Functional outcome and health-related quality of life after traumatic brain injury in the framework of the International Classification of Functioning, Disability and Health (ICF)

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Abstract

Traumatic brain injury (TBI) affects people of all ages and is a cause of long-term disability. In recent years, the epidemiological patterns of TBI have been changing. TBI is a heterogeneous disorder with different forms of presentation and highly individual outcome regarding functioning and health-related quality of life (HRQoL). The meaning of disability differs from person to person based on the individual's personality, value system, past experience, and the purpose he or she sees in life. Understanding of all these viewpoints is needed in comprehensive rehabilitation.

This study examines the epidemiology of TBI in Finland as well as functioning and HRQoL after TBI, and compares the subjective and objective assessments of outcome. The frame of reference is the International Classification of Functioning, Disability and Health (ICF).

The subjects of Study I represent the population of Finnish TBI patients who experienced their first TBI between 1991 and 2005. The 55 Finnish subjects of Studies II and IV participated in the first wave of the international Quality of life after brain injury (QOLIBRI) validation study. The 795 subjects from six language areas of Study III formed the second wave of the QOLIBRI validation study.

The average annual incidence of Finnish hospitalised TBI patients during the years 1991-2005 was 101:100 000 in patients who had TBI as the primary diagnosis and did not have a previous TBI in their medical history. Males (59.2%) were at considerably higher risk of getting a TBI than females. The most common external cause of the injury was falls in all age groups. The number of TBI patients ≥ 70 years of age increased by 59.4% while the number of inhabitants older than 70 years increased by 30.3% in the population of Finland during the same time period.

The functioning of a sample of 55 persons with TBI was assessed by extracting information from the patients' medical documents using the ICF checklist. The most common problems were found in the ICF components of Body Functions (b) and Activities and Participation (d).

HRQoL was assessed with the QOLIBRI which showed the highest level of satisfaction on the Emotions, Physical Problems and Daily Life and Autonomy scales. The highest scores were obtained by the youngest participants and participants living independently without the help of other people, and by people who were working. The relationship between the functional outcome and HRQoL was not straightforward.

The procedure of linking the QOLIBRI and the GOSE to the ICF showed that these two outcome measures cover the relevant domains of TBI patients' functioning. The QOLIBRI provides the patients' subjective view, while the GOSE summarises the objective elements of functioning. Our study indicates that there are certain domains of functioning that are not traditionally sufficiently documented but are important for the HRQoL of persons with TBI. This was the finding especially in the domains of interpersonal relationships, social and leisure activities, self, and the environment.

Rehabilitation aims to optimize functioning and to minimize the experience of disability among people with health conditions, and it needs to be based on a comprehensive understanding of human functioning. As an integrative model, the ICF may serve as a frame of reference in achieving such an understanding.

Tiivistelmä

Aivovamma aiheuttaa usein pitkäaikaisia toimintarajoitteita ja sen voi saada minkä ikäisenä tahansa. Aivovammojen ilmaantuvuudessa on viime vuosina tapahtunut muutoksia. Vammat ovat yksilöllisiä ja ne vaikuttavat monin tavoin toimintakykyyn ja terveyteen liittyvään elämänlaatuun. Vammautumisen merkitys ihmiselle vaihtelee persoonallisuuden, arvojen, aikaisempien kokemusten ja elämän tarkoitukseen liittyvien käsitysten pohjalta. Näiden näkökulmien ymmärtäminen on tärkeätä kuntoutuksessa.

Tässä väitöstutkimuksessa selvitetään aivovamman ilmaantuvuutta Suomessa sekä vammautuneen henkilön toimintakykyä ja terveyteen liittyvää elämänlaatua. Asiantuntijan tekemää arviota potilaan toimintakyvystä verrataan vammautuneen omaan arvioon hänen terveyteen liittyvästä elämänlaadustaan. Viitekehyksenä on Toimintakyvyn, toimintarajoitteiden ja terveyden kansainvälinen luokitus (ICF).

Ensimmäisen osatutkimuksen aineiston muodostavat suomalaiset, jotka saivat aivovamman vuosina 1991 – 2005. Toisen ja neljännen osatutkimuksen aineiston muodostavat 55 kansainväliseen QOLIBRI –validointitutkimuksen ensimmäiseen vaiheeseen osallistunutta suomalaista henkilöä. Neljännen osatutkimuksen aineiston muodostavat kansainvälisen QOLIBRI –validointitutkimuksen toiseen vaiheeseen osallistuneet 795 aivovamman saanutta henkilöä kuudelta kielialueelta.

Sairaalahoitoa vaatineiden aivovammojen ilmaantuvuus Suomessa vuosina 1991 – 2005 oli keskimäärin 101:100 000 henkilöillä, joilla aivovamma oli päädiagnoosina ja joilla ei ollut aikaisempia aivovammoja. Miehillä (59.2 %) oli suurempi riski saada aivovamma kuin naisilla. Kaatuminen tai putoaminen oli yleisin vammautumisen ulkoinen syy. Yli 70-vuotiaiden aivovammat lisääntyivät 59.4 % , kun vastaavana seuranta-aikana yli 70-vuotiaiden osuus Suomen väestössä lisääntyi 30.3 %.

Vammautuneiden toimintakyky kirjattiin käyttämällä apuna luetteloa keskeisistä ICF-luokituksen mukaisista toimintakyvyn kuvauskohteista (ICF checklist). Tiedot kerättiin käymällä läpi 55 aivovamman saaneen henkilön sairauskertomustiedot ja erityistyöntekijöiden lausunnot. Yleisimmät ongelmat liittyivät ICF-luokituksen Ruumiin/kehon toimintojen (b) sekä Suoritusten ja osallistumisen (d) alueille.

Terveyteen liittyvää elämänlaatua arvioitiin QOLIBRI -asteikolla, jonka mukaan tyytyväisyys oli suurinta asteikoilla: tunne-elämä, fyysiset ongelmat sekä päivittäinen elämä ja autonomia. Nuorimmat, ilman toisten apua asuvat ja työssä käyvät henkilöt olivat tyytyväisimpiä. Toimintakyky ja terveyteen liittyvä elämänlaatu eivät olleet suorassa yhteydessä toisiinsa.

Siltaamalla, eli yhdistämällä QOLIBRI- ja Glasgow Outcome Scale Extended (GOSE) –asteikkojen sisältämät toimintakykyä kuvaavat käsitteet ICF-luokituksen vastaaviin kuvauskohteisiin, voitiin osoittaa näiden kahden mittarin kattavan keskeiset aivovamman saaneen henkilön toimintakykyä kuvaavat aihealueet. QOLIBRIn avulla saavutetaan henkilön oma näkökulma ja GOSE tiivistää asiantuntijan näkemyksen.

Tutkimuksen perusteella aivovamman saaneen henkilön toimintakyvyssä on terveyteen liittyvän elämänlaadun kannalta tärkeitä osa-alueita, joita ei systemaattisesti kirjata. Näitä on erityisesti vuorovaikutuksen ja ihmissuhteiden, yhteisöllisen ja sosiaalisen elämän, sekä minään ja ympäristöön liittyvillä alueilla.

Kuntoutus tähtää mahdollisimman korkeaan toimintakykyyn ja toimintarajoitusten minimointiin. Kuntoutuksen perustaksi tarvitaan kokonaisvaltainen käsitys ihmisen toimintakyvystä. ICF- luokitus voi tarjota tähän viitekehyksen.

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List of original publications

This thesis is based on the following original articles, referred to in the text by their Roman numerals I - IV.

I   Koskinen, S., & Alaranta, H. (2008). Traumatic brain injury in Finland 1991–2005: A nationwide register study of hospitalised and fatal TBI. *Brain Injury 22*, 205–214.

II   Koskinen, S., Hokkinen, E.-M., Sarajuuri, J., & Alaranta, H. (2007). Applicability of the ICF checklist to traumatically brain injured patients in post-acute rehabilitation settings. *Journal of Rehabilitation Medicine, 39,* 467-472.

III   Truelle, J.-L., Koskinen, S., Hawthorne, G., Sarajuuri, J., Formisano, R., von Wild, K., Neugebauer, E., Wilson, L., Gibbons, H., Powell, J., Bullinger, M., Höfer, S., Maas, A., Zitnay, G., von Steinbüchel, N., & the QOLIBRI Task Force. (2010). Quality of life after traumatic brain injury: the clinical use of the QOLIBRI, a novel disease-specific instrument. *Brain Injury, 24,* 1272-1291.

IV   Koskinen, S., Hokkinen, E.-M., Wilson, L., Sarajuuri, J., von Steinbüchel, N., & Truelle, J.-L. (2011) Comparison of subjective and objective assessments of outcome after traumatic brain injury using the International Classification of Functioning, Disability and Health (ICF*). Disability and Rehabilitation,* May 3 [Epub ahead of print]

Abbreviations

ANOVA	Analysis of variance
GCS	Glasgow Coma Scale
GOS	Glasgow Outcome Scale
GOSE	Glasgow Outcome Scale Extended
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-related quality of life
HSD	Honestly significantly difference (Tukey)
ICC	Intraclass correlation coefficient
ICD-10	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICF components	
b	Body Functions
s	Body Structures
d	Activities and Participation
e	Environmental Factors
Kela	Social Insurance Institution of Finland
LOC	Loss of consciousness
LOS	Length of stay in hospital
PTA	Post traumatic amnesia
QoL	Quality of life
QOLIBRI	QOLIBRI – Quality of life after brain injury (instrument)
SD	Standard deviation
SPSS	Statistical package for the social sciences
TBI	Traumatic brain injury
WHO	World Health Organization
WHO-FIC	WHO Family of International Classifications

1 Introduction

1.1 Traumatic brain injury (TBI)

1.1.1 Definition

Traumatic brain injury (TBI) is a health condition that affects people of all ages and is the leading cause of long-term disability among children and young adults (National Institute of Health [NIH], 1999; Ragnarsson, 2002). It is the most common cause of death and disability during the first three decades of life and accounts for more productive years of life lost than cancer, cardiovascular disease, and HIV/AIDS combined (Zitnay et al., 2008). During the recent years patterns of TBI have been changing (Maas et al., 2008). There is an increasing incidence of military traumatic brain injury, and similar injuries are seen in civilians in war zones or terrorist incidents (Risdall & Menon, 2011). TBI is increasing in the oldest age groups and special attention has been paid to the various aspects and implications of aging with brain injury (Coronado et al., 2005; Felicetti, 2008; Flecher et al., 2007; Maas et al., 2008; Thompson et al., 2006).

TBI is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force (Menon et al., 2010). Alteration in brain function is defined as one of the following clinical signs: any period of loss or decreased consciousness; any loss of memory for events immediately before (retrograde amnesia) or after the injury (post-traumatic amnesia, PTA); neurologic deficits (weakness, loss of balance, change in vision, dyspraxia paresis/plegia, sensory loss, aphasia, etc.); any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc.). Other evidence of brain pathology includes visual, neuroradiological, or laboratory confirmation of damage to the brain (Menon et al., 2010). The central factor is that brain damage results from external forces, as a consequence of direct impact, rapid acceleration or deceleration, a penetrating object (e.g. gunshot), or blast waves from an explosion. The nature, intensity, direction, and duration of these forces determine the pattern and extent of damage. On the macroscopic level, damage includes shearing of white-matter tracts, focal contusions, haematomas, and diffuse swelling.

Besides this primary damage, secondary processes develop over hours and days after the initial event, and include neurotransmitter release, free-radical generation, calcium-mediated damage, gene activation, mitochondrial dysfunction, and inflammatory responses (Maas et al., 2008).

The present study is focused on adults with moderate and severe disabilities after closed TBI at the post-acute stage of recovery.

1.1.2 Epidemiology

It is difficult to interpret international data on the epidemiology of traumatic brain injuries while the definitions, regional coverage, methods and completeness of case findings, as well as reporting of the data are not uniform (Corrigan et al., 2010; Maas et al., 2010; Steudel et al., 2005; Tagliaferri et al., 2006). TBI has been called the „silent epidemic', referring to the fact that the problems resulting from TBI are often not visible, the actual number of TBIs is not known and much of the public is unaware of the impact of TBIs (Langlois et al., 2005).

In a large population based study in the US the annual rate of hospitalised TBI patients was 85.2/100 000 population. The rates of emergency department visits and deaths were 403.1/100 000 and 18.1/100 000, respectively. In almost every age group the TBI rate was higher in males than in females. Falls resulted in the greatest number of TBI-related emergency department visits and hospitalisations. Motor vehicle-traffic injury was the leading cause of TBI-related death. Adults aged 75 years or older had the highest rates of TBI-related hospitalisations and death (Langlois et al., 2006).

According to a review of European studies the overall annual incidence of hospitalised plus fatal TBI was 235/100 000 (Tagliaferri et al., 2006). A study of Northern Finland following a cohort of people who were born on 1966 showed an average annual incidence of 118/100 000 (Winqvist et al., 2007). Many of the studies from the European countries report motor vehicle related causes as the most common events leading to a TBI (Masson et al., 2001; Murray et al., 1999; Servadei et al., 2002) while others report falls as the most important external cause of injury (Alaranta et al., 2000; Andersson et al., 2003; Ingebrigtsen et al., 1998; Kleiven et al., 2003; Thornhill et

al., 2000). It has also been shown that the economic status has an effect of the epidemiological findings. An epidemiological study from Europe showed that patients from the wealthier regions were significantly older. Low-level falls and traffic accidents contributed to more than two-thirds of all cases. Violence-related trauma was significantly more frequent in „middle income' regions (Mauritz et al., 2008).

The estimates of the total annual rate of TBI in the Nordic countries are varied. Some long-term studies suggest rates remain rather constant (Kleiven et al., 2003), some that they are decreasing (Engberg & Teasdale, 2001) and some even slightly increasing (Alaranta et al., 2002). However, in all of these studies the incidence of TBI is increasing in the oldest age groups.

Estimates of the prevalence of TBI are only infrequently reported in the world's TBI literature and the number of people living with TBI-related disability is not known (Langlois et al., 2006; Tagliaferri et al., 2006). According to the available estimates the prevalence of TBI is 7.8 million in Europe (Tagliaferri et al., 2006). The most recent estimate of the prevalence of Americans living with disability subsequent to a TBI hospitalisation is 3.2 million (Zaloshnja et al., 2008) while the previous estimate was 5.3 million (Langlois et al., 2006). The seeming decrease in estimates is due to the different assumptions made and more accurate data becoming available (Corrigan et al., 2010). According to the Northern Finland birth cohort study 3.8% of the population born in 1966 had experienced at least 1 hospitalisation due to TBI by 35 years of age (Winqvist et al., 2007).

Most studies report only the hospitalised TBI patients. One part of the „silent epidemic' consists of the group of patients who are not diagnosed at the time of the injury and thus are excluded from the epidemiological data. However, even mild TBI, including concussion, can cause long-term problems that affect a person's ability to perform daily activities and to return to work. Based on the available epidemiological data it would seem important to estimate also the number of the non-hospitalised patients in order to create adequate preventive strategies and care. Other problems related to the „invisible disability' include persons with cognitive but not obvious physical problems, lack of medical insurance and the limited awareness of TBI among some healthcare providers (Langlois et al., 2006).

Examples of linking the rehabilitation of TBI patients to the epidemiological information have been reported from Denmark, Sweden and the Netherlands (Engberg, 2007; Lexell, 2007; Ribbers, 2007). It is important to be aware of the main changes in the incidence, types and the external causes of TBI as well as of the demographic profiles of the patients in order to identify the high-risk groups and to focus rehabilitation resources adequately.

1.1.3 General outcome

Traumatic brain injury is not only a long-term psychosocial problem but a chronic health condition as well. It fits the World Health Organization definition as having one or more of the following characteristics: it is permanent, caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, and/or may require a long period of observation, supervision, or care (Masel & DeWitt, 2010).

