the control group compared to the rehabilitation group on all but one scale, namely the subjects' isolation scale. On all scales the mean score as rated by the significant others from the control group is higher than those rated by the significant others from the rehabilitation group. On all scales the mean score as rated by significant others is higher than means as rated by the subjects in both the rehabilitation and control group.

Table 4.2 EBIQ Scales: Rehabilitation versus Control group

EBIQ Scales	Rehab group (n=37)				Control group (n=13)			
	Self		SO*		Self		SO*	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Somatic	1.52	0.40	1.66	0.52	1.75	0.41	1.80	0.61
Cognitive	1.60	0.36	1.73	0.51	1.86	0.40	2.03	0.56
Motivation	1.37	0.34	1.61	0.49	1.6	0.50	1.82	0.53
Impulsivity	1.62	0.42	1.73	0.53	1.74	0.38	1.90	0.56
Depression	1.48	0.43	1.59	0.51	1.84	0.52	1.88	0.68
Isolation	1.66	0.43	1.69	0.43	1.65	0.41	1.88	0.61
Physical	1.44	0.31	1.62	0.47	1.66	0.54	1.88	0.61
Communication	1.52	0.39	1.59	0.48	1.65	0.52	1.67	0.51
Core	1.50	0.34	1.66	0.45	1.75	0.39	1.90	0.54

* SO = Significant Other

An overall repeated-measure analysis of variance revealed a significant main effect of scale (F (5.7, 233.5) = 2.9, p = 0.012), indicating that some scales are rated higher than others. There was a small to medium-sized main effect of rater (own versus SO) (F (1, 41) = 2.9, p = 0.047, r = 0.26 (one-tailed according to hypothesis)). The significant others rated the symptoms higher in general than the subjects themselves. There was a significant and medium-sized between-subject effect of rehabilitation ((F (1, 41) = 3.8, p = 0.03 (one-tailed according to hypothesis), r = 0.29). The subjects and their significant others from the rehabilitation group reported lower levels of symptoms compared to the control group.

4.4.2 EBIQ: impact of brain injury on the significant other.

Table 4.3 lists the means of the three questions in the EBIQ that address the impact of the injury on the significant other. The first question concerns the impact of the injury at the time of the injury. The last two questions concern to what extent the significant other is affected today in terms of practical problems and/or whether their mood is affected.

An overall repeated-measure analysis of variance revealed a significant main within-subject effect of question (F (1.7, 63.6) = 21.3, p < 0.001); one question regarding whether life changed because of the brain injury, has a higher mean than the two other questions regarding current impact of brain injury. There was no effect of rater (own versus SO); the SO does not endorse higher levels of impact compared to the subject. There was a medium-sized and significant between-subject effect of rehabilitation (F (1, 38) = 4.4, p = 0.022 (one-tailed according to hypothesis), r = 0.32). In the rehabilitation group, both subjects and their significant others rated levels of impact lower than the control group. There was a small to medium size, significant two-way interaction between question and group (F (1.7, 63.6) = 4.0, p = 0.030, r = 0.24); the control and rehabilitation groups have similar ratings on the question of whether life changed as a result of the brain injury, whereas the rehabilitation group rated comparably lower on the questions addressing impact today. The significant others in the control group continue to have more current problems compared to the significant others in the rehabilitation group.

Table 4.3 EBIQ Impact on Significant Others: Rehabilitation versus Control group

EBIQ – questions regarding impact on significant others	Rehab group (n=37)				Control group (n=13)			
	Self		SO*		Self		SO*	
	Mean	SD	Mean	SD	Mean	SD	mean	SD
Did life change for the significant other as a result of the brain injury?	1.96	0.79	2.18	0.72	2.17	0.84	2.25	0.75
Does the significant other currently have problems as a result of the brain injury?	1.43	0.63	1.64	0.62	2.00	0.85	2.00	0.86
Is the significant other's mood currently affected?	1.29	0.54	1.61	0.69	1.92	0.67	2.00	0.74

* SO = Significant Other

4.4.3 PCRS

Table 4.4 PCRS Scales: Rehabilitation versus Control Group

PCRS – Scales	Rehab group (n=37)				Control group (n=13)			
	Self		SO*		Self		SO*	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
ADL (0-100 scale)	80	12	72	22	71	25	55	28
Cognition (0-100 scale)	72	17	69	20	64	23	59	16
Interpersonal (0-100)	74	19	67	20	65	16	61	19
Emotion (0-100)	69	17	63	21	59	16	51	22
Total (0-100)	74	13	68	18	65	15	57	17
Total score (30-150 scale)	119	15	111	22	108	19	98	20
Average item score	3.96	0.50	3.71	0.72	3.59	0.62	3.27	0.67

* SO = Significant Other

Table 4.4 shows the scale scores on the PCRS (ADL, Cognition, Interpersonal, Emotional and Total) converted into a 0-100 scale, as well as the conventional total score ranging from 30 to 150 and the average item score ranging from one to five.

The overall repeated-measure analysis of variance finds a significant main effect of scale (F (2.1, 87.7) = 4.0, p = 0.020); some scales are rated a little higher than others. There is a significant and medium-sized within-subject effect of rater (own versus SO) (F (1, 41) = 4.4, p = 0.022 (one-tailed according to hypothesis), r = 0.31). The significant others in general rated the subjects' competency lower than the subjects themselves did. There was a medium-size and significant between-subject effect of rehabilitation (F (1, 41) = 6.6, p = 0.007 (one-tailed according to hypothesis), r = 0.37); the subjects and their significant others from the rehabilitation group reported higher levels of competency than did the control group.

4.4.4 Awareness

The above-mentioned significant differences between subjects and significant others indicate a tendency for the former to underestimate brain injury symptoms and to overestimate their own competency. However, looking at typical answer style and mean differences between subjects and significant others, there were no results to indicate that the subjects in the rehabilitation group correlated more with their significant others on the rated items or that that there were smaller mean differences between subjects and significant others in the rehabilitation group (See Chapter 5, Section 5.9 for tables of the listed comparisons).

4.4.5 LoC and GSES

On average, the rehabilitation group experienced higher degrees of internal locus of control (M = 19.1, SD = 3.9) compared to the control group (M = 15.5, SD = 2.9). The difference was significant (t (45) = 3.0, p = 0.003 (one-tailed according to hypothesis)) and represented a medium sized effect (r = 0.41).

Subjects from the rehabilitation group also rated themselves as having a higher sense of self-efficacy (M = 30.1, SD = 7.0) compared to the control group (M = 26.4, SD = 5.4). This difference was significant when using a one-tailed t-test according to hypothesis, (t (46) = 1.75, p = 0.044), representing a small to medium-size effect (r = 0.25).

4.4.6 HADS

From Table 4.5 it can be seen that both the rehabilitation and control group have mean scores around seven or below, which is used as a cut-of score on both scales discriminating between normal scores and borderline scores.

Table 4.5 HADS Scales: Rehabilitation versus Control Group

HADS Scales	Rehab group (n=28)				Control group (n=12)			
	Self		SO*		Self		SO*	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Anxiety	6.0	4.2	3.5	3.9	7.7	2.8	7.7	5.7
Depression	4.6	4.1	2.9	2.8	7.8	2.8	5.8	5.3

* SO = Significant Other

An overall repeated-measure analysis of variance revealed a medium-sized significant main effect of scale (F (1, 38) = 5.4, p = 0.026, r = 0.35), indicating that anxiety levels are higher than levels of depression for the subjects and their significant others. There was a small to medium-sized significant effect of rater (own versus SO) (F (1, 38) = 3.3, p = 0.04 (one-tailed according to hypothesis), r = 0.28); the significant others rated levels of anxiety and depression as lower than the subjects. There was a medium size to large, significant between-subject effect of rehabilitation (F (1, 38) = 11.5, p=0.001 (one-tailed according to hypothesis), r = 0.48). In the rehabilitation group both subjects and their signficant others rated levels of anxiety and depression lower than the control group.

When comparing the subjects against a norm sample taken from a non-brain injured healthy Icelandic population (Magnusson, Axelsson, Karlsson, & Oskarsson, 2000), the subjects from both groups have more ‘borderline’ and ‘disorder indicated’ cases (scores above seven) than in the norms; however, the number of cases in the rehabilitation group is lower than in the control group. In the rehabilitation group, a total of 27% experienced anxiety problems at least at the borderline level (a score of eight or above) and among these, 13% could be considered to have an indication of clinical anxiety disorder (scores above ten). Among the control group, the corresponding percentages were 54% and 23%. In the Icelandic sample, 15% had at least borderline anxiety problems and only 6% were considered clinical cases. 23% of the rehabilitation group reported experiencing depression at least at borderline levels, and 7% could be considered to have a clinical disorder. Among the control group, the corresponding percentages were 54% and 15%. In the Icelandic sample, 10% had symptoms of depression at least at the borderline level and only 4% were considered clinical cases. (See Chapter 5 for tables over these comparisons)

4.4.7 QoL

As can be seen from Table 4.6, the rehabilitation group have higher mean scores on all scales of quality of life than the control group. In a repeated-measure analysis of variance there is a significant main effect of scale (F (2.1, 87.7) = 11.6, $p < 0.001$); in particular, the environmental scale was rated higher than other three. There is a medium-size within-subject effect of rater (own versus SO) (F (1, 40) = 8.1, p = 0.004 (one-tailed according to hypothesis), r = 0.41); the significant others have rated their own quality of life higher than have the subjects themselves. There is a significant two-way interaction between scales and rater (F (4,160) = 4.2, p = 0.003) reflecting the relatively larger differences between the subjects and their significant others on especially the psychological scale but also the physical scale compared to the other two scales. There is a medium-size between-subject effect of rehabilitation (F (1, 40) = 9.2, p = 0.002 (one-tailed according to hypothesis), r = 0.43); the subjects and their significant others in the rehabilitation group reported higher levels of quality of life than the control group.

Table 4.6 WHO-QoL BREF: Rehabilitation versus Control Group

WHO-QoL-BREF Scales	Rehab group (n=30)				Control group (n=12)			
	Self		SO*		Self		SO*	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
General quality of life (1-100)	66	22	77	14	59	21	63	26
Physical quality of life (1-100)	74	17	83	12	60	20	71	22
Psychological quality of life (1-100)	66	18	79	10	50	20	71	19
Social quality of life (1-100)	71	18	79	14	66	20	66	17
Environmental quality of life (1-100)	80	13	85	12	70	10	75	16

* SO = Significant Other

4.5 Discussion

4.5.1 Limitations

In considering the findings from this study, a number of limitations must be kept in mind. First, the matching of the control group could only be done on a limited number of variables. This, in combination with the relatively limited number of subjects, means that the two groups may differ on non-controlled injury-related characteristics. However, those subjects in both groups who have suffered a traumatic brain injury have typically sustained rather diffuse injuries, thus diminishing the potential factor of localization. Similarly, those who had cerebro-vascular accidents - having excluded persons with aphasia - will have made the two groups more comparable in terms of which problems they are facing.

Second, injury severity score is significantly higher and age at injury is non-significantly higher in the control group albeit that the average age in the two groups only differs by five years at the time of injury. Potentially this could bias report of brain injury symptoms, competency, and locus of control, self-efficacy, anxiety and depression and quality of life results, disfavouring the control group. As mentioned earlier the correlation between the questionnaire results and either injury severity score or age at injury are all very small and on no scales do these two variables explain more than 10% of the variance and is therefore not thought to be a major bias.

Third, the study is limited by its retrospective, non-randomised design, which potentially overlooks differences between the two groups that could have caused the different allocation to treatment, and which could explain the present outcome differences. One such potential issue is geographical location. Relatively more people from the rehabilitation group came from the eastern island of Sjaelland, on which Copenhagen is situated, whereas the control group subjects had been proportionately distributed over other regions also, e.g. the islands of Bornholm and Fyn and the Jutland peninsula. This does not, however, correspond to a simple urban/rural environmental difference, and in general social and economic conditions are relatively homogeneous across the country.

4.5.2 Symptoms of brain injury and impact on significant other

Our first hypothesis was that the level of symptoms of brain injury, and brain injury impact on significant others, were expected to be lower in the rehabilitation group. The rehabilitation group reported lower levels of brain injury symptoms compared to the control group irrespective of the rater being either the person with acquired brain injury or the significant other. This finding is consistent with a direct beneficial effect of the rehabilitation programme on experienced symptoms of brain injury. The two groups were close in reporting how much life had changed for the significant other after the brain injury. However, the rehabilitation group reported comparably lower levels of current impact on the significant other compared to the control group. The significant other in both groups endorsed higher levels of symptoms as well as impact on the significant other. This is consistent with earlier findings where this difference has been taken as indicating reduced awareness on the part of the persons with brain injury (Teasdale et al., 1997a).

4.5.3 Competency

The second hypothesis predicted that subjects who had received rehabilitation to achieve a higher degree of personal competency as experienced by themselves and their significant others. This was supported; both subjects and significant others in the control group rated the level of competency significantly lower compared to the rehabilitation group. As with the results on reporting symptoms this finding is also consistent with a beneficial effect of the rehabilitation programme. The rehabilitation group and control group subjects had similar profiles of personal competences but with the former having systematically better levels. The significant others seemed to differ especially concerning activities of daily living (ADL) and the significant others in the control group were furthest apart from their corresponding subjects on this scale. According to Sherer and colleagues (1998b), specific questions yields better agreement and it is assumed that the ADL-questions would have been easier to agree on in this context. Surprisingly, subjects from both groups rated themselves lowest on the emotional subscale, which in the literature has been reported as an area, where subjects tend to underestimate their problems compared to their significant others (Prigatano, 2005). It is clear that persons with brain injury experience reduced competency by comparison with a Danish norm population collected in connection with a follow-up of a group of 150 persons with brain injury elsewhere in Denmark (Johansen et al., 2004). This latter group was also found to have reduced competency. Like both groups with brain injury, the norm population also tended to rate themselves relatively lowest on the emotional scale.

4.5.4 Awareness

It was thirdly hypothesised that the subjects in the rehabilitation group would show more awareness as assessed by agreement/disagreement between the subjects and their significant others. Using three indices for this assessment (Hart, 2000) we found, however, no evidence to support the expectation. The main conclusion here is that there is a tendency for significant others to report more symptoms of brain injury and lower competency as compared to subjects, which possibly might indicate a lack of awareness in both the rehabilitation and control group.

4.5.6 Locus of control and self-efficacy

The fourth hypothesis was that subjects in the rehabilitation group would show a higher degree of internal locus of control and a higher degree of self-efficacy or personal agency. The results confirmed this. There was a medium sized effect of internal locus of control and a small sized effect of the self-efficacy measure, both of these being consistent with a beneficial effect of rehabilitation. Taken together, higher degrees of internal locus of control and of self-efficacy mean that the subjects in the rehabilitation group may not only feel that if they act, they can change their life for the better (internal locus of control) but they also feel that they are capable of this action (self-efficacy). Moore and Stambrook have reported, from a study of 53 men with traumatic brain injury (1992), that higher use of positive coping strategies (self-control and positive reappraisal) and higher degree of internal locus of control were associated with significantly lower mood disturbances, physical difficulties and a trend to be less depressed. The present study supports these findings; the rehabilitated group complained of less physical problems and reported higher competency and lower degrees of anxiety and depression.

4.5.7 Anxiety and depression

Thus, our results also supported the fifth hypothesis, namely that the rehabilitation group would show lower levels of anxiety and depression compared to the control group. Rehabilitation proved to have a medium size to large effect. There was a small to medium size effect of rater, thus the levels of anxiety and depression are higher in persons with brain injury compared to their significant others. So, even though scores on the scale were mostly within normal levels brain injury still showed an effect despite of rehabilitation and time. In the above-mentioned follow up study of 150 persons with brain injury, who had gone through a similar programme in Aarhus (Johansen et al., 2004), it was found that rehabilitation alleviated anxiety and depression, although rates of anxiety and depression remained elevated relative to probably applicable Icelandic norms (Magnusson et al., 2000). There seems to be an elevated occurrence of anxiety and depression even 12 to 22 years post-injury, even though rehabilitation could be acting as a buffer against this.

4.5.8 Quality of life

The sixth hypothesis predicted that members of the rehabilitation group would have a better quality of life than the control group and there was a medium sized effect of rehabilitation confirming the hypothesis. This is again consistent with a beneficial effect of rehabilitation. However, as with anxiety and depression, the subjects are not reporting as high levels of quality of life as their significant others. It was shown that the biggest differences between significant others and subjects themselves were on the psychological and physical quality of life scales and the smallest difference was on the environmental scale. This latter was perhaps to be expected given that Denmark is a fairly safe country with good options for handicap transport and the significant others and subjects otherwise share the same environmental conditions. The experience of quality of life that the subjects in the rehabilitation group is having is comparable to a Danish non-brain injured diabetic group of diabetics and their significant others experience quality of life at the mean level of a healthy Danish norm sample (Noerholm et al., 2004). This again is similar to what the Aarhus study found (Johansen et al., 2004).

The subjects in the control group experienced their quality of life as lower than a chronically ill Danish sample did (Noerholm et al., 2004) and their significant others were more comparable to the diabetic sample than the normal sample. This would appear to indicate that brain injury continues to have an impact on the quality of life of the person with brain injury, and to a lesser degree of his or her significant other, many years after the injury, notwithstanding that rehabilitation seems again to have a beneficial effect.

4.5.9 Summary

Overall**,** the results indicated a better outcome following post-acute intensive neuropsychological rehabilitation across broad domains of psychological well-being for persons with brain injury, and their significant others. In this study these domains have covered brain injury symptoms, impact of injury on significant others, competencies, degree of internal locus of control and self-efficacy, anxiety and depression and quality of life. Within the domains, differences, between persons who had experienced such rehabilitation and otherwise comparable persons who had not, were persistently significant and the effect sizes were most typically what would be regarded as medium sized (Field, 2005). Therefore, in spite of the recognised limitations of this study, we believe that this study overall serves as supportive evidence for the efficacy of post-acute intensive neuropsychological rehabilitation.

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Chapter 5. Other outcomes

This chapter presents analysis of other remaining topics covered in the interview together with supplementary analysis of the questionnaire data presented in the previous chapter. This chapter is thus structured in sections corresponding to the interview guide and according to the questionnaires. The chapter aims partly to give supplementary information about current and past similarities and differences between the rehabilitation and control groups.

- 5.1 Interview: Injury data
- 5.2 Interview: Health today
- 5.3 Interview: Complaints
- 5.4 Interview: Current use of public health services due to the injury
- 5.5 Interview: Employment
- 5.6 Interview: Leisure
- 5.7 Interview: Social network
- 5.8 Interview: Adaptation
- 5.9 Questionnaire data: Awareness,
- 5.10 Questionnaire data: Anxiety and Depression
- 5.11 Questionnaire data: Quality of life

Additional productivity hypotheses:

1. We expect the rehabilitation group to be capable of working a greater number of hours each week.

2. We expect the rehabilitation group to have been in their current productive situation longer due to better placements before they found the work they have today.

Additional leisure hypothesis:

1. We hypothesise that the survivors in the rehabilitation group, to a higher degree will have leisure activities that involve interaction with other people (and not as many passive entertainment activities like watching tv).

Hypotheses regarding social relationships:

1. The rehabilitation group is hypothesised to have more social connections (partner, family and friends) (quantity of social network).
2. The rehabilitation group is expected to be more satisfied with connections to partner, family and friends (the quality of their network).
3. The rehabilitation group is expected to receive more social/practical support from family, friends or neighbours.

Adaptation to life after brain injury

1. The rehabilitation group is expected to show more signs of a better psychological adaptation to life after brain injury.

5.1 Interview: Injury data

Table 5.1.1 Supplementary injury data	Rehab group n = 37		Control group n = 13		
	n	(%)	n	(%)	
Epilepsy requiring treatment as a consequence of the injury	8	(22)	3	(23)	n.s. †
Motor apparatus at discharge					
Normal	5	(14)	3	(23)	n.s. †
Unilateral paralysis	5	(13)	2	(15)	
Hemi-paralysis	22	(60)	6	(46)	
Fracture sequelae	5	(13)	2	(15)	
Mobility at discharge					
Normal gait	8	(22)	3	(23)	n.s. +
Independent, slightly abnormal	22	(60)	6	(46)	
With help	6	(16)	4	(31)	
Wheelchair	1	(3)	0	(0)	
	Mean	SD	Mean	SD	
Acute hospitalisation in days	87	(69)	68	(60)	n.s.*
Inpatient rehabilitation	129	(114)	146	(125)	n.s.*
Total hospitalisation	167	(153)	144	(151)	n.s.*

* = t-test, † = χ^2 test, + = Mann Whitney

Table 5.1.1. shows that regarding injury data the two groups are comparable in terms of hospitalisation and sequelae such as epilepsy, paralysis, fractures and ability to walk at time of discharge. In terms of length of hospital stay, the two groups are comparable not only in overall number of days but also when it comes to length of acute and inpatient stay. There are also large standard deviations in all measures of hospitalisation reflecting the variability within the groups.

5.2 Interview: Health Today

Table 5.2.1 Current health data	Rehab group n = 37		Control group n = 13		p
	Mean	(SD)	Mean	(SD)	
Number of stressful life events within the last year	1.0	(0.9)	0.7	(1.0)	n.s.+
	n	(%)	n	(%)	
Epileptic seizures within the last three months	4	(11)	1	(8)	n.s. †
Current epilepsy status					
Do not have	26	(70)	10	(77)	n.s. †
Not affected lately	4	(11)	1	(8)	
Affected	7	(19)	2	(15)	
Additional brain injury					
No	33	(89)	11	(85)	n.s. †
TBI	1	(3)	0	(0)	
Concussion	2	(5)	0	(0)	
Stroke	1	(3)	2	(15)	
Currently affected by the (old) brain injury	29	(78)	11	(83)	n.s. †
How much on a scale from 1 to 5 does it currently affect you, 1 being lowest and 5 highest	Mean 2.1	SD (1.2)	Mean 3.0	SD (1.6)	t(48) = -2.2, p = .034 (one-tailed)
Brain injury affects current life in a positive or negative way	n	(%)	n	(%)	
More positive than negative	17	(46)	2	(17)	χ^2-test = 3.2, p = .038 (one-tailed)
More negative than positive	20	(54)	11	(83)	

* = t-test, † = χ^2 -test, + = Mann Whitney

Results presented in Table 5.2.1 show that the two groups are comparable in terms of new brain injuries, number of recent stressful life events, how many had epileptic seizures recently and whether those with epilepsy felt affected by it. Some felt that the epilepsy was more life constraining than the other effects of brain injury. The proportion of persons with post-traumatic epilepsy is comparable in the two groups and of a magnitude to be expected after acquired brain injury. There is a prevalence of epilepsy of about 1% in the general Danish population (www.dst.dk) and the risk of developing epilepsy as a consequence of TBI is about 20-50% depending on the nature of the TBI, likewise the risk of developing epilepsy after other focal brain lesions such as after CVA is higher than for the general population (Paulson, Gjerris, Sørensen, & Juhler, 1999). The majority stated that they were still affected by the (original) brain injury. However the control group felt significantly more affected and there were a greater number in the rehabilitation group who felt that the brain injury affected their lives in a constructive or positive way today. The positive effects described included being better able to understand others in similar situations, having been forced to have a clearer prioritisation of what is important, cherishing being alive and a higher appreciation of nature, friends and family. Some positive changes such as getting closer as a family (though not always including the person with brain injury) have also been noted in other studies (Knight, Devereux, & Godfrey, 1998; Anderson, Linto, & Stewart-Wynne, 1995; Low, 1999; Pessar, Coad, Linn, & Willer, 1993; Thompson, Bundek, & Sobolewshubin, 1990). These findings have been interpreted and evidence has been provided that this is primarily because the family members support each other, have been through a lot together and because the family have ‘a joint task’(Pessar et al., 1993; Low, 1999; Knight et al., 1998).

Table 5.2.2 shows current health behaviour in terms of smoking, drinking and use of drugs. A large proportion of the participants smoke, more than 60% in both groups.

About 28% of the Danish population smoked in 2005 (http://cancer.dk/tobak/tal+og+statistik/voksnes+rygevaner/index.asp). There were no overall significant difference between the rehabilitation and control group in terms of injury type or number of cigarettes smoked daily.

The primary aim of this dissertation is to compare the rehabilitation and control group. However since smoking is a risk factor in terms of CVA, local smoking differences between the TBI and CVA group were compared within the rehabilitation and control groups. Significantly fewer of the participants with CVA as opposed to those with TBI smoked in the rehabilitation group (Chi-square (1) = 4.4, p = .035). This local difference was not found in the control group. Today the CRBI program lectures in how to follow a healthy lifestyle especially after CVA in terms of exercise, diet, and smoking.

The alcohol use in Denmark was registered in 2003 (http://www.sst.dk/upload/forebyggelse/cff/dokumentation/statistik2003.pdf.). Alcohol-wise about 15% of adult Danish males and 20 to 25% of adult Danish females are teetotalers. 65-70% males and 70 to 75% of the females drink within the limits of the recommendations given by the Department of Health. 15 to 20% of the males and 1 to 5% of the females drink more units of alcohol than recommended. The rehabilitation and control groups are fairly comparable to the general Danish population, with maybe slightly more teetotallers. This could reflect the fact that epilepsy is often a sequela of brain injury and it is recommended that epileptics avoid alcohol. Also, for some, the brain becomes much more vulnerable to the effects of alcohol. Both reasons were mentioned by participants in the interviews.

Table 5.2.2 Health behaviour	Rehab group n = 37		Control group n = 13		p
	n	%	N	%	
Smoking presently	23	(62)	8	(62)	n.s. †
Smokers with TBI	19	(73)	5	(56)	n.s. †
Smokers with CVA	4	(36)	3	(75)	n.s. †
	Mean	(SD)	Mean	(SD)	
No. of cigarettes (smokers only)	15	(6)	13	(6)	n.s.*
TBI	14	(7)	11	(6)	n.s.*
CVA	19	(1)	17	(5)	n.s.*
	n	%	N	%	
Alcohol	n = 33		n = 11		
No	8	(24)	3	(27)	n.s.+
Within limits of health department #	23	(70)	6	(55)	
More	2	(6)	2	(18)	
Units per week	10	(17)	9	(13)	n.s.*
TBI	13	(20)	7	(12)	n.s.*
CVA	5	(5)	14	(15)	n.s.*
Drug use					
Yes	2	(5)	1	(8)	n.s. †
No	35	(95)	12	(92)	

* t-test, † = χ^2 test, + = Mann Whitney

this means no more than 14 units per week for women and no more than 21 units per week for men

A large population study called the Glostrup study (Schroll & Jørgensen, 1991) examined exercise habits and found that moderate exercise defined as at least 4 hours of exercise per week was beneficial for various health factors.

Table 5.2.3 Level of weekly exercise	Rehabilitation group n = 37		Control group n = 13		p (Mann Whitney)
	n	(%)	n	(%)	
No or little exercise (< 2 hours per week)	11	30	4	31	n.s.
Light exercise : Walking, biking or active at least 2 to 4 hours per week	11	30	6	46	
Moderate exercise: light exercise at least 4 hours per week or intense activities 2 to 4 hours per week	13	35	3	23	
Intensive exercise, intense activity at least 4 hours per week	2	5	0	0	

Table 5.2.3 indicate that more than half of both groups are not reaching the recommended level of weekly exercise.

5.3 Interview: Complaints

The interview contained a section asking the participants to rate to what degree they felt troubled by symptoms of chronic brain injury. The symptoms were divided into the domains of physical, cognitive, emotional, social and practical problems. The ratings were done on a scale taken from the Portland Adaptability Inventory (Malec et al., 1993). The symptoms are rated on a scale from 0 to 4. 0 = No problem, 1 = Mild problem, does not interfere with activities, 2 = Mild problem: Interferes with activities less than 25% of the time, 3 = Moderate problem that affects activities from 25 to 75% of the time, 4 = Severe problem, interferes with activities more than 75% of the time. Table 5.3.1 compares the average number of complaints within the given domains which were rated 2 or greater, thus representing symptoms interfering with activities.

Table 5.3.1 Average number of complaints	Rehabilitation group		Control group		p
	Mean	(SD)	Mean	SD	(Mann Whitney)
Physical complaints	2.0	(1.9)	4.2	(3.2)	Z = -2.3 p = 0.02 r = -0.32
Cognitive complaints	2.1	(1.5)	2.5	(2.5)	n.s.
Emotional complaints	1.5	(1.6)	1.5	(2.6)	n.s.
Social complaints	0.5	(1.1)	0.2	(0.6)	n.s.
Practical complaints	0.9	(1.2)	1.8	(2.7)	n.s.

From Table 5.3.1 it can be seen that there are very few social complaints, and the only significant difference is the number of physical complaints which is higher in the control group; this is a medium-sized effect.

Figures 5.3.1 through 5 list the average ratings of complaints within the physical, cognitive, emotional, social, and practical domains. Physical complaints are rated highly, especially by the control group. Problems with concentration, memory and executive function (overview, planning, problem solving) are the cognitive complaints rated the highest by both groups. It can be seen that social and practical complaints are on average rated below 1.0, indicating that these problems are not influencing activities at present. But the rehabilitation group felt on average significantly (t(43.2) = 2.7, p = 0.009) more isolated (Mean = 0.7, SD = 1.4) than the control group (Mean = 0.1, SD = 0.3). All but two of the rehabilitation group lived independently, in accordance with the low average scores on practical problems. On measures of independent living both groups would score highly making this area of outcome less interesting to investigate.

