Long-term outcome after traumatic brain injury
Studies of individuals from northern Sweden

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ACKNOWLEDGEMENTS

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III. Jacobsson L, Westerberg M, Lexell J. Health related quality of life and life satisfaction 6 to 15 years after traumatic brain injuries in northern Sweden. *Brain Injury* (Accepted for publication).


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ABSTRACT

As traumatic brain injury (TBI) is one of the major causes of long-term disability, there is an increasing interest in the long-term outcome of TBI. The overall aim of this thesis was to increase our knowledge and understanding of the situation for individuals many years post injury, with regard to demographics, injury characteristics and primary outcome, long-term functioning and disability, health-related quality of life, life satisfaction, self-appraisal of the impact of the TBI and sense of coherence.

In study I, data was retrospectively collected on those individuals in Norrbotten, northern Sweden, with a computed tomography (CT) verified TBI and brain injury symptoms, who had been transferred for neurosurgical care from 1992 to 2001. A total of 332 individuals, 250 men and 82 women, were registered. The findings revealed that a majority were older men with a mild TBI following a fall. Younger individuals were fewer in number but more often had a severe TBI from a traffic accident. Most individuals received post-acute care and brain injury rehabilitation. A majority had a moderate or severe disability, but many were discharged back from hospital and sent home with no major changes in their physical or social environment.

In study II, 88 individuals (age between 18 and 65 at the time of assessment, to represent individuals of working age) were included and their functioning and disability were assessed with internationally established TBI outcome measures, on average 10 years (range 6-15 years) post injury. There was an improvement in overall outcomes from the time of discharge from inpatient rehabilitation to follow-up, and many had a high degree of motor and cognitive functioning, which enabled them to live independently in their own home without assistance. There remained, however, a disability related to community reintegration and social participation. This affected their productivity and to some degree their marital stability, factors which were related to the age at the time of injury and the severity of the injury.

In study III, health-related quality of life (HRQoL) and life satisfaction (LS) were assessed in 67 individuals, and compared with reference values from the general population. HRQoL, as well as LS, was lower compared with the general population. Multivariate statistical analyses showed that the individuals’ own appraisal of the impact of the TBI, along with vocational productivity, were strongly associated with their current physical health and overall satisfaction with life.
In study IV, sense of coherence (SOC) and the influence on self-rated LS of SOC, along with measures of functioning and disability, sex, age at injury, injury severity and time since injury were assessed in 66 individuals. SOC did not differ from the general population, and there was a strong relationship between SOC and LS indicating that the individuals’ sense of preservation of good health was strongly associated with high LS. High LS was also strongly associated with emotional factors and social participation, together with longer time post-injury and a more severe injury sustained at a later age.

In conclusion, the results indicate that many individuals with a TBI can achieve and maintain a high degree of functioning many years after the injury. However, emotional and inter-relational problems remain and impact on social activities and participation. Many individuals experienced a reduced HRQoL and LS. The individuals’ perception of the low impact of the injury and their positive SOC were firmly associated with high LS. These results confirm that TBI can lead to long-term disability and emphasize the need for support systems and rehabilitation programmes that can meet the individuals’ needs, with regard to emotional factors, social participation and overall satisfaction with life, in a long-term perspective.
# ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
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<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
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<tr>
<td>ICIDH</td>
<td>International Classification of Impairment, Disability and Handicap</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>LOS</td>
<td>Length of Stay (number of days of care and rehabilitation)</td>
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<td>GCS</td>
<td>Glasgow Coma Scale</td>
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<td>RLS 85</td>
<td>Reaction Level Scale 85</td>
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<td>CIQ</td>
<td>Community Integration Questionnaire</td>
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<td>DRS</td>
<td>Disability Rating Scale</td>
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<td>FIM</td>
<td>Functional Independence Measure</td>
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<td>GOS</td>
<td>Glasgow Outcome Scale</td>
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<td>MPAI-4</td>
<td>Mayo-Portland Adaptability Inventory – 4th version</td>
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<td>HRQoL</td>
<td>Health Related Quality of Life</td>
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<td>SF-36</td>
<td>The Short Form (36) Health Survey</td>
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<td>PF</td>
<td>Physical Functioning</td>
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<td>RP</td>
<td>Role Physical</td>
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<td>BP</td>
<td>Bodily Pain</td>
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<td>GH</td>
<td>General Health</td>
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<td>VT</td>
<td>Vitality</td>
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<td>SF</td>
<td>Social Functioning</td>
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<td>MH</td>
<td>Mental Health</td>
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<td>PCS</td>
<td>Physical Component Score</td>
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<tr>
<td>MCS</td>
<td>Mental Component Score</td>
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<td>LS</td>
<td>Life Satisfaction</td>
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<td>SWLS</td>
<td>Satisfaction With Life Scale</td>
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<td>SOC-13</td>
<td>Sense Of Coherence – 13 item Scale</td>
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PREFACE

In my work as a clinical psychologist, involving nearly 10 years in the field of outpatient adult psychiatry and since 1993 as a neuropsychologist in the Department of General medicine at Kalix hospital, I’ve met several individuals with acquired brain injuries. These patients have given me an insight into many aspects of the very complex and lengthy rehabilitation process – often taking several years - that follows acquired brain injuries. One person in particular (named Johan - he and his wife have given me permission to be mentioned in this manner in the thesis) has contributed with his experiences. He has also contributed to this thesis by the creation of a “puzzle heart” pictured on the front page. He was injured in 1993 at the age of 32 years and treated at the neurosurgical clinic at Umeå University Hospital. Johan was discharged on his own request from Kalix hospital directly after neurosurgical care. He claimed that nothing was wrong with him and he felt well. His wife subsequently told me, that she immediately after Johan’s surgery felt that something was very wrong with him. Within the first year Johan developed post injury epileptic seizures that complicated his daily life considerably.

We had the opportunity to raise funds for a project focusing on brain injury rehabilitation many years after the initial injury that paralleled the first seven years after Johan’s injury. With the project’s extra resources we could build a team that included myself as a neuropsychologist, an experienced neurologist, a social worker, occupational therapist, physiologist, work consultant, and, most importantly, a contact person that all participants could easily reach and who made frequent home visits. This project has its own story, waiting to be told, but it was one vital component of why I have worked with this thesis. Some of the individuals in the project, such as Johan, showed a remarkable strength and enthusiasm despite severe problems. Others could not profit from the support we offered, although they had the same or fewer number of problems in various aspects of cognitive, emotional, behavioural and social domains.

Even if the neuropsychological deficits evidently have a serious impact on rehabilitation and reintegration into society, there were also other factors that were not so easily identified. One important factor involved in enduring the “journey” of rehabilitation over several years, and which was verified by the individuals with TBI and their families, was social support from close relatives, health care professionals, social insurance and other authorities. Professor George Prigatano stated “Things takes
time\textsuperscript{3}, when talking about the value of symbols \textsuperscript{194} on a course I attended in 1993, regarding the topic of neuropsychological rehabilitation. This became a key phrase in our meetings with the participants in the project, a slogan used as self-encouragement when achievements were not reached as quickly as wished for. The slogan inspired Johan to create a wooden sculpture with the letters “ToT”, also pictured on the front page of this thesis (Swedish for the first letters in the words “time and patience”). Although there were many health problems in Johan’s daily life, and in this regard a problematic and low level of health related quality of life, we did not experience that Johan and his family considered themselves to have a low level of life satisfaction. Johan did not like expressions of a negative character and was always looking optimistically to the future. He had a drive or a “go” to meet the demands in life. I was starting to wonder if there is a difference between the experience of health and how one experiences one’s life satisfaction in a broader sense.

The process described fragmentally above ended in 1999, when Johan was employed part-time after being introduced to, and receiving support from, a job-coach and in collaboration with his current workmates. In Johan’s case it took about 6-7 years to reach a relatively stable living situation with an optimal community reintegration, in his case a return to work. This thesis tries to find out if Johan was an exception. Do the majority of the individuals that suffer a TBI have an equally long rehabilitation process or do those I’ve met in clinical settings represent a minority with more profound problems? There seem to be differences between individuals’ capacity to meet the demands that a brain injury imposes, which is also a vital consideration in neuropsychology. \textsuperscript{147, 192} In line with this reasoning, and in regard to the work of Alexander Lurija, \textsuperscript{36} it is important who suffers a brain injury, as well as what kind or severity of the brain injury, to understand its consequences. One concept that crossed my path is Aaron Antonovky’s sense of coherence \textsuperscript{7} (described in more detail in the thesis), which could be one factor in explaining individual differences. Therefore, it was interesting to see if this concept could add to an understanding of the long-term outcomes for individuals with TBI.

The above mentioned long-enduring rehabilitation process and individual differences were vital starting points for my work. I wanted, with this thesis, to capture relevant domains of both objective (assessments by professionals) and subjective (assessed by individuals with TBI) perspectives, as the participants in the above mentioned project had indicated its profound importance for their outcome.
BACKGROUND

Characteristics of traumatic brain injuries

Traumatic brain injury (TBI) occurs as a result of an outside force, e.g. a blow to the head in a fall or traffic accident, and is a major cause of death and disability all over the world, especially in children and young adults. The increased survival rate of TBIs makes it important to gain knowledge about demographics, injury characteristics, and various aspects of short and long-term outcome of TBI, in order to facilitate the planning of medical services and rehabilitation.

The history of TBI like other causes of injuries or malfunctions to the brain, is of course as long as human culture itself. It is, however, during the last centuries that knowledge about the brain and its relation to human behaviour has rapidly increased. The decade of the 1990’s was proclaimed in several countries as the “Decade of the Brain”. Several societies had been founded during the 1980’s and onward. In USA, the Brain Injury Association of America (1979), and in Sweden the Swedish brain foundation (1994, Hjärnfonden), were established. Several associations have been established, for example in approxamatly 1975 the Swedish Association for Survivors of Accident and Injury (Personskadeförbundet RTP), in 1978 the Cancer and Traffic Injury Fund (Cancer- och Trafikskadades Riksförbund), and in 1988 the Swedish Association of Brain Injured and their Families (Hjärnskadeförbundet Hjärnkraft).

Previous research on TBI has shown that the occurrence, causes and outcome vary greatly. Although the TBI population’s heterogeneous character varies from severe disability and death to full recovery, some general features can be extracted. The annual incidence of TBI in western society is frequently estimated to be 150-500/100 000 people. Two Swedish studies reported an annual rate of about 250/100 000, and a large review of the European countries reported an annual rate of 235 / 100 000 people. Commonly, three age peaks of higher risk and occurrence are reported for the very young, young adults and elderly. The incidence has, during the last decades, shown a tendency to decline. Swedish and other Scandinavian studies have shown a decline in younger ages, whereas TBI among elderly people has increased over time. The vast majority who suffer a TBI are men, about 1.5 to 3 times higher than women in western society. Severity is commonly listed in three categories, based on the assessment of the level of consciousness at admission to acute care: mild (estimated to about 70-90 % of TBI,
moderate (estimated about 10 - 20 % [24, 136, 242]), and severe (estimated about 5 - 10 % [24, 172]).

The most common causes of TBI are traffic accidents and falls, though recent studies from some countries, including Sweden, have shown a trend for reversed proportions, i.e. decreasing traffic accidents and increasing falls. [4, 10, 46, 79, 131, 141, 161, 241] The physical environments are associated with the causes of injury and are most frequently roads and home environments. [1] People living in rural areas with a greater distance to acute care facilities are at higher risk for complications and poorer outcomes. [55, 56, 75, 166] There is also a higher risk for TBI among socially and economically disadvantaged people. [247, 256] and alcohol is strongly associated with TBI. [38, 86, 112, 133, 137, 230, 259] Some Swedish studies have focused specifically on severe TBI in association with initial care [223, 270] and found that overall outcomes have improved. [56, 203] This is suggested as being due to the adherence to the national policy that individuals with a significant TBI are referred to a neurosurgical unit, but also due to an improved neurosurgical care. [81] As a consequence, individuals with TBI more often survive, [175] leading to an increased need for rehabilitation. [56, 203]

Some Swedish studies [40, 42, 43, 57, 58, 148, 151, 152, 178, 179, 187, 188, 218, 219, 220, 221, 274] have focused on those with mild TBI (70-90% of all treated brain injuries [28]). These studies have added knowledge about injury characteristics [166] and management. [42, 187, 274] Some studies have looked at the possibility of using a marker (a protein serum concentration called S-100) of cerebral damage [43, 179, 218] to identify those who are at risk of developing cognitive impairments. Swedish scientists have been part of the WHO Collaborating Centre Task Force on mild TBI focusing on diagnostic procedures, [16] incidence, risk factors, and prevention. [28] The task force has also reviewed the literature on epidemiology, diagnosis, prognosis and treatment. [103]

The rehabilitation process after TBI

The rehabilitation in Sweden is generally built on a policy of continuum of care, like a chain in a support system with subsequent interventions over time from ‘coma to community’. The aim of the initial inpatient rehabilitation process is to assure medical stability. It mainly emphasizes the physical rehabilitation aspects but also includes cognitive rehabilitation. The inpatient rehabilitation continues with out-patient rehabilitation programmes for those who have such needs. These programmes are often restricted to those with more severe injuries. In ideal cases the chain goes through
several phases with the goal of achieving community reintegration, vocational rehabilitation, and a good quality of life. \cite{27} Evaluations of TBI rehabilitation interventions are still in development, but generally studies have found that interventions of different specifically planned rehabilitation programmes are better than natural recovery. \cite{77, 155} An example of more specific interventions are cognitive rehabilitation for individuals with TBI, targeting problems like strategy training for mild memory impairment or attention deficits. \cite{32} However, very little to non-existent knowledge of rehabilitation interventions can be found with regard to individuals many years after TBI. \cite{76} Generally in Norrbotten, as well as most other parts of Sweden, those with minor disabilities are supposed to be handled by the primary health care, usually restricted to physicians, occupational therapists, and physiotherapists. \cite{146} Individuals with more severe disabilities have, since 1994, the opportunity to have one or several personal assistants. For those with lesser disabilities an important phase is that of vocational rehabilitation. In Sweden vocational rehabilitation is handled by the Swedish Social Insurance Agency and the shift in administration from medical to vocational rehabilitation has well-known problems in terms of keeping the ‘chain’ together. Generally, there are no special vocational reentry programs for individuals with TBI, such as those pioneered by Wehman et al., \cite{252, 254} e.g. a special job-coach to support work re-entry.

**Functioning and disability**

The term ‘outcome’ reflects a desirable effect after an initial disease or trauma. \cite{94} Often the terms ‘functioning’ and ‘disability’ are used to describe outcomes, indicating the level of abilities and restrictions to perform normal activities of daily living. \cite{94} Early in the rehabilitation process, functional abilities such as levels of independency in activities of daily living, e.g. manageability in self-care, are prominent, while outcome in a later phase is more often described in terms of social role fulfilment, e.g. ability to engage in leisure and work activities. The later phase is characterized by the ambition to return to an optimal level of participation in the community, and to be socially reintegrated. Three common components, i.e. relationships with others, independence in daily living, and meaningful activities, are included in most definitions of community integration. \cite{163}

Current perspectives on outcomes often use the WHO’s taxonomy entitled ‘International Classification of Functioning, Disability and Health’ (ICF). \cite{257} The ICF takes a biopsychosocial view on disability consisting of four domains divided into two
parts: Part 1: i) body functions, ii) body structures, iii) activities and participation, and Part 2 (Contextual factors): iv) environmental factors (and Personal factors, e.g. age, sex, lifestyle, etc., are included in the conceptual framework, but not classified due to the large individual differences that exist). The ICF provides a useful conceptual framework to define impairments, activity limitations, and participation restrictions, but does not include measures for the evaluation of outcomes. [190] Commonly used outcome measures focus on different phases of the rehabilitation process after TBI. As the process from injury to recovery and community reintegration after TBI is very complex, a set of reliable and valid outcome measures is needed to comprehensively capture functional outcome post-injury. [90] Outcome measures that focus on the initial early functioning and disability, e.g. Functional Independence Measure [83] and Disability Rating Scale [195] are complemented with instruments aimed to capture the long-term outcome, e.g. the Community Integration Questionnaire [261] and Mayo-Portland Adaptability Inventory. [157] Further information on these, as well as many other TBI related outcome measures, are available at http://www.tbims.org/combi/.

Health related quality of life, life satisfaction, and sense of coherence

The concept of quality of life (QoL) is complex and without consensus in term of its definition. [13, 69, 70, 144] The basis for the concept is that individuals have basic needs, as e.g. the theory by Maslow [160] or the order of importance in the list of 15 domains by Flanagan. [70] Originally the concept referred to social or political aspects with the assumption that a high socioeconomic welfare would contribute to peoples good quality of life. [51] This external view of QoL has shifted over the last decades to include the individuals subjective experience, paralleling the increased actuality during the 1980s of empowerment and self-care, [21, 117] and an increasing importance given to evaluating outcomes of effects of care and quality. [169] The positive outcome of care and rehabilitation is often evaluated in relation to achievements, for example regaining health status or productive and social roles, i.e. those characteristics that many people consider essential to a good life. Health is a key element in QoL and often termed as health related quality of life (HRQoL) and is used when describing subjective experiences related to health and disability. [51, 169] HRQoL is a concept that relies on the WHO definition of health: “a state of complete physical, mental and social well-being and not merely absence of disease or infirmity”. [258] However, there are some critiques of these usages of the concept QoL, and it is argued that HRQoL is nothing but a measure of health states and as such comprises two distinct concepts, and should therefore not be used interchangeably. [169] Moons et al. presented a critical evaluation
of the concept QoL which described different conceptualization categories and concluded that satisfaction with life was the conceptualization that best defined QoL.

Dijkers [51] presents a distinction between the subjective life satisfaction (LS) and affect, i.e. QoL equivalent to subjective well-being (SWB), and the more objective domain of achievements (where HRQoL is a part). The concept SWB is a broader concept than LS and includes the individual’s emotional responses (positive and negative affects), domain satisfactions (satisfaction with different domains, e.g. leisure, family life, work, sexual life, etc), and global judgments of life satisfaction. [48] The individual’s SWB can be viewed as a bottom-up approach (in the same way as the basic assumption regarding QoL outlined above), with the main idea that if circumstances allow a person to fulfil his/her needs, he or she will be happy. However, external circumstances have been found to be only weakly related to LS. [48] Because of the minor effects the theory changed to a top-down approach to explain variability in SWB, i.e. how psychological factors, like personality, could determine how events and circumstances are perceived. [48] An event like a TBI could change the individual’s living situation and alter external circumstances, as well as the individual’s psychological functioning. The scientific study of subjective well-being has, according to Diener et al., [48, 186] partly developed as a reaction to previous research emphasis on negative states. These negative states have also dominated the literature in studies of LS in individuals with TBI, [25, 31, 183] exemplified by the consistently reported relationships to depression. [20, 39, 246] Several authors [25, 31] have pointed out the need of finding factors, e.g. positive psychological factors that could support individuals with TBI in their efforts towards a more satisfied life situation. There seems to be an evolving interest in targeting positive psychological factors when understanding outcome after TBI, [31] but this is still an approach probably more common in qualitative research. [120, 264]

The salutogenic theory and the construct ‘sense of coherence’ (SOC) developed by A. Antonovsky, [7] has been proposed as a key personality variable in explaining different outcome after a critical event, e.g. a TBI. SOC includes three components: 1) explainability (cognitive); the ability for people to understand what happens around them, 2) manageability (instrumental/behavioural); the ability to manage the situation on their own or through significant others in their social network, and 3) meaningfulness (motivational); the ability to find the situation worthwhile. The theory assumed that SOC was not a coping strategy, [6] but based on genetic and psychosocial
grounds and would be relatively stable from the age of 30.\textsuperscript{[150]} The SOC represents an orientation with the ambition to explain preserved health and has been found to be strongly related to LS.\textsuperscript{[65]} There are no normative values for SOC so the threshold when SOC can be considered to lose its “protective character”\textsuperscript{[65]} is not known. Several studies of people with various diseases, disabilities, and health complaints, report mainly an inverse relation to SOC,\textsuperscript{[124, 129, 130, 189, 271]} i.e. supporting the relation of lower SOC with lower health status. Despite the relatively large number of studies there is no one that has specifically targeted a population with TBI. However, some studies\textsuperscript{[5, 17, 37, 174]} have used SOC with samples with acquired brain injury (i.e. injuries of other origins e.g. stroke, infections, tumor), where two studies included TBI. One study\textsuperscript{[5]} assessed 67 individuals three years after multiple trauma, reporting that a strong SOC was significant related to higher LS. The second study\textsuperscript{[37]} compared two groups with acquired (mainly stroke) brain injuries (one group mean 7 months, and one group mean 10 years, after injury). They found that median scores for SOC showed no noteworthy difference between early and late periods after injury, and were comparable with other groups undergoing rehabilitation for orthopaedic trauma, and high relative normative data.

The instrument most widely used to assess subjective rated HRQoL has been the generic health measure Short-Form 36 (SF-36).\textsuperscript{[264]} The SF-36 has been used in several studies over the years,\textsuperscript{[23, 153, 162, 173, 243, 244]} and is considered suitable to measure HRQoL in TBI populations.\textsuperscript{[68]} Normative values for the general Swedish population have been developed.\textsuperscript{[222]} The Satisfaction With Life Scale (SWLS)\textsuperscript{[47]} is an internationally used instrument designed to measure general life satisfaction on a single domain or factor. Comparisons with several other international studies and one Swedish study are available. The Swedish Sense of Coherence 13-item scale (SOC-13)\textsuperscript{[7]} has been used in several studies and has been judged satisfactory regarding reliability and concurrent validity, and there are also reference values from previous Swedish studies for comparison.\textsuperscript{[139, 140, 142]} The measures are presented in more detail in the Method section below.

So, on one hand the QoL concept is connected with efforts to evaluate subjective well being, e.g. life satisfaction, and on the other used as a complement to evaluations of cure and rehabilitation, e.g. health-related quality of life. In other words, the concepts QoL, HRQoL, and LS, are important in view of the rehabilitation after a TBI with aims to “… strive to restore not only everyday skills and abilities, however important these
ADL functions are. It must also strive to restore the patient’s sense of identity, satisfaction, and meaning of life”. (p 172, [30])

Short- and long-term outcome after traumatic brain injuries

Most studies on outcomes after TBI have been dedicated to the early time frame, including inpatient care and rehabilitation up to the first 3 to 5 years after injury. This interest is understandable as the goal was to develop an effective and high quality of hospital care and medical rehabilitation. However, the interest in long-term evaluations after TBI has increased, and recently Temkin et al [236] presented a systematic review on the topic ‘social functioning after traumatic brain injury’ including studies evaluating TBI 6 months or longer post injury. They presented 39 articles and used a broad definition that encompassed global functional status, employment, independent living, social relationships, leisure activities, and QoL. They could conclude from the findings that there is sufficient evidence for an association between i) a penetrating TBI and long-term unemployment, ii) a moderate to severe TBI and long-term adverse social-function outcomes, particularly unemployment and diminished social relationships. I was able to identify 34 of the 39 studies presented in the systematic review regarding the time post injury, and found that 27 (79%) were conducted on samples less or equal to 5 years post injury. Eighteen studies (53%) were on sample within one year post injury. Three of the 7 studies that exceeded 5 year post injury were evaluations of military personal or injuries from war incidents, [85, 164, 206] one concerned socioeconomic status 15 years post injury, [248] one study evaluated work and marital status 8 years after mild TBI, [251] and two studies from Denmark evaluated psychosocial outcome and subjective wellbeing in population-based samples on 5, 10, and 15 years post injury. [64, 235]

Studies that exceed 5 years post injury are relatively few and diminish even more for results concerning 10 years or more post injury. Up to the year 2003 (when data collection (study I) of the medical records was performed), I was able to find 18 articles [26, 41, 44, 84, 104, 105, 116, 127, 132, 134, 135, 196, 202, 208, 217, 239, 249] that had follow-up 10 years or more post injury. One of the 18 articles was a case report on an individual with complications of aphasia, [238] one was focusing frontal lobe damage, [208] and one was restricted to TBI suffered during childhood. [132] In contrast, I was able to find 27 articles [3, 34, 45, 53, 64, 72, 93, 99, 100, 102, 106, 107, 111, 119, 167, 176, 177, 180, 191, 199, 231, 235, 266, 267, 268, 269] published from 2003 to 2009. Two of the 27 articles concerned outcome in relation to heredity (genotype APOE), [111, 167] one was evaluating cognitive changes by
neuropsychological tests, \cite{102} and seven studies concerned individuals that suffered their TBI during childhood, adolescence, or as young adults. \cite{99, 100, 106, 107, 119, 176, 177} Taken together, there were 32 articles left with follow-up ten or more years after injury that targeted areas more closely to the themes in this thesis.

Studies on the very long-term outcome have mainly comprised individuals with moderate to severe TBI. In the context of long-term outcome, the studies by Thomsen \cite{239, 240} are often cited, with results that indicate that changes in the personality and emotional problems were more pronounced than physical disability, and that the individual differences in outcome could not be explained by injury severity. Wood \cite{265} supported these findings and stated that injury severity has less influence on long-term outcome as time from injury increases. \cite{19, 84} Furthermore, although remaining disabilities may exist, recovery might be better than expected many years after TBI. \cite{231} Some studies have indicated that very young and older individuals have less favourable outcomes, \cite{99, 158} whereas others have reported no significant associations between sex, age and outcomes. \cite{266} Findings regarding vocational status many years after a TBI have varied considerably from 39\% to 75\% return-to-work, \cite{127} but generally the less severely injured and those of younger age have better outcome. \cite{3, 9} The strain on close relationships after TBI has been thought to be a threat for an enduring marriage. A review from 2005 \cite{15} stated however that separation and divorce after a TBI are less common than anticipated.

Previous studies have shown that individuals with TBI usually report lower HRQoL compared to non-disabled persons. \cite{3, 79, 244} Some studies have reported lower HRQoL among those with mild TBI compared to moderate-and-severe TBI. \cite{22, 33, 68, 78} whereas others have not found any significant relationship with injury severity. \cite{52, 173, 244} Studies of life satisfaction (LS) following TBI have reported a negative impact of the injury and a reduced satisfaction with life. \cite{25, 51, 264} However, for both HRQoL and LS, studies have looked at these aspects in a more short-term perspective \cite{79} and therefore, our knowledge of the conditions many years post injury is very limited.