TBI increases long-term mortality and reduces life expectancy (Masel & DeWitt, 2010). According to Tagliaferri et al. (2006) the overall fatality rate in Europe is about 11 per 100 persons with TBI. The fatality rate in hospital was about 3 per 100 hospitalised TBI patients which reflects immediate deaths at the scene of the injury event. According to Sundström et al. (2007) the mortality rate of TBI patients in Finland (21.2/100 000) was about twice as high as in the other Nordic countries (9.5–11.5/100 000) in 1987–2001. Although most of the deaths occur immediately after the injury, studies have shown that compared to the general population, patients with TBI have a significantly higher mortality rate (Baguley et al., 2000; Cameron et al., 2008; Flaada et al., 2007). It remains high for at least seven years, and is particularly high for those aged less than 55 years (McMillan & Teasdale, 2007) and in functionally dependent patients (Baguley et al., 2008). The increased mortality rate in TBI patients below 40 years of age was also found in a 30-year follow-up study in Finland (Himanen et al., 2011). Harrison-Felix and colleagues (2009) observed that TBI patients were 49 times more likely to die of aspiration pneumonia, 22 times more likely to die of seizures, 3 times more likely to die of suicide, and 2.5 times more likely to die of digestive disorders than the general population matched for age, race, and gender (Harrison-Felix et al., 2009).

One indicator of early outcome after TBI is the length of stay (LOS) in hospital. Epidemiological studies from Europe report wide variety in the LOS (Kleiven et al,, 2003; Leppänen et al., 1999; Masson et al., 2001; O'Brien & and Phillips, 1996).

Investigators are conducting a wide array of studies intended to determine factors that are useful in predicting outcome after TBI and to determine the effectiveness of interventions intended to reduce disability and improve participation after TBI (Sherer et al., 2010). Outcome after TBI is assessed at different stages of recovery and for different purposes. Accurate outcome determination is a prerequisite for any TBI study but also for many clinical decisions, e.g. to assess the patient's overall functioning and help needed, the optimal timing and forms of rehabilitation and return to work. Outcome measures used in clinical investigations must be relevant to study participants and also be of scientific interest to clinical investigators. Investigators may be primarily interested in outcomes that reflect the neurologic process of recovery from TBI while injured persons and their families may be more interested in outcomes that reflect overall life satisfaction (Sherer et al., 2010). Factors related to functional outcome and health-related quality of life after TBI are presented in more detail in chapter 1.3.

The consequences of TBI are various and a complete description of the difficulties encountered by patients with TBI in everyday lives is lacking. Svestkova et al. (2010) state that in order to describe the complexity of TBI and its impact on a person's life a broader and more universal framework is needed, such as that offered by the International Classification of Functioning, Disabilities and Health, ICF.

1.2 International Classification of Functioning, Disability and Health (ICF)

1.2.1 WHO Family of International Classifications

The WHO Family of International Classifications (WHO-FIC) comprises classifications that have been endorsed by the World Health Organization to describe various aspects of health and the health system in a consistent manner (Madden et al., 2007). The purpose of the WHO-FIC is to assist the development of reliable statistical systems at

local, national and international levels, with the aim of improving health status and health care. Classifications are used to support statistical data across the health system. In the WHO classifications, health conditions such as diseases, disorders, and injuries are classified primarily in the ICD-10, International Classification of Diseases, 10th Revision (WHO classifications, 2011). Functioning and disability are classified separately in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The individual health experience in general can be described using the dimensions of the ICD and ICF. The needs of the user will determine the number of dimensions, and the level of specificity used (Madden et al, 2007; WHO, 2001).

According to Maas et al. (2010) recording details on the type, place, nature, and mechanism of injury is highly relevant, both from an epidemiologic perspective and because different pathophysiologic mechanisms occur in different types of injury. TBI is classified in the ICD-10 in chapter XIX: Injury, poisoning and certain other consequences of external causes. Slightly different diagnoses have been used in case definition in different epidemiological studies, mostly including numbers S02.0 – S02.9 to code skull fractures and numbers S06.0 – S06.9 for intracranial injuries (Kleiven et al., 2003; Steudel et al., 2005; Tagliaferri et al., 2006). As presented in Table 1, the Finnish current care guidelines for adult traumatic brain injuries (Adult traumatic brain injury: Current care guideline, 2008) includes also diagnoses from Chapter V: Other mental disorders due to brain damage and dysfunction and to physical disease (F06.x), Personality and behavioural disorders due to brain disease, damage and dysfunction (F07.x), as well as Sequelae of intracranial injury (T90.5). Clinically the most important primary injuries are diffuse axonal injury, contusions, and haemorrhages (Adult traumatic brain injury: Current care guideline, 2008; Aivovammojen diagnoosiluokittelu, 2011).

Table 1. TBI-related diagnoses according to the ICD-10 (Adult traumatic brain injury: Current care guideline 2008, ICD-10, 2007)

ICD-10 code	Title
S06.0	Concussion
S06.1	Traumatic cerebral oedema
S06.2	Diffuse brain injury
S06.3	Focal brain injury
S06.4	Epidural haemorrhage
S06.5	Traumatic subdural haemorrhage
S06.6	Traumatic subarachnoid haemorrhage
S06.7	Intracranial injury with prolonged coma
S06.8	Other intracranial injuries
S06.9	Intracranial injury, unspecified
F06.x	Other mental disorders due to brain damage and dysfunction and to physical disease
F07.x	Personality and behavioural disorders due to brain disease, damage and dysfunction
T90.5	Sequelae of intracranial injury

ICD-10 and ICF are complementary, and users are encouraged to utilize both of these classifications together. Two persons with the same disease can have different levels of functioning, and two persons with the same level of functioning do not necessarily have the same health condition. Hence, joint use enhances data quality for medical purposes (WHO, 2001).

1.2.2 Background and structure of the ICF

The ICF is WHO's framework for the description of health and disability at both individual and population levels (WHO classifications, 2011). The aim of the ICF is to provide a unified and standard language and framework for the description of health and health-related states. The domains contained in the ICF can be seen as health domains and health-related domains. In clinical settings the ICF is intended to be used as a framework for functional status assessment, goal setting, treatment planning and monitoring, as well as outcome assessment (WHO, 2001).

The ICF reflects the modern day thinking about disability and embodies a paradigm shift in the way health and disability are understood and measured. It is based on a bio-

psychosocial model, in which functioning and disability are seen as multi-dimensional phenomena experienced at the level of the body, the person, and society. In addition, a classification of environmental factors is included that allows users of the ICF to record the positive or negative impact of the environment on a person's functioning (WHO/ESCAP, 2009). The ICF acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity (WHO classifications, 2011).

The ICF has two *parts*, each with two *components*: Part 1 covers functioning and disability in (a) Body Functions and Structures and (b) Activities and Participation; Part 2 covers contextual factors (a) within the Environment and (b) within the Person (WHO, 2001). The ICF conceptualises disability, not solely as a problem that resides in the individual, but as a health experience that occurs in a context. Functioning is an umbrella term encompassing all body functions, activities and participation; similarly, disability serves as an umbrella term for impairments, activity limitations or participation restrictions. Disability and functioning are outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors (WHO, 2001; WHO/ESCAP, 2009). Figure 1 illustrates the interaction between the components of the ICF.
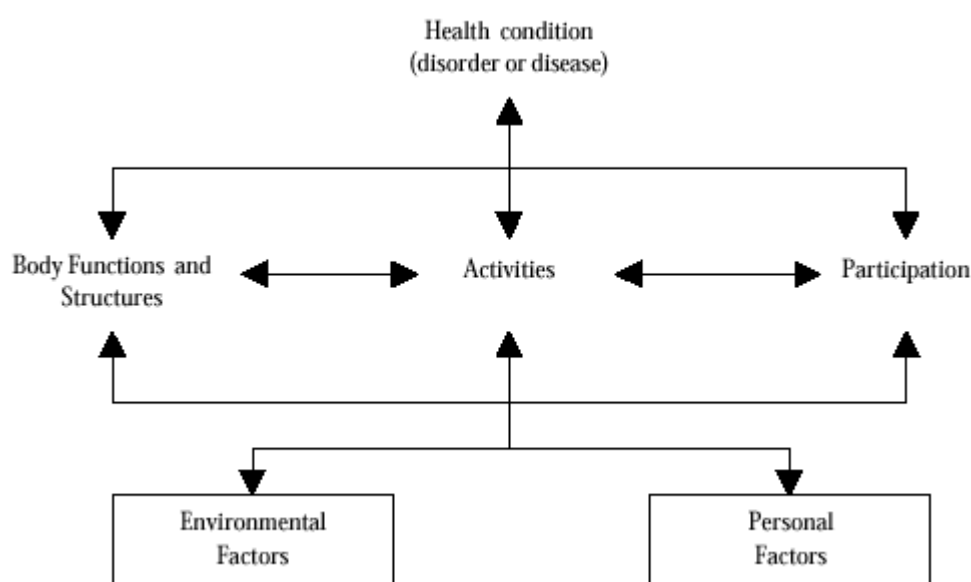
Figure 1. Interactions between the components of ICF (WHO, 2001).

Each component consists of various *domains*. The domains are a practical, meaningful set of related physiological functions, anatomical structures, actions, tasks, or areas of life. Domains make up the different chapters and blocks within each component. A list of the ICF domains is presented in the Appendix. Each domain consists of *categories*, which are the units of classification. Health and health-related states of an individual may be recorded by selecting the appropriate category and then adding *qualifiers*, which are numeric codes that specify the extent or the magnitude of the functioning or disability in that category (WHO, 2001; WHO/ESCAP, 2009).

Structurally, the ICF is based on three levels of functioning: Body Functions (b), Body Structures (s), and Activities and Participation (d) with parallel levels of disability (impairments, activity limitations and participation restrictions) (Table 2).

Table 2. ICF Levels of functioning and disability (WHO/ESCAP, 2009)

Dimensions of functioning	Dimensios of disability
Body Functions and Body Structures	Impairments
Activities	Activity limitations
Participation	Participation restrictions

The components are denoted by prefixes in each code: (b) for Body Functions, (s) for Body Structures, (d) for Activities and Participation, and (e) for Environmental Factors. The letters b, s, d and e are followed by a numeric code that begins with the chapter number (one digit), followed by the second level (two digits), and the third and fourth level (one digit each) (WHO, 2001; WHO/ESCAP, 2009). Example of the hierarchical coding system related to one language function is presented in Table 3.

Table 3. Example of the ICF coding system (WHO/ESCAP, 2009)

Level	Example	Coding
1st level (Chapter level)	Chapter 1: Mental functions	b1
2nd level	Mental functions of language	b167
3rd level	Reception of language	b1670
4th level	Reception of spoken language	b16700

The codes require the use of one or more qualifiers, which denote, for example the magnitude of the level of health or severity of the problem at issue. Qualifiers are coded as one, two or more numbers after a decimal point. Without the qualifiers codes have no inherent meaning (WHO, 2001). Example of the use of the codes and the qualifiers: b1670.3 = severe impairment in reception of language.

1.2.3 Application of the ICF in rehabilitation settings

The ICF classification provides a basis and conceptual model for rehabilitation practice and research, understood as a health strategy (Stucki et al., 2007; Stucki & Melvin, 2007). Rehabilitation can be defined as a health strategy aiming to enable people with health conditions who are experiencing or are likely to experience disability, to achieve and maintain optimal functioning in interaction with the environment (Stucki et al., 2007). Bilbao et al. (2003) state that the field of rehabilitation may be the one in which the ICF will have its greatest contribution, offering a unique theoretical and practical classification model.

Rehabilitation is a continuous process. It involves the identification of problems and needs, the relation of problems to impaired Body Functions and Structures, the factors stemming from the Person and the Environment, and the management of rehabilitation interventions (Stucki et al., 2003).

To use the ICF in clinical practice, ICF-based tools must be developed. ICF Core Sets (Cieza et al., 2004) were the first approach to providing ICF-based tools in clinical practice and research. In a multidisciplinary and systematic approach professionals describe at least all ICF categories from a Brief ICF Core Set and use the corresponding Comprehensive ICF Core Set as a pool from which additional relevant categories can be chosen for assessment. Besides the ICF Core Sets, other ICF-based tools such as the assessment sheet, a categorical profile and evaluation display, facilitate the understanding and description of functioning in a multidisciplinary rehabilitation process and hence support ICF-based rehabilitation management (Case studies, 2007; Rauch et al., 2008).

Until now only a few studies have been published considering the implementation of the ICF in rehabilitation practice. An interesting example has been presented by Rentsch et al. (2003) from Lucerne, Switzerland. Their interdisciplinary team first worked out checklists for the use of different specialist teams. During the rehabilitation process, these checklists and the ICF framework were used in rehabilitation conferences, in communication, goal setting and documentation. The first experiences showed good acceptance by the team members, improvements in communication and documentation, as well as substantial gains in content and handling rehabilitation conferences. Svestkova et al. (2010) implemented the ICF in rehabilitation of 100 patients with TBI in Prague. They concluded that the ICF enables the description of a variety of problems. ICF-derived data provided a holistic view of disability and enabled the impact of service interventions on functioning and participation. It also enabled clinicians to tailor intervention according to patient's actual needs. The work of Tempest and McIntyre in United Kingdom (2006) showed that the ICF has a potential to clarify team roles and demonstrate clinical reasoning within stroke rehabilitation. A recent work from Slovenia (Ptyushkin et al., 2010) explored retrospectively medical records of 100 TBI patients and linked them to the ICF. According to their findings, the ICF detected substantial improvement after rehabilitation regarding body functions and activities related to mobility and self-care and little improvement regarding mental functions and related activities. ICF also clearly outlined the environmental factors important for the recovery and functioning. Larkins from New Zealand (2007) gave an interesting case example of the rehabilitation of cognitive-communication disorders taking into account environmental barriers and facilitators as well as personal factors.

Experiences of implementing the ICF in neurorehabilitation in Finland have not been published thus far. However, Sjögren (2006) investigated the feasibility and the effects of workplace physical exercise intervention on physical and psychosocial functioning, work ability, and general subjective well-being using the ICF as a framework. Matinvesi (2010) concluded in his recent thesis that the ICF as such does not improve rehabilitation processes. However, it includes aspects which can be used when developing a theory of rehabilitation process. During the recent years, a remarkable effort has been put into defining good rehabilitation practice for neurorehabilitation in Finland. The importance of the ICF classification has been pointed out during this

process. According to the guidelines provided by the Social Insurance Institution of Finland (Kela), elegant and individual rehabilitation presupposes multidisciplinary high-quality teamwork, co-operation between organizations, a holistic approach, an evaluation of personal and environmental factors and of the needs and goals of clients, flexible communication, and long-term guidance, support and follow-up. ICF classification should be used as a theoretical framework (Paltamaa et al., 2011). According to the consensus statement for rehabilitation after acquired brain injury, the ICF framework should be applied in planning the rehabilitation process, in setting the goals and implementing the interventions (Konsensuslausuma, 2009).

1.3 Outcome after TBI

1.3.1 Functioning and disability

TBI is a heterogeneous disorder with different forms of presentation (Gordon et al., 2006; Maas et al., 2008; Zitnay et al., 2008). Earlier studies have shown that the most problematic consequences involve the individual's cognition, emotional functioning, and behaviour, which can affect interpersonal relationships, school, and work (NIH, 1999). The TBI Outcomes Workgroup (Wilde et al., 2010) recently selected twelve outcome domains that should be assessed after TBI (Table 4).

Table 4. TBI outcome domains (Wilde et al., 2010)

TBI outcome domain
Global outcome
Recovery of consciousness
Neuropsychological impairment
Psychological status
TBI-related symptoms
Behavioural function
Cognitive activity limitations
Physical function
Social role participation
Perceived generic and disease-specific health-related quality of life
Health economic measures
Patient-reported outcomes

Global outcome after TBI summarizes the overall impact of TBI, incorporating functional status, independence, and role participation (Wilde et al., 2010). The most commonly used global outcome measures after TBI are the Glasgow Outcome Scale (GOS) (Jennet and Bond, 1975) and the Glasgow Outcome Scale Extended (GOSE) (Wilson et al., 1998).

Neuropsychological impairments and cognitive activity limitations are well known after TBI. The most frequent cognitive sequelae after TBI involve mental slowness, attention deficits, memory impairments, and executive problems (Benedictus et al., 2010; Borgaro and Prigatano, 2002; Dikmen et al., 2009; Himanen et al., 2009; Kozlowski et al., 2002). Problems with awareness are common. Patients with moderately severe to severe TBI can demonstrate disturbances in self-awareness several months or years after injury (Prigatano, 2005). Patients may underreport cognitive and behavioural difficulties, which are the true consequences of their brain injury. Increasingly, research indicates that these disturbances in awareness greatly affect the process and outcome of rehabilitation (Prigatano et al., 1984; Sherer et al., 2003).