Figure 5.3.1 Rating of physical complaints

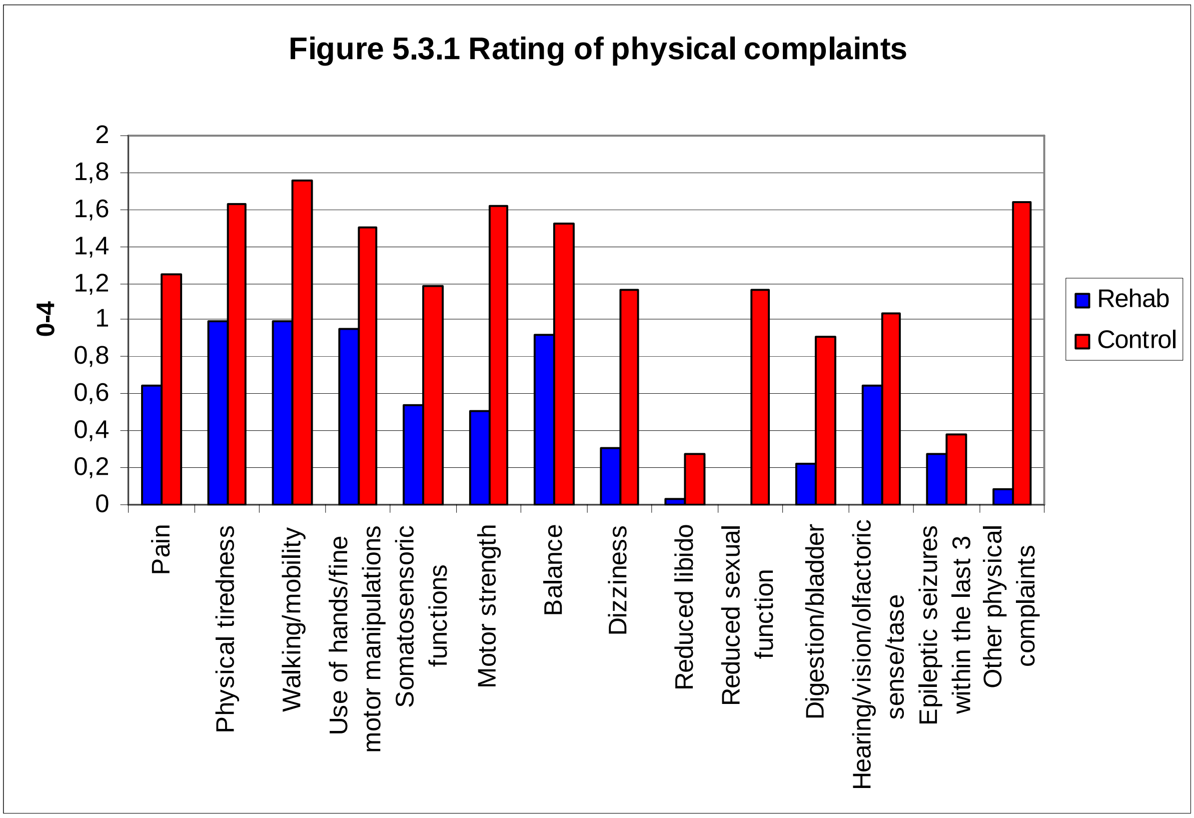


Figure 5.3.2 Rating of cognitive complaints

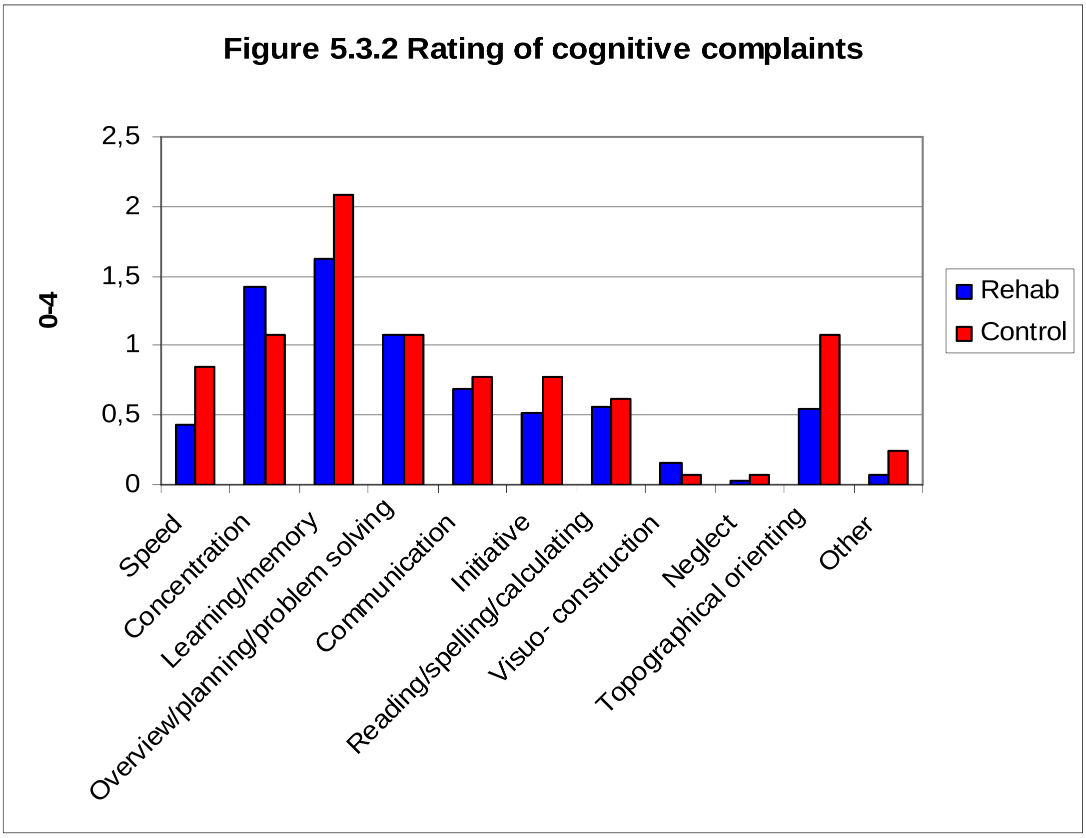


Figure 5.3.3 Rating of emotional complaints

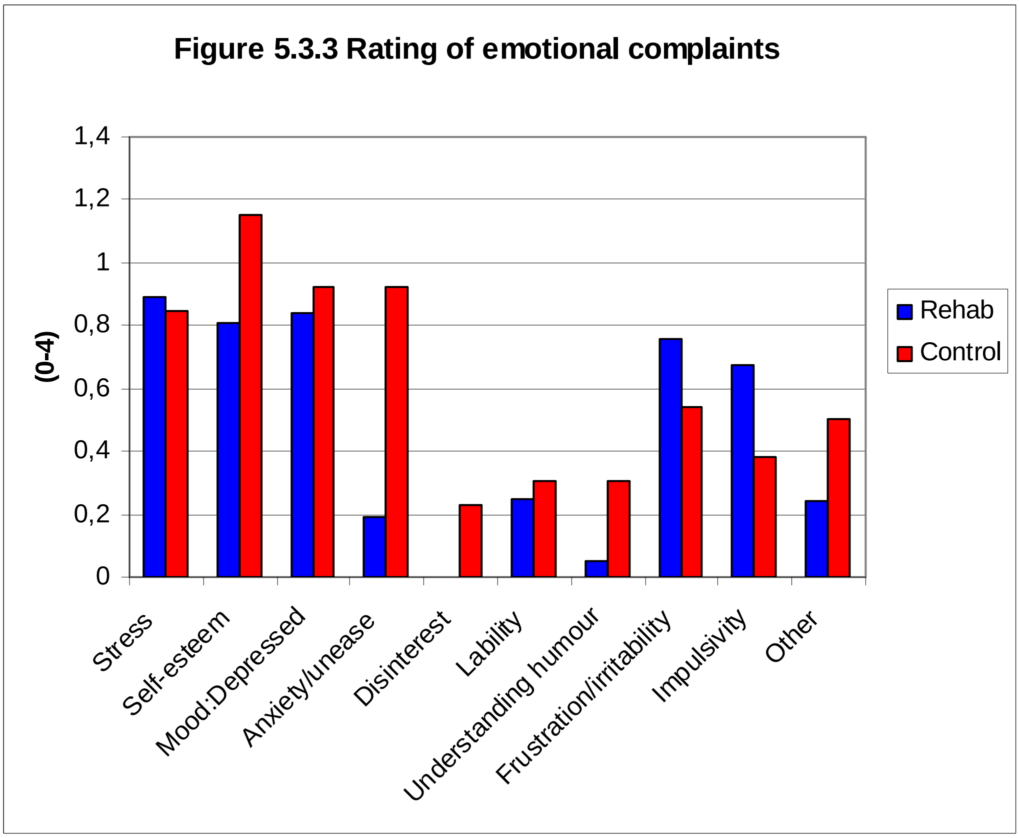


Figure 5.3.4 Rating of social complaints

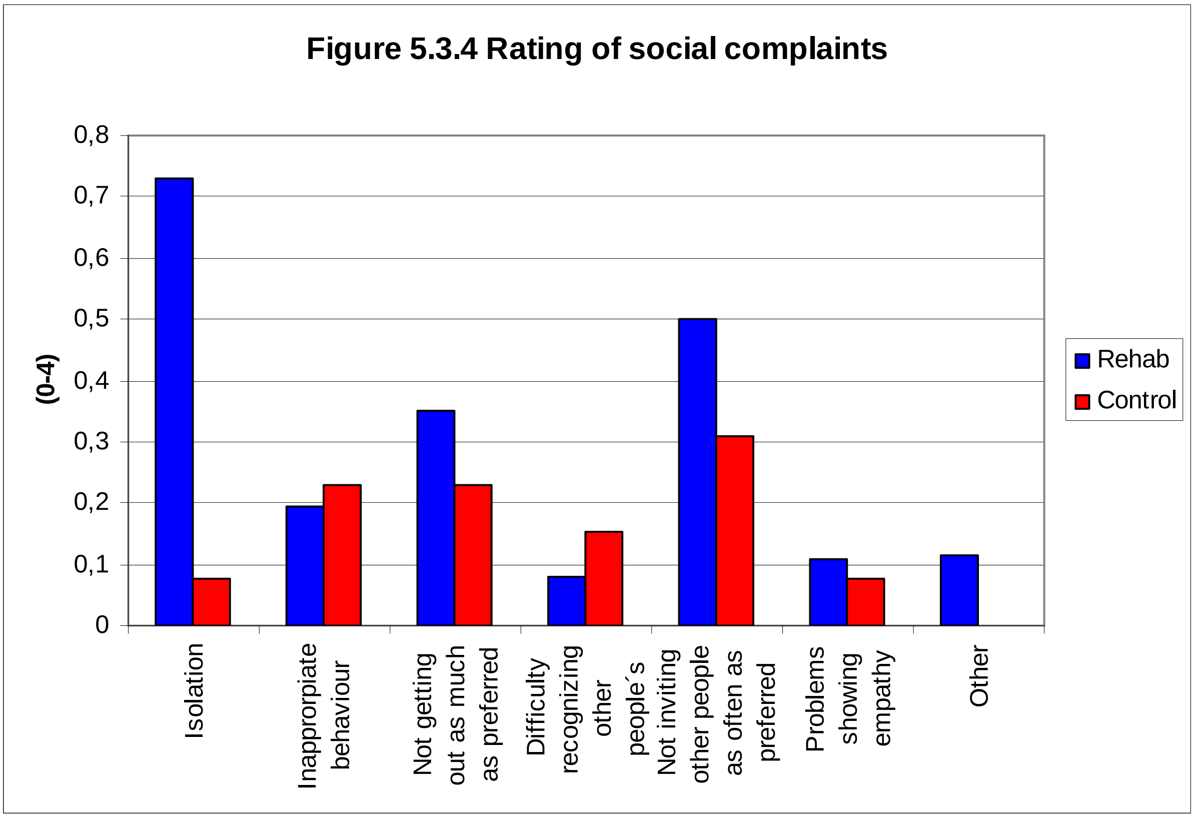
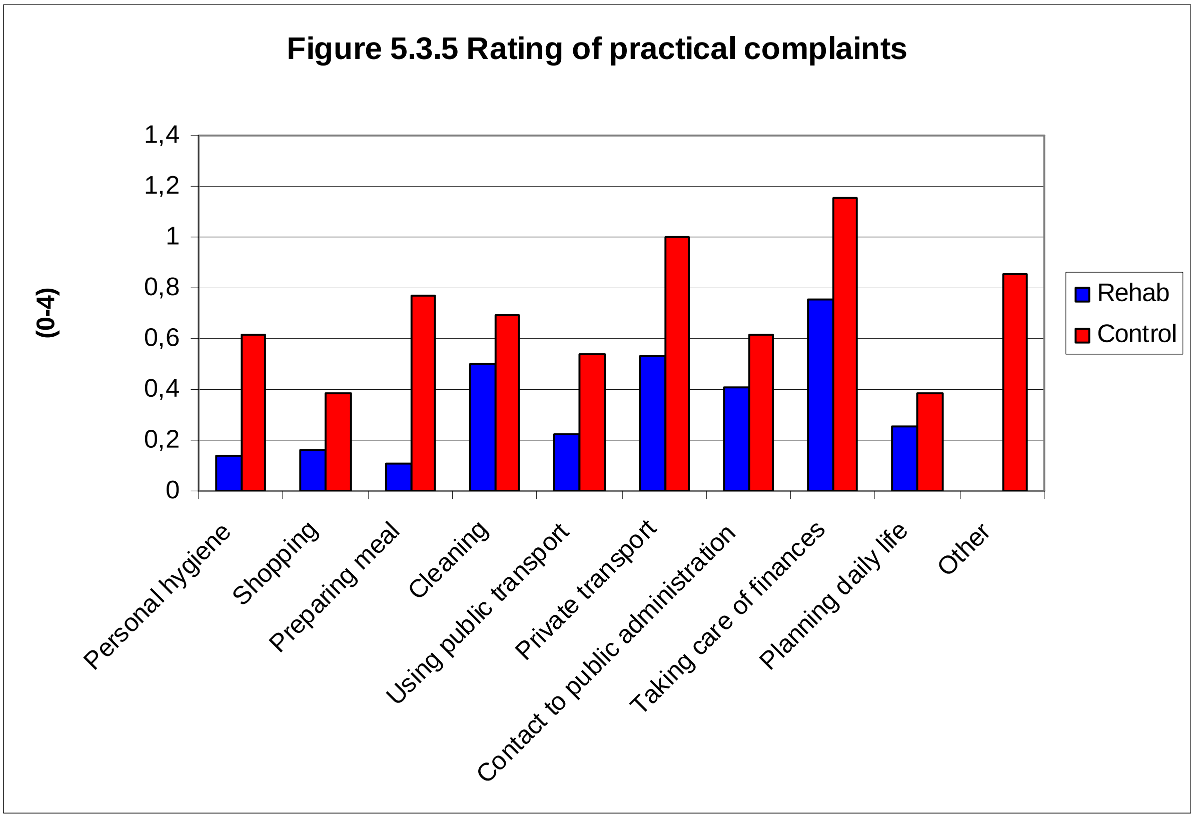


Figure 5.3.5 Rating of practical complaints



5.4 Interview: Current use of public health services due to the injury

Table 5.4.1 indicates that there are no significant differences between the frequencies of people receiving the various kinds of public help in the two groups, even though the percentage of participants receiving home help and physical therapy is higher in the control group. On average members of the rehabilitation group receive 1.5 (SD 1.7) kinds of help and a members of the control group receive on average 1.8 (SD=1.7) kinds. However significantly more of the control group (47%) feel that in connection with the brain injury they would like to be presently receiving physical therapy, compared with the rehabilitation group (19%) (See Table 5.4.2). On average members of the rehabilitation group feel the need for 1.0 (SD=1.0) kinds of help at present as a result of their injury, while members of the control group feel they currently need 1.5 (SD=1.7) kinds of help as result of their injury.

Table 5.4.1 Receiving help as a result of the brain injury	Rehabilitation group n = 37		Control group n = 13		p (X^2)
	n	%	N	%	
Home help	4	(11)	2	(15)	n.s.
Support person	5	(14)	2	(15)	n.s.
Home nurse	1	(3)	1	(8)	n.s.
Physical Therapist	4	(11)	3	(23)	n.s.
Psychologist	1	(3)	1	(8)	n.s.
Day care centre / Special education	5	(14)	2	(15)	n.s.
Other help (e.g. social worker)	6	(17)	2	(15)	n.s.

Table 5.4.2 Experiencing a need for help as a result of brain injury	Rehabilitation group n = 37		Control group n = 13		p (X^2) (two-tailed)
	N	(%)	n	(%)	
Home help	5	(14)	3	(23)	n.s.
Support person	4	(11)	2	(15)	n.s.
Home nurse	1	(3)	2	(15)	n.s
Physical Therapist	7	(19)	6	(46)	X^2 test = 3.5, df=1, p=.062
Psychologist	1	(3)	2	(15)	n.s.
Day Centre / Special education	8	(22)	2	(15)	n.s.
Other help (e.g. social worker)	9	(24)	3	(23)	n.s.

When asking the control group whether they think they would have wanted an intensive post-acute rehabilitation program at the time of their injury, 80% answered yes, 13.3% maybe and 6.7% answered no.

In general both the rehabilitation group and the control group seem to desire a little more help than they actually get. Surprisingly, the rehabilitation group did not receive significantly lower amounts of ongoing help than the control group.

What is interesting about the support results is that the control group desired more physical therapy than the rehabilitation group at a level approaching significance. This is in accordance with the previous section in which the control group reported significantly higher numbers of physical complaints at present (See Table 5.3.1). At time of injury the control group also had a higher total injury severity score compared with the rehabilitation group (See 2.2.4 Comparability) without differing on other injury severity measures. However at time of discharge the two groups were comparable in terms of paralysis, fractures and mobility (See 5.1.1). If the two groups were fairly comparable at discharge from hospital, how come a higher percentage of the control group feel they need more physical therapy today? One explanation could be that the rehabilitation group members might know, through training at the CRBI, to a greater extent than the members of the control group that they are their own best physical trainers and that the established system cannot help them more than they can help themselves by staying fit and knowing how to motivate themselves to keep doing so. However, more than half of both groups do not get the recommended amount of weekly exercise (see Table 5.3.3). An alternative explanation could be that other illness plays into the equation.

5.5 Interview: Employment

Table 5.5.1 Supplementary employment information	Rehabilitation group n = 37		Control group n = 13		p
	n	(%)	n	(%)	
Employment situation at time of injury					
At school	7	(18)	1	(8)	See chapter 3
At school, supported (e.g dyslexia)	1	(3)	0	(0)	
Employment education, normal terms	6	(16)	0	(0)	
Employed, normal terms	21	(57)	10	(77)	
Employed, sheltered, supported or Reduced hours	1	(3)	1	(8)	
Homemaker, no support	0	(0)	1	(8)	
Unemployed	1	(3)	0	(0)	
Income type at follow up					
Salary on normal terms	4	(11)	1	(8)	See chapter 3
State educational stipend	1	(3)	0	(0)	
Sick pay	1	(3)	0	(0)	
Supported employment salary	5	(14)	0	(0)	
Disability pension + income from supported work	7	(19)	4	(31)	
Disability pension and volunteer work	10	(26)	2	(15)	
Disability pension and education	2	(5)	0	(0)	
Disability pension and no employment or education activity	6	(16)	5	(38)	
Unemployment benefit	1	(3)	1	(8)	
Having work colleagues					
Yes	23	(62)	7	(54)	n.s.
No	14	(38)	6	(46)	†
	Mean	(SD)	Mean	(SD)	
Number of hours per week for those who are employed (Rehab n = 24, Controls n = 5)	25	(17)	23	(19)	n.s. *
Years in current situation	7	(5)	8	(6)	n.s. *

* t-test, † = χ^2 test, + = Mann Whitney

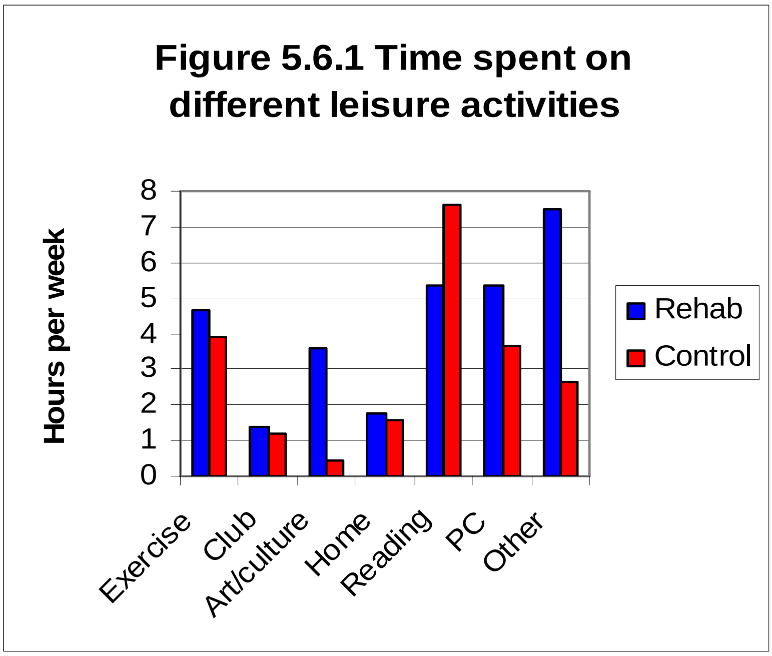
Table 5.5.1 presents in more detail pre-injury employment situation as well as employment situation and source of income in 2004. The many categories and small number of participants were the reasons for combining these categories into the ones presented in Chapter 3, Table 3.2. Since many participants mentioned having colleagues as a major motivating factor for taking or maintaining employment, the participants were asked whether they had work colleagues. Those without connection to the workforce were recorded as having none. The proportions of participants in each group having colleagues were similar, as were the number of weekly work hours for those with employment and years spent in their current situation, be it work or disability pension or unemployment. Even though there is some variation in stability or in their current situation, the general trend is that there is a certain degree of stability at this point after injury.

5.6 Interview: Leisure

As an extension of the leisure data presented in Table 3.2, Figure 5.6.1 shows the breakdown of the average number of hours of leisure activities into the categories of exercise (mainly walking (the dog) and biking, activities carried out in an unstructured setting and mainly by the participant on his or her own), club membership, art/culture (going to the theatre, museums, or the movies), home activities (gardening, working on the apartment/house or car, visiting a holiday house), reading (especially newspapers but also books and magazines), use of computer and 'other activities' (such as café-visits, taking care of pets, crafts, mechanics, shopping, evening school, playing billiards, writing a diary and going to bingo).

The only significant difference (t(42.6) = 2.4, p = 0.02) between the rehabilitation and control group was in terms of arts and cultural activities. The rehabilitation group (Mean = 3.6 hours per week, SD = 7.5) spends more time on these kinds of activities than the control group does (Mean = 0.5 hours per week, SD = 1.4).

Figure 5.6.1 Time spent on different leisure activities



The CRBI program does have as a goal for participants to actively engage in leisure activities. The participants from the rehabilitation group significantly (t(48) = 1.9, p = 0.03, one-tailed according to hypothesis) rate their leisure activities as more important for their quality of life (Mean = 4.1, SD = 1.0) compared to the control group (Mean = 3.5, SD = 1.1) on a scale from 1 to 5.

5.7 Interview: Social Network

Table 5.7.1 Social aspects	Rehabilitation group		Control group		p
	N	%	n	%	
Living situation at follow up					
With spouse (+ children)	18	(49)	9	(69)	n.s. †
With others	1	(3)	0	(0)	
Living alone	15	(40)	4	(31)	
Other living arrangements	3	(8)	0	(0)	
Spend most time with					
Family	18	(50)	8	(64)	n.s. †
Friends	15	(42)	4	(27)	
Equally family and friends	2	(5)	1	(9)	
Neither family nor friends	1	(3)	0	(0)	
Social role changed as a result of injury					
Yes	24	(66)	7	(58)	n.s. †
No	13	(34)	5	(42)	
Experience that other people lack understanding of brain injury					
Yes	31	(86)	7	(58)	$\chi^2 = 4.2$,
No	5	(14)	5	(42)	$p = 0.4$
Does lack of understanding hinder establishing contact with other people?					
Yes	9	(27)	4	(33)	n.s. †
No	25	(73)	8	(67)	
Is the brain injury something you tell others about when you meet them?					
No	6	(17)	0	(0)	n.s. †
Yes, straight away	3	(9)	0	(0)	
Yes, if they ask	22	(65)	8	(73)	
Other	3	(9)	3	(27)	

† = χ^2 test

Table 5.7.1 show the majority of both groups live with others. In both groups the majority spend most time with their family. In a study of 70 residents with brain injury in rehabilitation facilities and a non-brain injured control group (Zencius & Wesolowski, 1999) residents with traumatic brain injury had social networks consisting mainly of family (66%), while non injured respondents had mostly, in order of magnitude friends or acquaintances, coworkers, and family members.

In this study more members of the control group spend time with their family compared with the rehabilitation group and more from the rehabilitation group spend most of their time with friends compared with the control group. The majority of both groups felt that their social role had changed as a result of their brain injury; becoming more introverted or shy was a frequent answer. Even though more than half of the participants in each group experience that others lack understanding about brain injury, a significantly higher proportion in the rehabilitation group say they experience this. However only about a third of each group experience that other people's lack of understanding of brain injury hinders the participants from establishing contact with them. The preferred strategy of both groups in relationships concerning disclosure of the brain injury is that they are happy to talk about it if asked. One participant stated that she needed to talk about it to everyone she met in the beginning because it weighed on her mind. Another said that he used this strategy because he did not wish to make an issue of it, and yet another said that he had learned to spot whether people were able to handle the information, because he would not reveal it if he felt he would be pitied. More participants from the rehabilitation group than the control group said that they never told anybody about it.

Table 5.7.2 Partner	Rehabilitation group		Control group		p
	Mean	(SD)	Mean	(SD)	
Importance of relationship for quality of life (1-5)	4.4	(0.7)	4.3	(1.0)	n.s.*
Ability to meet potential partners (1-5)	3.7	(1.3)	4.4	(0.9)	n.s.*
Ability to maintain a relationship (1-5)	4.0	(1.0)	4.2	(0.7)	n.s.*
	n	%	n	%	
Does brain injury play a role in a relationship?					
Yes	17	(53)	6	(60)	n.s. †
No	15	(47)	4	(40)	
Has a partner at time of follow up					
Yes	18	(49)	9	(69)	n.s. †
No	19	(51)	4	(31)	
For those in a relationship:					
Knew partner prior to injury					
Yes	8	(44)	4	(44)	n.s. †
No	10	(56)	5	(56)	
	Mean	(SD)	Mean	(SD)	
Length of partnership in years	17	(13)	13	(8)	n.s.*
Participant’s satisfaction with relationship (1-5)	4.6	(0.6)	3.9	(1.3)	n.s.*
Partner’s satisfaction according to participant (1-5)	4.4	(0.7)	4.0	(1.0)	n.s.*
	n	%	n	%	
For those not in a relationship:					
Would like to have a partner					
Yes	15	(79)	3	(75)	n.s. †
No	4	(21)	1	(25)	
	Mean	(SD)	Mean	(SD)	
Time since last partner in years	6	(8)	3	(4)	n.s.*

* t-test, † = χ^2 test, + = Mann Whitney

Table 5.7.3 Other immediate family	Rehabilitation group		Control group		p
	n	%	n	%	
Grandparents					
Yes	7	(21)	2	(15)	n.s. †
No	27	(79)	11	(85)	
Parents					
Yes	29	(78)	9	(69)	n.s. †
No	8	(22)	4	(31)	
Siblings					
Yes	35	(97)	12	(92)	n.s. †
No	1	(3)	1	(8)	
Children					
Yes	20	(59)	12	(92)	$\chi^2 = 5.3$
No	15	(41)	1	(8)	$p = 0.02$
Grandchildren					
Yes	6	(17)	4	(31)	n.s. †
No	29	(83)	9	(69)	
Had contact with family last month					
Yes	30	(91)	12	(100)	n.s. †
No	3	(9)	0	(0)	
	Mean	(SD)	Mean	(SD)	
Family's importance for quality of life	4.5	(0.8)	4.6	(0.5)	n.s.*
Participant's satisfaction with relationship (1-5)	4.3	(0.9)	4.0	(1.0)	n.s.*
Family's satisfaction according to participant (1-5)	4.1	(1.0)	4.2	(1.0)	n.s.*

* t-test, † = χ^2 test

Table 5.7.4 Friends	Rehabilitation group		Control group		p
	n	%	n	%	
Have close friends					
Yes	30	(81)	9	(69)	n.s. †
No	7	(19)	4	(31)	
Had contact with friends last month					
Yes	29	(85)	9	(82)	n.s. †
No	5	(15)	2	(18)	
Would like to have more friends					
Yes	11	(34)	2	(25)	n.s. †
No	22	(66)	6	(75)	
	Mean	(SD)	Mean	(SD)	
Friends' importance for quality of life	4.4	(0.9)	3.9	(0.9)	t(46) = 1.8, p = 0.085
Participant's satisfaction with relationship (1-5)	4.2	(1.0)	4.1	(1.2)	n.s.*
Friend's satisfaction according to participant (1-5)	4.3	(0.9)	4.0	(1.1)	n.s.*
Ability to initiate potential friendships	3.7	(1.3)	4.0	(1.3)	n.s.*
Ability to maintain friendship	4.2	(1.0)	3.9	(1.1)	n.s.*

* t-test, † = χ^2 test

From Tables 5.7.2-4 it can be seen that the two groups are comparable in terms of their relationships with partners, family and friends, with the exception that significantly more from the control group have children, and non-significantly more in the control group have with a partner at follow-up. This could be due to the non-significantly higher age in the control group. It was hypothesised that members of the rehabilitation group would have been better able to reach out and be in a relationship and thus have maintained it for a longer time at follow-up, and likewise with friendship. However there was no difference between the rehabilitation and control groups: both groups rated fairly highly their ability to engage in and maintain relationships and friendships, and both groups rated highly their satisfaction with current relationships to partner, family and friends. They also regarded their social network as very important for their quality of life.

Table 5.7.5 shows that in both groups, both participants and significant others (SO) receive more assistance from families and friends than from neighbours. There is no significant difference between the rehabilitation and control groups. There are fewer in the control group who receive no help than in the rehabilitation group. When comparing the SO with the participants, more SOs receive some kind of support from their social network, perhaps indicating that they have a stronger social network than the participant. The participants and their SOs were, as part of the questionnaire, asked to rate to what extent the support they received from family, friends and neighbours fulfilled their experienced need for support. The SOs were asked to rate this for the participant as well as for themselves. This was done on a five point scale from 1 to 5, 1 indicating minimal support according to need and 5 indicating maximal support according to experienced need.

Table 5.7.5 Kind of support received by network	Rehabilitation group (n = 32 participants and n = 27 relatives) %			Control group (n = 12 participants and n = 12 relatives) %		
	None	Emotional or practical	Emotional & practical	None	Emotional or practical	Emotional & practical
Family						
Participant	16	23	61	0	50	50
Participant rated by SO	23	15	62	0	25	75
SO rated by SO	12	12	76	0	18	82
Friends						
Participant	29	26	45	17	25	58
Participant rated by SO	24	32	44	8	42	50
SO rated by SO	4	48	48	0	42	58
Neighbours						
Participant	56	25	19	42	25	33
Participant rated by SO	39	35	26	25	25	50
SO rated by SO	36	40	24	50	17	33

Figures 5.7.1 and 5.7.2 show to what extent the perceived support from family, friends and neighbours satisfies the experienced need. In accordance with the kind of support offered, family rather than neighbours seem to fulfil relatively more needs for both participants and SOs. On most scales the SO rates him or herself as receiving relatively more

support compared to the participant (with the exception of 'neighbours' within the control group), however the participant generally rates him or herself as receiving more support than according to the ratings from the SO. There is no significant difference between the rehabilitation and control groups.

Figure 5.7.1 Support given to the participant from family, friends and neighbours.