Several Swedish studies have evaluated outcomes from mild TBI up to the first year post injury, \cite{40, 57, 58, 106, 152, 220, 221} and one with a follow-up of 3 years post injury. \cite{219} Some Swedish studies have reported long-term follow-up on children and young adults with severe TBI. \cite{60, 61, 106, 107, 119} One Swedish study \cite{149} concerned the recovery of cognitive functions and activities of daily living during the first year of rehabilitation.
after severe TBI. Two studies [203, 204] evaluated individuals with severe TBI 5 to 8 years post injury, and two additional studies [225, 226] evaluated severe TBI from 2 years up to 5 years post injury. Finally, four qualitative studies have been published on meaning in life after TBI. [120, 121, 122, 123]

In summary, previous studies on outcomes 10 years or more after TBI have reported that even after severe injury gradual improvements can be seen in individual’s social, cognitive, physical, and emotional functioning. [202, 238, 239, 240, 269] Despite improvements, remaining disabilities have negative effects in e.g. return to work, the aspect that has received greatest attention in outcome studies. [236] In relation to the severity of the TBI, the probability of employment is decreased. [79] Injury severity has less influence on outcome as time from injury increases, [265] and individuals with TBI tends to rate their HRQoL and LS as lower than non-disabled people. [51, 79]

**RATIONALE**

This thesis concerns the long-term outcome of TBI as our knowledge in this area is very limited. To fully capture the complexity of the condition many years post injury, both objective (assessed by professionals or observable facts, e.g. return to work) and subjective (assessed by the individuals with TBI) perspectives are important. As time goes on, there are other factors than the TBI that may have an impact on their functioning, health and life satisfaction. The individual difference in the capability to cope with the TBI and other possible important factors in life are therefore important to address. Hence, this thesis concerns areas of long-term outcomes after TBI, with particular reference to functioning, disability, health related quality of life, life satisfaction, self-appraisal of the impact of the TBI, and sense of coherence.
AIMS

The overall aim of this thesis was to describe and explain the situation for individuals and the impact of the TBI many years post injury. The thesis was divided into four separate studies with the following aims:

i) To identify and describe demographics, injury characteristics and outcome for a group of individuals with a TBI referred to a Swedish regional neurosurgical clinic over a 10-year period.

ii) To assess 6 to 15 years post injury: (a) changes in overall outcome from discharge from inpatient rehabilitation to follow-up, (b) changes in living conditions, and (c) functioning and disability as assessed by internationally established TBI outcome measures.

iii) To describe 6 to 15 years post injury health related quality of life (HRQoL) and life satisfaction (LS), and assess possible associations with variables related to the time of injury and follow-up, and the individuals’ self-appraisal of the impact of the TBI.

iv) To assess sense of coherence (SOC) 6 to 15 years post injury, and explore the relationship between self-rated life satisfaction (LS) and SOC as well as measures of functioning and disability, sex, age at injury, injury severity and time post injury.
METHODS

Overview
This thesis used medical records to identify the study population of individuals with a confirmed diagnosis of a TBI and registered retrospective data that subsequently was followed up through structured person-to-person interviews and established evaluation instruments. An overview of participants, variables of interest, data from medical records and interviews along with measures from instruments, supplemental questions, and statistical analysis are presented in Table 1.

Participants

Study I
In Study I the task was to identify potential participants for the project, i.e. individuals that had sustained a confirmed TBI several years previously. The assumption, confirmed in discussion with practicing surgeons at the local hospital, was that those individuals from Norrbotten County that suffered more severe TBI most certainly would be transferred to the neurosurgical clinic at Umeå University hospital. This point has been discussed afterwards and it is possible that some individuals with moderate to severe TBI have been treated at their local hospital without contact with the neurosurgical clinic. However, those 332 individuals that were identified through the assistance from the neurosurgical clinic had a computer tomography-verified brain injury or brain injury symptoms (e.g. disturbed cognition or mobility or affected conscious), which fulfilled the criteria to have a diagnosed TBI. All patients from Norrbotten County with ICD-9 codes 850 to 854 and ICD-10 codes S06 to S09 were used. The registration was carried out on site at the neurosurgical clinic using prepared protocols. A total of 340 men and women were identified in the hospital database. Of these, the medical records of five individuals were missing and another three individuals were excluded, as their primary diagnosis was not one of the ICD-9 or ICD-10 codes. The final population comprised of 332 individuals, 250 men and 82 women.
Table 1. Participants, variables, data, measures, and statistical methods in the four studies

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants (n)</td>
<td>332</td>
<td>88</td>
<td>67</td>
<td>66</td>
</tr>
<tr>
<td><strong>Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Age</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Injury cause</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Injury type</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Injury severity</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Time post injury</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Living conditions</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Marital status</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational situation</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Health related quality of life</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life satisfaction</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-appraisal</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salutogenic factor</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Outcome measures</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GOS</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRS</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CIQ</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPAI-4</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SF-36</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWLS</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supplementary questions</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOC-13</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Statistics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Descriptives: mean, SD, median, range</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Non-parametric tests: Mann-Whitney, Kruskal-Wallis</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Chi-square</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parametric tests: t-test</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Associations: Spearman Rank Correlation</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Multivariate analyses:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discriminant analyses</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hierarchical regression</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In order to collect data on all patients who subsequently were transferred back to Norrbotten, permission was granted to repeat the register procedure on each of the five hospitals. The procedure to register records for the entire inpatient length of stay (LOS) made it possible to find richer information and also control for reliability and relevance in the medical records. The time frame of 10 years was judged to be sufficient to capture potential changes over the years.

**Study II - IV**

In the subsequent study (Study II) I wanted to assess changes in overall outcome and individuals current functioning and disabilities. One important and often reported indicator concerning outcomes is the individual’s ability to be vocationally productive. For this reason, the inclusion criteria was set to working age, i.e. between 18 and 65 years at the time of data collection (year 2007). Of the 125 individuals that fitted the criteria, 17 had deceased after discharge from rehabilitation to follow-up, and 2 had emigrated. All potential participants – 106 individuals – were contacted by post and telephone with information carefully explaining the study, an invitation to participate and an informed consent form. Eighty-eight individuals (83%) gave their written informed consent to participate, 13 (12%) declined to take part and 5 (5%) did not respond. Seventy-five individuals (85 %) could answer the questions independently and 8 individuals (9 %) had support from a relative but answered the questions independently. Five individuals (6 %) were too disabled to answer the questions, and information was collected from a close relative.

The interest in study III concerned the individual’s self-rated experience of their health and life satisfaction. Of the 88 individuals in study II, 67 were included in the present study; ten were excluded as they were too disabled (e.g. severe cognitive impairments) to complete the questionnaires and 11 did not return the mailed response (Table 2). No significant differences were found between the 67 participants and the 39 (out of the potential participants of 106 individuals at working age at follow-up identified from study I) and 21 (out of the 88 participants in study II) non-participants, respectively, regarding sex, age at time for injury, injury severity, cause and type of injury, or time since injury.

Study IV concerned the potential health resilience or salutogenic factor that sense of coherence (SOC) is suggested to be and its relation to life satisfaction in individuals with TBI. The same 67 individuals that participated in study III were also asked to rate
their SOC. One individual could not, due to fatigue and cognitive dysfunction, participate. Thus, the sample comprised 66 individuals.

The interviews (Table 2) were scheduled to take place as close to the respondents’ home as possible. It was, however, not always possible to do the interview in a person-to-person situation. Some respondents were not at home or informed that they could not come to the scheduled meeting, and the best way was therefore a telephone interview with the outcome measures GOS, FIM, DRS, CIQ, and MPAI-4. The self-rating questionnaires SF-36, SWLS, SOC, and supplementary questions on the impact of the TBI, were sent by mail and returned with a pre-paid letter.

Table 2. Summary on interviews in study II to IV

<table>
<thead>
<tr>
<th>Study</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants (n)</td>
<td>88</td>
<td>67</td>
<td>66</td>
</tr>
<tr>
<td>Non-participants (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rejected to participate</td>
<td>13</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Not reached</td>
<td>5</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Excluded due to their disability</td>
<td>–</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>No returned mailed response</td>
<td>–</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Total (n)</td>
<td>Participants + Non-participants</td>
<td>106</td>
<td>88</td>
</tr>
<tr>
<td>Situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Person-to-person meeting</td>
<td>67</td>
<td>60</td>
<td>59</td>
</tr>
<tr>
<td>Telephone interview</td>
<td>21</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Location</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondents home</td>
<td>35</td>
<td>29</td>
<td>29</td>
</tr>
<tr>
<td>Other place, e.g. Primary Care centre</td>
<td>32</td>
<td>31</td>
<td>30</td>
</tr>
<tr>
<td>Telephone/mailed response on self-ratings</td>
<td>21</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Self-rating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independently</td>
<td>–</td>
<td>60</td>
<td>60</td>
</tr>
<tr>
<td>Supported by close relative or specific other</td>
<td>–</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>
Data collection and outcome measures

Study I

Data was registered (Study I) from the medical records on sex, age, year of injury, injury severity, cause of the injury, type of injury, comorbidity (whether other ICD code diagnosis before the TBI was present), length of stay in the neurosurgical unit, in a general medicine and/or surgical ward, and in a subsequent inpatient rehabilitation until discharge to outpatient rehabilitation or back home. Injury severity variables (Table 3) were scores on Reaction Level Scale (RLS 85), \cite{215} assigned at the site of the injury or at admission to the hospital.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RLS</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Alert</td>
</tr>
<tr>
<td>2</td>
<td>Drowsy or confused</td>
</tr>
<tr>
<td>3</td>
<td>Very drowsy or confused, responsive to strong stimulation</td>
</tr>
<tr>
<td>4</td>
<td>Unconscious, localises pain but does not ward of pain stimulation</td>
</tr>
<tr>
<td>5</td>
<td>Unconscious, withdrawing movements on pain stimulation</td>
</tr>
<tr>
<td>6</td>
<td>Unconscious, stereotype flexion movements on pain stimulation</td>
</tr>
<tr>
<td>7</td>
<td>Unconscious, stereotype extension movements on pain stimulation</td>
</tr>
<tr>
<td>8</td>
<td>Unconscious, no response to pain stimulation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>GCS</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No eye opening</td>
<td>1. No verbal response</td>
</tr>
<tr>
<td>2. Eye opening in response to pain.</td>
<td>2. Incomprehensible sounds</td>
</tr>
<tr>
<td>3. Eye opening to speech.</td>
<td>3. Inappropriate words</td>
</tr>
<tr>
<td>4. Eyes opening spontaneously</td>
<td>4. Confused</td>
</tr>
<tr>
<td></td>
<td>5. Oriented</td>
</tr>
<tr>
<td></td>
<td>6. Obeys commands</td>
</tr>
</tbody>
</table>

\(^{1}\text{Each section in GCS; eye opening, verbal, and motor response, are rated and then summated to a GCS score ranging from 15 – 3, where higher scores indicates less severity.}\)

Reaction Level Scale (RLS 85) \cite{215} is designed for bedside assessment concerning the responsiveness of patients with acute cerebral disorders in eight grades from alert to
unconscious. The scale is developed and often used in Sweden, and has been proven to have a good inter-observer agreement. [216]

In 17 cases the RLS 85 level was not expressively noted in the record and the judgement of severity was done by the written description. For example, one record noted: “lowered consciousness, not adequate in the contact, motor agitated” which was rated in the protocol as RLS 85, level 2. With exception of the mentioned 17 cases, the records comprised details on level of consciousness and mostly also expressively declared the assessed RLS 85 level. To allow for a comparison with data from other studies, the RLS 85 scores were transformed into Glasgow Coma Scale scores (GCS). [118, 198, 237] GCS [233] is the internationally most commonly used scale. It comprises three subscales (Table 3.) with lower scores indicating more decreased level of consciousness. The GCS has been compared to RLS 85 in several studies, [118, 216, 237] and has been proven to have equal and good validity. RLS 85 has been found to be easier to use and more reliable in agreement between observers. The RLS 85 scores can be converted to GCS scores assessed at admission to hospital and used to classify injury severity. [249] Based on the GCS scores, the 332 individuals in the data base were grouped into the three commonly used TBI severity groups [233]: mild (RLS 85: 1-2 correspond to GCS 13–15), moderate (RLS 85: 3 correspond to GCS 9–12) and severe (RLS 85: 4-8 correspond to GCS 3–8).

The outcomes at discharge (or within first 6 months) were assessed with the Glasgow Outcome Scale (GOS) [113] (Table 4). The Glasgow Outcome Scale (GOS) is a brief descriptive categorisation that assesses outcome in five levels: dead, vegetative, severely disabled, moderately disabled, and good recovery. The scale is the most widely used outcome measure after TBI [262] but have limited sensitivity. In order to address the limitation of GOS, an extended version has been developed; the Extended Glasgow Outcome Scale (GOS-E). [234, 262] The GOS-E extends the original 5 categories to 8, and a structured interview improves reliability of rating. Compared to the GOS, the GOS-E are more sensitive to change in mild to moderate TBI. [145] Although the GOS has more limited sensitivity compared to GOS-E, the gross construction in five categories makes it useful for overall outcome assessments [88] when data are restricted to medical records. Apart from the argument of restricted information in medical records, the GOS instrument was chosen in order to facilitate comparison at follow-up.
Three discriminant analyses were performed to determine possible subgroups of associated variables: i) dependent variable: the three injury severity categories; independent variables: age, cause of the TBI and type of injury; ii) dependent variable: outcome (GOS); independent variables: age, total inpatient length of stay (LOS), comorbidities and discharge destination; iii) dependent variable: discharge destination; independent variables: age, injury severity categories and total inpatient LOS.

Study II

In study II the aim was to describe the living situation at follow-up (year 2007) and compare it with the situation at the time of injury and early outcome. The following data from the time of injury was considered to be included in study II-IV: sex, marital status, vocational situation, time for injury, injury cause, type and severity, as well as outcome at discharge (or within first 6 months) were obtained from the database in study I.

Changes in overall outcomes from discharge from inpatient rehabilitation to follow-up were assessed with the Glasgow Outcome Scale (GOS) [113] (Table 4). The measure has been criticized as being insensitive, especially to more favourable outcomes [250], and for emphasizing physical compared to cognitive or emotional problems. [262] However, as medical records are often scarce on detailed descriptions at discharge and early follow-up, it was suitable to use the gross measures provided by the GOS and obtained from the database in study I for a comparison of the situation at follow-up in 2007.

Some variables were dichotomized in broad categories to facilitate comparison between the situation at the time of TBI and follow-up. The living conditions were defined as: (i) living independently in one’s own home without assistance or (ii) living in institutions and/or dependent on personal assistance. Marital status was defined as: (i) single or (ii) married or cohabitant. Vocational status was defined as: (i) productive (i.e. studying, working full/part time in competitive work, sheltered work or looking for work) or (ii) not productive (i.e. full disability pension).

Measures on functioning and disability at follow-up were selected among internationally established TBI outcome instrument in order to optimize validity. Table 4 presents the selected instruments in study II: Functional Independence Measure (FIM), [83] Disability Rating Scale (DRS), [195] Community Integration Questionnaire (CIQ), [261] and Mayo-Portland Adaptability Inventory (MPAI-4). [157]
Table 4. Overview of instruments on functioning and disabilities

<table>
<thead>
<tr>
<th>Instrument; Scale</th>
<th>Items (Range)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GOS</strong>&lt;sup&gt;[113]&lt;/sup&gt;; Ordinal</td>
<td>5 (1-5)</td>
<td>Brief. Poor sensitivity of mild TBI&lt;sup&gt;[262]&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>FIM</strong>&lt;sup&gt;[83]&lt;/sup&gt;; 7-p. Likert</td>
<td></td>
<td>Score 7=complete independence, 1=total assist. Extensively evaluated&lt;sup&gt;[83, 95, 96]&lt;/sup&gt;, Ceiling effects in long-term outcome&lt;sup&gt;[89]&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Total</td>
<td>18 (18-126)</td>
<td></td>
</tr>
<tr>
<td>Motor</td>
<td>13 (13-91)</td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>5 (5-35)</td>
<td>outcome&lt;sup&gt;[89]&lt;/sup&gt;.</td>
</tr>
<tr>
<td><strong>DRS</strong>&lt;sup&gt;[195]&lt;/sup&gt;; Ordinal</td>
<td></td>
<td>Assess general functional change&lt;sup&gt;[195]&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Total</td>
<td>8 (0-29)</td>
<td>Brief. Good interrater reliability&lt;sup&gt;[80]&lt;/sup&gt; and validity&lt;sup&gt;[71]&lt;/sup&gt;. Poor sensitivity of mild TBI or very severe impairment&lt;sup&gt;[90]&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Physical</td>
<td>3 (0-12)</td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>3 (0-9)</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>2 (0-8)</td>
<td></td>
</tr>
<tr>
<td><strong>CIQ</strong>&lt;sup&gt;[261]&lt;/sup&gt;; Ordinal</td>
<td></td>
<td>Assess firstly the frequency of performed activities and secondary the assistance required in the activity.</td>
</tr>
<tr>
<td>Total</td>
<td>15 (0-28)&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Extensively evaluated in populations with TBI&lt;sup&gt;[200]&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Home integration</td>
<td>5 (0-10)</td>
<td></td>
</tr>
<tr>
<td>Social integration</td>
<td>6 (0-12)</td>
<td></td>
</tr>
<tr>
<td>Productivity</td>
<td>4 (0-6)&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td><strong>MPAI-4</strong>&lt;sup&gt;[157]&lt;/sup&gt;; 5-p. Likert</td>
<td></td>
<td>Assess difficulty and disruption in activities: 0= Does not interfere to 4= interferes with activities &gt;75% of the time. Extensively evaluated in populations with TBI&lt;sup&gt;[197]&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Total</td>
<td>35 (0-111)</td>
<td></td>
</tr>
<tr>
<td>Ability Index</td>
<td>12 (0-47)</td>
<td></td>
</tr>
<tr>
<td>Adjustment Index</td>
<td>9 (0-46)</td>
<td></td>
</tr>
<tr>
<td>Participation Index</td>
<td>8 (0-30)</td>
<td></td>
</tr>
</tbody>
</table>

<sup>1</sup>In the original version the subscale Productivity included a score of 5 points for: “Works full-time AND attends school part-time OR Attends School full-time AND works part-time (less than 20 hours per week)”. None in the present study fulfilled these criteria, why the maximum score was 28 and 6, not 7 and 29 as in the original version.

The time for interview was estimated to be 30-60 minutes, which was thought to be sufficient to complete the questionnaire without being too exhausting for the participants. It would have been desirable to include assessments of cognitive functions by neuropsychological tests, but this would have meant an extra interview which may potentially exhaust or discomfort the participants. As one of the included instruments (MPAI-4, described below) comprises items concerning cognitive functions, although
no actual tests are performed, the information on deficits from cognitive functions was covered. The same reasons concerned ratings of emotional states, as these aspects are also covered in MPAI-4. None of the participants had diagnosed or observable symptoms of clinical depression. To facilitate participation, the participants could choose the place for the interview, either in their own home, at another place (e.g. a primary health care centre nearby), or by phone. Evaluations of the FIM instrument, using Rasch analysis, has shown it consists of two separate parts, one motor and one cognitive domain. The instrument was developed and proven suitable for detecting changes during the early inpatient rehabilitation process, but has considerable ceiling effects in the long-term perspective. The Cronbach’s alpha in study II was for FIM motor 0.99, and FIM cognitive 0.98. Compared to FIM, the DRS has lower ceiling effects when assessing long-term outcome, which reflects the aim of the instrument to assess the whole process from “coma to community”. The Cronbach’s alpha for DRS in study II was 0.88. The CIQ is considered to be the most thoroughly evaluated outcome instrument assessing community integration after TBI. The three subscales, Home integration, Social integration, and Productivity, reflect the original idea to capture the issues of “living, loving, and working”. CIQ assesses how often activities are independently performed and if these activities are done alone or jointly with others and the nature of these other persons (i.e. if the other persons are relatives, friends or individuals with TBI). The Cronbach’s alpha for CIQ total in study II was 0.91. MPAI-4 is developed to assess indicators of functions, activities, and participation that are often affected by acquired brain injury (ABI). Using mainly Rasch analyses, the MPAI-4 has been developed to comprise an ultimate set of 30 items that satisfactorily represent the range of common problems in outcomes after ABI. MPAI-4 comprises the Ability Index (e.g. sensory, motor, cognitive abilities), Adjustment Index (e.g. mood, emotional factors, interpersonal interactions), and Participation Index (e.g. social contacts, initiation, money management). The Cronbach’s alpha for MPAI-4 total in study II was 0.96. MPAI-4 is now also available in Swedish, Danish, Spanish, French, German, Portuguese, Italian, and Hebrew versions. As the instruments DRS, CIQ, MPAI-4, and SWLS, were not available in Swedish versions, a forward-backward translation was made with cooperation with a native English-speaking person. The translations of MPAI-4, along with the other aforementioned described instruments in English, are obtainable from The Center for Outcome Measurement in Brain Injury on Internet: http://www.tbims.org/combi.
Study III

In study III, the individual’s subjective experiences expressed by their self-rated health related quality of life (HRQoL), life satisfaction (LS), and appraisal of the impact the TBI has had on their lives, was assessed and are presented in Table 5. The ratings were accomplished on the same occasion as the interview presented in Study II.

Table 5. Overview on instrument of self-rated measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Scale</th>
<th>Items (Range)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36 (^1)</td>
<td>8 Likert scales</td>
<td>10 (10-30)</td>
<td>From raw score a transformed scale score is obtained for each subscale with range 0-100.</td>
</tr>
<tr>
<td>PF</td>
<td>4 (4-8)</td>
<td>2 (2-12)</td>
<td>A generic health measure used in many studies, and also in populations with TBI (^3, 68). Swedish norms for general population available (^222).</td>
</tr>
<tr>
<td>RP</td>
<td>5 (5-25)</td>
<td>4 (4-24)</td>
<td>TBI (^3, 68). Swedish nationwide reference sample available (^109).</td>
</tr>
<tr>
<td>BP</td>
<td>2 (2-10)</td>
<td>3 (3-6)</td>
<td>Higher scores indicate higher rated life satisfaction. Midpoint Score= 20; 26-30= satisfied, 21-25= slightly satisfied, 15-19= slightly dissatisfied, 10-14= dissatisfied, 5-9= extremely dissatisfied (^185). Several studies in populations with TBI (^39, 190). Swedish nationwide reference sample available (^109)</td>
</tr>
<tr>
<td>GH</td>
<td>5 (5-30)</td>
<td>5 (5-30)</td>
<td>An anchoring phrase in each item, e.g. never to very often. No ideal values but higher scores indicate stronger SOC. Several Swedish studies on different, including general, populations (^66, 67)</td>
</tr>
<tr>
<td>VT</td>
<td>2 (2-10)</td>
<td>3 (3-6)</td>
<td>Two items was aggregated to the measure Self-appraisal of TBI</td>
</tr>
<tr>
<td>SWLS (^47)</td>
<td>7-point Likert</td>
<td>5 (5-35)</td>
<td>Higher scores indicate higher rated life satisfaction. Midpoint Score= 20; 26-30= satisfied, 21-25= slightly satisfied, 15-19= slightly dissatisfied, 10-14= dissatisfied, 5-9= extremely dissatisfied (^185). Several studies in populations with TBI (^39, 190). Swedish nationwide reference sample available (^109)</td>
</tr>
<tr>
<td>SOC-13 (^7)</td>
<td>7-point Likert</td>
<td>13 (13-91)</td>
<td>An anchoring phrase in each item, e.g. never to very often. No ideal values but higher scores indicate stronger SOC. Several Swedish studies on different, including general, populations (^66, 67)</td>
</tr>
<tr>
<td>Supplementary</td>
<td>5-point Likert</td>
<td>2 (1-5)</td>
<td>Two items was aggregated to the measure Self-appraisal of TBI</td>
</tr>
</tbody>
</table>

\(^1\) PF: Physical Functioning; RP: Role Physical; BP: Bodily Pain; GH: General Health; VT: Vitality; SF: Social Functioning; RE: Role Emotional; MH: Mental Health
The 36-Item Short Form Health Survey (SF-36) was originally developed in USA with the object of understanding how the health care system affects health. Since then it has been one of the most common instruments used to assess HRQoL and there currently exist several validated versions in different countries, including Sweden. The SF-36 \cite{222} (Table 5) is a generic health status questionnaire and several studies have used it over the past five years. \cite{23, 153, 162, 173, 243, 244} The SF-36 eight multi-item subscales range from 0 to 100 and higher scores indicate higher rated HRQoL. Scoring and calculation in study III was performed according to the Swedish manual \cite{222} obtained from the HRQL group at Sahlgrenska University Hospital (www.hrql.se). The subscales can be converted into two summary component scores, the Physical component score (PCS) and the Mental component score (MCS), converted to standardized T-scores (Mean score 50; SD = 10).

Several investigations have been performed during recent years concerning the question of whether the summary component scores adequately summarise the eight subscales. This question concerns mainly the assumptions of independency between PCS and MCS \cite{91}. The problems are most pronounced when extreme values exist either in the physical or mental subscales. \cite{222} Investigators have therefore urgently recommended that subscale scores are reported and compared with summary component scores for potential scoring problems. \cite{228} A recent study \cite{2} confirmed the eight-factor structure of SF-36, along with a second order two-factor structure representing physical and mental health. The findings did however imply that PCS and MCS are correlated, not independent, which is why the calculations should be done using an oblique factor rotation that reflect the interdependence of mental and physical health \cite{2, 91} instead of the original orthogonal rotation. In study III, the interdependency was controlled by several regressions, using subscales belonging to either physical (e.g. Physical Functioning) or mental (e.g. Mental Health) subscales, but without altered results compared when PCS or MCS were used as dependent variables. The SF-36 Web site (http://www.sf-36.org/nbcalc/index.shtml) does compute oblique scores based on US, Canadian, Norwegian or Swedish norms, and the results in the study were also checked by this method. The only noticeable change using oblique factor rotation, compared with using orthogonal rotation, was a slightly lower MCS compared to Swedish norms. The mean age was not significantly different from the normative sample for SF-36 on the general Swedish population, \cite{222} but the proportion of men was significantly higher.
(p <0.001). Therefore, an age- and sex-matched reference sample (n = 1224) was obtained from the database of the Swedish general population and used for comparison.

General life satisfaction assessed by the SWLS, [47] is a generic measure designed for subjective judgement upon one’s current life situation in relation to one’s expectations. The items are global in character and do not include specific domains, e.g. satisfaction with leisure activities, personal finances, sexual life, as for example the measure Life Satisfaction checklist with 9 or 11 items developed and frequently adopted in Sweden. [73, 74] An assessment with the individual’s own global values could be seen as an advantage compared with assessments of the individual’s judgements on specific components, such as health and good relationships, in the sense that more specific domains lead to a greater individual variety in assessed weights and standards. [185]

Several international studies, but no Swedish at the time of follow-up, have used SWLS in different populations. Since then, a study [109] has reported a psychometric evaluation of the SWLS on a nationwide Swedish sample of 2900 students, which was used for comparison in study III. To compare the score for the SWLS in study III (7-point Likert scale) with the score from the Swedish study [109] (5-point Likert scale), we recoded our results, i.e. the scores from the 7-point to 5-point scale as: 1 = 1; 2 & 3 = 2; 4 = 3; 5 & 6 = 4; 7 = 5.

