# Acquired Brain Injury in Children and Adolescents: Investigating Assessments of Communicative Participation in Daily Life Situations

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# Acquired Brain Injury in Children and Adolescents: Investigating Assessments of Communicative Participation in Daily Life Situations

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"A word after a word after a word is power"
Margaret Atwood

# ABSTRACT

**Aims** The overall aim of this thesis was to explore assessments of communicative participation in children and adolescents (hereafter: adolescents) with acquired brain injuries, mainly through evaluations in the Communicative Effectiveness Index (CETI) and in interviews with the participants. The aim was also to capture important changes in communication over time. Five sub-studies were carried out, presented in Papers I-V.

**Methods** Paper I: Pragmatic evaluations were explored in eight participants with severe brain injuries. The data were obtained in clinical surroundings by a speech language pathologist and rehabilitation assistants, using clinically applied pragmatic taxonomy, the Pragmatic Protocol (PP). Paper II: Descriptive and comparative methods were used to assess the communication outcome in an adolescent with ABI. The investigations included linguistic and cognitive test data and adolescent/parent evaluations of communication skills in the CETI, post-injury and at follow-up. Video recordings to explore communication management were analysed through self-evaluation and interview procedures. Paper III: The contribution of CETI in the assessment of ABI was examined through parent evaluations of communication in 30 adolescents, which were compared with linguistic, cognitive and brain injury data. Paper IV: Assessments of daily communication skills delivered by the parents of eight adolescents were compared with self-evaluations by the adolescents themselves. Interview data were analysed in particular by applying activity-based communication analysis, ACA (Allwood, 2013), and the theory of distributed cognition (Hutchins, 1995a). Paper V: Change scores in 30 adolescents between post-injury measurements and follow-up results were estimated.

**Results** Paper I: Seven of eight participants with severe brain injuries were assessed as having a highly reduced capacity to communicate within all the assessed pragmatic parameters that involved speech and language skills. Paper II: Self-evaluation of the video recordings and analyses of communication management in Paper II confirmed impaired communication, related to language comprehension difficulties, high speech rate and the number of speakers involved. Paper III: The CETI data showed that adolescents with more communication difficulties, according to their parents, also obtained significantly lower scores in tests of grammar comprehension and verbal IQ. The trend was similar for word comprehension, naming and perceptual IQ, although this was not supported by significant results. However, complex communicative interactions, such as fast conversations with several speakers involved, were affected in all participants, including those with higher results in linguistic and cognitive tests. As a result, complex communicative situations appeared to be particularly vulnerable to the effects of the brain injuries, regardless of injury severity. The aetiologies of the injuries did not affect the outcome in individual results. However, the majority of adolescents with more communication difficulties according to parent evaluations had left-hemisphere brain lesions. Paper IV: Overall high agreement between the adolescent and parental assessments was found. However, complex communicative situations more frequently received lower scores in the parental ratings. Analyses using the ACA and distributed cognition models and interview data pointed to the usability of

a systematic comparison of the shared views on communication after ABI in adolescence, to increase knowledge of the participation perspective in real-life communication. Paper V: The nature and extent of communication abilities after communication strategies applied by the parents at home showed a significant increase in ability in 30 participants ($p < .01$), but some tasks did not improve as much, even showing a reduction in capacity after the one-year application of communication strategies, according to parental estimations.

**Conclusions** One general conclusion in this thesis is that evaluations of communication abilities in adolescents with ABI benefit from analyses of interaction in everyday situations. The data obtained in the clinical surroundings, in particular, the results from cognitive, linguistic and cerebral lesion site data, appear to have a certain predictive value in terms of the communication outcomes rated in the CETI, thereby strengthening the content validity of the CETI in adolescent participants with ABI. The findings further point to the important role parents play in exploring the adolescents' communicative participation in real life by sharing their opinions in interviews, based on the CETI results. The participation perspective can be addressed in the self-assessments by the adolescents themselves, as was shown in analyses of video recordings and in the interviews exploring the activity-based communication analysis and distributed cognition perspectives. The mixed-method design applied in this thesis could provide information which could contribute to shaping fruitful individualised rehabilitation programmes in adolescents with ABI.

**Keywords** communicative participation, acquired brain injury, children and adolescents, parental evaluations, self-assessments, cognitive and linguistic factors

# LIST OF ORIGINAL PAPERS

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

## PAPER I

Fyrberg Å, Marchioni M, Emanuelson I. Severe acquired brain injury: rehabilitation of communicative skills in children and adolescents. *International Journal of Rehabilitation Research*. 2007 ; 30: 153-7.

## PAPER II

Fyrberg Å. Communication after traumatic brain injury in adolescence: a single subject comparative study of two methods for analysis. *Journal of Interactional Research in Communication Disorders*. 2013; 4: 157.

## PAPER III

Fyrberg, Å, Horneman, G, Åsberg Johnels, J, Thunberg, G, Ahlsén, E. Communication in children and adolescents after acquired brain injury – an exploratory study. Submitted to *Journal of Rehabilitation Medicine*, 2016.

## PAPER IV

Fyrberg, Å, Strid, K, Ahlsén, E, Thunberg, G. Everyday communication in adolescents after acquired brain injuries – a comparative study of self-ratings and parent evaluations using the CETI. Accepted for publication in *Journal of Interactional Research in Communication Disorders,* January 2017.

## PAPER V

Fyrberg, Å, Strid, K, Ahlsén, E, Thunberg, G. Communication before and after a home-based intervention in adolescents after acquired brain injury: applying the CETI as an outcome measurement

# CONTENTS

# PART II

## PAPER I

Severe Acquired Brain Injury: Rehabilitation of Communicative Skills in Children and Adolescents

## PAPER II

Communication After Traumatic Brain Injury in Adolescence: a Single Subject Comparative Study of Two Methods for Analysis

## PAPER III

Communication in Children and Adolescents After Acquired Brain Injury – An Exploratory Study

## PAPER IV

Everyday Communication in Adolescents After Acquired Brain Injuries – A Comparative Study of Self-ratings and Parent Evaluations Using the CETI

## PAPER V

Communication Before and After a Home-Based Intervention in Adolescents after Acquired Brain Injury: Applying the CETI as an Outcome Measurement

# ABBREVIATIONS

**ABI** Acquired brain injury

**ACA** Activity based Communication Analysis

**CCD** Cognitive-communication disorder

**CETI** The Communicative Effectiveness Index

**CM** Communication Management model

**DTI** Diffusion tensor imaging

**fMRI** Functional magnetic resonance imaging

**FSIQ** Full Scale Intelligence Quotient

**ICF** The International Classification of Functioning, Disability and Health

**IFOF** Inferior fronto-occipital fasciculus

**LHD** Left-hemisphere brain damage

**MRI** Magnetic resonance imaging

**NTBI** Non-traumatic brain injury

**PP** The Pragmatic Protocol

**PIQ** Performance IQ

**PPVT** Peabody Picture Vocabulary Test

**RHD** Right-hemisphere brain damage

**SD** Standard deviation

**SLP** Speech language pathologist

**TBI** Traumatic brain injury

**TROG** Test of the Reception of Grammar

**VIQ** Verbal IQ

**WAIS** The Wechsler Adult Intelligence Scale

**WISC** The Wechsler Intelligence Scale for Children

# PART 1

# ACQUIRED BRAIN INJURY IN CHILDREN AND ADOLESCENTS: INVESTIGATING ASSESSMENTS OF COMMUNICATIVE PARTICIPATION IN DAILY LIFE SITUATIONS

# INTRODUCTION

This thesis originates from a clinical perspective of communicative rehabilitation in school-aged participants with acquired brain injury (ABI). Specifically, the thesis focuses on contributing to the development of methods for assessing communication disorders in children and adolescents with ABI.

The overarching hypothesis which underpins the design of the thesis is based on the assumption that children and adolescents (hereafter: adolescents) with ABI present with diverse, complex symptoms and therefore constitute a heterogeneous group. While there might be certain common outcome features related to developmental and brain injury data, such as age at injury, injury location and injury severity, the individual communication outcome also depends on experiences in individual relationships and contexts. The investigation of these individual relationships and contexts is an important element in the assessment procedures, aiming to create a basis for designing fruitful rehabilitation interventions to enhance communicative participation.

In the initial phase of the study, the goal was to show that a selection of conventional clinical assessments of language and cognition, as well as parental evaluations, could clarify the communication outcome in adoles-

cents after ABI. However, the statistical analysis in Paper III of the results from a tool previously used for evaluating daily communication after acquired brain injury in adults, the Communicative Effectiveness Index, CETI (Lomas et al., 1989) showed that the internal consistency proved to be excellent. For this reason, to address the communication outcomes of these injuries in the adolescent population, we expanded the design, focusing more on the CETI to investigate how the tool can be used as a single evaluation measure of communication, as well as in combination with other clinical tests.

The thesis included adolescents with communication impairments after ABI of different aetiology. The inclusion of different aetiologies was based on the need to develop methods for assessment in both participants with traumatic brain injuries (TBI) and adolescents with non-traumatic brain injuries (NTBI).

All the five studies included in the thesis were conducted at a regional rehabilitation centre in Sweden.

The contribution of the thesis is to show that clinical test data measuring skills essential to communication abilities can provide insights into the communication outcome after ABI, but that the impact of these clinical data on real-world communication abilities needs further clarification. The results of the thesis also highlight the benefits of seeing communication as a context-dependent phenomenon, the study of which profits from self-exploration by the persons with ABI themselves and their significant others. By applying several points of view in the assessment procedures, the validity of the evaluations can be further secured. The overall aim of the thesis was to contribute to discerning the nature of communication disorders in adolescents with ABI, by investigating adolescent and parental evaluations of communication in everyday interaction and relating them to a selection of cognitive, linguistic and brain injury assessments.

## STATE OF THE ART

Acquired brain injury (ABI) continues to be a major cause of morbidity and mortality in young people, internationally and in Scandinavia (Falk, Cederfjäll, von Wendt, and Klang Söderkvist, 2005; Fyrberg, 2013; Fyr-

berg, Marchioni, and Emanuelson, 2007; Rosema, Crowe, and Anderson, 2012; Turkstra, Politis, and Forsyth, 2014; Yeates et al., 2013).

ABI is the outcome of an external trauma (traumatic brain injury, TBI) (McDonald et al., 2013), or is due to an internal cause (non-traumatic brain injury, NTBI) (Asemota, George, Bowman, Haider, and Schneider, 2012; de Kloet, 2014). Aetiologies include stroke, brain tumour, traffic accident, sports accident or fall accident, anoxic or toxic encephalopathy, infections of the CNS and non-degenerative and degenerative neurological diseases (see also *Definitions*).

According to the World Health Organisation, traumatic head injuries alone will surpass many diseases as the major cause of death and disability by the year 2020 (Hyder, Wunderlich, Puvanachandra, Gururaj, and Kobusingye, 2007). The overall impact of a brain injury has recently been classified as "a disease process, not an event" (Masel and DeWitt, 2010), implying that the outcome may not be a transitory experience but can, on the contrary, result in degenerative cerebral processes that may lead to the impairment of functions lasting throughout life, particularly in the moderate to severe cases.

As a consequence of the injuries, communication disorders can be a major challenge for many participants with brain injury (Bates et al., 2001; Turkstra, Williams, Tonks, and Frampton, 2008). Impaired communication skills frequently disrupt language and speech development and affect the ability to participate in daily life interactions, especially in participants with *sequelae after* moderate to severe injuries (Bedell and Dumas, 2004; Åsa Fyrberg, Strid, Ahlsén, and Thunberg, in press). In particular, communicative situations with a high level of complexity appear to be a challenge, even after milder injuries. For example, Chapman found that children with ABI have difficulty with complex tasks such as sequencing action, developing resolutions, extracting the moral of a story in discourse and producing gist-based texts on a novel measurement of summarisation (Chapman, 1997; Chapman et al., 2006). The difficulties were found in children with severe injuries, but a number of participants classified with milder injuries also had an impaired ability when it came to managing these complex tasks.

The location of brain injuries to the left hemisphere of the brain may affect the ability in adults and adolescents to supervise control in complex

communication situations, while qualitative or quantitative deviations of language production may not be as pronounced in younger participants (Bates et al., 2001). However, the outcome of a childhood brain insult related to the location of the injuries has been the subject of debate. For example, Chilosi et al. (2001) argued that the development of expressive lexicon and grammar was more delayed in left- than right-brain-injured children. An investigation by Anderson and colleagues (2005) found that children with left prefrontal lesions performed with a specific deficit characterised by difficulties with the on-line processing of auditory-verbal information.

In terms of the outcomes of injuries related to motor skill functions, e.g. walking, eating and talking, the functions might eventually be recovered in the rehabilitation process in individuals involved in rehabilitation programmes. These outer signs of recovery can in turn create hope for the person with ABI to return to previous activities at home and school. However, adolescents with communication difficulties, who do not show any visible symptoms of a brain injury, run a high risk of developing a "hidden handicap", related to the lack of bodily signs of the traumas, which in turn makes it difficult for their environment to understand the extent of the injuries (Chamberlain, 2006; Savage, DePompei, Tyler, and Lash, 2005).

In everyday situations, understanding communication skills in adolescents with ABI poses unique challenges (Cornwell, Murdoch, Ward, and Kellie, 2003; Dennis, Purvis, Barnes, Wilkinson, and Winner, 2001; Didus, Anderson, and Catroppa, 1999; Duff, Mutlu, Byom, and Turkstra, 2012; MacDonald, 2012; Ownsworth, McFarland, and Young, 2002). People with communication disorders may perceive information literally (Ylvisaker, 1993), have reduced verbal skills to give relevant explanations or to ask for relevant clarifications when needed (Wiseman-Hakes, Stewart, Wasserman, and Schuller, 1998), they may make comments that seem extraneous, random or inappropriate or have difficulty "reading" communication partners well enough to know when to be quiet and listen or when to take vocal-verbal turns in a conversation (Turkstra and Byom, 2010). All these communication impairments may result in considerable social and academic punishments, such as peer rejection or peer exclusion, as well as poor academic achievement and the need for special educational

support (Turkstra et al., 2008). The long-term effects might be reduced employment potential and, in severe cases, social stigmatisation and isolation (Larkins, Worrall, and Hickson, 1999).

Traditional methods of addressing the outcome of communication disorders after ABI have focused on the investigation of language functions and other cognitive skills, sometimes in combination with communicative evaluations by a clinician or others close to the participant. These investigations are common in habilitation contexts as well, involving participants with congenital disorders such as autism and related conditions affecting communication (Ferguson, Hall, Riley, and Moore, 2011; Kjellmer, Hedvall, Fernell, Gillberg, and Norrelgen, 2012). In participants with congenital disorders, however, the perspective of communication is different compared with the perspective of participants with ABI. Contrary to people with ABI, who can relate to typically developed communication skills acquired prior to the injuries, a participant with a congenital disorder is unable to relate to skills developed before the occurrence of a brain injury but nonetheless has a lived experience of the individual impairments, from birth. The differences between these groups may result in distinct approaches related to the professional interventions, such as adaptations of assessment procedures and strategies. However, what the groups have in common and what has a direct bearing on the strategies is that both participants with ABI and those with congenital disorders represent a heterogeneous population. As a result, individual strategies applied in both habilitation and rehabilitation contexts involve a common approach. The evaluation of communication in both groups may therefore benefit from evaluations based in the environment of the adolescents, reflecting special context-dependent needs and skills. Furthermore, particularly from a participation perspective, the assessments of communication should be based on the opinions of the adolescents themselves, while tests in clinical contexts may provide knowledge of cognition and language clarifying some of the impairments found in daily life.

A number of studies applying clinical test procedures have established that reduced language comprehension and language production correlate with impaired cognitive skills, in particular with executive functions and working memory (Ho, Epps, Parry, Poole, and Lah, 2011; Jordan and Murdoch, 1994). A study involving 56 school-aged children and adolescents

found that pragmatic language was impaired after mild as well as severe head injury. Specifically, the use of speech acts, i.e. a form of pragmatic communication, was predicted by pragmatic inference and working memory. It was concluded that poor working memory after childhood head injury had pragmatic and discourse consequences (Dennis and Barnes, 2000).

The close interdependence between language and other aspects of cognition is further manifested in daily communication situations with high demands on executive functions (Turkstra and Byom, 2010), but whether a fruitful communication exchange occurs depends on a host of other factors, related to context and the role of the conversation partner (MacDonald and Wiseman-Hakes, 2010; McDonald, 2000; Togher, 2000; Turkstra et al., 2014).

Serious attempts have been made during the last decade to emphasise the importance of combining explorations of language and cognition, on the one hand, and everyday communication related to the participation perspective of the person with the health condition, on the other hand. For instance, the position statement by ASHA, the American Speech-Language-Hearing Association, relates to cognitive-communication disorders (for ease of description, the concept of "cognitive communication" will henceforth be referred to as "communication", unless otherwise stated). Another example is the framework in the ICF, the International Classification of Functioning, Disability and Health (2005; WHO, 2007). In the ASHA position statement, the role of the speech-language pathologist is considered within the framework of the ICF and it is stated that the categories of the ICF classification (*Body structure and function, Activity and participation* and *Contextual factors*) can be applied to communication disorders. The collaboration with the person with the communication disorder is underlined, together with the challenge of the contextual demands and supports that emerge in daily communication situations. Contextual predictors of successful interventions include both environmental and personal factors. Both types of factor should be identified as either facilitators or barriers to communicative activity and participation (a more extensive description of the theoretical approach of the ICF is given in the Theoretical framework section).

Despite the increasing focus on context and participation in the rehabilitation area, issues related to communication in a complex everyday environment still remain poorly understood. The logical positivist tradition, aiming at transforming scores from individual data sources into general claims for larger populations, has prevailed as a conventional theoretical approach in brain injury rehabilitation practice. However, it has been argued that great caution is required regarding assessments with standardised tests during rehabilitation (Ylvisaker, Hartwick, Ross, and Nussbaum, 1994).

First, most standardised tests do not include participants with head injuries in the normative sample, thus compromising validity. The Children's Communication Checklist, CCC (Bishop, 1998b), used data from children with specific language impairments to target communication outcome. The Autism Diagnostic Observation Schedule-Generic, ADOS-G (Lord et al., 2000) was adapted to tap social and communication deficits in participants with problems related to the spectrum of autism. Even if both these tests were fitted to explore communication skills, the communication rehabilitation process associated with ABI is clearly different, compared with the processes associated with developmental language impairment or autism and using the tests might therefore not provide comprehensive information about the individual with ABI.

Second, participants with severe head injuries may have such pronounced cognitive or physical impairments that they are unable to participate adequately in any standardised assessment.

Third, test scores may overestimate daily performance and create false optimism if there has been a good recovery of previously acquired skills, or if the participant benefits from the high structure, short presentations and one-to-one interactions typical of the standardised procedures applied in clinical test situations (Farmer and Clippard, 1996).

In conclusion, the use of cognitive measurements available for young people with ABI based on actual performance in a natural environment still appears to be a challenge (Chevignard, Soo, Galvin, Catroppa, and Eren, 2012). Responding to this challenge, this thesis attempts to help to discern the nature of communication disorders in adolescents with ABI, by investigating communication in real-life surroundings and by relating the results to assessments of a selection of cognitive and linguistic data,

as well as to brain injury data. The thesis focuses on practices aimed at facilitating functional and individualised rehabilitation planning for adolescents with ABI.

First, the use of a clinical tool for pragmatic assessment, the Pragmatic Protocol (Prutting and Kirchner, 1987), is explored to capture communication abilities that require rehabilitation.

Second, two methods of investigation, (i) analysis of communication management in video-recorded interactions and (ii) self and parental assessments using the Communicative Effectiveness Index, CETI (Lomas et al., 1989), are investigated to capture communication change in a case of ABI.

Third, parental evaluations of 30 adolescents' communication skills, as well as cognitive and linguistic test data and brain injury data, is evaluated.

Fourth, a comparison of self- and other evaluations of communication by the adolescents themselves and the parents is examined.

Fifth, the assessment by parents of communicative change in 30 adolescents who participated in Study III is explored, one year after the introduction of targeted communication strategies applied by the parents at home.

## DEFINITIONS AND EXPLANATIONS OF SOME CENTRAL TERMS

In this section, definitions and/or explanations are presented in alphabetical order for some of the central concepts which are explored in the thesis. Moreover, a clarification is proposed of a selection of domain-specific measurements used in acquired brain injury practice.

### ACQUIRED BRAIN INJURY, ABI

ABI refers to an injury to a previously intact, typically developed brain. From a neurological perspective, the injury results in some form of brain pathology that affects a person at some point during his/her lifetime. ABI frequently produces a wide range of impairments including physical, neurocognitive and/or psychological functioning. ABI can result from traumatic or non-traumatic causes, labelled traumatic brain injury, TBI, and non-traumatic brain injury, NTBI (see below).