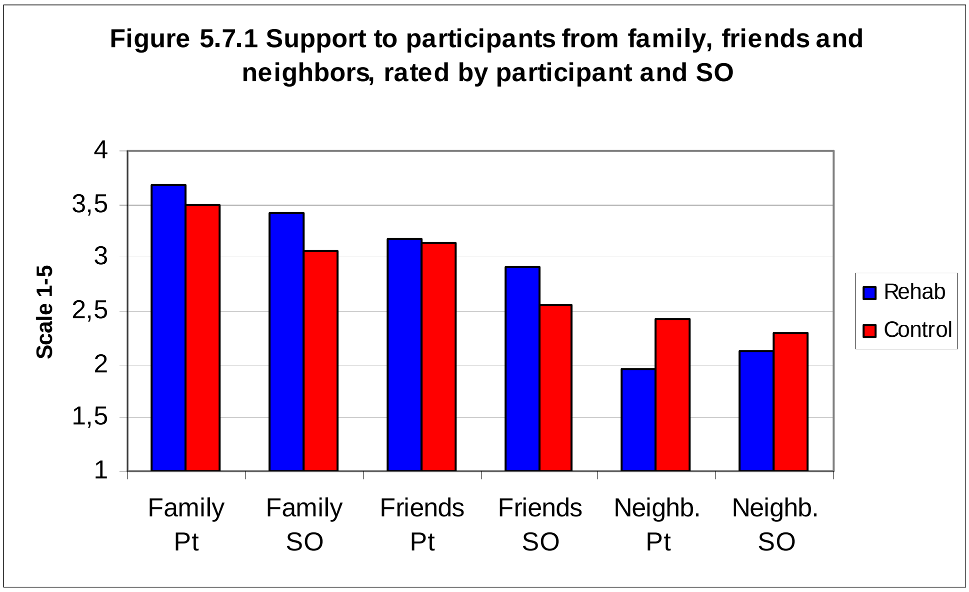
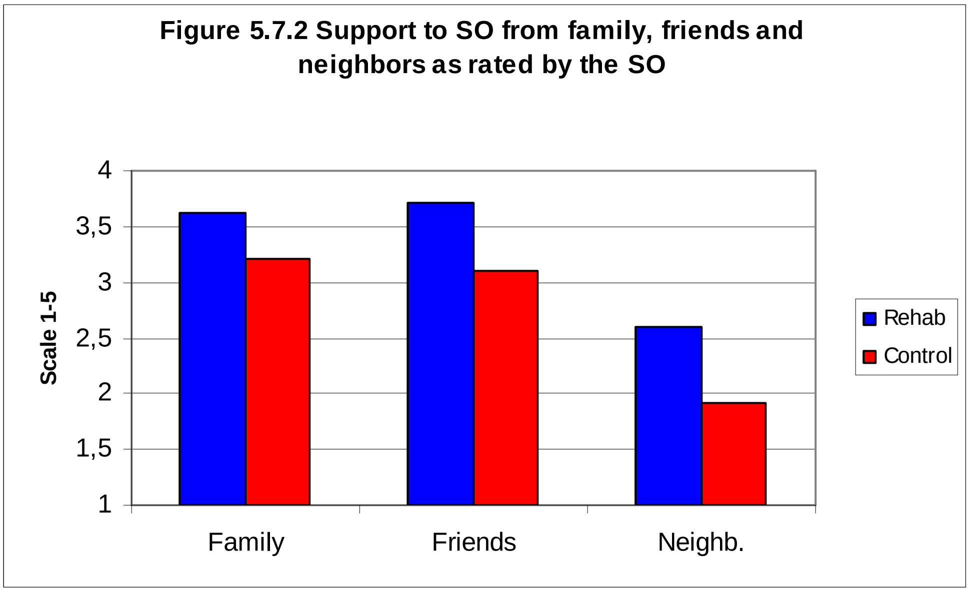


Figure 5.7.2 Support given to the SO from family, friends and neighbours.



5.8 Interview: Adaptation

Overall, most members of both the rehabilitation group and the control group expressed that they had learned to live with their injury over time, with an adjustment period ranging from ½ a year to 10 years after injury. Several expressed that they felt this adjustment falling into place when they returned to work, which supports the views of Prigatano(1989) and others, who see work as a sign of normality. However, this does not mean that they would have gone without rehabilitation or that they would not have wished to participate in rehabilitation had they had the opportunity. User satisfaction is high in the rehabilitation group where the majority (92%) felt the program helped them. In the control group the majority (82%) also retrospectively considered that an intensive rehabilitation program would have been good for them in the period following their injury.

Table 5.8.1	Rehabilitation group		Control group		p (t-test)
	Mean	(SD)	Mean	(SD)	
Since the brain injury:					
How great has the effort been to overcome the difficulties	4.4	(0.9)	3.9	(0.9)	t (47) = 1.8, p = 0.038 (one tailed)
How productive has life been	3.9	(1.1)	3.9	(0.7)	n.s.
How satisfactory has social life been	3.9	(1.1)	3.8	(1.1)	n.s.
Ability to engage in close social relationships	4.0	(1.0)	4.0	(1.1)	n.s.
Even though life may be different now, how meaningful is it	4.1	(0.9)	3.9	(0.8)	n.s.
How much in harmony now	4.2	(1.0)	3.7	(1.1)	n.s.

Maybe not surprisingly the rehabilitation group rated their effort to overcome difficulties higher than the control group. This result is in line with the higher self efficacy and internal locus of control in the rehabilitation group presented in Chapter 4. They also gave higher ratings for how meaningful life seems and how much they were in harmony, albeit not significantly so compared to the control group. This is in line with the higher levels of quality of life and lower levels of anxiety and depression (See Chapter 4). Quality of life and self-confidence were two of the areas where the CRBI program was rated as being most beneficial. The rehabilitation group rated their current work/pension situation as more satisfying in terms of their own self-expectations. The majority of both groups felt that the brain injury still affected them today (Table 5.2.1), however the control group reported a significantly greater influence (Table 5.2.1) and even though the majority felt the influence of the brain injury had been predominantly negative, significantly more in the rehabilitation group stated that it had had a predominantly positive effect, mainly in the sense of being better able to understand other people who were suffering, and that the brain injury had forced them to prioritise and appreciate their life more. These results could be seen as the rehabilitation group having readjusted better than the control group.

In other outcome areas, such as the amount of leisure activities and social social network and support, there is little difference between the two groups. Likewise there is no difference in the subjective evaluation of their social abilities or productivity, as shown in Table 5.8.1. The CRBI was also rated as having relatively low importance for social life, leisure and employment. Corrigan and Bogner (2004) argue that outcome in traumatic brain injury should be measured in three dimensions: activity; participation according to the WHO model of health; and subjective well-being as a separate domain of outcome. Other studies (Cicerone, 2004; Brown et al., 2004) have also indicated that outcome in terms of subjective well-being appear to be distinct from participation indicators such as employment and social network. The present work seems to present more evidence in favour of rehabilitation having a more general effect within the areas of subjective well being rather than increasing actual participation a long time after rehabilitation.

5.9 Questionnaire data: Awareness (EBIQ and PCRS)

This section gives details of the lack of findings presented in Section 4.4.4. The Patient Competency Rating Scale (PCRS) has not been primarily used as a measure of competency, but it has been used to calculate awareness measures in three different ways (Fleming, Strong, & Ashton, 1996):

1) The total score, or the average score across all items (average competency rating), may be calculated for both subject and significant other and then compared. This approach gives an overall measure of the discrepancy between self- and other-ratings but is insensitive to differences that may exist as a function of the type of item.

2) The actual magnitude of the difference between the subject's and respondent's ratings on specific items may be calculated. This method is sensitive not only to the degree of discrepancy, but to differences as a function of item type (e.g., cognitive / behavioural versus physical).

3) The following three scores may be computed: the # of items on which the subject's rating is higher than the respondent's; the # of items on which the respondent's rating is higher; and the # of items on which the ratings are identical. Subjects may then be classified according to

which of these three scores is highest. This will be referred to as typical answer style from now on.

The primary use of the European Brain Injury Questionnaire (EBIQ) has been to measure different symptoms occurring after brain injury, and the way in which it has been used to measure awareness has been to record if subjects deviated significantly from their significant others. Previous studies using the EBIQ have sometimes shown (Teasdale et al. 1997a) and other times not shown (Svendsen, Teasdale & Pinner, 2004) any difference between patients with acquired brain injury and their significant others. In order to compare the results of the EBIQ with those of the PCRS, some of the same metrics will be extracted, namely analysis methods two and three above. The reason for omitting analysis method one is that the EBIQ has traditionally not been calculated as a total score.

It could be argued that the level of knowledge the significant other has of the participant would influence the accuracy of the ratings of significant other. When filling out the questionnaires, the participants were asked how well they felt their significant others knew their abilities and competencies on a five-point Likert scale, from one (‘Hardly at all’) to five (‘Very well’). Their significant others were asked a similar question about how well they felt they knew the participants’ abilities and competencies.

Table 5.9.1 How well the SO knows the participant	Rehabilitation group n=33		Control group n=12		p (F-test)
	Mean	SD	Mean	SD	
How well does your significant other know your abilities and competencies?	4.1	(1.0)	3.1	(0.7)	F (1, 41) = 6.7, p = 0.013, r = 0.37
How well do you (SO) know the participants abilities and competencies?	4.6	(0.7)	4.9	(0.4)	n.s.

Table 5.9.1 contains the average score and standard deviations for the above mentioned questions. Both groups generally claim that the significant others have fairly good understanding of the participants' capacities. Repeated measures analysis of variance (or mixed model) revealed strong, significant within-subject effect of rater (participant versus SO) F (1, 41) = 43.1, p < .001, r = .72 reflecting the fact that the SOs rate themselves as knowing the participant better than the participant feels they do (the SOs in the rehabilitation group on average felt they knew the participant half a scale point better, whereas in the control group the mean difference was 1.8 scale points). The analysis also showed a strong, significant two-way interaction between rater and rehabilitation status F (1, 41) = 15.0, p< .001, r = .52 reflecting the fact that there is a much larger difference between the participant and significant other in the control group than in the rehabilitation group (0.5 versus 1.8 scale points). There was a moderate, significant between-subject effect of rehabilitation F (1, 41) = 6.7 p = .013, r = .37 indicating that the rehabilitation group generally rated the SO's knowledge of the participant higher than the control group did (4.4 versus 4.0).

Figure 5.9.1 Level of agreement: How well the SO know the participant

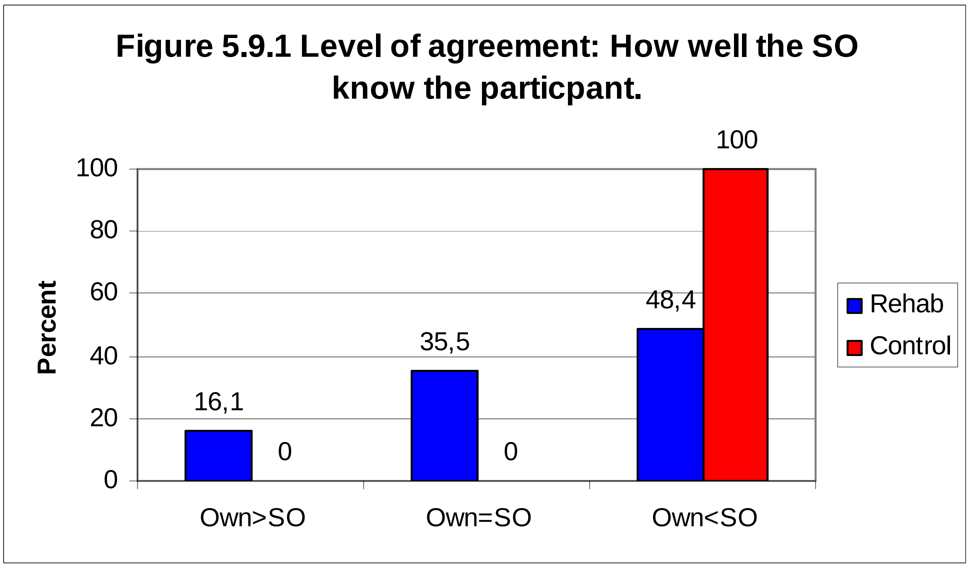


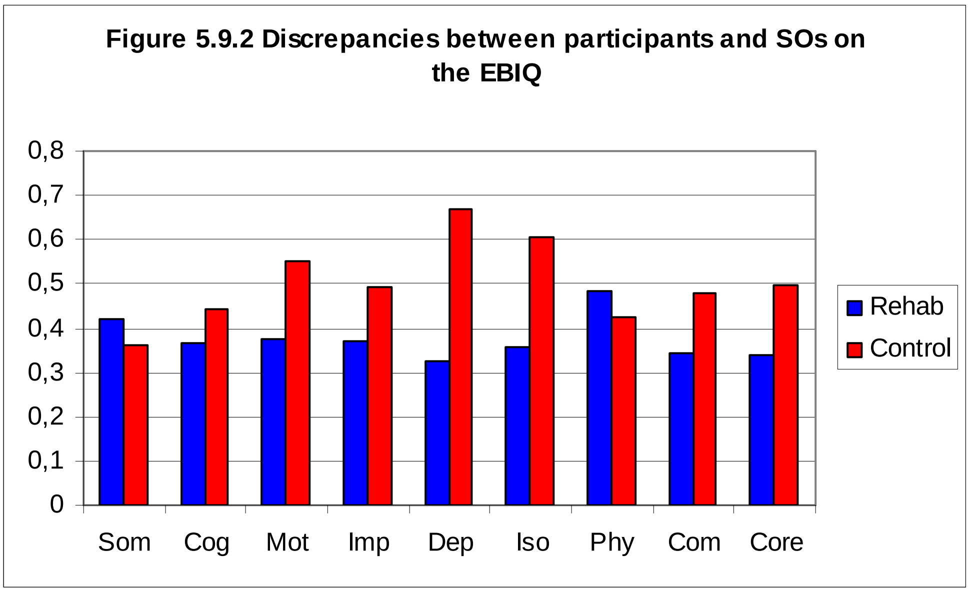
Figure 5.9.1 shows the frequency of the three categories of agreement or difference between the significant other and the participant on this single question. 16 % of the participants in the rehabilitation group have rated this question higher than their significant other, thus implying that they feel their significant other knows them better than their significant other says they do. In 36% of the cases, the participant and significant other rate their knowledge equally, and in 48% of the cases the participant feels the significant other knows them less well than the significant other claims. All the participants in the control group (100%) say that their significant other knows them to a lesser extent than their significant other claims to. This is a significant difference (Z = -3.0, p = .002 (two-tailed) Mann Whitney).

Table 5.9.2 Mean numeric scale differences between participants and SOs on the EBIQ

	Rehabilitation group n=37		Control group n=13		p (t-test, two-tailed)
	Mean	(SD)	Mean	(SD)	
Somatic	.42	(.33)	.36	(.22)	
Cognitive	.37	(.35)	.44	(.45)	
Motivation	.37	(.38)	.55	(.48)	
Impulsivity	.37	(.32)	.49	(.33)	
Depression	.32	(.31)	.67	(.50)	t=-2.7, df=42, p= 0.010, r = 0..39
Isolation	.35	(.35)	.60	(.38)	t=-2.1, df=42, p=0.043, r = 0.31
Physical	.48	(.40)	.43	(.31)	
Communication	.34	(.34)	.48	(.47)	
Core	.34	(.33)	.50	(.39)	

Figure 5.9.2 is based on the means displayed in Table 5.9.2

Figure 5.9.2 Discrepancies between participants and significant others on the EBIQ



From Table 5.9.2 and Figure 5.9.2 it can be seen that with two exceptions (the somatic and physical scales) the numeric differences are higher in the control group, though never higher than 0.7 scale score and with fairly large standard deviations (from 0.2 to 0.5). The variance in differences between the rehabilitation and control group range from 0.06 to 0.35 and there are only significant, moderate effects on the Depression scale (difference 0.35, t = -2.7, df = 42, p = 0.010, r = 0.39) and Isolation scale (difference = 0.25, t = -2.1, df = 42, p = 0.043, r = 0.31). Possibly with a larger sample size this difference could prove to be significant, because the standard deviations are quite large here.

Analyzing methods one and two: mean difference on total and specific scale scores on the PCRS

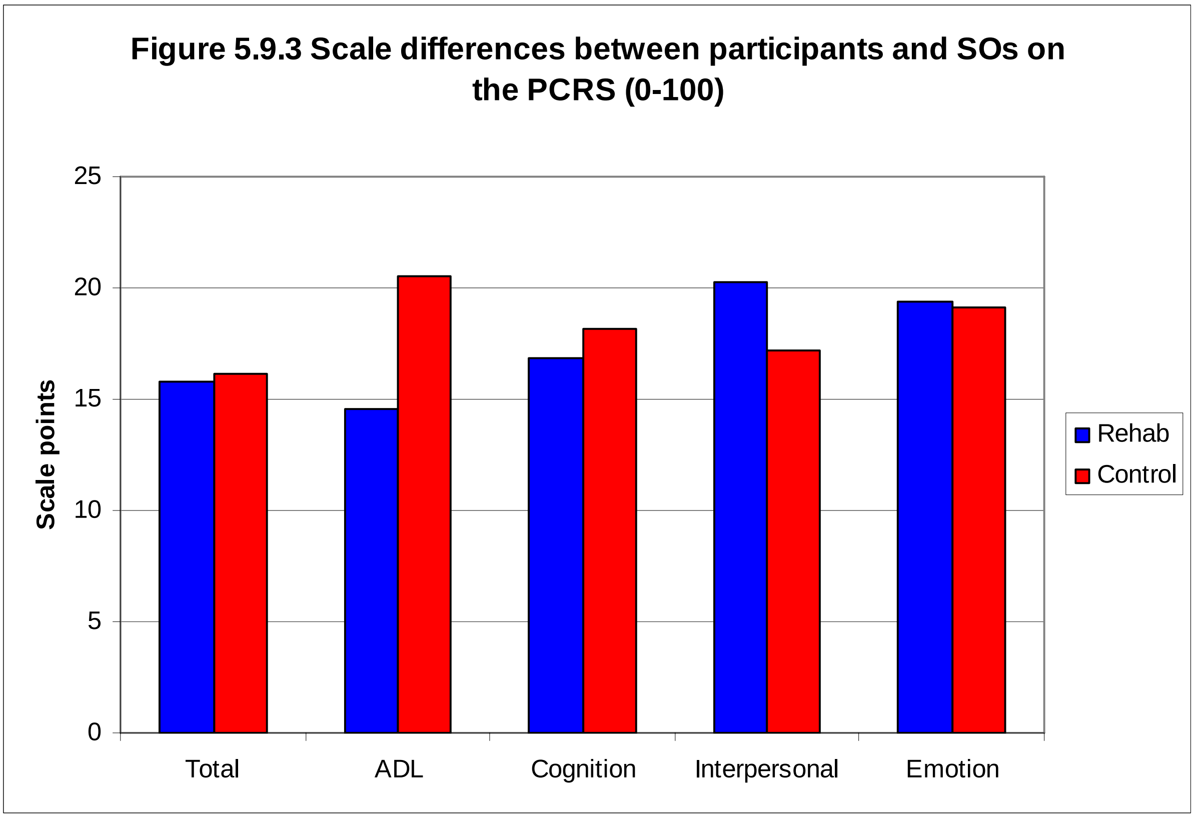
Table 5.9.3 Mean numeric scale (0-100) differences between participants and SOs on the PCRS	Rehabilitation group n=37		Control group n=13		p (t-test, one-tailed)
	Mean	SD	Mean	SD	
Average item score (1-5)	0.85	(0.51)	0.93	(0.44)	n.s.
Total unabridged scale (30-150)	19.0	(18.1)	19.3	(13.5)	n.s.
Total scale converted (0-100)	15.8	(15.1)	16.1	(11.3)	n.s.
ADL (0-100)	14.6	(14.7)	20.5	(20.0)	n.s.
Cognition (0-100)	16.8	(13.9)	18.2	(13.1)	n.s.
Interpersonal (0-100)	20.3	(17.8)	17.2	(12.8)	n.s.
Emotional (0-100)	19.4	(17.2)	19.1	(15.3)	n.s.

Table 5.9.4 shows the differences on the PCRS between participants and significant others. Positive numbers mean that in general the participant has rated their competency higher than their significant other.

Table 5.9.4 Mean scale (0-100) differences between participants and SOs on the PCRS	Rehabilitation group n=37		Control group n=13		p (t-test, one-tailed)
	Mean	SD	Mean	SD	
Average item score (1-5)	0.23	(0.83)	0.32	(0.72)	n.s.
Total scale converted (0-100)	6.1	(21.1)	8.2	(18.3)	n.s.
ADL (0-100)	7.4	(19.5)	15.7	(24.2)	n.s.
Cognition (0-100)	3.2	(21.8)	4.9	(22.5)	n.s.
Interpersonal (0-100)	7.4	(26.2)	3.8	(21.7)	n.s.
Emotional (0-100)	5.4	(25.6)	7.6	(23.9)	n.s.

Figure 5.9.3 is based on the mean differences of the converted scale scores ranging from 0-100 listed in Table 5.9.3.

Figure 5.9.3 Scale differences between participants and SOs on the PCRS



From Table 5.9.3 and Figure 5.9.3 it can be seen that all numeric scale differences between significant others and participants are within 21 converted scale score points (scale from 0-100). The two groups show a similar magnitude of difference; they are never more than 0.3 to 5.9 points apart. The rehabilitation group differs less on the Total, ADL and Cognition scale, where as the control group differs least on the Interpersonal subscale and Total scale. The total unabridged scale score differed (19 versus 19.3 scale scores) and the average item score differed (0.85 versus 0.93 points). None of these differences are significant.

Table 5.9.5 lists the distribution of parameters of typical answer style on the EBIQ scales. In the rehabilitation group 19 % of participants report fewer problems or underestimate their problems compared with the view of the significant other on the Total scale whereas as many as 33 % report fewer problems on the impact questions. In the control group the lowest level of underestimating problems is 8 % on the Somatic scale, but 54 % do so on the Isolation scale. Apart from the Somatic scale and in the Impact questions, the rehabilitation group shows lower levels of underestimating problems relative to the reporting of the significant others.

The level of agreement between raters is generally high in the rehabilitation group, ranging from 53 % on the impact questions up to 74 on the questionnaire in its entirety. With the exception of the Somatic scale and the Impact questions the control groups shows lower levels of agreement than the rehabilitation group. Levels of agreement in the control group range from 38 % on the Depression scale to 77 % on the somatic scale.

The proportion of both groups where the participant reports more problems than the significant other is fairly small. In the rehabilitation group only 2 % report more problems on the Motivational scale, while on the Somatic, Isolation and Physical Scales up to 16 % report more problems. Only 8% of the control group report more problems than their significant other on the Impact questions, however a total of 31 % report more problems on the Depression scale.

There was no significant difference between typical response style on the EBIQ scales, when comparing the rehabilitation and control group (with the non-parametric Mann Whitney test).

Table 5.9.5 Typical answer style on the different EBIQ scales and subscales

Scale	Answer style	Rehabilitation group n=31	Control group n=13	p
Total (except impact questions)	P rates more items as lower than SO	19 %	39 %	
	There is typically no difference btw P & SO	**74 %**	**46 %**	n.s.
	P rates more items as higher than SO	7 %	15 %	
Somatic	P rates more items as lower than SO	29 %	8 %	
	There is typically no difference btw P & SO	**52 %**	**77 %**	n.s.
	P rates more items as higher than SO	19 %	15 %	
Cognitive	P rates more items as lower than SO	26 %	39 %	n.s.
	There is typically no difference btw P & SO	**58 %**	**46 %**	
	P rates more items as higher than SO	16 %	15 %	
Motivation	P rates more items as lower than SO	29 %	31 %	n.s.
	There is typically no difference btw P & SO	**68 %**	**38 %**	
	P rates more items as higher than SO	3 %	31 %	
Impulsivity	P rates more items as lower than SO	29 %	46 %	n.s.
	There is typically no difference btw P & SO	**61 %**	**39 %**	
	P rates more items as higher than SO	10 %	15 %	
Depression	P rates more items as lower than SO	29 %	38 %	n.s.
	There is typically no difference btw P & SO	**65 %**	**31 %**	
	P rates more items as higher than SO	6 %	31 %	
Isolation	P rates more items as lower than SO	20 %	54 %	n.s.
	There is typically no difference btw P & SO	**61 %**	**23 %**	
	P rates more items as higher than SO	19 %	23 %	
Physical	P rates more items as lower than SO	32 %	46 %	n.s.
	There is typically no difference btw P & SO	42 %	39 %	
	P rates more items as higher than SO	26 %	15 %	
Communication	P rates more items as lower than SO	26 %	39 %	n.s.
	There is typically no difference btw P & SO	**58 %**	**30 %**	
	P rates more items as higher than SO	16 %	31 %	
Core	P rates more items as lower than SO	22 %	39 %	n.s.
	There is typically no difference btw P & SO	**71 %**	**46 %**	
	P rates more items as higher than SO	7 %	15 %	
Impact questions (3 items)	P rates more items as lower than SO	33 %	17 %	
	There is typically no difference btw P & SO	**53 %**	**75 %**	n.s.
	P rates more items as higher than SO	14 %	8 %	

Table 5.9.6 shows that the proportion of the rehabilitation group where the participant’s typical response style on the PCRS is to report higher levels of competency than described by the significant other ranges from 28 % on the Emotion and the ADL scale to 38 % on the Interpersonal scale. This is lower on the various scales (except on the Cognition scale) than for the control group, where the percentage of over-estimating participants ranges from 31 % on the Cognition scale to 54 % on the ADL scale.

Table 5.9.6 Typical answer styles on the PCRS total scale and subscales: Percentage of participants (P) reporting higher, equal or lower competence compared to the significant other (SO).

Scale	Answer style	Rehabilitation group	Control group	p
Total question-naire	P rates more items as higher than SO	34 %	46 %	n.s.
	There is typically no difference between P & SO	**50 %**	**39 %**	
	P rates more items as lower than SO	16 %	15 %	
ADL	P rates more items as higher than SO	37 %	54 %	n.s.
	There is typically no difference between P & SO	**50 %**	**38 %**	
	P rates more items as lower than SO	13 %	8 %	
Cognition	P rates more items as higher than SO	34 %	39 %	n.s.
	There is typically no difference between P & SO	**41 %**	**31 %**	
	P rates more items as lower than SO	25 %	30 %	
Inter-personal	P rates more items as higher than SO	41 %	54 %	n.s.
	There is typically no difference between P & SO	**38 %**	**31 %**	
	P rates more items as lower than SO	21 %	7 %	
			18 %	
Emotion	P rates more items as higher than SO	31 %	46 %	n.s.
	There is typically no difference between P & SO	**47 %**	**39 %**	
	P rates more items as lower than SO	22 %	15 %	

The proportion of the rehabilitation group where the participant agrees with the significant other ranges from 38 % on the Interpersonal scale to 50 % on the ADL scale and on the Total scale. This fraction is greater in the rehabilitation group on all scales than in the control group. The level of agreement in the control group ranges from 31 % on the Interpersonal and the Cognition scale to 39 % on the Total and the Emotion scale.

The tendency to underestimate one's competency in the rehabilitation group ranged from 13 % on the ADL scale to 22 % on the Cognition and Emotion scale. Similarly in the Control group 8 % underestimated their competency on the ADL scale whereas 18 % did so on the Interpersonal scale. There seemed to be no clear trend in the tendency to underestimate competency when comparing the rehabilitation and control groups. However there was no significant difference regarding typical answer style on the PCRS.

Table 5.9.7 Summary of typical answer style comparing the EBIQ and PCRS	Rehabilitation group		Control group	
	EBIQ Mean and range	PCRS Mean and range	EBIQ Mean and range	PCRS Mean and range
Underestimating severity of symptoms and Overestimating competency	20 % (10-26 %)	33 % (28-37 %)	31 % (8 – 39 %)	46 % (31 – 54 %)
Agreement	61 % (42-74 %)	45 % (38 – 50 %)	42 % (31 – 77 %)	35 % (31 – 39 %)
Overestimating severity of symptoms and underestimating competency	9 % (0 -16 %)	18 % (13 – 22 %)	18 % (15 – 31 %)	15 % (8 – 23 %)

Table 5.9.7 show that levels of underestimating symptoms are lower than levels of overestimating competency in both groups. The level of agreement is higher when it comes to reporting symptoms than when reporting competencies in both groups. Sherer et al. (1998) have stated that there may be higher levels of agreement on concrete questions and that

perhaps it is easier to rate symptoms than to rate competencies. To investigate this further, correlations between participants and significant others were calculated.

Table 5.9.8 shows the correlations on the EBIQ subscales between significant others and participants as a function of rehabilitation; the higher the level of agreement between participant and significant other, the stronger the correlation. Hence they have been tested with a one tailed test, because all correlations are expected to be positive. As can be seen there are significant, moderate-to-strong correlations on all scales except the Physical scale from the EBIQ questionnaire within the rehabilitation group. The correlation on the Physical scale is non-significant, weak and negative (r = -.16, p > .2).

Table 5.9.8 Correlations between own and significant other’s ratings on the EBIQ scales

Scale	Rehabilitation group n = 31		Control group n = 13	
	Pearsons r	p (one tailed)	Pearsons r	p (one tailed)
Somatic	**.39**	**.016**	**.48**	**.004**
Cognitive	**.41**	**.011**	.07	>.4
Motivation	**.40**	**.013**	.04	>.4
Impulsivity	**.51**	**.002**	.27	>.1
Depression	**.57**	**.000**	-.03	>.4
Isolation	**.33**	**.035**	.10	>.3
Physical	-.16	>.2	**.65**	**.011**
Communication	**.42**	**.009**	.13	>.3
Core	**.39**	**.014**	.12	>.3

In the control group there are only two significant but strong correlations on the Somatic scale (r = .48, p = .004) and the Physical scale (r = .65, p = .011). The other correlations are negligibly small.

Table 5.9.9 Correlations between own and significant other's ratings on the PCRS scales

Scale	Rehabilitation group		Control group	
	Pearsons r	P (one tailed)	Pearsons r	p (one tailed)
Total	.07	>.3	.36	> .1
ADL	**.47**	**.002**	**.59**	**.009**
Cognition	**.30**	**.028**	.36	>.1
Interpersonal	.12	>.2	.25	>.2
Emotion	.04	>.4	.28	>.1

Contrary to the correlations on the EBIQ within the rehabilitation group, Table 5.9.9 shows that there are only two significant, moderate to strong correlations on the PCRS scales of ADL (r = .47, p = .002) and Cognition (r = .30, p = .028) The other non-significant correlations are weak, but positive. In the control group there is only one strong and significant correlation on the ADL scale (r = .59, p = .009); the rest of the correlations are weak to moderate, but non-significant.

The results of the correlation calculations somewhat support the results when looking at the typical answer styles. There are more correlations for the EBIQ than the PCRS. This could reflect higher levels of agreement and the fact that the EBIQ is an easier, more concrete questionnaire thus facilitating agreement. This interpretation is very tentative, given the relatively small sample size and the possibility of obtaining false significant results when performing many calculations.

5.10 Questionnaire data: Anxiety and Depression

Tables 5.10.1 and 5.10.2 compare the ratings on HADS of participants and significant others from the rehabilitation and control group against norms from Iceland (Magnusson et al., 2000).

Table 5.10.1 “Caseness” on the HADS among the participants in the rehabilitation and control group compared to an Icelandic normal population

HADS “Caseness”	Rehabilitation group n = 30		Control group n = 13		Icelandic population	
	Anxiety	Depression	Anxiety	Depression	Anxiety	Depression
Non-case	73.3 %	76.7 %	46.2 %	46.2 %	84.7 %	90.2 %
Borderline	13.3 %	16.7 %	30.8 %	38.5 %	9.4 %	6.3 %
Case	13.3 %	6.7 %	23.1 %	15.4 %	5.9 %	3.5 %

Table 5.10.1 reveal that participants from both groups present more cases than the norms, although there are fewer cases in the rehabilitation group. In the rehabilitation group a total of 26.6 % experience appreciable anxiety problems and 13.3 % of these are considered to constitute clinical anxiety according to cut-off scores. More than half of the participants in the control group experience noticeable anxiety problems and 23.1 % could be considered clinical cases. In terms of the depression scores, a total of 23.4 % in the rehabilitation group experience noteworthy depression symptoms, and 6.7 % could be clinical cases of depression. In the control group 53.9 % rate themselves as having appreciable symptoms of depression and a total of 15.4 % could be considered clinical cases.