Both the SF-36 and the SWLS are generic instruments and do not specifically describe experiences following a TBI. To obtain information about the participant’s own experience of the impact of the TBI, two supplementary questions (in Swedish) were asked verbally and visually at the end of the interview:

1. To what extent has the TBI affected your life?
2. What importance has the TBI in relation to other events in your life?

Each question had five response options: “Not at all/none” (=1), “A little/small” (=2), “Moderate/moderate” (=3), “Much/great” (=4), and “Very much/very great” (=5). As the two questions were related both conceptually and empirically (Spearman’s rho = 0.56; p <0.001) they were aggregated to one variable.

Sixty individuals completed the questionnaires in study III by themselves, 3 individuals had a close relative present but completed the questionnaires independently, and 4 individuals had assistance reading and understanding some of the items in the questionnaires but then completed them by themselves.
Study IV

In study IV, possible promoting aspects of recovery by the health resilience factor conceptualized as sense of coherence (SOC), [7] along with measures of disability, was assessed in relation to life satisfaction. The instrument Mayo-Portland Adaptability Index (4th version) for functioning and disabilities and the SWLS for life satisfaction presented in study II and III respectively, were used. Among the instruments on functioning and disability in study II, the MPAI-4 was shown to have the lowest proportion of ceiling effect. The MPAI-4 was for this reason chosen to be used in study IV, along with the reason that it also covers a broad spectrum of potential limitations after TBI. The 13-item scale developed by A. Antonovsky [7] was used to measure the concept ‘Sense of Coherence’. The Swedish SOC-13 scale has been used in several studies and has been judged satisfactory regarding reliability and concurrent validity, and there are also reference values for comparison. [139, 140, 142, 143] Several Swedish studies have been performed but none specifically targeting individuals with TBI. A Swedish study [143] on 2003 individuals from the general population was used for comparison with the data in study IV. As the sample consisted of 66 individuals, we kept the number of independent variables in the regression analyses below 10 individuals per variable, as recommended in the literature. [227] The threat of multicollinearity by the three subscales of MPAI-4 was handled by performing several regressions with each of the three subscales and the total scale, respectively. This way we could analyse explained variance in each model.

Statistical analysis

In all the four studies differences between groups, such as those between men and women or injury severity, were analyzed using non-parametric tests, and relationships between variables were analyzed with the Spearman rank correlation coefficient, due to the ordinal data levels. In study III, the comparisons between means were analysed using independent sample t-tests, and the results from the SF-36 were compared with the age- and sex-matched sample from the Swedish general population using the chi square- ($\chi^2$) and t-tests.

Multivariate statistical methods were used in study I, III, and IV: In study I, three discriminant analyses were performed to determine possible subgroups of associated variables; i) possible subgroups of age, cause of the TBI and type of injury with regard to injury severity, ii) possible subgroups of age, total inpatient length of stay (LOS), comorbidities and discharge destination with regard to global outcome (GOS), and iii)
possible subgroups of age, injury severity categories and total inpatient LOS with regard to discharge destination. In studies III and IV, hierarchical multiple regression analyses were used to assess the influence of several independent variables on measures of HRQoL and LS.

The statistical analysis in study I was performed using Statistical Package for the Social Sciences (SPSS) version 11.0, in study II and III SPSS version 15.0, and in study IV SPSS Statistics 18.0.

**ETHICAL CONSIDERATIONS**

The first study (I) was restricted to the registration of data in medical records, a very common form of Swedish clinical research, and included no person-to-person interaction. In accordance with guidelines, the data was coded and all personal information was deleted. The coded and unidentified data were stored in a separate room in locked fireproofed archive (stored for 10 years) where I was the only keyholder. Information concerning the project was made public through the region’s daily press and internet. The results are published on a group level with no likely risk of threatening any individuals integrity.

In the remaining studies (II-IV) the approach to potential participants followed the principal of informed consent. All potential participants were contacted by post and telephone with information carefully explaining the study, an invitation to participate and an informed consent form. From my clinical experience, as well as the literature, I was well aware that individuals with TBI should be considered with special precaution and as having special needs. The problems after TBI are often complex and incorporate many different symptoms e.g. emotional alterations, difficulties in processing information, disabilities in communication. Therefore I approached these individuals with the aim of being cautious and attempted to show great respect for their integrity. However, the usefulness of illuminating these individuals’ life situation and description of outcomes are considered to exceed the potential risk for the individual. The aims of the studies are in line with the expressed ambitions from patients’ associations and as the data are published on a group level the risk for violating the principal of integrity is considered non-existent. Many participants were interested and willingly completed the interview. On request, at the end of the interview, most participants agreed to be
contacted at a later stage if needed and some expressively wanted feedback when the thesis was completed.

The studies have been approved by the regional ethical review board in Umeå, Sweden (Study I: Dnr 04-105M; study II-IV: Dnr 06-013M)

RESULTS

The results are organized in 2 parts. The first part consists of the results in study I, describing the demographics, injury characteristics, and primary outcome, for the whole study population that was transferred from Norrbotten county to the neurosurgical clinic at Umeå university hospital during the period 1992-2001. The second part consists of data at follow-up 6 to 15 years post injury.

Demographics, injury characteristics and primary outcome

A flowchart of the referrals for the 332 individuals in study I is presented in figure 1.

![Flowchart for 332 persons with TBI. The figure represents number of individuals and percent of total sample within brackets.](image-url)
A majority in study I were older men with a mild TBI and an acute or chronic subdural hematoma following a fall accident. Younger individuals were fewer in number but had more often a severe TBI from a traffic accident. Most individuals received post-acute care and brain injury rehabilitation. A majority had an early outcome of moderate or severe disability, but many were discharged back home with no major changes in their physical or social environment.

Almost 60% of the 332 individuals had sustained a mild TBI and about 25% a severe TBI. The frequency of mild TBI increased markedly with increasing age, with the highest number in the age group 70–79 years (Figure 2).

Figure 2: Distribution of severity of TBI for 250 men and 82 women. (Reproduced with permission from the publisher)

The most common causes of TBI were falls (66.0 %), followed by traffic accidents (25.3 %). Falls were the dominating cause among the older age group, whereas younger ages more commonly suffered the TBI from a traffic accident. The discriminant analysis revealed that age and type of injury had the strongest discriminatory power resulting in two categories, one category of mild TBI associated with old age, falls and
subdural hematoma, whereas the other category was characterized by severe TBI associated with young age, traffic accidents and isolated contusions.

A majority or 44% of the individuals, as assessed by GOS, had a moderate disability at discharge, 37% a severe disability, and not more than 15% had a good recovery. Two percent had died during inpatient care and 2% were in vegetative state at discharge. There was a significant relationship between overall outcome measured by GOS and age ($\mu = 0.30; P < 0.001$), injury severity ($\mu = 0.17; p < 0.01$), and total LOS ($\mu = 0.50; p < 0.001$). Overall, old age and poor outcome (severe disability or vegetative state) were associated with discharge to a disability centre or nursing home, whereas young age and good recovery were associated with a discharge home with no major changes.

Follow-up 6 to 15 years post injury

Sex and age

The overall ratio between men and women in all four studies was 3:1. In study II the women were significantly younger, and had better outcomes as assessed by CIQ subscales home and productivity. The men, but not the women, had significantly lower HRQoL (study III) compared with the reference sample for all SF-36 subscales except subscale Role emotional (RE: problems with work or other daily activities as a result of emotional problems). No significant bivariate relations or contribution in explained variance were found between sex and physical health, mental health or life satisfaction (study IV).

The inclusion criteria of working age at follow-up in study II-IV excluded the large proportion of individuals that were identified in study I with older age and often a mild TBI. Despite this exclusion, the participants in study II-IV showed a significant relation between older age and mild TBI. There was a significant correlation between age at injury and the outcome measures of disabilities (study II), indicating that younger individuals overall had better functioning. It was significantly more common for younger individuals (study III) to be vocational productive, but they also tended to experience somewhat lower mental health and life satisfaction.

Cause of injury and injury severity

Fall accidents as the major cause of injury for the entire group of 332 individuals in study I, changed as the inclusion criteria resulted in lower age at injury, and hence the
most common cause in study II-IV was traffic accidents. The majority (58%) of the 332 individuals in study I had suffered a mild TBI was reduced in study II, due to the inclusion criteria, to 45%. Individuals with a moderate or severe TBI had significantly \( (p = 0.009) \) more often full disability pension. Those with mild TBI were significantly \( (p = 0.001) \) more productive (study II). The mean scores and standard deviation for the three severity groups on outcome measures in study II are presented in table 6. The mean FIM motor and FIM cognitive scores, as well as the mean DRS scores indicated a high degree of overall functioning. All mean CIQ scores and MPAI-4 indicated a moderate reduction in community integration (Table 6).

Table 6. The Functional Independence Measure (FIM), Disability Rating Scale (DRS), Community Integration Index (CIQ) and Mayo-Portland Adaptability Index (MPAI-4) in 88 individuals 6-15 years after TBI

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI (n=40)</th>
<th>Moderate TBI (n=16)</th>
<th>Severe TBI (n=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor</td>
<td>86 16</td>
<td>86 16</td>
<td>83 19</td>
</tr>
<tr>
<td>Cognition</td>
<td>32 7</td>
<td>32 4</td>
<td>29 8</td>
</tr>
<tr>
<td><strong>DRS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2 5</td>
<td>3 3</td>
<td>4 5</td>
</tr>
<tr>
<td>Physical</td>
<td>0 1</td>
<td>0 0</td>
<td>0 2</td>
</tr>
<tr>
<td>Cognitive</td>
<td>1 2</td>
<td>0 1</td>
<td>1 2</td>
</tr>
<tr>
<td>Social</td>
<td>2 2</td>
<td>2 2</td>
<td>3 2</td>
</tr>
<tr>
<td><strong>CIQ</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>21 7</td>
<td>18 8</td>
<td>18 9</td>
</tr>
<tr>
<td>Home</td>
<td>7 3</td>
<td>6 3</td>
<td>7 4</td>
</tr>
<tr>
<td>Social</td>
<td>10 3</td>
<td>9 4</td>
<td>8 4</td>
</tr>
<tr>
<td>Productivity</td>
<td>5 2</td>
<td>3 3</td>
<td>3 3</td>
</tr>
<tr>
<td><strong>MPAI-4</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>22 25</td>
<td>29 22</td>
<td>34 25</td>
</tr>
<tr>
<td>Ability</td>
<td>8 10</td>
<td>11 9</td>
<td>12 10</td>
</tr>
<tr>
<td>Adjustment</td>
<td>11 11</td>
<td>14 10</td>
<td>16 11</td>
</tr>
<tr>
<td>Participation</td>
<td>6 9</td>
<td>9 8</td>
<td>11 10</td>
</tr>
</tbody>
</table>
In study III and IV, the injury severity groups were put together into the two categories of mild TBI (48 % study III, 47 % study IV), and moderate-to-severe TBI (52 % study III, 53 % study IV), a procedure done in previous research [33, 68] which gave the opportunity for comparisons. The moderate-to-severe category was coded as 0, and the category mild TBI as 1 in the analyses. There were however no significant differences between the mild and moderate-to-severe TBI groups in any of the SF-36 subscales or SWLS (study III). The results were confirmed in study IV with a small significant difference between the two injury severity groups for MPAI-4 but no difference for SWLS. There was also no significant difference between the two injury severity groups with regard to SOC.

Time since injury and change in outcome

The results of study II concern the very long-term outcome and showed an improvement in overall outcome from the time of discharge from inpatient rehabilitation to follow-up. The mean time since injury (study II-IV) was 10 years (median 9 years; SD 3; range 6–15 years). Comparing GOS at discharge from inpatient rehabilitation and at follow-up showed that 39 individuals (44%) improved (Table 7).

Table 7. Changes in outcome, assessed by Glasgow Outcome Scale (GOS), for 88 individuals with traumatic brain injury from discharge from inpatient rehabilitation to follow-up after 6-15 years

<table>
<thead>
<tr>
<th>GOS at follow-up</th>
<th>Vegetative state</th>
<th>Severe disability</th>
<th>Moderate disability</th>
<th>Good recovery</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOS at discharge</td>
<td>Vegetative state</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Severe disability</td>
<td>–</td>
<td>9</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Moderate disability</td>
<td>–</td>
<td>2</td>
<td>12</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>Good recovery</td>
<td>–</td>
<td>–</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1</td>
<td>11</td>
<td>20</td>
<td>56</td>
</tr>
</tbody>
</table>

Two individuals improved from severe disability to good recovery; both were young women with a severe TBI. Two middle-aged men had a worse outcome; one had a previous brain injury and one had a history of psychiatric illness. Although the changes according to GOS were improved, there was no significant correlation (Spearman’s rho) between time post injury and outcome measures of FIM, CIQ or MPAI (study II).
However, a weak relationship ($p=0.033$) between longer time post injury and higher life satisfaction was detected in study III. This is a relationship that was supported in study IV, where time post injury significantly contributed to explained variance in life satisfaction.

**Living condition, marital status and vocational situation**

About 70% (232 individuals) of the original group of 332 individuals (study I) were discharged home from hospital, some (24% or 56 individuals) with changes in physical adjustment in the home environment. As could be expected when the inclusion criteria at follow up was set to ages 18-65 years, the proportion that were independently living in their own homes without assistance increased in study II to 91%. In study III and IV, where the object was to rate their own experiences, living independently without assistance further increased to 94%. Two, of the four individuals included in study III and IV, had personal assistance for only heavy household work and transportation, whereas the other two had extensive assistance most hours of the day and some supervision during nights.

About half of the participants were married or cohabiting at follow up (study II-IV; 46-49%). Twenty-four percent of those that were married or cohabiting and 34% of those that were single at the time of injury remained their marital status at follow up (study II). Seventeen (19%) individuals who were married or cohabitating at the time of injury were single at follow-up. Those that were married or cohabitating in study III had significantly lower HRQoL compared with the age- and sex-matched reference sample on SF-36 subscales Role Physical and Vitality. Those who were single or divorced had significantly lower HRQoL compared with the age- and sex-matched reference sample on SF-36 subscales Physical Functioning, Role Physical, General Health, Vitality, Social Functioning, and Mental Health. Those who were married at follow up were also significantly more common ($p=0.002$) to have a high life satisfaction, and rate their appraisal of the impact from the TBI on their life as low ($p=0.029$). From the regression analysis in study III (Table 8.) it was shown that marital status was a significant contributor to explained variance in life satisfaction.
Table 8. Results of multiple hierarchical regressions on SWLS measures for 67 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th>Step</th>
<th>Variables entered</th>
<th>Beta</th>
<th>R²change</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sex</td>
<td>−0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age at injury</td>
<td>0.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Injury severity</td>
<td>−0.09</td>
<td>0.01</td>
<td>0.899</td>
</tr>
<tr>
<td>2</td>
<td>Years post-injury</td>
<td>0.30**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Marital status</td>
<td>0.35**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vocational situation</td>
<td>0.35**</td>
<td>0.35</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>3</td>
<td>Self appraisal of the TBI</td>
<td>−0.33**</td>
<td>0.08</td>
<td>0.005</td>
</tr>
</tbody>
</table>

R² =0.44   R²Adj=0.38

Sex: Woman=0, Men=1; Injury severity: Moderate-to-Severe=0, Mild=1; Marital Status: Single=0, Married=1; Productivity: Non productive=0, Productive=1

The analysis of the two categories of vocational situation gave several significant results, and showed that 60% were productive in study II and 66% in study III. In study II, it was found that individuals with a moderate or severe TBI had significantly (p = 0.009) more often full disability pension than those with mild TBI. As described above under the subtitle ‘sex and age’, those who were productive were (p=0.001 in study II; p=0.002 in study III) more commonly of a younger age. Those who were productive had significant lower HRQoL compared with the age- and sex-matched reference sample on the SF-36 subscales Role Physical and Vitality. The group that were not productive had significant lower HRQoL compared with the age- and sex-matched reference sample on all SF-36 subscales, except subscale Role Emotional. The regression analysis revealed (Table 8 and 9) that those who were productive were significantly more disposed to have a high life satisfaction (p=0.002), to rate their physical health as high (p<0.001), and rate their appraisal of the impact from the TBI on their life as low (p=0.005). In the multiple hierarchical regression analysis, the vocational situation was a strong contributor to explained variance of life satisfaction and physical health.
Generally the outcome measures in study II showed a relatively favourable outcome, but a gradual difference between the three injury severity groups (study II). In line with the results from study II, the results in study IV on raw score mean for MPAI-4 scales converted to T scores, indicated that the sample had on average relatively mild limitations. Along with results already presented above, there was a rather high proportion of maximum score or ceiling effect (Table 10).

<table>
<thead>
<tr>
<th>Step</th>
<th>Variables entered</th>
<th>PCS Beta</th>
<th>PCS R² change</th>
<th>PCS Sig.</th>
<th>MCS Beta</th>
<th>MCS R² change</th>
<th>MCS Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sex</td>
<td>−0.15</td>
<td>−0.11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age at injury</td>
<td>−0.21</td>
<td>0.34*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Injury severity</td>
<td>0.28*</td>
<td>0.12</td>
<td>0.045</td>
<td>−0.24</td>
<td>0.11</td>
<td>0.055</td>
</tr>
<tr>
<td>2</td>
<td>Years post-injury</td>
<td>0.05</td>
<td>0.11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Marital status</td>
<td>0.05</td>
<td>0.11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vocational sit.</td>
<td>0.44**</td>
<td>0.17</td>
<td>0.006</td>
<td>0.21</td>
<td>0.07</td>
<td>0.184</td>
</tr>
<tr>
<td>3</td>
<td>Self appraisal of the TBI</td>
<td>−0.38**</td>
<td>0.11</td>
<td>0.002</td>
<td>−0.20</td>
<td>0.03</td>
<td>0.138</td>
</tr>
</tbody>
</table>

R² =0.39        R²Adj=0.32  R² =0.21     R²Adj=0.12

Sex: Woman=0, Men=1; Injury severity: Moderate-to-Severe=0, Mild=1;
Marital Status: Single=0, Married=1; Productivity: Non productive=0, Productive=1
Table 10. Percent ceiling (maximum score) on outcome measures in 88 individuals 6 to 15 years after TBI

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI (n=40)</th>
<th>Moderate TBI (n=16)</th>
<th>Severe TBI (n=32)</th>
<th>Total (n=88)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIM</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor</td>
<td>78</td>
<td>75</td>
<td>56</td>
<td>69</td>
</tr>
<tr>
<td>Cognition</td>
<td>55</td>
<td>38</td>
<td>22</td>
<td>40</td>
</tr>
<tr>
<td><strong>DRS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>13</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td>Physical</td>
<td>90</td>
<td>88</td>
<td>81</td>
<td>86</td>
</tr>
<tr>
<td>Cognitive</td>
<td>88</td>
<td>69</td>
<td>66</td>
<td>76</td>
</tr>
<tr>
<td>Social</td>
<td>48</td>
<td>13</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td><strong>CIQ</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>6</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>Home</td>
<td>35</td>
<td>19</td>
<td>41</td>
<td>34</td>
</tr>
<tr>
<td>Social</td>
<td>45</td>
<td>31</td>
<td>34</td>
<td>39</td>
</tr>
<tr>
<td>Productivity</td>
<td>58</td>
<td>19</td>
<td>44</td>
<td>45</td>
</tr>
<tr>
<td><strong>MPAI-4</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>6</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Ability</td>
<td>20</td>
<td>13</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Adjustment</td>
<td>25</td>
<td>6</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Participation</td>
<td>43</td>
<td>19</td>
<td>16</td>
<td>28</td>
</tr>
</tbody>
</table>

\(^1\)Ceiling score: FIM motor=91; FIM cognition=35; DRS scales=0; CIQ total=29; CIQ home=10; CIQ social=12; CIQ productivity=6-7; MPAI scales=0

FIM: Functional Independence Measure; DRS: Disability Rating Scale; CIQ: Community Integration Questionnaire; MPAI-4: Mayo-Portland Adaptability Index - 4th version

The measures CIQ and MPAI-4 showed lower proportion of ceiling effects compared to FIM and DRS, so the remaining disabilities were hence more pronounced in this latter measures indicating higher proportion of problems in role fulfilment and social participation compared to physical or cognitive functioning.
Health related quality of life, life satisfaction and sense of coherence

The results of self rated outcome measures in study III as indications of the individuals own experiences of health and compared to reference sample presented in Table 11, together with the significant lower results for SWLS compared with the Swedish nationwide sample of healthy students, indicates a negative impact on HRQoL, as well as life satisfaction from the TBI.

Table 11. The Short Form 36 (SF-36) for the 67 individuals with a traumatic brain injury (TBI) compared with the age- and sex-matched reference sample.

<table>
<thead>
<tr>
<th></th>
<th>TBI sample</th>
<th>Reference sample</th>
<th>Significance test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>PF</td>
<td>75 (26)</td>
<td>89 (19)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>RP</td>
<td>54 (44)</td>
<td>83 (32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BP</td>
<td>63 (33)</td>
<td>74 (27)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>GH</td>
<td>65 (25)</td>
<td>75 (23)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>VT</td>
<td>54 (26)</td>
<td>69 (24)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SF</td>
<td>79 (26)</td>
<td>89 (20)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>RE</td>
<td>81 (33)</td>
<td>86 (28)</td>
<td>ns</td>
</tr>
<tr>
<td>MH</td>
<td>75 (19)</td>
<td>81 (19)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>PCS</td>
<td>42 (13)</td>
<td>50 (9)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>MCS</td>
<td>48 (11)</td>
<td>50 (11)</td>
<td>ns</td>
</tr>
</tbody>
</table>

1The difference between groups was tested with a two-sided t-test. Significance levels smaller than 0.05 represent statistical significance, whereas values greater than 0.05 were considered not significant (ns).
2Obtained from the database of the Swedish general population (n=1224).
PF: Physical Functioning; RP: Role Physical; BP: Bodily Pain; GH: General Health; VT: Vitality; SF: Social Functioning; RE: Role Emotional; MH: Mental Health; PCS: Physical Component Summery; MCS: Mental Component Summery

The measure SOC-13 in study IV showed no significant difference compared to a large Swedish reference sample. The expected positive relation between SOC and life satisfaction was very strong ($p<0.001$). The regression analysis reveals that (Table 12), given the presence of the limitations, a higher sense of coherence a longer time since injury in conjunction with older age and more severe injuries, are important factors in explaining higher life satisfaction several years after injury.
### Table 12. Results of hierarchical multiple regression analyses on life satisfaction for 66 individuals with TBI

<table>
<thead>
<tr>
<th></th>
<th>SWLS</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step 1</td>
<td>Step 2</td>
<td>Step 3</td>
<td>Step 3</td>
</tr>
<tr>
<td></td>
<td>abi</td>
<td>adj</td>
<td>part</td>
<td>tot</td>
</tr>
<tr>
<td>Sex¹</td>
<td>– 0.04</td>
<td>– 0.12</td>
<td>– 0.10</td>
<td>– 0.05</td>
</tr>
<tr>
<td>Age at injury</td>
<td>0.15</td>
<td>0.15</td>
<td>0.19</td>
<td>0.23*</td>
</tr>
<tr>
<td>Injury severity²</td>
<td>– 0.14</td>
<td>– 0.20</td>
<td>– 0.27*</td>
<td>– 0.31**</td>
</tr>
<tr>
<td>Time post injury</td>
<td>0.34**</td>
<td>0.27*</td>
<td>0.30**</td>
<td>0.26**</td>
</tr>
<tr>
<td>SOC-13</td>
<td>0.55***</td>
<td>0.42***</td>
<td>0.23*</td>
<td>0.36**</td>
</tr>
<tr>
<td>MPAI-4 Ability</td>
<td>– 0.28*</td>
<td>– 0.51***</td>
<td>– 0.43**</td>
<td>– 0.46***</td>
</tr>
<tr>
<td>MPAI-4 Adjust.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPAI-4 Partic.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPAI-4 Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

F-ratio 2.05 8.02 8.24 11.77 10.32 10.80
R² 0.12 0.40 0.46 0.55 0.51 0.52
R² Adj 0.06 0.35 0.40 0.50 0.46 0.48
Sig. 0.098 <0.001 <0.001 <0.001 <0.001 <0.001
F change 2.05 28.25 6.00 18.69 13.45 15.20
R² change 0.12 0.28 0.06 0.14 0.11 0.12
Sig F ch. 0.098 <0.001 0.017 <0.001 0.001 <0.001

Standardized beta coefficients are presented; ¹Woman = 0 (n=16), Men = 1 (n=50); ²Moderate-to-Severe = 0 (n=35), Mild = 1 (n=31); Correlation is significant (two-tailed) on *< 0.05, **< 0.01, and ***< 0.001 levels

Furthermore, the results on measures of disabilities (MPAI-4) in study IV showed strong correlation between all three subscales (p< 0.001) and self-rated life satisfaction. The strongest contributor of the MPAI-4 subscales in the regression analysis (Table 12) was the Adjustment subscale indicating that emotional factors are most strongly associated with life satisfaction. The disabilities measured by MPAI-4, and to a greater
extent of Adjustment and Participation subscales, indicate that the limitations caused by the TBI have a great influence on life satisfaction several years after the TBI.

**DISCUSSION**

This thesis describes demographics, injury characteristics and outcomes of individuals with a TBI transferred to the only neurosurgical clinic in northern Sweden. Many of the individuals at working age were found to have achieved and maintained a high degree of functioning, on average 10 years after the initial injury. Despite these improvements, remaining emotional and inter-relational problems are present and impact on social activities, participation, and reduce their health related quality of life and life satisfaction. Their self appraisal of the impact of the injury as low and their high sense of coherence were associated with high life satisfaction.

**Demographics, injury characteristics and primary outcome**

In order to accomplish the major aim, to illuminate the situation for individuals with a TBI several years after the injury, the identification and approach of potential participants are crucial. The population in this study are selected and restricted to an in-hospital sample, but it is reasonable to assume that patients with severe and a major part of moderate TBI are included due to routine admission to the only neurosurgical clinic in the region. The number referred yearly is anyhow much lower than expected. Hence, it may be that individuals with TBI are treated locally without referral to the neurosurgical clinic. Alternatively, but somewhat unlikely, is that the Norrbotten County, with a lower proportion of younger individuals, has an unusually low number of annual cases of moderate to severe TBI.

The classification into three severity groups based on GCS at admission to acute care has well-known limitations, e.g. substance abuse that could lead to misclassifications or the time when the assessment was performed. However, as the data consisted of medical records it seemed to be the most reliable way to register the severity. Other commonly used methods to classify injury severity include duration of coma, duration of impaired consciousness, and duration of post-traumatic amnesia (PTA). All these methods are well-established but each may be influenced by other factors than the severity of TBI. The task to reliably classify the RLS 85 level at
admission or on site of the injury was crucial, as the subsequent order of severity categories would be used in the further analyses. To limit the risk of misclassification, repeated controls were done, and in cases of ambiguity I asked for a second opinion from my supervisor.