TBI affects the psychological status and leads to emotional and behavioural problems. The most common problems include irritability, anxiety, aggression, and/or impulsivity, depression, affective lability, and apathy (Corrigan et al., 2001; Hesdorffer et al., 2009; Hibbard et al., 2004; Jorge, 2005; Vickery et al., 2005). Behavioural disturbances typically become obvious some time after the acute phase and these deficits are generally not as easily tolerated and understood by the family when compared to sensomotoric deficits (Lippert-Grüner et al., 2006). Limited/suggestive evidence for posttraumatic stress disorder (PTSD) has been shown in military populations with TBI (Hesdorffer et al., 2009).

A variety of "non-cognitive" consequences of acquired brain injury can have a devastating impact on social functioning through their interaction with the cognitive sequelae (Wood et al., 2008). TBI affects leisure and recreation, social relationships, functional status, quality of life, and independent living. It decreases the probability of employment after injury in those who were workers before their injury, lengthens the timing of their return if they do return to work, and decreases the likelihood that they will return to the same position (Temkin et al., 2009). Social isolation is one of the most profound life changes for persons with TBI with deterioration in the ability to maintain

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preinjury marital relationships, friendships, as well as in the ability to form new social relationships (Sander & Struchen, 2011).

Recent studies show that TBI is a chronic health condition that has a physiological impact on the organism. A significant proportion of TBI survivors face substantial disability and impaired overall health one year after injury (Andelic et al., 2010). TBI is related to premature death (Cameron et al., 2008; McMillan & Teasdale, 2007), epilepsy (Andelic et al., 2010), movement disorders, pain (Branca & Lake, 2004; Hoffman et al., 2007), dizziness, visual disturbances, sleep disturbances and fatigue (Baumann et al., 2007; Cantor et al., 2008; Kempf et al., 2010; Rao et al., 2008), progressive dementia, Parkinson's disease, and endocrine dysfunction, particularly hypopituitarism (Bazarian et al., 2009; Rutherford & Corrigan, 2009). Nonneurological medical complications include pulmonary, metabolic, nutritional, gastrointestinal, musculoskeletal, and dermatologic problems (NIH, 1999).

According to outcome studies functional recovery and global outcome are related to several demographic, treatment-related, and injury-related factors. The demographic factors include age, race, education (Mushkudiani et al., 2007), pre-injury unemployment, and pre-injury substance abuse (Willemse-van Son et al., 2007). The treatment-related factors include such factors as time to rescue, time to trauma care and type of care given, medical complications, presence and severity of other peripheral injuries, nutrition, pharmacological treatment, time to rehabilitation, and finally type, intensity and duration of rehabilitation (Yen & Wong, 2007). Injury-related factors include for example the duration of posttraumatic amnesia (Brown et al., 2005; Draper et al., 2007; Hiekkanen et al., 2009; Ponsford et al., 2008; Sigurdardottir et al., 2009; Willemse-van Son et al., 2007), CT and MRI characteristics, including the presence of traumatic subarachnoid hemorrhage (Hiekkanen et al., 2009; Maas et al., 2008; MRC CRASH, 2008; Sigurdardottir et al., 2009; Steyerberg et al., 2008), and disability at rehabilitation admission (Willemse-van Son et al., 2007). Injury severity has been shown to be predictive of life satisfaction, gender and relationship status to community integration, and age at injury to employment status (Wood & Rutterford, 2006).

1.3.2 Health-related quality of life

Health-related quality of life (HRQoL) refers to how health impacts an individual's ability to function and his or her perceived well-being in physical, mental and social domains of life (Coons et al., 2000). The concept relates to the subjective evaluation of well-being, satisfaction, functioning and disability: the same objective circumstances may be experienced in completely different ways by various individuals, based on their previous life experience and attainments in relation to their current expectations, goals and values (Dijkers, 1999; Fuhrer, 2000; Mailhan et al., 2005; Ueda & Okawa, 2003). The outcome assessment of patients with TBI has traditionally focused mainly on functional outcome, return to work, and productivity. Only during the recent years has HRQoL of life been introduced as an outcome criterion after TBI (Bullinger et al., 2002; Corrigan & Bogner, 2004; Neugebauer et al., 2002; von Steinbüchel et al., 2005).

Overall, quality of life is perceived lower or significantly lower after TBI than before it, or in a group of healthy controls (Dijkers, 2004; Emanuelson et al., 2003; Kalpakjian et al., 2004; Mailhan et al., 2005; Spearman et al., 2007). However, in a long-term population based study (Engberg & Teasdale, 2004) as many as 94-95% of the respondents found their life as a whole good or at least acceptable, only 5-6% found it hard to bear. In another population-based study Pickelsimer et al. (2006) found that 65% of the patients were satisfied with their lives 1 year after TBI. Central tendencies and distributions of life satisfaction as a whole seem to be consistent during many years after TBI (Corrigan et al., 2001; Johansson & Bernspång, 2003; Pagulayan et al., 2006).

Demographic variables show little or no relationships with satisfaction of life in most studies (Corrigan et al., 2001; Johansson & Bernspång, 2003; Kalpakjian et al., 2004; Pierce & Hanks, 2006; Vickery et al., 2005;). However, a few studies (Cicerone & Azulay, 2007; Mazaux et al., 2002; McCarthy et al., 2006; Seibert et al., 2002) showed that age or gender was related to life satisfaction and self-reported psychosocial health. The positive history of substance abuse has been reported to be negatively associated with subjective life satisfaction after TBI (Corrigan et al., 2001).

Studies show that the severity of the initial injury and the quality of life has either no relationship (Dikmen et al., 2003; Tomberg et al., 2005; Vickery et al., 2005) or that increased severity predicts lower life satisfaction (Teasdale & Engberg, 2005). On the

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contrary, in the study of Corrigan et al. (2001) subjects with the lowest GCS had slightly higher life satisfaction than other groups 1 year after injury.

Functional status and dependence on the help of other people have been shown to be among the factors most influencing the patients' HRQoL (Kozlowski et al., 2002; von Steinbüchel et al., 2010a; Mailhan et al., 2005; McCarthy et al., 2006). However, in the study by Mailhan et al. (2005) the relationships between life satisfaction and disability were not linear: the lowest satisfaction scores were reported by participants with moderate disability rated by the Glasgow Outcome Scale. Sleep-wake disturbances and fatigue (Bauman et al., 2007; Cantor et al., 2008; Emanuelson et al., 2003), and pain (Branca & Lake, 2004; Hoffman et al., 2002) have also been shown to be important factors associated with HRQoL. A growing literature has emerged in the field of neuroendocrine dysfunctions after TBI and their relation to quality of life of patients (Agha & Thompson, 2006; Aimaretti & Ghigo, 2005; Bondanelli et al., 2005; Masel, 2005; Leon-Carrion et al., 2005; Schneider et al., 2007).

The association between cognitive impairment (Kozlowski et al., 2002; McCarthy et al., 2006), communication skills (Dahlberg et al., 2006), emotional status and depressed mood (Corrigan et al., 2001; Hibbard et al., 2004; Kalpakjian et al., 2004; Koskinen, 1998; Mailhan et al., 2005; Vickery et al., 2005) and HRQoL has been shown in many studies. HRQoL is also strongly determined by behavioural and psychiatric disturbances (Jorge, 2005; Kozlowski et al., 2002). The neurobehavioral disturbances in the person with TBI have also been shown to be among the strongest predictors of satisfaction or distress of the significant others (Ergh et al., 2002; Koskinen, 1998; Machamer et al., 2002; Wells et al., 2005).

Community integration and level of social participation is one of the strongest predictors of life satisfaction (Corrigan et al., 2001; Pierce & Hanks, 2006, Ragnarsson, 2006). Employment has traditionally been a major determinant of QoL because it affects also many other important factors in QoL, such as standard of living, financial security, and opportunities to meet people (Dijkers, 2004; Mailhan et al., 2005; Opperman, 2004).

Cicerone and Azulay (2007) found that the greatest contribution to the prediction of global life satisfaction was made by the person's perceived self-efficacy, particularly perceived self-efficacy for the management of cognitive symptoms. Gordon et al.

(2006) state in their review that future research should also include social model research to examine the impact of societal barriers, including attitudinal barriers, on quality of life among people with TBI. The possibility that TBI may provide positive opportunities for improved QoL has also been pointed out (Dijkers, 2004; O'Donnell et al., 2005). These possibilities include reduced substance abuse, positive changes in mood and behaviour, finding new strengths in oneself, posttraumatic growth, and opportunities to establish new relationships.

1.3.3 The ICF as a framework in outcome assessment

The ICF is not an assessment tool and does not consist of specific assessment measures or evaluation protocols. A practical challenge to the application of the ICF is the size of the classification system with its 1424 categories. To address the issue of feasibility, ICF-based instruments have been developed, e.g. the ICF checklist (2003) and various ICF Core Sets for different patient groups (Cieza et al., 2004). The ICF checklist comprises 123 categories and makes it possible to generate a patient profile using the most important ICF categories. The checklist is developed for the needs of any patient, regardless of the diagnosis. However, from a medical perspective, functioning and health are seen primarily as a consequence of a specific health condition. Condition-specific Core Sets can be defined as a selection of ICF categories that include the smallest number of domains practical, while still being sufficiently comprehensive to cover the typical spectrum of limitations in functioning and health encountered in a particular condition (Cieza et al., 2004).

Recently the Core Sets have been developed for TBI. The preparatory phase of the project included a systematic literature review to identify parameters and outcomes reported in studies published from 2002-2007, a qualitative study with persons with TBI and their caregivers, an internet-based expert survey, and a multicentre cross-sectional study with 500 patients. Based on this preliminary work, an international consensus conference selected 143 ICF categories for the Comprehensive ICF Core Set for TBI (ICF Research branch, 2010). The consensus conference consisted of 23 international TBI experts from eight health professions who selected the categories by voting. These

categories can be taken into account when conducting a comprehensive, multidisciplinary assessment (e.g. in a rehabilitation setting). Out of the 143 Comprehensive ICF Core Set categories, 23 ICF categories were selected for the Brief ICF Core for TBI (Table 5). The Brief ICF Core Set can be used in settings in which a brief description and assessment of functioning of a person with TBI is sufficient (e.g. primary care or in research) (Aiachini et al., 2010; Bernabeu et al., 2009; ICF Research branch, 2010). The Core Sets have been the basis for developing ICF Tools for clinical practice, e.g. for rehabilitation. These tools allow the description of functioning, the illustration of the patient's experience of functioning and the relation between rehabilitation goals and appropriate intervention targets. They also give an overview over required resources, and the changes in functional states following rehabilitative interventions (Rauch et al., 2008).

Table 5. Brief ICF Core Set for TBI (ICF Research branch, 2010)

Brief ICF Core Set for TBI	
Body Functions	
b164	Higher-level cognitive functions
b152	Emotional functions
b130	Energy and drive functions
b760	Control of voluntary movement functions
b144	Memory functions
b280	Sensation of pain
b140	Attention functions
b110	Consciousness functions
Body Structures	
s110	Structure of brain
Activities & Participation	
d230	Carrying out daily routine
d350	Conversation
d450	Walking
d720	Complex interpersonal interactions
d845	Acquiring, keeping and terminating a job
d5	Self care
d920	Recreation and leisure
d760	Family relationships
Environmental Factors	
e310	Immediate family
e580	Health services, systems and policies
e115	Products and technology for personal use in daily living
e320	Friends
e570	Social security services, systems and policies
e120	Products and technologies for personal indoor/outdoor mobility & transportation

As Stucki et al. (2003) state, the success of the ICF will depend on its practicability and its compatibility with measures used in rehabilitation. Thus, it is expected to see the development of the ICF based on versions of currently used instruments and on the development of ICF Core Sets. In order to use the ICF as a reference framework in outcome research and rehabilitation, a concurrent use of both health-status measures and the ICF is necessary (Cieza et al., 2002). For practical reasons, systematic linking rules have been developed for linking health-status measures to the ICF (Cieza et al., 2002, 2005). Since the presentation of these rules, several health-status measures (Cieza et al., 2002) and HRQoL measures (Cieza & Stucki, 2005) have been linked to the ICF.

2 Aims of the study

The general aim of this study is to examine the outcome after TBI in the frame of reference of the WHO Family of International Classifications (ICD-10 and ICF). Outcome is defined by the perspective of both the professionals (assessments of the functional outcome) and the patients (HRQoL). The clinical utility of a new disease-specific HRQoL measure (the QOLIBRI) is evaluated, and the content of the QOLIBRI and the GOSE are analysed in the frame of reference of the ICF. The results are discussed in light of how they relate to rehabilitation.

The specific questions to be answered are:

1. What is the epidemiology and short-term outcome of TBI in Finland in 1991–2005? (Study I)

2. What are the most common problems documented in the functioning of post-acute TBI patients in rehabilitation settings? (Study II)

3. Measured by the QOLIBRI, what are the HRQoL associations with the socio-demographic, mental health, and functional outcome variables? (Study III)

4. Do the two TBI specific outcome measures (the GOSE and the QOLIBRI) cover relevant domains of functioning as defined in the frame of reference of the ICF? (Study IV)

5. How does functional outcome assessed by clinicians relate to the subjective HRQoL reported by patients? (Study IV)

3 Methods

3.1. Subjects

3.1.1 Study I

The subjects of study I consist of Finnish hospitalised patients whose primary diagnosis was TBI and who did not have a medical history of previous TBI, and fatal cases with TBI as the primary cause of death during the years 1991–2005. The data of the hospitalised patients were obtained from the National Hospital Discharge Register of Finland. Data related to the deaths were obtained from Statistics Finland's official cause-of-death register. The figures of the whole population of Finland were derived from Statistics Finland, a register in which every inhabitant of Finland is registered by his or her personal identification number.

3.1.2 Studies II and IV

A total of 305 patients with the primary diagnosis of TBI underwent their first inpatient rehabilitation period in the Käpylä Rehabilitation Centre, Helsinki, Finland from 1 January 2002 to 31 December 2004. They were referred to the rehabilitation centre by insurance companies, the Social insurance institution of Finland, Kela, or by the health care systems. These patients formed the basis of the Finnish participants in the first wave of an international multicentre quality of life study, QOLIBRI (von Steinbüchel et al 2010 a and b). The inclusion criteria for the QOLIBRI study (and so also the present study) were: age 18–60 years at the time of assessment, minimum age at injury 15 years, available informed consent form, diagnosis of TBI made by a physician according to ICD-10, and time since injury 3 months to 15 years. The exclusion criteria were: GOSE < 3, spinal cord injury, patients with known past or present psychiatric conditions, ongoing severe addiction, inability to understand, co-operate and answer, and terminal illness. The QOLIBRI questionnaire was mailed to the 305 patients and was completed by 133 patients. Of these, 9 did not meet the inclusion criteria and were

excluded. The reasons for exclusion were over 15 years time since injury, inability to fill out the questionnaire, or severe addiction. No patients were excluded due to past or present psychiatric conditions. For 16 patients the Glasgow Coma Score (GCS) was unknown and these patients were excluded following the procedure of the international QOLIBRI validation study. Of the remaining 108 patients a systematic sample of 55 patients was formed: every second patient was picked up from the alphabetical list of the patients' surnames. The first patient on the list was drawn by lot. Compared to the main population of the 305 patients, this sample contains relatively more patients referred by the insurance companies (52.7% compared to the original 45.1%) and less patients referred by the Social insurance institution of Finland (Kela) (29.1% compared to the original 32.5%) or health care systems (18.2% compared to the original 22.4%). The distribution of the external causes of injury corresponded to each other in the sample and in the main population. Table 6 presents the patient characteristics.