Table 5.10.2 “Caseness” on the HADS among the significant others in the rehabilitation and control group compared with an Icelandic normal population

HADS “Caseness”	Rehabilitation group n = 28		Control group n = 12		Icelandic population	
	Anxiety	Depression	Anxiety	Depression	Anxiety	Depression
Non-case	92.9 %	89.3 %	58.3 %	66.7 %	84.7 %	90.2 %
Borderline	3.6 %	10.7 %	16.7 %	16.7 %	9.4 %	6.3 %
Case	3.6 %	.0 %	25.0 %	16.7 %	5.9 %	3.5 %

When comparing the significant others against the norms, the rehabilitation group appear to contain fewer ‘cases’ and the control group seems to exhibit a little more than the norms. In the rehabilitation group a total of 7.2 % experience appreciable anxiety problems and 3.6 % of these are considered according to cut-off scores to have clinical anxiety. Among the participants in the control group a total of 41.7 % experience noticeable anxiety problems and 25.0 % could be classified as clinical cases. Looking at the depression scores, a total of 10.7 % in the rehabilitation group experience symptoms of depression that are worthy of mention, however none experience it sufficiently severely to be diagnosed clinical cases of depression. In the control group 33.4 % rate themselves as having appreciable depression symptoms and a total of 16.7 % could be considered clinical cases. This is consistent with other studies of SOs of TBI and CVA patients showing that approximately ¼ - ½ (and in some studies even higher) of the relatives describes symptoms of a magnitude making it likely that they would score caseness on scales of e.g. anxiety and depression (Douglas & Spellacy, 2001; Knight et al., 1998; Anderson et al., 1995; Thompson et al., 1990). However as presented in chapter 4 both groups of SOs have an average level of reported symptoms falling in the normal range consistent with the findings of Wood and Rutterford (2006b) reporting similarly low levels of anxiety and depression 17 years after traumatic brain injury.

5.11 Questionnaire data: Quality of life

Table 5.11.1 Comparing rehabilitated participants' quality of life with three different Danish sub-populations

WHO-QoL-BREF	Participants' Rehabilitation group n = 35		Chronically Ill n = 35		Diabetic n = 84		Healthy n = 47	
	Mean	SD	Mean	Difference	Mean	Difference	Mean	Difference
Global	66.3	22.1	58.6	7.7	65.3	1.0	84.8	- 18.6
Physical	73.5	16.5	64.5	9.0	76.6	-3.1	88.9	- 15.4
Cognitive	66.5	18.4	65.7	0.8	71.2	-4.7	78.1	- 11.6
Social	71.4	18.5	70.2	1.2	70.3	1.1	74.6	- 3.2
Environmental	80.0	13.1	75.1	4.9	76.4	3.6	80.3	- 0.3

The normative data used for comparison in this and following four tables stems from a study by Noerholm and colleagues (2004) of the general Danish population as well as subpopulations. As can be seen from Table 5.11.1, the participants in the group who received rehabilitation experience a quality of life fairly close to that of a group of diabetics. They experience a better quality of life than patients with chronic illness, and a lower quality of life compared to a healthy sample.

Table 5.11.2 Comparing control participants' quality of life with three different Danish sub-populations

WHO-QoL-BREF	Participants control group n = 12		Chronically Ill n = 35		Diabetic n = 84		Healthy n = 47	
	Mean	SD	Mean	Difference	Mean	Difference	Mean	Difference
Global	59.4	20.7	58.6	.8	65.3	- 5.9	84.8	- 25.4
Physical	59.6	20.0	64.5	- 4.9	76.6	- 17.0	88.9	- 29.3
Cognitive	50.3	20.0	65.7	- 15.5	71.2	- 21.0	78.1	- 27.9
Social	66.2	19.8	70.2	- 4.0	70.3	- 4.1	74.6	- 8.4
Environmental	69.9	10.4	75.1	- 5.2	76.4	- 6.5	80.3	- 10.4

According to Table 5.11.2, the control participants experience a lower quality of life than the chronically ill, diabetic patients, and healthy populations.

Table 5.11.3 Comparing the quality of life of rehabilitation group significant others with three different Danish sub-populations

WHO-QoL-BREF	SO from Rehabilitation group n = 30		Chronically Ill n = 35		Diabetic n = 84		Healthy n = 47	
	Mean	SD	Mean	Difference	Mean	Difference	Mean	Difference
Global	76.7	14.2	58.6	18.1	65.3	11.4	84.8	- 8.1
Physical	82.7	12.4	64.5	18.2	76.6	6.1	88.9	- 6.2
Cognitive	78.8	10.2	65.7	13.1	71.2	7.6	78.1	0.7
Social	79.4	14.1	70.2	9.2	70.3	9.1	74.6	4.8
Environmental	84.7	11.6	75.1	9.6	76.4	8.3	80.3	4.4

Table 5.11.3 shows the differences between average scale scores as the significant others of the rehabilitation group rate themselves compared to chronically ill, diabetic and healthy Danish samples. The significant others feel a better quality of life compared to the two samples with health conditions, and apart from the global and physical scale where they report a lower quality of life, they are comparable to a healthy sample.

Table 5.11.4 Comparing the quality of life of significant others from the control group with three different Danish sub-populations

WHO-QoL-BREF	SO from control group n = 12		Chronically Ill n = 35		Diabetic n = 84		Healthy n = 47	
	Mean	SD	Mean	Difference	Mean	Difference	Mean	Difference
Global	62.5	25.6	58.6	3.9	65.3	- 2.8	84.8	- 22.3
Physical	71.4	22.2	64.5	6.9	76.6	- 5.2	88.9	- 17.5
Cognitive	71.3	19.4	65.7	5.6	71.2	0.1	78.1	- 6.8
Social	66.1	17.3	70.2	- 4.1	70.3	- 4.2	74.6	- 8.5
Environ-mental	75.4	16.1	75.1	0.3	76.4	- 1.0	80.3	- 4.9

As per Table 5.11.4, the significant others in the control group experience better quality of life compared to the chronically ill sample in all categories apart from the social quality of life measure. They do seem on average to report a lower quality of life than the diabetic and healthy samples.

5.12 Summary

This chapter presented analyses not (yet) submitted for publication. Injury data showed comparability of the two groups in terms of epilepsy, how long they had been hospitalised in acute and inpatient rehabilitation wards as well as discharge status in terms of physical paralyses and mobility. Current health issues and use of health services revealed further similarities between the two groups. Both groups were similar in terms of the proportion of participants whom had had a recent seizure, and those who felt affected by their epilepsy and brain injury, what kinds of public health services they receive currently, as well as the 11-15% who had suffered an additional brain injury. These results do not contradict the findings indicating similarity of injuries in the two groups presented in chapter two (with the exception of injury severity score as also described in chapter two).

Even though the majority in both groups still feel affected by the brain injury today, the rehabilitation group feels less affected and a greater number considered that the brain injury also had affected their life positively. If the two groups did have comparably similar brain injury and consequences from it, these differences could indicate that the rehabilitation group to a greater extent had accepted their injury.

Immediate stress could potentially colour the answers within the areas of complaint, perceived locus of control, quality of life and emotional domains. The equal number of recent stressful life-events serves potentially as an indicator that answers given on, in particular, measures of well being could be said to be at least equally distorted by immediate stress. However, the used measure of stressful life events does not account for potentially different magnitude of recent stressors and does not exclude this explanation entirely.

Health behaviour (amount of exercise, smoking, drinking and using drugs) is fairly similar in the two groups. Both groups get less exercise than recommended and over twice as many smoke tobacco compared with the general Danish population. Since 1987-1992 the national smoking policy has grown increasingly strict. Today the CRBI program encourages healthy behaviour, the physical therapists lectures on diet, smoking and exercise. It is their experience that it is easier for students in the program to increase exercise than to give up smoking and unhealthy eating habits. Those who give up smoking after brain injury seems to do so in intensive care.

Despite that the rehabilitation group felt less affected by the brain injury, the only difference in complaints between the rehabilitation and control group was in terms of physical complaints. The control group had significantly more symptoms that affected their lives and (as a consequences hereof) a larger proportion wished to receive physical therapy. The difference in physical complaints can not be excluded as a potential explanation for some of the difference between the two groups in terms of current quality of life and experienced anxiety and depression.

Surprisingly few differences were seen within psychosocial outcome. Notwithstanding the overall differences in percentages in employment reported in Chapter 3, the two groups did not differ in terms of weekly working hours (those productive), stability of employment situation; nor did they differ in type of leisure activities or type and supportiveness of their social network. As will be seen in the next chapter, the CRBI program was not evaluated as having had as great an importance for these areas of participation as for more general measures of well-being such as quality of life and self-confidence.

Even though the rehabilitation group rated themselves as having a more meaningful life, being more in harmony than the control group, only their self reported effort to overcome difficulties after the rehabilitation was significantly higher. This taken with the more positive appraisal of the influence of the injury could be seen as trend towards the rehabilitation group experiencing a better individual adaptation. But, not surprisingly, there was no difference in their ratings of productivity or social abilities.

Albeit, the CRBI emphasises awareness as a goal, the extensive results revealed no difference between the two groups. The control group indicate larger discrepancies in how well the participant and SO know each other, which could potentially bias the results. But if the two groups had similar levels of awareness after injury there appears to be no long-term effect of the program within this area, which is a thought-provoking result. Ownsworth and co-workers (2000) have demonstrated that rehabilitation can increase in self-awareness by using other measures of self-awareness than used in this study. This could mean either that the CRBI did not increase awareness in the areas measured, or that awareness of deficits and competencies improves with time among non-rehabilitated persons with brain injury, catching up with the awareness achieved in the rehabilitation program.

Compared to an Icelandic non-brain injured group the levels of caseness of anxiety and depression in the participants and SOs of the control group are higher. Participants in the rehabilitation group also show slightly higher levels of anxiety and depression compared to the non-brain injured group, but rehabilitation SOs show similar levels to the non-brain injured control group. Compared to a Danish sample of non-brain injured healthy, diabetic and chronically ill, the rehabilitation participants showed similar levels of quality of life to the diabetic sample and the control participants showed lower levels of quality of life compared to all control samples. Thus the rehabilitation SO group was mainly comparable to the healthy sample whereas the control SO group shared more similarity with the diabetic group. Since the SOs were asked about their own health it is possible that these differences have other explanations than rehabilitation.

Chapter 6. Rehabilitation in retrospect

This chapter has the form of the article submitted for publication.

Rehabilitation in retrospect:

A 12-15 year follow-up of patients completing a post-acute rehabilitation program.

Henriette Aa. Svendsen

Centre for Rehabilitation of Brain Injury and Department of Psychology, University of Copenhagen

Thomas W. Teasdale

Department of Psychology, University of Copenhagen

Frank Humle

Centre for Rehabilitation of Brain Injury, University of Copenhagen

Correspondence to Henriette Aa. Svendsen, Centre for Rehabilitation of Brain Injury, University of Copenhagen, Njalsgade 88, DK-2300 Copenhagen S. E-mail henriette.svendsen@psy.ku.dk, Telephone + 45 35 32 49 34, Fax +35 32 48 02

6.1 Abstract

This study reports results from 49 adult persons with either traumatic brain injury or stroke who underwent a neuropsychologically-based, intensive, post-acute rehabilitation program in 1987-92. In 2004 the participants were interviewed concerning, among other issues, their perception of the usefulness of the rehabilitation program, their satisfaction with different program elements, how beneficial the program had been for different areas of outcome as well as how often they used compensatory techniques. Over ninety percent felt that the rehabilitation had been beneficial. Physical training, sharing the rehabilitation with others who had similar diagnosis and problems as well as the cognitive group training were the three program elements rated most helpful among the participants. The program was rated especially important for general quality of life, self-confidence and cognitive and physical problems. Using a calendar to keep appointments and writing lists were used very frequently by more than half of the participants. This study further documents how neuropsychological rehabilitation is perceived by those who receive it.

6.2 Introduction

Corrigan has pointed out that outcome can be defined from the perspective of the health care professionals treating the individual with acquired brain injury, the society in which the individuals live and from the perspective of the individual who has experienced the acquired brain injury (Corrigan, Whiteneck and Melleck, 2004). Recent years have witnessed a growing recognition that the evaluation of outcome following brain injury rehabilitation should involve measures which are ecologically valid and meaningful to the participant (Fleminger & Powell, 1999). Meaningful measures can include satisfaction with the service provided, what areas of life the rehabilitation was perceived helpful to and which elements of the rehabilitation the participant considered to be most beneficial. The results can then be used by the professionals to improve the rehabilitation program.

Within the field of rehabilitation, many different models and theories are in use, but the common basic aim of the process is to ameliorate, reduce or alleviate the patients´ complex symptoms (Wilson, 2002). Since it is a process requiring active participation from the person with acquired brain injury, it is not only the results achieved but also how they are achieved that is important. For example, several studies have shown the importance of the therapeutic alliance with the rehabilitation professionals and program compliance for outcome of rehabilitation (Bieman-Copland & Dywan, 2000; Klonoff, Lamb, Henderson, & Shepherd, 1998; Klonoff et al., 2001; Schonberger, Humle, & Teasdale, 2006). Having information about what the participants like and feel to be helpful in a program and in a therapist can assist rehabilitation professionals to motivate their clients. Darragh, Sample and Krieger (2001) interviewed 51 persons with acquired brain injury about their perceptions of the useful roles of the healthcare provider, which services they considered helpful and what kind of characteristics in a professional that they valued. Being an advocate, friend, mentor, and team member were valued provider roles. Perceptions of helpfulness of the services included relevance, meaningfulness, practical application, skill development potential, and whether periodic feedback on progress was provided. Personal characteristics of the provider that were valued by the participants were clear and honest communication, support, respect, and understanding as well as the provider being a good listener.

Knowledge of what clients of rehabilitation in general like can also be useful in matching of the clients' needs with what they want (van den Broek, 2005); according to Bajo and Fleminger (2002) this is becoming increasingly important since health care services are moving towards more patient-centred approaches.

The perspective of the person with acquired brain injury has been investigated concerning perception of the consequences of the injury (Svendsen et al., 2004), met and unmet needs experienced and user-satisfaction (Man et al., 2004). These domains have mainly been investigated using qualitative or semi-structured interviews and questionnaires and can be used in addition to other measures when looking at the need for and efficacy of rehabilitation; taken alone, however, they are vulnerable measures given their subjective nature.

Needs after brain injury, especially unmet needs have been investigated in several studies at state wide levels in the United States. In one of these (Corrigan, Whiteneck, & Mellick, 2004) as a telephone survey was conducted of a prospective cohort of all people hospitalised with traumatic brain injury in the state of Colorado during 2000 (n=1802). More than half experienced one or more unmet needs during the first year post-injury. The most frequently experienced needs were concerning memory and problem solving, managing stress and managing the economy at home. If a need were unmet it most often concerned cognitive functions, employment and substance abuse.

Heinemann, Sokol, Garvin and Bode (2002) conducted a survey of 895 persons with traumatic brain injury recruited from the Brain Injury Association in Illinois and rehabilitation service recipients. The most prevalent unmet needs were to improve memory or problem solving skills (51.9%), to improve income (50.5%) and job skills (46.3%). They also found that persons with greater unmet needs tended to report lower life satisfaction and worse medical health and psychological well-being. Predictors of unmet needs were marital status, age at injury, time since injury, dependency in one or more activities of daily living and race. Unmet needs could indicate the necessity for rehabilitation in order to help the person become more self-sufficient. However, what professionals intend to do is not always achieved.

In a study by Põssl and Von Cramon (1996), 130 mild to moderately brain injured adults who had undergone neuropsychologically based rehabilitation were interviewed by a person not belonging to the treatment staff. They also filled out questionnaires concerning depression and hopelessness. All but 13% were generally satisfied with the rehabilitation. Those who were not satisfied described difficulties understanding the intervention, unsatisfactory contact to the therapist, desire for more therapy especially physical therapy, desire for more individual therapy instead of group therapy and that their vocational needs were not adequately addressed by the rehabilitation program. In addition the unsatisfied clients experienced too much negative feedback, by either directly or indirectly being confronted with their handicap and weaknesses, leading to a feeling of incompetence and low self-esteem.

Winter and Keith (1988) looked at user-satisfaction in a group of 113 patients of differing ages and diagnoses using a qualitative interview and a questionnaire covering schedule, transportation, sessions, therapists, progress and economy. High levels of satisfaction were reported although a third wished for further treatment and about 20% were unsatisfied with the progress.

Several studies within the field of post-acute comprehensive neuropsychological rehabilitation have shown positive results with regards to improvement of community integration, vocational and psychosocial functioning (Cicerone et al., 2004; Sarajuuri et al., 2005; Klonoff et al., 2006; Prigatano et al., 1994). However, it has been noted that it is hard to know the effects of the specific components or tools of such programs (Wilson, 2002) and as yet only few studies have investigated this issue (Anson & Ponsford, 2005). One place to start is to register what the persons participating in the rehabilitation found useful.

To our knowledge only one such study has been published in the context of neuropsychological post-acute rehabilitation. Johansen, Pedersen and Lauersen (2004) conducted a longitudinal study of 150 persons with acquired brain injury who had undergone a neuropsychological post-acute comprehensive rehabilitation program one to ten years prior to follow-up. Only nine percent perceived that the rehabilitation program was ‘a waste of time’, 87% explicitly disagreed in this. A third wished to have had more rehabilitation. Due to limited resources the program could only give support for a fixed period of time, but 54 % were interested in participating in a 'brush-up' or follow-up course if they were to be given the chance. This confirms what has been seen in the other studies mentioned above, namely that living with an acquired brain injury often creates a need for longer term support. Regarding the specifics of the program, 27% felt that the program had too much emphasis on the difficulties. This is in spite the program's strong emphasis on the residual resources of the individual and it probably reflects the frustrating process of becoming more aware of the consequences of the brain injury in order to be able to compensate better: 85 % felt they had become more aware of their own difficulties and 77% felt they had become better able to compensate for their difficulties as a result of the program as opposed to 9% who did not feel that the program had helped them to be better able to compensate for their difficulties. About half or more than half of the group felt that the program was beneficial in terms of giving them more self-confidence, enabling them to be in better control emotionally, and be better able communicate and socialise with other people. When clients were asked to rate how often they used seven specific compensation strategies, 68% answered that they used a calendar often or always and 57% stated that they very often or always write things down. Half of the clients stated that they always or very often checked whether they had performed a task correctly. Forty-three percent always or very often planned their activities before starting in order not to loose their overview, 35 % indicated they always or very often used breaks to handle their assignments better and less than twenty percent always or very often withdraws from a situation in order to regain emotional control.

In a survey of the use of memory aids among 101 people with acquired brain injury (Evans, Wilson, Needham, & Brentnall, 2003) it was found that the use of external aids such as calendars, notebooks or wall charts were most commonly used and by between 54 % and 72 % of the sample. Writing lists were done by 63% of the sample, 54% used an appointment diary and 16% used a journal. Being independent, being younger of age, the shorter time since injury, the using of aids before injury and the fewer attentional problems the more memory aids was one likely to use.

The present study has used semi-structured interview data derived from persons with brain injury, twelve to seventeen years after they completed a post-acute comprehensive neuro-psychological rehabilitation program. We have explored four issues and examined some hypotheses relating to them. First, we have predicted that the majority would have been satisfied with the rehabilitation program and still feel that it to have been helpful twelve to seventeen years post-program. Second, we wish further to explore which program elements they felt had been the most important, third, in which areas of life they found the rehabilitation program to have been most helpful and fourth, which compensation strategies were used and how frequently.

6.3 Method

6.3.1 Intervention

Our data stem from participants who had sustained an acute brain injury and who had completed the rehabilitation program at the Center for Rehabilitation of Brain Injury (CRBI) in Copenhagen which is here presented in some detail. The program, which has been inspired by the work of Ben-Yishay (Daniels-Zide & Ben-Yishay, 2000) and Prigatano (1984) adopts an interdisciplinary, holistic approach which is tailored to the individual in the light of neuropsychological assessments. The CRBI program is designed to promote awareness and acceptance of injury and deficits resulting from the injury and to help participants return to an active life, reduce long-term neurobehavioural, cognitive, emotional and psycho-social problems and also to help significant others to the participants cope better with the effects of brain injury. The participant population consists of adults in the age range from 18 to 64 with non-progressive acquired brain injury of mixed aetiologies, the majority being stroke and traumatic brain injury. Participants are admitted to the program in groups of about 16, and the program runs for about four months with day attendance at the centre. This is followed by close contact and monitoring of progress in the community for at least a further six months. Exclusion criteria include alcohol and drug abuse, together with psychiatric or progressive neuro-degenerative illness. A degree of motivation and independence (ability to travel, feed, groom etc.) is also required in order to participate.

The participants attended four days a week, five to six hours a day. The integrated treatment includes trans-disciplinary staff roles with co-ordinated goal-setting and monitoring. The major elements of the program are as follows:

1) Morning Meeting: This activity began every day of the program and lasted one hour. It had a set structure with given assignments that the participants were responsible for in turn. Assignments were chairing the meeting, choosing a song to begin the meeting with, reporting a national and international news piece for debate and taking minutes from the meeting to be handed out next day. The meeting ended with self-evaluation and feedback from the other participants to those carrying out the given assignments. The purpose was to help facilitate taking responsibility, promote communication and interpersonal skills.

2) Primary therapist: Each participant had their own primary therapist, usually a neuropsychologist. The participant would have at least one and usually two hours of individual contact with the primary therapist every day. The content of those hours could be counselling, cognitive training and planning of work trial. The primary therapist is the case manager of the participant and helps him/her to adapt to the program and handles contact to the local authorities as well as any work trial and individual follow-up in a period of at least six months after the program.

3) Cognitive training: This is conducted in groups of two to four participants. The groups are put together trying to match the individual levels of cognitive functioning and sometimes particular deficits such as memory problems. Usually, the group will go through three main areas of cognitive functions during the program: attention/concentration, memory and executive functions. It involves mainly paper-and-pencil assignments and there is an emphasis

on promoting awareness and acceptance of the individual participants functioning within the given domain of cognition.

4) Group Psychotherapy: This is carried out in two groups of six to eight participants once a week for one hour during the program. The purpose is to promote intrapsychic and interpersonal adaptation (Pepping & Prigatano, 2003). There are set themes in the beginning such as perceptions of past, experience of injury and hospitalisation and expectancies of the future, but themes raised by the group are given priority.

5) Physical Training: This emphasises muscle-building and cardiovascular activities and is carried out in the local fitness centre for periods of two hours, twice a week. The purpose is to promote the feeling of normality and the participants' own responsibility for a healthy lifestyle. Cognitive training and observation is a part of this activity, and the participant has to record and evaluate the progress of their exercise activity.

6) Other individual activities: These can include voice training and special education. According to the needs of the participant extra individual activities are offered. Voice training was carried out by a trained opera-singer and was especially, but not exclusively, offered to participants with dysarthria. The purpose was to improve self-confidence and personal expression as well as dysarthria if the latter was present. Special education within the areas of writing and grammar as well as mathematics was offered if needed with the purpose of improving the participant’s skills within these areas.

Central to the program is the promotion of awareness and acceptance to help participants and their significant others cope with the effects of the brain injury in order to help them return to work or an active life and adjust to the changes. The significant others are welcome to follow the daily program and are offered individual family meetings and a significant others' group (one for spouses and one for other significant others) meets every other week. Significant others are also encouraged to take part in the weekly educational lecture attended by staff and patients. These lectures cover lifestyle such as exercise and diet, social rights, sexuality, outcome and support organisations.

The participant to therapist ratio is 2:1. The therapists meet every morning to handle day-to-day issues and there is a weekly conference evaluating the participants individually and a weekly meeting evaluating group activities. Neuropsychological evaluation takes place at the beginning and at the end of the program. The evaluation includes cognitive tests, questionnaires about symptoms of brain injury and a comprehensive interview covering areas such as emotional and psychosocial adjustment, need for help from the social system, employment and satisfaction with rehabilitation among others.

6.3.2 Subjects

For the purposes of the present study we initially selected all 97 participants with either traumatic brain injury (TBI) or cerebro-vascular accident (CVA) who underwent the CRBI program between January 1987 and December 1992. Not all 97 participants were available for the study; 14 were deceased by the time of follow-up in 2004 and addresses could not be obtained for 11. Thus, 72 participants were invited by explanatory letter to participate in the study; 49 (68%) did so; the remaining 23 either responded negatively to the invitation or failed to respond. Table 6.1 shows the basic medical and demographic characteristics for these two groups; there were no significant differences between them with the single exception of the interviewed group having somewhat better scores on the Glasgow Outcome Scale at discharge from hospital.

Table 6.1 Demographic and medical characteristics of participants

Variables	Not Interviewed n = 23		Interviewed n = 49		p*
Sex	N	(%)	N	(%)	
Male	14	(61)	32	(65)	n.s.
Female	9	(39)	17	(35)	
Injury type					
TBI	15	(65)	26	(53)	n.s.
CVA	8	(35)	23	(47)	
Post Traumatic Amnesia (TBI only)	13		25		
< One week	2	(15)	0	(0)	n.s.
< Two weeks	1	(8)	4	(16)	
< One month	1	(8)	10	(40)	
>= One month	9	(69)	11	(44)	
Level of wakefulness seven days after trauma (CVA only)	8		23		
Clear and awake	5	(63)	14	(61)	n.s.
Somnolent, confused	2	(26)	6	(25)	
Uncontactable	1	(12)	3	(13)	
Glasgow outcome scale at discharge	23		48		
Severe disability	0	(0)	1	(2)	
Moderate to severe disability	14	(61)	12	(25)	Z = -2.1
Moderate disability	7	(31)	28	(58)	p = 0.034
Moderate disability to good recovery	1	(4)	7	(15)	
Good recovery	1	(4)	0	(0)	
Aphasia at rehabilitation	5	(22)	12	(25)	n.s.
	Mean	(SD)	Mean	(SD)	
Hospitalisation (days)	207	(167)	170	(140)	n.s.
Days on life support (respirator)	8	(9)	5	(7)	n.s.
Duration of coma in days (TBI only)	13	(9)	13	(10)	n.s.
Injury Severity Score (TBI only)	22	(9)	18	(7)	n.s.
Mean Age at time of injury (years)	28	(11)	28	(10)	n.s.
Time from injury to post-acute rehabilitation in years	2.6	(2.7)	2.4	(1.5)	n.s.
Chronicity of injury in 2004 (years)	18	(4)	17	(2)	n.s.

* derived from Chi-Squared, Mann-Whitney, or t- tests as appropriate

6.3.3 Instrument

The study used a semi-structured interview with both qualitative and quantitative data. All interviews were conducted by the first author. The participants were initially asked if they felt they had benefited from the program in general. They were then asked open-ended qualitative questions concerning why they felt the program had been helpful or not, what other factors had helped them after their brain injury and whether they considered that anything had been lacking in the program. Thereafter they were then asked to rate, in order of importance, up to five program components from a presented list of 11 which, in addition to those listed above, included

7) Specific help with social/legal system e.g. concerning disability pensions,
8) Individual follow-up,
9) Monthly group follow-up meetings,
10) The environment of being together with other persons who had suffered a brain injury
11) The professional staff in general, and
12) Speech therapy (for those with aphasia only)

The element they felt had been the most important was rated as '5', the second best element was rated as '4' etc. In some cases participants could pick five elements they considered to be important but were not able to prioritise; in those cases all the five elements were rated as '3'. All the remaining non-chosen elements were rated as '0'.

The participants were also asked how much they felt the rehabilitation program had helped in 12 different outcome areas in their lives:

1) Cognitive problems,
2) Physical problems,
3) Emotional problems,

4) Awareness,
5) Communication skills,
6) Compensatory skills,
7) Social skills,
8) General quality of life,
9) Self confidence,
10) Return to labour market,
11) Family life,
12) Resumption of leisure activities

These ratings were done on a five-point Likert scale (from 1 = 'No Influence' to 5 = 'Great Influence').

The participants were also asked to rate how often they used eight specific compensation strategies. These were a selection of general compensation strategies not necessarily derived from what they had specifically learned at the CRBI program, but taken from a follow-up study carried out at a similar program elsewhere in Denmark (Johansen et al., 2004).

6.4 Results

6.4.1 Qualitative responses

The majority of the participants (92%) felt the program had helped them. Two participants (4%) were not sure and another two participants (4%) felt the program had not helped them. When asked the open question about what had helped them, both specific and general program elements and names of individual therapists, as well as more general qualities, were mentioned. In terms of general qualities one stated that the program as a whole had been helpful, but fifteen participants mentioned the social aspect of the program in some form either because the program made it possible for them to meet and talk to others in the same situation, or it had broken their isolation and had been an opportunity to make new friends. Two participants felt it had been helpful to see that others could be worse off than themselves. Fourteen participants felt the program had been helpful because they had been motivated and activated through challenges and hard work. Several participants mentioned the program had been helpful because they had felt understood, the program had increased their awareness, they had learned new skills, regained self confidence and had received help to accept their situation and the situation had been ‘normalised’. One participant mentioned the program had helped him to 'feel alive' and another, that she felt the program had taught her fellow participants and herself to be human again. Working in groups being able to observe how others react and respond to the situation at hand was also being mentioned as a helpful program component. Especially cognitive training and physical training, but also the morning meeting as well as speech training, were mentioned by participants. Talking about the future and getting help to do a work trial, even if it did not end in a placement, was also mentioned. One felt that the program had helped him to regain control over his life and another felt that she had first experienced the true benefits of the program after she had graduated.

When asked what had not been helpful or what could have been better, several had wanted more follow-up either in the form of a more detailed action plan and help with job-placements or the social system. One mentioned that his hopes had been raised unrealistically high in terms of employment. Another felt the program should have been longer since this would have increased her gains. One wanted more structure and clearer goals as well as more practical assignments and had felt neglected. A better assessment of individual needs as well as a more differentiated cognitive training was also mentioned as factors that would have improved the helpfulness of the program.

To the question of what else had helped them after their brain injury, answers from 29 participants fell into three distinct categories: personal qualities, social support and support from the system. Twelve participants mention love, support, understanding, being good at talking together and not being treated with pity from parents, parents-in-law, spouse, girlfriend, children, friends and employer as important in their recovery. Important environmental supports were mentioned: having a car, being able to take an education, explanation from social worker, gaining confidence from teaching voluntarily, the epilepsy clinic in which a participant had regular control visit, and the rehabilitation centre. Stubbornness, will power, endurance, patience, being a 'fighter' and optimism were mentioned by several participants as helpful personal qualities, but also: ambition, good communication skills, humour, willingness to accept and work emotionally with the situation, having a problem-focused approach, looking ahead instead of looking back, courage, appreciate what one has, helping others, being in good physical shape and keep doing what you did before the injury as much as possible, were items mentioned as being helpful personal qualities or actions.

When asked if anything had been lacking in the program, only a few answered. One had missed not having a place to go out to. One would like to have a motivational group to help with initiative. One needed more help and support especially in the beginning.