The subgroup comprising a large proportion of elderly men with a subdural haemorrhage is considered as a special group within the TBI population due to the features of sustaining the bleeding, despite a relative mild blow and a slow, gradual onset of symptoms. This group is often classified as mild TBI, as the symptoms gradually evolve over time, and the individual seeks care when the symptoms becomes disturbing. As these individuals are often of advanced age, the probability of other health problems is higher and could have an impact on the outcome. This group, i.e. elderly men with a subdural haemorrhage, differs considerably from individuals more commonly associated with mild TBI and diagnosed with concussion. Individuals with an uncomplicated concussion with RLS 85 levels of 1-2, would normally not be considered for referral to a neurosurgical clinic. Hence, the large proportion of mild TBI in this study is therefore explained by the need for neurosurgical surgery, and not due to severity per se. Even though our data do not represent the total TBI population in the region, our results of a large proportion of older men suffering a TBI due to a fall accident resembles the findings in a large nationwide Swedish study. [131]

In the nationwide study, [131] they found that the incidence rate of TBI was stable and falls increased while traffic accidents decreased. This trend of change was however not noticed in study I, possibly due to the smaller sample size compared to the nationwide sample. At discharge from rehabilitation, a majority had a moderate or severe disability as assessed by GOS, despite the fact that many had sustained a mild TBI. A majority of those with a mild TBI were older individuals often with one or more comorbidities. As suggested by the relationship between increased age and GOS, the older individuals were less likely to have a favourable outcome, partly due to the TBI and partly to their comorbidities. This is consistent with previous studies which have shown increased mortality and deteriorating functional outcome in older individuals despite lower injury severity. [170, 224] With a world-wide growing older population, this will increase the need for community prevention, improved rehabilitation and changed living conditions as a result of TBI.
The trend of decreasing incidence of traffic accidents [92, 131] with suggested explanations concerning road safety development and protective facilities as helmets, seat belts, etc. has made traffic accidents and their consequences less devastating. Still, the traffic accidents are one of the major causes for severe TBI. Our study showed a marked difference between young age/traffic accident/severe TBI and the elderly/fall/mild TBI. Hence, this study confirms previous findings of an association with young age, traffic accident, intracerebral damage and severe injury. [62]

**Long-term functioning and disability**

The project continued, with the ambition to illuminate aspects of the living situation several years after injury, by approaching those individuals that at the time of follow-up in year 2007 were of working age, 18-65 years. One consequence of this selection criterion was that a large proportion of those of relatively old age at the time of injury were excluded, and hence the sample changed in the characteristics regarding injury related variables. Forty-five percent were in study II classified as mild TBI, compared to 60 % in study I. Traffic accidents were the most common cause for injury in study II, and in study I the most common cause was accidents related to a fall. Despite the changes, there were still a significant relationship between older ages and less severe injuries. This indicated that there was a remaining proportion of relatively older individuals that suffered a mild TBI, which might have made an impact on the results. Given the increase of older individuals living in society, the subgroup of older individuals with a TBI that was excluded in study II-IV warrants further studies.

The interview design with a standardized manner with prepared interview questions and established outcome measures was done to ascertain optimal reliability. The translations of instruments not previously used in Swedish versions were done according to recommendations, but no further testing was performed, e.g. a pilot study. The interviews were performed in different locations, according to the participant’s request. It is possible that the choice of place may have limited opportunities for relevant observational information, e.g. the individual’s ability for house hold work, residential circumstances, etc. Naturally the telephone interviews gave the least opportunity to make supplementary observations.

Their current living situation was assessed and compared with the situation at the time of injury and discharge from inpatient care and early rehabilitation, on average 10 years previously. The improvement in overall outcomes since injury was unexpectedly
favourable but in accordance with other studies, and was especially notified regarding motor and cognitive functions. There were, however, remaining disabilities related to community integration and social participation that were most clearly observed in changes of vocational situation. About 60% of the individuals in this study were productive, i.e. either working or studying full or part-time, actively looking for work or employed in sheltered work, which is in agreement with other studies with comparable TBI severity groups and time after injury. Many studies have focused on the individual’s ability to return to work after a TBI, but few have looked at changes over time postinjury. One study found that those who worked part-time tended to keep their employment 7 years after injury, indicating that full time work is not always the optimal goal for vocational rehabilitation. Vocational rehabilitation regarding long-term outcome and interventions for individuals with TBI, is a complex area that clearly needs further studies.

It is known that there is a ceiling effect for several evaluation instruments used in early outcome (e.g. FIM and DRS), so that they may not capture the full extent of functional outcomes after TBI. The MPAI-4 covers a broad spectrum of encountered problems after an ABI, which may explain why this instrument had the lowest number of individuals reaching maximum score (study II). The results also indicate that, although other evaluation instruments reflected an overall good outcome, the more detailed MPAI-4 and CIQ showed remaining disabilities in social role fulfilment, i.e. mainly problems associated with the ICF activity and participation domain. A recent review stated that CIQ items may reflect the ICF domain of activities more than participation. The results in study II stress however the need to use an outcome measure that captures different aspects of physical, cognitive and behavioural functioning, community integration and features of the social and physical environment.

One finding in study II was that those with mild TBI had worse outcome than expected. The measure of injury severity is crucial, as it is expected that degrees of severity will have a direct impact on subsequent outcome. In research and literature the most widely used measure on TBI severity is Glasgow Coma Scale. There have been discussions on what measure is valid and reliable in relation to later outcome. Several studies have been reported that GCS predict early outcome, but more important in this context, an inconsistent relation to aspects of long-term outcomes. With regard to the concepts from ICF, the measures of the TBI severity are carried out on the level or domain of ‘body function and structure’. The reasoning that underlain the
International Classification of Impairment, Disease, and Handicap (ICIDH), the nosology that preceded the ICF, was a linear relationship, e.g. between injury of the brain and consequences on disabilities. The linear relationship assumed that harm to the body and function, caused by injury or disease, affected the adverse ability to perform normal activities, leading to limitations in role fulfilment. This assumption of linearity was criticised \cite{1159} and led from an essentially linear model in ICIDH, where one level causes the other, to the current model in ICF, a model with double directed relationships. The disablement, i.e. the adverse effects from injury or disease, was supplemented with possibilities of enablement, i.e. the effects of gain and positive outcome. Hence, in models exemplified by ICF, there are important distinctions and double directed relationships between the ‘body function and structure’ and ‘activity and participation’. With the same reasoning the measures on injury severity, based on the domain of body function and structure, are insufficient for prediction of long-term outcomes with focus on activity and participation. An alternative way to assess severity would be to measure early outcomes and thereby enhance prediction on later outcomes. \cite{128, 168, 205} Hitherto the measures on early outcomes most frequently in use have been those that track changes during inpatient care and early rehabilitation, e.g. the FIM instrument. It seems important to implement routines that enhance the use of adequate early outcome measures that also suit the long term outcome. These measures are important in order to differentiate and select those that need continued support and further rehabilitation interventions. In summary, we need to develop a better understanding of the relationship between impairments and activity limitations in relation to long-term outcomes.

One outcome measure used to assess long-term outcomes is CIQ. The CIQ is considered as one of the most evaluated outcome instrument for community integration. \cite{200} Five studies, \cite{26, 45, 263, 266, 269} evaluating moderate-to-severe TBI, have used CIQ as outcome measure. The total mean score varied in the studies from 16.5, \cite{45, 269} 17.1 (this sample comprised 15 % with a mild TBI), \cite{266} 18.0 \cite{26}, to 18.4. \cite{263} The results from the cited studies are in agreement with the results in study II, if the same injury severity groups are compared. Women had significant better results on CIQ subscales Home integration and Productivity. The finding that women have higher scores on Home integration has been reported in several studies, \cite{200} while the scores regarding productivity have been reported to favour men. \cite{200} In agreement with other studies, older age were significantly related to poorer community integration. \cite{50, 126}
A revised CIQ scale has been presented \[201\] with new scoring guidelines. The original version was kept in study II as the results, using the revised version, did not differ essentially from the original version. Furthermore, as previous studies have used the original version, there was also an argument for comparison purposes.

The MPAI-4 seemed to be a valuable evaluation instrument with the lowest proportion of maximum scores (ceiling effect). The instrument has not yet been used as broadly as CIQ, \[49\] but the relatively new translated versions in several countries indicate an increased use. The MPAI-4 seems to be more related to the ICF concept participation. This is supported by a study \[197\] that evaluated participation content in several measures and found MPAI-4 to be 1 of the 5 most comprehensive instruments. The most coverage for the ICF participation domain was found in the chapter ‘Learning and Applying Knowledge’. In an unpublished study (Lexell, Malec and Jacobsson), we found that all items in MPAI-4 could be linked to ICF, and the subscale Participation contained the highest number of concepts. MPAI-4 is therefore suggested to be the preferred outcome measure in the Swedish national database of neurological rehabilitation, to assess outpatient rehabilitation and long-term outcomes.

Factors other than the selected variables could be considered, e.g. socio-economic or the nature of previous and current employment, that would give broader and more detailed information. More detailed data on family situation and aspects of profession and education could also be considered. However, the dichotomization of marital status and vocational situation has the benefit of facilitating the statistical analyses. Despite the dichotomization of some variables that decreased categories to be analyzed, the relatively small sample size restricts the ability to generalize from the statistical analyses.

**Health related quality of life and life satisfaction**

Outcome assessments have traditionally relied on a more external materialistic view, e.g. the ability to return to work, but have changed to incorporate the individual’s subjective experiences and value of their health and quality of life. \[51, 264\] Study III sought therefore the participants’ own experiences of their TBI, perceived health and life satisfaction. The participants significantly lower reported HRQoL and LS was not surprising as this is in general agreement with other studies on individuals with TBI. \[8, 18, 22, 33, 109, 173\] The men had significantly lower HRQoL compared with the reference sample. In contrast, the women did not differ in HRQoL compared to the reference
sample. However, the women in study III, comprised a relatively small number of individuals (n=16) which might explain the differing results in relation to expected levels regarding both the reference sample and the general Swedish population. [222] Previous studies on outcomes after TBI have indicated that women have worse outcomes compared to men for the first years post injury, [265] and this difference increases with injury severity. [235] Other findings suggest that with time the differences between men and women level out. [266] In contrast to perceived HRQoL, there were no differences between men and women with regard to life satisfaction in study III, in agreement with reports on healthy individuals. [109] However, little is known about the situation for women after TBI. The common pattern that men outnumber women has often led to the argument that it is difficult to use gender as a variable. The need to focus on women living with consequences after TBI has been suggested as an area for further research. [87]

Previous studies, mostly on individuals with moderate to severe TBI, have reported inconsistent findings regarding the impact of injury severity on perceived HRQoL. [33, 68, 79] Our results showed no significant differences between the two injury severity groups with regard to any of the subscales of SF-36, which is in line with a study from Canada [33] that assessed two subgroups of mild and moderate-to-severe TBI on average six years after injury. However, as this study concerned a selected group and those with mild TBI might be not representative for the TBI population, caution is recommended in interpreting the findings.

To be married or in a partner relationship is an indication of a valuable social identity and close relationship, which in turn can be expected to enhance life satisfaction and HRQoL. [138, 217] The expected difference was revealed when compared with the reference sample, i.e. those being married or cohabiting reported significantly higher HRQoL.

To be productive was also, as expected, [217] of importance. Individuals with a disability pension rated significantly lower on all SF-36 subscales, except RE. In addition, individuals who were productive reported significantly higher life satisfaction than those with a disability pension. This is not surprising, reflecting the importance productivity has on social identity, e.g. independence, financial security and participation in productivity. [181, 245] In the regression analyses the importance of being vocationally productive in relation to experienced good physical health and life
satisfaction was emphasized. This underscores that being productive is a cornerstone in reaching a high HRQoL. The finding in study II of 40% with a disability pension stresses the need of vocational rehabilitation, but also other interventions to meet the needs of those with disability pensions. Important goals of rehabilitation are optimal level of independent living and, as one of the most important and evaluated target, to regain vocational productivity. There are 6 larger TBI rehabilitation centres in Sweden, where rehabilitation is generally built on interdisciplinary teams consisting of physicians, nurses, nurse assistants, physiotherapists, occupational therapists, social worker, speech and language pathologist, and neuropsychologists. The rehabilitation of TBI in Norrbotten County is centralized to Sunderby hospital. The four other hospitals in the County organize mixed integrated rehabilitation for different types of patients with brain injuries, such as stroke and trauma. The same professions are in charge of the rehabilitation on this level, but special competence is usually lacking, such as certified rehabilitation medicine physicians and neuropsychologists. The resources are mainly concerned to regain basic functioning from ‘hospital to home’ capabilities. Outpatient rehabilitation rarely includes home based interventions, e.g. support and consultations for family relations. As the TBI population is heterogenic with regard to age and sex, there are also difficulties to differentiate outpatient intervention adapted to specific needs, e.g. regarding younger individuals and women with TBI. Vocational rehabilitation is generally not included in the responsibilities of medical rehabilitation resulting in obvious difficulties to organize interventions and support from ‘coma to community’. The results from the current studies indicate that there is an urgent need for further research and to develop suitable vocational rehabilitation programs for the individuals that have remaining disabilities. Should vocational rehabilitation aim to return the patient to a previous or different but equivalent job? What modifications are required, and is the environment satisfying? Should it be full- or part-time, and what kind of training or support is required? Is the final job situation stable, satisfying, and meaningful? Many questions, besides the lack of unitary organisation over the whole rehabilitation process, remain to be answered regarding vocational rehabilitation.

Although the model with mental health showed weak relationships, the pattern with age at injury and injury severity as the strongest contributors to explained variance were consistent in all the steps of the regression analyses. This could indicate that older age at injury and more severe injuries might be associated with better perceived mental health. Some studies on long-term outcome post TBI have reported, in line with
the general population, a decreased health status with increasing age, but others have found no significant differences \cite{18, 138, 217} within the TBI population. One study \cite{18} found no differences in health symptoms in younger versus older persons with TBI, in relation to none-injured individuals, with the exception of more disturbed sleep patterns among younger ages. One recent study \cite{29} noted that mental health in the general population improves with age, which could explain our results.

The regression analyses indicated a complex relationship between several aspects and LS. The current life situation expressed as a longer time since injury, to be married and vocationally productive, was more important than age at injury and injury severity. However, given that the individual was married and productive, the longer time since injury and older age at injury had significant importance. This suggests that those individuals that are older at the time of injury, \cite{26} with a longer time since injury and are currently productive and married, \cite{39} are more satisfied with life. Some studies have indicated that passage of time may decrease the impact many years post injury. \cite{135, 265}

The supplementary two questions that made up the variable ‘self-appraisal of the TBI’ were created as there are no specific questionnaire on HRQoL and LS for individuals with TBI. Along with the argument for more specificity, it was also possible that other life events could have become more important as time passed. \cite{202} The regression analysis showed that higher reported self-appraisal of the TBI was, as expected, significantly related to lower scores on the summery component score of physical health and life satisfaction. Self-appraisal clearly indicates, being the strongest contributor to explained variance in the regression analysis, that individuals’ own perception of the TBI has a strong influence on life satisfaction. The individuals’ self-rated experience of the impact of the TBI may in itself be a good predictor of physical health and life satisfaction. However, the questions regarding appraisal of the TBI that were stated have not been validated. The questions are broad evaluations of consequences from the TBI event that demands the informer to reflect holistically on their life. Like other similar questions, specific problems concerning memory deficits, emotional problems, and altered ability in judgement and insight could be a threat to its validity and reliability.

In study III, the chosen variables were more capable of explaining the outcome in terms of life satisfaction than the outcome in terms of HRQoL, which implies that life satisfaction comprises other factors besides health condition. \cite{14, 48} It confirms,
however, that life satisfaction is a broad concept with important relations to several intervening factors that are not easily categorized and predicted by demographic or injury related variables.

When the results on SF-36 were compared to the general population, the reference sample comprised age- and sex-matched subsample from the large Swedish database on SF-36. This opportunity was not present with regard to the results on SWLS. There are however several samples, including general populations, from other countries on SWLS that were used for comparisons to control the results with reference to the Swedish study. However, as LS has been found to be culture specific, there is a small possibility that the results from this study would change if it were compared to a Swedish age- and sex-matched sample of healthy individuals. There are always concerns about which variables to choose that reflect the important associations. The independent variables chosen are commonly used in previous studies of similar approach. However, the choice of variable to indicate injury severity may not be the most suitable and other variables related to outcome should be considered in future studies.

**Sense of coherence**

During the last decades an increased interest has evolved to study factors that could explain more positive outcomes after TBI. One area that has attached much interest is the individual’s psychological capacities. For example the concept ‘self-efficacy’, i.e. an individual’s belief on their capacity to ‘make a difference’, to reach the goal that oneself has formulated, has been reported in recent studies on TBI. In line with the interest in psychological resilience factors, the fourth study included a measure on ‘sense of coherence’, which is believed to have a protective effect on adverse health under stressful life events. The SOC comprises the three components of comprehensibility, manageability, and meaning or purpose. This could be expressed as, individuals who experience their lives as purposeful, understandable, and feel that they are capable of managing problems and situations, are more successful in dealing with situations that threaten health.

The sample in study IV, was considered to have relatively mild limitations according to results from MPAI-4 as compared with samples published in the manual. However, the sample also included a range covering the severe end of the limitation continuum.
We found that those with more severe injuries tended to have more problems in both activities carried out on their own and in societal participation.

Injury severity was however, not associated with LS. Previous studies\cite{26, 97, 190} on the relationship between LS and levels of limitations several years after TBI have found more consistent relationships of LS to societal participation than to demographic or injury related variables. Consistent with our findings, Smith et al.\cite{213} suggested that “the ability to carry out a greater number of tasks independently may not influence an individual’s global appraisal of their life satisfaction” (p. 136). Corrigan et al.\cite{39} stated that, like the general population, studies of individuals with TBI have found LS to be associated with societal participation, marital status, and employment. In study IV, the strongest relationship with LS was found with measures of emotional states and personal relations. Several studies have indicated that mental health problems, like symptoms of depression and anxiety, are common after TBI.\cite{53, 135}

The concept ‘rehabilitation’ is often defined by its literal meaning, to once again become able, and characterises the strive to become independent and towards a sense of normalcy.\cite{120} The individual’s own perceptions are therefore important as the rehabilitation back to the community also implies a movement from being a patient towards being a participating citizen. The wellness measures, in the current studies the SWLS, could be an important aspect in rehabilitation interventions to capture the subjective perspective and not only functional independence.

The level of SOC in this study was very similar to that of a large Swedish reference sample from the general population.\cite{143} The SOC-13, similar to LS, showed the strongest relationship to measures of emotional states and personal relations.

Our results from the hierarchical multiple regression analyses indicate that LS may improve over time. Previous findings have shown increased LS or no difference compared to the general population several years after injury.\cite{14, 31, 39} SOC explained considerable increased variance to LS, and confirmed the expected positive association between SOC and LS. The strong relationship between SOC and LS has been suggested to be bidirectional,\cite{214} i.e. that a strong SOC might lead to high LS, and vice versa. There are no normative values, so the threshold when SOC can be considered to lose its “protective character”\cite{65} is not known. SOC is considered to be relatively stable over time,\cite{65, 98} although not as stable as Antonovsky suggested.\cite{7} We do not
know the SOC score before the TBI, but the results of nonsignificant correlation between injury severity and SOC suggest that SOC was not altered in a direct sense by the TBI. Furthermore, the contribution from SOC decreased as a result of the stronger contributions from the measures on mental states and social participation. The SOC-13 scale is considered to be sensitive as a measure of negative affectivity \cite{142} and several studies have reported strong associations with depression, \cite{66, 212} which could explain the strong relationship in study IV with measures of emotional states. It has been questioned if SOC and measures on mental problems, e.g., anxiety and depression, are two ways of measuring the same concept. \cite{214} Depression and anxiety have a strong relation to psychological interpretations, e.g. arbitrary inference, and selective abstraction, as described in the theory of cognitive therapy. \cite{12} An individual who has difficulties to understand and manage their life and perhaps also loses their meaning of life, are naturally at risk to develop a state of depression and feel anxious. It seems plausible that a weak SOC would be strongly related to states of depression and anxiety, but not necessarily synonymous concepts, which was also concluded in a review on SOC in relation to health. \cite{66} The subjective perceived symptoms of anxiety and depression, revealed by the Adjustment subscale, and its relationship with SOC and LS, indicate the great importance of these factors in the long-term outcome after TBI. The results are in line with previous findings \cite{135, 190, 213, 239} of stronger associations between LS and factors of mental states and social participation, than with impairment or activity limitations.

The pattern of results shows that factors of emotional and social participation are strongly associated with LS several years after a TBI, indicating that the actual impairment caused by the TBI influence LS. However, when controlling for these actual limitations (MPAI-4), we can see that besides a higher SOC and a longer time post injury, factors such as more severe injury and older age at the time of injury are important factors to explain higher life satisfaction several years after injury. Thus, given that a person has a certain level of ability, adjustment and participation, he or she will be worse off in terms of LS when having a milder injury and a lower age. The finding that higher LS was associated with more severe injuries, also observed in other studies. \cite{18, 22, 33, 68, 78, 181} suggests that individuals with more severe injuries may have difficulties to rate the impact of the TBI or have found an adaptive way to reduce the importance of the TBI. Another explanation is that individuals with mild TBI might develop an “oversensitivity”. \cite{190} Emotional states, such as mood, are important for life
satisfaction, and an inclusion of a measure of their mood state could have broadened our understanding of factors that determine life satisfaction.

Psychological factors, which could explain why some individuals adapt more successfully than others, are shown an increased interest. Psychological resilience factors, e.g. sense of coherence, could be a valuable indicator on who needs more support to adapt to life after TBI, but further research is needed. As only direct effects from the examined variables on LS were examined, other effects such as interactions are not shown. However, the relatively small sample in this study restricts further analysis of these associations. Possible interaction effects between SOC and other variables, e.g. age or gender are possible as a recent study has found differences in this matter for the general population.

**CLINICAL IMPLICATIONS AND FUTURE RESEARCH**

Many impressions and possible implications could be drawn from this research, but I will focus on the implications that in my personal opinion are the most important. An overall impression from this research is that the outcome was fairly good with regard to overall functioning but in contrast their perceived health and life satisfaction was not. Although many improved in their functioning there were also many that had remaining disabilities, in all severity levels of the TBI. This implies a need to develop a support system that accommodates these individuals’ needs, often over several years and for some perhaps, a whole life time. Their needs are often complex and related to e.g. mood states, role fulfilment, and other aspects of social participation. This leads to a second implication, that long-term follow-up needs to be organized in rehabilitation teams with a broad competence and professional skill, in particular rehabilitation medicine physicians, occupational therapists, social workers and neuropsychologists. These teams need to be developed within each county, as it can not be expected to be handled within the primary health care system.

The above stated implications lead to suggestions for future research, where a key question is to find early indicators/predictors for those that may need long-term support. Secondly, further researches are needed to find out what important factors, other than those focused on in this thesis, that influence LS. Thirdly, there is a need to evaluate interventions that aim to support these needs even many years after TBI, in
particular to show the effectiveness of long-term support systems as described above. Finally, there is a need to explore and evaluate individuals’ positive psychological capability to cope with consequences from the TBI over time, what has been termed as ‘post-traumatic growth’. Future studies could be to assess the individuals in this thesis in a further follow-up after, as a suggestion, another five years.

CONCLUSIONS

The following main conclusions can be drawn from this thesis:

- Of the 332 individuals with TBI from northern Sweden, a majority were older men with a mild injury following a fall. Younger individuals were fewer but more often had a severe injury from a traffic accident. This confirms the relationship between age, cause of injury and injury severity found in previous studies.

- Most individuals received post-acute care and brain injury rehabilitation at their local hospital, and many were discharged back home, despite remaining disabilities, with no major changes in their physical or social environment.

- At follow-up, on average 10 years after the TBI, many individuals had achieved a high degree of motor and cognitive functioning, which enabled them to live independently in their own home without assistance, but there remained a disability, mainly related to community integration and social participation, which were associated with increasing age and more severe injuries.

- Although a high degree of functioning was achieved many years after TBI, HRQoL and LS were lower than the general population and healthy individuals. Overall, individuals with mild TBI rated their LS lower than those with severe injuries.

- Individuals that were vocationally productive rated their perceived physical health higher compared to individuals with full disability pension, and individuals that were vocationally productive and married/cohabiting rated their
LS higher compared to individuals who were single and/or had full disability pension.

- Age at the time of injury, injury severity, time since injury, marital status, vocational situation, and the appraisal of the importance of the TBI, were more strongly related to LS than HRQoL.

- The individuals’ own appraisal of the impact of the TBI was strongly associated with their current physical health and LS, which indicates the importance of the impact of the injury on the individuals’ self-perceived values of health, quality of life and LS.

- This group of individuals with TBI did not differ in their SOC compared with the general population, and a high SOC was related to high LS. Sense of coherence, together with emotional factors, social participation, and time since injury, were more influential than sex, age at injury, and injury severity in explaining LS.

- TBI related outcome measurements are important tools for our understanding of the long-term outcome. To be clinically and scientifically useful, such tools should capture different aspects of physical, cognitive and behavioural functioning, mood states, community integration and features of the social and physical environment.

EPILOGUE

Many of the individuals I have met in this project have succeeded in adapting to the changes the TBI have inflicted on their lives. Others have stated themselves to be fully recovered; a few individuals stated this despite an initial severe injury, and seemed to live an ordinary family life with children, and had returned to full-time employment. On the other hand, I have also met individuals that had an enormously difficult situation with unfulfilled needs and disturbed social relations. A few individuals I’ve met had obvious physical disabilities, but still claimed to have a better current life compared with the situation prior the TBI.
The experiences this thesis have given, has strengthened my belief that it is important to identify individuals in need of the (limited) resources that could be allocated to rehabilitation several years after TBI. Even if individuals have recovered well with regard to their physical functioning, the results in this thesis confirm my clinical experience that many have pronounced problems in social participation, e.g. to meet the demands in fulfilling social interaction at home, in leisure activities, and employment situations. The organisation should be dynamic and overcome the gaps between different areas of rehabilitation, such as medical, social and vocational rehabilitation. If such organisation could be accomplished, the target to support individuals with TBI from ‘coma to community with optimal quality of life’ would be considerably improved. I am grateful to have found a promising evaluation instrument in the MPAI-4. The search for questionnaires that tap the subjective experiences and psychological positive factors has just begun, but hopefully this research area will expand and add knowledge that can improve the current state of rehabilitation after TBI.