## COMMUNICATION

First, the overarching definition of communication which was used in the thesis is given. The definition is related to Activity based Communication Analysis, ACA (Allwood, 2013) (see also *Theoretical framework* and *Paper IV*). The ACA approach describes communication not as a transmission between sender and receiver but as a joint activity, where communication is shared and co-activated. Both the receiver and the sender are seen as active co-constructors of the communication content.

Following the model of Allwood, a definition of communication is proposed:

> Communication = sharing of information, cognitive content or understanding with varying degrees of awareness and intentionality, often interactive involving information exchange, often conventionally regulated (Ibid. 2013, p. 34).

Second, a definition is given, formulated in a position statement by the American Speech and Hearing Association:

> Cognitive-communication disorders […] encompass difficulty with any aspect of communication that is affected by disruption of cognition. Communication may be verbal or nonverbal and includes listening, speaking, gesturing, reading, and writing in all domains of language (phonologic, morphologic, syntactic, semantic, and pragmatic). Cognition includes cognitive processes and systems (e.g. attention, perception, memory, organization, executive function). Areas of function affected by cognitive impairments include behavioural self-regulation, social interaction, activities of daily living, learning and academic performance, and vocational performance (ASHA, 2005, p. 1).

The advantage of the ASHA definition is that the term *communication* is used to cover both *cognitive* and *communication,* due to the close interdependence between the two domains needed to produce relevant interaction between interlocutors in daily environments. Unless otherwise stated, this thesis has adopted this approach. However, the ASHA definition does

not include a perspective on communication as a co-constructed activity; instead, the impairment perspective is underlined as a broad description of individual skills and cognitive areas commonly affected by the disruption of cognition are listed. ACA, on the other hand, emphasises the interactive and contextual aspects of communication which were investigated in this thesis. For this reason, the framework was subsequently chosen as the main definition of communication.

## HIGH-LEVEL COMMUNICATION, I.E. COMPLEX COMMUNICATION

*High-level/complex communication* (hereafter: *complex communication*) has been associated with a number of cognitive functions (e.g. memory, attention and processing speed). It has been shown that complex language competence depends on functional integration across the cerebral networks, with a central role for the frontal lobes in abstracting meaning from complex information (Chiu Wong et al., 2006). The injuries, in particular in the moderate to severe cases, are assumed to cause impairments affecting higher order symbolic language processes, e.g. meta-linguistic tasks, abstract and indirect language and complex lexical-semantic and morpho-syntactic manipulation (see also *Literature review*) (Chapman et al., 2006; Ylvisaker and Feeney, 2007). Impaired complex communication skills are common after ABI and may frequently cause difficulties in daily interactions. In particular, high-speed conversations involving several people in environments rich in visual and auditory stimuli can be a challenge.

## MEASUREMENT, ASSESSMENT AND EVALUATION

*Measurement* is the quantification of an observation against a standard, while *assessment*, or *evaluation* also involve the interpretation of the obtained measurements (Wade, 1992). In clinical practice, however, *measurement* may refer to the detection of a phenomenon, as well as to assessments or evaluations of the phenomenon. As a result, in this study, the three concepts of *measurement, assessment,* and *evaluation* are used interchangeably, unless otherwise stated.

The potential use of the measurements can be described from three different groupings: *discrimination, prediction* and *evaluation*. In this thesis, all three dimensions of the concept of *measurement* have been applied.

First, a *discriminative index* is used to assess differences between individual participants or groups on an underlying dimension, when no external criterion or gold standard is applicable to validate these dimensions. Intelligence tests, for example, are used to distinguish between children's learning abilities.

Second, to classify participants into a set of predefined measurement categories when a gold standard is available, a *predictive index* is used. The aim is to determine whether individuals have been properly classified, either concurrently or prospectively. The predictive index is often used as a screening or diagnostic instrument to identify individuals who have, or will develop, a specific condition or outcome.

Third, an *evaluative index* is used to assess the magnitude of longitudinal change in an individual or a group in the dimension of interest (Kirshner and Guyatt, 1985). Examples of measurement outcomes are a categorisation, different scales (ordinal, interval or ratio scales), quantitative discrete data or quantitative continuous data. The results of the measurements will determine the choice of statistical methods that can be applied (Svensson, 2005).

## NON-TRAUMATIC BRAIN INJURY, NTBI

NTBI is the outcome of an internal trauma to the brain. Aetiologies include brain tumour, stroke related to aneurysm/vascular malformations, anoxia, intoxication, infections such as meningitis or encephalitis and non-degenerative and degenerative neurological diseases.

## OUTCOME

Outcome signifies a sequela, consequence, end point or a particular finding which occurs as a result of an acquired brain injury (Rosenthal, 1999). The World Health Organisation (WHO) has defined outcome as:

> The effect the process has had on the people targeted by it. These might include, for example, changes in their self-perceived health status or changes in the distribution of health determinants, or factors which are known to affect their health, well-being and quality of life (WHO, 2016a).

## PRAGMATICS

Pragmatics signifies the use of language. However, as has been stated previously, "dealing with clinical cases forces us to go beyond standard theories of pragmatics" (Perkins, 2005, p. 368 ). Perkins points out that the transmission of meaning depends not only on language in a narrow sense but also on the features associated with communication, such as gestures, mimicking, silent pauses, eye gaze and posture, which are described as pragmatic phenomena, even in the absence of verbal language. Pragmatics applied in communicative situations is characterised by rules for communicative interaction, such as the rules for taking turns, the adaptation of style of speech appropriate for varying listeners, the choice and shift of topics (Ahlsén, 2006, p. 97; Bee, 1992, p. 315).

The label *inappropriate pragmatic behaviour* has been used in research on pragmatic skills, for example in the Pragmatic Protocol, PP (Prutting and Kirchner, 1987). The term is somewhat problematic, as the nature of what is regarded as "inappropriate" pragmatic behaviour is based on subjective experiences of the people involved in a conversation. However, Prutting and colleagues provided a framework which further clarified the intended use of the concept in the evaluation procedures in PP: "It is important that judgments of appropriate or inappropriate be made relative to the subject, partner, and other aspects of the context that are known. For instance, a 5-year-old child is able to be cohesive but perhaps in fewer ways or using a more restricted number of syntactic forms than an adult. When using this protocol, judgments must be made taking both chronology and context into account" (Ibid., p. 108).

### REHABILITATION AND INTERVENTION

Rehabilitation has been defined by the WHO as follows:

> Rehabilitation is instrumental in enabling people with disabilities whose functions are limited to remain in or return to their home or community, live independently, and participate in education, the labour market and civic life. Access to rehabilitation can decrease the consequences of disease or injury, improve health and quality of life and reduce the use of health services (WHO, 2016b).

The rehabilitation process should include several steps: assessment, goal-setting, intervention and evaluation. The *interventions* can consist of continued data collection, support to maintain the patient's well-being and treatment activities (Wade, 2005). Examples of interventions in ABI are compensatory strategies, direct skills training or interventions directed towards shaping the context of the person with the health condition, including, for example, applications of communication strategies by significant others. In the present study, *rehabilitation* has been used as being similar to *intervention*, adding *further contextual specifications* as relevant.

### TRAUMATIC BRAIN INJURY, TBI

TBI is the outcome of an injury to the brain with an external cause. Common traumatic causes include motor vehicle accidents, falls, assaults or sports injuries.

## LITERATURE REVIEW

Historically, participants with head injuries have been assessed using formal tests of speech and language abilities. Up to 30% or 40% of the older participants with TBI will definitely show signs of impaired speech and language skills on standardised test batteries (where everyday communication is usually not assessed) and the speech- and language-related difficulties can consist of anomia, expressed, for example, as impaired confrontation naming, word-finding, verbal association and/or comprehension (Ahlsén, 2006). However, a conventional investigation of language

competence based on phonological, syntactical and semantic skills fails to detect the problems in communication experienced by many individuals with head injuries (McDonald, 2000). For example, the majority of participants with TBI do not display conventional aphasic symptoms, particularly in the chronic stages post-trauma. Instead, they frequently demonstrate the recovery of specific language functions (Vas, Chapman, and Cook, 2015).

Likewise, communication impairments in a younger population may depend on more or less reduced specific language abilities causing word retrieval problems and language comprehension deficits. Even so, it appears that the majority of difficulties, above all in the moderate and severe cases of ABI, rely on a more general impairment affecting higher order symbolic language processes, e.g. meta-linguistic tasks, abstract and indirect language and complex lexical-semantic and morpho-syntactic manipulation.

Furthermore, cognitive interference associated with communication abilities has been found in the following areas: working memory, theory of mind and behavioural self-regulation, impairments commonly associated with frontal lobe injury, e.g. difficulty with complex organisational and planning tasks (Chapman et al., 2006; Ylvisaker and Feeney, 2007).

Clinical tools aimed at evaluating skills associated with communicative abilities in children can typically involve clinical assessments of intellectual ability and language (Anderson et al., 1997). Clinically established communication rating scales applied in the paediatric population are commonly based on delayed or deviant language development in children. These tools comprise the previously mentioned (page 10) Children's Communication Checklist, CCC (Bishop, 1998a), and MacArthur Communicative Development Inventories (Fenson et al., 1993), a parent-report instrument for the assessment of early lexical and grammar development in infants and toddlers. The Vineland Adaptive Behaviour Scales (VABS) is a caregiver interview tapping four domains of adaptive behaviour: socialisation, communication, daily living and motor skills (Sparrow, Balla, and Cicchetti, 2005). The VABS is a frequently used evaluation tool in participants with syndromes and autism spectrum disorders. It has also been applied as an implicit participation measurement in a systematic review of determinants of participation by children and adolescents with acquired brain injury (de

Kloet et al., 2015). Factors associated with participation were identified in the review, but they were frequently related to behaviour, cognitive competence and learning difficulties and not specifically to communication abilities, except in one study: Anderson et al., who used the VABS to study outcome after mild head injury in young children (Anderson, Catroppa, Morse, Haritou, and Rosenfeld, 2001).

The La Trobe Communication Questionnaire (Douglas, 2010) is one of the few scales explicitly constructed to gauge social communication ability in adolescents with TBI. Data collection in the LaTrobe can be completed by the person with the brain injury, as well as by the parents, depending on the severity of injury in the person with TBI. Although the initial results are based on a small sample of predominantly male subjects with TBI (n=19), it could be a promising evaluation tool for other school-aged subjects with ABI as well. A newly constructed standardised activity-level test for adolescents is the Functional Assessment of Verbal Reasoning and Executive Strategies – S-FAVRES (MacDonald, 2014). The S-FAVRES is specifically constructed clinically to evaluate adolescents' complex cognitive-communication skills in a number of predefined tasks carried out in the clinic.

Evaluation assessments used in a real-world environment are frequently constructed for adults, predominantly for those with aphasia. Examples of commonly applied tools are: the Communication Outcome after Stroke, COAST (Long, Hesketh, Paszek, Booth, and Bowen, 2008), Communicative abilities in daily living, CADL (Holland, 1980), the Functional Communication Profile, FCP (Sarno, 1969), the Amsterdam Nijmegen Everyday Language Test, ANELT (Blomert, Kean, Koster, and Schokker, 1994), the Functional Assessment of Communication Skills for Adults, ASHA FACS (Frattali, 1995), and the Communicative Effectiveness Index, CETI (Lomas et al., 1989). There has also been an increasing focus on self-report measurements during the last few decades, likewise primarily related to aphasia in adults (Le Dorze, Brassard, Larfeuil, and Allaire, 1996). However, available measurements do not always meet demands relating to the evaluation of participation as defined by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2007). This is not surprising, as many of the persons with moderate to severe injuries might not be able to conduct a self-evaluation,

as a result of the cognitive impairments related to the injury, as a result of which they are dependent on clinicians or significant others to perform the evaluations, which might not be as "participating" as intended. Furthermore, it appears that the participation perspective, according to the ICF, is not that easy to refine. A recent crosswalk of participation in assessments of adults identified 90 instruments that were self-reported. Of these instruments, 29 contained more than 50% participation items, while only two contained 100% participation items. Furthermore, it was concluded that "self-report measurements of participation vary widely in content and response metrics and often include activity, body function, environmental and quality of life items (Brandenburg, Worrall, Rodriguez, and Bagraith, 2014)".

A review of six self-report instruments applied in speech-language pathology found no existing tool solely dedicated to evaluating communicative participation (Eadie et al., 2006). The majority of the items aimed to measure general communication. In this study, several instruments that are commonly used in clinical settings were excluded, because the evaluations in these instruments were made by clinicians and/or family members instead of the person with the communication disorder. However, a content analysis was performed on two of these instruments, the ASHA FACS and the CETI, which showed that a large proportion of items in these two instruments were consistent with communicative participation per se. In the case of the CETI, 14 of 16 items (87%) were estimated to be consistent with communicative participation. In the CETI, 16 communicative situations which frequently occur in real-life contexts are surveyed through individual ratings (Table 1).

Table 1. The CETI.

| | |
|---|---|
| 1. Getting somebody's attention | 9. Communicating physical problems such as aches and pains |
| 2. Getting involved in group conversations that are about him/her | 10. Having a spontaneous conversation (i.e. starting the conversation and/or changing the subject) |
| 3. Giving yes and no answers appropriately | 11. Responding to or communicating anything (including yes or no) without words |
| 4. Communicating his/her emotions | 12. Starting a conversation with people who are not close family |
| 5. Indicating that he/she understands what is being said to him/her | 13. Understanding writing |
| 6. Having coffee-time visits and conversations with friends and neighbors (around the bedside or at home) | 14. Being part of a conversation when it is fast and there are a number of people involved |
| 7. Having a one-to-one conversation with you | 15. Participating in a conversation with strangers |
| 8. Saying the name of someone whose face is in front of him/her | 16. Describing or discussing something in depth |

The ratings are made on a 100 mm VAS scale, where 100 equals "As able as before the injury" and 0 equals "Not at all able". The scores can be used qualitatively, visualising the results for each situation to reflect a perceived improvement or impairment. They can also be converted into a score by laying a template marked with 1-mm divisions over the 10-cm VAS and reading off a value between 1 and 100. The CETI has previously shown generally high reliability between cultures in assessments of changes in functional communication in adult participants (Pedersen, Vinter, and Olsen, 2001; Penn, Milner, and Fridjhon, 1992). What might not be revealed in the CETI is a complex view of participation based on reports from all participants in the interaction, as communication is typically assessed by the significant others of the person with the communication impairments (see also *The validity and reliability of the methods applied in the thesis*, p. 37).

Over the last few decades, the debate relating to the usability of conventional clinical approaches when it comes to understanding cognitive and communication impairments found in a real-world setting has increased (Chevignard et al., 2012). Arguments have been put forward, suggesting

that there are a number of evaluation purposes that might be best met by non-standard procedures. Specifically, Coelho et al. (2005) have suggested five purposes: 1) determine competences in domains for which there are no standardised tests, e.g. discourse, 2) describe performance in the context of real-world settings and activities, 3) identify cognitive and communication demands of relevant real-world contexts, 4) describe the communication and support competences in everyday communication partners and 5) explore the effects of systematic changes in communication demands and partner support. A second similar context-sensitive approach in rehabilitation practice after brain injury has been outlined by Mark Ylvisaker, including two theoretical premises: (1) cognitive functioning is essentially related to a person's goals, emotions, contexts of action and domains of content and (2) aspects of cognition are essentially interconnected (Ylvisaker, 2003). In conclusion, there are convincing reasons to examine the evidence for non-standard approaches to communication interventions.

During the rehabilitation process after an ABI, the impact of the cognitive load in the home or school environment may expose difficulties that were just hinted at in the clinical setting. For this reason, a key limitation in clinical assessment procedures is that tests of language functions tend to focus on the impairment perspective, failing to detect and define the consequence of these deficits in terms of communication skills (LaPointe, Murdoch, and Stierwalt, 2010).

Other approaches might address these types of problem more adequately, as has more frequently been pointed out during the last two decades. A step away from traditional clinical assessments towards a description of the individual's communication in his/her own environment may make a major contribution to understanding and rehabilitating communication skills. In general, there appears to be a growing debate on the importance of the participation perspective in the paediatric ABI research context. For example, participation has been suggested as the most significant outcome of rehabilitation interventions, indicating that an understanding of the communication disorders in daily surroundings should always rely on descriptions of the person with the health condition (Baylor, Burns, Eadie, Britton, and Yorkston, 2011).

Applying a social rather than a medical model requires a shift in perspective and in promoting the investigation of social communication within natural contexts (Simmons-Mackie, 2000). Video recordings and direct observations are two methods that are frequently used to meet the need for more contextualised methods of evaluation (Samuelsson, Hammarström, and Plejert, 2016; Worrall, 2000, pp. 19-33). The contextualised observations are justified by the fact that subjects with head injuries often perform surprisingly better or worse in everyday contexts than can be predicted from standardised test performance (Ylvisaker, Hanks, and Johnson-Greene, 2002). So, in addition to existing standardised tests, involving self-assessments compared with the evaluations of significant others, this appears to be a fruitful approach to exploring the perceptions and providing guidelines on how to support the rehabilitation of adolescents with head injuries (Gauvin-Lepage and Lefebvre, 2010).

## EPIDEMIOLOGY

Acquired brain injury is the most common cause of death and permanent limitations in function in young people in Europe and in the United States (Kraus, 1993; Ylvisaker and Feeney, 2007).

A European study of the burden of injuries in the young population showed that, among all injury types, ABI and spinal cord injury resulted in the highest total impact related to life-long disability (Polinder, Haagsma, Toet, Brugmans, and van Beeck, 2010).

Data from the USA show that the age groups most likely to incur a TBI are children 0 to 4 years old, adolescents 15 to 19 years old and adults 65 years and older. The rates were higher for males than females in all age groups. Falls produced the greatest number of TBI-related emergency department visits and hospitalisations. Motor vehicle traffic was the leading cause of TBI death, with rates highest among those aged 20-24 years. (Faul, Xu, Wald, Coronado, and Dellinger, 2010).

In Sweden, of the total population of 9.9 million inhabitants, about 7,200 children and adolescents (age 0-19 years) are hospitalised every year due to head traumas and the total annual cost of the acute management of head trauma in all age groups has been estimated at 100 million Swedish crowns (12 million €) (SBU - The Swedish Council on Technology Assess-

ment in Health Care, 2000). A study of the annual injury incidence rate in Sweden from 1987 to 2000 showed that there was a decline in younger ages experiencing a head injury, while head injuries among older persons increased. Falls persisted as the main cause of head injury (Kleiven, Peloso, and Holst, 2003). The most common subgroup consists of children with mild or minor head injury (concussion), which accounts for at least 90% of all head traumas (Emanuelson and v Wendt, 1997).

# THEORETICAL FRAMEWORK

Within the frameworks of pragmatics, linguistics and cognitive science, there are several theoretical models associated with communication participation in human interaction. First, a brief overview of the theoretical stances in the field is presented, focusing on some of the more central theoretical influences. Second, the theoretical approaches chosen for this thesis are introduced in more detail.

It has been emphasised that utterances in a communicative interaction should be analysed in relation to the context in which they take place, as utterances convey different meanings depending on the context. Utterances can be analysed as actions with a specific purpose, i.e. *speech acts;* for example, the phrase "it is warm in here" could be interpreted as a statement "it is warm", or a request, "could you please close the window?", (Austin, 1978; Searle, 1969). Furthermore, to achieve fruitful communication exchanges, *the co-operation principle* describes how conversations in everyday situations are based on a mutual acceptance of rules between speaker and listener to achieve effective communication (Grice, 1975). The co-operation principle is divided into four maxims, labelled the Gricean Maxims: (i) make a contribution that is true, (ii) make the contribution as informative as necessary, (iii) be relevant and (iv) be perspicacious, i.e.

make brief, unambiguous, orderly contributions. It is interesting to note that, when these principles are learned during communication development, the individual may use them to joke and to use irony by ignoring or consciously breaking the principles. These "rule-breaking" behaviours are associated with complex communication skills.

Another approach to creating meaning in exchanges has been suggested, in relation to a philosophical view of meaning (Wittgenstein, 1953). Wittgenstein argues that reflecting on words and meaning independently of their context, usage and grammar is to deprive language of the ability to do its work. This viewpoint is probably true not only from a philosophical standpoint but also in everyday communication situations where a more pragmatic use of language is suggested.