6.4.2 Ratings of program elements

The prioritised ratings of program elements are shown in Table 6.2. There are 55 pair wise comparisons of the 11 listed program elements, excluding the monthly group follow up meeting. After applying Bonferroni's correction (Howell, 2001) – = 0.05/55 = 0.0009 – almost none of these comparisons, using Wilcoxon's Signed ranks test, is statistically significant. It is, however, perhaps instructive to consider trends in the results. It is striking that the monthly follow-up meetings were never included in the most important five elements. Similarly, individual follow-up and specific help with the social and legal systems were very rarely considered among the most important elements. More than half of the participants rated the elements contact with other participants, physical and cognitive training as well as the primary therapist as being among the most important. Among participants with aphasia this was also true for the speech-training. Between 37% and 46% rated group psychotherapy, the staff in general and the morning meeting among the most important elements.

There were no clear relationships between the ratings of program elements and the major medical and demographic characteristics listed in Table 6.1. Isolated significant associations did not occur above the chance level.

6.4.3 Ratings of the programs significance for outcome

Participants' evaluations of how much the rehabilitation program had helped concerning twelve selected outcomes are listed in Table 6.3. Half of the 66 pair wise comparisons among these 12 outcomes are statistically significant (Wilcoxon's Signed ranks test) beyond the Bonferroni-corrected level p=0.05/66=0.0008. General areas of well-being were the rehabilitation centre was rated as being more important than more concrete areas of outcome. General quality of life, self-confidence and cognitive problems were the outcome areas rated highest and some of the areas rated lowest were return to work, resumption of family life and leisure activities. Awareness, communication and compensatory skills were rated higher than physical and emotional problems.

Table 6.2 Participants ratings of program elements

	Rehabilitation group n = 44							
Program elements rated	5	4	3	2	1	0	Mean	SD
Physical therapy	11	9	31	2	7	39	2.00	1.84
Contact with other participants	7	9	18	16	27	23	1.84	1.54
Primary therapist	0	7	30	20	9	34	1.66	1.40
Other program elements (including voice training and special education)	16	5	13	5	9	52	1.57	1.96
Cognitive training	5	11	14	14	11	45	1.48	1.65
Group psychotherapy	7	11	21	0	7	54	1.48	1.82
Staff in general	9	7	7	9	9	59	1.20	1.75
Morning meeting	5	5	16	9	2	63	1.12	1.61
Speech training (aphasics only)	0	9	9	9	27	46	1.09	1.38
Help with social/legal system	2	3	0	3	2	91	0.28	1.01
Individual follow up	3	0	3	0	0	94	0.19	0.88
Monthly group follow up meeting	0	0	0	0	0	100	0.00	0.00

Table 6.3 Ratings of the programs significance for outcome

	Rehabilitation group n = 49						
Different outcomes rated	Great importance (5)	Considerable importance (4)	Some importance (3)	Little importance (2)	No importance (1)	Mean	SD
General quality of life	36	23	24	6	11	3.68	1.32
Self confidence	32	28	21	6	13	3.60	1.35
Cognitive problems	33	22	25	7	13	3.56	1.37
Awareness	17	28	15	17	23	2.98	1.45
Communication skills	23	9	30	19	19	2.98	1.42
Compensatory skills	9	23	25	11	32	2.66	1.37
Social skills	17	8	28	13	34	2.62	1.47
Physical problems	19	13	15	13	40	2.57	1.58
Emotional problems	13	15	15	4	53	2.30	1.55
Return to labour market	11	15	9	18	47	2.27	1.47
Family life	11	7	18	2	62	2.05	1.46
Resumption of leisure activities	7	2	15	13	63	1.76	1.20

We have examined potential relationships between program elements and the demographic and medical variables listed in Table 6.1. Some associations were seen. Aphasics rated the program as more beneficial for communication skills than non-aphasics and the length of hospitalisation was negatively correlated to the importance of the program for return to work (Kendall's Tau = -0.31, p = .007) and gaining awareness (Kendall's Tau = -0.28, p = 0.01). The only element that the Glasgow Outcome Scale at discharge was positively correlated to was the importance of the program for general quality of life (Kendall's Tau = 0.26, p = 0.045). The higher GOS at discharge the more likely a participant would rate the program beneficial for general quality of life.

6.4.4 Compensatory techniques

The use of eight specific compensatory techniques is listed in Table 6.4. Between 33% and 90% of the participants used these compensation strategies. Almost half of the 28 pairwise comparisons among these eight techniques showed differences (Wilcoxon's Signed ranks test) beyond the Bonferroni-corrected significance level p=0.05/28=0.002. It can be seen that using a calendar to note appointments and writing check-lists were the only two strategies that more than half of the participants used at all times. Asking for help was the third most frequently used strategy, all though only 35% of the participants used this strategy always or very often. In contrast more than half of the participants never used the strategies of writings things down in general in order not to forget them, or taking breaks in order to better perform a given task, or stepping out of a situation in order to regain emotional control. One participant did not use any and three participants used all of the listed compensation strategies. On average the participants used 4.8 strategies (SD = 2). The strategies were on average used at a frequency between rarely and often.

Table 6.4 Use of compensatory techniques

	Rehabilitation group n = 49						
Different outcomes rated	Always (4)	Very often (3)	Often (2)	Rarely (1)	Never (0)	Mean	SD
I write appointments into my (electronic) calendar	57	8	10	10	14	2.8	1.5
I take notes/writing task lists/checklists	53	0	8	21	18	2.5	1.7
I ask others for help if I can not resolve a task myself	33	2	16	39	10	2.1	1.5
I control my performance in order to fulfil my tasks correctly	33	6	10	8	43	1.8	1.8
I plan my tasks before I perform them in order not to loose overview	31	6	8	8	47	1.7	1.8
I write things down so that I do not forget them	25	0	12	12	51	1.4	1.7
I deliberately take breaks in order to perform my tasks better	10	4	15	10	61	0.9	1.4
Sometimes I step out of a situation for a while in order to regain control over my emotions	4	4	4	21	67	0.6	1.0

There were no clear relationships between the ratings of compensatory techniques and the major medical and demographic characteristics listed in Table 1. Isolated significant associations did not occur above the chance level.

6.5 Discussion

6.5.1 Limitations

In considering the findings from this study, a number of limitations must be kept in mind. The sample is not particularly large and lacks representatives with acquired brain injury aetiology other than TBI and CVA - such as anoxia, meningitis and tumor resections - in order for it to generalise to all the participants seen in this program. Almost a third of the available participants in the program did not participate. Those who were not interviewed had more severe disability at discharge as the only difference from those who were interviewed. Injury severity might influence how much one can benefit from this kind of rehabilitation. An earlier study of a military population showed that those with loss of consciousness over an hour benefited more from the program than those with a shorter loss of consciousness. Potentially those who chose not to participate in the follow-up could be those who felt they did not benefit from the program. In this study, the level of disability at discharge was, however, only related to one item of outcome and level of disability showed only a relatively weak correlation with the rating of the CRBI as helpful for general quality of life, more severe disability corresponded in a rating of the program as less beneficial for general quality of life. Thus, given the similarity of the two groups on the other demographic and injury severity measures and the relatively little influence of the disability measure on the outcome measures used, the difference on the GOS is not thought to be a major bias.

Even though the CRBI program contains the defining features of comprehensive holistic post-acute rehabilitation programs (Malec et al., 1996) the program elements listed will not be found in all other programs of this nature and the referral policy might also differ. There has also been a development in Denmark over the last ten years in terms of social legislation and the possibility of getting social support following a brain injury, which might affect how useful the program will be rated in terms of return to work. Another aspect of importance is the issue of aphasia and memory in this evaluation; certainly some participants stated they were not able to remember all of the given elements to rate. In those cases they rated the elements they remembered thus introducing a potential bias. One participant with severe aphasia was not able to complete the ratings but indicated that he felt the program had helped him.

The compensational strategies measures were general ones. If we had used goal attainment scaling and individual outcome measures the use of compensational strategies could have been used as an outcome measure. The present data can not be taken as evidence that the program has been beneficial in terms of teaching people how to compensate. Furthermore, the rating of the use of these strategies would perhaps have had greater validity if it had been made by an observer instead of by self-evaluation, particularly when this was done in front of an interviewer, where the participant could be prone to giving socially desirable answers; nor do we have any baseline data on how often persons without brain injury use these strategies and with what success.

6.5.2 Qualitative statements

The qualitative statements brought out individual differences and nuances reflecting to a certain degree whether the program fulfilled participants' needs. If a given service is perceived as living up to the individuals expectations of what is needed in a current situation there is a higher chance that the participant will actively engage in the rehabilitation. Motivation for engaging in holistic rehabilitation is considered crucial for success; however, it can be impeded by lack of awareness of deficits. Two participants also stated that at first they had not felt they needed the rehabilitation but as soon as they discovered their need they were able to engage better and experienced the program as helpful. Most of the participants were also able to give reflected, individual answers to the question of what was it that had been helpful about the program, so even though memory problems were an issue for some, the participation in the program have made a lasting impact. Aspects stressed by several participants were the fact of being with others with similar problems to observe and learn from as well as seeing a general activation as a helpful part of the program. This corresponds to the clinical concept within comprehensive rehabilitation of a safe community where participants grow and learn from each other. Even though it is the belief of the authors that the transdisciplinary staff roles as part of the integrated treatment are vital for creating a comfortable and inspiring atmosphere, it was not listed among the more important responses and the above-mentioned statements could potentially be expressed in different non-holistic settings, though this remains to be seen. The CRBI program provides individually tailored treatment and was a four month program with a limited follow-up period, and for some participants this was not perceived as enough and a few felt the tasks presented had been too easy which reflects room for improvement. Recently, the program has changed its uptake policy to accommodate different needs.

Will power, stubbornness and endurance and the importance of family and social support were not surprisingly mentioned as personal qualities needed when learning to live with a brain injury and trying to improve level of functioning. In the program of Ben-Yishay the participants in rehabilitation undergo several interpersonal exercises with the purpose of increasing their awareness of personal qualities helping them succed in their rehabilitation and coming to terms with their existential situation (Ben-Yishay et al., 2000; Daniels-Zide et al., 2000).

6.5.3 Program elements

We had no specific hypothesis regarding the prioritisation of programme elements and none of the elements were rated significantly higher than others in any consistent manner. The ipsative scaling ensured that more than half of elements would receive zero in every participant's evaluation. Thus, these results can not be used to decide which program elements to include or exclude from rehabilitation since we have no data to link the prioritisation to actual gains during rehabilitation and the participants' perceptions may have changed over time. However, the rating may indicate the face validity of the given elements and may as such serve to indicate which program elements needs better integration and explanation. There was no pattern relating to variables pertaining to injury characteristics or demography. Showing no difference between the two injury types this may increase the generalisability of the results. The fact that more than half of the participants rated contact with other participants, the primary therapist and cognitive training as very important concurs with the qualitative answers, underlining the importance of the social aspect and that the program was being considered important for cognitive problems. It is striking that the monthly follow-up meetings were never included in the most important five elements. This may relate to the 12-15 year time lapse, limited and infrequent post-program group meetings being harder to remember than the intensive part of the program. This could also explain why individual follow-up and specific help with the social and legal systems were very rarely considered among the most important elements. It has not been possible to quantify how much individual follow-up was given, nor need for intervention estimated. However, for the participants with aphasia more than half rated speech therapy as important, thus indicating that the rating of individual therapies could be related to perceived need.

6.5.4 Ratings of the programs significance for outcome

The given areas of outcome on which the CRBI program were rated as having has the most importance were general quality of life, self-confidence and cognitive problems. These areas were also reflected in the answers to the open-ended question of what it was about the CRBI that had helped. Some of the areas that had lowest ratings were return to work, resumption of family life and leisure activities. Awareness of difficulties, compensational skills as well as communication and social skills were also given fairly high ratings and were also mentioned spontaneously. Awareness of difficulties and learning new skills also by observing others were mentioned directly whereas one could see the spontaneous mentioning of the helpfulness in meting others with similar problems, breaking the isolation and making new friends as correlates to the fairly high rating of the program having importance for communication and social skills.

Returning to work was being mentioned by some participants as an area where the program could have been of greater assistance. Even though return to an active life was an explicit purpose of the program, given the limited time, this goal may have been hard to accomplish for all participants. Turnover in staff may also have resulted in some participants not being as followed up by the same primary therapist as they had in the program increasing the difficulty in making a smooth transition into society. Consistent with the ratings, none of the qualitative answers mentioned help in resumption of family life or leisure activities as something that was missing in the CRBI program or that the program had been particularly helpful with. It could reflect that it was not a focus in the program for the given participant; most participants were fairly young at time of injury and program and did not have major problems in terms of independent living. It could also reflect that it did not weigh as heavily on the participants' minds when answering the question.

The program was not rated as having a high impact on either physical or emotional problems, whereas the spontaneous answers had included physical training and getting help to learn to accept the situation as helpful parts of the program. We do not think that this is contradictory evidence. Physical training was rated as important as well as being activated in general and even though the program aims at alleviating physical symptoms a major focus is also the general benefits of physical exercise in terms of well-being. The infrequent use of strategies to prevent emotional outbursts could simply indicates that fairly few participants experience problems in this area.

6.5.5 Use of compensatory techniques

There were no correlations between current use of eight specific compensatory techniques and whether the program was rated useful in terms of learning to compensate. Likewise we found no effect of either disability or age at injury or chronicity of injury. This is perhaps unsurprising since our data do not reveal whether these were techniques the participant needed to use or if they used them efficiently (Evans et al., 2003) or if they had (re-)learned these techniques at the CRBI program. Keeping a calendar for appointment and writing lists are techniques widely used in the general population and several of the participants also stated that they had always used these strategies. The popularity of these techniques in this study is consistent with other studies (Evans et al., 2003; Johansen et al., 2004).

6.5.6 Summary

In summary we would note that few previous studies have reported long-term perceptions of the usefulness of specific program elements in comprehensive post-acute rehabilitation seen from the user's perspective. Overall**,** the results indicated a high level of satisfaction with rehabilitation as also has been seen in other evaluations of rehabilitation. The importance of sharing the rehabilitation with others, having cognitive and physical training as well as a primary therapist was underlined. In a long-term perspective, the comprehensive rehabilitation program is seen as having most importance for general quality of life, self-confidence, cognitive problems and awareness of deficits. The user perspective thus reflects major aims in post-acute comprehensive rehabilitation. Despite the recognised limitations of this study, we believe that overall it provides valuable indications of user perceptions of specific program elements and the overall helpfulness of rehabilitation.

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Chapter 7. Summary and conclusion

This concluding section of the dissertation evaluates how the results match the original study objectives and places it within the framework of ongoing research into the value of holistic rehabilitation. The overall objective of this study was to see whether post-acute, holistic neuropsychological rehabilitation of people with acquired brain injury has a lasting effect on these individuals' psychosocial situation and well-being. The study investigated current (2004) psychosocial status in a group of participants 12 to17 years after receiving intensive post-acute holistic neuropsychological rehabilitation at the Centre for Rehabilitation of Brain Injury, University of Copenhagen (CRBI).

Literature on this subject has generally shown positive results as presented in Chapter 1. However, only a few studies have incorporated control groups. Out of the seven controlled studies reviewed, one study failed to show a better effect of holistic neuropsychological rehabilitation on cognitive abilities and psychosocial adjustment compared to a cognitive remediation program (Ruff & Nieman, 1990). Nor according to a study of vocational status was holistic rehabilitation superior to a limited home-based program in a randomised study (Salazar et al., 2000). A third study contrasted three different types of post-acute intervention, controlling for the number of treatment hours, but varying the amount of cognitive remediation and interpersonal group exercises. There was no differential effect on vocational abilities, although some results suggested differential effects on cognitive and interpersonal abilities. Potentially this could be interpreted as the efficacy of the program lying in non-specific factors of therapy such as attention and general activation. Another four controlled studies did, however, find a positive effect of post-acute holistic, neuropsychological rehabilitation on independence, participation in society and both vocational and cognitive abilities when compared with either conventional rehabilitation programs or no post-acute rehabilitation. Studies of this kind of intervention have yet to tease out the differential effect of various program elements, thus research has not yet revealed which parts of the holistic intervention are responsible for which effects.

The ability to generalise from and compare the results from study to study is affected by many factors. Mainly, this is due to differences in the characteristics of participants, the measures of outcome, and intensity of intervention. Thus, the fact that one of the studies did not find an effect on vocational abilities has been ascribed limited generalisability. The subjects in that study were military personnel and mostly male, living in a system that may have provided more vocational opportunities than the wider public system. Additionally, the injuries sustained were of a milder nature than would generally be referred to a post-acute rehabilitation program. In fact, the study did find a beneficial effect on fitness for military duty on a subset of the more severely injured. The rehabilitation programs in both of the controlled studies that did not find an effect were also of limited duration. Most studies of post-acute neuropsychological rehabilitation have involved rehabilitation for at least four months and 400 hours or more, and regard this intensity as important for participants to learn and generalise compensational strategies.

A second feature of these studies is that none of them have looked at outcome longer than 12 years after rehabilitation. Those studies that have addressed sustainability of results have done so by measuring at several points in time, usually within three years after rehabilitation. The two centres which provided information from cross-sectional studies up to twelve years after rehabilitation found sustainability of productivity levels achieved through rehabilitation, whereas studies of nil or non-specific intervention have observed a tendency for productivity to decline. The existing literature points to the importance of separating actual participation and subjective satisfaction with life in general. The WHO model of health includes three domains: body function or impairment, activity and participation and suggests that overall health within these three domains can be affected by personal and environmental factors. Some of the research thus also points to the importance of including measures of subjective wellbeing, which at least in one study has proved to be unrelated to levels of activity and participation.

Methodologically, the question “Does post-acute, holistic neuropsychological rehabilitation of people with acquired brain injury have a lasting effect on these individuals’ psychosocial situation and well-being?” was answered by a questionnaire and interview study of consecutively treated subjects participating in the CRBI program from 1987-1992.
A control group receiving the same questionnaires and interview were recruited from an epidemiological study of subjects having sustained a brain injury in the years 1982, 1987, or 1992. In a questionnaire study conducted in 1997, all participants from the control group had answered that they had been unable to resume work immediately after hospitalisation. This selection criterion was used since it was characteristic of most of those receiving rehabilitation at the CRBI from 1987-1992 and indicative of the lasting functional severity of the injury. On the basis of a retrospective extraction of data from hospital records, the rehabilitation and control groups were found to be comparable except on one measure of injury severity. The retrospective design does, however, contain the weakness that individual differences (e.g. the ability to get accepted into rehabilitation or having a belief that training works and that one has the willpower to complete the training) can not automatically be assumed to be equally distributed between the different groups.

The purpose of rehabilitation at the CRBI was to support the person with acquired brain injury in recovering his or her ability to work, have fun, have an active leisure life, be attached to other people, be responsible, and to stimulate personal growth, in order to prepare the individual for handling the changes that life brings. On the basis of the literature, several hypotheses were proposed and tested regarding long-term social and psychological well-being after post-acute, neuropsychological rehabilitation.

As expected, the rehabilitation group proved to be significantly more engaged in productive activities and were significantly more satisfied with their placements and vocational status in general. The odds-ratio of being productive after vs. without rehabilitation was 4.4. However, the rehabilitation group was not found to earn more, could not work longer hours, nor did they seem to have more stability in their vocational placements. On average, both groups had been in their vocational situation (be it productive or non-productive) for about seven to eight years, yielding no conclusions regarding stability. There was no difference in the amount of leisure activities or whether the leisure activities were of a social nature.

Regarding hypotheses of social networks, there seemed to be no essential differences between the two groups in terms of quality or quantity of relationships, receipt of social support or their appraisal of their network, except that there was a non-significant trend for more from the control group to be married or in a *de facto* relationship. Earlier studies at the CRBI showed a decrease in leisure activities from injury to program start and then an increase from program start to follow-up. The same tendencies were seen for marriage or de-facto relationships. If the control group experienced same post-injury decrease their situation has long since stabilised 12 to 22 years after the injury and no further changes are detectable.

Those who underwent rehabilitation experience fewer symptoms of brain injury and their significant others experience less of a daily impact, as confirmed by the EBIQ.

Furthermore, those who received rehabilitation also experienced a higher degree of competency within activities of daily living (ADL), social, emotional and cognitive skills, according to the Patient Competency Rating Scale. Symptom levels are rated higher and competency levels rated lower compared to Danish non-brain injured samples. Thus an effect of the brain injury is still seen, but almost everybody interviewed said that by now they had learned to live with the consequences of their brain injury. Furthermore, the self-rating by the rehabilitation group of how much the brain injury affected their daily lives was lower than that of the control group. However, contrary to expections about rehabilitation raising self-awareness, the size of the significant discrepancies between the participants and their significant others were the same for both groups regarding symptoms of brain injury and competency. Thus awareness deficits resulting from brain injury appear to be permanent.

Anxiety and depression among participants and their significant others were generally at normal levels. However as expected, those in the rehabilitation group proved to have lower levels than the control group according to results from the Hospital Anxiety and Depression Scale. Also, the significant others were not as anxious and depressed as their injured partners. Both groups had average scores that mostly lay within the normal range, in concord with a long-term outcome study that also reported low average scores on the HADS. In comparing the control group scores of the participants with brain injury in this study both with their significant others and also with an Icelandic norm group, almost a third of the control participants show ‘caseness’ or significant depression and/or anxiety. This level has also been reported in other studies of the prevalence of anxiety and depression in groups of TBI or CVA survivors at various times after injury. While in some studies, physical symptoms and reduced productivity have been shown to relate to experienced anxiety and depression, this study is not able to illuminate the cause of the heightened levels of anxiety and depression in the control group.

We expected, and found, that the participants in the rehabilitation group have a higher degree of self-efficacy and internal locus of control than the participants of the control group, according to their own self-ratings. The study could not demonstrate whether differences in these personal factors played a role in entering rehabilitation or are an effect thereof.

The hypothesis that members of the rehabilitation group would score more highly in general measure of quality of life was confirmed by the WHO-QoL_BREF questionnaire. Concurring with the psychological and physical nature of the effects of brain injury, compared with their significant others, the participants with brain injury from both groups scored lower on these two aspects of quality of life in particular. The significant others of those in the rehabilitation group reported a higher quality of life than those of the control group, showing again that rehabilitation benefited not only the primary recipient.

The final area of outcome concerns user satisfaction and evaluation of the CRBI program and was explorative in nature. More than 90% of the participants felt that the CRBI program had been helpful. The most popular aspects of the program were physical therapy, being with other participants, and having a primary therapist. The high rating of physical therapy may reflect the activating quality of the CRBI program. The ascribed importance of being with others reflects the fact that a cornerstone of the therapeutic milieu of in post-acute holistic rehabilitation programs is the interplay between the participants. The high rating of having a primary therapist could be seen as reflection of the structure the program brings and the psychological focus. There is a potential bias in these ratings, given the long interval between treatment and evaluation. For example, one participant said he could not remember the specifics of the program, just that he felt it had helped him ‘get going again’. Interestingly the participants felt that the CRBI program had most impact on their general quality of life, self-confidence and cognitive abilities, which is in keeping with the psychological and neuropsychological aims of the program. Certainly, there was a difference in self-rated quality of life, locus of control, self-efficacy, reported symptoms and competency, reflecting perhaps some of these qualities. Return to work, leisure activities and social life were rated among the outcome areas on which the rehabilitation program had less influence. This subjective rating does not contradict the above-mentioned objective results regarding current leisure and social activity, but misses the objectively better vocational outcomes measured. Returning to work has received more attention within the program than either leisure or social life. According to psychological thinking, the influence of rehabilitation upon employability, leisure activity and social life could be said to be achieved indirectly through a bettering of, for example, emotional adjustment and amelioration of cognitive deficits. On the other hand, rehabilitation could actually have least power to influence the areas of leisure and social network.

A factor that potentially limits the generalisability of the results is the less than 80% participation rate. However, no differences in terms of basic characteristics of injury severity and demographic variables were seen between those who participated in this study and those who refrained. There are two further limitations. First, the results from the present study are derived only from persons having suffered TBI or CVA, and these may not generalise adequately to other forms of brain injury, such as anoxia and cerebral infections. Second, the study has been restricted to individuals with a range of injuries of sufficient severity to make them unable to return to employment after hospitalization, but not of so great a severity as to disqualify them from the type of rehabilitation offered by the CRBI; it therefore does not explore the possibilities of rehabilitation outside of this range, i.e., for those whose injuries were of lesser or greater severity than these.

Overall, and within the study's methodological limitations, the results suggest that post-acute, holistic, neuropsychological rehabilitation can indeed have an enduring beneficial effect on the lives of persons who have suffered a brain injury.

Many questions remains: Given the positive results, should health and social institutions prioritise establishing more centres of this kind? How large is the pool of potential participants who are not receiving this kind of rehabilitation due to lack of capacity? To what extent will this kind of rehabilitation be useful for other brain-injured groups and what kind of modifications should be made to target, for instance, the more severely injured, or people with substance abuse problems?

Hopefully the results from this study can inspire professionals in neuropsychological rehabilitation to reflect upon the goals of intervention, to conduct further much needed research into the efficacy of different program elements, and to improve and strengthen the components of the program, in order to help future participants adapt better to the increasing demands and expectations of a rapidly changing contemporary society.

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Appendixes A to F

Appendix A: List of data regarding demographic and injury related variables recorded from hospital files.

Appendix B: Invitation and Study Information

Appendix C: Participant Questionnaire

Appendix D: Significant other Questionnaire

Appendix E: Interview Guide

Appendix F: Interview Scales

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Appendix A: List of data recorded from hospital files

The list is in Danish, content is described in the method section and author of the list is Aase Engberg (Teasdale et al., 2005a).

REGISTRERINGSSKEMA

Løbenummer:___________________
Cpr.nr:__________________________Føde år:______
Navn:__________________________
Adresse:_________________________ Hjemamt:__________Hjemamts nummer:
Diagnosekategori 1, 2, 2a, 3, 4, 5

I. Registeroplysninger

Udskrivninger med hjerneskadediagnoser, for hver udskrivning**:

Indlæggelsesdato:	Antal dage indlagt (R*):	Sygehus: Kode 1(hj) Kode 2	Afdelingsnavn**:	Afdelingskode: (3 cifre u. ko)	Diagnoser: (5cifre u. komma)	Operationer:	Udskrevet til/afslutningsmåd:
▨		1					
		2					
		1					
		2					
		1					
		2					
		1					
		2					
		1					
		2					

* Antal dage i respirator; ** NK, N, Med, Ort, Andre, Rehab, Dagho,
** I tilfælde af flere end tre diagnoser, marker de 3 vigtigste.

Flest akutdage på sygehus (kode):___________ Afd. nr.:_____
Total akutdage= Takut+Rehab+Grehab:______________
ISS-score: overføres fra sygdomskategori:_____________
E-diagnose:______________

Efterkontrol/ behandling:

1. Behandlingskrævende symptomatisk **epilepsi** forårsaget af aktuelle sygdom/skade
   1 Ja
   2 Nej
   9 Ikke oplyst

2. Ambulant **kontrol** /kontrolindlæggelser vedr. **mentale** følger/tilstanden som helhed:
   1 Ja
   2 Nej
   9 Ikke oplyst
   Hvis ja, Antal:____
   Heraf undersøgt at neuropsykolog:________

3 **Kontrol** /kontrolindlæggelser kun vedr. specifikke **fysiske** følger (f.eks. øjenlæge, ørelæge, frakturfølger)
   1 Ja
   2 Nej
   9 Ikke oplyst
   Hvis ja, Antal:_________

4. **Henvist** til **hjerneskadecenter**: 0 nej 1 Ja Hvis ja, **Center navn**:____________________________________

II. Demografiske data

1. Navn:____________________ 2. NR:______________________

3. Køn: (sæt kryds) 1 Mand 2 Kvinde

4. Årstal for debut af aktuelle hjerneskade:__________(4 cifre)

5. Alder ved debut af aktuel hjerneskade:_________ (2 cifre)

6. Civilstand ved debut af aktuel hjerneskade: En cirkel (2 år senere: to cirkler)
   1 Ugift (aldrig gift)
   2 Samlevende i parforhold
   3 Gift
   4 Separeret
   5 Fraskilt
   6 Enke(mand)
   9 Ikke oplyst

7. Uddannelses- eller erhvervssituation ved aktuel skadesdebut: En cirkel, 2 år senere: 2 cirkler.
   1 Skolepligtig, går i alm. skole/HF/Gymnasium
   2 Skolepligtig, modtager særundervisning
   3 Under erhvervsuddannelse, normal
   4 Under erhvervsuddannelse, beskyttet/revalidering
   5 Erhvervsarbejde på normale betingelser (løn, arbejdstid, arbejdets indhold)
   6 Erhvervsarbejde, beskyttet/reduceret tid/ offentligt tilskud
   7 Hjemmegående husmoder / -fader uden hjælp
   8 Hjemmegående husmoder / -fader med hjemmehjælp
   9 Jobtilbud som arbejdsløs
   10 Ledig arbejdsløs/kontanthjælpsmodtager
   11 Førtidspensionist (årsag:)
   12 Alderspension/efterløn/overgangsydelse
   13 Andet __________________________
   19 Uoplyst

8. Den familie- og socialgruppe, som den skadede, forældrene eller, for hjemmegående, partneren tilhørte på skadestidspunktet: en cirkel; 2 år senere to cirkler; (tre krydser ved CFH-programstart - kodes ikke))

10 Social gruppe I: Overklasse og højere middelklasse
(Godsejere / selvstændige med 21 underordnede og derover uanset uddannelse / selvstændige med akademisk baggrund uanset antal underordnede / funktionærer med 51 underordnede og derover uanset uddannelse / funktionærer med akademisk uddannelse uanset antal underordnede)

20 Social gruppe II: Mellemste middelklasse
(Gårdejere med 4 eller flere underordnede / selvstændige i byerhverv med 6-20 underordnede (ikke akademikere) eller med en mellemlang videregående uddannelse / funktionærer med 11-50 underordnede eller med en mellemlang videregående uddannelse f.eks. lærere)

30 Socialgruppe III: Lavere middelklasse
(Gårdejere med 0-3 underordnede / selvstændige i byerhverv med 0 -5 underordnede (ikke videregående uddannelse) / funktionærer med 1-10 underordnede (ikke videregående uddannelse) eller "ekspert"- betonet arbejde)

40 Socialgruppe IV: Højere arbejderklasse:
(Husmænd / funktionærer uden underordnede, uden videregående uddannelse og uden "ekspert"-betonet arbejde / faglært arbejde)

50 Socialgruppe V: Mellemste og lavere arbejderklasse
(Ufaglærte arbejdere / gadesælgere / socialt stigmatiserede)

9. Hjerneskade før aktuelle?
91 Nej 92 Ja 99 Ikke oplyst
Hvis ja (92): 21 medfødt 22 erhvervet efter fødslen
Hvis erhvervet (22)
1 Spontan subarachnoidalblødning, årstal:
2 Apopleksi, andre vaskulære, årstal:
3 Indlagt for commotio cerebri, årstal:
4 Indlagt for kraniebrud, årstal:
5 Indlagt for traumatisk hjernekontusion/ blødning, årstal:
6 Anerkendt opløsningsmiddelskade, årstal:
7 Kulmonoxidforgiftning, årstal:
8 Godartet hjernesvulst, årstal for diagnose:
9 Meningit/ encephalit/ hjerneabcess, årstal:
10 Misbrugsbetinget hjerneskade med social deroute: _________
11 Anoxiskade, årstal:____ *(111 Hjertestop/lavt BT; 112 Nær-drukning;*
113 Narkoseulykke; 114 Nær-kvælning;
119 Anden anoxi-skade, ukendt Skal ikke tastes ind)
12. Degenerativ hjernesygdom (præsenil demens og andre (AH, DS, mm)
13 Senil demens
99 Ikke oplyst