The intention of this thesis was to capture the same spirit that The Swedish Association of Brain Injured and their Families has expressed: “A life that is saved needs to be lived” (Translated from Swedish by the author). With regard to the main results in this thesis the cited expression could be stated as: Individuals that are saved also need to be supported to regain an optimal participation in their community. I hope that this thesis has added a piece of understanding in the complex pattern of the process that individuals with TBI go through, from the injury, over several years to their current situation. Future research will give additional pieces of knowledge and help us understand this very complex puzzle of factors in a life that ‘needs to be lived’.
SVENSK SAMMANFATTNING (SUMMERY IN SWEDISH)

Levnadssituationen för traumatiskt hjärnskadade i Norrbotten

Det finns ett ökat intresse att studera konsekvenserna en längre tid efter en traumatiskt hjärnskada (THS), eftersom man funnit att THS är en av de vanligaste orsakerna till livslångt funktionshinder. Det övergripande syftet med denna avhandling var att öka vår kunskap för och förståelse av personers situation flera år efter en THS med avseende på demografi och skadekarakteristik, funktionsförmåga och funktionshinder, hälsorelaterad livskvalitet, livstillfredsställelse, egenvärdering av THS inverkan på sitt liv, samt känsla av sammanhang.


I studie III kartlades 67 personers hälsorelaterade livskvalitet och livstillfredsställelse, samt jämfördes med referensvärden från svensk normalbefolkning. Såväl hälsorelaterade livskvalitet som livstillfredsställelse var lägre jämfört med normalbefolkning. Multivariata statistiska analyser visade att personernas egna
värderingar av inverkan av THS tillsammans med arbetsförmåga var starkast relaterad till deras aktuella fysiska hälsa och allmänna livstillfredsställelse.

I studie IV kartlades 66 personers känsla av sammanhang (KASAM), resultatet var i nivå med normalbefolkning. KASAM utgör ett mått på personers upplevelse av mening, hanterbarhet och förutsägbarhet i livet och har visats vara positivt relaterad till bevarande av hälsa. KASAM var starkt positivt relaterad till livstillfredsställelse. Tillsammans med mått på funktions- och aktivitetsinskränkningar, samt kön, ålder vid skada, skadegrad och tid efter skada, undersöktes KASAM påverkan på deras livstillfredsställelse. Hög livstillfredsställelse var också starkt relaterad till emotionella faktorer och social delaktighet, men även längre tid efter skada, svårare skadegrad och högre ålder vid skadetillfället var betydelsefulla relaterade faktorer.

Sammanfattningsvis påvisar resultaten att många personer flera år efter THS kan uppnå och vidmakthålla en hög grad av förmåga men med kvarstående emotionella och relationella problem som påverkar social aktivitet och delaktighet. Många upplever en nedsatt hälsorelaterad livskvalitet och livstillfredsställelse. Den egna värderingen av skadans lägre grad av inverkan och känsla av sammanhang var positivt relaterad till livstillfredsställelsen. Resultaten bekräftar att THS kan leda till långvarig funktionsnedsättning och aktivitetsinskränkning, vilket påtalar behov av stöd och rehabiliteringsprogram som kan möta dessa personers behov avseende emotionella aspekter, social delaktighet och livstillfredsställelse i ett längre tidsperspektiv.
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STUDY I
Demographics, injury characteristics and outcome of traumatic brain injuries in northern Sweden

Introduction

Traumatic brain injury (TBI) is an important global health problem (1,2). The occurrence, causes and outcome vary greatly (1,2). In a review (3) of European investigations over the last 20 years, outcome and disability findings were mixed and inconsistent, and it was emphasized that further studies of the short- and long-term consequences of TBI are needed.

In Sweden, the incidence of TBI has been assessed in four studies. One included only children (4) and one reported an unusually high rate of TBI (5). The two remaining studies reported an annual rate of about 250/100,000 (6, 7), which is comparable with a European annual rate of 235/100,000 (3). External causes are reported in three Swedish studies (4, 5, 7). The two studies that included adults (5, 7) reported a decrease of traffic accidents and an increase of falls. There was also a decline in younger ages, whereas TBI among elderly people increased over time. Similar results have been reported from other Nordic countries indicating that a somewhat unique epidemiologic pattern may be developing in these countries (7–10).

Mild TBI has been the focus in three Swedish studies (11–13) and all indicated the potential risk for long-term disability. Some Swedish studies have focused specifically on severe TBI in association with initial care (14, 15) and found that overall outcome has improved (16, 17). This is suggested to be due to the adherence to the national policy that individuals with a significant TBI are referred to a neurosurgical unit, but also due to an improved neurosurgical care. As a consequence, individuals with TBI more often survive (18), leading to an increased need for rehabilitation (16, 17).

Even though these studies have increased our knowledge of TBI in Sweden, there is overall a dearth of information. The overall aim of this study was therefore to describe the demographics, injury characteristics and outcome for a group of individuals with a TBI referred to a Swedish

Objectives – To describe demographics, injury characteristics and outcome of traumatic brain injury (TBI) in northern Sweden over 10 years. Material and methods – Data were retrospectively collected on those individuals (n = 332) in Norrbotten, northern Sweden, with a TBI who had been transferred for neurosurgical care from 1992 to 2001. Results – A majority were older men with a mild TBI and an acute or chronic subdural hematoma following a fall. Younger individuals were fewer but had more often a severe TBI from a traffic accident. Most individuals received post-acute care and brain injury rehabilitation. A majority had a moderate or severe disability, but many were discharged back home with no major changes in their physical or social environment. Conclusions – Our data confirm the relationship between age, cause of injury, injury severity and outcome in relation to TBI and underscore the need for prevention as well as the importance of TBI as a cause of long-term disability.

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Key words: accidental falls; accidents; traffic; brain injuries; Glasgow Outcome Scale; rehabilitation

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regional neurosurgical clinic over a 10-year period.

Material and methods
This retrospective study was carried out in Norrbotten, the northernmost and geographically largest county of Sweden. Of the entire Swedish population at the end of 2003 (8,975,670), 2.8% (or 252,585) were living in Norrbotten. Compared with the national average, a slightly larger proportion was in the age range 45–74 years (38%; national average 34%). The study comprised all individuals who had been transferred for neurosurgical care to the Neurosurgical clinic, Umeå University Hospital following a TBI during the period 1 January 1992 to 31 December 2001. The neurosurgical clinic is located about 160 km south of the county border and has been responsible for all neurosurgical care in northern Sweden over the last 25 years. All patients who subsequently required rehabilitation were transferred back to one of the hospitals in Norrbotten. The study was approved by the Research Ethics Committee of Umeå University, Sweden.

Demographics and injury characteristics
Using the ICD-9 codes 850–854 and ICD-10 codes S06–S09, a total of 340 individuals were identified in the University Hospital database. The medical records of five individuals were missing and another three individuals were excluded as their primary diagnosis was not one of the ICD codes. The final population comprised 332 individuals: 250 men (75.3%) and 82 women (24.7%). All the 332 individuals had a computer tomography-verified brain injury and brain injury symptoms (e.g., disturbed cognition or mobility or affected conscious) that required neurosurgical care. From their medical records, data on sex, age, year of injury, injury severity, cause of the injury, type of injury and length of stay (LOS) in the neurosurgical unit were obtained. The injury severity was defined by the Reaction Level Scale scores (RLS) (19) assigned at the site of the injury or at admission to the hospital. To allow for a comparison with data from other studies, the RLS 85 scores were transformed into Glasgow Coma Scale scores (GCS) (20–22). Based on the GCS score, all the 332 individuals were then grouped into the three commonly used TBI severity groups (23): mild (GCS 13–15), moderate (GCS 9–12) and severe (GCS 3–8). The cause of injury was defined from the description in the medical records and the complementary ICD codes as: a fall, traffic accident, assault or suicide attempt, sport and recreational activity, or other cause (not defined). Based on the initial computed tomography (CT), the type of injury was defined as isolated contusions, isolated subdural hematoma (acute or chronic) or mixed injury (a combination of two or more of the following: contusions, subdural hematoma, subarachnoidal hemorrhage, epidural hematoma and diffuse axonal injury).

Outcome
For each individual who survived the initial neurosurgical care and was transferred back to Norrbotten for rehabilitation, their medical records at one of the hospitals in Norrbotten were reviewed. Data on inpatient LOS, comorbidities, outcome at discharge (assessed with the Glasgow Outcome Scale, GOS) (24), discharge destination and need of care and/or assistance post-discharge were obtained. Inpatient LOS was defined as the total number of days of care in a general medicine and/or surgical ward and in a subsequent inpatient rehabilitation unit until discharge to outpatient rehabilitation or back home. A comorbidity, such as cardiovascular diseases, diabetes and previous cerebrovascular disorder, was defined to be present when a diagnosis (ICD code) before the TBI was present in the medical records.

Statistics
Descriptive data are presented as means, standard deviations, medians, minimum and maximum, where appropriate. Differences between groups, such as men and women, between subgroups, such as injury severity and over time, were analyzed using non-parametric tests (chi-square, Mann–Whitney, Kruskal–Wallis and chi-squared test of independence). Relationships between variables were analyzed with the Spearman rank correlation coefficient. A discriminant analysis was performed to determine possible subgroups of associated variables. In the first set of analysis, the dependent variable was the injury severity categories (mild, moderate and severe) and the independent variables were age, total inpatient LOS, comorbidities and discharge destination. In the third set of analysis, the dependent variable was discharge destination (home or disability center/nursing home) and the independent variables were age, injury severity categories and total...
inpatient LOS. All statistical analyses were performed using SPSS version 11.0. Exact significance levels are given for values in the range 0.001–0.05, whereas <0.001 represents significant levels less than 0.001. Significance levels above 0.05 are considered statistically not significant (NS).

Results

Demographics and injury characteristics

There was a higher occurrence of TBI in the older age groups (Fig. 1) with the highest number in the age group 70–79 years (71 persons; 21.4%). There were few women in the age groups 30–39 and 40–49 years. The occurrence of TBI varied from 21 in 1996 to 60 in 1999. The overall ratio between men and women was 3:1 and varied from 8:1 to 1.5:1.

There was no significant difference between the 250 men and the 82 women regarding their age (NS) and injury severity (Table 1). Almost 60% of the 332 individuals had sustained a mild TBI and about 25% a severe TBI (Table 1). During the treatment in the neurosurgical unit, 12 men (mean age 48.8, 13–76 years) and three women (mean age 31.3, 12–65 years) died: 13 of these individuals had sustained a severe TBI, one a moderate TBI and one a mild TBI. No significant variation in the number of deaths was detected over the 10-year period (NS).

Isolated contusions were present in 71 individuals (21.4%), isolated subdural hematoma in 170 individuals (51.2%; 86 of these, 50.6%, had a chronic subdural hematoma), and mixed injury in 87 individuals (26.2%). In four individuals (1.2%), no signs of intracerebral injury or hemorrhage were detected on CT. The mean LOS in the neurosurgical unit was 6.5 days (1–31 days; median 5.0); there was a significant positive relationship between the LOS and the injury severity ($\rho = 0.17; P = 0.002$).

The frequency of mild TBI increased markedly with increasing age, with the highest number in the age group 70–79 years (Fig. 2). The frequency of moderate TBI was similar across the population, whereas severe TBI were most common in the youngest age group (Fig. 2).

The main causes of TBI were falls (66.0%) and traffic accidents (25.3%). There were no significant differences between men and women regarding the causes of TBI (NS). Falls were the most common cause in the older age groups (Table 2); the highest occurrence of falls (64 individuals) was in the age group 70–79 years. Traffic accidents were most common in the younger age groups, with car accidents as the most common traffic accident. Assaults, suicide and sports and recreational injuries were uncommon but generally more common in the younger age groups than in the older.

Figure 1. Distribution of age for 250 men and 82 women with traumatic brain injury.

Table 1 Age and injury severity of traumatic brain injury in 332 men and women

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Men ($n = 250$)</th>
<th>Women ($n = 82$)</th>
<th>Total ($n = 332$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>55.8 (21.1)</td>
<td>56.5 (24.0)</td>
<td>56.0 (21.8)</td>
</tr>
<tr>
<td>Range</td>
<td>2–90</td>
<td>3–85</td>
<td>2–90</td>
</tr>
<tr>
<td>Reaction Level Scale (RLS 85)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>2.9 (2.0)</td>
<td>2.6 (1.8)</td>
<td>2.8 (2.0)</td>
</tr>
<tr>
<td>Median</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Glasgow Coma Scale (GCS)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>11.1 (3.9)</td>
<td>11.4 (3.7)</td>
<td>11.1 (3.8)</td>
</tr>
<tr>
<td>Median</td>
<td>13</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Severity categories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild (GCS 13–16)</td>
<td>143 (42.9%)</td>
<td>48 (58.5%)</td>
<td>191 (57.6%)</td>
</tr>
<tr>
<td>Moderate (GCS 9–12)</td>
<td>44 (13.9%)</td>
<td>15 (18.3%)</td>
<td>59 (17.9%)</td>
</tr>
<tr>
<td>Severe (GCS 3–8)</td>
<td>63 (25.2%)</td>
<td>19 (23.2%)</td>
<td>82 (24.7%)</td>
</tr>
</tbody>
</table>

Figure 2. Distribution of severity of traumatic brain injury for 250 men and 82 women.
The discriminant analysis with injury severity (mild, moderate and severe) as the dependent variable showed 63.0% correct classification of the original group and 59.9% of the cross-validated group. The independent variables, age and type of injury, had the strongest discriminating power: mild TBI were associated with old age, falls and subdural hematoma, whereas severe TBI were associated with young age, traffic accidents and isolated contusions.

Outcome
A majority of the 317 surviving persons – 296 (94.3%) – were transferred back to Norrbotten for rehabilitation (Table 3). Of the remaining 21 individuals, two men and one woman (mean age 31.7 years, range 14–60) were transferred outside the northern region, two women (75 and 85 years of age) and one man (84 years of age) were transferred to a nursing home, and 11 men (mean age 49.7 years, range 20–76) and four women (mean age 33.3 years, range 18–52) were discharged directly back home.

The mean inpatient LOS in a general medicine and/or surgical ward for the 296 individuals was 10.6 days (SD 15.2, range 0–158 days) and in a rehabilitation unit 21.5 days (SD 42.5, range 0–320 days). The total mean inpatient LOS was 32.2 days (SD 50.3, range 1–376 days) (Table 3); there was no relationship between the age of the individuals and the LOS ($\rho = 0.04; \text{NS}$) but a significant relationship between the injury severity and the LOS ($\rho = 0.41; P < 0.001$). One or more comorbidities were present in 120 (53.6%) of men and 44 (61.1%) of women; there was a significant relationship between old age and comorbidities ($\rho = 0.50; P < 0.001$). The mean total LOS for individuals with one or more comorbidities was 29.6 days, (SD 42.0) and for those without comorbidities 35.4 days, (SD 58.9) (NS).

The overall mean and median GOS score was 3.7 and 4, respectively (Table 3), with no significant difference between men and women (NS). A majority of the individuals had a moderate disability at discharge (44%), more than a third a severe disability (37%) and not more than 14.5% a good recovery. Seven men but no woman died during the inpatient rehabilitation period. There was a significant relationship between age and GOS ($\rho = -0.30; P < 0.001$), between the injury severity and GOS ($\rho = -0.17; P < 0.01$) and between the total LOS and GOS ($\rho = 0.50; P < 0.001$). Individuals without comorbidities had a significantly ($P < 0.001$) better GOS than those with one or more comorbidities. The discriminant analysis with outcome (GOS) as the dependent variable showed 68.2% correct classification of the original group and 67.6% of the cross-validated group. Overall, a short LOS, no comorbidities and young age were associated with a better GOS, whereas a long LOS, one or more comorbidities and old age were associated with a worse GOS.

A majority of the 289 surviving individuals – 232 (80.3%) – were discharged back home (Table 4); 131 of the 289 individuals (45.3%) were discharged back home with no major changes in their physical or social environment, whereas 101 (34.9%) were discharged back with assistive devices, physical

### Table 2
Distribution of main causes of traumatic brain injury for 250 men and 82 women

<table>
<thead>
<tr>
<th>Age groups (years)</th>
<th>Falls</th>
<th>Traffic accidents</th>
<th>Assaults and suicide attempts</th>
<th>Sports and recreational activities</th>
<th>Other causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–19</td>
<td>27 (11.9)</td>
<td>28 (11.5)</td>
<td>2 (0.9)</td>
<td>3 (1.3)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>20–29</td>
<td>18 (12.3)</td>
<td>19 (13.5)</td>
<td>2 (1.3)</td>
<td>1 (0.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>30–39</td>
<td>10 (12.2)</td>
<td>9 (11.4)</td>
<td>4 (4.1)</td>
<td>0 (0.0)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>40–49</td>
<td>21 (12.8)</td>
<td>8 (6.1)</td>
<td>8 (5.1)</td>
<td>0 (0.0)</td>
<td>7 (5.0)</td>
</tr>
<tr>
<td>50–59</td>
<td>31 (19.4)</td>
<td>8 (4.9)</td>
<td>8 (4.9)</td>
<td>1 (0.6)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>60–69</td>
<td>43 (21.0)</td>
<td>10 (5.1)</td>
<td>1 (0.5)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>70–79</td>
<td>64 (23.9)</td>
<td>71 (27.4)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>80–89</td>
<td>44 (16.0)</td>
<td>43 (16.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>&gt;90</td>
<td>1 (0.4)</td>
<td>1 (0.4)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

The discriminant analysis with injury severity (mild, moderate and severe) as the dependent variable showed 63.0% correct classification of the original group and 59.9% of the cross-validated group. The independent variables, age and type of injury, had the strongest discriminating power: mild TBI were associated with old age, falls and subdural hematoma, whereas severe TBI were associated with young age, traffic accidents and isolated contusions.

### Table 3
Age, length of stay and outcome of 296 men and women with traumatic brain injury

<table>
<thead>
<tr>
<th>Age groups (years)</th>
<th>Men ($n = 224$)</th>
<th>Women ($n = 72$)</th>
<th>Total ($n = 296$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>56.6 (21.1)</td>
<td>58.9 (22.8)</td>
<td>57.1 (21.5)</td>
</tr>
<tr>
<td>Median</td>
<td>60.5</td>
<td>67</td>
<td>61.5</td>
</tr>
<tr>
<td>Range</td>
<td>2–90</td>
<td>3–95</td>
<td>2–90</td>
</tr>
<tr>
<td>Inpatient length of stay (LOS) (days)</td>
<td>33.8 (SD 24.4)</td>
<td>27.0 (SD 33.4)</td>
<td>32.2 (SD 50.3)</td>
</tr>
<tr>
<td>Median</td>
<td>14</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Range</td>
<td>1–1376</td>
<td>1–152</td>
<td>1–1376</td>
</tr>
</tbody>
</table>

Glasgow Outcome Score (GOS)

<table>
<thead>
<tr>
<th>Score (GOS)</th>
<th>Good recovery</th>
<th>Moderate disability</th>
<th>Severe disability</th>
<th>Vegetative state</th>
<th>Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>28 (12.5%)</td>
<td>15 (20.8%)</td>
<td>15 (16.9%)</td>
<td>0 (0.0%)</td>
<td>7 (2.4%)</td>
</tr>
</tbody>
</table>

*1inpatient length of stay was defined as the total number of days of care in a general medicine and/or surgical ward and in a subsequent inpatient rehabilitation unit until the patient was discharged to outpatient rehabilitation or back home.
 adaptations or personal assistance. A smaller proportion – 57 individuals (19.7%) (median GOS 3) – were discharged to a nursing home or disability center. The discriminant analysis with the dependent variable discharge destination (home or disability center/nursing home) showed 81.3% correct classification of the original group and 78.8% of the cross-validated group. Overall, old age and poor outcome (severe disability or vegetative state) was associated with discharge to a disability center or nursing home, whereas young age and good recovery was associated with a discharge home with no major changes.

Discussion

This study has shown that demographics, injury characteristics and outcome of the 332 individuals with a TBI transferred to the only neurosurgical clinic in northern Sweden were stable over a 10-year period. A majority were older men with a mild TBI due to falls. Younger individuals were fewer but had more often a severe TBI from traffic accidents. Most individuals received post-acute care and brain injury rehabilitation. A majority had a moderate or severe disability, but many were discharged back home with no major changes in their physical or social environment. Even though this study was based on a selected sample (i.e. individuals with a TBI transferred for neurosurgical care and not all individuals with a TBI in the region), data on demographics and injury characteristics are in general agreement with previous Nordic and international studies (2). There was a strong association between young age, severe TBI and traffic accidents (25). However, the incidence was much lower compared with international studies (2). This supports results from other Nordic countries showing a decline in severe TBI following traffic accidents (7, 8). This, in turn, may indicate that a unique epidemiologic pattern is developing in these countries (10), possibly as a result of successful prevention of head injuries in adolescents and young adults (7, 8). Furthermore, a large proportion was older men with a mild TBI from a fall. Recent trends point towards an increasing number of falls among the elderly as the main cause of TBI (7, 10, 26).

About one quarter of the individuals in the present study had an isolated chronic subdural hematoma, a common consequence of falls in the older population (27, 28), and this explains the high proportion of older men with a mild TBI. These individuals constitute a specific subgroup of mild TBI and were included here for completeness, as they had brain injury symptoms that required neurosurgical care. Finally, there was no major trend in the annual number of TBI over the 10-year period. Other studies have shown a decline in the annual rate of TBI (29, 30). These studies were based on larger populations, which more easily detect trends in the incidence.

At the time of discharge from rehabilitation, a majority had a moderate or severe disability as assessed by GOS, despite that many had sustained a mild TBI. A majority of those with a mild TBI were older individuals, who also had one or more comorbidities. As suggested by the relationship between increased age and GOS, the older individuals were less likely to have a favorable outcome, partly due to the TBI and partly due to their comorbidities. This is consistent with previous studies which have shown increased mortality and worse functional outcome in older individuals despite lower injury severity (31, 32). With a worldwide growing older population, this will increase the need for community prevention, improved rehabilitation and changed living conditions as a result of TBI.

Nearly 50% of the individuals were discharged back home without any major changes in their physical or social environment. Based on the GOS score, which showed that only about 15% had a good recovery, this indicates that a significant proportion of the individuals may have returned home without sufficient support to resume their daily activities. However, the GOS is a rather crude outcome measure and is related to other factors than the severity of the TBI, and this may partly explain the findings. Further studies are therefore required to determine the long-term consequences on participation in daily activities after a TBI across all ages.

A factor often addressed in the study of TBI is sex/gender. As expected, men were in a majority, but there were no significant differences between men and women regarding their age and injury.
severity. Some studies have indicated that women have a poorer outcome after a TBI (33); such a difference was not found here.

Retrospective studies have limitations that may influence the quality of the data. Less than 2% of the medical records in the neurosurgical clinic were missing, but the remaining medical records and those in the rehabilitation units were sufficiently complete to allow for inferences regarding the collected data on demographics, injury characteristics and outcome. Still, data on the site for TBI was incomplete and information about substance abuse was rarely verified by an analysis of blood. In addition, some demographic data, such as vocational situation and marital status were infrequently reported and not possible to record.

In conclusion, this study confirms previous studies regarding the relationship between age, cause of injury, injury severity and outcome in relation to TBI. The large number of older individuals with a mild TBI due to a fall and the relatively low number of young individuals with a severe TBI following a traffic accident underscore the need for continuous prevention. The overall outcome also confirms the importance of TBI as a major cause of disability, and the need for rehabilitation and long-term follow-up.

Acknowledgements

This study was supported by grants from the Cancer and Traffic Injury Fund, Norrbotten County Council, Norrbottens-akademien, Skane county council’s research and development foundation, Norrbucks-Eugenia Foundation and the Crafoord Foundation. The support and practical assistance from the Department of Neurosurgery, the University Hospital of Northern Sweden, Umeå, is greatly appreciated.

References


STUDY II
Introduction

Traumatic brain injury (TBI) is one of the major causes of long-term disability (1). As improvements in acute care and early intervention have led to decreased mortality, there is an increased interest in the long-term consequences of TBI and a need for further studies of functioning and disability many years post-injury (2).

Assessments more than 5 years post-injury have shown a gradual improvement (3, 4), but residual symptoms and activity limitations can be present and prevent successful community reintegration (5–7). Most studies are based on individuals with a moderate-to-severe TBI, so there is a need to assess across the entire range of injury severities. Some studies have indicated that very young and older individuals have less favourable outcome (8, 9), whereas others have reported no significant associations between sex, age and outcome (10). The risk of separation and divorce is increased, but findings are inconsistent (11). The ability to participate in productive life after TBI is often used as an indicator of successful community reintegration (2). A recent review (12) stated the need for further studies, as there is no universal agreement on measures of productivity. Studies from different societal contexts may therefore lead to a better understanding of both marital stability and productivity following TBI. As the process from injury to recovery and community reintegration many years after TBI is complex, a set of reliable and valid outcome measures is needed to comprehensively capture post-injury functioning and disability (13).

To increase our knowledge of the long-term consequences of TBI, an evaluation of all individuals with a TBI in northern Sweden that required neurosurgical care from 1992 to 2001 has been initiated (14). The aims of this study were to assess 6–15 years post-injury: (i) changes in overall outcome from discharge from inpatient rehabilitation to follow-up, (ii) changes in living condition, marital status and vocational status as a result of discharge from inpatient rehabilitation to follow-up. Many individuals had a high degree of motor and cognitive functioning, which enabled them to live independently in their own home without assistance, but there remained a disability related to community reintegration and social participation. This affected their productivity and to some degree their marital stability. The remaining disability and reduced productivity were related to the age at injury and the injury severity. Conclusions – Our data showed that individuals with a TBI can achieve and maintain a high degree of functioning many years after the injury. Increasing age and a greater injury severity contributed to their long-term disability.
the TBI and (iii) functioning and disability as assessed with internationally established TBI outcome measures.

Methods

Participants

Participants were obtained from the previous study (14), which comprised all individuals \( n = 332 \) from Norrbotten with a computed tomography verified TBI and/or brain injury symptoms that had been transferred to the Neurosurgical Clinic, Umeå University Hospital, for neurosurgical care during the period 1 January 1992 to 31 December 2001. From this study, all individuals between 18 and 65 years at the time of data collection (year 2007; to represent individuals at working age), who had survived the initial care and rehabilitation, were selected. Of the 125 individuals, 17 had deceased after discharge from rehabilitation to follow-up, and 2 had emigrated. All potential participants – 106 individuals – were contacted by post and telephone with information carefully explaining the study, an invitation to participate and an informed consent form. Eighty-eight individuals (83%) gave their written informed consent to participate, 13 (12%) declined to take part and 5 (5%) did not respond. The study was approved by the regional ethical review board in Umeå, Sweden (Dnr 06-013M).