It has been argued that the classical definition of *pragmatics,* [the study of] the use of language, has developed into a "broader and less exclusively language-oriented view" and that aspects of multimodality are needed to complete the picture (Perkins, 2005, p. 368 ). Perkins suggests that "rather than focusing so exclusively on linguistic pragmatics, as linguists and pragmaticians have tended to do so far, it might be more fruitful to consider in a more integrated fashion the role of nonlinguistic as well as linguistic, and of nonverbal as well as verbal, competencies in pragmatic functioning" (ibid.).

Responding to these theoretical approaches, which underline the importance of context, co-operation and multimodality to achieve meaningful communication, the following five theoretical frameworks were applied in the thesis: the International Classification of Functioning Disability and Health, ICF; Activity based Communication Analysis, ACA (including Communication Management analysis); distributed cognition and the Johari Window model.

The overarching framework was the ICF and to some extent also ACA, which influenced the general theoretical approach of the thesis. The remaining theories were mainly chosen to scaffold methods used in specific studies. The properties of each framework and the application of the theories to the studies in this thesis are explained in more detail below.

# INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF-CY)

The International Classification of Functioning, Disability and Health – ICF (WHO, 2001) was used as an overall theoretical framework in the design of this thesis. Below, the ICF is discussed from its origins, including a controversy over one of the constructs of the ICF, the participation construct, which has had a particular impact on the present study (Figure 1).

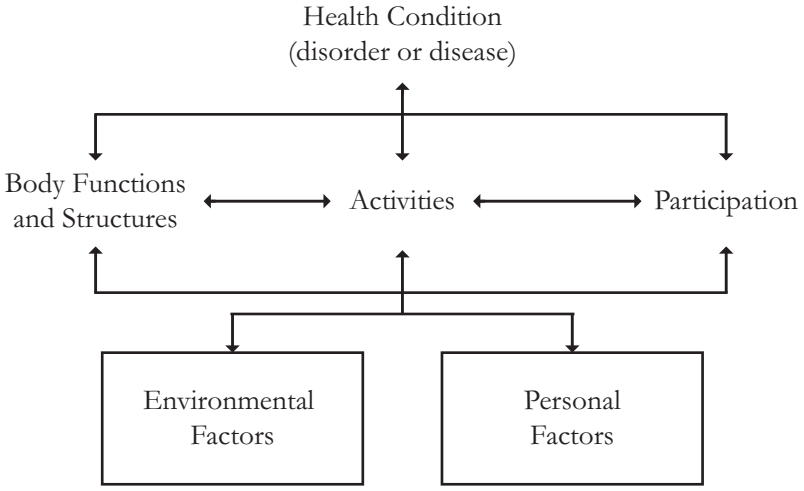


Figure 1. The ICF model: interaction between the ICF components

The ICF was created in 2001 by the WHO as a classification of health and health-related domains. It was officially endorsed by all WHO member states as the international standard to describe and measure health and disability. The ICF also includes a taxonomy of personal and environmental factors, since the health and disability of a person are thought to be expressed and made visible depending on the personal and environmental context.

A children and youth version of the ICF (ICF-CY) was launched in 2007 (WHO, 2007). One of the goals of the ICF-CY, which was explicitly articulated by the WHO, is to increase children's participation in everyday

life in the world. In this thesis, the participation perspective according to the ICF-CY was thereby applied as a central part of the theoretical framework.

The wider aim of the ICF was to support communication among rehabilitation and health professionals, thereby promoting worldwide understanding and research exchange between different scientific fields. The shaping of the ICF reflected a shift in rehabilitation standpoints, from one aiming to recover an individual's impairments to that of one promoting full participation in society (Simeonsson, 2001). The ICF is based on a previous model, the WHO's International Classification of Impairment, Disability and Handicap – ICIDH (1980), and a change in the definitions of the ICIDH concepts propelled the development of the model towards the ICF in the late 1980s. Whereas previous indicators of health had relied on the mortality rates of the population, the focus was changed from cause, to impact, activities and health. A paradigm based on health and the ability to act and function in society was proposed, as opposed to the ICIDH classification focusing on dimensions of the disease and disability of the person with the health condition (Fugl-Meyer and Fugl-Meyer, 1987).

The creators of the ICF wanted to provide a tool to investigate how people with health conditions live their daily lives and how the conditions for an active, satisfying life could be improved. Terms based on personal limitations were changed for terms denoting knowledge and capacity. Persons in charge of their own lives were the model of the change, as personal factors and contextual factors of the environment of the person with the health condition were more clearly accounted for. The message of the ICF, contrary to the previous ICIDH classification, was that impairments remaining after a trauma or disease may not necessarily result in a handicap. On the contrary, with proper interventions and accommodations, the impairment might not impede activities of daily living to the extent that the label "handicap" was justified. Accordingly, the classification in the ICF of the health condition is not normative but relative, as it involves individual attainable goals as a method to regain abilities after a disease or a trauma.

However, despite the advancements of the ICF over the ICIDH of 1980, it has been argued that there is "an important 'missing' element"

(Ueda and Okawa, 2003, p. 596). Ueda claims that, although aspects of participation are taken into account in the model, there is no concept or classification in the ICIDH or the ICF to describe the *subjective dimensions* of functioning and disability. As a result, subjective views of everyday communication situations are not covered, as the factors in the ICF "belong to the objective world, or the objective dimension of human life" (ibid.). This implies that subjective perceptions after ABI, such as the experiences of strengths and weaknesses in daily communicative participation, might not be readily accounted for by applying the framework in its present form.

Following the same line of reasoning, it has also been pointed out that the importance of *context* has been undervalued in the ICF and that there has been a "disproportionate emphasis on individuals' functioning at the expense of their life context" (Cruice, 2008, p. 38).

The relevance to this thesis relates to a call for definitions that take account of the meaning or purpose of social activities from the viewpoint of the participants' own experience of participation in their own personal surroundings. Cruice argues that the personal *context* "continues to be problematic for clinicians and researchers who wish to discuss the importance of Personal Factors and Environmental Factors within client-centred intervention and health care provision" (ibid.).

In accordance with these critical notes, and to add to the body of knowledge related to participation and subjective dimensions of the ICF, certain measures were taken to further expand on these topics in this thesis. These measures relate to a change of direction in the assessment and rehabilitation procedures of persons with ABI since the introduction of the ICF. Specifically, more recent areas of investigation connected to the home-based rehabilitation and training of conversation partners have emerged (Togher, McDonald, Tate, Power, and Rietdijk, 2009). Involving significant others in the assessment procedures of a participant's daily communication has also proven to be a promising approach. In fact, the notion that communication assessment and training are best served in a home-based environment is slowly gaining ground (Braga, da Paz Júnior, and Ylvisaker, 2005).

# ACTIVITY BASED COMMUNICATION ANALYSIS, INCLUDING COMMUNICATION MANAGEMENT

Activity based Communication Analysis (ACA) is a theoretical approach to communication and pragmatics, with the emphasis on everyday communication skills and ecological validity (Allwood, 1976, 1995). Central to the ACA are the notions of communication and activity.

ACA was chosen to provide an overall focus on ecological validity in the studies in this thesis. It was also applied in more detail in the analysis of data in **Papers II** and **IV**. ACA was developed by Allwood and colleagues and has been previously applied in different areas of research: aphasia and autism and in other contexts with groups of participants with complex communication needs (Ahlsén, 1995; Ferm, Ahlsén, and Björck-Åkesson, 2005; Rydeman, 2010; Saldert, 2006; Thunberg, Ahlsén, and Sandberg, 2007).

In ACA, two main types of influencing factor which determine communication outcome, *collective factors* and *individual factors,* have been described.

Collective factors refer to questions related to a specific communication activity, such as why it is done, what are the obligations and the rights of the participants, what are the physical and other conditions of the activity, what artifacts are used for communication and how they are applied in the context.

Individual factors refer to the background of a specific participant participating in a communicative exchange, i.e. individual experiences, characteristic features, for example, social, psychological and biological features of the identity.

ACA scaffolds models for a more detailed exploration of the participant's abilities to communicate in different everyday situations, leading to a highly *composite assessment* which makes the model particularly suitable for studies with a mixed-methods design. Composite assessments signify the use of several types of method for analysing observations of functional assessments. In ACA, the *observation of video-recorded interaction* is the most common method of empirical observation. It comprises a more detailed microanalysis of the primary observation, i.e. a detailed analysis of specific factors, features and/or sequences occurring in communication

exchanges. Furthermore, ACA can be used to analyse *quantitative measurements* of the interaction as a part of the analysis of behaviour.

The elements in the theory that are of relevance to this thesis point to the more detailed analysis of data relating to observations of communication in different contexts by different participants. An important part of ACA is the analysis of interaction patterns, especially communication management.

The Communication Management (CM) model described by Allwood, Nivre and Ahlsén (1990) was applied in **Papers II and IV** to evaluate the results of the assessments of live conversations and of video recordings. The model was chosen based on its multimodal analysis of interpersonal communication.

In the model, Own Communication Management (OCM) is regarded as a basic feature in face-to-face interaction. OCM represents a speaker's planning and implementation of an intended message in a dialogue. OCM has also been described in terms of hesitation, planning, disfluency, self-correction, editing and self-repair. Another type of communicative mechanism is Interactive Communication Management (ICM), aiming at managing the interaction between interlocutors through systems for turn-taking, feedback and sequencing. To conduct a dialogue, the speaker will need to plan what to say, as well as when to say it, and he or she will also need constantly to moderate the message, depending on the response from the other speaker. The response can take the form of a verbal reply, a facial gesture, a change in body posture or movements of arms and hands, incorporating gestures as significant features of functional communication (Allwood, 2002). Analyses of the patterns for feedback according to different *moods (Declarative, Interrogative, Imperative or Exclamative)* provide examples of the interlocutors' management of their own communication and of ways to manage turn-taking and sequencing in relation to the other speaker, as OCM and ICM frequently coincide. Consequently, OCM and ICM are closely related and in a continuous interactive process with the main message (MM). The overall purpose of the interactions is to share main messages among speakers and to make communication as smooth and fluent as possible (Figure 2).

The contribution of the theory for exploring the data in the thesis includes the emphasis on the multimodal aspects of communication and on assessments of interactive communication in everyday activities.

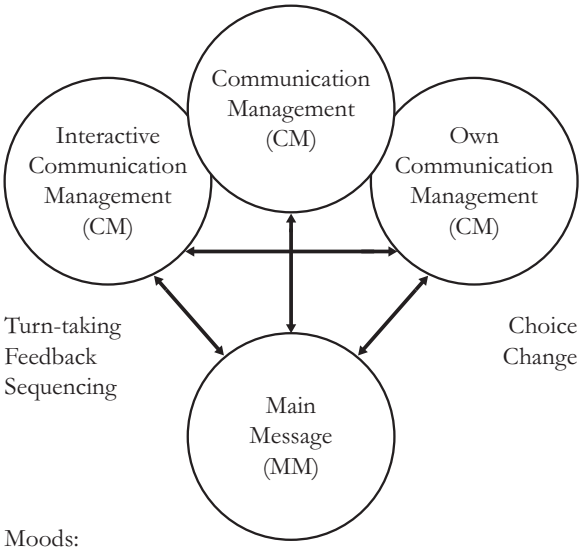


Figure 2. Main functions of Communication Management (CM).

## DISTRIBUTED COGNITION

A theory of integrated communication has been presented by Lev Vygotsky, who argued that the most central question for human consciousness concerns the relationship between thinking and language. He claimed that early egocentric language in the child is an essential part of social communication which gradually develops in dialogues with other people. Through others, one gets to know oneself and, for this reason, neither language nor thought will evolve in a child without an interactive social communication context (Vygotsky, 1987).

Vygotsky's theory of the importance of context for the development of communication skills relates to the cognitive science perspective on

cognition in real-world environments, a perspective that has been developed in particular by Edwin Hutchins (1995b). Derived from cognitive science, distributed cognition analyses the organisation of cognitive systems by exploring the interaction between participants engaged in an activity, the representational media involved (e.g. artifacts, objects, materials) and the environment in which the activity occurs.

According to Hutchins et al., the central idea behind distributed cognition relies on at least three kinds of observation (Hollan, Hutchins, and Kirsh, 2000; Hutchins, 2000):

- Cognitive processes may be distributed across members of a social group
- Cognitive processes may involve co-ordination between internal and external (material or environmental) structure
- Processes may be distributed through time in such a way that the outcome of earlier events can transform the nature of later events.

The distributed cognition perspective is particularly interesting for investigating communication after ABI; first, because the model connects communication to overall cognitive abilities like memory, attention, affect and perception; second, communication is distributed between members of a social group; third, communication involves co-ordination between internal and external structure and, fourth, communication processes may be distributed through time in such a way that the outcome of earlier communication exchanges can transform the nature of later events.

In this way, the distinction between *people, material/environment and temporal aspects* in the definition appears to be a fruitful approach when describing factors related to outcome after ABI. Even though the communication partner and the surrounding environment are both part of the overall context during a conversation, it may be important methodologically to separate the two units of analysis, as they may affect a person's ability to communicate in different ways. For example, the comprehension ability of a person with ABI may be highly related to the speed of conversation of the conversation partner. As a result, a fast-paced conversation may reduce the comprehension skills in the person with the communication disorder and an adjustment by the communication partner to a lower con-

versational speed may significantly increase these comprehension abilities. This phenomenon was studied in **Paper II**. However, there might be aspects of communication that depend on other factors, such as visual or auditory stimuli. In this case, the main analytical focus is on the effects of the surrounding environment and the impact on the individuals acting in it. For instance, the location of a conversation may be visually cluttered or noisy, which can impair language comprehension during the communication exchange, in particular in participants with auditory or visual impairments after ABI. In the selected participants in the thesis, the majority were affected by these impairments.

Further, there are temporal aspects of communication which are clearly relevant to the adolescents with ABI in this sample. All the participants were developing typically prior to the brain injuries. The communication skills they had acquired before the injuries could therefore be related to abilities post-injury and the previous communication experiences could frame the further rehabilitation interventions. This perspective was underscored in **Papers II, III, IV and V,** where the nature and/or extent of the communication abilities before the injuries were compared with post-injury data and to follow-up data.

Temporal aspects of the distributed cognition approach have been used previously to examine communication after ABI. Duff and colleagues (Duff et al., 2012) proposed distributed cognition as a framework to interpret the communicative interaction in adult participants, based on assessments of multimodal interactions with interlocutors who seek to accomplish a functional activity. Duff argues that the traditional approach to analyse discourse has been too static, e.g. generating a percentage of utterances that were on topic, or a percentage of time the participant was looking at the interlocutor. They point out that average alone does not produce all the relevant information since "conversations are also non-linear, as changes over time cannot be predicted from the initial state but rather are emergent and change as a function of interactions between participants among materials and the environment" (Ibid., p. 50)

In conclusion, the relevance of distributed cognition to the thesis is multidimensional and relates to the basic principles of the distributed cognition framework, which focus on an understanding of the processes that are involved in communication between individuals in an everyday con-

text. These processes are based on cognition, in the sense that "cognition is a fundamentally cultural process" (Hutchins, 1995a, p. 374).

## PUTTING CETI ITEMS INTO CONTEXT THROUGH THE ACA AND DISTRIBUTED COGNITION PERSPECTIVES

In a previous study of communication in adult participants with brain injuries, a factor analysis of the CETI items suggested that there were two underlying factors for the CETI scores: Factor 1, concerning communicative interactions that require a vocal-verbal output, and Factor 2, related to communication which might be conducted by only using non-verbal means such as pointing, mimicry and other body gestures (Pedersen et al., 2001). Pedersen found the highest loading for Factor 1 (vocal-verbal) on CETI items 2, 3, 6, 7, 8, 10, 12, 14, 15 and 16. Factor 2 (non-verbal) was related to items 1, 4, 5, 9 and 11: *Getting somebody's attention, Communicating his/her emotions, Indicating that he/she understands what is being said to him/her, Communicating physical problems such as aches and pains and Responding to or communicating anything (including yes or no) without words*. The CETI data obtained in the present thesis likewise showed that the vocal-verbal CETI items associated with Factor 1 were the most difficult to manage, as they were assigned the lowest scores by the participants, in particular by the parents. For example, items 2, 12, 14, 15 and 16: *Getting involved in group conversations that are about him/her, Starting a conversation with people who are not close family, Being part of a conversation when it is fast and a number of people are involved, Participating in a conversation with strangers* and *Describing or discussing something in depth* were rated lowest of all the items by the parents, ranging between 46.20-76.40 of 100 on the VAS scale. The perceived reduction in the communicative ability of the adolescents was analysed from the viewpoint that Factor 1 items were associated with a higher degree of complexity compared with Factor 2 items and that the interactions typically occurring in Factor 1 items were commonly occurring in the complex daily interactions that took place in the participant's family, at school and with friends. The complexity of the Factor 1 items was related to interactions with rapid speech and language processing, high demands on cognitive skills,

for example, demands on short- and long-term memory, maintaining and shifting attention functions and maintaining a generally high processing speed. In fact, it could be argued that complexity is associated with Factor 2 items as well, which is probably true to some extent, but the inclusion of the vocal-verbal output in Factor 1 items appears to increase the demands on communication management substantially. Furthermore, other interesting pieces of information emerged in the studies in this thesis, related to communication complexity, such as the goal of the exchange, the people involved in the interaction, the role of the participants, the use of artifacts and of coping strategies, the influence of the environment where the communication occurred, multimodal aspects of the complex interactions and the temporal aspects of the assessments. To clarify and organise the information and the impact on daily communicative participation, the ACA and the distributed cognition frameworks were applied as theoretical lenses, in particular in Papers II-V. With this introduction, some examples of the applications of the frameworks mainly related to Factor 1 items now follow, to describe communicative situations in which the vocal-verbal output was an important part of the interaction.

The ACA perspective pointed to the social activity in which the communication occurred. These situations comprised talking with other family members at home, for example, at dinner-time. Situations in which communication occurred were also activities in the school environment; in class or during breaks. Another social activity for communication was leisure time when interacting with peers. The goal of the communicative activities was to start, or be a part of, conversations in order to socialise, or to apply communication strategies to cope with difficulties after the ABI. The reported physical environments were frequently face-to-face interactions in surroundings rich in both visual and auditory stimuli. It was also commonly reported that the activities involved several interlocutors and conversations that were conducted at a rapid speed. The proficiency needed in these conversations comprised cognitive skills and language comprehension abilities to decode vocal-verbal messages and produce their own contributions to the interactions. When it came to their own Communication Management (CM), speech production was needed, as well as sufficient language abilities to provide relevant content to the verbal-vocal expressions. Furthermore, the CM perspective included the use

of communicative responses related to patterns for turn-taking, facial gestures, changes in body posture or movements of arms and hands, incorporating gestures.

The distributed cognition perspective provided a framework (i) to specify the distribution of cognition across the members of the group, i.e. to explore how the patterns for communication in a group with typically developed peers or family members influenced the communicative abilities in a participant with ABI; (ii) to investigate the internal experience of the communication disorder in the adolescents themselves and the coordination between the internal experience and external perceptions of others' activity in communicative situations, plus the coping strategies that were applied, and (iii) to explore the significance of the temporal influences on the communicative skills.

## THE JOHARI WINDOW MODEL

It has been suggested that the self has a clear advantage over others because of the total amount of information available to the self. In a guide to different types of self-report, it was proposed that the notion that people are best qualified to judge their own personalities is supported by the indisputable fact that no one else has access to more information about a person (Vazire and Paulhus, 2007). However, there is support for a more complex viewpoint of self-evaluations as well. Results show that, first, the self appears to be the best judge of traits that are low in observability (and accordingly difficult for others to judge) and low in appraisal (hence not distorted by self-protective biases). The self was therefore consistently the best assessor of neuroticism-related traits such as self-esteem and anxiety (Vazire, 2010).

The Johari Window model has been used in studies of the perception of personality traits, to explain and predict asymmetries of evaluations made by the self, compared with evaluations made by others than the self. The method has been applied to meet the need for more information about the potential in each perspective to highlight aspects of personality (Luft and Ingham, 1955; A. K. Shenton, 2007; Vazire, 2010).

The model is a grid of four quadrants: (a) aspects of personality known to both the self and others (arena), (b) aspects known to the self but not

others (façade), (c) aspects known to others but not the self (blind spot) and (d) aspects unknown to both the self and others (unknown) (Figure 3).

| | **Known to self** | **Unknown to self** |
|---|---|---|
| **Known to others** | Arena | Blind spot |
| **Unknown to others** | Façade | Undiscovered potential |

Figure 3. Johari Window

The motive for adopting the model in this thesis was a hypothesis that it could be a useful tool to clarify the different perceptions of daily communication abilities between the adolescents participating in the study, together with the perception of their parents. This was an important perspective, as an understanding of the nature and extent of communicative participation in the adolescents provided a basis for subsequent rehabilitation interventions.