10. Fysisk helbred op til debut af aktuel skade: En cirkel (2 år senere: to cirkler, ved ankomst til cfh tre cirkler)
10 Rask
20 Lettere fysisk sygdom/ handicap (herunder hypertension!)
30 Svært funktionshæmmet pga. dårligt fysisk helbred
99 Uoplyst

11. Psykisk helbred op til debut af aktuel skade: En cirkel (2 år senere: to cirkler, ved ankomst til cfh tre cirkler)

10 Rask
20 Lettere socialt/arbejdsmæssigt funktionshæmmet pga. psykisk lidelse/misbrug
30 Svært funktionshæmmet pga. psykisk lidelse/misbrug
99 Uoplyst

Boforhold

12. Op til debut af aktuel hjerneskade	13. Ved endelig udskrivelse: en cirkel; 2 år senere: to cirkler, ved beg. på cfh tre kryds
1. Bor hos forældre	1
2. Aleneboende i alm. bolig eller ældrebolig	2
3. Samboende med ægtefælle/samlever i alm bolig eller ældrebolig	3
4. Bor hos søn/datter eller anden familie/venner	4
5. Beskyttet bolig/bofællesskab med tilknyttet personale	5
6. Institution for børn/unge	6
7. Plejehjem	7
8. Andet (hvad:)	8 _________
11. Bor med andre (bofællesskab mv)	11
99. Ikke oplyst	99

Hjælpebehov

14. Op til debut af aktuel skade: en cirkel.	15. Ved endelig udskrivning: et kryds, 2 år senere to kryds, ved beg. på cfh tre kryds.
10 Klarer sig alene uden hjælp	10
20 Hjemmehjælp 1 gang ugentlig	20
30 Hjemmehjælp flere gange ugentlig	30
40 Plejehjem eller lignende forhold hjemme	40
99 Uoplyst	99

16. Kranienerve udfald pga. aktuelle skade fortsat tilstede ved endelig udskrivelse

	1. Ingen nye	2. Unilateralt nedsat/bortfald	3. Bilateralt nedsat/bortfald	9. Ikke oplyst
1. Lugtesans	110	120	130	19
2. Visus	210	220	230	29
3. Synsfelt	310	320	330	39
4. Øjenstyring	410	420	430	49
5. Facialisfnkt	510	520	530	59
6. Hørelse	610	620	630	69
7. Synkning	710	720	730	79

III Funktionsskemaer

NR.______________

Bevægeapperatets funktion	20) Op til debut af aktuelle sygdomsforløb	21) 7 døgn efter debut/seneste CNS operation i aktuelle forløb	22) Ved evt. overflytning til lokal sygehus	22) Ved evt. overflytning til rehab sygehus	23) Ved endelig udskrivning
Normal	10	10	10	10	10
OE parese/ ataxi/ dystoni	21 unilateral let Svær 22 bilateral	21 unilateral let Svær 22 bilateral	21 unilateral let Svær 22 bilateral	21 unilateral let Svær 22 bilateral	21 unilateral let Svær 22 bilateral
UE parese/ ataxi/ dystoni	31 unilateral let Svær 32 bilateral	31 unilateral let Svær 32 bilateral	31 unilateral let Svær 32 bilateral	31 unilateral let Svær 32 bilateral	31 unilateral let Svær 32 bilateral
Hemiparese / hemiataxi/ dystoni	40	40	40	40	40
Tetraparese/ tetraataxi/ dystoni	50	50	50	50	50
Frakturfølger	60	60	60	60	60
Ubedømmelig	70	70	70	70	70
Uoplyst	9	9	9	9	9

Mobilitet	24) Op til debut af aktuelle sygdomsforløb	25) 7 døgn efter debut/seneste operation i aktuelle forløb	26) Ved evt. overflytning til lokal sygehus	26) Ved evt. overflytning til rehab sygehus	27) Ved endelig udskrivning
Normal gang	10	10	10	10	10
Selvst., let abnorm, evt skinne	20	20	20	20	20
Selvst. Gang med hjælpemiddel	30	30	30	30	30
Gang kun med personstøtte (+ evt hjælpemiddel)	40	40	40	40	40
Kørestol	50	50	50	50	50
Ikke ud af seng	60	60	60	60	60
Uoplyst	9	9	9	9	9

III Funktionsskemaer NR:______________

Talen	28) Op til debut af aktuelle sygdomsforløb	29) 7 døgn efter debut / seneste operation i aktuelle forløb.	30) Ved evt. overflytning til lokal (en cirkel) sygehus	30) Ved evt. overflytning til lokal sygehus	31) Ved endelig udskrivning
Normal	10	10	10	10	10
Let dysarthri	20	20	20	20	20
Svær dysarthri/ anarthri (forstås kun af få/ ingen)	30	30	30	30	30
Let afasi	40	40	40	40	40
Svær/ global afasi	50	50	50	50	50
Andet	60	60	60	60	60
Ubedømmelig pga. bevidstheds-svækkelse	70	70	70	70	70
Ikke oplyst	9	9	9	9	9

Kognitiv funktion	32) Op til debut af aktuelle sygdomsforløb		33) 7 døgn efter debut/ seneste operation i aktuelle forløb		34) Ved evt. overflyt. til lokal sygehus		34) Ved evt. overflyt. til rehab sygehus		35) Ved endelig udskrivning	
	N	A	N	A	N	A	N	A	N	A
Normal	N10	A10	N10	A10	N10	A10	N10	A10	N10	A10
Let forringet	N20	A20	N20	A20	N20	A20	N20	A20	N20	A20
Svært forringet (skønnes arbejdshindrende)	N30	A30	N30	A30	N30	A30	N30	A30	N30	A30
Ubedømmelig pga. bevidsthedssvækkelse	N40	A40	N40	A40	N40	A40	N40	A40	N40	A40
Uoplyst	N99	A99	N99	A99	N99	A99	N99	A99	N99	A99

N-psyk: Neuropsykologisk vurdering, An: Anden vurdering (f.eks. i j. om hukommelsessvækkelse, koncentrationsbesvær, mental reduktion, mangelfuld indsigt i egne deficit, neglekt, påklædningsapraksi)

III Funktionsskemaer

NR:______________

Adfærd	36) Op til debut af aktuelle sygdomsforløb	37) 7 døgn efter debut/ seneste operation i aktuelle forløb	38) Ved evt. overflytning til **lokal** sygehus	38) Ved evt. overflytning til **rehab** sygehus	39) Ved endelig udskrivning
1. Normal	10	10	10	10	10
2. Let forstyrret	20	20	20	20	20
3. Svært forstyrret (skønnes sikkert arbejdshindrende)	30	30	30	30	30
4. Udslukt coma	40	40	40	40	40
9. Ikke oplyst	99	99	99	99	99

Total Mental funktions evne	56) Op til debut af aktuelle sygdomsforløb	57) 7 døgn efter debut/ seneste operation i aktuelle forløb	58) Ved evt. overflytning til lokal sygehus	58) Ved evt. overflytning til rehab sygehus	59)Ved endelig udskrivning
Uændret fra før skade/ ingen bemærkn.	10	10	10	10	10
Synes i det væsentlige uændret	20	20	20	20	20
Moderat deficit (klart arbejdshindrende, men kan bo hjemme) (vil kunne være overset i journal)	30	30	30	30	30
Svært deficit (indskrænker dagligdagsfunktioner, kan ikke bo hjemme)	40	40	40	40	40
Ubedømmelig pga. bevidsthedssvækkelse	50	50	50	50	50
9. Ikke oplyst	99	99	99	99	99

III Funktionsskemaer NR:_____________

NB: skal så vidt muligt udfyldes, evt. cirkel om flere muligheder, hvis tvivl.

Total ADL funktionsevne (Rankin)	46) Op til debut af aktuelle sygdomsforløb	47) 7 døgn efter debut/ seneste operation i aktuelle forløb	48) Ved evt. overflytning til lokal sygehus	48) Ved evt. overflytning til rehab sygehus	49)Ved endelig udskrivning
Ingen betydende deficits	10	10	10	10	10
Lette deficits, pers. selvhjulpen	20	20	20	20	20
Moderat funktionsindskrænkning, kan gå selvstændigt, hjælp til påklædning	30	30	30	30	30
Sværere funktionsindskrænkning, personhjælp til gang og påklædning	40	40	40	40	40
Meget svær funktionsindskr. Bundet til seng/ stol, konstantpleje og opsyn.	50	50	50	50	50

NB: skal så vidt muligt udfyldes, evt. cirkel om flere muligheder, hvis tvivl.

Glasgow Outcome Scale	66)Ved evt. overflytning til lokal sygehus	66)Ved evt. overflytning til rehab sygehus	67) Ved endelig udskrivning	68) Opfølgningsdato
1. Fortsat i coma	10	10	10	10
2. Vegetativ tilstand, (vågen, ingen kommunikation, ingen tegn på meningsfuld aktivitet)	20	20	20	20
3. Ved bevidsthed, men afhængig af andre døgnet rundt	30	30	30	30
4. Personlig selvhjulpen, klarer off. transp. evt. beskytt. arbejde	40	40	40	40
5. Klarer normal tilværelse socialt og arbejdsmæssigt	50	50	50	50

SAH Sygdomskategori I: Subarachnoidalblødning ICD 430

Navn:____________________________________ NR:______________________

Dato for sygdomsdebut: ____*____*____ Aktuel diagnose: ___________(5-cifret m. 2 dec.)

Er blødningen verificeret vha:

	1. Ja	2. Nej	9. Uoplyst
1. CT- verificeret (subarachnoidalblødning)	1	2	9
2. lbp-ver Lumbalpunktur	1	2	9
(3. A-grafi/MR angiografi (aneurisme(r), der har blødt) Tastes ikke ind!!!	*1*	*2*	*9)*

3.1 Lokalisation af **aneurisme**(r):
11 Carotisgebetet
12 Vertebralisgebet
13 Communicans posterior
19 Ikke oplyst
(OBS spørgsmål 4 er udgået)

5) Er det en vaskulær malformation?
1 Ja
2 Nej
Hvis ja, er det: 11 Carotisgebetet 12Vertebralisgebetet 19 Uoplyst

6) Behandling
1 Nimotop/Nimodipin
2 Kraniotomi, extern liquordrænage, shunt (**se forsiden)**
3 Coil, Embolisering
4 Stråling
5 Konservativ
6 Andet:_______________________
9 Uoplyst

7) Seneste CT/MR-scanning: dato:________ og fund:
1 Normal
21 Højre hemisfære infarkt, (frontalt, temporalt, occipitalt, parietalt)
22 Venstre hemisfære infarkt, (frontalt, temporalt, occipitalt, parietalt)
23 Bilateral hemisfære infarkt
24 Hjernestamme/cerebellart infarkt
3 Blødning i regression
4 Kraniotomifølger (Evt. clips, shunt)
5 Coilet aneurisme, Emboliseret vaskulær malformation
6 Uændret fra første CT/MR
7 Hydrochephalus
8 Hygrom
9 Uoplyst

8) Kendte resterende malformationer/aneurisme(r)
1 Ja
2 Nej
9 Uoplyst

Bevidsthed-niveau	Op til debut af aktuelle sygdomsforløb	Dårligste før operation/ kons. beh.	7 dage efter debut / seneste CNS operation	Ved overflytning til lokal sygehus	Ved overflytn. til rehab sygehus	Ved endelig udskrivning
Vågen og klar	10	10	10	10	10	10
Somnolent/ konfus	20	20	20	20	20	20
Ukontaktbar	30	30	30	30	30	30
Uoplyst	99	99	99	99	99	99

Apopleksi III. Sygdomskategori 2: jfr: ICD-diagnoser: 431-4, 436.

1) Navn:____________________________________ 2) NR:______________________

3) Dato for sygdomsdebut: *____*____*____

4) Aktuel diagnose:______________________ (fem-cifret, 2 decimaler)

ICD 431 Haermorrhagia cerebri
ICD 432 Occlusio arteriae praecerebralis
ICD 433 Thrombosis cerebri
ICD 434 Embolia cerebri
ICD 436 Morbus cerebrovascularis acutus male definitus

5) Baggrund for diagnose
51: Alene klinisk eller
52: CT/MR scanning, dato for *første* vedr. aktuelle:____*_____*_____
53: CT/MR scanning, dato for *mest oplysende* subakutte/akutte scanning:___________
54: Totale antal CT/MR vedr. aktuelle apopleksi_______

6) Scanningsfund ved *mest oplysende* scanning (hvis flere fund, sæt cirkel om hvert)

CT/MR fund	0= tom	1. Hø.	2. Ve.	3. Bilat.	9. uoplyst
Normal 1= ja;	0	xxxx	xxxx	xxxxxx	
Infarkt					
Lacunært (mindre, dybtligg) infarkt, incl. capsul. int.; 0 hvis tom	0	1	2	3	9
(**frontalt**) Cerebri anterior infarkt	0	1	2	3	9
(**frontoparietal**, fissura Sylvii) Watershed infarkt	0	1	2	3	9
(**parietalt, parieto-temporalt**) Cerebri media inf.	0	1	2	3	9
(**parietooccipitalt**) Watershed infarkt	0	1	2	3	9
(**occipitalt**) Cerebri posterior infarkt	0	1	2	3	9
(**total hemisfære**-inf.) Carotis interna occlusion	0	1	2	3	9
Hjernestamme infarkt	0	1	2	3	9
Cerebellart infarkt	0	1	2	3	9
Multi-infarkt	0	1	2	3	9
Andet, uoplyst	0	1	2	3	9
Blødning					
Lacunær blødning	0	1	2	3	9
Intracerebral blødning, større	0	1	2	3	9
Hjernestammeblødning	0	1	2	3	9
Cerebellarblødning	0	1	2	3	9
Andet, uoplyst	0	1	2	3	9

78. **Ledsagefænomener**
1 Ødem
2 Kompression af ventrikelsystemet
3 Midtlinjeforskydning
4 Hydrocephalus
5 Gennembrud til ventrikelsystemet

Andre scanningsfund
79 Cortical atrofi
80 Central atrofi
81. Leukodystrofi
82. Vaskulær malformation
83. Andre fund af betydning for diagnosen:____________________________________

Bevidsthedniveau	Op til debut af aktuelle sygdomsforløb	Dårligste før operation/ kons. beh.	7 dage efter debut / seneste CNS operation	Ved overflytning til lokal sygehus	Ved overflytn. til rehab sygehus	Ved endelig udskrivning
Vågen og klar	10	10	10	10	10	10
Somnolent/ konfus	20	20	20	20	20	20
Ukontaktbar	30	30	30	30	30	30
Uoplyst	9	9	9	9	9	9

TBI III. Sygdomskategori 5 Traumatisk hjerneskade, ICD diagnoser: 851 - 854

ICD 851 Contusio, dilaceratio, conquassatio cerebri, ICD 852 Haemorrhagia subduralis, extraduralis, subarachnoidalis, ICD 853 Haemorrhagia intracranialis alia, ICD 854 Laesio intracranialis alia et non specificata.

1) Navn:___________________________________ 2) NR:_____________________
3). Dato for aktuel sygdomsdebut:*_____*______*_____
4) Aktuel diagnose:_______________________
5). Samtidig kraniefraktur
51 Nej 52 Ja, hvis ja, er den: 52.1 Allerede på diagnoseliste 59. Ikke oplyst
52.2 Ikke på diagnoseliste. Sæt den på! (s1.)
6) Verifikation af hjernelæsionsdiagnose: 61 Klinisk;

Variabel
61.1 Ukontaktbar > 15 min. 0= tom 1= ja 2 = nej 99= uoplyst
61.2 PTA > 1 time: hvor længe:__________ 0= tom 1= ja 2 = nej 99= uoplyst
61.3 Fokale neurologiske udfald 0= tom 1= ja 2 = nej 99= uoplyst
Varighed af comalængde i dage
Minimal comalængde (dage):_________
Maksimal comalængde (dage):__________
Comalængde ikke oplyst
61.11Glasgow Coma Scale score ved **ankomst** GCS0:_______
Ved **6 timer**, GCS6:_________
GCS lavest i første døgn = 99
GCS 24 timer = 99
Timer før GCS=9__________
61.19 GCS totalt uoplyst = 19
PTAT = 99
PTAD estimat (dage):________
Hvis PTA ikke er nøjagtigt oplyst, angiv da minimale varighed af PTA i dage
PTAMIT= 99
PTAMAT= 99
PTAMID = mindste antal dage:
PTAMAD= max antal dage: altid 99
61.29 PTA uoplyst

62 **Radiologisk** verifikation
62.1 Dato for første CT/MR scanning vedr. aktuelle skade:*_____*____*______*
62.2 Dato for mest oplysende CT/MR scanning akut/subakut:*_____*_____*_____*
62.3 Total antal CT/MR scanninger vedr. aktuelle TBI:___________________________

63 **Scanningsfund ved mest oplysende** scanning akut/subakut, dvs. efter evt. initial progression: (hvis flere fund, sæt cirkel om hver)
CTC/MR Normal 0 = tom 1= ja 2= nej 99 ikke oplyst
Oedema cerebri 21
Kompression af ventrikelsystem 22
Midtlinjeforskydning 23
Hemisfærekontusion (31:højre; 32:venstre; 33:bilat.; 39 side uoplyst)
SDH: Subduralt hæmatom akut/subakut (41:højre; 42:venstre; 43:bilat.; 49 side uoplyst)
SAH: Subarachnoidalblødning (51:højre; 52:venstre; 53:bilat.; 59 side uoplyst)
EDH: Epiduralt hæmatom (61:højre; 62:venstre; 63:bilat.; 69 side uoplyst)
Hjernestamme-kontusion/-blødning (71:højre; 72:venstre; 73:bilat.; 79 side uoplyst)
Cerebellar kontusion/blødning (81:højre; 82:venstre; 83:bilat.; 89 side uoplyst)
9. Andet / scanningsfund uoplyst

64: CT-påvist **senere komplikation/ændringer**

1 Hydrocephalus
2 Absces/infektion
3 Central atrofi
4 Cortical atrofi
5 Hygrom
6 Normal, trods tidligere forandringer
7 Lav-absorptive områder svarende til tidl. kontusion
8 Andet:____________________________
9 Ikke oplyst

7). **Kontakt-/Skadesårsag**

1 Færdselsuheld med motorkøretøj involveret
2 Fald fra cykel intet motorkøretøj involveret
3 Fald på gaden intet motorkøretøj involveret
4 Vold
5 Arbejdsulykke (ikke trafik)
6 Sports-ulykke
7 Ulykke på legeplads
8 Hjemme-/fritidsulykke bortset fra vold, sport og legeplads
9 Selvmutilering
10 Andet:_________________
19. Ikke oplyst

Funktionsmæssigt betydende diagnoser, som ikke er på diagnoseliste:

8.1: Beregning af **ISS** ud fra diagnoser:________________

Appendix B: Letter of invitation, information about the study and form of consent

The letter and information is in Danish.

Henriette Aaby Svendsen
cand.psych., ph.d.-studerende

Københavns Universitet Amager
Institut for Psykologi

Fornavn Efternavn
Gade nr.
Postnummer By

København den dato

Kære Fornavn Efternavn

Jeg henvender mig til dig for at spørge, om du vil være med i en videnskabelig undersøgelse.

På næste side er der forklaret, hvad undersøgelsen går ud på, og hvordan du deltager, hvis du vil være med.

Hvis du vælger at deltage, kan du til enhver tid vælge at træde ud af undersøgelsen – uden at komme med nogen forklaring på, hvorfor du alligevel ikke vil være med.

Jeg vil gerne bede dig om at udfylde og indsende deltagerblanketten i den vedlagte frankerede svarkuvert eller sende en mail eller ringe til mig. Jeg har telefonsvarer på, så du kan altid lægge en besked.

Hvis du ønsker at deltage vil jeg så kontakte dig, så vi kan aftale et tidspunkt for interviewet.

Med venlig hilsen

Henriette Aaby Svendsen

Telefon 35 32 87 53 ***Fax 35 32 86 82***
Njalsgade 88, 2300 København S ***Henriette.svendsen@psy.ku.dk***

Deltagerinformation til tidligere patienter og deres pårørende

Grunden til at jeg henvender mig til dig, er at landspatientregistret har registreret, at du på et tidspunkt i perioden 1978-1992 har haft en indlæggelse med en diagnose i form af enten traumatisk hjerneskade, blodprop eller hjerneblødning.

Jeg vil bede dig om at deltage i en videnskabelig undersøgelse, hvor jeg er interesseret i din oplevelse af dit helbred, dine levevilkår og din livskvalitet her længere tid efter du fik skaden.

Mit langsigtede mål er at skaffe bedre viden om levevilkår og livskvalitet længere tid efter en skade. Dette vides der ikke nok om i Danmark såvel som internationalt. Jeg håber, at resultaterne vil bidrage til bedre behandling, rådgivning og hjælp til mennesker, der har været udsat for en skade, samt til deres pårørende. For at afdække dette, vil jeg gerne spørge til, hvorledes det går dig og din nærmeste.

Undersøgelsen består af spørgeskemaer samt et interview. Spørgeskemaerne vil du få tilsendt, hvis du har lyst til at deltage. Der er to spørgeskemaer. Et du selv bedes udfylde og ét som én af dine nære familiemedlemmer eller venner om muligt bedes udfylde. Det vil tage cirka 45 minutter at udfylde spørgeskemaerne. Interviewet er med dig alene. Selve interviewet vil tage højst 2 timer og omhandler helbred, levevilkår og livskvalitet.

Da jeg ikke har mulighed for at betale transport forestiller jeg mig at interviewet skal foregå i dit hjem og at jeg kommer ud for at interviewe dig der. Jeg tilbyder gerne en samtale om undersøgelsesresultaterne

Alle informationer vedrørende helbredsforhold er omfattet af tavshedspligt og ved en offentliggørelse af resultaterne er dine data anonymiseret.

Denne undersøgelse er støttet af Socialministeriet og er godkendt af Det Videnskabsetiske Komitésystem ((KF) 01-107/00) samt Datatilsynet.

Deltagerblanket

Identifikationsnummer:

Navn: Fornavn Efternavn

___ Ja, jeg vil gerne deltage

Jeg kan kontaktes pr. telefon:___________________________

Jeg træffes bedst: ___________________________

Jeg kan kontaktes via e-mail:___________________________

___ Nej, jeg ønsker ikke at deltage

Appendix C: Participant Questionnaire

The questionnaire is in Danish and contains:

- The European Brain Injury Questionnaire,
- The Patient Competency Rating Scale,
- The Hospital Anxiety and Depression Scale,
- The WHO Quality of Life Questionnaire – short version,
- The Generalised Self Efficacy Scale,
- A Locus of Control Scale,
- A Diary and
- Questions about perceived social support.

Participant number

Københavns Universitet Amager ***Institut for Psykologi***

Deltager spørgeskema

Helbred, levevilkår og livskvalitet

Indhold:
Spørgeskema om livskvalitet
Skema til vurdering af evner og færdigheder
Skema til vurdering af humør
Oplevelse af hverdagsproblemer
Skema til vurdering af holdninger til livet
Socialt netværk
Dagbog

Participant number

Spørgeskema om Livskvalitet

De følgende spørgsmål handler om, hvordan du føler din livskvalitet, din sundhed og andre områder af dit liv er.
Hvis du er usikker på, hvilket svar du skal vælge, så vælg det du synes er mest passende.

Lad være med at tænke for meget over det, det er oftest din første indskydelse, der er den mest passende. Der er ingen rigtige eller forkerte svar.

Du bedes venligst besvare alle spørgsmål.
Du skal svare udfra, hvordan du føler dit liv har været indenfor de sidste 2 uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget dårlig	Dårlig	Hverken god eller dårlig	God	Særdeles god
1	Hvordan mener du din livskvalitet er ?					

De følgende spørgsmål handler om, i hvilken grad du har oplevet visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget utilfreds	U-tilfreds	Hverken tilfreds eller utilfreds	Tilfreds	Særdeles tilfreds
2	Hvor tilfreds er du med dit helbred ?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Lidt	I nogen grad	Meget	Virkelig meget
3	I hvilken grad føler du at smerter forhindrer dig i dine gøremål ?					
4	I hvilken grad har du brug for medicinsk behandling for at fungere i dagligdagen?					
5	I hvilken grad nyder du livet ?					
6	I hvilken grad opfatter du dit liv som meningsfuldt ?					
7	Hvor god er du til at koncentrere dig ?					
8	Hvor tryg føler du dig i dagligdagen?					
9	Hvor sundt er det fysiske miljø du bor i ?					

Participant number

De følgende spørgsmål handler om, hvor godt
du har været i stand til visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Næsten ikke	I nogen grad	For det meste	Fuld-stændig
10	Har du energi nok til at klare dagligdagen ?					
11	Kan du acceptere sådan som din krop ser ud?					
12	Har du penge nok til at dække dine behov ?					
13	Kan du skaffe den information, som er nødvendig for dig i din hverdag ?					
14	I hvilken grad har du mulighed for at dyrke fritidsaktiviteter ?					

I de følgende spørgsmål skal du svare på, hvor tilfreds du har været med forskellige sider i dit liv indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Lidt	I nogen grad	Meget	Virkelig meget
15	Hvor godt er du i stand til at komme omkring ?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget utilfreds	Utilfreds	Hverken tilfreds eller utilfreds	Tilfreds	Særdeles tilfreds
16	Hvor tilfreds er du med din søvn ?					
17	Hvor tilfreds er du med din evne til at udføre daglige gøremål ?					
18	Hvor tilfreds er du med din arbejdsevne?					
19	Hvor tilfreds er du med dig selv ?					
20	Hvor tilfreds er du med dit forhold til andre mennesker?					
21	Hvor tilfreds er du med dit seksualliv ?					
22	Hvor tilfreds er du med den støtte du får fra dine venner ?					
23	Hvor tilfreds er du med levevilkårene i din bolig ?					
24	Hvor tilfreds er du med den hjælp du kan få til dine helbredsproblemer ?					
25	Hvor tilfreds er du med dine transportmuligheder ?					

De følgende spørgsmål handler om, hvor ofte du har følt visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Aldrig	Sjældent	Ret tit	Meget tit	Altid
26	Hvor tit har du haft negative følelser som for eksempel nedtrykthed, fortvivlelse eller angst?					
27	Er du glad for tilværelsen ?					

Vurdering af evner og færdigheder

I dette spørgeskema bedes du tage stilling til dine evner og færdigheder i forhold til en række forskellige praktiske gøremål og situationer.

Nogle af spørgsmålene angår måske gøremål eller situationer, som ikke er relevante for dig i din hverdag, som den er lige nu. Hvis dette er tilfældet bedes du alligevel besvare spørgsmålene, og prøve at forestille dig, hvordan det ville være, hvis du alligevel skulle gøre det der står anført.

Læs hvert udsagn og vurder, hvor let eller svær den givne opgave eller situation er for dig.
Du bedes venligst besvare alle spørgsmål.

Sæt kun 1 kryds ud for hvert spørgsmål!		Kan ikke	Har meget svært ved	Kan med noget besvær	Kan ubesværet	Kan med lethed
1.	Hvor stort et problem har jeg med at lave min egen mad ?					
2.	Hvor stort et problem har jeg med at tage tøj på?					
3.	Hvor stort et problem har jeg med at udføre min personlige hygiejne ?					
4.	Hvor stort et problem har jeg med at vaske op?					
5.	Hvor stort et problem har jeg med at vaske tøj?					
6.	Hvor stort et problem har jeg med at tage mig af min økonomi ?					
7.	Hvor stort et problem har jeg med at holde mine aftaler til tiden ?					
8.	Hvor stort et problem har jeg med at starte en samtale i en gruppe ?					
9.	Hvor stort et problem har jeg med at være vedholdende i arbejdsaktiviteter, når jeg keder mig eller er træt ?					
10.	Hvor stort et problem har jeg med at huske, hvad jeg fik at spise i aftes ?					
11.	Hvor stort et problem har jeg med at huske navne på folk, jeg ofte ser ?					
12.	Hvor stort et problem har jeg med at huske mine daglige gøremål ?					
13.	Hvor stort et problem har jeg med at huske de vigtige ting, jeg skal gøre ?					
14.	Hvor stort et problem har jeg med at køre bil ?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Kan ikke	Har meget svært ved	Kan med noget besvær	Kan ubesværet	Kan med lethed
15.	Hvor stort et problem har jeg med at søge hjælp, hvis jeg bliver forvirret ?					
16.	Hvor stort et problem har jeg med at tilpasse mig, når der sker uventede ændringer ?					
17.	Hvor stort et problem har jeg med at klare diskussioner med folk jeg kender godt ?					
18.	Hvor stort et problem har jeg med at modtage kritik fra andre ?					
19.	Hvor stort et problem er det for mig at kontrollere min gråd ?					
20.	Hvor stort et problem har jeg med at opføre mig passende, når jeg er sammen med mine venner ?					
21.	Hvor stort et problem har jeg med at vise mine følelser til andre ?					
22.	Hvor stort et problem har jeg med at deltage i gruppeaktiviteter ?					
23.	Hvor stort et problem har jeg med at erkende, når noget jeg siger eller gør sårer andre mennesker ?					
24.	Hvor stort et problem har jeg med at planlægge daglige gøremål ?					
25.	Hvor stort et problem har jeg med at forstå nye instruktioner ?					
26.	Hvor stort et problem har jeg med, vedholdende, at klare de daglige ansvarsområder ?					
27.	Hvor stort et problem har jeg med at kontrollere mit temperament, når et eller andet bringer mig ud af balance ?					
28.	Hvor stort et problem har jeg med at undgå at blive trist eller deprimeret ?					
29.	Hvor stort et problem har jeg med at kontrollere mine følelser således at de ikke påvirker min evne til at klare de daglige gøremål ?					
30.	Hvor stort et problem har jeg med at kontrollere min latter ?					

Hvor godt kender din pårørende dine evner og færdigheder? (Sæt kryds ud for det som passer bedst)	Næsten ikke	Ikke særlig godt	Rimelig godt	Godt	Meget godt

Participant number

Skema til vurdering af humør

De følgende udsagn handler om hvordan du har det humørmæssigt

Læs hvert udsagn grundigt, og vurder i hvor høj grad det pågældende udsagn passer, når du tænker på den sidste uges tid.

Der er ingen rigtige eller forkerte svar.

Du bedes venligst besvare alle spørgsmål.

Sæt kun 1 kryds ud for hvert udsagn		Slet ikke / Næsten ikke	Ind i mellem/ Kun lidt	Ofte / I nogen grad	Meget ofte / Det meste af tiden
1	Jeg føler mig anspændt eller kørt op.				
2	Jeg kan nyde livets glæder lige så godt som før i tiden.				
3	Jeg føler undertiden en ubestemmelig frygt, som om der skal ske noget frygteligt.				
4	Jeg kan le og more mig.				
5	Der kører bekymringer rundt i hovedet på mig.				
6	Jeg føler mig munter.				
7	Jeg kan slappe helt af når det passer mig				
8	Jeg føler mig noget sløv og hæmmet.				
9	Jeg er undertiden så nervøs at jeg har sommerfugle i maven				
10	Jeg er holdt op med at interessere mig for mit udseende.				
11	Jeg føler mig rastløs og urolig.				
12	Jeg kan glæde mig til noget, der skal ske.				
13	Jeg får pludselige anfald af panik eller uro				
14	Jeg kan nyde en god bog eller et godt radio eller TV program				

Participant number

Oplevelse af hverdagsproblemer

Disse spørgsmål handler om forskellige problemer eller vanskeligheder, som mennesker af og til oplever i deres liv. Jeg vil gerne vide, hvor meget du mener, at du har været udsat for nogle af disse **inden for den sidste måned**. Vær venlig at læse hvert spørgsmål og give respons ved at sætte et kryds under **'slet ikke', 'lidt',** eller **'meget'**. Lad være med at bruge for meget tid på et enkelt spørgsmål. Skriv bare din umiddelbare reaktion.