Table 6. Patient characteristics (studies II and IV)

	n	mean (SD)	range
Sex (men / women)	38 / 17		
External cause of injury			
Traffic	35		
Fall	12		
Other	8		
ICD-10			
S06.2 – S06.5	10		
T90.2 – T90.5	45		
Age at injury (years)		36.4 (12.6)	15.3 – 56.5
Age at assessment (years)		39.1 (12.1)	20.1 – 57.4
Chronicity* (years)		2.7 (2.6)	0.3 – 13.8
GCS (worst during the first 24 hours)		9.6 (3.9)	3 – 15
Median	8		
PTA (days)		42.5 (66.7)	0 – 365
Median	20		
GOS		3.9 (0.4)	3 – 5
GOSE		4.7 (0.7)	3 – 6
FIM motor		89.2 (4.0)	72 – 91
FIM total		120.6 (5.2)	106 – 126

*Time from injury to assessment at rehabilitation period.
GCS, Glasgow coma score; PTA, posttraumatic amnesia; GOS, Glasgow outcome scale; GOSE, Glasgow outcome scale extended; FIM, Functional independence measure

3.1.3 Study III

The sample of 795 persons with TBI in study III was the second wave of the international QOLIBRI validation study sample (von Steinbüchel et al 2010 a and b) with participants from nine countries with six languages: Dutch (12%), English (12%), Finnish (20%), French (19%), German (19%), and Italian (17%). Most countries/centers recruited convenience samples from rehabilitation facilities. The inclusion criteria were: ICD-10 diagnosis of TBI; age 15 or more at injury and 17- 68 years at recruitment to the study; three months to 18 years after injury, capacity to give informed consent; and adequate cognitive and behavioural functioning to understand, answer, and cooperate. Exclusion criteria were: GOSE < 3; spinal cord injury; pre-traumatic or current psychiatric disease; known ongoing addiction; and terminal illness. A total of 921 participants were recruited altogether. Due to missing data the current study is based on the 795 participants for whom GCS and GOSE data were available. Table 7 presents the characteristics of the participants of study III.

Table 7: Characteristics of participants

	Category	% (a)
Gender	Male	72.1%
Age	Years (mean, SD)	39.0 (13.3)
Education attainment	Primary	5.7%
	High/Secondary	25.0%
	Trade certificate	29.5%
	College diploma/degree	23.4%
	University degree	11.9%
Partner status (b)	Single	40.6%
	Partnered	47.2%
	Post-partnered	12.1%
Living arrangements	Living independently	58.3%
	Supported by partner, family, or	34.0%
	Living in sheltered accommodation (c)	7.8%
Labour-force participation (d)	Working	44.1%
	Unable to work	10.2%
	Unemployed	15.0%
	Out of the workforce	30.8%
Time since injury (interviewed)	Months (mean, SD)	59.9 (46.7)
Lesion site (e)	No lesion	14.9%
	Frontal	32.6%
	Posterior	20.6%
	Diffuse	31.8%
PTA (e)	<1 day	19.3%
	1-7 days	23.9%
	8-28 days	20.2%
	29+ days	36.6%
Glasgow Coma Scale classification (e)	Mild (13-15)	32.1%
	Moderate (9-12)	9.6%
	Severe (3-8)	58.4%

a Base number of participants = 795. Percentages are valid percentages, after excluding missing cases and 'other' responses. Missing: gender (N=0), age (0), education (89), partner status (52), living arrangements (74), labour force (96), time since injury (3), lesion site (10), PTA (133), GCS (0).
b Partnered = married or de facto; Post-partnered = separated, divorced, widowed
c Sheltered housing, community housing, nursing home or hospital ward
d Working = fulltime, part-time, self-employed; Unable to work = temporarily, permanently; Out of the labour-force = homemaker, student, voluntary work, retired
e Data from the medical record

3.2 Measures and procedures

3.2.1 Registers

Two national registers were used in study I. Data for hospitalised TBI patients were obtained from the National Hospital Discharge Register of Finland. Patients were registered according to the first TBI in their medical history. This was confirmed by using the patients' national identification numbers which were allowed to exist only once in the sample. The medical history was taken into account during the years when either ICD-9 or ICD-10 had been in use in Finland, i.e. from the year 1987. Data related to the deaths were obtained from Statistics Finland's official cause-of-death register. The figures of the whole population of Finland were derived from Statistics Finland, a register in which every inhabitant of Finland is registered by his or her personal identification number. The data of the diagnoses from 1991–1995 are based on the International Classification of Diagnosis revision 9 (ICD 9) and from 1996–2005 on revision 10 (ICD 10).

3.2.2 QOLIBRI

The QOLIBRI (von Steinbüchel et al., 2010 a, 2010b) is the first disease-specific cross-culturally validated HRQoL instrument specifically developed for TBI patients. The items of the QOLIBRI focus on the individual's subjective evaluation of satisfaction with different domains typically affected after TBI and presents the questions in a positive manner: „How satisfied are you with your…?' , or in domains where expression of satisfaction is not relevant: „How bothered are you by …?'.

The QOLIBRI includes 37 items in six Likert-formatted scales. Four scales contain "satisfaction" items (Cognition, Self, Daily Life and Autonomy, Social Relationships) and two scales contain "bothered" items (Emotions and Physical Problems). Total scores are obtained by simple summation of 37 item scores (graded 1-5), after reversal of 10 „bothered' items. The maximum score therefore is 37 x 5 = 185. The individual QOLIBRI scores are then transformed into percentages out of the

maximum and presented on a 0 (worst possible score on the QOLIBRI) to 100 (best possible score) scale. This is described as a 0-100 point scale.

The QOLIBRI has been validated in two large multinational TBI populations (N>1500, N>900) with different grades of disease, showing good psychometric properties. It is brief, is publicly available, and exists in more than 10 languages (Steinbüchel et al., 2010a, 2010b; Wilde et al., 2010).

3.2.3 GOSE

The Glasgow Outcome Scale Extended (GOSE) (Wilson et al., 1998) is an extended version of the Glasgow Outcome scale GOS (Jennett & Bond, 1975). Together, these scales are the ones most commonly used as TBI global outcome measures. The GOSE subdivides the initial categories of severe disability, moderate disability, and good recovery into an upper and lower category, based on evaluation of independence at home, shopping and travel, work, social and leisure activities, family, friendship, and return to normal life. The rating is performed by a health professional using a structured interview as well as all other available information on the subject. The outcome categories of the GOSE are (from 1 to 8): Dead, Vegetative State, Lower Severe Disability, Upper Severe Disability, Lower Moderate Disability, Upper Moderate Disability, Lower Good Recovery, and Upper Good Recovery. The GOSE is in line with the principles of the WHO classification of impairments, disabilities and handicaps and its validity is supported by good correlations with results of neuropsychological testing and assessments of general health status (Bullinger et al., 2002). The GOSE has shown consistent relations with other outcome measures including subjective reports of health outcome (Mazaux et al., 2002).

3.2.4 Other questionnaires

In study III, depression and anxiety were assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The SF-36 (Ware & Sherbourne,

1992) was used as a patient-reported generic health outcome measure. Patients also filled out a questionnaire concerning social and demographic information, including age, gender, relationship status, educational background, occupation, level of independence, number of social contacts, participation in leisure activities, and use of alcohol and recreational drugs. Need for help was assessed in five specific areas (personal needs, mobility, activities of daily living, transportation, and organization & management). In addition, a health questionnaire covering 28 comorbid health conditions and problems adapted from Power and associates (2005) by von Steinbüchel and colleagues (2006) was used. The professionals completed a questionnaire based on medical documents and by interviewing the patients. This questionnaire covered information concerning clinical background, including post-traumatic amnesia and current medication, and a rating of disorders in 10 areas (epilepsy, hemiparesis, visual and auditory deficits, extra-cerebral injuries, communication problems, attention dysfunction, memory dysfunction, executive dysfunction, and affective and behavioural disorders) (von Steinbüchel et al., 2010a, 2010b).

3.2.5 ICF checklist

Study II is based on the use of the ICF checklist, Version 2.1a, Clinician Form (2003). The ICF checklist is a short form of the whole ICF classification presenting the 4 components: Body Functions (b), Body Structures (s), Activities and Participation (d), and Environmental Factors (e); 29 one-level chapters (see Appendix); and 123 two-level categories. Following the checklist instructions the categories of Body Functions, Body Structures, and Activity and Participation are coded using qualifier values from 0 to 4; 0 = no impairment; 1 = mild impairment / difficulty (problem present less than 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days; to 4 = complete impairment / difficulty (problem present more than 95% of the time, with an intensity, which is totally disrupting the person's day to day life and which happens every day over the last 30 days). The qualifiers of Environment (e) were graded from 0 to +4 (0 = no barriers / facilitators to 4 = complete barrier and +4 = complete facilitator).

3.2.6 ICF coding procedure

Two professionals (clinical neuropsychologist Sanna Koskinen and physiotherapist Eeva-Maija Hokkinen), both having more than 20 years' experience in rehabilitation and assessment of patients with TBI, analysed independently the written medical documents of the TBI patients using the ICF checklist (2003). The checklist was chosen because in 2006 when this study started the ICF Core Sets for TBI had not yet been developed. At the time of this study it was considered the most relevant list of categories for identifying the problems in the functioning of all patients. If the ICF Core Sets for TBI had been available at that time, the Comprehensive ICF Core Set for TBI would have been used.

The data were extracted from a total of 350 written documents: 55 documents from a neurologist, nurse, neuropsychologist and physiotherapist; 54 from a social worker; 53 from a speech and language pathologist; and 23 from an occupational therapist. It took on average 90 minutes (range 30–245 minutes) for the rater to go through the documents of one patient and to complete the checklist. The coding was based purely on the written documents included in the medical files and produced by experienced professionals using regular clinical assessment methods. Training of the raters involved familiarization with the principles of the ICF from the ICF handbook (WHO, 2001), the Finnish translation of the ICF handbook (WHO, 2004), and other literature; five one-day workshops arranged by Stakes (National Research and Development Centre for Welfare and Health, Finland); thorough discussions of the principles of coding as well as coding and analysing the documents of three pilot patients before the initial study.

3.2.7 ICF linking procedure

The QOLIBRI and GOSE items were linked to the ICF categories by two independent raters employing the systematic linking rules (Cieza et al., 2002, 2005; Cieza & Stucki, 2005). Following the linking rules, functional concepts (e.g. expressing oneself) in the QOLIBRI and GOSE items were first identified and then linked to the ICF category best representing this concept. If an item contained more than one concept, each concept was

linked separately. For example the QOLIBRI item „How satisfied are you with your ability to *express yourself* and *understand others* in a *conversation*?' was linked to the following ICF categories: d330 = speaking, d310 = communicating – receiving spoken messages, and d350 = conversation.

After having linked the items independently the raters compared their results and in cases of disagreement, sought to find a common consensus. If no consensus was found, a third person with expertise in the theoretical framework and use of the ICF was consulted. Finally, this third person made an informed decision after a discussion with the original raters. The QOLIBRI was linked to the ICF by Sanna Koskinen and Eeva-Maija Hokkinen. The third person leading the consensus conference was Dr Seija Talo, one of the most experienced professionals in the ICF in Finland. The GOSE was linked to the ICF by Sanna Koskinen and Lindsay Wilson. The third person leading the consensus conference was Dr Alarcos Cieza from the ICF Research Branch of WHO, Munich.

3.3 Statistical methods

In study I, the data derived from the national registers were analysed and presented in forms of total numbers, percentages and average incidences per 100 000 inhabitants. While the data were drawn from the entire population of Finland the numbers are not sample-based estimates and therefore statistical analyses characteristic for sample-based estimates were not used.

In study II, the statistical analyses were conducted with the SPSS statistical software (13.0 for Windows). The agreement between the raters was analysed by Cohen's Kappa and intraclass correlation. The kappa statistics is used widely in clinical research in the evaluation of categorical data to measure how much agreement exists beyond the amount expected by chance alone. However, a well-known and disturbing paradox in using the Kappa is that particularly high values of observer agreement (Po) may result to low values of Kappa (Lantz & Nebenzahl, 1996). In our study the Kappa remained low in many ICF categories due to the homogeneity of the sample. For that reason the ICC is also presented. A rigorous definition for the ICC is that the ICC is the correlation

between one measurement on a target and another measurement obtained on that target (Shrout & Fleiss, 1979). There are numerous versions of the ICC. In this study the version ICC(3,k) was used.

In study III, the statistical analyses were conducted with the SPSS statistical software (version 15.0). Categorical data are presented as counts or percentages and chi-square (χ^2) was used for the analysis. Continuous variables are reported as means and standard deviations (SD). Examination of skewness revealed that all QOLIBRI scales were statistically skewed. Therefore, all statistical analyses were carried out on square-root transformed data although non-transformed means and SDs are presented for easy reader interpretation. To compare between mean transformed scores on the QOLIBRI scales, the paired t-test was used. For differences between known groups QOLIBRI scale scores (transformed) were analysed with analysis of variance (ANOVA) and where omnibus statistical significance was reported differences between known groups were examined using the post-hoc Tukey HSD (honestly significantly difference) test. Pearson correlations were used to report relationships between scale scores.

In study IV, the statistical analyses were conducted using SPSS 17.0 for Windows. The results are presented as counts or percentages in categorical data and as means and standard deviations in continuous variables.

4 Results

4.1 Epidemiology and short-term outcome of TBI in Finland in 1991–2005 (Study I)

The total number of hospitalised TBI patients during 1991 - 2005 was 77 959, giving an average of 5197 new cases annually (Table 8).

Table 8. First-time hospitalised TBI patients according to the 5-years periods and gender, 1991-2005

	Male		Female		Total	
	n	per 100 000	n	per 100 000	n	per 100 000
5-year period						
1991 – 1995	14379	117	10121	78	24500	97
1996 – 2000	15532	124	10789	82	26321	102
2001 – 2005	16246	127	10892	82	27138	104
Total	46157	122	31802	80	77959	101

The average incidence was 101/100 000, showing a slight but constant increase in males. Males (59.2%) are at considerably higher risk of getting a TBI than females (40.8%). Figure 2 presents the average age and gender adjusted incidence per 100 000 population during 2001–2005. During the 15-year period the absolute number of patients 70 years of age or older sustaining a TBI increased by 59.4% while the number of patients less than 70 years decreased by 2.4%.
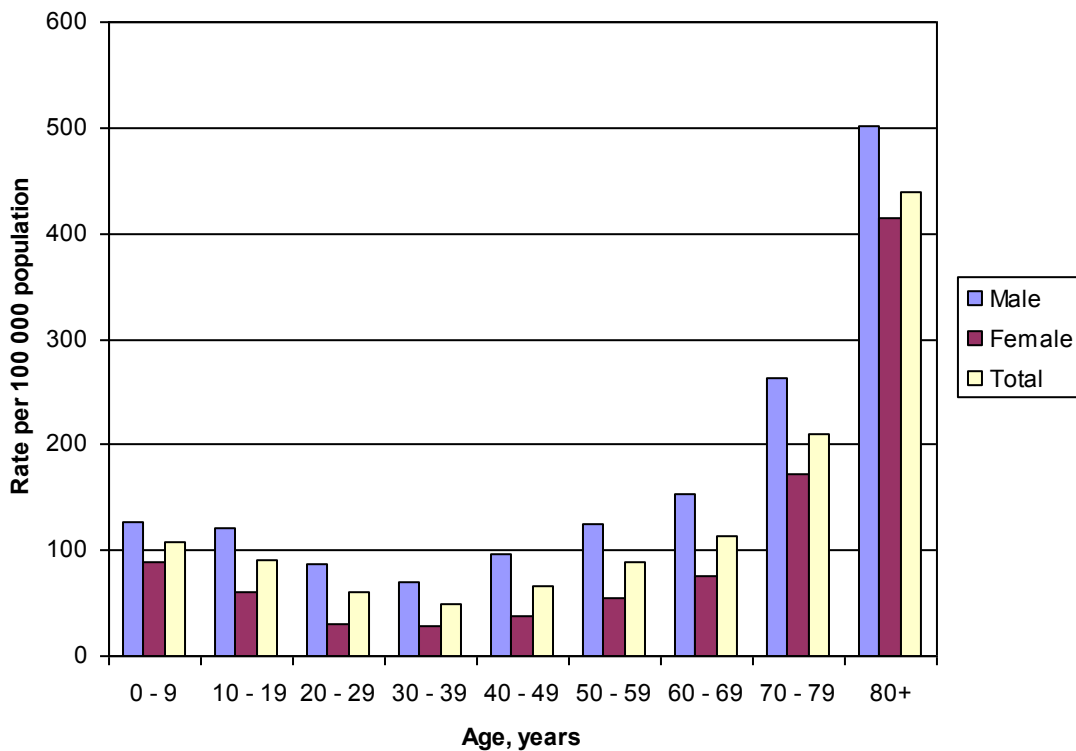
Figure 2. Age and population adjusted annual rate of the hospitalised TBIs per 100 000 population, 2001-2005.