To summarise, the features of the applied theories, ICF, ACA and distributed cognition, were relevant parts of a complex theoretical lens to study different aspects of communication in the participants in this thesis. The approaches partly overlapped, with the ICF as the overarching model, relevant in all the studies. Furthermore, the Johari Window model provided inspiration to visualise the level of knowledge of the communi-

cation strengths and needs of the participants following the brain injury. In Study I, the ICF aspects of communication in different activities were particularly highlighted. Study II used ACA in a video-recorded analysis of multimodal features of communication and also applied the perspective of distributed cognition. The distinction between *people, material/environment and temporal aspects* of distributed cognition was relevant not only to Study II but also overlapped in the other studies, in particular in Studies III, IV and V. In Study IV, the ACA approach was again a highly relevant approach, to investigate the *collective factors* and *individual factors* in self and parental ratings, performed by adolescents themselves and their parents. In the discussions with the participants, the Johari model helped to clarify the responses. Study V was particularly related to the distributed cognition perspective, *Processes may be distributed through time in such a way that the outcome of earlier events can transform the nature of later events,* associated with the follow-up of communication after a period of intervention in the home environment.

# AIMS

The overall aim was to contribute to discerning the nature of communication disorders in adolescents with ABI, by investigating adolescent and parental evaluations of communication in everyday interaction and relating them to a selection of cognitive, linguistic and brain injury assessments. One specific focal point was to validate the Communicative Effectiveness Index, CETI (Lomas et al., 1989), for use in adolescents with ABI.

The research questions which are the basis of this thesis are:

Paper I How can the use of a clinical tool for pragmatic assessment, the Pragmatic Protocol (Prutting and Kirchner, 1987), help in exploring communication abilities that require rehabilitation in adolescents with ABI?

Paper II How can two methods of investigation, (i) analysis of communication management in video-recorded interactions and (ii) self and parental assessments using the CETI capture communication change in a case of ABI?

Paper III How do parental assessments of communication in adolescents with ABI, applying the CETI, correlate with the results of conventional linguistic/cognitive tests and brain injury data and what does each of the methods contribute to clarifying the outcomes?

Paper IV How can agreements between adolescent self-reports and parental reports of communicative participation reveal and explain similarities and differences between adolescents' and parents' perceptions? Can semi-structured interviews further clarify the differences?

Paper V How are parental ratings of communication in adolescents with ABI developing 12 and 24 months post injury after a period of applying communication strategies in the home environment?

# METHODS

First, a general overview of the thesis design is given.

Second, the participants are described to account for demographic and brain injury data. An overview of the number of adolescents included in the thesis is given, followed by a more detailed description of the participants in each of Studies I-V.

Third, ethical considerations related to the inclusion of participants with brain injuries and their relatives are accounted for.

Fourth, the outcome measurements used in Studies I-V of the linguistic, cognitive and communication aspects are described in detail, related to each study.

Fifth, the settings and the procedures for data collection in the thesis are described.

Sixth, an account of the data analyses and statistics used in the thesis is given.

# DESIGN

The thesis comprises five studies. They are multidisciplinary, prospective studies comprising data from the speech language pathology, medical, nursing and neuropsychological professions, with the emphasis on the speech and language pathology results.

To meet the research requirements associated with the complexity of this type of investigation, a mixed-methods design was used, comprising both qualitative and quantitative data. Parallel data gathering was conducted, collecting qualitative and quantitative data at the same time. The purpose of the method was to ensure that understanding was improved by confirming that the limitations of one type of data were balanced by the strengths of another (Creswell, 2013; Tashakkori and Teddlie, 2010). An overview of the included papers (I-V) is presented in Table 2.

Table 2. Overview of the thesis design

| Paper | Design | Inclusion criteria | Participants | Data collection | Time post trauma | Data analyses |
|---|---|---|---|---|---|---|
| I Clinical inter-rater data on pragmatic functions<br>(Study I) | Longitudinal<br>Comparative | ≤ 18 years old<br>ABI diagnosis | 8 adolescents with ABI | Face to face<br>Clinical inter-observer agreement data<br>Pragmatic functions<br>PP taxonomy<br>Brain injury data<br>Cognitive/linguistic assessment | 6-14 months | Descriptive and comparative statistics<br>Interpretative analyses |
| II Self-ratings compared with outcome of background data and parental assessments of daily communication. Actual behaviour in video-recorded dialogues<br>(Study II) | Single subject<br>Comparative<br>Exploratory<br>Follow-up study | Participated in Studies III, IV and V<br>≤ 18 years old<br>ABI diagnosis | 1 adolescent with TBI<br>2 conversation partners<br>The parents of the adolescent | Self-assessment<br>Parental assessment<br>CETI index<br>Video recordings<br>Open-end interviews<br>Cognitive/linguistic assessment | Follow-up at 6 and 15 months | Descriptive statistics<br>Interpretative<br>Hermeneutical analyses |
| III Clinical test evaluations related to background brain injury data and to parental measurements of communication<br>(Study III) | Prospective<br>Longitudinal<br>Exploratory<br>Between-group design | Participated in Studies III, IV and V<br>≤ 18 years old<br>ABI diagnosis | 30 adolescents with ABI<br>30 parental evaluations | Language comprehension<br>IQ data<br>CETI index<br>Demographic data<br>Brain injury data<br>Parental assessments | M=12 months | Descriptive statistics<br>Interpretative<br>Hermeneutical analyses<br>Cronbach's alpha<br>Mann-Whitney tests<br>Chi-square test |
| IV Everyday communication in adolescents after acquired brain injuries – a comparative study of self-ratings and parental evaluations using CETI<br>(Study IV) | Comparative<br>Exploratory<br>Interview study<br>Theory development | Participated in Studies III, IV and V<br>≤ 18 years old<br>ABI diagnosis | 8 adolescents with ABI | Self-assessment<br>Parental assessment<br>Open-end interviews | M=24 months | Descriptive statistics<br>Interpretative<br>Hermeneutical analyses<br>Spearman rho<br>Wilcoxon signed-rank test |
| V Measuring change after intervention in the home environment<br>(Study V) | Comparative<br>Exploratory<br>Interventional<br>Follow-up study | Participated in Studies III, IV and V<br>≤ 18 years old<br>ABI diagnosis | 30 adolescents with ABI<br>30 parental evaluations | Language comprehension<br>IQ data<br>CETI index<br>Demographic data<br>Brain injury data<br>Parental assessments | Follow-up at M=12 and 24 months | Descriptive statistics<br>Interpretative<br>Hermeneutical analyses<br>Wilcoxon signed-rank test<br>Chi-square test |

A uni-centre, interdisciplinary design was used as a basis for all the studies.

In the first study **(Paper I)**, a comparative, prospective design was used to describe the participants' everyday communication in a clinical environment.

Loss of consciousness (LOC) was investigated as a measurement of injury severity (Horneman, 2006). Demographic and clinical variables, as well as inter-rater observations, recorded in the Pragmatic Protocol, PP (Prutting and Kirchner, 1987), were obtained from professional evaluations of eight adolescents, six to 14 months after the trauma.

The eight participants in Study I were only included in that particular study, while the participants in Studies II-V were all selected from the same sample (n=30). As a result, a total of 38 adolescents participated in Studies I-V.

The second study **(Paper II)** was a single-subject comparative study, exploring two methods for analysing communication after ABI in a 16-year-old participant: Analysis of communication management in video-recorded 'first acquaintance' conversations, involving the young man with ABI and one or two interlocutors. The other method for analysis involved ratings using the Communicative Effectiveness Index (CETI). CETI data from parental ratings, as well as self-assessments by the adolescent himself, were evaluated six months post-onset, with follow-up at 15 months post-onset. The video recordings were made at follow-up, 15 months post-onset.

The third study **(Paper III)** applied a prospective, longitudinal, between-group design, aimed at exploring parental assessments of the communication abilities, according to the CETI, of 30 adolescents, 12 months post-injury. Clinical assessments of cognitive and linguistic abilities, as well as data on lesion site and aetiology, were explored. The aim of this study was to investigate associations between parental ratings of daily communication in the adolescents and the results of a selection of linguistic and cognitive tests. In addition, the study also checked how information from the parental communication ratings and linguistic/cognitive tests related to background data on lesion site and aetiology, i.e. (i) whether participants with a particularly poor communicative outcome in real-life situations also had cerebral lesions located in the left hemisphere

and (ii) whether there was any difference in results depending on the aetiology of the injuries.

Study four **(Paper IV)** was a comparative descriptive qualitative study applying ACA and distributed cognition in combination with the Johari Window model as analytical tools. In study four, CETI data and interviews were used to analyse aspects of self- and other-judgements of communication in daily situations after ABI. Nineteen participants (8 adolescents with ABI and their parents) were included in the study.

The last study **(Paper V)** was a follow-up study of parental ratings of daily communication using the CETI (n=30). The study compared data between 12 and 24 months post-injury, after a period of applying communication strategies in the home environment. The study is an extension of the data presented in Paper III. The overall purpose of the study was to assess changes in parental ratings of communication in the participants with ABI. The purpose was also to check the sensitivity of the CETI in capturing individual daily communication circumstances that could explain the results.

A second purpose of this study was to explore whether children who had more severe communication impairments displayed different recovery patterns after the period of applied parental strategies, compared with children with milder communication impairments, according to parents' evaluations.

## PARTICIPANTS

This is a clinically based study with 40 originally registered consecutive participants with ABI. Of the original sample, 27 adolescents had suffered a TBI and 13 an NTBI. An overview of the adolescents who participated in Papers I-V is shown in Figure 4.

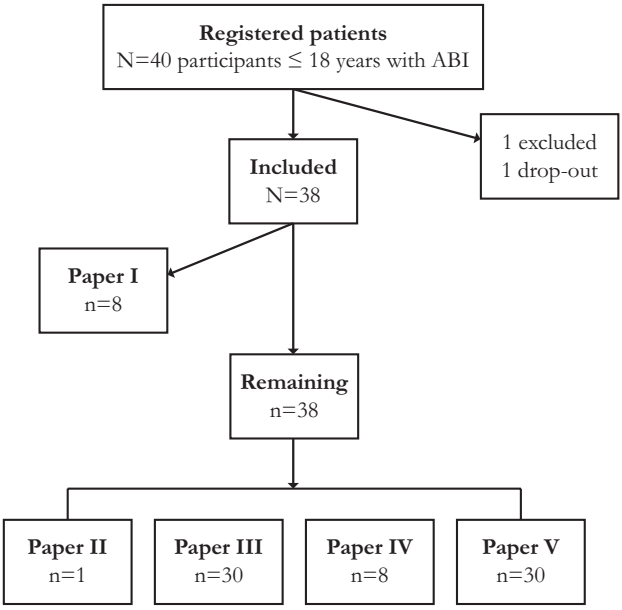


Figure 4. Overview of the children and adolescents with ABI who participated in the studies in this thesis. Data from eight participants were included in Paper I, while the data collected from the remaining 30 participants were investigated in Papers II, III, IV and V.

## INCLUSION OF PARTICIPANTS WITH NON-TRAUMATIC BRAIN INJURY (NTBI)

Previous studies have shown that cognitive impairments in young people with TBI may cause communication problems in everyday social communication (Turkstra et al., 2014). Injury severity appears to be strongly related to cognitive outcome: more severe injuries are associated with poorer IQ, impaired linguistic functions and emerging memory deficits (Anderson et al., 1997). However, impaired cognitive outcome and related communication problems are not restricted to individuals with injuries caused by traumas, since NTBI are also known to cause communication disorders (Rispoli, Machalicek, and Lang, 2010; Zetterqvist and Jennische, 2010). Furthermore, there appears to be an increase in the number of

young people with NTBI related to different aetiologies. For example, the improved survival rates for adolescents with brain cancer and stroke (Greenham, Gordon, Anderson, and Mackay, 2016; Siegel, Miller, and Jemal, 2016), as well as the dynamic and constantly changing epidemiological profile of survivors of meningitis, all have a role to play in the augmentation of injuries (Harrison, 2010). Moreover, it has been argued that the heterogeneous profile of individuals with ABI may be the cause of their under-representation in the research literature (Sohlberg, Griffiths, and Fickas, 2015). However, recruiting an acceptable number of participants within each of the NTBI aetiologies for particular group-design studies might be practically unfeasible, as a result of the low incidence within specific aetiologies.

In conclusion, people with traumatic ABI, as well as those with non-traumatic ABI, frequently have communication impairments related to their brain injuries. An exploration of both subgroups to clarify differences as well as similarities in outcome could add useful knowledge when developing communication interventions for the entire ABI group. Consequently, adolescents with both TBI and NTBI participated in this study.

The aetiology of the injuries in the participants was heterogeneous, but multifocal injury location was the more common neurological status, involving both TBI and NTBI (n= 25). For the TBI, the following causes of injury were recorded: (i) traffic accident, (ii) sporting accident or (iii) physical assault. For the NTBI, the following causes of injury were recorded: (i) tumour, (ii) intracranial arteriovenous malformation, (iii) anaesthesia-related morphine overdose, (iv) stroke and (v) meningitis or encephalitis.

The participants were recruited from consecutive admission to a regional rehabilitation unit at the Queen Silvia Children's Hospital, in the south-western health-care region in Sweden. They had been admitted for assessment after the conclusion of hospital-based treatment procedures. The included families had to live in the catchment area of the south-western health-care region to be referred to the clinic. All the participants but one were eight years old or above at the time of injury. The inclusion criteria were: no previous history of neuropsychiatric disorders or neurological deficits and Swedish as a first language.

Of 40 selected families, one family declined to take part in the communication evaluation during the clinical assessment period with reference to other more urgent rehabilitation needs for the child. Another participant was excluded from the study due to the interruption of the clinical evaluation procedures, on the family's own initiative. The final sample comprised 38 participants (23 males and 15 females), all of whom had neurologically assessed complex clinical pictures after head injuries, resulting in cognitive and communicative impairments.

Of the 38 participants assessed with conventional neurological measurements, there were 21 severe, nine moderate and eight mild cases of ABI. However, a closer look at the data obtained from neuroimaging assessments of the brain showed that seven of eight of the participants with "mild" injuries had visible sequelae manifested as injuries to different cerebral locations. Consequently, in accordance with observations in previous studies (Williams, Levin, and Eisenberg, 1990), the outcomes in these seven participants were not as "mild" as had been indicated in the initial assessments. A more accurate approximation of the injury severity in these seven cases was probably that of a "complicated mild" or "moderate" head injury outcome.

## CHARACTERISTICS OF PARTICIPANTS IN EACH OF THE STUDIES

### Paper I

Eight adolescents with ABI, four girls and four boys, participated. Their mean age at assessment was 13.43 years (median 13.58, SD 2.19, range 9.3-16.1). The time that passed between the head injuries and assessment was a mean of 9.89 months (median 9.00, SD 2.40, range 6-14 months). Six of the participants had been involved in traffic accidents, one had been injured in a fall accident and one had suffered a stroke. Seven of the participants had severe head injuries, while one of the adolescents was diagnosed with a moderate injury.

Paper II

The participant was a 16-year-old male with a moderate TBI. The parents of the young man also participated in evaluations of daily communication.

Papers III, IV and V

Thirty participants with ABI, 19 males and 11 females, were included. The mean age at assessment was 14:2 years (SD 2:7, range 8:6-17:8). The mean age at injury was 12:7 years (SD 3:2, range 2:6-17:5). The assessments were concluded on average 12 months post-injury with follow-up on average 12 months later. The total results of the neurological ratings of injury severity were 14 severe, nine moderate and seven mild cases. The parents of the 30 adolescents participated in the communicative evaluations.

## ETHICAL CONSIDERATIONS

Approval of the study was obtained from the Regional Ethical Review Board of Gothenburg, in the southwest region of Sweden. Oral and written information about the study was communicated to the participant with brain injury and his/her parents during the clinical assessment period. Since all the participants were under age and because of the nature and extent of their injuries, not everyone was able to give informed consent to participate in the study. It was therefore essential that the parents were informed about the study, particularly as a major part of the intervention relates to parental evaluation and communication support in everyday life.

Parents were also informed that, if they wanted to withdraw from the project, this decision would not affect treatments or other interventions that were planned for their child. They were also assured of confidential and anonymous handling of the research data.

# MATERIALS AND MEASUREMENTS

## INJURY SEVERITY VARIABLES

Estimations of injury severity were obtained for all participants. The severity of TBI was determined by the on-scene paramedics or rated at the time of presentation at the emergency room. The Glasgow Coma Scale – GCS (Teasdale and Jennett, 1974) or the Swedish equivalent, the RLS 85 – the Reaction Level Scale (Starmark, Stalhammar, and Holmgren, 1988), were applied. Both taxonomies evaluate the same basic information (response to speech, touch and pain), thereby making a comparison of injury severity possible (Tesseris, Pantazidis, Routsi, and Fragoulakis, 1991). Estimations of post-traumatic amnesia (PTA) were a primary source of information in eight participants (McCauley et al., 2012). Furthermore, in Study I, the main measurement of injury severity was based on measurements of loss of consciousness (LOC).

TBI was considered mild if the GCS was 13-15, moderate if the GCS was 9-12 or severe if the GCS was > 9. According to the PTA measurements, injury severity was considered mild if PTA was < 1 hour, moderate if PTA was 1-24 hours and severe if PTA was one to seven days or more (Teasell et al., 2007). According to the LOC taxonomy, mild TBI corresponded to an LOC of 30 minutes, moderate TBI to an LOC ranging from 30 minutes to 24 hours and severe TBI to an LOC of six hours to one week or more (Horneman, 2006).

The collected injury data for the participants from GCS, RLS 85, PTA or LOC estimations were converted into a three-grade scale, where 1 equals mild, 2 equals moderate and 3 equals severe injury.

The severity of NTBI was scored after admission for assessment to the rehabilitation centre where this study was conducted. Participants with no records of reduced levels of consciousness or presence of amnesia related to the brain injuries (n=6) were scored according to an adapted version of the paediatric Modified Rankin Scale – mRS (Bonita and Beaglehole, 1988; de Kloet et al., 2013):

- (i) Mild injury: minor motor limitations and/or minor problems with communication (mRS 0, 1)
- (ii) Moderate injury: moderate motor impairments and/or moderate problems with communication (mRS 2, 3)
- (iii) Severe injury: severe motor impairments and/or severe problems with communication (mRS 4, 5).

## LINGUISTIC, COGNITIVE AND COMMUNICATION MEASUREMENTS

Paper I

*The Pragmatic Protocol (PP)* was developed to provide an overall clinical index of pragmatic functions for school-age children, adolescents and adults (Prutting and Kirchner, 1987). The PP aims to reveal problems using language in socially appropriate and effective ways (Appendix 1). It contains 30 aspects that cut across different levels of the communicative system: speech production, speech comprehension and non-vocal communication, such as gesture, eye gaze or mimic. Prosodic features are also investigated. The protocol has been widely used in clinical settings to measure the occurrence/non-occurrence of deviating pragmatic performance, judged by professional staff from communicative interaction with the person with the health condition (Togher, 2000). It was chosen in this study as a primary evaluation tool, to learn about the communication ability in the participants through clinical interobserver agreement data.

Paper II

The neuropsychological assessments comprised the *Wechsler Adult Intelligence Scale – III: WAIS-III* (Wechsler, 2003), the *Rey Auditory Verbal Learning Test: RAVLT* (Rey, 1941), the *Dichotic Listening Test – monaural presentation* (Hugdahl and Asbjørnsen, 1994).

The speech language assessment consisted of the *Peabody Picture Vocabulary Test III: PPVT III,* assessing receptive word comprehension skills (Dunn and Dunn, 2001) and the *Test for Reception of Grammar: TROG-2,* assessing receptive comprehension skills in grammar (Bishop, 2009).

Previous findings point to correlations between Verbal IQ and PPVT-III scores in typically developing school-aged participants, indicating "rather strong evidence that PPVT-III is an effective screening device for verbal ability" (Dunn and Dunn, 1997, Examiners manual, p 57). It has also been shown that language-disordered children and adolescents with expressive grammatical problems did poorly on both the TROG and the PPVT (Bishop, 1979). So, to further add to the body of knowledge in participants with communication problems after head injury, the TROG and PPVT were chosen to investigate language comprehension skills related to the complexity of expressive speech.

Further, the *Boston Naming Test: BNT,* a visual confrontational naming test (Kaplan, 1983), and *LäsKedjor*, a standardised reading test (Jacobson, 2001, 2009), were used.