Du bedes venligst besvare alle spørgsmål.

Hvor meget har du været udsat for de følgende indenfor den sidste måned?

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
1	Hovedpine			
2	Ude af stand til at få gjort tingene til tiden			
3	Reagerer for hurtigt på, hvad andre siger og gør			
4	Problemer med at huske			
5	Svært ved at tage del i en konversation			
6	Føler at andre ikke forstår mine problemer			
7	Alting virker besværligt			
8	Ude af stand til at planlægge, hvad jeg skal			
9	Synes at fremtiden ser håbløs ud			
10	Hidsighedsanfald			
11	Forvirret			
12	Føler mig ensom, selvom jeg er sammen med andre mennesker			
13	Humørsvingninger uden grund			
14	Tilbøjelig til at være kritisk overfor andre			
15	Må gøre tingene langsomt for, at det skal blive korrekt			
16	Svimmel			
17	Skjuler mine følelser overfor andre mennesker			
18	Føler mig trist			
19	At jeg er bestemmende eller dirigerende			
20	Ikke interesseret i mit udseende			

Participant number

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
21	Svært ved at klare min økonomi			
22	Koncentrationsproblemer			
23	Lægger ikke mærke til andre menneskers sindsstemninger			
24	Føler vrede imod andre mennesker			
25	Bliver let såret			
26	Kan ikke tage mig sammen til at få tingene gjort			
27	Bliver ærgerlig eller irriteret			
28	Problemer med at klare hjemlige gøremål			
29	Mangel på interesse for hjemlige hobbies			
30	Føler mig isoleret			
31	Føler mig mindreværdig overfor andre mennesker			
32	Problemer med at sove			
33	Føler mig utilpas i en større forsamling			
34	Råber ad folk i vrede			
35	Svært ved at give udtryk for, hvad jeg ønsker			
36	Føler mig usikker på, hvad jeg skal gøre i farlige situationer			
37	Stædig			
38	Uinteresseret i mine omgivelser			
39	Har en ringe tidsfornemmelse			
40	Har mistillid til andre mennesker			
41	Har let til tårer			
42	Svært ved at orientere mig i nye omgivelser			
43	Tilbøjelig til at spise for meget eller for lidt			
44	Kommer let op at skændes			
45	Træt eller sløv			
46	Mangel på selvværd			
47	Mangel på hobbies udenfor hjemmet			
48	Prioriterer mine egne interesser frem for andres			
49	Rastløs			
50	Anspændt			

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
51	Reagerer uhensigtsmæssigt i sociale sammenhænge			
52	Føler, at livet ikke er værd at leve			
53	Glemmer aftaler			
54	Overlader til andre at tage initiativet i samtaler			
55	Nedsat seksuallyst			
56	Mister selvbeherskelsen, når jeg bliver vred			
57	Foretrækker at være alene			
58	Svært ved at tage beslutninger			
59	Har mistet kontakten til mine venner			
60	Mangel på interesse for nyhedsstof			
61	Opfører mig taktløst			
62	Har problemer i almindelighed			

Vær nu venlig også at besvare de følgende spørgsmål **om din nærmeste pårørende:**

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
63	Er hans/hendes liv blevet forandret, efter at du pådrog dig din skade?			
64	Har han/hun problemer på grund af din nuværende situation?			
65	Er hans/hendes humør påvirket af din nuværende situation?			

Participant number

Holdninger til livet

Dette spørgeskema handler om forskellige holdninger til livet.
Du bedes sætte kryds ud for den svarmulighed der passer bedst på dig.
Der er ingen rigtige eller forkerte svar, så tænk ikke for meget over hvert enkelt svar.
Du bedes venligst besvare alle spørgsmål.

Sæt kun 1 kryds ud for hvert udsagn		Passer slet ikke	Passer en smule	Passer nogen-lunde	Passer præcist
1	Jeg kan altid løse vanskelige problemer, hvis jeg prøver ihærdigt nok				
2	Hvis nogen modarbejder mig, finder jeg en måde til at opnå det, jeg vil				
3	Det er let for mig at holde fast ved mine planer og realisere mine mål				
4	Jeg er sikker på, at jeg kan håndtere uventede hændelser				
5	Takket være mine personlige ressourcer, ved jeg, hvordan jeg skal klare uforudsete situationer				
6	Jeg kan løse de fleste problemer, hvis jeg yder den nødvendige indsats				
7	Jeg bevarer roen, når der er problemer, da jeg stoler på mine evner til at løse dem				
8	Når jeg støder på et problem, kan jeg som regel finde flere løsninger				
9	Hvis jeg er i vanskeligheder, kan jeg som regel finde en udvej				
10	Lige meget hvad der sker, kan jeg som regel klare det				
11	Jeg har styr på mine tanker, følelser og handlinger				
12	Jeg føler tit, at omverdenen/andre styrer mit liv				
13	Jeg oplever, at jeg har meget stor indflydelse på min nuværende situation				
14	Jeg føler mig tryg ved fremtiden, fordi jeg mener, at jeg selv kan forme den				
15	Jeg oplever tit, at jeg bliver overvældet af alle de krav omverdenen stiller til mig				
16	Jeg oplever at det er svært for mig at tage ansvar for min nuværende situation				

Oplevet socialt netværk og støtte:

Familie

1. Hvor meget støtte/hjælp får du fra din familie?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du har brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

2. Hvilken slags støtte og hjælp yder din familie? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Venner

3. Hvor meget støtte/hjælp får du fra dine venner?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du oplever at have brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

4. Hvilken slags støtte og hjælp yder dine venner dig? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Naboer

5. Hvor meget støtte/hjælp får du fra dine naboer?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du har brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

6. Hvilken slags støtte og hjælp yder naboerne? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Participant number

Dagbog

For at få et indtryk, af hvad du laver i løbet af en uge, og hvor meget tid du bruger på de ting du laver, har jeg lavet et skema over en uge.

Hver dag er inddelt i tidsrum og jeg vil bede dig så nøjagtigt som muligt at notere, hvad du foretager dig i disse tidsrum i løbet af den kommende uge.

Du kan enten vælge at skrive, hvad du foretager dig eller bruge tal fra den aktivitetsliste, jeg har skrevet nedenfor.

Du behøver ikke at starte en mandag med at udfylde skemaet, bare du skriver datoen på den dag du starter og de dage du udfylder. Hvis du f.eks. arbejder i mere end en time i træk - må du meget gerne markere tidsrummet og så kun skrive det én gang.

Du må også gerne skrive flere ting i hver rubrik.

Det er vigtigt at du noterer, hvad der sker lige i den uge og ikke hvad du plejer at gøre.

Aktivitetsliste

Hjemmet:
1: sover/hviler;
2: spiser/drikker kaffe;
3: laver mad;
4: vasker op/vasker tøj;
5: gør rent;
6: personlig hygiejne.
7: har gæster;
8: dyrker en hobby, hvilken?
9: køber ind
10: andet, hvad

Arbejde/uddannelse/transport
11: arbejde
12: uddannelse a: undervisning
b: forberedelse
13: transport

Fritidsinteresser:
20: ser fjernsyn, hører radio
21: dyrker sport,
22: foreningsliv (f.eks. skak, spejder mm.);
23: kunst/kultur (a: tilskuer; b: udøver):
24: hus/have;
25: mekanik/teknik;
26: håndarbejde;
27: læser bøger/aviser,
28: samvær med andre: (a: kæreste b: familie c: venner d: arbejds-/ studiekammerater)
29: computer
30: går ture
31: andet: skriv gerne hvad (f.eks. biograf, værtshus, cafe, restaurant osv.)

Pleje/behandling:
32: frisørbesøg
33: tandlægebesøg
34: lægebesøg
35: sagsbehandler/ offentlig instans
36: anden behandling, skriv gerne hvilken

Participant number

Dagbog

Har det været en almindelig uge?:________________________________

	Tid Dag	Mandag, d.	Tirsdag, d.	Onsdag, d.	Torsdag, d.	Fredag, d.	Lørdag, d.	Søndag, d.
Morgen/	6-7 7-8							
Formiddag	8-10							
	10 - 12							
Eftermiddag	12-14							
	14-16							
	16-18							
Aften	18-20							
	20-22							
	22-24							
Nat	0-6							

Tusind tak for din hjælp

Hvis du har nogle spørgsmål du gerne vil have afklaret inden jeg kommer og interviewer dig er du meget velkommen til at kontakte mig:

Henriette Aaby Svendsen
Institut for Psykologi, Københavns Universitet
Njalsgade 88, DK-2300 København S
Tlf. direkte: 35 32 87 53
E-mail: henriette.svendsen@psy.ku.dk

Appendix D: Significant others Questionnaire

The questionnaire[1] is in Danish and contains:

- The European Brain Injury Questionnaire,
- The Patient Competency Rating Scale,
- The Hospital Anxiety and Depression Scale,
- The WHO Quality of Life Questionnaire – short version,
- Questions about demographic variables and perceived social support.

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[1] The questionnaire comes in two versions according to the gender of the participant. This version is for relatives of a male participant.

Participant number

Københavns Universitet Amager **_Institut for Psykologi_**

Pårørende spørgeskema

Helbred, levevilkår og livskvalitet

Indhold:
Demografiske oplysninger
Skema til vurdering af evner og færdigheder
Oplevelse af hverdagsproblemer
Spørgeskema om egen livskvalitet
Skema til vurdering af eget humør
Socialt netværk

Participant number

Oplysninger om køn, alder, uddannelse og beskæftigelse

Navn på den person som du er pårørende til:________________________

Hvad er du til den person, du er pårørende for (ægtefælle, forældre, barn, ven etc.)?: ______

Alder: ________

Køn: mand___ kvinde____

Skolegang:__________________

Videreuddannelse:_____________

Er du i arbejde? Ja_____Nej______

Hvad er din stilling?:__________________________

Har du kendt den person du er pårørende til før skaden? Ja______ Nej______

Hvad er din civilstand?: Gift:_____ Ugift:____ Separeret/skilt:___ Enke/Enkemand:___

Hvis du er gift/samlevende, hvor længe har du da boet sammen med din nuværende partner:______

Participant number

Skema til vurdering af evner og færdigheder

Vurdering af den persons evner og færdigheder som du er pårørende til

I dette spørgeskema bedes du tage stilling til hans evner og færdigheder i forhold til en række forskellige praktiske gøremål og situationer.

Nogle af spørgsmålene angår måske gøremål eller situationer, som ikke er relevante for ham i hans hverdag som den er lige nu. Hvis dette er tilfældet bedes du alligevel besvare spørgsmålene, og prøve at forestille dig, hvordan det ville være, hvis han alligevel skulle gøre det der står anført.

Læs hvert udsagn og vurder, hvor let eller svær den givne opgave eller situation er for ham. Du bedes venligst besvare alle spørgsmål.

Sæt kun 1 kryds ud for hvert spørgsmål!		Kan ikke	Har meget svært ved	Kan med noget besvær	Kan ubesværet	Kan med lethed
1.	Hvor stort et problem har han med at lave sin egen mad ?					
2.	Hvor stort et problem har han med at tage tøj på?					
3.	Hvor stort et problem har han med at udføre sin personlige hygiejne ?					
4.	Hvor stort et problem har han med at vaske op?					
5.	Hvor stort et problem har han med at vaske tøj?					
6.	Hvor stort et problem har han med at tage sig af sin økonomi ?					
7.	Hvor stort et problem har han med at holde sine aftaler til tiden ?					
8.	Hvor stort et problem har han med at starte en samtale i en gruppe ?					
9.	Hvor stort et problem har han med at være vedholdende i arbejdsaktiviteter, når han keder sig eller er træt ?					
10.	Hvor stort et problem har han med at huske, hvad han fik at spise i aftes ?					
11.	Hvor stort et problem har han med at huske navne på folk, han ofte ser ?					
12.	Hvor stort et problem har han med at huske sine daglige gøremål ?					
13.	Hvor stort et problem har han med at huske de vigtige ting, han skal gøre ?					
14.	Hvor stort et problem har han med at køre bil ?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Kan ikke	Har meget svært ved	Kan med noget besvær	Kan ubesværet	Kan med lethed
15.	Hvor stort et problem har han med at søge hjælp, hvis han bliver forvirret ?					
16.	Hvor stort et problem har han med at tilpasse sig, når der sker uventede ændringer ?					
17.	Hvor stort et problem har han med at klare diskussioner med folk han kender godt ?					
18.	Hvor stort et problem har han med at modtage kritik fra andre ?					
19.	Hvor stort et problem er det for ham at kontrollere sin gråd ?					
20.	Hvor stort et problem har han med at opføre sig passende, når han er sammen med sine venner ?					
21.	Hvor stort et problem har han med at vise sine følelser til andre ?					
22.	Hvor stort et problem har han med at deltage i gruppeaktiviteter ?					
23.	Hvor stort et problem har han med at erkende, når noget han siger eller gør sårer andre mennesker ?					
24.	Hvor stort et problem har han med at planlægge daglige gøremål ?					
25.	Hvor stort et problem har han med at forstå nye instruktioner ?					
26.	Hvor stort et problem har han med, vedholdende, at klare de daglige ansvarsområder ?					
27.	Hvor stort et problem har han med at kontrollere sit temperament, når et eller andet bringer ham ud af balance ?					
28.	Hvor stort et problem har han med at undgå at blive trist eller deprimeret ?					
29.	Hvor stort et problem har han med at kontrollere sine følelser således de ikke påvirker hans evne til at klare de daglige gøremål ?					
30.	Hvor stort et problem har han med at kontrollere sin latter ?					

(Sæt kryds ud for det som passer bedst)	Næsten ikke	Ikke særlig godt	Rimelig godt	Godt	Meget godt
Hvor godt kender du hans evner og færdigheder, som du er pårørende til?					

Participant number

Oplevelse af hverdagsproblemer

Disse spørgsmål handler om forskellige problemer eller vanskeligheder, som mennesker af og til oplever i deres liv. Jeg vil gerne vide, hvor meget du mener, at den person, som du er pårørende til, har været udsat for nogle af disse **inden for den sidste måned**. Vær venlig at læse hvert spørgsmål og give respons ved at sætte et kryds under **'slet ikke', 'lidt',** eller **'meget'**. Lad være med at bruge for meget tid på et enkelt spørgsmål. Skriv bare din umiddelbare reaktion.

Hvor meget har den person, du er pårørende til været udsat for det følgende indenfor den sidste måned?

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
1	Hovedpine			
2	Ude af stand til at få gjort tingene til tiden			
3	Reagerer for hurtigt på, hvad andre siger og gør			
4	Problemer med at huske			
5	Svært ved at tage del i en konversation			
6	Føler at andre ikke forstår hans problemer			
7	Alting virker besværligt			
8	Ude af stand til at planlægge, hvad han skal			
9	Synes at fremtiden ser håbløs ud			
10	Hidsighedsanfald			
11	Forvirret			
12	Føler sig ensom, selvom han er sammen med andre mennesker			
13	Humørsvingninger uden grund			
14	Tilbøjelig til at være kritisk overfor andre			
15	Må gøre tingene langsomt for, at det skal blive korrekt			
16	Svimmel			
17	Skjuler sine følelser overfor andre mennesker			
18	Føler sig trist			
19	At han er bestemmende eller dirigerende			
20	Ikke interesseret i sit udseende			

Participant number

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
21	Svært ved at klare sin økonomi			
22	Koncentrationsproblemer			
23	Lægger ikke mærke til andre menneskers sindsstemninger			
24	Føler vrede imod andre mennesker			
25	Bliver let såret			
26	Kan ikke tage sig sammen til at få tingene gjort			
27	Bliver ærgerlig eller irriteret			
28	Problemer med at klare hjemlige gøremål			
29	Mangel på interesse for hjemlige hobbies			
30	Føler sig isoleret			
31	Føler sig mindreværdig overfor andre mennesker			
32	Problemer med at sove			
33	Føler sig utilpas i en større forsamling			
34	Råber ad folk i vrede			
35	Svært ved at give udtryk for, hvad han ønsker			
36	Føler sig usikker på, hvad han skal gøre i farlige situationer			
37	Stædig			
38	Uinteresseret i sine omgivelser			
39	Har en ringe tidsfornemmelse			
40	Har mistillid til andre mennesker			
41	Har let til tårer			
42	Svært ved at orientere sig i nye omgivelser			
43	Tilbøjelig til at spise for meget eller for lidt			
44	Kommer let op at skændes			
45	Træt eller sløv			
46	Mangel på selvværd			
47	Mangel på hobbies udenfor hjemmet			
48	Prioriterer sine egne interesser frem for andres			
49	Rastløs			
50	Anspændt			

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
51	Reagerer uhensigtsmæssigt i sociale sammenhænge			
52	Føler, at livet ikke er værd at leve			
53	Glemmer aftaler			
54	Overlader til andre at tage initiativet i samtaler			
55	Nedsat seksuallyst			
56	Mister selvbeherskelsen, når han bliver vred			
57	Foretrækker at være alene			
58	Svært ved at tage beslutninger			
59	Har mistet kontakten til sine venner			
60	Mangel på interesse for nyhedsstof			
61	Opfører sig taktløst			
62	Har problemer i almindelighed			

Vær nu venlig også at besvare de følgende spørgsmål **om dig selv:**

Sæt kun 1 kryds ud for hvert udsagn!		Slet ikke	Lidt	Meget
63	Er dit liv blevet forandret, efter at din pårørende fik sin skade?			
64	Har du problemer på grund af hans nuværende situation?			
65	Er dit humør blevet påvirket af hans nuværende situation?			

Participant number

Spørgeskema om Livskvalitet

De følgende spørgsmål handler om, hvordan du føler din egen livskvalitet, din sundhed og andre områder af dit liv er.
Hvis du er usikker på, hvilket svar du skal vælge, så vælg det du synes er mest passende.

Lad være med at tænke for meget over det, det er oftest din første indskydelse, der er den mest passende. Der er ingen rigtige eller forkerte svar.

Du bedes venligst besvare alle spørgsmål.
Du skal svare udfra, hvordan du føler dit liv har været indenfor de sidste 2 uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget dårlig	Dårlig	Hverken god eller dårlig	God	Særdeles god
1	Hvordan mener du din livskvalitet er ?					

De følgende spørgsmål handler om, i hvilken grad du har oplevet visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget utilfreds	Utilfreds	Hverken tilfreds eller utilfreds	Tilfreds	Særdeles tilfreds
2	Hvor tilfreds er du med dit helbred ?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Lidt	I nogen grad	Meget	Virkelig meget
3	I hvilken grad føler du at smerter forhindrer dig i dine gøremål ?					
4	I hvilken grad har du brug for medicinsk behandling for at fungere i dagligdagen?					
5	I hvilken grad nyder du livet ?					
6	I hvilken grad opfatter du dit liv som meningsfuldt ?					
7	Hvor god er du til at koncentrere dig ?					
8	Hvor tryg føler du dig i dagligdagen?					
9	Hvor sundt er det fysiske miljø du bor i ?					

Skemaet fortsætter på næste side

De følgende spørgsmål handler om, hvor godt du har været i stand til visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Næsten ikke	I nogen grad	For det meste	Fuld-stændig
10	Har du energi nok til at klare dagligdagen?					
11	Kan du acceptere sådan som din krop ser ud?					
12	Har du penge nok til at dække dine behov ?					
13	Kan du skaffe den information, som er nødvendig for dig i din hverdag ?					
14	I hvilken grad har du mulighed for at dyrke fritidsaktiviteter ?					

I de følgende spørgsmål skal du svare på, hvor tilfreds du har været med forskellige sider i dit liv indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Slet ikke	Lidt	I nogen grad	Meget	Virkelig meget
15	Hvor godt er du i stand til at komme omkring?					

Sæt kun 1 kryds ud for hvert spørgsmål!		Meget utilfreds	Utilfreds	Hverken tilfreds eller utilfreds	Tilfreds	Særdeles tilfreds
16	Hvor tilfreds er du med din søvn ?					
17	Hvor tilfreds er du med din evne til at udføre daglige gøremål ?					
18	Hvor tilfreds er du med din arbejdsevne?					
19	Hvor tilfreds er du med dig selv ?					
20	Hvor tilfreds er du med dit forhold til andre mennesker?					
21	Hvor tilfreds er du med dit seksualliv ?					
22	Hvor tilfreds er du med den støtte du får fra dine venner ?					
23	Hvor tilfreds er du med levevilkårene i din bolig ?					
24	Hvor tilfreds er du med den hjælp du kan få til dine helbredsproblemer ?					
25	Hvor tilfreds er du med dine transportmuligheder ?					

De følgende spørgsmål handler om, hvor ofte du har følt visse ting indenfor de sidste to uger.

Sæt kun 1 kryds ud for hvert spørgsmål!		Aldrig	Sjældent	Ret tit	Meget tit	Altid
26	Hvor tit har du haft negative følelser som for eksempel nedtrykthed, fortvivlelse eller angst?					
27	Er du glad for tilværelsen ?					

Participant number

Skema til vurdering af humør

De følgende udsagn handler om hvordan du har det humørmæssigt

Læs hvert udsagn grundigt, og vurder i hvor høj grad det pågældende udsagn passer, når du tænker på den sidste uges tid.

Der er ingen rigtige eller forkerte svar.

Du bedes venligst besvare alle spørgsmål.

Sæt kun 1 kryds ud for hvert udsagn		Slet ikke / Næsten ikke	Ind i mellem/ Kun lidt	Ofte / I nogen grad	Meget ofte / Det meste af tiden
1	Jeg føler mig anspændt eller kørt op.				
2	Jeg kan nyde livets glæder lige så godt som før i tiden.				
3	Jeg føler undertiden en ubestemmelig frygt, som om der skal ske noget frygteligt.				
4	Jeg kan le og more mig.				
5	Der kører bekymringer rundt i hovedet på mig.				
6	Jeg føler mig munter.				
7	Jeg kan slappe helt af når det passer mig				
8	Jeg føler mig noget sløv og hæmmet.				
9	Jeg er undertiden så nervøs at jeg har sommerfugle i maven				
10	Jeg er holdt op med at interessere mig for mit udseende.				
11	Jeg føler mig rastløs og urolig.				
12	Jeg kan glæde mig til noget, der skal ske.				
13	Jeg får pludselige anfald af panik eller uro				
14	Jeg kan nyde en god bog eller et godt radio eller TV program				

Participant number

Oplevet socialt netværk og støtte:

Familie

1. Hvor meget støtte/hjælp får den person du er pårørende til fra familien?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte hjælp vedkommende har brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

2. Hvilken slags støtte og hjælp yder familien? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

3. Besvar nu venligst samme spørgsmål i fht. dig selv. Hvor meget støtte/hjælp oplever du at modtage fra din familie?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du oplever at have brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

4. Hvilken slags støtte og hjælp yder din familie dig? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Venner

5. Hvor meget støtte/hjælp får den person, som du er pårørende til, fra venner?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte hjælp vedkommende har brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

6. Hvilken slags støtte og hjælp yder vennerne? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Venner, fortsat

7. Besvar nu venligst samme spørgsmål i fht. dig selv. Hvor meget støtte/hjælp oplever du at modtage fra dine venner?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du oplever at have brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

8. Hvilken slags støtte og hjælp yder dine venner dig? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Naboer

9. Hvor meget støtte/hjælp får den person, som du er pårørende til, fra naboer?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte hjælp vedkommende har brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

10. Hvilken slags støtte og hjælp yder naboerne? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

11. Besvar nu venligst samme spørgsmål i fht. dig selv. Hvor meget støtte/hjælp oplever du at modtage fra dine naboer?
Sæt venligst kryds på nedenstående skala fra 1-5, hvor 1 betyder minimal støtte og hjælp i fht. behov og 5 betyder al den støtte/hjælp du oplever at have brug for.

1 **2** **3** **4** **5**
Minimal støtte Maksimal støtte

12. Hvilken slags støtte og hjælp yder dine naboer dig? (Sæt kun 1 kryds)
   1. Ingen
   2. Følelsesmæssig
   3. Praktisk
   4. Begge dele

Er der noget jeg ikke har spurgt dig om som du synes er vigtigt eller gerne vil meddele?

____
____
____

Tusind tak for din hjælp

Hvis du har nogle spørgsmål er du velkommen til at kontakte mig:

Henriette Aaby Svendsen
Institut for Psykologi, Københavns Universitet
Njalsgade 88, DK-2300 København S
Tlf. direkte: 35 32 87 53
E-mail: henriette.svendsen@psy.ku.dk

Appendix E: Interview guide

The interview is in Danish and contains nine sections:

- Health since brain injury,
- Physical, Cognitive, Emotional, Social and Practical Complaints and use of compensatory techniques,
- Received therapy and help due to the brain injury today,
- Employment situation,
- Leisure activities,
- Social network,
- Satisfaction with own adaptation after the brain injury,
- Satisfaction and rating of the CRBI program and perceived helpful factors after brain injury
- Interviewers rating

SPØRGSMÅL TIL FORSKELLIGE OMRÅDER:

1. Helbred siden årsag til inklusion i denne undersøgelse.
2. Vanskeligheder og brug af kompensationsstrategier.
3. Aktuel støtte, genoptræning og offentlige tilskud.
4. Arbejdsliv.
5. Fritidsliv.
6. Socialt: Familie, venner, parforhold.
7. Tilfredshed med egen tilpasning.
8. Tilfredshed med Center for Hjerneskade og opfattelse af hjælpende faktorer efter skade.
9. Interviewers vurdering.

Interview dato:____________

Skadesår:_____

Jeg vil gerne have et billede af den sidste måneds tid
Vil du sige at den har været normal?

	0 Nej, hvis Nej hvad:	1 Ja
Mht. arbejde		
Mht. fritid		
Mht. social liv		

Har du indenfor det sidste halve år oplevet følgende større livsforandringer? (The social readjustment rating scale (1967)):

Sæt kryds	0 Nej	1 Ja
1. Ægtefælles død		
2. Skilsmisse		
3. Separation		
4. Fængselsstraf		
5. Nærtstående familiemedlems død		
6. Personlig skade eller sygdom		
7. Blevet gift		
8. Afskediget på arbejde		
9. Ægteskabelig forsoning		
10. Pension		
11. Sygdom i familien		
12. Graviditet		
Andet		

1. Helbred siden skade på hjernen

Har du været indlagt på et hospital indenfor de sidste 10 år? 0. Nej 1. Ja

Hvis ja, for hvad:_____________
Antal hospitalsindlæggelser indenfor de sidste tre måneder:__________, dage i alt:_________
Hvad skyldes eventuelle indlæggelser:____

Ellers gå til spørgsmål om alkohol og rygning

Har du været indlagt for nyt kranietraume/ny hjerneblødning/hjernelidelse siden indlæggelsen (/ efter CFH – skal ikke siges) den ______? 0.nej 1.ja, hvis ja: hvornår:______

Hvis ja, skade type:
1. Hjernekvæstelse
2. Hjernerystelse
3. Blodprop
4. Blødning
5. Tumor/svulst
6. Iltmangel
7. Infektion
8. Organiske opløsningsmidler
9. Anden forgiftning
10. Progredierende hjernelidelse: demens, altzheimers
11. anden:_________________

Har du haft nogle kropslige eller psykiske lidelser efter din skade på hjernen?

	Syg 1	Syg 2	Syg 3
Hvad hed sygdommen?			
Fysisk/Psykisk/Bege dele/uklart?	1. Fys 2. Psyk 3. begge 4. uklart	1. Fys 2. Psyk 3. begge 4. uklart	1. Fys 2. Psyk 3. begge 4. uklart
Hvornår var det (årstal)?			
Hospitalsindlæggelse	0. nej 1. ja	0. nej 1. ja	0. nej 1. ja
Ambulant/lægebehandli	0. nej 1. ja	0. nej 1. ja	0. nej 1. ja
Anden behandling	0. nej 1. ja	0. nej 1. ja	0. nej 1. ja
Er du fortsat i beh Ja/nej	0. nej 1. ja	0. nej 1. ja	0. nej 1. ja
Påvirker det dig i dag Ja/nej	0. nej 1. ja	0. nej 1. ja	0. nej 1. ja

Rygning aktuelt
1. Ryger daglig antal___
2. Ikke ryger

Alkohol aktuelt
1. Nyder alkohol antal genstande ugt._____
2. Nyder ikke alkohol

Bruger du andre rusmidler/stoffer
0. Nej
1. Ja

Participant Number

2. Klager indenfor den sidste måned

Fylder hjerneskaden og de problemer den umiddelbart måske førte med sig stadig noget i dit liv?	0. nej	1. ja

Hvis Ja, hvor meget har skaden fyldt den sidste måned? Skala fra 1-5:

næsten intet	1	2	3	4	5 Har fyldt noget hele tiden

Fylder skaden på en overvejende positiv eller negativ måde?	0. Negativ	1. Positiv

Participant Number

2. Fysiske klager den sidste måned, adspurgt

Klage Området	Emne Beskriv nærmere under de enkelte kategorier	0. Slet ikke et problem	1 Et lille problem, der ikke påvirker mine aktiviteter	2.Et mildt problem, der påvirker mine aktiviteter < end 25% af tiden.	3. Et moderat problem, der påvirker mine aktiviteter 25-75% af tiden.	4.Et stort problem, der påvirker mine aktiviteter mere end 75% af tiden
Fysisk Har du haft andre fysiske klager den sidste måned som følge af skaden på hjernen?	Smerter: f.eks. hovedpine					
	Fysisk træthed:					
	Gang/ bevæge sig rundt:					
	Brug af hænder / finmotorik					
	Sensorisk følesans Motorisk kraft					
	Balance:					
	Svimmelhed					
	Nedsat seksuel lyst					
	Nedsat seksuel evne					
	Fordøjelse/blære					
	Hørelse/syn/lugt/smag/:					
	Epileptiske anfald de sidste 3 måneder? **0= nej 1= ja**					
	Andet:					

2. Kognitive klager adspurgt

Klage Området	Emne Beskriv nærmere under de enkelte kategorier	0. Slet ikke et problem	1 Et lille problem, der ikke påvirker mine aktiviteter	2.Et mildt problem, der påvirker mine aktiviteter < end 25% af tiden.	3. Et moderat problem, der påvirker mine aktiviteter 25-75% af tiden.	4.Et stort problem, der påvirker mine aktiviteter mere end 75% af tiden
Kognitivt Har du haft andre kognitive klager den sidste måned som følge af skaden på hjernen?	**Tempo**: Oplever du, at du tænker langsomt?					
	Koncentration: Har du svært ved at koncentrere dig?					
	Indlæring/hukommelse: Er glemsomhed et problem?					
	Overblik/planlægning/problemløsning.: Har du svært ved at planlægge/organisere ting, bliver du let forvirret? Eller kaster du dig ud i flere projekter end du kan magte?					
	Kommunikation: Har du svært ved at forstå/ gøre dig forståelig overfor andre? Eller svært ved at følge med i en samtale? Eller svært ved at finde det rette ord?					
	Initiativ: Har du brug for opfordringer til at få ting gjort? (Eks. Er det svært for dig at føle dig motiveret?)					
	Læse/stave/regne:					
	Visuel konstruktion: Har du svært ved at tegne/ samle møbler efter tegning/ sætte ting sammen/ lægge puslespil?					
	Neglekt: Overser du nogle gange dit venstre synsfelt? Eller glemmer du at inddrage den svage arm?					
	Topografisk orientering: Kan du have vanskeligheder med at finde rundt?					
	Andet?					