Concussions were the most typical diagnoses followed by contusions (including traumatic cerebral oedema, diffuse brain injury, and focal brain injury) or haemorrhages, and fractures. During the 15-year period the proportion of contusions or haemorrhages increased from 31.9% to 41.2% and the proportion of concussions decreased from 60.9% to 53.0%. Falls were the most common external causes followed by traffic accidents in all age groups. As Figure 3 shows, falls were especially common in the youngest and oldest age groups. In the age group 20–29 years falls and traffic accidents were almost equally common. One third of the traffic accidents occurred to drivers or passengers in cars (36.8%) and one third to cyclists (34.6%). Most of the falls took place from standing height (1 m) or less.
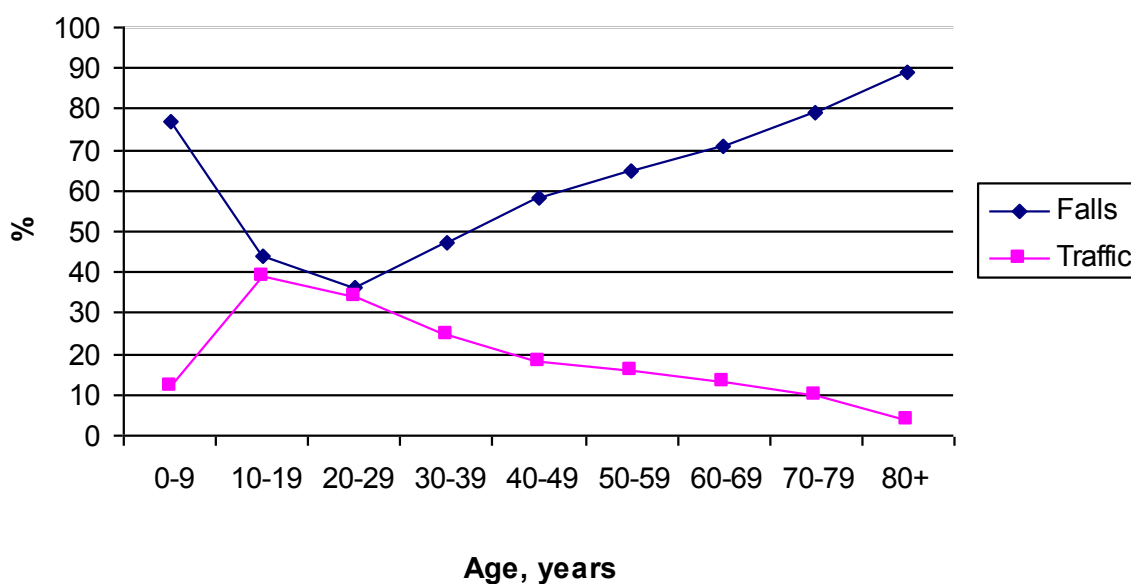
Figure 3. Falls and traffic accidents as the external cause of TBI in different age groups (%), 2001 –2005 (available data).

The length of stay in hospital (LOS) is one indicator of short-term outcome after TBI. The mean LOS for males was 6.6 days and for females 7.8 days. The LOS was related to the diagnosis, age and gender. The longest LOS was found in patients with contusions or haemorrhages (males 11.1 days; females 14.6 days) and with fractures (5.8 and 11.4 days, respectively). Females had longer LOSs in all diagnostic groups. According to the hospital records, 46.0% of the patients were independent or nearly independent after discharge, 26.2% needed continuous, almost continuous or repeated care and 27.8% needed occasional care.

According to the Statistics Finland's register of deaths a total of 14 131 persons (10 515 males, 3616 females) died during 1991–2005 with TBI as the primary cause of death. The average mortality rate during the 15 years was 18.3/100 000 population. The number of deaths decreased during the 15-year-period in males but not in females. The highest mortality risk (in absolute numbers) was found in males in the age groups of 40–49 and 50–59 years. In females the mortality risk increased after the age of 70.

Age was strongly related to all indicators of short-term outcome. The oldest patients stayed at hospital 6.8 times longer than the youngest (Figure 4). Death in hospital due to TBI was 15.5 times more common in patients over 70 years of age compared to patients less than 20 years of age.
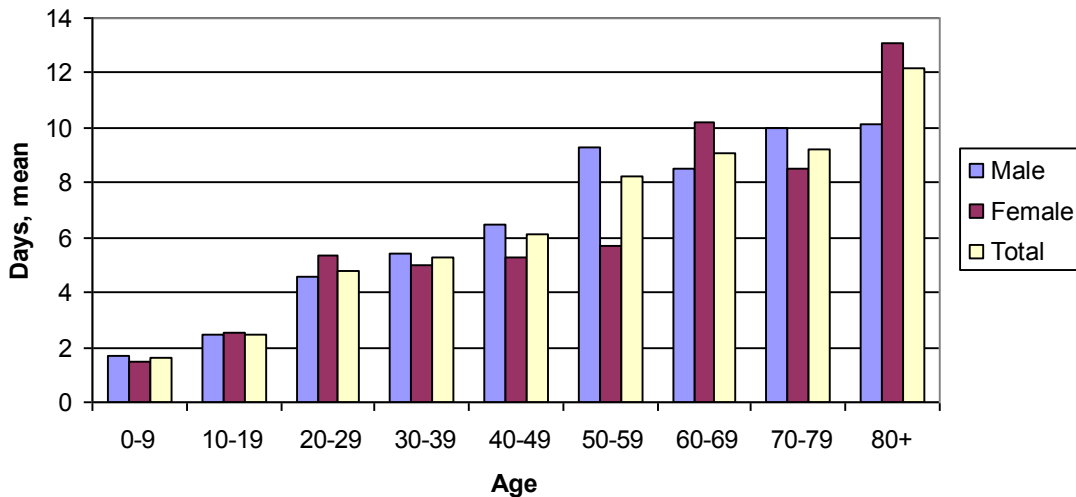
Figure 4. Length of stay in hospital due to TBI in different age groups, 2001–2005.

4.2 Functioning and disability after TBI (Study II)

The profile of disability in the sample of 55 persons with TBI is first presented by using the categories of the ICF Checklist on the one-level classification (chapter level). The existence of the patients' problems were dichotomized as 0 = no problem and 1 = problem existing. Figure 5 presents the most typical problems identified by both raters in the same patients and shows the high diversity of disability after TBI. It shows the impairments of Body Functions (b) and Structures (s), Activity limitations and participation restrictions (d), as well as the barriers in the Environment (e).
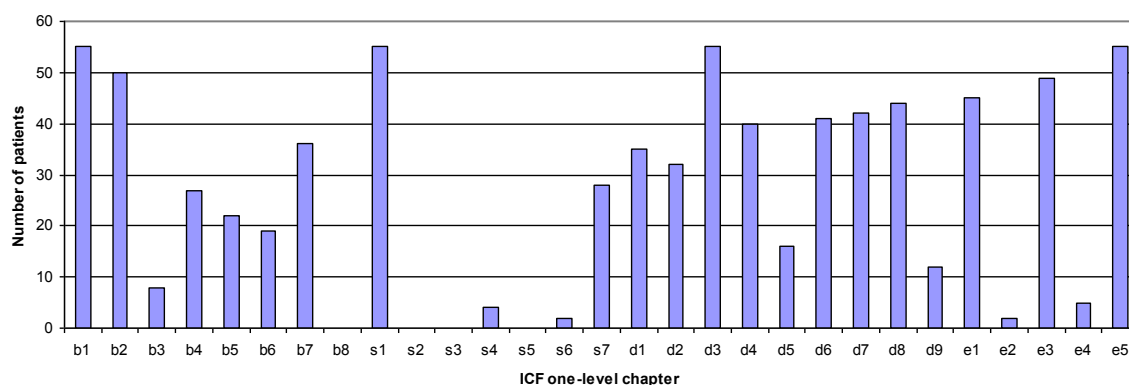
Figure 5. Number of the patients experiencing problems in chapters of the ICF (one-level classification) out of the total of 55 patients. (Dichotomized; qualifier codes 0 = no problem, 1 – 4 = problem).

Of the total of 29 one-level ICF chapters, 25 (86%) were documented in the records of the patients. The most common chapters, in which the patients had problems in at least one category, were b1: mental functions, b2: sensory functions and pain , b7: neuro-musculoskeletal and movement related functions, s1: structure of the nervous system, s7: structure related to movement, d1: learning and applying knowledge, d2: general tasks and demands, d3: communication, d4: mobility, d6: domestic life, d7: interpersonal interactions and relationships, d8: major life areas, e1: products and technology, e3: support and relationships, and e5: services, systems and policies.

Descriptions of 100 (81%) categories out of the 123 two-level categories in the checklist were identified from the written documents. In earlier studies (Ewert et al., 2004; Grill et al., 2005) the cut-off point of at least 30% of the patients having a problem has been used to indicate the most typical problems in a specified condition. A total of 30 of the categories in the checklist were identified in the documents of at least 17 patients (at least 30% of the patients) by both raters (Table 9).

Table 9. ICF-checklist categories in which both of the raters identified at least 30% of the patients having a problem. (Dichotomized; qualifier codes 0 = no problem, 1 – 4 = problem)

ICF category		n	%
b144	Memory	55	100.0
b164	Higher level cognitive functions	55	100.0
b140	Attention	53	96.4
b152	Emotional functions	53	96.4
b130	Energy and drive functions	47	85.5
b167	Language	42	76.4
b134	Sleep	40	72.7
b280	Pain	38	69.1
b235	Vestibular (incl. balance)	37	67.3
b730	Muscle power	26	47.3
b210	Seeing	25	45.5
b156	Perceptual functions	20	36.4
s110 Brain		55	100.0
d850	Remunerative employment	55	100.0
d350	Conversation	49	89.1
d330	Speaking	45	81.8
d720	Complex interpersonal interactions	38	69.1
d175	Solving problems	33	60.0
d220	Undertaking multiple tasks	32	58.2
d620	Acquisition of goods and services	32	58.2
d440	Fine hand use	25	45.5
d310	Communication/receiving spoken messages	22	40.0
d640	Doing housework	21	38.2
d475	Driving	19	34.5
e580	Health services, systems and policies	55	100.0
e355	Support and relationships/health professionals	53	96.4
e310	Support and relationships/immediate family	45	81.8
e570	Social security, services, systems and policies	40	72.7
e110	Products and techn. for personal consumption	35	63.6
e115	Prod. and techn. for personal use in daily living	27	49.1

In this study the 30 categories presented in Table 9 reached a prevalence of 30% in the assessments of both raters. Thus, 93 out of the total 123 categories of the checklist were considered less relevant for this sample of patients with TBI. At least 1 irrelevant category was found in every one-level chapter. On the other hand, the medical documents frequently contained information typical of patients with TBI and related to

specific ICF categories, but missing from the checklist. According to the study design this information was not systematically recorded, but was noted as an additional remark. These remarks included nine categories of Body Functions (b) and four categories of Activities and Participation (d).

The agreement between the two raters in using the qualifier codes 0–4 indicating the difficulty level of each problem was analysed using Cohen's Kappa and ICC (Fleiss, 1981; Shrout & Fleiss, 1979). Table 10 presents the agreement on the qualifiers in each of the four ICF components. The agreement was highest in the component of Body Structures (s) and lowest in Activities and Participation (d).

Table 10. Agreement between the two raters in the ICF components (qualifier codes 0-4) (N = 55)

ICF component	Kappa	ICC (3,k)
Body Functions (b)	.57	.91
Body Structures (s)	.71	.96
Activities and Participation (d)	.37	.77
Environment (e)	.52	.84

In order to analyse the agreement in more detail, the differences between the raters in the values of the qualifiers were calculated patient by patient in the 30 categories that reached the prevalence of 30% or above. In the components of Body Functions (b), Body Structures (s), and Environment (e) more than 50% of the ratings of the two raters were identical, and in 86% of the categories the differences in the ratings were at most 1 point.

4.3 Health-related quality of life after TBI (Study III)

This sample of 795 persons with TBI consists of participants from six language areas. As presented earlier in Table 7, almost three-quarters of the participants were middle-aged males. Almost half of the participants were partnered, and the most common educational attainment was holding a trade qualification (vocational school). Almost two-thirds were living independently, and just under half were working. The mean time since TBI at interview was five years (the range was 3-214 months). The most common

lesion types were frontal and diffuse, and the highest proportion of cases were in PTA for a month or more post-TBI. On the GCS, 58% were classified as severe brain injury.

The QOLIBRI total scores are presented in Figure 6 showing that the most commonly obtained scores fell within the bandwith 71 – 75% of maximum satisfaction. The scales with the highest scores were Emotions, Physical Problems, and Daily Life and Autonomy.
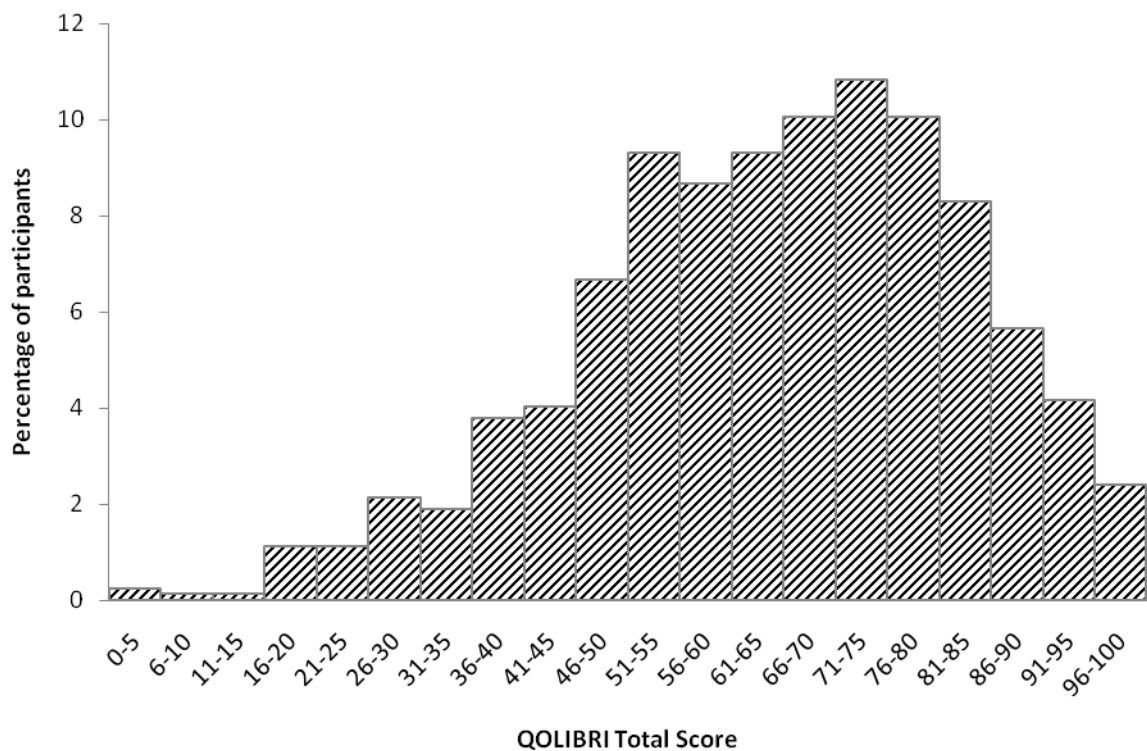
Figure 6: QOLIBRI total score: distribution of mean scores on 0 to100 scale.

Most participants reported they were in good health. In spite of that, 70.6% of the participants reported ≥3 health complaints. Self-reported health complaints involving >30% of participants were lack of energy (43.3%), lack of physical strength (37.3%), sleep disorders (37.2%), vision problems (35.8%), headache or migraine (35.7%), nervousness (36.1%), back pain (33.8%), restricted movements (32.3%), and depression (30.6%). The most commonly reported levels of functioning on the GOSE were lower moderate disability and upper moderate disability. The majority of the participants (53.7%) needed a carer for at least one activity of daily living. On the Hospital Anxiety

and Depression Scale 19.2% of the participants reported moderate or severe anxiety symptoms, and 16.7% reported depressive symptoms.

QOLIBRI scores varied systematically by age on four scales as well as on the QOLIBRI total score. The highest scores were obtained by the youngest participants aged 17 – 34, and the lowest by those aged 35 – 54. The only scale which varied by gender was the Physical Problems scale in which males obtained scores higher than females.