*The Communicative Effectiveness Index, CETI* (Lomas et al., 1989), was chosen to study parental estimations of communicative participation in real-life situations and it was translated into Swedish with the kind permission of the author. The CETI was chosen as an assessment tool because (i) it covers a range of communicative behaviours associated with ABI, (ii) it is well known in the domain of acquired functional communication disorders, (iii) it is based on descriptions by significant others of communication performance in daily communication situations in persons with ABI and (iv) the administration of the test is not especially time consuming (see also *Literature review,* p. 16)

Videotaped recordings of "first acquaintance" conversations were obtained. These recordings consisted of two situations, each containing a ten-minute semi-structured conversation: (i) the two-party conversation and (ii) the three-party conversation.

Paper III

The test battery included the *WAIS III,* or the *Wechsler Intelligence Scale for Children– WISC III/IV* (Wechsler, 1991, 2007), depending on the participant's age at assessment; *PPVT III, TROG-2 and BNT*. The *CETI* taxonomy was administered to the parents.

Paper IV

This paper is based on *CETI ratings* and individual *interviews* with the adolescents with ABI and their parents.

Paper V

*WAIS III* or *WISC III/IV* were applied in this study, depending on the participant's age at assessment. *PPVT III, TROG-2, BNT* and *CETI* were also used. *Individualised communication strategies* were applied by the parents in the home environment during a one-year intervention, between the two assessment times.

## SETTINGS AND PROCEDURES

The participants in this study were referred to a regional rehabilitation centre in Sweden. The participants were recruited from consecutive admission during a four- to six-week assessment period assigned to map the overall outcomes of the acquired brain injuries.

First, the participants with ABI were evaluated with conventional linguistic and cognitive tests and through the CETI assessments, during the assessment period in the regional rehabilitation clinic. At this point, the individually based intervention in the home environment was also planned and initiated. Second, follow-up measurements of the communicative intervention in the home environment were collected in the CETI when the families returned with the adolescents to the clinic for follow-up assessments of outcome, about one year after the first evaluation. Third, the communicative interventions were also evaluated by interviews with a selection of the parents and adolescents, at the clinical follow-up**.** Video recordings were made at follow-up in the case study (Paper II).

The participants were admitted to the clinic after discharge from hospital after treatment related to TBI or NTBI. In the TBI cases, the acute care hospital treatments involved treatments such as head trauma care after traffic accidents. In the NTBI cases, medical treatments consisted, for example, of cerebral tumour therapies, such as radiation and surgery, or in haemorrhage interventions after childhood stroke.

The clinical findings in the thesis, i.e. linguistic and cognitive results, as well as brain injury and demographic data, were obtained using an

interdisciplinary teamwork approach (Thylefors, Persson, and Hellström, 2005), in collaboration between professionals in a rehabilitation team. The additional team members who participated were, apart from the undersigned speech language pathologist (SLP), two SLPs, a neuropaediatrician, rehabilitation assistants, a social worker and a neuropsychologist.

Demographic and brain injury data were collected from the clinical case records of the adolescents with ABI. Data on injury locations for each participant with ABI were obtained through available medical records related to the accidents or treatments. The records were provided either through examinations with computed tomography (CT) or through magnetic resonance imaging (MRI) results. Evaluations of the nature and extent of the injuries were made by a neurologist as part of clinical practice. Injury aetiology was heterogeneous; however, multifocal injury locations were the more common neurological status.

Further procedures involved the assessment of cognition, language comprehension and communication. All the measurement procedures in each of the studies are described below.

Paper I applied the Pragmatic Protocol to measure clinical interobserver agreement data obtained from daily interactions with the participants with ABI. The rehabilitation assistants and a speech language pathologist who were involved in the clinical rehabilitation procedures in the adolescents with ABI performed the assessments. Interdisciplinary team discussions, which formed a basis for the interpretation of the data, also included the neuropaediatrician and the social worker.

Paper II studied a single case, a 16-year-old adolescent with ABI, using different methods. The study applied evaluations at the clinic at six months post-injury with a comprehensive neuropsychological and speech language test battery. Video recordings were made of "first acquaintance" conversations, involving the young man with ABI and one or two interlocutors who were both typically developing young men. The setting was a lab at the university and the participants gave their informed consent to participate. The two typically developing young men who participated were not informed about the young man's head injury, only that the experiment was being conducted to investigate communication patterns in a

"first acquaintance" conversation. The conversations were filmed with three video cameras from three different angles simultaneously: from the back, from the right side and from the left side. The distance between the cameras and the subjects was about three metres. The instructions were to assume relaxed standing positions at a convenient communicative distance from each other. Further, the participants were instructed to communicate freely for ten minutes, trying to get to know one another. The research administrator left the room in which the video recordings took place, during the conversations between the adolescents.

Ratings using the CETI by the parents and the adolescent with ABI himself were made. The linguistic and cognitive data relevant to communication were also obtained in clinical trials, applying standard test procedures, but the linguistic tests were conducted in quiet surroundings and under no time-pressure conditions to enhance the participation perspective of the adolescent in the test procedures. The parents took part in the data collection in the CETI, as well as in continuous discussions during the clinical trial period, to manage the communication support for their son. CETI data from parental ratings, as well as self-assessments by the adolescent himself, were evaluated six months post-onset, with follow-up at 15 months post-onset. Between these two measurement points, a period of 10 months intervention was conducted with an on-line training programme in the adolescent's own home and school environment, including 22 sessions at the clinic with the speech pathologist (SLP) and four sessions with parents, the adolescent and SLP. The programme was based on the CETI data obtained in the adolescent and the parental evaluations. From these evaluations, important communication "trouble spots" were identified together with the participants and the individual strategies to facilitate communicative interactions at home, with friends and at school were planned.

The video recordings were made at follow-up and 15 months post-onset and were evaluated through discussions with the adolescent after watching the results of the recordings.

Paper III applied parental evaluations of the communication in 30 adolescents with ABI. Assessments based on a selection of tests of language and cognition, which were possible to use with participants with brain

injuries and relating to data on lesion site and aetiology in the adolescents, were also applied. The feasibility of conducting specific tests measuring language production was restricted due to overall cognitive impairments in some of the participants. The linguistic tests were therefore limited to language comprehension tasks and naming, as a basis for the further exploration of language production related to communication in daily interactions.

Paper IV used the CETI in adolescents' self-assessment procedures and in parental evaluations. The time of assessment, on average 2.11 years post injury, was chosen because the adolescents were in a more stable phase of their recovery at follow-up, compared with the earlier stages of the rehabilitation process and they were subsequently able to participate more readily in the evaluation procedures. Three experienced SLPs assisted the adolescents and the parents in the rating procedures. The interviews were related to the follow-up of the CETI assessments at the clinic and the session lasted a total of approximately 60-90 minutes. Family members were interviewed individually to prevent bias. The parents made a joint evaluation (n=3), but a single evaluation was made when only one parent was available (n=5). The interview results were analysed in collaboration with the researchers.

Paper V assessed the usability of the CETI as a measurement of change by comparing data from two measurement points, at the start and at follow-up after a period of home-based communicative rehabilitation strategies used by the parents. The framing of the home-based strategies programme comprised a model of cognitive and linguistic strategies, relying on previous recommendations (Forsyth, 2010; MacDonald, 2012; Ylvisaker, 2003). The evaluation data consisted of parental ratings of the adolescents' daily communication. Further, the communication data were compared with the linguistic and cognitive skills at the start of the rehabilitation period. The applied strategies during the period of communicative rehabilitation were planned at the clinic by the SLP in charge of the study, in collaboration with the parents, and the adolescents who could participate, to match the individual needs of each child. It consisted of several

communicative approaches to be applied in the home environment during interactions between the parents, siblings and the adolescent with ABI.

The model consisted of six communicative approaches to be applied daily in communication situations with the adolescent with ABI and were based on:

1. a reduction of communicative interactions in noisy environments
2. an adaptation of visual material or the position of the conversation partner to enable the adolescent with visual impairments, for example visual field loss, to make use of use his/her visual competence in the communication situation;
3. an adjustment of the speed of the interlocutors' speech so that short sentences with only one message at the time was used in conversation with participants with comprehension difficulties
4. an overall adaptation of the interlocutor's own language production to a level that might augment the adolescent's comprehension of the meaning of the words, syntax and grammatical constructions
5. to have one or maximum two people as the preferred number of interlocutors to be involved at the same time in a group conversation with the participant who has impaired executive and memory problems, and
6. a consideration of the short attention span in some adolescents, who might need help to stay on task in a dialogue.

The above collection of communication strategies was a very frequent approach in this group of participants, since many adolescents were subjected to extensive communication disorders, in combination with visual and auditory impairments. The parents were encouraged to use the compensatory strategies and accommodations routinely in the everyday communication situations with their child.

## THE VALIDITY AND RELIABILITY OF THE METHODS APPLIED IN THE THESIS

The CETI was used in this thesis as a measurement of communication in daily contexts. The tool has been applied by researchers across countries and it has shown generally high reliability in the assessment of par-

ticipants with communication difficulties after head injuries (Åsa Fyrberg, 2013; Hinckley, 2002; Pedersen et al., 2001; Penn et al., 1992). However, the CETI has been criticised for shortcomings related to the participation perspective. It has been argued that the participation perspective is not appropriately conceptualised, as communication skills are assessed by the significant other of the person with communication difficulties. Consequently, in a review of available self-report instruments in speech-language pathology (Eadie et al., 2006), the CETI was not included, as the original design of the questionnaire relies on evaluations by the significant other and not by the person with the disorder. Even so, it was concluded that 14 of the 16 items (87%) *per se* were consistent with the communicative participation concept. Furthermore, clinical experience suggests that the administration of the CETI items is easy and not particularly time consuming. Thirty to forty-five minutes were generally sufficient to conduct the evaluations. The decision to include the CETI in the present studies therefore appeared to be justified, particularly as it was applied as an assessment tool in this thesis not only by the relatives to predict communication difficulties in their children in daily life but also by the adolescents themselves.

The comparison between the parental and adolescent evaluations helped to clarify the participation perspective by exploring changes in actual communication abilities over time, as well as changes in the participants' perception of their personal experience of these changes **(Paper IV).**

As has previously been pointed out, ecological validity in the study of communication is highly dependent on analyses of interaction in natural contexts (Ahlsén, 1995). High ecological validity can be obtained in direct observations of interactions in the individual's own home or school environment, in video recordings and in analyses using interview procedures (Chevignard et al., 2012; Gioia and Isquith, 2004). However, ecological validity is related not only to the environment but also to the person performing the evaluations. The importance of self-evaluations to obtain valid results has been previously underscored, emphasising the fact that questionnaires designed to evaluate communication skills do not capture the individual's perception, i.e. the insider perspective, as the ratings were made by people other than the person with the health condition (Eadie

et al., 2006). The capacity of the ICF to identify the personal experience of everyday life of the person with the disorder has been questioned (Cruice, 2008) and it has been argued that evaluations should be made by the person with the communication disorder, if they are to be valid (Ueda and Okawa, 2003). However, when it comes to cognitive problems of self-awareness, there are many adolescents with moderate to severe ABI who are unable to perform these evaluations independently (Henry, Burkhart, Elbin, Agarwal, and Kontos, 2015; Lloyd, Ownsworth, Fleming, and Zimmer-Gembeck, 2015). Even in participants with uncomplicated mild injuries, there is evidence from studies applying subjective measurements that a minority of paediatric patients suffer from persistent problems (Kirkwood et al., 2008).

In fact, the aim of analysing communication in natural contexts is a pertinent issue, as most natural contexts are characterised by multiple intervening variables which cannot be controlled for and a specific communicative situation does not appear twice. The conventional methods in language and neuropsychological testing rely on a tradition of psychometric test standards and the view that reliability can be provided by maintaining rigour in the testing procedures. However, this rigour in the testing procedures can be difficult to maintain in participants with ABI. As was shown in the results of the clinical linguistic evaluations in this thesis **(Paper I)**, adolescents with ABI might need help with specific strategies in word retrieval, naming and sorting out the different components in abstract or semantically complex tasks, to manage the cognitive task load during formal tests. Phonological prompting in naming tasks and a 'no time pressure' condition are other examples of the adaptations of overall test procedures which might be required.

Like evaluations of communication in real-world contexts, the result of the adaptation of procedures is a loss of reliability but a gain in ecological validity.

## DATA ANALYSES AND STATISTICS

The Statistical Package for the Social Sciences (SPSS), version 20.0 for Windows, was used to analyse the numerical data. The level of significance was set at $p < 0.05$ (two-tailed). In the formal tests, percentile values

were transformed into standard scores in order to compare standard deviations. Categorical data are displayed as numbers, percentages and transcriptions; continuous data are displayed as means, medians, range and/or standard deviations. Non-parametric Mann-Whitney U-tests were used to compare demographics and a number of clinical variables in relation to the communicative level of the participants, defined as impaired or not on the CETI.

Paper I

Descriptive and comparative analyses were used to illustrate the results. As a result of the small size of the subgroup, no statistical calculations were performed in Paper I. Instead, the results were presented in numerals, mean, median, standard deviation and range.

Paper II

Descriptive and comparative interpretations of data were used to illustrate the results, at the beginning of the intervention and at follow-up. Transcriptions of video interactions on an event-based timeline were analysed in sub-sequences of utterances. A *Communication Management* analysis model (Allwood et al., 1990) was applied in investigations of the videotaped recordings of "first acquaintance" conversations. CETI data from parental ratings, as well as self-assessments by the adolescent himself, were evaluated six months post-onset, with a follow-up at 15 months post-onset. The video recordings were made at follow-up and 15 months post-onset and were evaluated through discussions with the adolescent after watching the results of the recordings together with the SLP. The analyses by the adolescent of the most salient communication sub-sequences were put down in writing by the SLP during the interview.

Paper III

Cronbach's alpha was used to examine the internal consistency (reliability) of the 16 parameters included in the CETI, i.e. to see whether the 16 items produced similar scores related to measurements of the same general construct. Group comparisons were made using non-parametric Mann-Whitney U-tests for continuous variables and chi-square tests for categorical variables.

A cut-off was established based on an average total scale score of 75 points. This cut-off created two almost equally sized groups: the CETI+ group, which had a score above 75 (n = 16), and the CETI− group, with participants (n = 14) who were assigned a score below 75. These two groups were compared to assess how communication impairments and abilities could be explained by analyses of cognitive or linguistic data.

Paper IV

Descriptive statistics were applied using Spearman's rank correlation test for correlations between the overall CETI mean scores delivered by (i) the parents and (ii) the adolescents. Wilcoxon's signed rank test was also applied in analyses of differences between participant ratings of the individual CETI items. Self-evaluations by the adolescents were compared with the parents' CETI assessments of the adolescents. By adopting these procedures, it was expected to be possible to clarify the participants' responses and further probe their lines of reasoning.

Further, interview data were obtained from the participants to elicit the core meaning of a selection of the CETI statements. The central themes in the participants' statements were negotiated between the SLP and the interviewee and the themes were put down in writing. The interview data were stored separately for each participant, but the CETI ratings were made available to the participants. The aim was to highlight differences in self- and other people's perceptions of the rated communication activities and to provide food for thought in the discussions with the participants about the results. The interview data were analysed in relation to the frameworks of ACA and distributed cognition. The analysis was also inspired by the Johari Window model (see also *Theoretical framework*) (Luft and Ingham, 1955; A. K. Shenton, 2007).

As a result, not only the CETI items but also other key concerns related to the assessed communicative situations were further probed with follow-up questions, using an open-ended interview approach. Responses from the participants were compared pairwise to reveal differences and similarities between the perceptions of parent/s and adolescent/s belonging to the same family. The responses were also examined to detect differences and similarities between the parental and the adolescent ratings in the whole sample.

The factors used in the analyses of the responses related to the ACA framework, comprising *collective factors* and *individual factors*. These two factors were used as analytical lenses to provide information about, first, why the communication activity was performed, the obligations and rights of the participants in the activity, the artifacts that were used for communication and how these artifacts were applied in the context. Second, the subjective experiences were highlighted, looking at the consequences of the communication impairments for the social role of the participants, the effect of the communication difficulties related to psychosocial well-being and associations with changes in biological features, for example, visual or auditory disorders. Coping strategies were also clarified by interpreting the subjective experiences.

The distributed cognition framework provided three types of analytical factor: first, the distribution of communication across the members of the group, second, the co-ordination between internal and external structures, for example, the influence of conversational speed on the participants' comprehension ability. Third, distributed cognition placed the focus on the changes in the participants' perception of the communication processes through time.

The Johari Window provided a structure for the participants' comprehension of the impact of their injuries on daily communication. The terms presented in the Johari Window were used to clarify the degree of visibility of the communication changes that had occurred as a consequence of the injuries.

Paper V

For Paper V, the statistical analyses and the division of the study group into two subgroups based on an average total scale score of 75 points were conducted, similar to the design of Study III. Furthermore, differences in CETI mean scores between the two measurement points at the start of the applied strategies period and at follow-up were estimated using Wilcoxon's signed rank test.

# RESULTS

In keeping with the research questions posed for the study, the results are presented in five parts, corresponding to Papers I-V. This section provides a summary of the main findings in each paper.

## PAPER I

The use of descriptive pragmatic taxonomy for the assessment of communicative abilities, the Pragmatic Protocol (PP), was explored. The PP contains 30 items that cover different aspects of the communicative system (production and understanding of verbal speech and language, non-verbal communication, such as gestures, eye gaze and mimic).

Eight participants with severe ABI were assessed using the PP during a six-week rehabilitation period. Observations of communication by an SLP and rehabilitation assistants were evaluated independently (to avoid bias) and then compared.

The results suggest that the number of inappropriate pragmatic behaviours was relatively high, above all regarding aspects of speech/language and non-verbal communication. For instance, body posture was thought to disturb interaction in five patients. Failure to control movements of

the extremities, impaired control of the mimicry muscles in the face and management of eye contact deviated in four of the patients.

The label "inappropriate pragmatic behaviours" was used in the original construction of the PP taxonomy. Although not unproblematic (see also *Definitions; Pragmatics*), it was decided to use this label to describe the observed communication behaviours in the present study.

Seven of the eight participants with severe brain injuries were assessed as having a highly reduced capacity to communicate within all the assessed parameters that involved speech and language skills. For these patients, the loss of consciousness, LOC, covered more than seven days, confirming that, the greater the duration or depth of coma, the poorer the prognosis for recovery (Asikainen, Kaste, and Sarna, 1998). The total of 232 assessments of the participants' communicative skills were agreed on between the assessors, except on 13 occasions. In overall terms, the inter-observer agreement reached 95% between assistants and SLP. Possible reasons for the diverging assessments are the different communicative settings in which the participants were observed. The participants' ability to express themselves varied with the character of the situation and the conversational partner, i.e. everyday interaction during daily activities on the rehabilitation ward, in contrast to specific and individualised training and/or assessment sessions.

Data indicate the use of the PP as a useful clinical screening tool to trace aspects of communicative competence in need of further, detailed exploration. Information relating to intact communication skills is clarified and can be used when designing interventions.

However, what the PP does not offer, and what is important in order to understand the individual capacity, is an individualised assessment of functional communication in various daily interactions with different speakers. For this reason, a suggested approach when it comes to continued method development is a design with the emphasis on the context, including the subjective views of the person with the health condition, as well as the communication partner.

## PAPER II

A mixed-methods design was used in this case study to explore the communication in a 16-year-old male participant with moderate head injury after TBI. At the time of injury, he was a first-year high-school student, but, after failing to cope with his home and school environment due to fatigue and recurrent headaches, he was referred for assessment and suggestions for further interventions.

A clinical evaluation was performed six months post-injury with a comprehensive neuropsychological and speech language test battery. His own communication skills were scored by the participant in the CETI, before and after a period of 10 months' intervention with an on-line training programme in his own home and school environment. The programme comprised 22 individual sessions between the participant and the SLP and four sessions at which parents, the adolescent himself and the SLP met. The parents also scored the adolescent's communication, before and after the intervention. A comparison of the data was made. The results are shown in Figures 5 and 6.