Data from the time of injury and at discharge from inpatient rehabilitation were obtained from the database in the first study (14). The injury severity was defined by the Reaction Level Scale (RLS 85) at admission to the emergency department and were then transformed into Glasgow Coma Scale scores (GCS). Based on the GCS scores, the 88 individuals were grouped into the three commonly used TBI severity groups: mild (GCS 13–15), moderate (GCS 9–12) and severe (GCS 3–8) (15). Inpatient length of stay (LOS) was defined as the total number of days of care in a general medicine and/or surgical ward and in a subsequent inpatient rehabilitation unit until the patient was discharged to outpatient rehabilitation or back home.

Overall outcome

Changes in overall outcome from discharge from inpatient rehabilitation to follow-up was assessed with the Glasgow Outcome Scale (GOS) (16). GOS is a descriptive tool that assesses outcome in five categories from Death to Good recovery. Data on GOS at discharge were obtained from the database in the first study (14) and were compared with the GOS at follow-up.

Living condition, marital status and vocational status

Living condition was defined as: (i) living independently in one’s own home without assistance or (ii) living in institutions and/or dependent on personal assistance. Marital status was defined as: (i) single or (ii) married or cohabitant. Vocational status was defined as: (i) productive (i.e. studying, working full/part time in competitive work, sheltered work or looking for work) or (ii) not productive (i.e. full disability pension). Data at the time of injury were obtained from the database in the first study (14) and were compared with the data collected at follow-up.

Functioning and disability at follow-up

Functioning and disability at follow-up was assessed with four internationally established TBI outcome measures: Functional Independence Measure (FIM), Disability Rating Scale (DRS), Community Integration Questionnaire (CIQ) and Mayo-Portland Adaptability Inventory (MPAI-4) (information about the measures can be obtained from The Center for Outcome Measurement in Brain Injury; http://www.tbims.org/combi). As DRS, CIQ and MPAI-4 have not been published in Swedish, a forward–backward translation was performed by the authors in collaboration with a native English-spoken person.

Functional Independence Measure (Swedish version of FIMSwTBI) (17) rates the amount of assistance required to perform personal activities of daily living. It consists of 18 items separated into two domains: the motor domain and the cognitive domain. Each item is scored on a 7-point Likert scale, where one indicates total assistance and seven complete independence. A sum score of 78 and above in the motor domain (total score 91) and 30 and above in the cognitive domain (total score 35) indicates complete or modified independence. DRS (18) is an 8-item instrument that assesses various physical and cognitive impairments, level of functioning and employability. The maximum score a person can obtain is 29 indicating an extreme vegetative state, whereas a person with no disability scores 0. CIQ (19) consists of 15 items assessing community integration after a TBI in three categories: home integration, social integration and productive activities. The basis for scoring is primarily the frequency of performing activities or roles and secondarily whether or not activities are performed jointly with others and the
nature of these other persons. The overall score can range from 0 to 29, and higher scores indicate greater integration. MPAI-4 (20) is a 35-item instrument that assesses disability after brain injury. Items are scored on a 5-point Likert scale and represent the range of physical, cognitive, emotional, behavioural and social problems that people with acquired brain injury may encounter. The instrument also provides an assessment of major obstacles to community reintegration as well as features of the social and physical environment. MPAI-4 has three subscales: Ability Index (range 0–47), Adjustment Index (range 0–46) and Participation Index (range 0–30), with an overall score of 0–111, where lower scores indicate greater integration. As some items contribute to both the Adjustment subscale and the Participation subscale, the total score is less than the sum of the three subscales.

Data collection

Data at follow-up were collected by the first author, in accordance with the participant’s request, in their own home (n = 35), at another place (e.g. a primary health care centre; n = 32) or by phone (n = 21; individuals interviewed at home were more severely injured than those interviewed at another place or by phone). Seventy-five (88%) individuals responded by themselves and 8 (9%) were supported by a relative or significant other. Five participants (6%) were unable to participate meaningfully (severely cognitive or physical disability); information was here obtained from a close relative or significant other and by observations.

Data analysis

Data are presented as mean, median, SD, minimum and maximum, where appropriate. As data from the outcome measures were ordinal, differences between groups were analyzed using non-parametric tests (Chi-square, Mann–Whitney, Kruskal–Wallis and Chi-square test of independence), and relationships between variables were analyzed with the Spearman rank correlation coefficient using SPSS version 15.0 (SPSS Inc., Chicago IL, USA, 2006). Exact significance levels are given for values in the range 0.001–0.05, whereas <0.001 represents significant levels less than 0.001.

Results

There were no significant differences between the 88 participants and the 18 non-participants regarding their sex, age, time since injury, cause of injury, type of injury, injury severity and outcome at discharge from inpatient rehabilitation. Data on the 88 individuals at the time of injury are presented in Table 1. The mean time since injury was 10 years (median 9 years; SD 3 years; range 6–15 years) and their current mean age 44 years (median 46; SD 13 years; range 19–64 years). Women were significantly younger than men at the time of injury (P = 0.015). There was a significant correlation between age at injury and injury severity (P = 0.001). Individuals with a mild TBI were significantly older than those with a moderate or severe TBI (P = 0.004). Traffic accidents were the most common cause of injury. A majority (74%) had isolated contusions or a combination of several types of injuries and 66 individuals (75%) were operated (63% of the mild, 81% of the moderate and 88% of the severe TBI). Inpatient LOS varied considerably and there was a

<table>
<thead>
<tr>
<th>Type of injury (%)</th>
<th>Mild (n = 40)</th>
<th>Moderate (n = 16)</th>
<th>Severe (n = 32)</th>
<th>Total (n = 88)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls</td>
<td>40</td>
<td>44</td>
<td>32</td>
<td>42</td>
</tr>
<tr>
<td>Mixed injury</td>
<td>25</td>
<td>56</td>
<td>59</td>
<td>42</td>
</tr>
<tr>
<td>Isolated contusions</td>
<td>27</td>
<td>32</td>
<td>38</td>
<td>32</td>
</tr>
<tr>
<td>Traumatic</td>
<td>28</td>
<td>6</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Isolated contusion</td>
<td>27</td>
<td>32</td>
<td>38</td>
<td>32</td>
</tr>
<tr>
<td>Acute subdural</td>
<td>17</td>
<td>6</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Epidural haematoma</td>
<td>17</td>
<td>6</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>No signs of</td>
<td>3</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Chronic subdural</td>
<td>28</td>
<td>6</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Haematoma</td>
<td></td>
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</tr>
<tr>
<td>Isolated contusions</td>
<td>27</td>
<td>32</td>
<td>38</td>
<td>32</td>
</tr>
<tr>
<td>Mixed injury</td>
<td>25</td>
<td>56</td>
<td>59</td>
<td>42</td>
</tr>
<tr>
<td>No signs of</td>
<td>3</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Traumatic</td>
<td>28</td>
<td>6</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Isolated contusion</td>
<td>27</td>
<td>32</td>
<td>38</td>
<td>32</td>
</tr>
<tr>
<td>Acute subdural</td>
<td>17</td>
<td>6</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Epidural haematoma</td>
<td>17</td>
<td>6</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>No signs of</td>
<td>3</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
significant correlation between injury severity and LOS ($P < 0.001$).

Changes in overall outcome

Comparing GOS at discharge from inpatient rehabilitation and at follow-up showed that 39 individuals (44%) improved (Table 2). Two individuals improved from severe disability to good recovery; both were young women with a severe TBI. Two middle-aged men had a worse outcome; one had a previous brain injury and one had a history of psychiatric illness.

Changes in living condition, marital status and vocational status

A majority, 80 (91%) individuals, lived independently in their own home without assistance. The remaining eight individuals (9%) lived in institutions and/or were dependent on personal assistance. Two of these lived in institutions preinjury because of a previous brain injury, two had a severe preinjury psychiatric illness, which was exacerbated by the TBI and four had pronounced post-injury cognitive dysfunction that required institutional living.

Forty-one individuals (46%) remained married or cohabitant at follow-up or were single at injury and married or cohabitant at follow-up (Table 3). Seventeen (19%) individuals who were married or cohabitant at the time of injury were single at follow-up (one was a widow). Changes in marital status were not significantly associated with injury severity.

Fifty-three individuals (60%) were productive in some form at the time of injury and remained productive at follow-up (Table 4). Twenty-six individuals (30%) had full disability pension as a result of their TBI. Nine individuals (10%) had full disability pension both at the time of injury and at follow-up. Individuals with a moderate or severe TBI had significantly ($P = 0.009$) more often full disability pension than those with mild TBI, who were significantly ($P = 0.001$) more often productive.

Functioning and disability at follow-up

Table 5 presents the data on the mean and range for FIM, DRS, CIQ and MPAI-4 and the proportion of individuals that had reached maximum score on each measure (% ceiling).

The mean FIM motor and FIM cognitive scores as well as the mean DRS scores indicated overall a high degree of functioning, with a gradual difference between the three injury severity groups. All mean CIQ scores indicated a moderate reduction in integration and the percent ceiling for the CIQ Total was generally low. The mean MPAI-4 indicated remaining problems and reduced community reintegration, and the percent ceiling was the lowest of the four outcome measures.
In Table 6, the Spearman correlation coefficients (\(q\)) and their significance levels between the outcome measures and sex, age at injury and injury severity are presented. There was a significant correlation between sex and outcome as assessed with CIQ, indicating that women had better integration. There was a significant correlation between age at injury and the outcome measures, indicating that younger individuals overall had better functioning. There was also a significant correlation between injury severity and FIM, DRS and MPAI-4 but not CIQ; individuals with mild TBI had better functioning than those with moderate who had better than those with severe TBI.

### Discussion
This study has assessed 88 individuals on average 10 years after a TBI. There was an improvement in overall outcome and many had at follow-up a high degree of motor and cognitive functioning, which enabled them to live independently in their own home without assistance. Despite these improvements, there remained a disability related to community reintegration and social participation. This affected their productivity and to some degree their marital stability. The remaining disability and reduced productivity were related to the age at injury and the injury severity.

The assessment with GOS showed that many individuals had improved after discharge from inpatient rehabilitation and remained fully or

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### Table 5: The Functional Independence Measure (FIM), Disability Rating Scale (DRS), Community Integration Index (CIQ) and Mayo-Portland Adaptability Index (MPAI-4) for 88 persons with traumatic brain injury at follow-up after 6–15 years

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI (n = 40)</th>
<th>Moderate TBI (n = 16)</th>
<th>Severe TBI (n = 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor</td>
<td>86</td>
<td>86</td>
<td>83</td>
</tr>
<tr>
<td>Cognition</td>
<td>32</td>
<td>32</td>
<td>29</td>
</tr>
<tr>
<td><strong>DRS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Physical</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cognitive</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Social</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CIQ</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Home</td>
<td>5.9</td>
<td>5.9</td>
<td>7</td>
</tr>
<tr>
<td>Social</td>
<td>10</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td><strong>MPAI-4</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>Ability</td>
<td>8</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Adjustment</td>
<td>11</td>
<td>11</td>
<td>11</td>
</tr>
</tbody>
</table>

### Table 6: Correlation between the outcome measures and sex, age at injury and injury severity

<table>
<thead>
<tr>
<th></th>
<th>Sex at injury</th>
<th>Injury severity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIM</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor</td>
<td>-0.06</td>
<td>-0.21*</td>
</tr>
<tr>
<td>Cognition</td>
<td>-0.17</td>
<td>-0.30**</td>
</tr>
<tr>
<td><strong>DRS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>0.17</td>
<td>0.27**</td>
</tr>
<tr>
<td>Physical</td>
<td>0.15</td>
<td>0.11</td>
</tr>
<tr>
<td>Cognitive</td>
<td>0.10</td>
<td>0.21*</td>
</tr>
<tr>
<td>Social</td>
<td>0.13</td>
<td>0.28**</td>
</tr>
<tr>
<td><strong>CIQ</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>-0.21*</td>
<td>-0.15</td>
</tr>
<tr>
<td>Home</td>
<td>-0.26*</td>
<td>-0.01</td>
</tr>
<tr>
<td>Social</td>
<td>0.01</td>
<td>-0.18</td>
</tr>
<tr>
<td><strong>MPAI-4</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>0.17</td>
<td>0.26*</td>
</tr>
<tr>
<td>Ability</td>
<td>0.13</td>
<td>0.27*</td>
</tr>
<tr>
<td>Adjustment</td>
<td>0.18</td>
<td>0.23*</td>
</tr>
<tr>
<td>Participation</td>
<td>0.19</td>
<td>0.27**</td>
</tr>
</tbody>
</table>

Injury severity was defined as mild, moderate and severe. The correlation between variables were analyzed with the Spearman rank correlation coefficient (\(q\)).

*\(P < 0.05\); **\(P < 0.01\).*
partially recovered at follow-up, which confirms that even those with a severe injury can improve over time (21). Although the GOs is a rather crude measure and can be related to other factors than the severity of TBI, the results indicate that long-term overall outcome may be somewhat more favourable than expected (4).

Almost half of the individuals were living in a stable relationship at follow-up. Previous studies have found varying degrees of marital stability, but generally separation and divorce after a TBI is less common than anticipated (11). Similarly, vocational status after a TBI have varied considerably from 39% to 75% return-to-work (22), mainly because of differences in the definition of productivity (2, 23). The result here of about 60% of the individuals being productive at follow-up is therefore in agreement with previous studies (6, 22). Our results also confirm that age at injury and injury severity are important factors for return to productivity (8).

With the FIM and DRS, a majority of the individuals had a high degree of motor and substantial cognitive functioning, as indicated by the large number of individuals who had reached maximum score at the time of assessment and the high overall mean values. It is known that there is a ceiling effect for both the FIM and the DRS, so that they may not capture the full extent of functional outcome after TBI (13, 24). Our results do, however, indicate that many individuals with a TBI, even those with a severe injury, can achieve and maintain a high degree of functioning in a long-term perspective.

Although many individuals had a high degree of functioning, there remained some disability as assessed by the CIQ. This measure captures what is generally referred to as ‘community integration’ and for that purpose is considered to be the best measure (24). For all three subscales – home integration, social integration and productive activities – a relatively small number of individuals had reached the maximum score. However, the result of CIQ total (mean 18–21) is close to a control group without a history of TBI (mean 20.71) (19), explaining why a majority of the 88 individuals could live independently in their own home without assistance. The finding that women had better results on CIQ has been reported previously (25, 26), which is interpreted as a psychosocial influence, i.e. gender culture, rather than a difference because of the brain injury per se (27).

As the MPAI-4 covers a broad spectrum of encountered problems after a TBI, it is not surprising that it had the lowest number of individuals reaching maximum score. This underscores the importance of TBI as a cause of long-term disability and the need to use an outcome measure that captures different aspects of physical, cognitive and behavioural functioning, community integration and features of the social and physical environment.

Studies assessing outcome of TBI, from mild to severe, more than 5 years post-injury are relatively few. Two studies with a similar distribution of sex, age and injury severity, as the present study, focused on vocational status (22) and activity limitations (6). The results are in general agreement with the present study. Five studies (3, 10, 26, 28, 29), with moderate-to-severe TBI, used CIQ as outcome measure. The total mean score varied between 16.5 and 18.35, which is also in agreement with the results for the same injury severity groups here. Four Swedish studies (5, 30–32) assessed long-term outcome of children, adolescents and young adults with severe TBI. Although they continued to improve, a majority had psychosocial limitations at follow-up several years after the injury (30, 31).

A limitation of this study is that the sample comprised individuals with a TBI transferred to the Neurosurgical Clinic, and not the entire TBI population. This may explain why those with a mild TBI were more affected at follow-up than expected. In addition, the classification into three severity groups based on GCS at admission to acute care has well-known limitations (33), e.g. substance abuse that could lead to misclassifications. A careful and repeated control of the medical records was performed to limit the risk of misclassification. Reliability is always an issue in every type of assessment, and care was therefore taken to standardize the interviews and only use established outcome measures. The outcome measures used here do not, however, reflect the individuals' subjective experiences of living with a TBI so there is a need to assess quality of life and life satisfaction to understand long-term outcome (30, 31). There was variability in the outcome related to injury severity, so further studies are needed to determine the relationships between objective and subjective perspectives and pre- and post-injury features to establish predictors of long-term outcome.

In conclusion, this study confirms previous findings that individuals with a TBI can continue to improve, and achieve and maintain a high degree of functioning many years after the injury, but can have a remaining disability related to community reintegration and social participation.

Acknowledgements

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References


Long-term disability after traumatic brain injury

STUDY III
Health related quality of life and life satisfaction 6 to 15 years after traumatic brain injuries in northern Sweden

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ABSTRACT

Objective: To describe health related quality of life (HRQoL) and life satisfaction many years after a traumatic brain injury (TBI), and assess possible associations with variables related to the time of injury and follow-up, and the individuals’ self-appraisal of the impact of the TBI.

Method: Sixty-seven individuals (18 to 65 years) on average 10 years post injury were interviewed. Data on HRQoL, using the Swedish versions of the SF-36 questionnaire, were compared with a Swedish age- and sex-matched reference sample, and life satisfaction, using the Satisfaction With Life Scale (SWLS), were compared with a nationwide Swedish sample of students. The participant’s self-appraisal of the TBI was assessed with two supplementary questions. Data were analyzed with hierarchical multiple regression analyses.

Results: HRQoL as well as life satisfaction were lower compared with the reference samples. From the regression analyses, the individuals’ own appraisal of the impact of the TBI and whether they were vocationally productive or not were strongly associated with their current physical health and life satisfaction.

Conclusion: These results confirm the importance of TBI as a cause of long-term disability and the impact of the injury on the individuals’ self-perceived values of health, quality of life and life satisfaction.

Keywords: long-term outcome; outcome assessment; traumatic brain injury; quality of life; questionnaires
INTRODUCTION

Improvements in acute care and early intervention following traumatic brain injury (TBI) have led to decreased mortality. More and more people survive, but with a life-long disability. Studies addressing the long-term outcome of TBI have generally focused on remaining symptoms, behavioural and emotional issues, and objective aspects such as activities of daily living and return to work. Over the past decade there has been an increased interest in the individuals’ own subjective experiences and more recent studies have also assessed self-perceived values of health, quality of life and life satisfaction post TBI [1].

The concept Quality of Life (QoL) has changed from a more external materialistic view, such as socioeconomic conditions, to include the individuals’ own experiences and subjective perspectives of health related QoL (HRQoL) and satisfaction with life [2]. The broader concept of subjective well-being is often defined by the independent dimensions positive affect, negative affect, and a more cognitive conscious reflection upon life, usually referred to as life satisfaction [3]. Even though there is no existing consensus about a model or measure of HRQoL [1,4,5], it is regarded as one important goal of TBI rehabilitation.

Previous studies have shown that individuals with TBI usually report lower HRQoL compared to non-disabled persons [6-8]. There are, however, mixed findings regarding the relationship between injury severity and HRQoL. Some studies have reported lower HRQoL among those with mild TBI compared to moderate-and-severe TBI [9-12], whereas others have not found any significant relationship with injury severity [6,13,14]. Several studies have also reported the negative impact of TBI on employment, close relationships and HRQoL [15-18].

Life satisfaction is often defined as a subjective judgement upon one’s current life situation in relation to one’s expectations. It has been assessed in people with TBI using different instruments [2]. Some instruments assess subjective experiences in domains linked to highly valued aspects of life, such as vocation, leisure, social contacts, close relationships and sexual life. Other instruments, like the Satisfaction With Life Scale (SWLS) [19], which has been used in several studies [2,15,20], provide a global measure of satisfaction with life, as an overall summation of the life situation. Studies of life satisfaction following TBI have reported a negative impact of the injury and a reduced satisfaction with life [1,2,21]. However, for both HRQoL and life satisfaction,
studies have looked at these aspects in a more short-term perspective [7] and therefore, our knowledge of the long-term consequences of TBI is limited.

As time goes on, other life events occur that could potentially alter the relative impact of the TBI and thereby change an individual’s self-perceived HRQoL and life satisfaction. The individuals’ own appraisal of the consequences of the injury in relation to other life events is therefore important to elucidate, in order to understand their current perception of HRQoL and life satisfaction.

To increase our knowledge of the long-term consequences of TBI, a survey of individuals with a TBI in northern Sweden that required neurosurgical care from 1992 to 2001 has been pursued. In the first study [22], demographics, injury characteristics and outcome of 332 individuals with TBI were described. In the second study [23], functioning and disability in a subgroup comprising 88 individuals, 18 to 65 years (i.e., working age), was described. The aim of this study was to describe 6 to 15 years post injury HRQoL and life satisfaction, and assess possible associations with variables related to the time of injury and follow-up, and the individuals’ self-appraisal of the impact of the TBI.

METHODS

Participants

Participants were obtained from the previous study [22], which comprised individuals (n = 332) from Norrbotten (a region in northern Sweden with approximately 250,000 inhabitants) with a computed tomography (CT) verified TBI and brain injury symptoms that had been transferred to the Neurosurgical clinic, Umeå University Hospital, for neurosurgical care during the period 1992 to 2001. From this study, individuals between 18 and 65 years at the time of data collection (year 2007; to represent individuals at working age) who had survived the initial care and rehabilitation were selected. Of the 125 individuals, 17 had died after discharge from rehabilitation up to the time of data collection and two had emigrated.

All potential participants – 106 individuals – were contacted by post and telephone with information carefully explaining the study, an invitation to participate and an informed consent form. A total of 88 individuals volunteered to participate in the first part of the study where their functioning and disability was assessed [23]. Of the 88 individuals, 67 were included in the present study; ten were excluded as they were too disabled (e.g. severe cognitive impairments) to complete the questionnaires and 11 declined to participate. No significant
differences were found between the 67 participants and the 39 (out of 106) and the 21 (out of 88) non-participants, respectively, regarding sex, age at time for injury, injury severity, cause and type of injury or time since injury. None of the 67 participants had a clinically verified depression or showed symptoms at the interview of major depression. The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 06-013M).

Data from the time of injury
Data from the time of injury were obtained from the database describing the demographics and injury characteristics of the initial population (n = 332) [22]. The injury severity was defined by the Reaction Level Scale scores (RLS 85) [24] at admission to the emergency department. The RLS scores were then transformed into Glasgow Coma Scale scores (GCS), and, based on the GCS scores, the participants were grouped into the three commonly used TBI severity groups: mild (GCS 13-15), moderate (GCS 9-12) and severe (GCS 3-8) [25]. As previous studies have often combined the moderate and severe TBI into one group, this was also done here to allow for a comparison. It should be noted that those with mild TBI, based on the GCS score, were not typical of this injury severity group and had often gone on to developing more severe complications, as will be seen from the Results section. It has been shown that post-traumatic amnesia (PTA) may be better than GCS in predicting outcome [26]. However, the results in the present study are based on a retrospective review of medical records and the information was not detailed enough to allow for ratings of PTA.

Living condition, marital status and vocational situation
To facilitate the statistical analysis the following data were dichotomized: Living condition: i) living independently in one’s own home without assistance or ii) living in institutions and/or dependent on personal assistance; Marital status: i) single or ii) married/cohabitant; Vocational situation: i) productive (i.e. studying, working full/part time in competitive work, sheltered work or looking for work) or ii) not productive (i.e. full disability pension).

Health related quality of life
The Short Form 36 (SF-36) is a generic health status questionnaire that assesses health related quality of life (HRQoL) in eight multi-item subscales including physical and mental health domains. The SF-36 is considered a suitable
instrument to measure HRQoL in TBI populations [10] and several studies have used it over the past five years [6,13,27-30].

The physical domain consists of the subscales: i) physical functioning (PF; 10 items); ii) role limitations due to physical problems (RP; 4 items); iii) bodily pain (BP; 2 items); and iv) general health perceptions (GH; 5 items). The mental domain consists of the subscales: i) vitality (VT; 4 items), ii) social functioning (SF; 2 items); iii) role limitations due to emotional problems (RE; 3 items); and iv) mental health (MH; 5 items). A further single item represents reported health transition over the past year. The scale ranges from 0 to 100 and higher scores indicate higher rated HRQoL. The eight subscales of the SF-36 can be converted to two summary component scores: i) Physical component score (PCS) and ii) Mental component score (MCS), which are reported in standardized T-scores (Mean score 50 (SD = 10)). Scoring and calculation was performed according to the Swedish manual [31]. The mean age (44 years) of the 67 participants was not significantly different from the normative sample for the general Swedish population (43 years) [31], but the proportion of men was significantly higher ($p < 0.001$). Therefore, an age- and sex-matched reference sample ($n = 1224$) was obtained from the database of the Swedish general population.

**Life satisfaction**

The Satisfaction With Life Scale (SWLS) [19] is an instrument designed to measure general life satisfaction on a single domain or factor. The SWLS comprises five questions, rated on a 7-point Likert scale, with a total score ranging from 5 to 35. Higher scores indicate higher rated life satisfaction and a score of 20 represents a midpoint between satisfied and dissatisfied with life. The SWLS has demonstrated good internal consistency with alpha coefficients exceeding 0.80 [20] and the capacity to differentiate among different populations, e.g. psychiatric patients and prison inmates [15]. As the SWLS had not been published in Swedish at the time of data collection, a forward-backward translation was performed by the authors in collaboration with a native English-spoken person. Since then, a study [32] has reported the psychometric evaluation of the SWLS on a nationwide Swedish sample of 2900 students and found support for a unidimensional scale that was sensitive for age. With permission from the authors, we compared the two versions of the SWLS and found them equivalent in wording but different in scales; Hultell et al. [32] used a 5-point Likert scale whereas we used the original 7-point Likert scale.
Supplementary questions
Both the SF-36 and the SWLS are generic instruments and not specifically describing experiences following a TBI. To obtain information about the participants’ own experience of the impact of the TBI, two supplementary questions (in Swedish) were asked at the end of the interview:

1. To what extent has the TBI affected your life?
2. What importance has the TBI in relation to other events in your life?

Each question had five response options: “Not at all/none” (=1), “A little/small” (=2), “Moderate/moderate” (=3), “Much/great” (=4), and “Very much/very great” (=5). The questions were presented verbally and visually to the participants. The two questions were then combined, by taking the mean value, into a single factor labeled “Self appraisal of TBI”, which was used in the statistical analysis.

Data collection
Data were collected by the first author, in accordance with the participant’s request, in their own home (n = 29), at another place (e.g. a primary health care center) (n = 31) or by post (n = 7). Sixty individuals completed the questionnaires by themselves, 3 individuals had a close relative present but completed the questionnaires independently, and 4 individuals had assistance reading and understanding some of the items in the questionnaires but then completed them by themselves. The average length of an interview, including also the assessment of their functioning and disability for the first part of the study [23], was 69 minutes (SD = 27). There was no significant difference in the length of the interview between the mild and the moderate-to-severe TBI groups.

Statistical analysis
Data are presented as mean, median, standard deviation, minimum and maximum, where appropriate. Differences between dichotomized groups were analysed using nonparametric tests (Chi-square, Mann-Whitney, Kruskal Wallis and Chi-square test of independence), comparisons between means were analysed using independent sample t-tests and relationships between variables were analyzed with the Spearman rank correlation coefficient.