The closest association between key socio-demographic variables and the QOLIBRI scores were found in labour-force participation and living arrangements (Table 11). People who were working obtained higher scores on all QOLIBRI scales than people not working. People living independently obtained higher scores across all QOLIBRI scales than people living at home with support or in sheltered accommodation. There were also significant differences by partnership status on Social and Physical Problems scales. On the Social scale, those with a partner obtained significantly higher QOLIBRI scores compared to those who had never been partnered (Tukey HSD, p <0.01) or were post-partnered (p<0.01). However, on Physical Problems scale, those who were single obtained scores significantly higher than those with a partner (p=0.04). Finally, the QOLIBRI Cognition, Daily Life and Autonomy, and Physical Problems scales were sensitive to educational attainment. Post-hoc Tukey HSD analysis showed significantly lower QOLIBRI scores in the group that had achieved primary school level education only.

Table 11. QOLIBRI scale scores by demographics and self-reported health status

		N	Cognition		Self		Daily life and autonomy		Social relationships		Emotions		Physical problems		QOLIBRI total	
			Mean	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*
Education attainment	Primary	42	52.00	23.23	50.37	24.52	54.46	22.48	62.60	23.99	67.38	25.76	58.04	23.08	56.79	19.29
	High/Secondary	185	60.40	22.40	62.01	21.20	66.83	21.94	64.30	23.00	69.88	25.02	69.06	23.41	64.92	18.04
	Trade certificate	218	62.06	21.92	60.76	21.76	66.53	22.13	64.58	21.87	72.49	24.21	67.82	24.11	65.21	18.28
	College	173	61.42	21.61	59.83	22.72	64.88	24.02	64.09	23.38	72.91	25.37	67.43	22.95	64.62	18.72
	University degree	88	66.31	20.84	60.58	23.17	72.94	21.32	64.84	22.49	77.12	22.32	74.57	21.98	68.74	17.61
			$F=2.49, p=0.03$		$F=1.78, p=0.11$		$F=4.20, p<0.01$		$F=0.05, p=0.99$		$F=1.7, p=0.13$		$F=3.06, p<0.01$		$F=2.43, p<0.03$	
Partner status	Single	302	62.97	20.64	61.78	21.11	67.01	21.30	61.54	21.44	72.68	24.18	71.25	21.60	65.65	16.98
	Partnered	351	60.34	23.23	59.84	22.61	66.66	23.99	67.97	22.50	72.64	24.19	66.43	24.92	65.15	19.21
	Post-partnered	90	60.26	21.62	56.61	23.22	63.40	22.74	59.88	24.57	68.22	27.09	66.58	23.20	62.03	18.91
			$F=1.13, p=0.32$		$F=1.85, p=0.16$		$F=1.02, p=0.36$		$F=8.78, p<0.01$		$F=0.94, p=0.39$		$F=3.06, p=0.05$		$F=1.33, p=0.26$	
Living arrangements	Independent	420	64.41	21.36	62.62	21.34	71.95	20.60	66.53	22.18	74.95	23.76	72.26	22.14	68.32	17.39
	Supported	245	55.21	22.19	55.89	22.54	56.78	23.48	60.76	23.26	68.51	24.60	61.27	24.10	59.07	18.51
	Sheltered	56	62.44	20.54	58.50	23.47	62.84	20.46	61.98	22.52	65.27	26.20	69.73	23.11	63.06	17.67
			$F=14.27, p<0.01$		$F=7.51, p<0.01$		$F=38.74, p<0.01$		$F=5.24, p<0.01$		$F=8.82, p<0.01$		$F=17.40, p<0.01$		$F=21.35, p<0.01$	
Labour-force participation	Working	308	65.68	21.05	66.04	19.96	73.93	21.42	69.47	20.45	77.59	22.36	74.57	21.99	70.66	17.17
	Unable to work	71	55.48	25.65	51.83	26.14	54.84	24.41	55.48	24.97	64.64	25.58	56.41	25.69	56.05	20.47
	Unemployed	105	57.01	20.55	56.73	21.22	61.05	19.94	60.17	23.10	66.64	26.86	65.44	22.13	60.67	17.02
	Out of workforce	215	58.94	21.58	56.29	22.51	62.30	22.24	62.01	23.86	68.94	25.00	65.28	23.34	61.78	17.90
			$F=8.30, p<0.01$		$F=14.04, p<0.01$		$F=25.16, p<0.01$		$F=10.35, p<0.01$		$F=10.54, p<0.01$		$F=16.00, p<0.01$		$F=21.43, p<0.01$	
Self-reported health status	Excellent	55	73.83	21.17	77.13	21.23	80.11	20.13	74.09	20.79	77.48	24.83	81.95	19.23	77.07	18.07
	Very good	184	70.97	19.61	69.61	19.80	78.62	18.64	71.22	21.59	82.24	18.15	80.68	16.76	74.97	15.16
	Good	337	60.86	19.37	60.80	17.37	66.44	18.24	63.58	20.94	71.55	24.41	69.42	20.62	64.95	14.44
	Fair	175	52.53	19.72	48.07	20.85	53.44	21.91	56.53	20.74	63.16	24.10	52.48	23.37	53.96	15.69
	Poor	29	31.55	21.96	23.40	22.52	33.04	26.35	35.57	25.32	40.18	26.40	37.11	19.45	32.92	16.07
			$F=41.15, p<0.01$		$F=63.67, p<0.01$		$F=61.80, p<0.01$		$F=25.54, p<0.01$		$F=29.06, p<0.01$		$F=62.52, p<0.01$		$F=81.35, p<0.01$	

Statistics: ANOVA$_{adj.}$

There were statistically significant differences between the GOSE functional outcome groups on all QOLIBRI scales. However, across the GOSE, there were different patterns among the QOLIBRI scales, suggesting that different scales are differentially sensitive to different levels of functioning. In the groups with severe disability the Emotional scale had the highest score and the problems lay within the Self and the Daily Life and Autonomy, whereas in the groups with good recovery the Physical Problems were less of a concern but the Social Relationships scale showed lower scores.

All the QOLIBRI scales were statistically significantly sensitive to participants' mental health status. Cognition and Physical Problems were more sensitive to anxiety than to depression, but the other QOLIBRI scales were equally sensitive to the two mental health states. Further details of relationships between the QOLIBRI and the GOSE and mental health are given in article III.

A feature of all the tables and figures is that the standard deviations were typically about 20% of the QOLIBRI scale range. This implies that within the known groups analysed, or within the bandwidths described, there was considerable variation in QOLIBRI scores. The implication is that within these classifications some cases obtained scores on the QOLIBRI indicating a higher HRQoL than might be expected for their level of disability and others a lower HRQoL than might be expected for their level of disability. Figure 7 illustrates this by presenting two cases, one with a severe disability (GOSE 4) and high scores on the QOLIBRI, the other with upper moderate disability (GOSE 6) and low scores on the QOLIBRI.
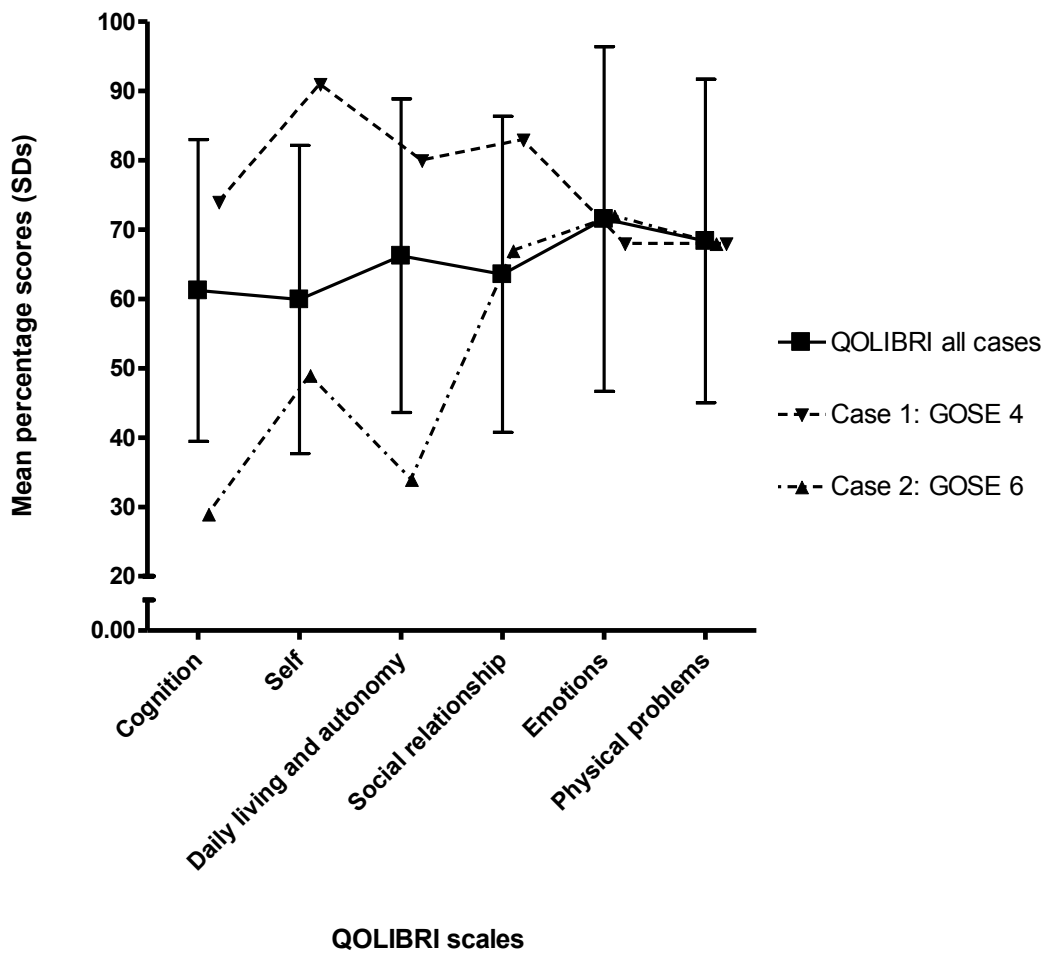
Figure 7. Six QOLIBRI subscales mean scores and standard deviations in two illustrative cases (Case 1: GOSE 4 and high QoL: case 2: GOSE 6 and lower QoL).

4.4 Subjective and objective assessments of outcome after TBI (Study IV)

The results of linking the 37 QOLIBRI items to the ICF categories are presented in Appendix 1 of study IV. As one item in a questionnaire can contain one or more concepts, it can be linked to one or more ICF categories. In this study 56 functional concepts were identified in the QOLIBRI items. These concepts were linked to 42 different ICF categories. Four of the concepts could not be linked to any specific ICF category.

The concepts identified in the QOLIBRI covered 12 out of the total of 29 main ICF chapters (Figure 8). The ICF component of Activities and Participation (d) was most completely covered. Categories of Body Functions (b) were best represented in chapter b1 „Mental functions'. Eight out of the nine one-level chapters of Activities and Participation were represented in the QOLIBRI. The most frequent categories of Activities and Participation were found in chapter d7 „Interpersonal interactions and relations'.

The items of the GOSE are presented in a descriptive manner and include examples to help in the assessment (Appendix 2 in study IV). Therefore, each item contains more than one functional concept and has to be linked to more than one ICF category A total of 102 functional concepts were identified and linked to 57 different ICF categories, 18 concepts could not be linked to any ICF categories. On the one-level classification the concepts identified in the GOSE covered 14 out of the total of 29 main ICF chapters (Figure 8). The ICF component of Activities and Participation (d) was most completely covered. Eight out of the nine one-level chapters of Activities and Participation were represented in the GOSE. Categories of Body Functions (b) were best represented in chapter b1 „Mental functions'. The most frequent categories of Activities and Participation were found in chapter d7 „Interpersonal interactions and relations'. Three out of the five chapters of Environment (e) were covered.
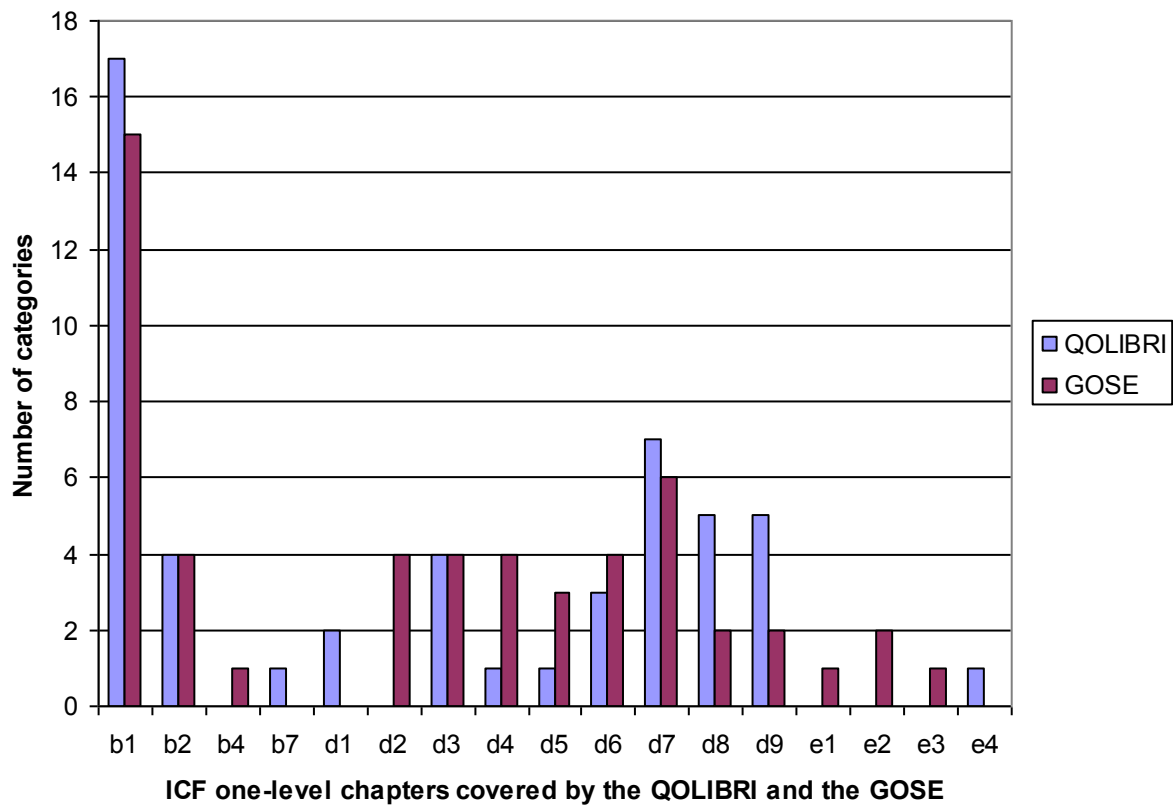
b1 = Mental functions, b2 = Sensory functions and pain, b4 = Functions of the cardiovascular, haematological, immunological and respiratory systems, b7 = Neuromusculoskeletal and movement-related functions, d1 = Learning and applying knowledge, d2 = General tasks and demands, d3 = Communication, d4 = Mobility, d5 = Self-care, d6 = Domestic life, d7 = Interpersonal interactions and relations, d8 = Major life areas, d9 = Community, social and civic life, e1 = Products and tehnology, e2 = Natural environment and human-made changes to environment, e3 = Support and relationships, e4 = Attitudes.

Figure 8. QOLIBRI and GOSE items linked to the ICF at one-level classification.

The Brief ICF Core Set for TBI consists of 23 two-level categories and these represent the minimum considered necessary to cover the typical spectrum of problems in functioning in TBI patients. Twelve of them are represented in the QOLIBRI and 17 in the GOSE. Together the QOLIBRI and the GOSE cover 18 (78%) of the categories of the Brief ICF Core Set for TBI (Table 12). The categories of the component of Body Functions (b) are completely covered, in the component of Activities and Participation (d) only one category is missing (d450 walking). Although the component of Environment (e) is not completely covered by all the categories on the second-level classification, it is covered on the one-level classification, with the exception that

chapter 5, Services, Systems and Policies. In the component of Body Structures (s) the only category of the Brief Core Set (s110 structure of brain) in not specifically mentioned in the items of these questionnaires.