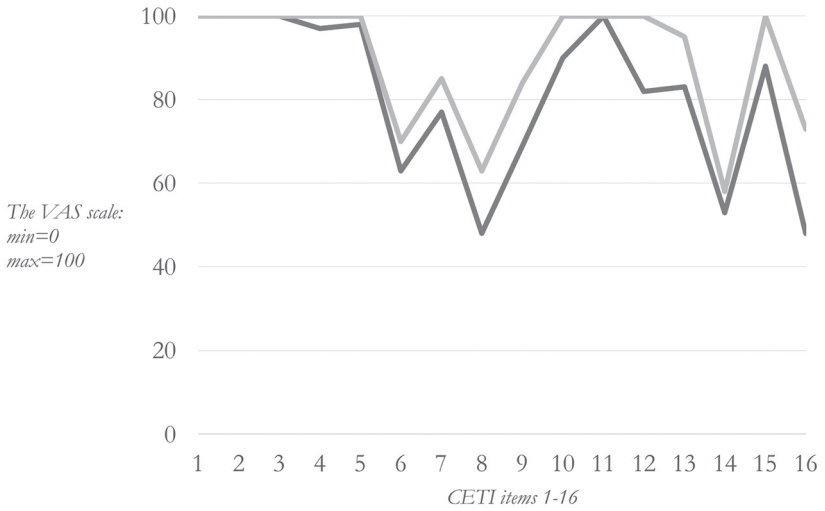


Figure 5. Adolescent (A) CETI scores in 16 communicative situations. **A1**=the beginning of the intervention, **A2**=follow-up

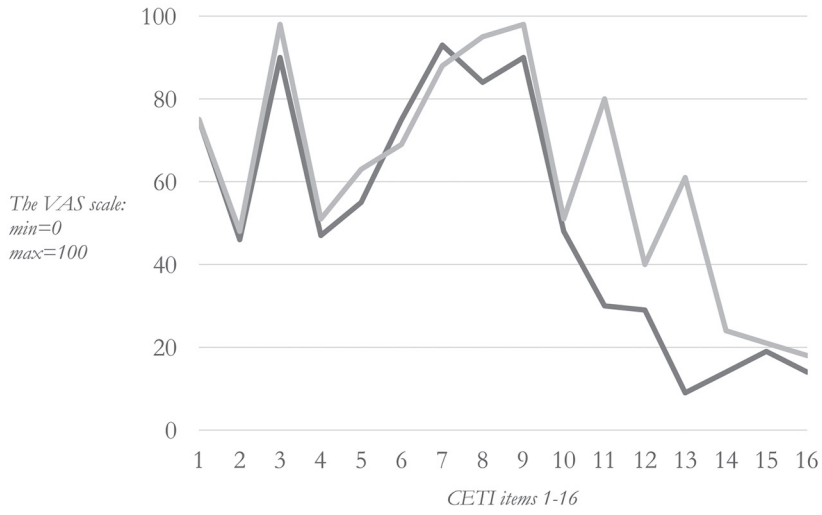


Figure 6. Parental (P) CETI scores in 16 communicative situations. **P1**=the beginning of the intervention, **P2**=follow-up

Furthermore, interactive communication was recorded on video in the two live conversations, a two-party conversation and a three-party conversation.

The test results were unable to confirm clear evidence of impaired cognition or language, even if the sub-tests in the WAIS indicated weaker performance in the verbal domain. However, the CETI ratings by the adolescent and his parents, the analyses of video-recorded interactions and the interview data revealed difficulties in everyday communication

In general, the CETI ratings by the adolescent himself were centred around higher values than the ratings in his parents' evaluation and it is possible to argue that this was a reflection of the adolescent's perception of a greater preserved communicative ability than his parents would agree with. Complex communication situations were the most difficult to manage, for example, rapid conversations with several speakers involved.

The adolescent's self-evaluation of the video recordings confirmed difficulties in communication management, depending on pronounced language comprehension difficulties related to high speech rate and the number of speakers involved. The speech rate of one of the interlocu-

tors in the three-party conversation was perceived as high, something that limited the adolescent's overall language comprehension in the dialogue.

Intentional turn-taking and initiative were more easily managed in the two-party dialogue, as the speech rate of the interlocutor was slower here. The production of utterances was limited for the adolescent in both conversations, compared to the performance of the other interlocutors. However, talking to one person optimized the potential as he could deliver utterances more easily and raise questions more frequently, compared to the three-party conversation. As a result, when he was talking to one person, there were more interruptions, since he expressed himself more frequently in this conversation. The fact that he was interrupted to a lesser degree in the three-party conversation mirrored his reduced verbal capacity in this discussion. Furthermore, the interruptions in the three-party conversation were caused by failed attempts by the adolescent to initiate utterances, since his initiatives were delayed and consequently ignored by the other speakers who had already moved on to a new topic.

Participation as a listener was facilitated by gestures of inclusiveness, such as smiles, facial expressions and eye contact. The adolescent with ABI did not want to laugh so much during the conversations and he wanted to use his hands more for gesturing. When unable to understand, he did not ask for a clarification. His overall feeling was that new people do not regard him as serious. He also reported an experience of interlocutors avoiding eye contact with him.

The results of this study support the notion that a mixed-methods design is a promising approach to analysing the consequences of communication impairment after TBI, in particular involving a comparison of adolescent and parental evaluation data and the observation of video-recorded interaction, which provided a fruitful basis in the discussions with the family about intervention planning.

## PAPER III

The validity of the CETI taxonomy was explored through a prospective, longitudinal, between-group design in thirty participants. A cut-off was established for severely impaired communication outcome on the CETI scale, based on an average total scale score of 75 points, or below

(75 thus signifying 75% preserved function of a 100% pre-injury ability). The cut-off level was justified by a combination of clinical experience of the scale (parents of children with more severe communication difficulties tend to choose evaluation scores below 75 on the CETI) and for analytical purposes.

The cut-off created two almost equally sized groups: the CETI+ group, which had a score above 75 (n = 16), and the CETI− group, with participants who were assigned a score below 75 (n = 14).

Evaluations of communication in daily social contexts were related to a selection of tests measuring language comprehension, visual confrontational naming and IQ. Lesion site data and aetiology were also explored.

In the statistical analysis of the results, the level of significance was set at $p < 0.05$ (two-tailed). Cronbach's alpha was calculated to examine the internal consistency of all 16 parameters in the CETI. There were a total of nine missing values on the CETI (of a total of 480 assessed items, i.e. less than 2%) and these were imputed using the mean value for the item in question. The internal consistency on the CETI proved to be excellent, with a Cronbach's alpha of .97, both with and without the imputation of missing values.

The CETI results were compared with the test scores from the *TROG, PPVT, BNT, VIQ* and *PIQ* to see whether there were any differences in communication outcome that could be explained in the results. The data showed that this was the case (Table 3, except for the BNT data, see below).

Table 3. Subgroup comparison

| | **Group CETI+ (n=16)** | **Group CETI- (n=14)** | |
|---|---|---|---|
| **Measurement** | **M (SD) or n** | **M (SD) or n** | **Statistical comparison** |
| Chronological age at injury | 12.41 (3.53) | 13.26 (2.56) | p = .82, ns |
| Chronological age at CETI assessment | 13.94 (2.78) | 14.37 (2.65) | p = .64, ns |
| Gender distribution (f/m) | 6/10 | 5/9 | p = 1.0, ns |
| Severity rating | 2.12 (.89) | 2.42 (.76) | p = .40, ns |
| Intact families | 15 | 11 | |
| Localisation: left temporal-frontal/right only/"other" | 2/6/8 | 9/0/5 | $X^2$ = 11.06, p = .004 |
| Type of injury (traumatic/non-traumatic) | 8/8 | 10/4 | p = .28, ns |
| PIQ | 83.06 (17.83) | 71.43 (28.13) | p = .21, ns |
| VIQ | 84.87 (14.67) | 65.14 (25.80) | U = 161, p = .043 |
| PPVT | 103.19 (11.03) | 81.14 (34.60) | p = .22, ns |
| TROG | 98.75 (13.79) | 70.43 (32.77) | U = 164, p = .028 |

Specifically, adolescents in the CETI− subgroup obtained significantly lower scores on the TROG and VIQ tests. The differences in PPVT or on PIQ between the two subgroups did not quite reach significance, although the trend was similar. However, it is noteworthy that both subgroups tended to obtain generally low scores on the WISC, including verbal and perceptual tests. Data measuring visual confrontational naming

ability obtained in the BNT was scored in nineteen adolescents who managed to carry out the evaluations. As a result of the rather high attrition rate, statistical comparisons were rejected and examination was conducted of the individual stanine scores derived from the BNT test data. Very low - low average results were reported in six adolescents (stanine 1 - 4); average results (stanine 5 - 6) were reported in ten participants, and two adolescents performed above average – very high (stanine 7 and 9). A closer inspection of the data revealed that a majority of those who performed very low – low average results, and those who had not been able to participate in the BNT test at all belonged to the CETI – group, while a majority of those who completed the BNT with average or high results belonged to the CETI+ group.

The CETI+ and CETI− subgroups did not differ in terms of overall injury severity. Nor did they differ with regard to chronological age at injury, chronological age at time of assessment, gender distribution or family constellation.

However, the two subgroups differed in terms of the localisation of the brain injury. The majority (nine of eleven) of those with injury to the left temporal and/or frontal cortex belonged to the CETI− subgroup. Among those with selective right hemisphere injury, none scored below cut-off on the CETI. A chi-square test with the left temporal-frontal hemisphere group versus the right hemisphere group versus "other" localisations [e.g. central] over the communicative effectiveness group revealed a statistically significant difference.

Finally, we examined whether differences in the communication evaluations, results from the linguistic/cognitive tests or lesion site location were affected by the aetiology of the injuries. There were no differences related to aetiology, in communicative ability according to the CETI ($p > .2$), in any of the cognitive or linguistic tests ($p > .5$), or in relation to lesion site ($p > .3$).

In conclusion, the CETI provided unique information about daily communication, which is not easily seen in other linguistic and cognitive tests. The CETI results were supported in the other test results and also in analyses of lesion site data, which shows that a combination of data from different contexts can be a fruitful approach in ABI analyses, aiming to

creating a basis for explaining the outcome of the injuries in participants with ABI. The aggregated information can be used in rehabilitation procedures in intervention planning with the adolescents and their parents.

## PAPER IV

The study involved eight participants with ABI and their parents. It aimed to explore how adolescents perceived their own communication in daily life contexts and the extent to which their perception was confirmed or unconfirmed by the parents. The aim was also to discuss the possible use of the approach for designing future communication interventions in adolescents with ABI. The results were evaluated by applying the frameworks of ACA and distributed cognition and the analyses were inspired by the Johari Window model, a framework for self- and other personality judgements.

Data collection involved self-evaluations of communication in daily situations, scored in the CETI questionnaire by the participants with ABI. Parental ratings of their children's communication were also scored in the CETI. Semi-structured interviews were conducted separately with a selection of the adolescents themselves (n=5), as well as with the parents of six adolescents

The results show that there was a significant positive correlation (Spearman rho = .77, $p < .05$) between the overall CETI mean scores given by the parents and the adolescents. The total mean CETI score for the parents was 81.52 (SD = 14.96, range = 61.25-97.38). For the adolescents, the mean was 84.77 (SD = 17.91, range = 45.75-100.00). Even if the mean scores in the items pointed in the same direction, the adolescent scores for their preserved communication ability were generally higher (in 11 of 16 CETI items). The items with higher adolescent scores specifically related to communication in situations with high complexity, for example: *Participating in a conversation with strangers, Having coffee-time visits and conversations with friends and neighbours (around the bedside or at home)* and *Starting a conversation with people who are not close family.* In one particular item: #14 *Being part of a conversation when it is fast and there are a number of people involved,* the difference was statistically significant (Wilcoxon, $p < .05$) between adolescents' (M = 63.75) and parents' (M = 42.63) evaluations. This item is particularly

difficult to master after an ABI, as the skills required in this task demand complex communicative abilities which are commonly impaired following brain injury (MacDonald, 2012). As a result, an adolescent who frequently experiences difficulties in everyday communication situations with friends at school and in similar settings, and who is aware of the problem, might not want to lose face in these situations. This interpretation can explain the higher adolescent scores, compared with the parents' lower ratings.

Another possible interpretation is that the higher adolescent values might mirror the participant's own perception of a greater preserved actual communicative ability in daily situations than the parents would agree with. In this case, a general conclusion may be that, apart from a conscious strategy to save face, the adolescent ratings were also expressions of limited self-awareness, due to the brain injury.

The results of the interviews based on the CETI ratings were grouped around three identified themes according to an adapted model for the categorisation of self- and other evaluations (Le Dorze et al., 1996). These themes comprised:

- Situations in which communication difficulties were reported
- Coping behaviours used by participants to manage communication difficulties
- Causes of the communication difficulties

Relating the results to the ACA framework, communication activities primarily occurred in interactions with relatives at home, talking with teachers and peers at school and socialising with friends during leisure time. The factors associated with obligations and rights according to the ACA perspective in these situations involved coping behaviours to enhance communicative participation. For example, interacting with an adolescent with ABI involved the need for the interlocutors to adapt their own communication style. One important adaptive factor was the rate of speech in dialogues, which both parents and adolescents identified as one key to the adolescents' comprehension abilities in conversations. The coping behaviours to manage difficulties related to speech rate were described by the parent of one participant:

> He needs more time to communicate, in particular when several people are involved. Otherwise, he loses track of the conversation (P-8-17).

The parental strategy in this situation was to help reduce time pressure in conversations to make it easier for the adolescent to keep track of the conversation. Furthermore, interview results depicted comprehension problems related to other temporal dimensions of conversations, which were important for the participants' ability to participate on equal terms in communicative interactions. For example, a slower response to auditory stimuli in conversations and a reduced ability to talk and listen simultaneously in a conversation were mentioned as barriers to communicative participation. Taken together, it seems that temporal factors were important determinants of participation in the daily communicative situations explored in the study. Other examples of temporal factors were related to the timing of the intervention during the rehabilitation process and how timing and the ability to observe communication patterns in daily life interacted. For example, the opportunities to detect the scope of the communication difficulties appeared to be limited in some participants because communication in daily life had not yet occurred.

The evaluation of the results using the ACA and distributed cognition frameworks revealed that the difference between the subjective experience of the communication performance of the participant with ABI and the opportunity for the parent fully to interpret the communication signals might be clarified using ACA and distributed cognition. They can be used as a framework in discussions about the focus of rehabilitation interventions in co-operation with rehabilitation team members, as well as with the adolescent with ABI and his/her family. The ACA perspective of the subjective view of the communicative activity, such as why it is done, what are the obligations and the rights of the participants, what are the physical and other conditions of the activity, what artifacts are used for communication and how they are applied in the context can reveal important features in the evaluation procedure.

The subjective views of the importance of adapting complex communicative conditions in everyday interactions, for example, the speech rate of the conversational partner in a noisy environment, can be supported

to shape qualified assessments based on the participation perspective. The aim is to generate interventions that are meaningful to people with ABI and their families.

## PAPER V

The study aimed to measure change in the parental evaluations of communication skills in their children, after an individualised communicative rehabilitation period based in the home environment. The communication outcome was compared for 30 adolescents at 12 and 24 months post-injury.

A group-level analysis showed that there was a significant increase in the mean scores for communication skills at follow-up. The measured improvement occurred in the CETI− group, where the mean scores increased from 50.69 to 66.69 ($Z = -3.11$, $p < .01$). Participants in the CETI+ group did not report any change in mean scores at follow-up: M= 91.81 at the initial assessment, M = 91.79 at follow-up ($Z = -.31$, p = ns).

In-depth analyses showed that the parents of 21 children reported specific remaining difficulties in communicating in everyday contexts, regardless of the communication impairment level of the child. In both the CETI− and the CETI+ group, item 14 *Being part of a conversation when it is fast and there are a number of people involved* showed a 50% reduction in estimated communication ability at the start of the intervention, as well as at follow-up in both groups. Item 15, *Participating in a conversation with strangers* was another task which did not improve much in the one-year intervention in both groups (5% change, from 65.10 at the beginning of the intervention to 70.26 at follow-up). Similar results were obtained in item 16, *Describing or discussing something in depth.*

The parents who reported reduced scores at follow-up gave different explanations for their evaluations. These explanations were important when it came to understanding the parents' experiences of change during the intervention period. The explanations also provided material for the on-going planning of rehabilitation interventions. One common reason given by the parents was that specific communication impairments in their child had been easier to detect in the later post-traumatic stages,

when the adolescent had recovered the physical strength necessary to be able to participate more actively in daily communication situations.

Another common remark was that *In the beginning, I did not understand how badly the injury had affected my child's ability to communicate in everyday social interactions because she was not as socially active after the injury as she was before.*

A third interpretation retrieved from interviewing the parents of the children was that those parents who were experiencing a deep crisis themselves related to the injuries of their children, particularly in cases where the child had sustained a traumatic injury, might not completely be able to perceive the status of their child, even in the post-acute phases after the traumas.

A fourth explanation was provided by the parents of a child who had undergone extensive treatment for a posterior brain tumour. The parents said that new symptoms related to difficulties with word mobilisation had occurred in their child, between the beginning of the rehabilitation period and at follow-up. Unfortunately, the progress of cognitive impairments resulting in new symptoms is not uncommon in children after combined treatment with surgery, chemotherapy and radiotherapy for CNS tumours. In this case, the occurrence of a slowly progressing deterioration in skills was not unexpected (Armstrong et al., 2010; Duffner, 2010; Grewal et al., 2010).

In all the adolescents, the communication ability as evaluated by the parents was significantly associated with language comprehension, and verbal IQ. Both latter domains were clinically impaired in participants with more severe injuries, while those with milder injuries performed close to the normative mean. Results of the visual confrontational naming test (BNT) showed that a majority of those who performed very low – low average results, and those who had not been able to participate at all, belonged to the CETI – group, proposing that expressive language ability such as naming was particularly associated with communicative impairments in everyday interactions.

# DISCUSSION

## GENERAL DISCUSSION OF THE FINDINGS

In this thesis, adolescents with communication impairments after acquired brain injuries, ABI, participated in studies based on test data from formal assessments at the clinic, self-evaluations of daily communication in the CETI, interview data provided by the adolescents themselves and their parents and on analyses of video-recorded interactions. Furthermore, clinical observations of pragmatic skills provided by an SLP and by rehabilitation assistants were analysed (Study I). The International Classification of Functioning Disability and Health (ICF), the Activity Based Communication Analysis (ACA) and distributed cognition were used as overall theoretical frameworks. The relevance of the reported data is highlighted below, in a selection of the results obtained in the studies.

**Study I** used observations of communication by an SLP and rehabilitation assistants that were evaluated independently (to avoid bias) and then compared.

Analyses revealed a high inter-rater reliability in the assessments, using descriptive taxonomy for evaluating communication: the Pragmatic Protocol (PP). As a result, among the total of 232 assessments of the participants' communicative skills, all were agreed on by the assessors, except on 13 occasions. In overall terms, the inter-observer agreement reached 95% between assistants and SLP and the data indicated high internal validity, i.e. the high level of consensus on the results was probably associated with communication strengths and needs in the eight participants with ABI. It was shown that the PP can be a useful tool in tracing aspects of communicative competence requiring a more in-depth diagnosis, thus providing a basis for individualised discussions and co-operation with relatives and nursing staff.

**Study II** demonstrated that a mixed-methods design, involving tests of language comprehension, naming, reading and linguistic abilities, as well as CETI evaluations by parents and adolescent, plus multimodal analyses of video-recorded live conversations, can be a promising approach to analysing communicative changes in a young person with TBI. In particular, the inclusion of a comparison of adolescent and parental evaluation data provided a fruitful basis in the discussions with the family about intervention planning. The complex interplay between different degrees of intentionality was highlighted in the detailed analyses of the adolescent's use of different channels of communication. For example, the degree of conscious control of a spoken message and ability to 'symbolically' express an opinion seemed to increase when the pace of the dialogue was low and the topic familiar. In the face to face communication, movements of arms, hands and head were used to convey a message and participate as a listener, however, the intentional control of these actions seemed to be rather low

**Study III** showed that there need not be any obvious associations between communication ability, as reported by the parents of 30 adolescents using the Communicative Effectiveness Index (CETI), and injury severity, chronological age at injury, chronological age at time of assessment, gender distribution, aetiology or family constellation. However, factors related to the cerebral localisation of the injury and also to language

skills and to the level of cognitive functioning appeared to have an impact on communication abilities in daily life. The study also showed excellent internal consistency in the CETI, indicating that it is a valid tool for examining a selection of communication situations occurring in the daily life of adolescents with ABI.

**Study IV** points to the value of applying an analytical framework, comprising Activity based Communication Analysis, ACA, and distributed cognition to examine the adolescents' understanding of their own communication behaviours and the parents' understanding of these behaviours. The analyses were based on data obtained in the CETI, as well as on individual interviews with parents and adolescents. The results showed that coping strategies in the adolescents could be clarified. Further, the parents' perceptions of the impact of the injuries on daily communication abilities could be demonstrated.