The results from the SF-36 were compared with the age- and sex-matched sample from the Swedish general population using the chi square- ($\chi^2$)
and t-tests. To compare the score for the SWLS (7-point Likert scale) with the score from the study by Hultell et al. [32] (5-point Likert scale), we recoded our results, i.e. the scores from the 7-point to 5-point scale as: 1 = 1; 2 & 3 = 2; 4 = 3; 5 & 6 = 4; 7 = 5.

Hierarchical multiple regression analyses were used to assess the influence of several independent variables on the following dependent variables: the two summary scores of HRQoL (SF-36 PCS and SF-36 MCS) and the measure of life satisfaction (SWLS; 7-point scale). As the PCS and MCS affect each other, i.e. all 8 subscales are used in the calculation of both PCS and MCS, some words of caution have been presented [33,34]. Therefore, we checked our results by performing the regressions using the subscales that are the most pure measures of physical (PF) and mental health (MH). As the results were essentially the same, we used the summary component scores in the regression analysis. In the first step of the regression analysis, three variables representing the situation at the time of injury were used: i) sex; ii) age at injury; and iii) injury severity. In the second step, three variables representing the situation at follow-up were added: i) time since injury; ii) marital status; and iii) vocational situation. In the third and final step, the single factor representing “Self appraisal of TBI” was added. All statistical analysis was performed using SPSS version 15.0 (SPSS Inc., Chicago Ill., USA, 2006). Significance levels smaller than 0.05 represent statistical significance, whereas values greater than 0.05 were considered not significant (ns).

RESULTS

Data on the 67 participants are presented in Table 1. The mean time since injury was 10 years (median = 9 years; SD = 3; range: 6-15 years) and their current mean age 44 years (median = 46; SD = 13; range: 19-64 years). Participants with a mild TBI were significantly older than those with a moderate-to-severe TBI ($p <0.01$). Traffic accidents were the most common cause of injury (31 % of the mild TBI and 53 % of the moderate-to-severe TBI). A majority (51 participants; 76 %) were neurosurgically operated as a result of their TBI (59 % of the mild TBI and 89 % of the moderate-to-severe TBI).

Table 1

All participants were living in their own house or apartment. Four were not completely independent and had some form of personal assistance. For two
participants, the personal assistance included only heavy household work and
transportation, whereas the other two had extensive assistance most hours of the
day and some supervision during nights. About half of the participants were
married or cohabitant, the other half single or divorced. Six participants were
single and lived with their children and two were still living with their parents.
No significant relationship was found between injury severity and marital status.
About 66 % of the participants were still productive whereas about 34 % of the
participants had full disability pension (28 % of those with mild TBI and 40 %
of those with moderate-to-severe TBI). Those who were productive were
significantly younger ($p <0.01$).

Health related quality of life
There were no significant differences between the mild and moderate-to-severe
TBI groups for any of the SF-36 subscales, so the results for all the 67
participants on each subscale and the two summary component scores of the SF-
36 and the age- and sex-matched reference sample are presented in Table 2.
Compared with the reference sample, the 67 participants had significantly lower
HRQoL, except for subscale RE (Role Emotional) and the mental component
summary score (MCS).

Table 2

The results for each subscale and the two summary scores of the SF-36 for the
67 participants separated by sex, marital status and vocational situation, and
compared with the age- and sex-matched reference sample are presented in
Table 3. The men, but not the women, had significantly lower HRQoL
compared with the reference sample for most SF-36 subscales. In addition, those
who were not productive and single or divorced had significantly lower HRQoL
compared with the age- and sex-matched reference sample.

Table 3

One item in the SF-36 assesses the participant’s experiences of a difference in
health between follow-up and one year before follow-up (i.e., in the last year, at
the time of assessment). Those with a longer time since injury perceived
significantly better health than those that were injured more recently ($p <0.01$).
Life satisfaction
The mean total score was 20.8 (SD=8.2) for the mild and 21.8 (SD=7.8) for the moderate-to-severe TBI (7-point Likert scale). The results for each of the five SWLS questions for the 67 participants and the nationwide Swedish sample of 2900 students [32] are presented in Table 4 (5-point Likert scale). There were significant differences (p <0.001) between the 67 participants and this sample for all five questions.

Table 4

Self appraisal of TBI
The results of the two supplementary questions are presented in Figure 1 for the two injury severity groups. In general, the moderate-to-severe injury group rated the impact of the TBI very high. The mean (median) for the single factor labeled “Self appraisal of the TBI” was 3.3 (3) for the mild TBI and 4.0 (4.5) for the moderate-to-severe. Higher rated ‘Self appraisal’, i.e. greater impact of the TBI, was significantly related to lower scores on the eight subscales of the SF-36 (p <0.001 to 0.004) and SWLS (p <0.001).

Figure 1

Hierarchical multiple regression analysis
The correlations between the variables for the 67 individuals are presented in Table 5. As can be seen, sex was not significant related to any of the variables. A higher self appraisal of the TBI was significantly related to a more severe injury, being single, not productive and having a lower score on both PCS and SWLS.

Table 5

In table 6, the results of the hierarchical multiple regression analyses assessing the influence of the three sets of independent variables on the two summary scores of HRQoL (SF-36 PCS and SF-36 MCS) and the measure of life satisfaction (SWLS) are presented.

The regression analysis with PCS as dependent variable reached significance at the first step, with data representing the situation at the time of injury and the variable injury severity as a significant contributor (p = 0.030). As
the variables representing the situation at follow-up were entered, i.e. time since injury, marital status and vocational situation, vocational situation was the only significant contributing variable \((p = 0.001)\) and the added variables explained an additional 17 % of PCS. In the third and final step, Self appraisal of the TBI contributed significantly together with vocational situation \((p = 0.002 \text{ and } p = 0.012)\), respectively) to the explained variance and added a further 11 %. In the final model, the variables explained 39 % of the variance in PCS \((R^2 = 0.39)\). The model with MCS as dependent variable was not significant until the third step with all the variables entered. The pattern in the model was unchanged throughout the three steps, with injury severity and age at injury as the most important variables.

The regression analysis with SWLS as the dependent variable did not reach significance at the first step with data representing the situation at the time of injury. At the second step, with data representing the situation at follow-up, all variables, except sex, contributed significantly. In the third step, the variable Self appraisal of the TBI was the strongest predictor, adding a further explained variance of 8 %. In this final model, with SWLS as the dependent variable, the variables age at injury \((p = 0.012)\), injury severity \((p = 0.009)\), time since injury \((p = 0.003)\), marital status \((p = 0.011)\), vocational situation \((p = 0.042)\) and Self appraisal of the TBI \((p = 0.005)\), were all significant contributors and explained 44 % \((R^2 = 0.44)\) of the variance in SWLS.

**Table 6**

**DISCUSSION**

In this study, HRQoL and life satisfaction, on average 10 years after a TBI, were assessed. The main findings were: i) HRQoL, assessed with the Swedish version of SF-36, was lower compared with a Swedish age- and sex-matched reference sample; ii) life satisfaction, assessed with the Satisfaction with Life Scale (SWLS), was also significantly lower compared with a large sample of Swedish students. From the hierarchical multiple regression analyses, the individuals’ own appraisal of the impact of the TBI was, among a set of variables, the one most strongly associated with physical health and life satisfaction. Individuals, who rated the impact of the TBI low, were more likely married or cohabitant and productive at follow-up, had higher life satisfaction, which, in turn, was linked to older age at the time of injury and, somewhat surprisingly, a more severe injury.
In line with several other studies on individuals with TBI [9,11,13,35], we found significantly lower HRQoL and life satisfaction compared to the general population and healthy individuals [3,32], except for subscale RE (Role Emotional). Compared to other studies using SF-36 [8,10,11], the result on subscale RE in the present study was higher and a relatively large number of participants reached the maximum score, which may explain the non-significant difference. A ceiling effect for this subscale has been reported and in the new version – SF-36 V2 – the response format is extended for the three items in this subscale from a dichotomous ‘yes-no’ response to a five-step response format [36]. As opposed to both the reference sample and the general Swedish population [31], the men had significantly lower HRQoL than women. Our result should, however, be interpreted with some caution, as there were only 16 women. Previous studies on long-term outcome have reported lower self-rated health in men [17,37], while other studies [13,38] have not found any significant difference between men and women. Although previous studies have indicated that women have worse outcome compared to men the first years post injury [39], and that the difference increases with injury severity [40], other findings suggest that with time the differences between males and females level out [41]. Previous studies on subjective well being or life satisfaction in healthy individuals does not report any differences between men and women [32].

In this study, we found a weak but significant relationship between older age and better mental health. Some recent findings [42] indicate that mental health in the general population improves with age, so our results may not be specifically associated with the TBI. Life satisfaction is generally not associated with age [43]. However, the Swedish study using SWLS [32] found that item 4 and 5 were age-dependent. We could not find this in our study. Instead, our data confirm previous findings that the SWLS is essentially unidimensional [44] and independent of sex and age [20]. Previous studies, mostly on individuals with moderate to severe TBI, have reported inconsistent findings regarding the impact of injury severity on HRQoL [7,10,11]. Our results showed no significant differences between the two injury severity groups with regard to any of the subscales of SF-36, which is in line with a study from Canada [11] that assessed two subgroups of mild and moderate-to-severe TBI on average six years after injury. However, as noted previously (see Methods), other variables are better in predicting outcome [26] and future studies should take this into account.
The mean scores of SWLS in the present study were not significantly different from, and essentially similar, to other studies assessing individuals with TBI [41,43,45]. Importantly, our results were consistently lower than the SWLS scores from several other studies with diverse samples of non-disabled individuals in adult ages cited in a review from 1993 [20], and also compared to recently published data from Israel [46] and Brazil [47]. Thus, even though our results on the SWLS were not age- and sex-matched, we believe that the significant differences between the TBI group and the 2900 students represent a true reduction in life satisfaction.

Those with longer time since injury tended to report better health (on the one item in SF-36) in the last year. There are studies indicating that passage of time may decrease the impact of even severe initial injuries many years later [39,41,48,49]. As time goes on, it is possible that other factors may become more important for life satisfaction than the injury itself. In addition, individuals with a TBI develop strategies and adjust or adapt to the consequences of the TBI. Over the past decade, there has been a growing interest in the concept ‘post-traumatic growth’ [50]. Our cross-sectional design does not specifically support this concept. It is, however, an interesting area for future research and further longitudinal studies could add to our understanding of the positive psychological changes that may take place after a TBI.

To be married or in a partner relationship is an indication of a valuable social identity and close relationship, which in turn can be expected to enhance life satisfaction and HRQoL [17,38]. We therefore expected that those being married or cohabitant compared to single or divorced would have higher reported health. We could not, however, find this for HRQoL within the sample, but the difference was revealed when compared with the reference sample. Those being married or cohabitant reported significantly higher life satisfaction, indicating a difference between the measures for HRQoL and life satisfaction.

To be productive was also, as expected [17], of importance. Individuals with disability pension rated significantly lower on all SF-36 subscales, except RE, but also those being productive had significantly lower HRQoL compared to the reference sample for subscales RP and VT. In addition, individuals who were productive reported significantly higher life satisfaction than those with disability pension. This is not surprising, reflecting western society culture and the importance that a productive employment has on social identity, e.g. independence, financial security and participation in
productivity [16,51]. The reason for the non-significant difference for RE is not clear but may be the same as discussed earlier.

The hierarchal multiple regression analyses indicated that the variables representing the situation at the time of injury yielded divergent contributions in the models, and sex did not contribute significantly in any of the models. The models with physical health and life satisfaction as dependent variables showed more robust results than the model with mental health as dependent variable. Although the model with mental health showed weak relationships, the pattern with age at injury and injury severity as the strongest contributors to explained variance were evident in all the steps of the regression analyses. This could indicate that older age at injury and more severe injuries might be associated with better mental health. Some studies on long-term outcome post TBI [9,37] have reported, in line with the general population, a decreased health status with increasing age, but others have found no significant differences [17,35,38] within the TBI population. One study [35] found no differences in health symptoms in younger versus older persons with TBI, in relation to none-injured individuals, with the exception of more disturbed sleep patterns among younger ages. One recent study [42] noted that mental health in the general population improves with age, which could explain our results.

The model with physical health as a dependent variable indicated that injury severity is related to reported physical health but that the capability to be productive has a stronger influence. This underscores that being productive is a cornerstone in reaching a high HRQoL [17,51]. Self-appraisal showed a strong influence in explained variance to physical health, indicating that the individuals’ self-rated experience of the impact of the TBI is in itself a good predictor of physical HRQoL.

The model with life satisfaction as a dependent variable was the strongest model with all independent variables, except sex, as significant contributors to the explained variance. The background variables in step one, including age at injury and injury severity, did not on their own contribute significantly to life satisfaction. In conjunction with the added variables of the individuals’ current life situation in step two, i.e. time since injury, marital status and vocational situation, age at injury showed a significant contribution to the model. This suggests that those individuals that are older at the time of injury [52], with a longer time since injury and are currently productive and married [15], are more satisfied with life. Some studies have indicated that passage of time may decrease the impact many years post injury, even severe
However, other events may become more important as time goes on, when people rate their HRQoL and life satisfaction [49]. Higher reported self-appraisal of the TBI was, as expected, significantly related to lower scores on the summary component score of physical health and life satisfaction.

It is reasonable to assume that life satisfaction is related to a large number of factors. Based on our results, age at injury and injury severity are as important as marital status and vocational situation. Individuals that have rated the impact of the TBI relatively low, are married or cohabitant and able to work, rated their life satisfaction higher. The finding that individuals who were older at the time of injury and had a more severe injury rated their life satisfaction higher than those with a mild TBI is somewhat counter intuitive, but has been observed also in other studies [9,11,12,15,16,35]. This could indicate that individuals with a more severe injury may find it difficult to rate the impact of the TBI on their life, or may have found an adaptive way to reduce the importance of the TBI, compared to other factors in life. Another explanation is that individuals with milder injury severity might develop an “oversensitivity” [9,53]. This could be a way to make other people aware of their “deceivingly small” problems. However, it should be remembered that those with mild TBI, based on the GCS score, were not typical of this injury severity group. As self-appraisal was entered in the last step in the regression and was found to be the strongest contributor, it clearly indicates that individuals’ own perception of the TBI has a strong influence on life satisfaction, and with obvious associations to other psychological factors like self-efficacy [39] and sense of coherence [54]. Furthermore, altered insight and judgement are other potentially important factors [12] that could partially explain their ratings.

In this study, the chosen variables were more capable of explaining the outcome in terms of life satisfaction than the outcome in terms of HRQoL, which could imply that life satisfaction comprises other factors besides health condition. It confirms, however, that life satisfaction is a broad concept with important relations to several intervening factors that are not easily categorized and predicted by demographic or injury related variables. Moreover, the individual’s own appraisal is of crucial importance. As there are still relatively few studies on the relationships between the individual’s own measures on quality of life and various factors many years post injury, further studies are needed to elucidate this complex pattern.
Limitations
A limitation of this study is the relative small sample size (67 individuals) that restricts the ability to generalize from the statistical analyses. Since the population investigated comprised former patients treated at a neurosurgical clinic, this makes it a selected sample, and especially those with a mild TBI (many also being operated neurosurgically) may not represent this TBI population. The lack of an age- and sex-matched sample of healthy individuals for the SWLS can hopefully be overcome in the future. There are always concerns which variables to choose to reflect the important associations. The independent variables used here represent those commonly used in previous studies of similar approach. However, the choice of variable to indicate injury severity may not be the most suitable and other variables related to outcome should be considered in future studies. Emotional states, such as mood, are important for life satisfaction. Although no one was clinically depressed, the inclusion of a measure of their mood state could have broaden our understanding of factors that determine HRQoL and life satisfaction many years post TBI.

Conclusion
In conclusion, health related quality of life and life satisfaction in this group of men and women, on average 10 years after a TBI, was lower compared with the general population and healthy individuals. The individual’s own appraisal of the impact of the TBI and their current situation regarding productivity were more important than background variables, such as sex, age at injury and injury severity, for their physical health and life satisfaction. In addition, being productive was an important factor in explaining their current physical health and life satisfaction. The results confirm the importance of TBI as a cause of long-term disability and the impact of the injury on the individuals’ self-perceived values of health, quality of life and life satisfaction.

ACKNOWLEDGEMENTS
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DECLARATION OF INTEREST
The authors report no conflicts of interest.
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33. Hann M, Reeves D. The SF-36 scales are not accurately summarised by independent physical and mental component scores. Quality of Life Research 2008;17:413-423.
42. Charles ST, Piazza JR, Luong G, Almeida DM. Now you see it, now you don't: age differences in affective reactivity to social tensions. Psychology and Aging 2009;24:645-653.
Table 1. Data on the 67 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI&lt;sup&gt;1&lt;/sup&gt; (n=32)</th>
<th>Moderate-to-severe TBI&lt;sup&gt;1&lt;/sup&gt; (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>75</td>
<td>77</td>
</tr>
<tr>
<td>Women</td>
<td>25</td>
<td>23</td>
</tr>
<tr>
<td><strong>Age at time of injury (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>39 (13)</td>
<td>30 (12)</td>
</tr>
<tr>
<td>Range</td>
<td>12-56</td>
<td>14-54</td>
</tr>
<tr>
<td><strong>Cause (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Traffic accidents</td>
<td>31</td>
<td>53</td>
</tr>
<tr>
<td>Falls</td>
<td>34</td>
<td>22</td>
</tr>
<tr>
<td>Other causes&lt;sup&gt;2&lt;/sup&gt;</td>
<td>34</td>
<td>25</td>
</tr>
<tr>
<td><strong>Marital status at follow-up (n)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or cohabitant</td>
<td>14</td>
<td>19</td>
</tr>
<tr>
<td>Single or divorced</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td><strong>Vocational situation at follow-up&lt;sup&gt;3&lt;/sup&gt; (n)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Productive</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>Not productive</td>
<td>9</td>
<td>14</td>
</tr>
</tbody>
</table>

<sup>1</sup>The injury severity groups were based on the Glasgow Coma Scale (GCS) scores obtained at admission to the emergency department.

<sup>2</sup>Other causes include assaults or suicide attempts and sports and recreational activity.

<sup>3</sup>Vocational situation was defined as: productive (i.e. studying, working full/part time in competitive work, sheltered work or looking for work) or not productive (i.e. full disability pension).
Table 2. The Short Form 36 (SF-36) for the 67 individuals with a traumatic brain injury (TBI) compared with the age- and sex-matched reference sample.

<table>
<thead>
<tr>
<th></th>
<th>TBI sample</th>
<th>Reference sample</th>
<th>Significance test</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>75 (26)</td>
<td>89 (19)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>RP</td>
<td>54 (44)</td>
<td>83 (32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BP</td>
<td>63 (33)</td>
<td>74 (27)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>GH</td>
<td>65 (25)</td>
<td>75 (23)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>VT</td>
<td>54 (26)</td>
<td>69 (24)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SF</td>
<td>79 (26)</td>
<td>89 (20)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>RE</td>
<td>81 (33)</td>
<td>86 (28)</td>
<td>ns</td>
</tr>
<tr>
<td>MH</td>
<td>75 (19)</td>
<td>81 (19)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>PCS</td>
<td>42 (13)</td>
<td>50 (9)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>MCS</td>
<td>48 (11)</td>
<td>50 (11)</td>
<td>ns</td>
</tr>
</tbody>
</table>

Data (raw scores) are presented as means and standard deviation (SD). Higher scores reflect better health-related quality of life (HRQoL). PF = Physical functioning; RP = Role functioning physical; BP = Bodily pain; GH = General health; VT = Vitality; SF = Social functioning; RE = Role functioning emotional; MH = Mental health; PCS = Physical component summary score; MCS = Mental component summary score.

The difference between groups was tested with a two-sided t-test. Significance levels smaller than 0.05 represent statistical significance, whereas values greater than 0.05 were considered not significant (ns).

The age- and sex-matched reference sample was obtained from the database of the Swedish general population (n=1224).
Table 3. The Short Form 36 (SF-36) for the 67 individuals with a traumatic brain injury (TBI) separated by sex, marital status and vocational situation and compared with the age- and sex-matched reference sample.

<table>
<thead>
<tr>
<th>Sex</th>
<th>Men (n=51)</th>
<th>Women (n=16)</th>
<th>Married/ Cohabiting (n=33)</th>
<th>Single (n=34)</th>
<th>Productive (n=44)</th>
<th>Not Productive (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>ns</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>RP</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>&lt;0.01</td>
<td>&lt;0.001</td>
<td>&lt;0.01</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BP</td>
<td>&lt;0.01</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>0.001</td>
</tr>
<tr>
<td>GH</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>ns</td>
<td>&lt;0.01</td>
<td>ns</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>VT</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>&lt;0.01</td>
<td>&lt;0.01</td>
<td>&lt;0.01</td>
<td>0.001</td>
</tr>
<tr>
<td>SF</td>
<td>&lt;0.01</td>
<td>ns</td>
<td>ns</td>
<td>&lt;0.01</td>
<td>ns</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>RE</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>MH</td>
<td>&lt;0.05</td>
<td>ns</td>
<td>ns</td>
<td>&lt;0.05</td>
<td>ns</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>PCS</td>
<td>&lt;0.001</td>
<td>ns</td>
<td>&lt;0.01</td>
<td>&lt;0.001</td>
<td>&lt;0.05</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>MCS</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

PF = Physical functioning; RP = Role functioning physical; BP = Bodily pain; GH = General health; VT = Vitality; SF = Social functioning; RE = Role functioning emotional; MH = Mental health; PCS = Physical component summary score; MCS = Mental component summary score.

Higher scores indicate higher rated HRQoL.

The age- and sex-matched reference sample was obtained from the database of the Swedish general population (n=1224).

The difference between groups was tested with a two-sided t-test.
Table 4. The Satisfaction With Life Scale for the 67 individuals with a traumatic brain injury (TBI) compared with the reference sample.

<table>
<thead>
<tr>
<th>Scale</th>
<th>TBI Sample</th>
<th>Reference Sample</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWLS 1: In most ways my life is close to my ideal</td>
<td>4.03 (1.97)</td>
<td>3.42 (1.18)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SWLS 2: The conditions of my life are excellent</td>
<td>4.24 (2.18)</td>
<td>3.15 (1.43)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SWLS 3: I am satisfied with my life</td>
<td>4.72 (1.82)</td>
<td>3.42 (1.18)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SWLS 4: So far I have gotten the important things I want in life</td>
<td>4.21 (2.17)</td>
<td>3.12 (1.40)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SWLS 5: If I could live my life over, I would change almost nothing</td>
<td>4.21 (2.17)</td>
<td>3.12 (1.40)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Data are presented as means and standard deviation (SD). Higher scores reflect better life satisfaction.

1To compare our results (7-point Likert scale) with the reference sample (5-point Likert scale), we recoded our scores: 1 = 1; 2 & 3 = 2; 4 = 3; 5 & 6 = 4; 7 = 5.
2The reference sample was obtained from the study of a nationwide Swedish sample of students (n=2900).
3The difference between groups was tested with a two-sided t-test.
Table 5. Correlation matrix for the different variables for the 67 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>SF-36 PCS</th>
<th>SF-36 MCS</th>
<th>SWLS</th>
<th>Sex¹</th>
<th>Age at injury</th>
<th>Injury severity¹</th>
<th>Time since injury²</th>
<th>Marital status¹</th>
<th>Vocational situation¹</th>
<th>Self appraisal of the TBI¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36: MCS</td>
<td>-0.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWLS</td>
<td></td>
<td>0.41**</td>
<td>0.48**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex¹</td>
<td>-0.19</td>
<td>0.01</td>
<td>-0.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at injury</td>
<td>-0.14</td>
<td>0.29*</td>
<td>0.05</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Injury severity¹</td>
<td>0.20</td>
<td>-0.10</td>
<td>-0.06</td>
<td>-0.03</td>
<td>0.32**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since injury</td>
<td>0.13</td>
<td>0.06</td>
<td>0.30*</td>
<td>-0.05</td>
<td>-0.15</td>
<td>0.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status¹</td>
<td>0.11</td>
<td>0.06</td>
<td>0.36**</td>
<td>-0.01</td>
<td>-0.18</td>
<td>-0.11</td>
<td>0.08</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational situation¹</td>
<td>0.48**</td>
<td>-0.02</td>
<td>0.32**</td>
<td>-0.11</td>
<td>-0.37**</td>
<td>0.13</td>
<td>0.11</td>
<td>0.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self appraisal of the TBI¹</td>
<td>-0.54**</td>
<td>-0.12</td>
<td>-0.46**</td>
<td>0.09</td>
<td>-0.05</td>
<td>-0.31**</td>
<td>-0.04</td>
<td>-0.27*</td>
<td>-0.35**</td>
<td></td>
</tr>
</tbody>
</table>

¹Dichotomous variables: Sex: Woman=0 (n=16), Men=1 (n=51); Injury severity: Moderate-to-Severe=0 (n=35), Mild=1 (n=32); Marital Status: Single=0 (n=34), Married/Cohabiting =1 (n=33); Vocational status: Non productive (i.e. full disability pension) =0 (n=23), Productive (i.e. studying, working full/part time in competitive, sheltered or looking for work) =1 (n=44)
²Time since injury=years

Correlation (Spearman’s rho) is significant (two-tailed) on *0.05, and **0.01 levels
Table 6. Results of multiple hierarchical regression on SF-36 summary component measures and SWLS total score for the 67 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>PCS</th>
<th>MCS</th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex – 0.15</td>
<td>0.15</td>
<td>0.15</td>
<td>0.12</td>
</tr>
<tr>
<td>Age at injury</td>
<td>0.21</td>
<td>0.02</td>
<td>–</td>
</tr>
<tr>
<td>Injury severity</td>
<td>0.28</td>
<td>0.15</td>
<td>–</td>
</tr>
<tr>
<td>Years post-injury</td>
<td>0.05</td>
<td>0.06</td>
<td>0.11</td>
</tr>
<tr>
<td>Marital status</td>
<td>0.05</td>
<td>–</td>
<td>0.11</td>
</tr>
<tr>
<td>Vocational situation</td>
<td>0.44</td>
<td>0.32</td>
<td>0.21</td>
</tr>
<tr>
<td>Self appraisal of the TBI</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Vocational situation</td>
<td>0.35</td>
<td>0.27</td>
<td>–</td>
</tr>
<tr>
<td>Mental health</td>
<td>0.05</td>
<td>0.04</td>
<td>0.11</td>
</tr>
<tr>
<td>Peer social support</td>
<td>0.02</td>
<td>0.04</td>
<td>0.11</td>
</tr>
<tr>
<td>Injury severity</td>
<td>0.05</td>
<td>0.04</td>
<td>0.11</td>
</tr>
<tr>
<td>Age at injury</td>
<td>0.15</td>
<td>0.15</td>
<td>0.15</td>
</tr>
<tr>
<td>Sex</td>
<td>0.15</td>
<td>0.15</td>
<td>0.15</td>
</tr>
</tbody>
</table>

Significance levels: *0.05; **0.01

Standardized beta coefficients are presented. Dichotomous variables: Sex: Woman=0, Men=1; Injury severity: Moderate-to-Severe=0, Mild=1; Marital status: Single=0, Married=1; Vocational situation: Non productive=0, Productive=1.
Figure 1: The two supplementary questions – ‘To what extent has the TBI affected your life?’ and ‘What importance has the TBI in relation to other events in your life?’ for the two injury severity groups.
STUDY IV
Sense of coherence and disability and the relationship with life satisfaction 6 to 15 years after traumatic brain injuries in northern Sweden

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ABSTRACT

Objective: To assess sense of coherence (SOC) many years after a traumatic brain injury (TBI) and explore the relationship between self-rated life satisfaction (LS) and SOC as well as measures of functioning and disability, sex, age at injury, injury severity and time post injury.