2. Følelsesmæssige klager, adspurgt

Klage Området	Emne Beskriv nærmere under de enkelte kategorier	0. Slet ikke et problem	1 Et lille problem, der ikke påvirker mine aktiviteter	2.Et mildt problem, der påvirker mine aktiviteter < end 25% af tiden.	3. Et moderat problem, der påvirker mine aktiviteter 25-75% af tiden.	4.Et stort problem, der påvirker mine aktiviteter mere end 75% af tiden
Emotionelt Har du haft andre følelsesmæssige klager den sidste måned som følge af skaden på hjernen?	Er **stress** et problem:					
	Hvad med **selvtillid**					
	Humør: **Deprimeret**/ trist/nedtrykt:					
	Angst/uro: Bliver du let ængstelig?					
	Ligegyldighed					
	Labilitet: Kommer til at grine eller græde uden at det svarer til situationen					
	Har du svært ved at **forstå ironi**/sarkasme eller at forstå når andre laver sjov/ ping-pong/ vittigheder					
	Frustration/vrede, Kort lunte/**irritabilitet**: kommer let op at skændes med andre					
	Impulsivitet: Kommer du til at handle og tale før du får tænkt dig om?					
	Andet					

2. Sociale klager adspurgt

Klage Området	Emne Beskriv nærmere under de enkelte kategorier	Omfang				
		0. Slet ikke et problem	1 Et lille problem, der ikke påvirker mine aktiviteter	2.Et mildt problem, der påvirker mine aktiviteter < end 25% af tiden.	3. Et moderat problem, der påvirker mine aktiviteter 25-75% af tiden.	4.Et stort problem, der påvirker mine aktiviteter mere end 75% af tiden
Socialt Har du haft sociale problemer den sidste måned, som følge af hjerneskaden?	**Isolation**: Føler du dig socialt isoleret?					
	Upassende adfærd: Siger du eller gør du ting i selskab med andre som du fortryder?					
	Kommer ikke ud af huset så ofte, som jeg gerne vil:					
	Er det svært for dig at lægge mærke til **andres humør?**					
	Får ikke inviteret andre så ofte som jeg gerne vil?:					
	Selvcentrerethed/Empati: Har du svært ved at indleve dig i andres situation?					
	Andet:					

2. Praktiske klager adspurgt

Klage Området	Emne Beskriv nærmere under de enkelte kategorier	0. Slet ikke et problem	1 Et lille problem, der ikke påvirker mine aktiviteter	2.Et mildt problem, der påvirker mine aktiviteter < end 25% af tiden.	3. Et moderat problem, der påvirker mine aktiviteter 25-75% af tiden.	4.Et stort problem, der påvirker mine aktiviteter mere end 75% af tiden
Praktisk Har du haft praktiske vanskelig-heder den sidste måned som følge af hjerneskaden?	Personlig **hygiejne og påklædning:**					
	Indkøb (finde rundt, huske, betale):					
	Madlavning: (halvsidig lammelse, læsning, struktur, initiativ) springer han over måltider/ synes han at han laver OK sund mad					
	Rengøring:					
	Benytte **offentlig transport**:					
	Egen transport (køre bil/ cykle):					
	Kontakt til det offentlige: Læse breve fra det offentlige					
	Økonomi: Har du problemer med din økonomi?					
	Planlægge hverdagen: Holde aftaler, træffe beslutninger					
	Andet:					

Anvender du kompensationsmekanismer?

Hvor tit bruger du dem?

		0Aldrig	1Sjældent	2Ofte/Tit	3Meget tit	4Altid
1	Jeg skriver ting ned for ikke at glemme dem					
2	Jeg skriver aftaler ned i kalender/elektronisk kalender for at kunne huske dem?					
3	Jeg holder bevidst pauser for at klare mine opgaver bedre					
4	Jeg planlægger mine opgaver før jeg går i gang for at undgå at miste overblikket					
5	Jeg kontrollerer at jeg har gjort det rigtigt, når jeg har udført en opgave					
6	Jeg trækker mig nogle gange tilbage midlertidigt tilbage for at genvinde kontrollen over mine følelser					
7	Jeg beder andre om hjælp, når jeg ikke selv kan løse en opgave					
8	Jeg tager notater, skriver huskelister/tjeklister					

3. Aktuel støtte, genoptræning og offentlige tilskud

Modtaget hjemmehjælp ugentligt? ugentligt gennemsnit de sidste tre måneder

0: ingen
1: 0-1 time pr uge
2:2-3 timer pr uge
3: 4-5 timer pr uge
4: 6-7 timer pr uge
5: 8-9 timer pr uge
6: 10-11 timer pr uge
7: 12-13 timer pr uge
8: 14-15 timer pr uge
9: 16 timer eller derover pr uge

Af hvilken årsag: 1: hjerneskaden, 2: andet,
hvad:____________________________

Mener du selv du nu har behov for hjemmehjælp på grund af hjerneskaden:
0. Nej 1. Ja

Antal timer støtteperson ugentlig igennem de sidste 3 måneder?

0: ingen
1: 0-1 time pr uge
2:2-3 timer pr uge
3: 4-5 timer pr uge
4: 6-7 timer pr uge
5: 8-9 timer pr uge
6: 10-11 timer pr uge
7: 12-13 timer pr uge
8: 14-15 timer pr uge
9: 16 timer eller derover pr uge

Af hvilken årsag: 1: hjerneskaden, 2: andet,
hvad:___________________________

Mener du selv du nu har behov for støtteperson på grund af hjerneskaden:

0. Nej 1. Ja

Hjemme sygepleje ugentligt gennemsnit de sidste tre måneder

0: ingen
1: 0-1 time pr uge
2:2-3 timer pr uge
3: 4-5 timer pr uge
4: 6-7 timer pr uge
5: 8-9 timer pr uge
6: 10-11 timer pr uge
7: 12-13 timer pr uge
8: 14-15 timer pr uge
9: 16 timer eller derover pr uge

Af hvilken årsag: 1: hjerneskaden, 2: andet,
hvad:___________________________

Betalt af: 1. socialforvaltning
2. selv
3. andet, hvad:____________________________

Mener du selv du nu har behov for hjemmesygepleje på grund af hjerneskaden:

0. Nej 1. Ja

Modtaget ergo/fysioterapi ugentligt gennemsnit de sidste tre måneder?

0: ingen
1: 1 time pr uge
2: 2 timer pr uge
3: 3 timer pr uge
4: 4 timer pr uge
5: 5 timer pr uge
6: 6 timer pr uge
7: 7 timer pr uge
8: 8 timer pr uge
9: mere end 8 timer pr uge

Af hvilken årsag: 1: hjerneskaden, 2: andet, hvad:___________________________

Betalt af:
1. socialforvaltning
2. selv
3. andet, hvad:____________________________

Mener du selv du nu har behov for behandling/optræning ved ergo/fysioterapi på grund af hjerneskaden: 0. Nej 1. Ja

Antal psykologtimer ugentligt gennemsnit de sidste tre måneder

0: ingen
1: 1 time pr måned
2: 2 timer pr måned
3: 3 timer pr måned
4: 4 timer pr måned
5: 5 timer pr måned
6: 6 timer pr måned
7: 7 timer pr måned
8: 8 timer pr måned
9: mere end 8 timer pr måned

Af hvilken årsag: 1: hjerneskaden, 2: andet, hvad:___________________________

Betalt af:
1. socialforvaltning
2. selv
3. andet, hvad:____________________________

Mener du selv du nu har behov for behandling/optræning ved psykolog på grund af hjerneskaden:
0. Nej 1. Ja

Daghøjskole/Specialundervisning/Dagcenter indenfor den sidste måned?
0= nej
1= deltid: ....timer pr. uge (2 variable: deltid/fuldtid og timer)
2= fuldtid: ....timer pr. uge

Mener du selv du nu har behov for Daghøjskole/Specialundervisning/Dagcenter på grund af hjerneskaden: 0. Nej 1. Ja

Andet genoptræning/hjælp/behandling
0= nej 1= ja
Angiv arten:..

Mener du selv du nu har behov for anden behandling/opfølgning på grund af hjerneskaden f.eks. Socialrådgiver/logopæd, speciallærer:
0. Nej 1. Ja, hvis ja, hvilken:______________________________

Medicin taget regelmæssigt i den sidste måned?
0= nej, 1 = ja
Hvis ja, hvad er taget? ____________________ For hvad:____________________
Hvis ja, hvad er taget? ____________________ For hvad:____________________
Hvis ja, hvad er taget? ____________________ For hvad:____________________
Hvis ja, hvad er taget? ____________________ For hvad:____________________
Hvis ja, hvad er taget? ____________________ For hvad:____________________

Angstdæmpende:....
Antiepilepsi:.......
Smertestillende:..........
Antidepressiva:..........
Antipsykotisk:.........
Sovemedicin:.........
Andet:...........

Antal lægebesøg hos egen læge og eller speciallæge indenfor de sidste tre måneder:________
Hvad skyldes eventuelle lægebesøg?____________________________________
Mener du selv du nu har behov for læge på grund af hjerneskaden af:
0. Nej 1. Ja, hvis ja, hvilken:______________________________

Antal kontakter til hospital til ambulant behandling/kontrol indenfor de sidste 3 måneder:____
Hvad skyldes eventuelle kontakter?____

4. Arbejde/ Uddannelse

(Skal ikke stilles som spørgsmål, men bare rates)

Hvad er din erhvervsmæssige situation (TWT og Aase Engbergs spørgeskema)?

1. Skolepligtig, går i alm. skole/HF/Gymnasium
2. Skolepligtig, modtager specialundervisning
3. Under erhvervsuddannelse, normal
4. Under erhvervsuddannelse, beskyttet/revalidering
5. Erhvervsarbejde på normale betingelser (løn, arbejdstid, arbejdets indhold)
6. Erhvervsarbejde, beskyttet/reduceret tid/ offentligt tilskud
7. Hjemmegående husmoder / -fader uden hjælp
8. Hjemmegående husmoder / -fader med hjemmehjælp
9. Jobtilbud som arbejdsløs
10. Ledig arbejdsløs/kontanthjælpsmodtager
11. Førtidspensionist (årsag:)
12. Alderspension/efterløn/overgangsydelse
13. Andet ___________________________
99. Uoplyst

Hvad er dit økonomiske forsørgelsesgrundlag (GPI-2000) ?		**Kr. pr. måned**
1	Løn	
2	SU	
3	Dagpenge	
4	Kontanthjælp	
5	Ingen kontanthjælp pga partners formue	
6	Social pension	
7	Sygedagpenge	
8	Sygemeldt med løn	
9	Bruttorevalideringsydelse	
10	Flexjob	
11	afventer fleksjob + kontanthjælp	
12	forskud på førtidspension	
13	førtidspension ? Deltidslønarabejde	
14	førtidspension + skånejob (1/3 stilling)	
15	førtidspension + uformel arbejdstillknytning	
16	Andet	

Anden beskæftigelse (Johansen, Pedersen & Laursen, 2004)

Sæt kun 1 kryds		0Aldrig	1Sjældnere	3Månedligt	4Ugentligt	4Næsten dagligt
1	Andet betalt arbejde (fx hjælpe naboer og bekendte, gå til hånde på tidligere arbejdsplads)					
2	Ulønnet arbejde (fx hjælpe naboer og bekendte, gå til hånde på tidligere arbejdsplads)					
3	Frivilligt arbejde (fx indsamlinger, foreningsarbejde, genbrugsbutik, besøgsven)					
4	Dagcenter/aktivitetscenter					

For dem som er i arbejde:

Er arbejdet anderledes end før skaden? **0: nej 1: ja**

Skyldes det hjerneskaden? **0: nej 1: ja**

Er arbejdet i samme tidsmæssige omfang som før hjerneskaden? **0: nej 1: ja**

Hvis nej, skyldes det da følger efter hjerneskaden? **0: nej 1: ja**

Består arbejdet af de samme funktioner, som du havde før din hjerneskade? **0: nej 1: ja**

Hvis nej, skyldes det da følger efter hjerneskaden? **0: nej 1: ja**

Svarer arbejdsindholdet til de **forventninger** du har til dig selv **0: nej 1: ja**

Alle

Hvor længe har du været i denne situation/dette arbejde osv i **flg Pamela Klonoffs work history (1998) (tabel).**

Jeg vil gerne have et indblik i din tilknytning til arbejdsmarkedet/en uddannelse, så jeg vil gerne have vi bevæger os bagud i tiden, hvad lavede du før det du laver nu?

Participant Number

Hvornår (årstal)	Arbejdsplads	Arbejdsfunktion	Arbejdstype	Varighed **(uger)**	Ugentlig arbejdstid **(timer)**
I DAG			0. Arbejdsløs 1. Frivilligt 2. Forrevalidering 3. Revalidering 4. Fleksjob 5. Skånejob 6. Job på almindelige vilkår 7. Uddannelse		

Nævn tre grunde til at du er i arbejde eller ikke er i arbejde:

Vurder hvor stor betydning arbejde har for din livskvalitet på en skala fra 1 (ingen betydning, f.eks. pension) til 5 (meget stor betydning).

1 2 3 4 5

Vurder hvor stor betydning din økonomi har for din livskvalitet på en skala fra 1 (ingen betydning) til 5 (meget stor betydning).

1 2 3 4 5

5. Fritidsaktiviteter - uafhængighed

Når den enkelte har fået rehabilitering - kan man formode at det burde optimere den enkeltes aktivitetsniveau i egne fritidsinteresser, såvel som i gruppebaserede sammenhænge (holdsport, politik)

Har du dyrket fritidsaktiviter den sidste måned? 0 = Nej 1 = Ja , hvis ja, hvilke: (udfyld for neden)

Dyrker du det/dem regelmæssigt?
0 = Nej
1 = Ja , hvis ja, er det: **Frekvens**: 1= sæsonbestemt
2 =årlig
3 =månedlig
4 = ugentlig
5 = daglig

Type Fritidsaktivitet**:**

1= Sport (hvilke)
2= Foreningsliv (hvilke, hjerneskadefore)
3= Kunst/kultur (aktiv eller tilskuer)
Musik, maling, sociale besøg, museum
4= Hus/have (hvilke)
10= Computer

5= Mekanik/Teknik (hvilke)
6= Læse bøger/aviser/blade
7= Håndarbejde (hvilke)
8= gå på aftenskole
9= TV
11= Andet

Navn & Type :________________________frekvens ___ alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ alene/ m andre Ant timer pr gang ___

5.02 Har du andre interesser som du ikke har dyrket den sidste måned ? 0 = Nej 1 = Ja , hvis ja, hvilke: (udfyld for neden)

Navn & Type :________________________frekvens ___ 0 alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ 0 alene/ m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ 0 alene/ m andre Ant timer pr gang ___

Hvis ja, Hvad er grunden til, at informanten ikke har brugt tid på dette den sidste måned (hvis det ikke skyldes sæson er det så manglende planlægning, initiativ, manglende kørsel etc)?

____
____
____

Kunne du ønske dig nogle fritidsaktiviteter i fremtiden ?
0 = Nej
1 = Ja , hvis ja, hvilke ?:

Navn & Type :________________________frekvens ___ 0 alene m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ 0 alene m andre Ant timer pr gang ___
Navn & Type :________________________frekvens ___ 0 alene m andre Ant timer pr gang ___

Hvad forhindrer dig i at gøre det du gerne vil?

____
____
____

(Glostrup undersøgelse)
Hvilken af følgende grupper mener du selv, din fritidsbeskæftigelse omfatter?:

1. Stillesiddende:
Du sidder som regel og læser, ser fjernsyn, går i biografen eller tilbringer fritiden med stillesiddende sysler, aktivitet mindre end 2 timer pr. uge.

2. Let motion:
Du går tur, kører lidt cykel eller er i legemelig aktivitet mindst 2-4 timer om ugen (lettere fritidsbyggeri, bordtennis, bowling eller lettere have/husarbejde).

3. Motion:
Du er aktiv idrætsudøver, løber, svømmer, spiller tennis eller badminton. Med lettere fysisk niveau i mindst 4 timer om ugen eller med anstrengende aktiviteter2-4 timer om ugen. Hvis du ikke dyrker nogen sport, men hver uge udfører tungt havearbejde eller tungt fritidsarbejde i de anførte tidsperioder, hører du også til denne gruppe.

4. Træner hårdt:
Du dyrker konkurrence idræt, eksempelvis svømmer, spiller fordbold eller løber lange distancer flere gange om ugen, dvs. højt anstrengelsesniveau mindst 4 timer om ugen.

Vurder hvor stor betydning fritid har for din livskvalitet på en skala fra 1 (ingen betydning) til 5 (meget stor betydning) (de får et papir med skalaen på så de selv kan krydse af).

1 2 3 4 5

Participant Number

6. Netværket: Hvem har du haft kontakt med den sidste måned? / Beskriv de mennesker du kommunikerer med jævnligt

Familie /partner
Hvor mange familiemedlemmer har du?
Partner ja/nej
Børn ja/nej
Børnebørn ja/nej
Søskende + partnere ja/nej
Partners familie ja/nej
Forældre ja/nej
Bedsteforældre ja/nej
Andre:____________________
Hvem havde du social kontakt med den sidste måned?

Venner
Har du nogen nære venner? 0 nej 1 ja
Hvor mange nære venner har du?
Hvor mange havde du kontakt med den sidste måned?

Dig:____________

Arbejde / uddannelses aktiviteter
Møder du nogen på dit arbejde? 0 nej 1 ja
Hvor mange kollegaer møder du dagligt (den sidste måned)?

Fritid
Møder du nogen I dine fritidsaktiviteter? 0 nej 1 ja
Hvor mange ca.?
Hvor mange havde du social kontakt med den sidste måned?

6. Socialt: familie, venner, parforhold, roller, konflikter

Hypoteser:
10 år efter en hjerneskade ses stadig isolation og sociale klager fra den hjerneskadede og de pårørende. Genoptræning kunne muligvis betyde:
a) større netværk (både at vedligeholde venskaber og at skabe nye)
b) større tilfredshed med relationer generelt

Tegn et **billede af det sociale netværk** på side (19).

Mit sociale liv efter hospitalisering og evt. genoptræning er?(deltager skalaer)

Min evne til at indgå i nære sociale forhold er? (deltager skalaer)

Interviewede bor med:
☐Partner (og børn)
☐Forældre (eller anden familie)
☐Andre
☐Alene
☐Andet, hvad: ______________________

Parforhold

Er du i et parforhold nu? 9 ja 9 nej,
Hvis ja: Hvor længe har det varet (i år)/ går det tilbage fra før skaden
->gå så til *

Hvis nej: Er det noget du gerne vil have? 1. ja 0. nej, hvor længe er det siden sidste partner (i år):............
Hvis nej, gå til Familie

Hvis ja Hvor god er du til at skabe kontakt til en mulig partner (1-5)
Hvor god er du til at vedligeholde et parforhold (1-5)
Synes du at hjerneskaden spiller en rolle i forhold til at være i et parforhold?

* Hvor tilfreds er du med dit parforhold (1-5)?

1 2 3 4 5

Hvor tilfreds, tror du din partner er med jeres parforhold (1-5)?

1 2 3 4 5

Hvor meget betyder samvær i et parforhold, for din livskvalitet (1-5)

1 2 3 4 5

Familie

E**r den kontakt du har til din familie tilfredsstillende** for dig (forældre, børn)?

1 2 3 4 5

Tror du, at den kontakt du har med familien er **tilfredsstillende for dem** (angiv forældre børn)?

1 2 3 4 5

Hvor meget betyder samvær med familien for din livskvalitet (1-5)

1 2 3 4 5

Venner

Hvordan vurderer du dit forhold til dine venner - er det tilfredsstillende for dig?

1 2 3 4 5

Hvor tilfredsstillende er jeres forhold for dem?

1 2 3 4 5

Har du behov for at skabe nye kontakter 1 ja 0 nej

Hvis ja - Hvor god synes du at du er til at skabe nye kontakter? (1-5)

1 2 3 4 5

Hvis ja - Hvor god er du til at vedligeholde nye venskaber (1-5)

1 2 3 4 5

Hvor meget betyder samvær med venner for livskvalitet (1-5)

1 2 3 4 5

Hvem tilbringer du mest tid sammen med 1) familie eller 2) venner?

Har din rolle i sociale sammenhænge ændret sig: 0. Nej 1. Ja
Hvordan________________________________ (F.eks. er du blevet mere indadvendt?)

Har du oplevet at andre mennesker har fordomme/manglende viden om det at være hjerneskadet?? 0. Nej 1. Ja

Betyder fordomme om hjerneskade noget for at skabe kontakt til andre? 0. Nej 1. Ja
a) indledningsvist, ikke senere
(skal ikke tastes ind)
b) jeg opnår aldrig kontakt

Foretrækker du
0) Ikke at fortælle om din skade
1). At fortælle om den med det samme
2) Ja, hvis de spørger
3) Andet_____________________________________

7. Tilfredshed med egen tilpasning

Min indsats for at overvinde vanskelighederne efter hjerneskaden/under genoptræningsperioden har været:

Ikke noget specielt ……………..................................En bemærkelsesværdig præstation

1 2 3 4 5

Selvom mit nuværende liv er forskelligt fra det, det var før skaden, har det den sidste måned/ er det:

Akkurat lige tåleligt……..Meget meningsfyldt

1 2 3 4 5

Efter hjerneskaden/ genoptræningsperioden har jeg ført et:

1 2 3 4 5

Uproduktivt liv..Meget produktivt liv

Efter genoptræning/hjerneskaden/den sidste måned føler jeg, at jeg:

stadig ikke er i harmoni med mig selv............................er i fuldstændig harmoni med mig selv

1 2 3 4 5

8. Tilfredshed med det offentlige og Center for Hjerneskade

For elever der har gået på CfH evalueres dette

Synes du optræningsprogrammet hjalp dig? 0. Nej 1. Ja

Hvis ja, hvad var det der hjalp:

Hvis nej, kan du uddybe det? Var der noget du mener dagprogrammet ikke tog højde for?
Eller skete der andre ting i dit liv, som forhindrede at du fik noget ud af det?

Prioriter de fem vigtigste

_______ Kontakten med de andre elever
_______ primærterapeut
_______ personalet som helhed
_______ samtalegruppe
_______ fysisk træning
_______ kognitiv træning
_______ stemmetræning
_______ sprogtræning
_______ specialundervisning
_______ morgenmøde/andre gruppeaktiviteter
_______ støtte til sagsbehandler/arbejde/økonomi
_______ follow-up møderne (indviduelt/i gruppe)
_______ andet

På en skala fra 1-5, hvilken **betydning** har opholdet på Cfh haft for:

Sæt kun 1 kryds ud for hvert udsagn		1 ingen betydning	2 lille betydning	3 Nogen betydning	4 væsent-lig be-tydning	5 stor betydning
1	Tilbagevenden til arbejdsmarkedet					
2	Genoptagelse af fritidsaktiviteter					
3	Familielivet					
4	Livskvalitet generelt					
5	Selvtillid					
6	Fysiske vanskeligheder					
7	Kognitive vanskeligheder					
8	Følelsesmæssige vanskeligheder					
9	Indsigt i mine vanskeligheder					
10	Min evne til at kommunikere med andre mennesker					
11	Min evne til at kompensere for mine vanskeligheder					
12	Min evne til at være sammen med andre mennesker					

Må centret kontakte dig i fremtiden:	0. nej	1 Ja
Har du lyst til at være med på fredagsforedrag	0. nej	1 Ja
Vil du være med til gruppeinterview	0. nej	1 Ja

For kontroller:
Add. Område 5.Har du nogensinde fået (offentlig) hjælp/støtte til at komme i gang med en fritidsbeskæftigelse/arbejde/familiestøtte efter din hjerneskade?

Hvad har hjulpet dig?

Er der noget du har manglet?

Nu om dage eksisterer der intensive genoptræningsprogrammer - ville det have været en god idé for dig på daværende tidspunkt?

Afsluttende:
Er der noget væsentligt jeg ikke har spurgt dig om, som du kunne tænke dig jeg spurgte dig om?

Tak for din deltagelse!

9. Interviewers vurderinger

Har vedkommende brug for intervention?	0. none 1. Akut - hvilken slags og hvorfor 2. Langsigtet - hvilken slags og hvorfor

Hvor høj grad af awereness har den enkelte (skala fra 1-5) 1: ubekymret
5: fuldt ud klar over sine problemer, både intellektuelt og anticipatorisk

Vurderer jeg at deltageren socialt eller emotionelt let kunne være en belastning?
1.Overhovedet ikke 2.overvejende ikke 3. i nogen grad 4. I høj grad

Appendix F: Interview scales

The interview (appendix E) contains questions to be answered by markings on scales. These scales are listed in this appendix and pertain to questions within the areas:

- Complaints and use of compensatory techniques,
- Employment situation,
- Leisure activities,
- Social network,
- Satisfaction with own adaptation after the brain injury,
- Satisfaction and rating of the CRBI program and perceived helpful factors after brain injury

The version received by the participants from the control group did not include the questions regarding the CRBI program, but otherwise the two groups received exactly the same version.

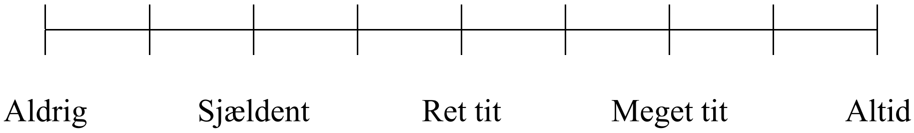
Deltager skalaer

Helbred, levevilkår og livskvalitet

Hvor meget har skaden fyldt den sidste måned?

1	2	3	4	5
Næsten intet				Virkelig meget

Skala til brug ved kompensationsmetoder



LIVSKVALITET: Arbejde og økonomi

Hvor stor betydning har arbejde for din livskvalitet ?

1	2	3	4	5
Ingen betydning				Meget stor betydning

Hvor stor betydning har din økonomi for din livskvalitet ?

1	2	3	4	5
Ingen betydning				Meget stor betydning

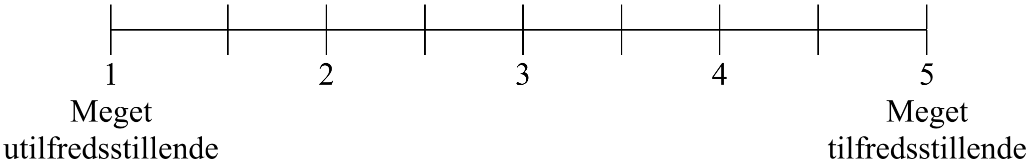
LIVSKVALITET: Fritid

Hvor stor betydning har fritidsaktiviteter for din livskvalitet?

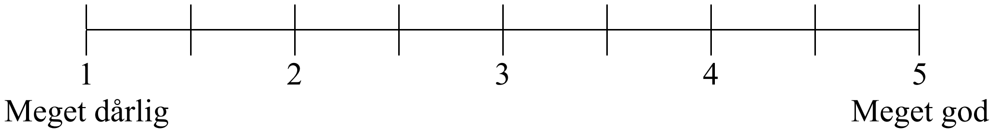
1	2	3	4	5
Ingen betydning				Meget stor betydning

SOCIALT

Mit sociale liv efter hospitalisering og evt. genoptræning er?



Min evne til at indgå i nære sociale forhold er?



Parforhold

Hvor tilfreds er du med dit parforhold ?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor tilfreds tror du din partner er med jeres forhold ?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor meget betyder samvær i et parforhold, for din livskvalitet?

1	2	3	4	5
Ingen betydning				Meget stor betydning

Hvor god er du til at skabe kontakt til en mulig partner ?

1	2	3	4	5
Har meget svært ved det				Har meget nemt ved det

Hvor god er du til at vedligeholde et parforhold?

1	2	3	4	5
Har meget svært ved det				Har meget nemt ved det

Forhold til familie

Hvor tilfreds er du med den kontakt du har til din familie ?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor tilfreds er din familie med den kontakt de har til dig?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor meget betyder samvær med familien, for din livskvalitet?

1	2	3	4	5
Ingen betydning				Meget stor betydning

Forhold til venner:

Hvordan vurderer du dit forhold til dine venner – hvor tilfreds er du med den kontakt I har?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor tilfreds tror du dine venner er med jeres forhold?

1	2	3	4	5
Meget utilfreds				Meget tilfreds

Hvor god er du til at skabe nye mulige venskabskontakter?

1	2	3	4	5
Har meget svært ved det				Har meget nemt ved det

Hvor god er du til at vedligeholde nye venskaber?

1	2	3	4	5
Har meget svært ved det				Har meget nemt ved det

Hvor meget betyder samvær med venner, for din livskvalitet?

1	2	3	4	5
Ingen betydning				Meget stor betydning

Tilfredshed med tilpasning

Min indsats for at overvinde de vanskeligheder, jeg har fået pga. hjerneskaden, har i løbet af optræning/generelt været:

1	2	3	4	5
Ikke noget særligt				En enestående præstation

Skønt mit liv er anderledes end før hjerneskaden, er det nu:

1	2	3	4	5
Akkurat tåleligt				Meget meningsfuldt

Siden hospitaliseringen/optræningen har mit liv været:

1	2	3	4	5
Uproduktivt				Meget produktivt

I dag føler jeg, at jeg:

1	2	3	4	5
Stadig ikke hviler helt i mig selv				Hviler helt i mig selv

Genoptræning

Prioriter de fem vigtigste ting som du synes hjalp ved Center for Hjerneskades program:

________ Kontakten med de andre elever
________ primærterapeut
________ personalet som helhed
________ samtalegruppe
________ fysisk træning
________ kognitiv træning
________ stemmetræning
________ specialundervisning
________ morgenmøde/andre gruppeaktiviteter
________ støtte til sagsbehandler/arbejde/økonomi
________ opfølgningsmøder
________ andet

Hvilken betydning har opholdet på Center for Hjerneskade haft for:

Sæt kun 1 kryds ud for hvert udsagn		**1 ingen betydning**	**2 lille betydning**	**3 nogen betydning**	**4 væsentlig betydning**	**5 stor betydning**
1	**Tilbagevenden til arbejdsmarkedet**					
2	**Genoptagelse af fritidsaktiviteter**					
3	**Familielivet**					
4	**Livskvalitet generelt**					
5	**Selvtillid**					
6	**Fysiske vanskeligheder**					
7	**Kognitive vanskeligheder**					
8	**Følelsesmæssige vanskeligheder**					
9	**Indsigt i mine vanskeligheder**					
10	**Min evne til at kommunikere med andre mennesker**					
11	**Min evne til at kompensere for mine vanskeligheder**					
12	**Min evne til at være sammen med andre mennesker**					