**Study V** provides significant data associated with changes in communicative abilities from an investigation of communication development after a home-based intervention for 30 adolescents between 12 and 24 months post-injury ($p < .01$), as scored by the parents. In general, the data pointed to an increase in communication ability in the participants at follow-up, particularly in the CETI− group, while participants in the CETI+ group reported a minor change in mean scores at follow-up. The result in the CETI+ group was not surprising, since the mean scores at the beginning of the intervention were high and the lack of increase in scores might have been be associated with a ceiling effect. However, communicative functions in dialogues with particularly high demands on complex linguistic and cognitive skills, i. e. *Participating in a conversation with strangers, Fast paced conversations with several speakers* and *Describing or discussing something in depth* were assigned the lowest score of all the rated tasks in both groups, showing about a 50 % reduction of communication ability at the beginning of the intervention and about 30 % reduction at follow-up, in all of the participants. As a result, our conclusion is that there might be large remaining challenges to manage complex communicative situations in participants with residual sequelae initially regarded as "mild" as well as in those with moderate to severe injury outcomes.

Instances of *decreased scores* between the beginning of the intervention and follow-up were also reported and they appeared to have been related mainly to (i) a gradually more impaired ability to communicate in the participant as a consequence of tumour treatments, or (ii) the reduced ability of the parent initially to perceive the level of the communication difficulties. The interval of 12 months between the first and the second scoring occasion appeared to have helped the parent to comprehend the scope of the communication difficulties in the child.

The communication barriers and facilitators that were reported by the participants in the studies in this thesis were mainly analysed using the perspectives of ACA and distributed cognition. The usability of the two frameworks is discussed below, illustrated in particular in two examples of item analysis: item 14 *Being part of a conversation when it is fast and there are a number of people involved* and item 16 *Describing or discussing something in depth*. Both these items were related to Factor 1, which included CETI items with communicative interaction that require a vocal-verbal output. It was shown that a majority of those who performed very low – low average result in the clinical tests of naming ability using the BNT, and those who had not been able to participate to the naming test at all, all of them belonged to the CETI – group. The data indicate that that vocal-verbal (or expressive) language ability such as naming was particularly associated with communicative impairments in everyday interactions (see also *Theoretical framework: Putting CETI items into context through the ACA and distributed cognition perspectives*).

Items 14 and 16 received the lowest score of all the rated CETI items, about a 50% reduction, according to parent evaluations, and were regarded as two of the more "difficult" items in the CETI sample. Interviews with adolescents and parents helped clarify the specific challenges associated with these communicative situations. Difficulties in *Being part of a conversation when it is fast and there are a number of people involved* occurred in a number of situations, at home as well as at school and with friends during leisure time. At school, this would be reported as a difficult situation in class but also during breaks and the variation was described as depending on the influences from the environment. For example, the noisy surroundings in class could be difficult to manage in participants who were sensitive to sounds, as a result of the ABI. In those cases, the ability to participate in

the conversations was reduced by difficulties associated with maintaining attention and augmented fatigue, but difficulties could also be related to auditory disorders, for example, hearing impairments caused by the ABI. Difficulties participating could also be related to impaired word-finding processes and the collected consequences of the impairments caused by the injuries were highlighted. The impact on the social role of the participants was significant and clearly related to psychosocial well-being. In one participant, the coping behaviours related to slow processing speed and reduced language comprehension resulted in coping strategies to save face. In overall terms, the goals for the adolescents in the complex communicative situations were multifaceted; some of them described coping strategies, using hearing aids or hearing protectors to manage the auditory stimuli from the environment. Avoidance behaviour, reported as a method of coping with the communication barrier which was caused by either hearing too much of the sounds from the environment, or hearing too little, was associated with the auditory disorders. At group level, others described a frequent barrier to communication which involved the high speech rates used by typically developed conversational partners in daily interactions. Coping strategies used by the participants in these cases involved asking the conversational partners to speak one at the time, with the aim of reducing the pace of the dialogues and providing the adolescent with ABI with more opportunities to decode what was being said, and to facilitate turn-taking. In cases in which comprehension difficulties were compromised by the fast-paced conversations, it was stated that strategies described in CM as part of the ACA perspective were applied to save face. The strategies included mimicry, eye contact, smiles and body postures. The analyses of the interaction between internal and external activities and perception, according to distributed cognition, helped the participants to understand these processes. By using this perspective, it was possible to clarify on the one hand how the communication interactions were played out at group level and, on the other hand, the individual perception of the facilitators and barriers. Another example of the interplay between internal and external perspectives was found in the analysis of *Describing or discussing something in depth*. Parents explained that one of the adolescents had a reduced ability to participate in these conversations as an expression of communication difficulties related to the ABI, but the external

observation by the parent was very different from the perception of the interaction in the adolescent in this case. The distribution of cognition could be labelled as a completely internal process, as the adolescent did not want to share deep thoughts with the parent but kept them to herself and to her friends. The parent's "outside" perspective contributed little to the understanding of the participation perspective in the adolescent but instead explained the parent's own feeling of not being able to participate in *Describing or discussing something in depth* together with the adolescent.

The distributed cognition perspective underlines the importance of seeing cognition as a socially distributed phenomenon (Hutchins, 1995a). However, Hutchins emphasises that distributed cognition "does not study any particular kind of cognition; it is an approach to the study of all cognition [..] Distributed cognition sees real-world cognition as processes that involves the interaction of the consequences of past experiences (for individual, groups, and material world) with the affordances of the present [..] From a cultural point of view, cognition is distributed through time, between a person and a culturally constructed environment, and among persons in socially organized settings" (Hutchins, 2006, pp. 376-377) .

It was useful to explore the temporal aspects of distributed cognition in the studies in this thesis, as the communication activity changed over time, as did the perception of the activity. For instance, parents reported that they had not been able to perceive the extent of the communication difficulties in their children, until after a period of time had passed between the occurrence of the injuries and the assessments. By applying a temporal perspective in the analyses, it became clear that some of the scores given by the parents did not reflect a rating of factual communication abilities in their children but rather whether the parent was able to perceive the differences at the moment in time when the assessments took place.

Our conclusion is that the assessed changes in outcome can mirror real changes in communication abilities in the child, but they may also reflect some of the parents' own difficulties in fully perceiving the impact of the injuries on their children's altered communication in the early stages of rehabilitation. Either way, the CETI can serve as a powerful tool in the planning of communication rehabilitation together with adolescents with ABI and their parents.

A final comment on the assessment procedures relates to the seemingly impossible mission of studying communication in context as a phenomenon in which everything is seemingly connected to everything else. Moreover, exploring real-world interactions of high complexity, such as communication in daily interactions, is more complicated than understanding systems of simple linear relationships. However, as was previously pointed out, more complex cognitive problems are sometimes easier to solve than what appears to be the case with simpler problems (ibid. 394). A system of multiple interacting subsystems, such as cognitive and linguistic abilities involved in communicative interactions, can provide information more easily than trying to obtain all the information from one subsystem. An investigation of the communication interactions after ABI might actually be facilitated if it is acknowledged that one system interacts with another. For example, communication difficulties after ABI have been related to impaired auditory comprehension, verbal expression, discourse and social interaction that occur as a result of underlying cognitive disturbance (attention, memory, organisation, speed of processing, reasoning, problem-solving, executive functions) (MacDonald, 2015). As a result, to explore communication after ABI, one fruitful approach might be to appreciate data that depict rich interactions among systems operating in different areas of expertise. This appreciation might be needed to conduct relevant assessments of the skills needed for communicative participation after ABI in daily contexts.

## MAIN FINDINGS IN THE LIGHT OF PREVIOUS BRAIN INJURY RESEARCH

Knowledge about the pathways of the brain, the cerebral representation of cognitive and linguistic functions and factors related to the level of severity after brain injury are some of the related data which underpin communication functions. The following section therefore aims to provide an overview of the current state of knowledge in these areas, associated with the results of the thesis.

The neurologically established level of injury severity appeared not to have affected communication outcome, as evaluated by the parents of the participants' in daily interactions in the studies in the present thesis.

Nor did the aetiology of the injuries appear to have affected the communication outcome. The participants' daily communication may have been associated with other factors, related to, on the one hand, the cerebral localisation of the injury as parts of cerebral networks and, on the other hand, the level of cognitive functioning. These findings will be discussed in greater depth below.

The lateralisation of the injuries appeared to impact the communication abilities so that those individuals with more communication difficulties had injuries to the left temporal and/or frontal cortex. Although the data have to be interpreted with caution due to the small sample size, there are some interesting findings to consider from previous research on the relationship between the localisation of the injury and the cognitive and communicative outcome.

The complexity of the outcome related to the site of the lesion has been shown in investigations of the subcortical pathways that connect frontal cerebral areas to other parts of the brain. The prefrontal cortex is particularly exposed in TBI, commonly caused by coup-contrecoup injuries. A coup-contrecoup injury occurs when the head strikes a fixed object. First, the coup injury occurs at the site of the impact and, second, the contrecoup injury occurs on the opposite side, causing multiple cerebral injury locations as a result of the traumas (Figure 7).

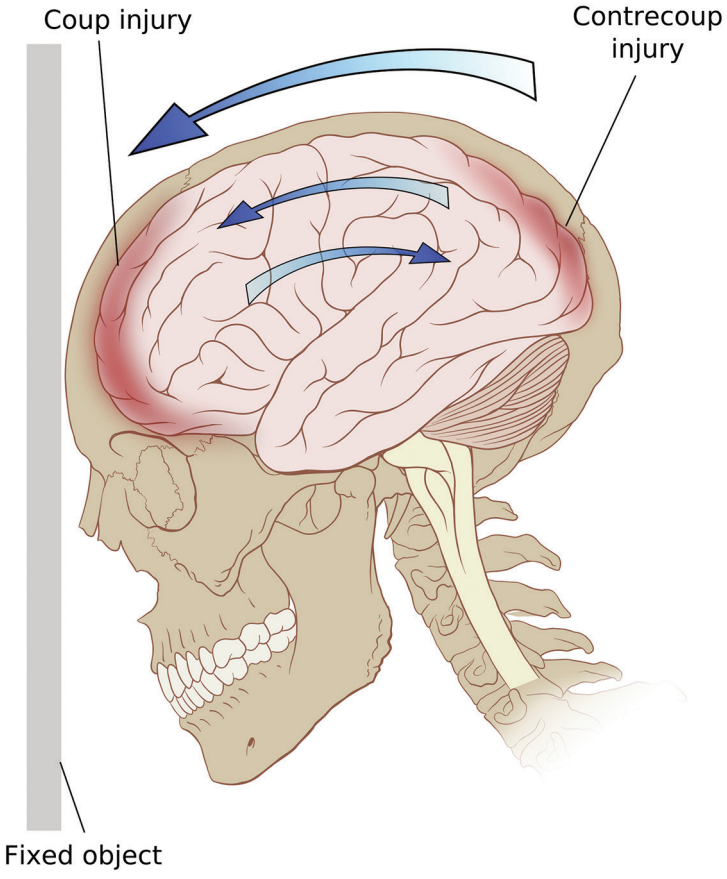


Figure 7. The coup-contrecoup injury. From Wikipedia, downloaded on 28 July 2016. Patrick J Lynch, medical illustrator – modified version.

As a result, a loss of functional cerebral integration between the frontal lobes and other parts of the brain is a frequent outcome related above all to TBI. Further, it has been shown that high-level language competence depends on functional integration across the cerebral networks, with a central role for the frontal lobes in abstracting meaning from complex information (Chiu Wong et al., 2006).

## ANTERIOR-POSTERIOR PATHWAYS

Impaired anterior-posterior pathways can result from structural disconnections caused by subcortical lesions or axonal injury, DAI. In particular the inferior fronto-occipital fasciculus, the IFOF, has been shown to affect the ability to supervise complex cognitive processes. The IFOF connects the frontal lobe directly to the postero-lateral temporal, parietal and occipital lobes. Electrical stimulation of the IFOF has been shown to cause temporal language impairments, regardless of the portion of the IFOF that was stimulated: frontal, insular, or occipito-temporal (Martino and De Lucas, 2014). As a result, the ability to supervise control of complex communication situations appears to depend on activities in the anterior-posterior pathways of the brain. The overall activities of these pathways are managed by the prefrontal cortex (PFC). Damage to the PFC has been known to cause severe disruption to multiple cognitive functions, including self-evaluation skills, emotional regulation and discourse abilities (Chen, Abrams, and D'Esposito, 2006; Chiu Wong et al., 2006; Ylvisaker and Feeney, 2007). Further exploration of the relationship between the PFC and functions related to complex cognitive abilities shows that awareness of mental states, beliefs, intentions and irony can be severely affected. Dennis et al. (2001) found that comprehension of first- and second-order intentionality, such as that involved in understanding irony and deception, was impaired in children with both mild and severe head injuries. Some 70% of these subjects were diagnosed with a frontal lobe injury, which was associated with the comprehension difficulties.

In the present thesis, the majority of the participants (n=23) had injuries located in the frontal and/or temporal lobes, which probably contributed to comprehension impairments and communication difficulties in daily contexts.

One important area related to the pathways connecting the different parts of the brain is the question of the lateralisation of the brain lesions.

## CEREBRAL LATERALISATION

It has been argued that linguistic functions are particularly vulnerable to left hemisphere injury in the mature brain. For instance, Tyler et al., (2011) found that syntactic processing was impaired in older participants with left hemisphere injury, compared with a group of healthy controls. However, as was previously shown in findings related to the IFOF pathway, a functional relationship between several areas of the brain was also discovered, involving the left Brodmann area 45 and the left posterior middle temporal gyrus. The authors suggest that a breakdown in a relationship between the brain areas, through damage either to a specific region or to the connections between the regions, results in impaired syntactic processing. It was concluded that "the left inferior frontal gyrus may not itself be specialized for syntactic processing, but plays an essential role in the neural network that carries out syntactic computations" (Ibid., p. 415).

In a study by Bates et al., (2001), a comparison was made between the effects of unilateral lesions on the speech and language production of children and adults. The children in the study were five to eight years old at the time of testing and had sustained their injuries prior to six months of age. The investigation compared the amount of speech produced (in total utterances, word tokens, word types and morphemes), together with a common measurement of average utterance length (mean length of utterance in morphemes, or MLU). This was followed by a discussion of propositional and syntactic complexity (based on no more than 100 utterances for each participant), ending with the results of error analyses (total errors, omissions and morphological and lexical errors). The results show that children with left hemisphere damage scored far better than their adult counterparts on measurements of speech production. This outcome was attributed to the neural and behavioural plasticity associated with brain damage in childhood. However, as has also been pointed out, even if children with early left hemisphere damage might go on to acquire language abilities within the normal range, their cognitive performance is often at the low end of the normal range spectrum (Bates and Roe, 2001)

In a study in the present thesis, a closer look at the lesion site of the participants with explicit communication difficulties (**Paper III**) revealed that there was a high proportion of adolescents with left temporal and/or

frontal brain damage. An interpretation of the results suggests that injury location might provide a general prediction of the severity of the communication impairments in the participants. The results may also reflect a gradually more specialised cerebral organisation of language areas in adolescents aged 12-18 years, compared with the cerebral organisation at younger ages with the specialisation of brain functions yet to emerge.

## CLASSIFICATION OF INJURY SEVERITY

Injury severity related to communication outcome was an area of interest in this thesis. However, the predictive effect of injury severity on outcome could not be demonstrated. One reason might be that the overall cognitive and communicative outcomes after acquired head injuries are not easily defined, as there appears to be a somewhat poor correlation between the available classifications of the relationship between injury severity and outcome (see also *Methods; Outcome measurements,* for further descriptions of the classification of injury severity).

In relation to the more frequent use of neuroimaging data in clinical practice in the last few decades, it has been shown that the general prognosis for mild traumatic injury (mTBI, or concussion) might turn out to be more favourable than was initially expected from brain imaging findings such as CT or fMRI and the converse. One main reason for the lack of correspondence between the brain imaging findings and the severity of outcome is the difficulty involved in capturing diffuse axonal injuries (DAI), using these assessment methods. Neither CT nor fMRI appears to be sensitive enough to detect DAI, the main brain injuries in mTBI (M. E. Shenton et al., 2012). However, it has been argued that identified focal brain lesions or depressed skull fractures increase the severity of injury. As a result, participants with mild injuries complicated by these brain or skull traumas had an outcome in tests of memory, information processing and verbal fluency functions that was similar to that of individuals with moderate head injuries. Consequently, it has been suggested that participants with mild impairments of consciousness complicated by a depressed skull fracture and/or intracranial lesion should be classified as having sustained a moderate head injury (Williams et al., 1990).

As has previously been stated in relation to injury severity in the 38 participants in this thesis, there were 21 severe, nine moderate and eight mild cases of ABI, classified according to conventional neurological measurements. However, a closer look at the data obtained from neuroimaging assessments of the brain showed that seven of eight of the participants with "mild" injuries had visible sequelae manifested as injuries to different cerebral locations. Consequently, in accordance with observations in previous studies (Ibid.), the outcomes in these seven participants were not as "mild" as had been indicated in the initial assessments. A more accurate approximation of the injury severity in these seven cases was probably that of a "complicated mild" or "moderate" head injury outcome.

Further, the prediction of outcome for the cognitive and linguistic abilities in participants with ABI is complicated by the fact that the available test batteries are not adapted for this population. As a result, in participants with head injuries, there is proof that even a small change of 1 SD below the mean can result in impaired functions. This is somewhat contrary to the neuropsychological results in typically developing individuals, where a difference of 1 SD is within the expected mean and is an anticipated result within the normal variation for the age group. A previous investigation of patterns of eye-to-face gaze (also known as eye contact) involved adolescents with TBI and their typically developed peers (TD). The results show that 1 SD from the mean represented a significant difference in score distribution between the participants' TBI and the TD group and the difference in results mirrors the fact that 1 SD below the mean in typically developed participants does not indicate difficulties in patterns of eye-to-face gaze during communicative interaction (Turkstra, 2005).

In agreement with this knowledge, cut-off levels have been introduced in clinical ABI practice, so that values of $-> 1$ SD have been applied to detect participants with difficulties identified as "functionally significant" regarding persistent sequelae of the injuries (Catroppa, Godfrey, Rosenfeld, Hearps, and Anderson, 2012; Horneman, 2006, p. 38).

## CONVENTIONAL DIVISION OF TBI AND NTBI

The brain injury aetiologies in the participants in the present study had different origins. Of the original sample, 27 adolescents had suffered a TBI and 13 an NTBI. Most participants had extensive, multifocal injuries after ABI (23 adolescents were estimated to have moderate to severe injuries and 25 had injuries with a multifocal injury location) and they typically shared many patterns of impaired communication and cognitive skills, which was also evident from the parental ratings.

Traditionally, there appears to be have been a division of the two groups in research contexts, perhaps as a convenient way more easily to account for age at injury, neurological status at the time of injury and the like. However, according to our clinical experience, there are more common points that unite the two groups rather than separating them, which justified the inclusion of both groups. The mixed-ABI concept appears to be a common occurrence in a number of other projects as well, including a study by van't Hooft et al. of 38 children with ABI (2005), which was subsequently assigned a Class II rating in a meta-analysis of ABI studies by Laatsch et al. (2007). Another investigation of participants with either TBI or NTBI was unable to find clear evidence of differences in physical or cognitive data obtained in the two groups, suggesting that injury to the brain from either cause was likely to result in a similar range of long-term sequelae (Pentland, 2001). For this reason, the mixed-ABI approach appears to be commonly chosen as a valid method when designing studies within the acquired head injury domain (Anderson, Anderson, Northam, Jacobs, and Mikiewicz, 2002; Anderson et al., 2009; Boylan, Linden, and Alderdice, 2009; Chevignard et al., 2012; de Kloet et al., 2015; de Kloet et al., 2013; Zetterqvist and Jennische, 2010).

In this thesis, we wanted to create a consecutive, representative group of participants with ABI and we consequently invited all the children and their families to participate in the study. An examination was made to see whether differences in the communication evaluations and results of the linguistic/cognitive tests were affected by the aetiology of the injuries. There were no differences related to aetiology, in communicative ability according to the CETI ($p > .2$) or in any of the cognitive or linguistic tests ($p > .5$). Individual communication difficulties in these adolescents appear

to depend on factors other than aetiology, such as the lateralisation of the injury, cognitive status and time post-onset. There might also be a connection with the volume of subcortical brain structures after the injuries, a phenomenon which has been studied in typically developing participants. Pangelinan et al. (2011) found a significant relationship between general cognitive ability and the volume of subcortical brain structures in a group of 172 typically developing children and adolescents aged six to 13 years.

## IMPLICATIONS FOR IMPROVEMENT OF ASSESSMENTS AND INTERVENTIONS

The ability to participate in daily communication situations was a main concern for the adolescents in the study.