Table 12. The QOLIBRI and GOSE items linked to the Brief ICF Core Set for TBI

Brief ICF Core Set for TBI		QOLIBRI	GOSE
b164	Higher-level cognitive functions	+	+
b152	Emotional functions	+	+
b130	Energy and drive functions	+	+
b760	Control of voluntary movement functions	+	-
b144	Memory functions	+	+
b280	Sensation of pain	+	+
b140	Attention functions	+	+
b110	Consciousness functions	-	+
s110	Structure of brain	-	-
d230	Carrying out daily routine	-	+
d350	Conversation	+	-
d450	Walking	-	-
d720	Complex interpersonal interactions	-	+
d845	Acquiring, keeping and terminating a job	+	+
d5	Self care	+	+
d920	Recreation and leisure	+	+
d760	Family relationships	+	+
e310	Immediate family	-	(+) e3
e580	Health services, systems and policies	-	-
e115	Products and technology for personal use in daily living	-	(+) e1
e320	Friends	-	(+) e3
e570	Social security services, systems and policies	-	-
e120	Products and technology for personal indoor/outdoor mobility & transportation	-	(+) e1

Linking the QOLIBRI items to the ICF categories makes it possible to compare the patients' own satisfaction with their functioning to the professionals' assessment of the same domains. The detailed profile from the QOLIBRI (the patients' assessment of their satisfaction) is shown in Figure 9, and from the ICF (the professionals' assessment of the extent of disability) in Figure 10. The highest values in Figure 10 represent the professionals' assessment of the highest disability on the ICF categories, and the highest values in Figure 9 represent the poorest HRQoL on the QOLIBRI.
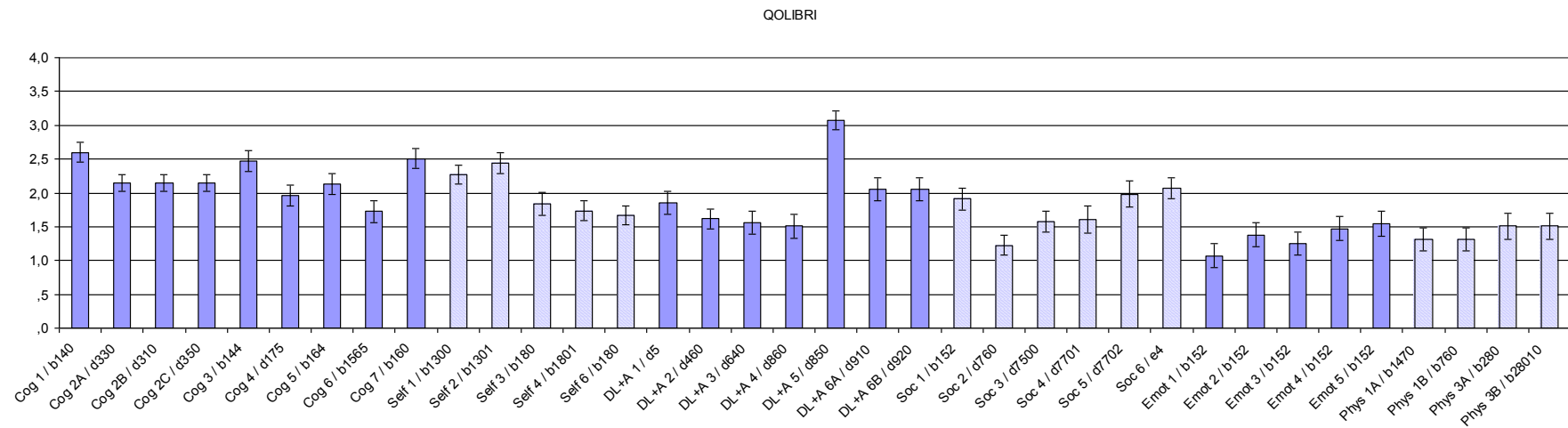
QOLIBRI

QOLIBRI scales: Cog = Cognition, Self = Self, DL+A = Daily Life and Autonomy, Soc = Social, Emot = Emotional, Phys = Physical Problems
0 = very satisfied
1 = quite satisfied
2 = moderately satisfied
3 = slightly satisfied
4 = not at all satisfied

ICF components: b = Body Functions, d = Activities and Participation, e = Environment

Figure 9. Means of the QOLIBRI items linked with the ICF categories (error bars represent standard errors). The bars are shaded to indicate items belonging to each of the six scales.
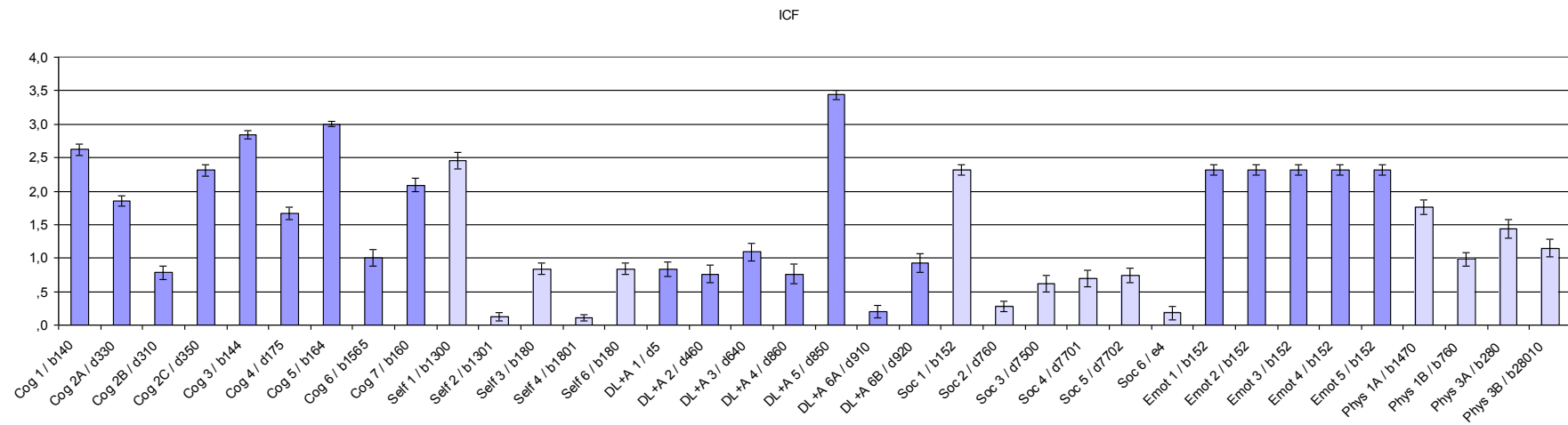
ICF

QOLIBRI scales: Cog = Cognition, Self = Self, DL+A = Daily Life and Autonomy, Soc = Social, Emot = Emotional, Phys = Physical Problems

ICF components: b = Body Functions, d = Activities and Participation, e = Environment
0 = No impairment/difficulty/barrier/facilitator
1 = mild impairment/difficulty/barrier/facilitator
2 = moderate impairment/difficulty/barrier/facilitator
3 = severe impairment/difficulty/barrier/facilitator
4 = complete impairment/difficulty/barrier/facilitator

Figure 10. Means of the ICF categories linked with the QOLIBRI items (error bars represent standard errors). The bars for the QOLIBRI are shaded to indicate items belonging to each of the six scales.

Overall, the closest similarity between the QOLIBRI profiles from the patients' and the professionals' point of view was found on the Physical Problems scale and the Cognition scale. However, on the Cognition scale, a discrepancy was found in the items considering communication (Cog 2B/d310) and visuospatial perception (Cog 6/b1565) in which the patients reported poorer satisfaction than would have been expected based on the professionals' assessment. On the contrary, in the field of higher level cognitive functions (Cog 5/b164) the patients reported higher satisfaction than would have been expected. On the Daily Life and Autonomy scale, participation in work (d850) corresponded closely in the assessments: none of the patients were working and the patients expressed low satisfaction on this domain (represented by the prominent peaks in the middle of Figures 9 and 10). Ability to carry out domestic activities (d640) also corresponded in the assessments. On the Self scale the professionals' evaluation that there was severe disability in the level of energy (b1300) was reflected in the patients' low satisfaction with that function. On the Social scale, the patients reported poor satisfaction with their ability to feel affection towards others (Soc 1/b152) which corresponded with the professionals' assessment.

There are some domains in which the professionals' evaluation of disability is relatively more prominent than the patients' report of low HRQoL. This group of domains include all the QOLIBRI items on the Emotions scale. The patients appear less bothered by emotional problems than would be expected based on the professionals' assessment of the severity of the impairments in emotional functions (b152).

There are a number of ICF domains in which the patients are relatively less satisfied than would be expected based on the documentation of the professionals which report mild or no disabilities. These domains belong to the QOLIBRI scales of Self, Daily Life and Autonomy, Social Relationships, and Cognition. Ten out of these 16 domains belong to the ICF component Activities and Participation (d). The discrepancy is most prominent in the domain of interpersonal interactions and relationships (d7, e.g. relationships with family, friends, partner, sexual relationships), followed by participation in social and leisure activities (d9). On the QOLIBRI Self scale the professionals rarely recorded problems regarding the patients' motivation, body image, or experience of self („The way you look', „The way you perceive yourself', „Your self-esteem') although the patients find these have a strong effect on satisfaction.

5 Discussion

This study examines outcome after TBI in the frame of reference of the WHO Family of International Classifications. As a health status, TBI is first defined according to the ICD-10. The epidemiology and short-term outcome of TBI is described based on long-term data derived from the Finnish national registers. On the individual level, functioning and disability is then analyzed according to the information given by the ICF, based on the documentation of the professionals. Health-related quality of life is identified as a patient-reported outcome. Outcome is examined both from the "objective" and "subjective" points of view aiming at getting an overview of the patient's individual perspective.

5.1 Incidence of TBI in Finland

The incidence of hospitalised TBI as the primary diagnosis in patients who did not have a previous TBI in their medical history was on the average 101/100 000, and 59% of the patients were males. This number is smaller than in earlier studies from Europe (Tagliaferri et al., 2006) but higher than in those from the US (Langlois et al., 2006). The case definition is variable in different studies. In this study only first-time TBI as the primary diagnosis was taken into consideration because the focus was on the number of patients sustaining a TBI and not on the number of TBIs per se. According to earlier studies, only a proportion of TBI patients are admitted to hospital (Langlois et al., 2006; Sosin et al., 1996; Tagliaferri et al., 2006) and based on the estimates provided by the these previous studies, the annual total number of new patients suffering from TBI in Finland might be as high as 21 000 – 31 000. Based on the estimates of Tagliaferri et al. (2006) and Langlois et al. (2006) the prevalence of TBI in Finland is about 101 000 – 105 000.

The in-hospital case fatality rate was 5.1 per 100 hospitalised patients and the average mortality rate was 18.3/100 000. The mortality rate decreased during the follow-up period in males but not in females. The average death rate for TBI in other Nordic countries is 9.5–11.5/100 000 (Sundstom et al., 2007) which is considerably

lower than in this study. However, the results of the present study are similar to results from the US. The differences in the death rates between Finland and the other Nordic countries may reflect the actual situation but may also reflect the accuracy in diagnosis. As Sundstrom et al. (2007) state, autopsies are performed in about 90% of all accident-related fatalities in Finland while the percentage of autopsies in Sweden is 73% and in Denmark and Norway only 26% and 32%, respectively.

The most common external cause of the injury was a fall in all age groups, and especially in the oldest and youngest age groups. The most common type was falling from standing height (1 m) or less. These findings are in concordance with earlier studies (Coronado et al., 2005; Fletcher et al., 2007; Kannus et al., 1999a, 1999b; Thompson et al., 2006).

As in the other Nordic countries (Kleiven et al., 2003; Engberg & Teasdale, 2001) concussions make up the single largest diagnostic group. In Sveden (Kleiven et al., 2003) concussions made up a diagnostic cluster of 70% of the injuries while in the present study in Finland the proportion of concussions was 53% in 2005. The proportion of concussions tend to decline and the proportion of focal and diffuse injuries show a relative increase in Sweden, Denmark and Finland.

An important finding in this study was the increase in the incidence (+59.4%) of patients aged 70 years or older, and the relationship between age and short-term outcome. The oldest patients required a 6.8-times longer stay in the hospital than the youngest. One reason for this increase in incidence with age may be that presently elderly people, even in poor health and with difficulties in mobility, live longer, and take active part in hobbies with increased risk of falling. In earlier studies the high number of comorbid conditions, effects of alcohol consumption and medication have been presented as possible explanations for the high risk of TBI in the elderly (Coronado et al., 2005).

The findings of this study indicate that TBI is a key public health problem in all age groups. The final conclusion for the future is that the results of this study should be taken into consideration when planning the procedures of prevention, increasing the awareness of TBI, as well as improving the acute care, rehabilitation and long-term care facilities.

5.2 Documented problems in the functioning of post-acute TBI-patients

This cross-sectional study applied the ICF checklist in order to identify the most common problems documented in a sample of TBI patients in a rehabilitation setting. The agreement between two raters with different professional backgrounds (neuropsychology and physiotherapy) in using the checklist was also studied. This study design is unique: until now, it is the only published study using the ICF as a classifier of the state of functioning in TBI patients (Scarponi et al., 2009).

Problems related to 100 out of the 123 categories of the checklist were identified in the medical documents reflecting the high diversity of the sequelae of TBI. Of these 100 categories, 30 were identified by both raters in the documents of at least 30% of the patients and were thus considered most relevant for this sample of patients with TBI. The distribution of the components was the same as in earlier studies with stroke patients (Ewert et al., 2004) and with non-selected neurological patients in early post-acute rehabilitation (Stier-Jarmer et al., 2005); the most common problems were found in the components of Body Functions (b) and Activities and Participation (d). This reflects the broad manifestation of injuries in body functions in neurological patients as well as the focus on Activities and Participation in rehabilitation settings.

According to our results published in 2007, neither the ICF checklist nor the ICF Core Sets which existed at that time for neurological patients (Ewert et al., 2005; Grill et al., 2005; Stier-Jarmer et al., 2005;) adequately characterized patients with TBI in the later stages of recovery. Our conclusion was that developing an ICF Core Set specially designed for patients with TBI might prove useful. Three years after the publication of our study, the ICF Core Sets for TBI were published in 2010 (ICF Research branch, 2010), which makes it possible now to compare our initial results with the newly developed Core Sets. It turns out that the most common problems identified in our study were also considered the most relevant in the development of ICF Core Sets for TBI: each of the 30 most common categories of our study are now included also in the list of the 143 most important categories of the Comprehensive ICF Core Set for TBI (ICF Research branch, 2010).

The total of 23 categories in the Brief ICF Core Set includes ten categories which are not identified as the most common in our study: control of voluntary movement functions (b760), consciousness (b110), carrying out daily routine (d230), walking (d450), acquiring, keeping and terminating a job (d845) (instead, our study included d850 remunerative employment), self care (d5), recreation and leisure (d920), family relationships (d760), friends (e320), as well as products and technology for personal indoor and outdoor mobility and transportation (e120). The first two of these missing catogories (b760 and d230) were not included in the ICF checklist and were therefore not systematically investigated in our study. Impairments of consciousness, restrictions in self-care, walking, and the need for assistive products for mobility were documented relatively rarely in our sample, as the patients with the poorest outcome were excluded. The remaining three categories; recreation and leisure, family relationships, and support of friends must be given closer examination. They were included in the ICF Core Sets but not identified as the most commonly documented in our study by the multidisciplinary rehabilitation team. This may reflect an important shortcoming in the documentation and in clinical practice, and should therefore be given closer examination in the future. As Engberg and Teasdale (2004) state: in the long run, an important factor influencing survival among cerebral lesion patients seems to be whether relations with family and friends can be maintained at the pre-injury level.

In our study, the medical documents of the patients frequently contained information related to ICF categories relevant to TBI patients but missing from the ICF checklist. Fourteen such categories were found in our study and 12 of them are included also in the present Comprehensive ICF Core Set for TBI.