Method: Sixty-six individuals (18-65 year) 6 to 15 years post injury were interviewed. Data on SOC (SOC-13 item scale), measures of functioning and disability (Mayo-Portland Adaptability Inventory, MPAI-4), LS (Satisfaction with life scale, SWLS), and sex, age at injury, injury severity and time post injury were analyzed with hierarchical multiple regression analyses.

Results: SOC did not differ from the general population and was strongly associated with LS. Regression analyses revealed that emotional factors, social participation, SOC, and time since injury, were more influential than sex, age at injury, and injury severity in explaining LS.

Conclusion: SOC in this group of individuals with TBI many years post injury was similar to nondisabled individuals. SOC, together with emotional factors, social participation and injury related factors, were determinants of LS. These results confirm that LS after TBI is a complex phenomenon dependent on several factors.

KEY WORDS

long-term outcome; outcome assessment; traumatic brain injury; quality of life; questionnaire
INTRODUCTION

With improvements in acute care, many individuals survive after a traumatic brain injury (TBI) but with a life-long disability and an impact on their subjective contentment with life, i.e., life satisfaction (LS). LS is a result of an individual’s adaptation process. It is defined as a cognitive appraisal or judgement upon one’s current life situation and reflects the degree to which individuals perceive that their aspirations (goals) and achievements are met [1,2]. High LS is often seen as an endpoint in rehabilitation following TBI. Knowledge about factors that have an impact on LS in a long-term perspective is therefore important and could guide interventions intended to improve rehabilitation.

Up to five years post TBI, LS is generally reduced [1,3] but the relationship to injury severity is weak [4]. Counterintuitively, those with mild TBI report more symptom complaints than the more severely injured [5-10]. There is an initial decline in LS during the first years following injury with a subsequent improvement up to five years post injury [11]. Other factors, such as sex and age at time of injury, and limitations in activities of daily living, have also been found to be weakly related to LS [9,12-16].

The effect on LS as long as 10 years or more post injury is virtually unknown. In a recent study [17], we assessed LS on average 10 years post injury. LS was significantly lower compared with a reference sample of healthy individuals. Furthermore, we found that those with low LS rated the impact of the TBI as high, were more likely to be single, not productive, and younger at the time of injury and less severely injured. As our knowledge of the long-term consequences of TBI on subjective satisfaction with life is not yet complete, there is a need for further studies of the relationship between LS and factors that could impact LS.

Of particular interest in understanding LS after TBI is the assessment of different aspects of physical, cognitive and behavioural functioning, community integration and features of the social and physical environment. One such instrument for this type of assessment is the Mayo-Portland Adaptability Inventory (MPAI-4). This instrument covers a broad range of common problems and limitations individuals with TBI encounter in their rehabilitation and community reintegration. MPAI-4 consists of three subscales: Ability, Adjustment and Participation. With this
instrument a relatively broad understanding of the long-term consequences of TBI and its relationship to LS can be ascertained.

The concept ‘sense of coherence’ (SOC) was developed to explain preserved health and has been found to be related to LS [18]. SOC was introduced [19] as a psychological factor associated with the preservation of good health, despite external strains [20], and thereby a factor in the adaptation to the overall strains of TBI. SOC includes three components: i) explainability (cognitive); the ability for people to understand what happens around them; ii) manageability (instrumental/behavioural); the ability to manage the situation on their own or through significant others in their social network; and iii) meaningfulness (motivational); the ability to find the situation worthwhile. Several studies of people with various diseases, disabilities and health complaints, reported a strong relationship between individuals’ perception of their health status and SOC, as well as a negative relationship with anxiety and depression and a strong positive relationship with optimism and self-esteem [21-25]. To the best of our knowledge, no study has assessed SOC in individuals with TBI and related it to LS.

To increase our knowledge of the long-term consequences of TBI, a survey of individuals with a TBI in northern Sweden that required neurosurgical care from 1992 to 2001 has been pursued. In the first three studies [17,26,27], demographics, injury characteristics and outcome following initial rehabilitation [26], their functioning and disability [27], and health related quality of life (HRQoL) and LS [17] 6 to 15 years post TBI, were described. The aim of this study was to assess SOC 6 to 15 years post TBI, and explore the relationship between self-rated LS and SOC as well as measures of functioning and disability, sex, age at injury, injury severity and time post injury.
METHODS

Participants
Participants were part of a previous study [26], which comprised all individuals (N=332) from Norrbotten, a region in northern Sweden, with a computed tomography (CT) verified TBI and brain injury symptoms that had been transferred to the Neurosurgical clinic, Umeå University Hospital, for neurosurgical care during the period 1 January 1992 to 31 December 2001. From this study, all individuals between 18 and 65 years at the time of data collection (year 2007; to represent individuals at working age) who had survived the initial care and rehabilitation were selected. Of the 125 individuals, 17 died after discharge from rehabilitation up to the time of data collection and 2 had emigrated. All potential participants – 106 individuals – were contacted by post and telephone with information carefully explaining the study, an invitation to participate and an informed consent form. A total of 88 (83 %) individuals responded and data on their functioning and disability have been reported [27]. Of those, 67 individuals participated in the study on HRQoL and LS [17]. Ten of the 21 non-participants were excluded as they were too disabled (e.g. severe cognitive impairments) to complete the questionnaires and 11 declined to participate. These 67 individuals were also asked to rate their SOC. One individual could not, due to fatigue and cognitive dysfunction, participate. Thus, the final sample comprised 66 individuals. Data were collected by the first author, in accordance with the participant’s request, in their own home (n=29), at another place (e.g. a primary health care center) (n=30) or by post (n=7). The study was approved by the regional ethical review board in Umeå, Sweden (Dnr 06-013M).

Data collection
Demographics
Data at time of injury (sex, age at injury, injury severity, and time post injury) were obtained from the database presented in the first study [26]. The injury severity was defined by the Reaction Level Scale scores (RLS 85) at admission to the emergency department, and was transformed into Glasgow Coma Scale scores (GCS) [28]. Based on the GCS scores, the individuals were grouped into the three commonly used TBI severity groups: mild (GCS 13-15), moderate (GCS 9-12) and severe (GCS 3-8) [29]; to allow for a comparison with previous studies, the moderate and severe TBI were combined into one group.
Mayo-Portland Adaptability Inventory – 4th version (MPAI-4)

MPAI-4 [30] is a 35-item instrument that assesses disability after acquired brain injury (ABI). Items are scored on a five-point Likert scale and represent the range of physical, cognitive, emotional, behavioural, and social problems that people with ABI may encounter. The instrument also provides an assessment of major obstacles to community reintegration as well as features of the social and physical environment. MPAI-4 has three subscales: Ability Index (range 0-47), e.g., sensory, motor, cognitive abilities; Adjustment Index (range 0-46), e.g., mood, emotional factors, interpersonal interactions; and Participation Index (range 0-30), e.g., social contacts, initiation, money management. Three items (Initiation, Social contact, Leisure/recreational activities) contribute to both the Adjustment Index and the Participation Index, with an overall score of 0 to 111, where lower scores indicate greater integration. The manual (http://www.tbims.org/combi/) provides the opportunity to compare the results converted to T-scores with two reference samples of people treated for ABI. For comparison, it is suggested that T-scores below 30 are considered as relatively good outcomes, 30 to 40 as mild limitations, and above 60 as severe limitations, even compared to other individuals with ABI. Data for 88 individuals with TBI assessed with the Swedish version of the MPAI-4 have been presented previously [26].

Sense of Coherence

In this study, the 13-item scale (SOC-13) developed by A. Antonovsky [19] to measure the concept ‘sense of coherence’ was used. The scale comprises a 7-point Likert scale ranging from agreement to disagreement with anchoring phrases at each end (e.g., never and very often). The score from each item is summed to a total score, with a range from 13 to 91. There are no ideal values but higher scores indicate stronger SOC. The Swedish SOC-13 scale has been used in several studies and has been judged satisfactory regarding reliability and concurrent validity, and there are also reference values for comparison [31-33]. The range of mean varies in different studies [34]. A Swedish study [35] on 2003 individuals from the general population reported mean values for men and women, of 65 and 64, respectively, and this study was used for comparison with the data in the present study.

Life satisfaction

Satisfaction With Life Scale (SWLS) [36] has been used in several studies on TBI [1,2,13]. SWLS gives a global measure on subjective judgement upon one’s current
life situation in relation to one’s expectations. It comprises five questions, rated on a 7-point Likert scale. The scores are aggregated, with a range from 5 to 35. A score of 20 represents a midpoint on the axes between satisfied and dissatisfied with life. The SWLS has demonstrated good internal consistency with alpha coefficients exceeding 0.80 [2], capacity to differentiate among populations with different qualities of life, e.g., psychiatric patients and prison inmates [13]. Data for 67 individuals with TBI assessed with the Swedish 7-point version of the SWLS have been presented previously [17].

Data analysis
Means, medians, standard deviations, and minimum and maximum values are reported where appropriate. As data from the measures on background variables were nominal or ordinal, differences between groups within the TBI sample were analysed using the Mann-Whitney nonparametric test and relationships between variables were analyzed with the Spearman rank correlation coefficient. The data on SOC in the present study were compared with data from a nation-wide Swedish sample using the two-sided t-test.

Hierarchical multiple regression analyses were used to assess the influence of the independent variables, i.e. SOC, the three subscales and the total score of MPAI-4, sex, age at injury, injury severity and time post injury on LS (aggregated score of SWLS), which served as the dependent variable. As the sample consisted of 66 individuals, we kept the number of independent variables below 10 individuals per variable, as recommended in the literature [37]. The threat of multicollinearity by the three subscales of MPAI-4 was handled by performing several regressions with each of the three subscales and the total scale, respectively. This way we could analyse explained variance in each model. Collinearity diagnostics using measure of variance inflation factor (VIF) revealed acceptable levels from 1.1 to 1.8 for all models. In the first step of the regression analysis, sex, age at injury, injury severity and time post injury were used. In the second step, the value of SOC-13 was entered. In the third and final step, the three subscales and the total score of MPAI-4 were entered in four separate regressions.

All statistical analysis was performed using SPSS Statistics 18.0 (SPSS Inc., Chicago Ill., USA, 2010). Significance levels smaller than 0.05 represents statistical significance, whereas values greater than 0.05 were considered not significant (ns).

RESULTS

Data on the 50 men and 16 women are presented in Table 1. There were no significant differences between the 66 participants and the 40 non-participants
regarding their sex, age at injury, injury severity and time post injury. The mean time since injury was 10 years (median 9 years; SD 3; range 6-15 years) and their current mean age 44 years (median 46; SD 13; range 19-64 years).

Table 1

Outcome measures
Data on MPAI-4, SOC and SWLS for the 66 individuals are presented in Table 2. The results on raw score means for MPAI scales converted to T scores indicated that this sample had on average relatively mild limitations. There was a small significant difference between the two injury severity groups for MPAI-4, but no difference for SWLS or SOC. The values of the 66 individuals were very similar and not significantly different from the reported mean values for Swedish men and women, of 65 and 64, respectively [35]. The t-tests on the whole sample, as well as separated into the two injury severity groups and men and women, were not significantly different from to the reference groups.

Table 2

Relationships
Correlations between the dependent variables, MPAI-4 and SOC, and the independent variable SWLS, for the 66 individuals are presented in Table 3. There was no significant correlation between sex and the other variables. There was a significant positive correlation between age at injury and injury severity (indicating that younger individuals had a more severe injury) and between injury severity and two of the three subscales of MPAI-4. There were strong significant correlations between the three subscales of MPAI-4, SOC and SWLS. Higher values on the three subscales of MPAI-4 (i.e., worse outcome) were associated with lower values on SOC. Similarly, higher values on the three subscales of MPAI-4 were associated with lower values on SWLS. In addition, a positive value on SOC was associated with a high value on SWLS.

Table 3
Hierarchical Multiple Regression analyses
The results of the hierarchical multiple regression analyses are presented in Table 4. In the first step, with sex, age at injury, injury severity and time post injury, the model did not reach significance. As the variable SOC was entered in step 2, the model was significant and explained 40 % ($R^2=0.40$) of the variance in SWLS. The strongest contributing variable ($p<0.001$) was SOC. Along with SOC, the variable time post injury ($p=0.011$) contributed significantly to the model.

In step 3, the three subscales of MPAI-4 were entered in four separate models. The model with the Ability subscale entered in step 3 explained 46 % ($R^2=0.46$) of the variance in SWLS, with SOC ($p<0.001$) and time post injury ($p=0.004$), as the greatest contributing variables. The variables injury severity ($p=0.016$) and the Ability subscale ($p=0.017$) did also contribute significantly to the explained variance in SWLS. The model with the Adjustment subscale explained 55 % ($R^2=0.55$) of the variance in SWLS, with the Adjustment subscale ($p<0.001$) as the greatest contributing variable. The variables injury severity ($p=0.003$), time post injury ($p=0.006$), age at injury ($p=0.030$), and SOC ($p=0.047$) also contributed significantly to the explained variance in SWLS. The model with the Participation subscale explained 51 % ($R^2=0.51$) of the variance in SWLS, with the Participation subscale ($p=0.001$) and SOC ($p=0.001$) as the strongest contributing variable. The variables injury severity ($p=0.002$), time post injury ($p=0.003$), and age at injury ($p=0.006$), also contributed significantly to the explained variance on SWLS. The model with the total MPAI-4 scale explained 52 % ($R^2=0.52$) of the variance in SWLS, with the total scale ($p<0.001$) as the greatest contributing variable. The variables time post injury ($p=0.003$), injury severity ($p=0.003$), SOC ($p=0.014$) and age at injury ($p=0.019$), also contributed significantly to the explained variance in SWLS.

DISCUSSION
This study assessed SOC 6 to 15 years post TBI and explored the relationship with self-rated LS along with measures of functioning and disability, sex, age at injury, injury severity and time post injury. The main findings were that the SOC did not differ from the general population and was strongly associated with LS. The hierarchical multiple regression analyses revealed that emotional factors, social
participation, SOC, and time post injury, were more influential than sex, age at injury, and injury severity in explaining LS.

With reference to the MPAI-4 manual, the individuals in the present study were considered to have relative mild limitations on all scales but included also a range covering the severe end of the limitation continuum. We found that those with more severe injuries tended to have more problems in both activities on their own (Ability subscale) and in society (Participation subscale). However, injury severity was not associated with LS. Previous studies [14-16] on the relationship between LS and levels of limitations several years after TBI have found more consistent relationships of LS to societal participation than to demographic or injury related variables. In the present study, the strongest relationship with LS was found with measures of emotional states and personal relations (Adjustment subscale). Several studies have indicated that mental health problems, like symptoms on depression and anxiety, are common after TBI [38,39]. Consistent with our findings, Smith et al. [12] suggested that “the ability to carry out a greater number of tasks independently may not influence an individual’s global appraisal of their life satisfaction” (p. 136). Corrigan et al. [13] stated that, like the general population, studies of individuals with TBI have found LS to be associated with societal participation, marital status, and employment.

The level of SOC in this study was very similar to that of a large Swedish reference sample from the general population [35], and Antonovsky has reported a mean value for adults ranging from 62 to 69 [40]. To the best of our knowledge, no study has evaluated individuals with TBI using SOC-13. However, there are some studies that have used SOC on individuals with ABI. Two studies included some individuals with TBI, one [41] assessed 67 individuals three years after multiple trauma, reporting a SOC-13 mean score of 60 (SD=13), median 63, range 29-81, and a strong relationship with LS. A British study [42] compared two groups with ABI, mainly cerebrovascular disease (one group mean 7 months and one group mean 10 years, after onset), with the aim to investigate positive psychological change. They found that median SOC-13 score for the early group was 67, range 54-79, and the late 68, range 35-84. The scores for SOC showed no noteworthy differences between early and late time after injury, and were comparable with other groups undergoing rehabilitation for orthopaedic trauma and high relative normative data. SOC in our study was lower and with a larger range than the British study [42] but higher than
the group suffering multi-trauma [41]. The SOC-13, similar to LS, showed the strongest relationship to measures of emotional states and personal relations (Adjustment subscale). The SOC-13 scale is considered to be sensitive as a measure of negative affectivity [31] and several studies have reported strong associations with depression [34,43], which could explain the strong relationship in the present study with measures of emotional states (Adjustment subscale).

Previous results on the relationship between time after injury and LS, 10 years or more after TBI, are scarce. Our results from the hierarchical multiple regression analyses indicate that LS may improve over time, as time post injury is consistently positive. Previous findings have shown increased LS or no difference compared to the general population several years after injury [13,44,45]. SOC explained considerable increased variance to LS, and confirmed the expected positive association with LS. The strong relationship between SOC and LS has been suggested to be bidirectional [46], i.e. a strong SOC might lead to high LS, and vice versa. In predictive sense, the question has also been raised if a low SOC leads to low LS. No normative values have, however, been proposed, so the threshold when SOC can be considered to lose its “protective character” [18] is not known. SOC is considered to be relatively stable over time [18,47], although not as stable as Antonovsky suggested [19]. We do not know the SOC score before the TBI, but the nonsignificant correlation between injury severity and SOC suggests that SOC was not altered in a direct sense by the TBI. Furthermore, the contribution from SOC decreased as a result of the stronger contributions from the measures on mental states and social participation. It has been questioned if SOC and measures on mental problems, e.g., anxiety and depression, are two ways of measuring the same concept [46]. Eriksson and Lindström [34] concluded in their review, that SOC is closely related to mental health and mental wellbeing, but it is not the same as mental health but a health resource promoting resilience. The subjective perceived symptoms of anxiety and depression, revealed by the Adjustment scale, and its relationship with SOC and LS, indicate the great importance of these factors in the long-term outcome after TBI. The results are in line with previous findings [12,16] of stronger associations to factors of mental state and social participation, than cognitive impairments or activity limitations.

The pattern of results shows that factors of emotional and social participation are strongly associated with LS several years after a TBI, indicating that the actual impairment caused by the TBI has a great influence on LS. However, when
controlling for these impairments (MPAI-4), we can see that a higher SOC and a longer time post injury, as well as a more severe injury and older age at the time of injury, contribute to higher life satisfaction several years after injury. Thus, given that a person has a certain level of ability, adjustment and participation, he or she will be worse off in terms of LS when having a milder injury and a lower age. The finding that higher LS was associated with more severe injuries – also observed in other studies [5-8,10,13] – suggests that individuals with more severe injuries may have difficulties to rate the impact of the TBI or have found an adaptive way to reduce the importance of the TBI. Another explanation is that individuals with mild TBI might develop an “oversensitivity” [16]. For age, the result seems logical. Given the same impairment, an older person will find it easier to accept the situation and not let it affect LS negatively, while a younger person is more likely to find the life bleaker.

As this study only investigated direct influence from the examined variables on LS, other effects such as interactions are not shown. However, the relatively small sample in this study restricts further analysis of these associations, e.g. possible interaction effects between SOC and other variables, such as age [48]. There seems to be a growing interest, but still relative few studies, in the relationships between LS many years after a TBI and psychological factors, e.g., SOC. Further studies are therefore needed to elucidate the importance of various psychological factors that could explain positive and negative long-term outcome after a TBI.

**Limitations**
The relatively small sample of 66 individuals restricts the ability to generalize from the statistical analyses. Furthermore, the sample investigated was comprised of former patients treated at a neurosurgical clinic, making it a selected sample, and those with a mild TBI may not have been adequately represented. This could be an explanation why the intercorrelation between the subscales of MPAI-4 is larger than findings from a much larger group previously reported [30].

**Conclusion**
In conclusion, SOC in this group of individuals with TBI did not differ from general population and was strongly associated with LS, indicating that their sense of preservation of good health was strongly associated with high LS. High LS was also strongly associated with fewer emotional disturbances and better social participation, together with longer time post-injury and a more severe injury sustained at a higher
age. Taken together, these results confirm that LS after TBI is a complex phenomenon dependant on several factors.

ACKNOWLEDGEMENTS

This study was supported by grants from the Norrbacka-Eugenia Foundation, the Cancer and Traffic Injury Fund, Norrbotten County Council, the Swedish Association of Brain Injured and their Families and Skane county council’s research and development foundation.

References


Table 1. Data on the 66 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI (n=31)</th>
<th>Moderate-to-severe TBI (n=35)</th>
<th>Total (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at injury (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>39 (13)</td>
<td>30 (13)</td>
<td>34 (14)</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>42 (12-56)</td>
<td>26 (14-54)</td>
<td>35 (12-56)</td>
</tr>
<tr>
<td><strong>Time post injury (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>10 (3)</td>
<td>10 (3)</td>
<td>10 (3)</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>9 (6-15)</td>
<td>9 (6-15)</td>
<td>9 (6-15)</td>
</tr>
</tbody>
</table>

The TBI severity groups were based on the Glasgow Coma Scale (GCS) scores obtained at admission to the emergency department following the injury.
Table 2. Data on outcome measures of 66 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>Mild TBI (n=31)</th>
<th>Moderate-to-severe TBI (n=35)</th>
<th>Significance test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Median (Range)</td>
<td>T score</td>
</tr>
<tr>
<td><strong>MPAI</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>6 (6)</td>
<td>10 (7)</td>
<td>0.012</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>5 (0-24)</td>
<td>10 (0-29)</td>
<td></td>
</tr>
<tr>
<td>T score</td>
<td>34/35</td>
<td>40/42</td>
<td></td>
</tr>
<tr>
<td><strong>Adjustment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>9 (9)</td>
<td>13 (10)</td>
<td>ns</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>8 (0-29)</td>
<td>13 (0-34)</td>
<td></td>
</tr>
<tr>
<td>T score</td>
<td>38/34</td>
<td>43/41</td>
<td></td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>5 (5)</td>
<td>8 (7)</td>
<td>0.031</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>1 (0-15)</td>
<td>7 (0-26)</td>
<td></td>
</tr>
<tr>
<td>T score</td>
<td>33/36</td>
<td>37/40</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>16 (15)</td>
<td>27 (19)</td>
<td>0.030</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>15 (0-45)</td>
<td>26 (0-65)</td>
<td></td>
</tr>
<tr>
<td>T score</td>
<td>28/28</td>
<td>37/38</td>
<td></td>
</tr>
<tr>
<td><strong>SoC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>66 (14)</td>
<td>63 (15)</td>
<td>ns</td>
</tr>
<tr>
<td>Median</td>
<td>68 (26-88)</td>
<td>65 (26-88)</td>
<td></td>
</tr>
<tr>
<td><strong>SWLS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>21 (8)</td>
<td>22 (8)</td>
<td>ns</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>22 (5-33)</td>
<td>23 (5-32)</td>
<td></td>
</tr>
</tbody>
</table>

The raw scores were converted to T scores using staff rating results from MPAI-4 manual on two reference samples (www.tbims.org/combi/). The difference between groups was tested with the Mann-Whitney nonparametric test.
Table 3. Correlation matrix (Spearman’s rho) between the different variables in 66 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>Age at injury</th>
<th>Injury severity</th>
<th>Years post injury</th>
<th>MPAI Ability</th>
<th>MPAI Adjustment</th>
<th>MPAI Participation</th>
<th>MPAI Total</th>
<th>SOC</th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex¹</td>
<td>0.23</td>
<td>−0.03</td>
<td>−0.05</td>
<td>0.02</td>
<td>0.12</td>
<td>0.13</td>
<td>0.09</td>
<td>0.14</td>
<td>−0.01</td>
</tr>
<tr>
<td>Age at injury (years)</td>
<td>0.32**</td>
<td>−0.15</td>
<td></td>
<td>0.09</td>
<td>0.10</td>
<td>0.23</td>
<td>0.15</td>
<td>0.03</td>
<td>0.05</td>
</tr>
<tr>
<td>Injury severity²</td>
<td>0.09</td>
<td>−0.31*</td>
<td>−0.23</td>
<td>−0.27*</td>
<td>−0.27*</td>
<td>0.10</td>
<td>0.07</td>
<td>0.31*</td>
<td></td>
</tr>
<tr>
<td>Time post injury (years)</td>
<td>−0.03</td>
<td>−0.15</td>
<td>−0.11</td>
<td>−0.10</td>
<td>0.07</td>
<td>0.31*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPAI</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability</td>
<td>0.83***</td>
<td>0.81***</td>
<td>0.92***</td>
<td>−0.46***</td>
<td>−0.43***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustment</td>
<td>0.90***</td>
<td>0.96***</td>
<td>−0.55***</td>
<td>−0.60***</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Participation</td>
<td>0.94***</td>
<td>−0.46***</td>
<td>−0.55***</td>
<td>−0.57***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>0.92***</td>
<td>0.94***</td>
<td>−0.52***</td>
<td>−0.57***</td>
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<td></td>
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<tr>
<td>SOC</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.46***</td>
<td></td>
</tr>
<tr>
<td>SWLS</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

¹Woman=0 (n=16), Men=1 (n=50);  
²Moderate-to-Severe=0 (n=35), Mild=1 (n=31)  
Correlation is significant (two-tailed) on *< 0.05, **< 0.01, and ***< 0.001 levels
Table 4 Results of hierarchical multiple regression analyses for 66 individuals with a traumatic brain injury (TBI).

<table>
<thead>
<tr>
<th></th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sex^1</td>
</tr>
<tr>
<td></td>
<td>-0.04 0.15</td>
</tr>
<tr>
<td></td>
<td>-0.12 0.15</td>
</tr>
<tr>
<td></td>
<td>-0.10 0.19</td>
</tr>
<tr>
<td></td>
<td>-0.05 0.23*</td>
</tr>
<tr>
<td></td>
<td>-0.10 0.25*</td>
</tr>
<tr>
<td></td>
<td>-0.07 0.25*</td>
</tr>
</tbody>
</table>

Standardized beta coefficients are presented

^1Woman=0 (n=16), Men=1 (n=50);

^2Moderate-to-Severe=0 (n=35), Mild=1 (n=31)

Correlation is significant (two-tailed) on *<0.05, **<0.01, and ***<0.001 levels
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