The agreement between the two raters was relatively high. In 86% of categories the difference in the values of the qualifiers indicating the severity of the problem (range 0 – 4) was at most 1 point. The highest agreement between the raters was found in components that were either the most objective, in which the criteria for measuring was clear, or in which the tradition in documentation was systematic, such as remunerative employment (d850) or higher-level cognitive functions (b164). The lowest agreement was found in components that either required expert professional knowledge (e.g. b152: emotional functions), or were not clearly defined, documented, operationalized, or measured (e.g. d220: undertaking multiple tasks). Assessing these components required

interpretation and "reading between the lines". Exact use of the qualifiers would require more specific measures and more detailed documentation of the patient's management in everyday situations.

The use of the ICF checklist in this study was based on the common clinical practice and written medical documents of one experienced rehabilitation centre and no specific assessment tools were developed for the purposes of the study. One aim of this study was to go beyond specific instruments by using data that are provided by present clinical practice. As a consequence, we concluded that it would be interesting to examine the applicability of ICF classification to long-term outcome during the rehabilitation process and to quality of life. This was carried out later in the Study IV.

5.3 The QOLIBRI in clinical practice

The QOLIBRI is the first disease-specific scale for assessing HRQoL in TBI patients, published in 2010 after an extensive validation process (von Steinbüchel et al., 2010a, 2010b). According to the present study, the QOLIBRI captures life satisfaction rather than health function, and is sensitive to disability and mental health, demographic and socioeconomic factors. Importantly, it captures a different perspective on outcome than is provided by the GOSE assessments performed by professionals.

The participants reported highest level of satisfaction in the Emotions, Physical Problems and Daily Life and Autonomy scales. Lower levels of satisfaction were reported on the Social Relationships, Cognition and Self scales. These domains with low level of satisfaction are the same that were identified in Study II, representing topics that were not systematically documented by the professionals. Study IV identified domains in which the patients are relatively less satisfied than would be expected based on the documentation of the professionals. Again, the discrepancy between the professionals and the patients was most prominent in the domain of interpersonal interactions and relationships, participation in social and leisure activities, as well as domains related to self (e.g. motivation, self-esteem).

The highest scores were obtained by the youngest participants aged 17-34. Participants living independently without the help of family members or other

caregivers were significantly more satisfied than participants needing help. People who were working obtained higher scores on all QOLIBRI scales than people not working. Those results were expected and coherent with the literature.

The QOLIBRI is not only a measure for scientific studies but also a tool in clinical work, especially within the neuropsychotherapeutic approach. The items not only cover disabilities but also the issues with which the patients are satisfied in their lives. This helps the patients to focus not only to weaknesses, but also to the strengths and to his/her whole life situation. For the therapist, the QOLIBRI provides understanding of the patient's feelings. As Prigatano (1999, 2000) states, the process of neuropsychological rehabilitation begins with understanding what the patients experience. Successful neuropsychological rehabilitation is built on understanding the symptoms and helping the patient and family cope with them. Asking the patients for their subjective opinion is crucial to prioritizing therapeutic goals, taking into account their personal needs, values and hopes and improving goal attainment. It also facilitates the therapeutic alliance, thus helping the participant to build a new life via a new ego-identity, in his/her own cultural, social and environmental context (Tomberg et al., 2005; Zitnay et al., 2008). In addition, QOLIBRI data allow the assessment of individual progress or deterioration – through the patients' subjective opinion. This opinion is a component in assessing and comparing programmes of service delivery and their cost-effectiveness.

The observed variability in QOLIBRI ratings within and between the GOSE categories is of importance and of great relevance as the implication is that different perspectives on outcome are captured by the two approaches, as illustrated by two cases. The discordance between QOLIBRI and GOSE ratings raise the fundamental question of the most relevant outcome measure: functional outcome assessed by professionals or the quality of life perceived by the patient. This question is examined in study IV.

5.4 Functioning and disability compared to health-related quality of life

Based on the findings of our earlier studies, we wanted to compare subjective and objective assessments of outcome after TBI using the ICF classification. The GOSE was used as an objective measure of functional outcome and the QOLIBRI as a measure of subjective health-related quality of life (HRQoL). The QOLIBRI was linked to 42 and the GOSE to 57 ICF categories. Together these outcome measures covered 78% of the most relevant ICF two-level categories of the Brief ICF Core Set for TBI. At the less detailed one-level classification all but one of the main chapters were covered. Our conclusion is that the results of the linking procedure showed that both the QOLIBRI and the GOSE as short outcome scales can capture a wide range of problems encountered after TBI. The use of both of these measures can produce a comprehensive overview of TBI patients' functioning and HRQoL.

The results showed that the closest agreement between the assessments of the professionals and the patients themselves was found in the QOLIBRI Physical Problems scale and the Cognition scale. This indicates that professionals see these as important areas of functioning while the patients regard them as significant for HRQoL.

On the Emotions scale, the participants appeared less bothered than would have been expected based on the professionals' assessment. As has been shown with other instruments (Cieza & Stucki, 2005), category b152 „Emotional functions' was presented in the QOLIBRI and in GOSE more than once and in more detail than is made possible by the ICF, i.e. the ICF does not differentiate this category sufficiently. Cieza and Stucki (2005) have proposed a more fine-grained definition of category b152 in a future version of the ICF that covers specific features of emotional functions, such as sadness, happiness, anxiety, and anger. Based on the results of our study, this specification might prove to be a valuable refinement.

Finally, the ICF domains in which the participants are relatively less satisfied than would be expected based on the documentation of the professionals, belong to the QOLIBRI scales of Self, Daily Life and Autonomy, Social Relationships and Cognition. These areas in which the participants report low satisfaction, but which are not identified by a comprehensive clinical examination, are important to note from the

clinical point of view. The results identified domains on which the professionals may not focus sufficient attention. In the daily clinical practice of neurorehabilitation, the domains related to interpersonal relationships, social and leisure activities, self, and attitudes tend to be less actively assessed and documented than impairments in mental or physical functions. However, these domains are important to the persons with TBI and, therefore should have greater emphasis in clinical practice and documentation.

Recent studies (Gradinger et al., 2011; Scarponi et al., 2009) have stated that the ICF is a flexible instrument which is useful in determining relevant aspects of functioning and contextual factors from the patient perspective, in monitoring outcome and in defining the goals of rehabilitation. They also state that it is desirable to define and validate ICF related assessment tools that can be easily used in capturing the full biopsychosocial aspects of TBI. The results of our study show that the QOLIBRI and the GOSE together cover relevant domains of TBI patients' functioning defined by the ICF frame of reference. The QOLIBRI provides the patients' subjective view and feelings while the GOSE identifies the objective elements of functioning relevant to persons with TBI. These findings have important implications related to rehabilitation.

5.5 Evaluation of the study

There are some limitations to the studies that need to be taken into consideration. The main limitation of the study I is the difficulty in comparing the epidemiological results with the earlier studies because of the variability in data coding, definitions, and collection procedures. This is a common problem in TBI epidemiology. Our study covers only patients treated in a hospital and therefore a large number of patients treated in emergency rooms only or in e.g. occupational health services are missing. According to Sosin et al. (1996) only 25% of all TBI patients are admitted to the hospital. In addition to this, earlier studies have shown that all diagnoses are not documented in the registers, and all injuries are not diagnosed in the first place. This seems to be the situation especially when the patient has multiple injuries or spinal injuries (Tolonen et al., 2007). Engberg & Teasdale (2001) showed in a subsample of 200 hospital records that diagnoses were not confirmed in about 12% of cases. Engberg (1995) also showed

earlier that up to 1/3 of patients who had a posttraumatic amnesia exceeding a week were coded as concussions or cranial fractures, thus representing an under-recording of cerebral contusions. Laalo et al. (2009) have shown a marked variation between readers in the detection of brain contusion findings on acute brain CT leading to missing diagnoses. During the 15 year follow-up period two versions of the ICD classifications were used internationally which may have had some confounding effects. The proportion of missing data on external causes of injury was high during 1991-2000 (23-30%). The large number of patients aged 70 years and over may reflect the tendency of the elderly patients to be admitted to hospitals with milder TBIs than the younger patients because in their case the need for help may already exist. This might exaggerate the proportion of the falls as a cause of TBI as they are especially prevalent in elderly people compared to traffic accidents in younger patients. In spite of all these problems, register studies are regarded as valuable tools regarding the development with time (Engberg & Teasdale, 2001).

The main strength of study I is that it is based on the whole population of Finland, and covers a period of 15 years. Recently the Working Group on Demographics and Clinical Assessment (Maas et al., 2010) has developed recommendations on the coding of clinical and demographic variables for TBI studies applicable across the broad spectrum of TBI. These recommendations will hopefully in the future lead to epidemiological data which are more comparable than at present.

The results of studies II and IV can not be generalized to the whole population of persons with post-acute TBI since they were carried out in only one rehabilitation centre which provided inpatient services to the study group. Patients in rehabilitation facilities usually represent a subgroup of moderate to severe TBI patients who have been considered to benefit from rehabilitation. The mildest cases are usually not referred to inpatient rehabilitation centres. There is no standard system for a person to be referred to the rehabilitation centre. The professionals in the local health care units, university hospitals, as well as the insurance systems refer patients to rehabilitation based on their own policies and practices. However, these studies deliberately focused on one centre in order to obtain as systematic an understanding as possible of the functioning of the patients based on a documentation tradition used by an experienced neurorehabilitation centre. Had data from a less experienced centre been included, the initial assessments

might have been less accurate. The other limitation in generalizing the results to the whole post-acute TBI population is that the patients with the poorest functional outcome were excluded. The aim was to focus on a group of patients who themselves were able to communicate reasonably well and to respond to complex methods of assessments in cognitive functioning and quality of life issues.

A major limitation of the study III is the patient recruitment protocol. The primary aim of this international convenience sample was to investigate psychometric properties and to validate the QOLIBRI scale across a wide range of settings. We deliberately chose to recruit participants from different settings and at variable times after injury. Consequently the sample was „scale-oriented', rather than „patient-focused'. The study was not designed to assess specific cohorts or at fixed time periods after injury. Thus, interpretation of clinical findings and comparisons between groups should be done with caution. Almost three-quarters of the participants were middle-aged males and most of the injuries were classified as severe according to the PTA and GCS. It is a well-known fact that TBI is more common in males than females. However, the emphasis on middle-age and severe injuries has to been borne in mind when interpreting the results. Further investigation is needed to assess the applicability of the QOLIBRI with milder injuries and younger persons with TBI.

A major concern of Study IV is the time interval between the collection of different data: the assessment of the participants' functioning was carried out on average 1.3 years earlier than filling out the QOLIBRI. The results of this study would without doubt have been stronger if the documentation of functioning and the HRQoL had been accomplished at the same time. Associations between functional disability and HRQoL may tend to dissolve over time and other variables, such as psychological and social components may become more important for HRQoL at a later stage. This may have changed some of the results. However, the average time from the injury to the functional assessment was 2.7 years and thus most of the participants had already reached a neurological plateau by that time. Although most of the persons with TBI had reached the plateau, 29% of the participants were assessed less than one year after injury and their global functioning might have improved over a longer time perspective, including ability to work and social functioning.

There are some limitations and strengths of the linking procedure, as well. The QOLIBRI was linked to the ICF by two raters from one rehabilitation centre, representing two different professions (neuropsychology and physiotherapy). The GOSE was linked to the ICF by two professionals from different countries and different settings (a rehabilitation centre in Finland and a university psychology department in Scotland), representing one professional background (neuropsychology). The third person acting as the specialist making the final decisions was a psychologist in both cases, one of the most experienced professionals in the ICF from Germany and Finland.

Finally, the comparison between the QOLIBRI items and the ICF is based simply on inspection of profiles. Inspection of mean values does not distinguish between domains in which many people report a modest reduction in HRQoL and those in which a few people reported very substantial reduction. Such a detailed analysis was beyond the scope of this study, but might yield further insight into relationships in the future.

5.6 Conclusions

The answers to the specific questions presented are:

1. What is the epidemiology and short-term outcome of TBI in Finland in 1991–2005?

The register-based incidence of hospitalised TBI in Finland was on the average 101/100000, and 59% of the patients were males. The most common external cause of the injury was a fall in all age groups, and especially in the oldest and youngest age groups. The mean length of stay in hospital was 6.6.days for males and 7.8 days for females. The majority of the patients (54%) needed at least occasional care after discharge from the hospital. The in-hospital case fatality rate was 5.1 per 100 hospitalised patients and the average mortality rate was 18.3/100 000, referring to an annual average of 275 deaths before admission to a hospital and 667 deaths during the stay in hospital. Length of stay in hospital, need for care after discharge, and the risk of death was highest among the oldest age groups.

2. What are the most common problems documented in the functioning of post-acute TBI patients in rehabilitation settings?

Problems related to 100 out of the 123 categories of the ICF checklist were identified in the medical documents of 55 persons with TBI during their first rehabilitation period. The most common problems were found in the components of Body Functions (b) and Activities and Participation (d). Over 80% of the patients had documented problems in memory, higher level cognitive functions, attention, emotional functions, energy and drive functions, structure of the brain, remunerative employment, conversation, and speaking. The agreement between the two raters was high.

3. Measured by the QOLIBRI, what are the HRQoL associations with the socio-demographic, mental health, and functional outcome variables?

The participants reported highest level of satisfaction in the QOLIBRI's Emotions, Physical Problems and Daily Life and Autonomy scales. The lowest scores were obtained by the subjects aged 35-54 and by subjects with primary school level education. Males scored higher than females on the Physical Problems scale, no other gender related associations were found. All the QOLIBRI scales were statistically significantly sensitive to mental health states, i.e. anxiety and depression. People who were working and living independently after the injury obtained higher scores on all QOLIBRI scales. Statistically significant differences were found between the GOSE functional outcome groups on all QOLIBRI scales.

4. Do the two TBI specific outcome measures (the GOSE and the QOLIBRI) cover relevant domains of functioning as defined in the frame of reference of the ICF?

The QOLIBRI and the GOSE together cover 18 (78%) categories of the Brief ICF Core Set for TBI. The Brief ICF Core Set is defined as the minimum considered necessary to cover the typical spectrum of problems in the functioning of TBI patients. Accordingly, it can be stated that the QOLIBRI and the GOSE cover relevant domains in TBI patients' functioning.

5. How does functional outcome assessed by the clinicians relate to subjective HRQoL reported by the patients?

The closest similarity between the professionals' assessment of the severity of the problems and HRQoL was found in the QOLIBRI's Physical Problem scale and the Cognition scale. The patients appear to be less bothered by emotional problems than would be expected bases on the professionals' assessments of the severity of these problems. On the contrary, the patients were less satisfied than would be expected on the QOLIBRI scales of Self, Daily Life and Autonomy, Social Relations, and certain aspects of Cognition. The discrepancy is most prominent in the domains of interpersonal interactions and relationships, and participation in social and leisure activities. These are findings that should be taken into account in rehabilitation.

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Appendix. List of ICF domains (chapter headings)

Domain	Categories
BODY FUNCTIONS	
1. Mental functions	b110 – b199
2. Sensory functions and pain	b210 – b299
3. Voice and speech functions	b310 – b399
4. F. of the cardiovascular, haematological, immunological and respiratory systems	b410 – b499
5. Functions of the digestive, metabolic and endocrine systems	b510 – b599
6. Genitourinary and reproductive functions	b610 – b699
7. Neuromusculoskeletal and movement-related functions	b710 – b799
8. Functions of the skin and related structures	b810 – b899
BODY STRUCTURES	
1. Structures of the nervous system	s110 – s199
2. The eye, ear and related structures	s210 – s299
3. Structures involved in voice and speech	s310 – s399
4. Structures of the cardiovascular, immunological and respiratory systems	s410 – s499
5. Structures related to the digestive, metabolic and endocrine systems	s510 – s599
6. Structures related to the genitourinary and reproductive systems	s610 – s699
7. Structures related to movement	s710 – s799
8. Skin and related structures	s810 – s899
ACTIVITIES AND PARTICIPATION	
1. Learning and applying knowledge	d110 – 199
2. General tasks and demands	d210 – d299
3. Communication	d310 – d399
4. Mobility	d410 – d499
5. Self-care	d510 – d599
6. Domestic life	d610 – d699
7. Interpersonal interactions and relationships	d710 – d799
8. Major life areas	d810 – d899
9. Community, social and civic life	d910 – d999
ENVIRONMENTAL FACTORS	
1. Products and technology	e110 – e199
2. Natural environment and human-made changes to environment	e210 – e299
3. Support and relationships	e310 – d399
4. Attitudes	e410 – e499
5. Services, systems and policies	e510 – e599