In **Paper II**, a detailed account of communication abilities after ABI was given, based on the individual's own perception of strengths and needs in communicative situations. The use of self-evaluations of video-recorded multimodal communication strategies appeared to have improved the understanding of managing his own and interactive communication after TBI. The ability to keep and take turns and to ask questions, as well as the use and the frequency of mimicry, body posture and other multiple functions of gestures, could be studied in detail in the video analysis. To further enhance the participation perspective and to explore aspects of the interaction between the interlocutors, an individualised analysis of recorded situations is recommended. The use of the video recordings can clarify the degree of intentional communication control in self-evaluations of the interactions. By using video recordings, the participant might more easily identify the dialogue entries that were performed with low intentional control during the conversations. This approach can be useful since more intention, strategy and attention can be assigned to the selected communication "trouble spots".

Communicative participation has been suggested as the most significant outcome of rehabilitation interventions, underscoring that an understanding of the communicative participation in daily life should always rely on descriptions of the person with the communication disorder (Baylor et al., 2011). However, a survey of accessible clinical evaluation tools in speech pathology therapy for adults found no specific instrument

which exclusively measured communication participation in daily contexts (Eadie et al., 2006). A survey of data by the author of this thesis for corresponding materials adapted for adolescents with ABI came to the same conclusion, although the La Trobe Questionnaire (Douglas, 2010), gauging perceived social communication in adolescents with TBI, is a very good alternative.

It could be argued that it is not at all obvious that material measuring communicative participation after ABI should be available, given that adolescents with these injuries constitute a heterogeneous group, with different needs and strengths within a variety of areas, such as cognition, language comprehension, pragmatic ability and speech and voice functions. Furthermore, the children and adolescents are of different ages when the injuries occur and consequently at different stages of communication development.

Nevertheless, contrary to other groups of participants with brain injuries associated with congenital communication disorders, the individuals with ABI have a common denominator: they were all typically developing people prior to the disease or the trauma they experienced. In relation to the age at injury, the specific stages of typical cognitive and communicative development were commonly experienced by all the participants. As a result, all the adolescents in this study had experienced managing communication in daily situations. From this perspective, it was not surprising that the aetiology of the injuries was unrelated to the communication difficulties, as reported by the parents, but was related to a previous typically developed communication ability **(Paper III)**. Further, as was shown in Paper III, differences could be attributed to the lateralisation of the injuries and to the level of overall cognitive functioning. These patterns of the sequelae in participants with ABI have previously been confirmed. Pentland and Hellawell (2001) examined the reports from relatives of adolescents and adults who had sustained either a TBI or a subarachnoid haemorrhage. In a study population of 209 participants (126 with a TBI and 83 with a subarachnoid haemorrhage), the ten symptoms most frequently reported were language, memory, physical, emotionally disturbed behaviour, social behaviour, subjective symptoms and dependence. The results showed that there was a considerable degree of overlap of sequelae reported by the relatives or other informants of both patient groups. So,

despite the differences between groups in terms of demographic characteristics and mechanisms of injury, it was suggested that injuries to the brain from either TBI or subarachnoid haemorrhage were likely to result in a similar range of long-term sequelae.

In this thesis, the outcome also points to the benefits of specifying the methods for assessment and the related interventions which are suitable for participants with TBI, as well as those with NTBI. The results of the thesis indicated that there were no differences between the participants with TBI and NTBI which could be related to the cause of the injuries and for this reason the framing of the specification of interventions is recommended for all participants with ABI. Using a specification of this kind, it would be possible to plan the interventions individually to match each participant's abilities and need for rehabilitation. At the same time, the guidelines for interventions in both groups could be specified. The focus of the interventions should be based on a participation point of view, thereby directly eliciting responses from the participants with ABI. If obtaining a coherent response directly from the participant with ABI is not possible, as a consequence of the injury to the ability to communicate, there are alternative approaches guided by the participation perspective. Carol Prutting, the author of the Pragmatic Protocol (Study I), stated that judgements of appropriate or inappropriate communicative behaviour should always be made relative to the person with the communication disorder, the conversational partner and other aspects of the context that are known. She emphasised that the age-related abilities in the person with ABI and the context where the communication occurs require particular consideration in the evaluation procedure (Prutting and Kirchner, 1987).

Designing guidelines for this group of participants could help to clarify the demarcation of ABI from other medical, social and developmental conditions in children and adolescents, such as intellectual disabilities or autism spectrum disorder, which are conditions that may also affect communication ability.

The creation of an adapted health-care programme targeting communication impairments after ABI in childhood and adolescence could be a significant step towards creating a basis for future international guidelines for clinical trials and other rehabilitation interventions in this group.

The design of a programme like this would benefit from the inclusion of significant others at an early stage in the rehabilitation programme. Many of the participants with moderate to severe ABI are under-aged, with severely impaired cognitive and physical functions, and they will depend on their parents and other significant persons for extensive support needs during their entire lifetime. Furthermore, the inclusion of parents in the investigations of communication skills can provide valuable information that is not easily obtained by professionals in the clinical environment. In the present thesis, the co-operation between parents, professionals and the adolescent with ABI highlighted not only the communication facilitators and barriers in the adolescents but also the ability of the parents to recognise the communicative change over time **(Papers IV and V).**

As a result, the information that can be extracted from the significant others of the participant with ABI might offer potentially valuable knowledge. First, information about the adolescent's strengths and needs in daily interactions in the home environment can be highlighted. This information might not emerge in structured clinical surroundings, nor might the adolescents themselves observe the communication behaviour, due to limited awareness as a result of the injury. Second, the information given by the parents could provide a background to the current communication status, relating to the adolescent's individual developmental during childhood. Third, the information can reveal the nature and extent of the parents' own psychosocial adjustment related to the injuries in their children. By knowing more about these processes, the professionals in the rehabilitation team can tailor the necessary support, by helping parents to adapt their communication style to increase the adolescents' daily communication ability, for example. This approach is supported in previous studies, showing that the communication training of significant others of teenagers and adults can improve communication abilities in the person with ABI in the chronic stages post-injury (Togher, McDonald, Tate, Power, and Rietdijk, 2013).

Furthermore, general emotional support for the parents appears to be an important area to consider in the communication processes after head injuries. The adolescents with communication problems could clearly benefit from parental programmes targeting parental support as part of a context-sensitive intervention (Taylor et al., 2002; Ylvisaker, 2003).

In conclusion, a tailored health-care programme should be adapted to adolescents with impairments after ABI to enhance participation in daily communicative situations. Depending on individual needs, the programme could include evaluations using the CETI in combination with follow-up interviews of selected items which are important in order to manage daily communication for the individual participant. Video recordings in combination with self-assessments should be the chosen methods to highlight the participation perspective. Other measures might include specific skills training, compensatory strategy training, the use of technology to support and improve communication skills and the adaptation of the significant others' own communication style, as well as therapy to provide emotional support to significant others and the adolescents affected by the traumas.

**Some general theoretical conclusions** can also be drawn from the results in this thesis, related to the contemporary theoretical context of ABI research. A general increase in the demand for evidence-based trials during the last few decades has probably had an impact on the choice of theoretical models in ABI research as well, such that studies with a positivist approach have increased in research contexts.

The increasing demand for evidence-based clinical trials points to randomised controlled trials (RCT) as the gold standard. However, the gold standard position of these trials has been seriously challenged. First, a survey investigated the effects of medical treatment in observational studies, i.e. studies which draw inferences from a sample to a population in which the independent variables were not under the control of the researcher because of ethical concerns or logistical constraints, compared with the similar effects reported in randomised, controlled trials. The data showed little evidence of any differences in treatment effects between the two study designs. Second, a meta-analysis identified randomised clinical trials and observational studies that examined the same clinical topics. It was reported that, for the five clinical topics and 99 reports, the average results of the observational studies were remarkably similar to those of the randomised, controlled trials. The conclusion of both these surveys was that the results of well-designed observational studies do not systematically overestimate the magnitude of the effects of treatment as compared with those in randomised, controlled trials on the same topic (Benson and Hartz, 2000; Concato, Shah, and Horwitz, 2000).

Furthermore, in studies involving human beings, there are often problems related to the demands relating to the randomisation of the participants related to RCT studies. For example, Togher and colleagues (2013) aimed to investigate the effectiveness of communication training for partners of people with severe TBI in a multicentre RCT. However, it was discovered that randomisation was not possible due to an inadequate number of participants with communication partners who were able to attend the planned training intervention. Instead, the study had to adopt a single blind clinical trial.

Despite the high level of formal control surrounding RCTs, there is evidence that complications occurring in daily contexts prevent the procedures from being executed according to the manual, which adds to the already challenged claim of the strict scientific control associated with the RCT (Bohlin and Sager, 2011). The theory of randomisation claims to generate models to control an infinite number of different hypotheses. However, randomisation per se may not entirely master these competing hypotheses but only depict them as improbable.

Another key limitation in theories that focus on test data associated with communication after ABI is the risk of too easily generalising data from one context to the other, without taking account of the fact that communication is a pronounced context-dependent activity (Ahlsén, 1995; Allwood, 2013). For example, tests tend to focus on assessing impaired functions in clinical settings and, in doing so, fail to define the consequences for functions in everyday contexts (LaPointe et al., 2010, pp. 247-250). Tests may indeed be "functional", in the sense that they assess "functions" with standardised instruments, such as questionnaires and checklists (Holland, Frattali, and Fromm, 1999). However, the tests are always limited when it comes to describing the full potential of an individual's communication life (Fyrberg et al., 2007).

The development along the two theoretical lines described above – on the one hand, the interpretative approach relying on qualitative data and, on the other hand, the positivist approach involving quantitative data, has generated methods in rehabilitation practice that embrace both views. The development of the two fields is interesting, as it has been argued that theories generating a mixed-method research design can result in superior research, compared with mono-method studies (Johnson and Onwueg-

buzie, 2004). The future development of both theoretical stances might provide new integrative models to capture the seemingly contradictory and complex conditions that are frequently seen in childhood ABI.

# CONCLUDING REMARKS

## THEORETICAL RELEVANCE OF THE REPORTED DATA

The results of **Study I** were based on data collected by professionals in clinical environments. The taxonomy applied in the assessment procedures, the Pragmatic Protocol, was explicitly designed within a scientific paradigm for conceptualising pragmatic aspects of language, for clinical and research purposes. In the 1980s, when the PP was introduced, the authors concluded that "to date there is no documentation of how language-disordered populations fare when assessed on a range of pragmatic abilities" (Prutting and Kirchner, 1987, p. 106). In fact, Prutting and Kirchner were clearly forerunners in shaping evaluation tools for communication outcome. However, the introduction of PP took place before the release of the ICF, which appeared in 2001. In the 1980s, the older version of the ICF, the ICIDH, was still the internationally applied theoretical model in the rehabilitation area. As a result, indicators of health status that relied on the mortality rates of the population had not yet changed from cause to the subsequent terminology including impact, activities and

health, which came with the introduction of the ICF. Furthermore, the discussion of communication related to the participation and ecological perspectives had not yet emerged in ABI contexts. For this reason, the PP was widely accepted by clinicians as a usable tool with a new taxonomy for clinical measurements of pragmatic abilities. In spite of this, from a participation perspective, it is a shortcoming of the taxonomy that it only takes account of the professionals' evaluations of pragmatic functions. Given that communication is a context-dependent phenomenon, the evaluation of the interactions occurring in clinical contexts with professional staff can only be recommended as a screening procedure for tracking daily communication behaviours requiring deeper analyses, which was also one of the conclusions drawn in Study I.

The conditions for clinically based conversations probably differ essentially from daily conversations with significant others in a home environment, for better or worse. Moreover, the participation perspective as it has been depicted in the ICF might not readily be reflected in evaluations made by clinicians, as 1) the persons with the health condition were not involved as respondents in the assessment procedures and 2) the assessors, despite their professional knowledge of communication related to ABI, generally have a very limited knowledge of the communication abilities of the person with ABI before the injuries, which further restricts their understanding of the communication outcome after the injuries. A method to compensate for the above-mentioned study limitations was suggested by using the inter-rater agreement evaluations of the data, which was introduced accordingly as an analytical tool in Study I. By using ratings that were made independently by two assessors, a higher degree of validity could be attained, compared with ratings made by one professional. Differences in perceptions of the adolescents' communication could be analysed in discussions between the raters and related not only to the activity of the particular situation where the assessment occurred but also to the environment of the communicative interaction and to the role of the conversation partners. For example, it was shown that everyday interaction during daily activities on the rehabilitation ward, in contrast to specific and individual training and/or assessment activities, affected the communication outcome in the adolescents, i.e. the ability to participate in communicative interactions (Paper I).

In summary, including the ICF perspectives associated with activity, environment and participation in the analyses of data obtained in Paper I resulted in some benefits. It was shown that, despite the shortcomings of the model associated with a lack of individualised assessments to explore the subjective views of the participants, the ICF perspective played a significant role in modelling the design not only in Study I but also in the remaining papers included in the thesis. Future studies of the participation construct related to ABI should investigate the views of the person with the health condition and also of the significant others, to further develop the participation construct of the ICF.

**Study II** used the ACA theory and in particular the study of communication management to analyse video-recorded material in face-to-face interactions. The contribution of the data to exploring interpersonal communication includes the emphasis on the multimodal aspects of communication, i.e. the study of verbal reply, patterns for turn-taking, facial gestures, changes in body posture or movements of arms and hands, incorporating gestures as significant features of functional communication. It also emphasises the benefits of a mixed-model approach, including data from clinical evaluations, as well as recordings from on-line conversations.

By applying a CM analysis, the specific communicative behaviours included in the model, as well as interactions between interlocutors in the investigated video recordings, could be explored in collaboration with the young man with ABI who participated in self-assessments in the study. The contribution of the theory to exploring the data in the thesis includes the emphasis on the multimodal aspects of communication and on assessments of interactive communication between the participants in the video-recorded interactions. The distributed cognition perspective (i) helped to connect communication features to overall cognitive abilities like memory, attention, affect and perception and (ii) enabled communication to be investigated as a phenomenon distributed between members of the investigated group. Furthermore, (iii) communication could be studied as a co-ordination between internal and external structure, including degree of intentionality and (iv) communication processes were seen as being distributed through time in such a way that the outcome of earlier communication exchanges can transform the nature of subsequent events.

**Study III** explored the test results from clinical evaluations of language comprehension, naming, reading abilities and linguistic functions, as well as data from observations of communication in daily environments obtained from relatives of the participants. A combination of theories, in particular the ACA and ICF, could be used and aspects related to the environment and the role of the parents (ACA), as well as the inspection of activity and participation in the communicative situations (ICF), were investigated. The theoretical relevance of the data reported in Study III relates strongly to the mixed-model design of the study. In this way, both qualitative and quantitative data could be collected, which provided an overview of the complex picture of cognitive, linguistic and communicative outcome after ABI (see also *Some general theoretical conclusions*, above).

**Study IV** used differences in self-other perceptions of everyday communication evaluated through ACA and distributed cognition. Moreover, a quadrant model of analysis based on the theories put forward in the Johari Window model was used. The analysis model provided a framework for qualitative analysis of the differences in the perception of daily communication between the adolescents participating in the study and the perception of their parents. The results of the analyses between the quadrants of the model varied according to the estimations of different CETI items and different parent-youth constellations.

The data in this study indicated that not only were the estimated communication skills in the adolescents based on the analysis using the model, but the parents' ability/inability to interpret the communicative signals of the adolescent were highlighted as well. First, this ability, or inability, appears to be directly dependent on the impaired communication skills in the adolescent in some cases and, second, it could also be related to aspects of the construct of *façade,* as the participant might not want to convey all the requested information to the parent, and, third, the recovery phase (timing) of the child's communication ability might also have influenced the parents' ability to understand the nature of the communication abilities of the child post-injury. As a result, the construct of *unknown* in this sample could be applied to a situation where neither the parent nor the adolescent had recognised the communication problems at the time of assessment. This phenomenon could occur early post-trauma, show-

ing that the scope of the communication outcome in everyday communication situations needed time to emerge among the family members in daily interactions, after the discharge from hospital environments after the injuries.

Analyses through ACA and distributed cognition theoretical approaches highlighted the interplay between the *collective factors* and *individual factors* in daily interactions. First, CETI data were analysed, related to the environment in which the communication activity was performed, which were the obligations and rights of the people participating in the activity, the artifacts that were used for the communication activity and how were they applied in the context. Second, the subjective experiences were highlighted in the CETI self-assessments by the adolescents and in the parent evaluations. ACA also helped focus on the consequences of the communication impairments for the social role of the participants, the effect of the communication difficulties related to psychosocial well-being and associations to changes in biological features, such as visual or auditory disorders.

The distributed cognition framework helped to analyse the interplay between external and internal factors influencing the understanding of the communication abilities of the participants, in clinical surroundings as well as in the adolescents' own home environment, reported by the parents and by the adolescents themselves.

The usability of the combination of these frameworks was confirmed in the study, as a first attempt to apply it in a study of participants with ABI, and, for this reason, it could benefit from further exploration in ABI contexts.

**Study V.** The central ideas behind distributed cognition had a particular impact in Study V (see Theoretical framework). The distinction between *people, material/environment and temporal aspects* in the definition appears to be a fruitful approach when describing factors related to outcome after ABI. The complexity of the interactions associated in particular with Factor 1 CETI items, including vocal-verbal communication, was analysed to trace possible changes in communication patterns, between the first ratings and at follow-up. The framework helped to understand the interplay between internal and external processes in the person who reported the communi-

cation activities and between the person and the conversation partner, as well as the role of the environment in which the communication occurred. In conclusion, by using the distinction between *people, material/environment and temporal aspects,* the interplay between the units of analyses could be clarified.

The temporal aspects of distributed cognition theory were reflected in the participants in this sample, who were typically developing adolescents prior to the brain injuries. Consequently, the communication skills they had acquired before the injuries could be taken into account in the evaluations and discussions post-injury and used as a platform for further rehabilitation interventions. The coping strategies involved in the communication strategies could be associated with the previously experienced strategies the participant had practised in everyday situations, before the occurrence of the brain injuries. This perspective was also underscored in **Studies II and IV**, where the nature and/or extent of the communication skills before the injuries were also related to follow-up data. It seems that it is particularly important to take account of the temporal aspects accounted for in distributed cognition in children and adolescents, as information about the individual's communication profile before the injuries may affect the understanding of the nature and the degree of communicative development after ABI from a life perspective. Assessments of communication are frequently not adapted to adolescents with ABI but constructed according to a population with other diagnoses, i.e. autism, developmental language delay and adults with aphasia. In these diagnoses, the temporal aspects of the disorders are quite different compared with ABI, as people with autism and developmental language disorders have no previous knowledge of a typically developed ability to communicate and adults with aphasia have a life-time history of fully developed communication. As a result, there are no skills that can be equally compared with a "before" and "after" the injury and the development of communication skills in these groups travels along different routes, according, among other things, to the nature and level of the abilities acquired in the past. Future research is clearly warranted to further explore these questions, taking account of the previously acquired knowledge of communication in the participants when designing investigations.

The author Chimamanda Ngozi Adichie proposes that "being familiar with only one story about a person […] can result in fatal misunderstandings. The consequence of one single story is this: it robs people of dignity. It makes our recognition of an equal humanity difficult. It emphasizes how we are different rather than how we are similar" (2009).

This conclusion is particularly true for participants with communication impairments after ABI. The adolescents participating in this study were typically developing individuals prior to their head injuries, all with previously functional communication skills relevant to their age. The similar factors were important to consider in the data analyses, even though each participant had a unique communication profile. As has been previously stated, there is a huge variation in performance in this group. That is why there is a need for individual evaluations (Anderson, 2016).

Depending on a variety of ABI-related phenomena, such as the lateralisation of the injuries, cognitive abilities and contextual factors, the outcomes of the studies in this thesis varied and therefore contributed to different "stories" about the participants' individual communication. The variations appeared to occur not only between participants but also in one and the same person, depending on contextual factors and on who was the judge of the communicative situation. As a result, highlighting the meaning of context was important in order to hear the story of the participant with ABI, as well as the story from the significant others, describing communication activities in real-world situations from different perspectives.

Clinical evaluations were made to assess the prerequisites for communication, like word and sentence comprehension, cognitive functions, hearing, visual and auditory skills; all of them important measurements when it came to providing background information to the communication performances. The results show that children with more severe communication disorders, as evaluated by the parents, also obtained significantly lower results on IQ tests. Lesions in the left hemisphere were the most common injury location in this group. Of the 38 participants, there were 21 severe, nine moderate and eight mild injuries. However, in relation to data obtained from neuroimaging assessments, it was subsequently concluded that seven of eight with "mild" injuries had visible cerebral

sequelae, signifying a "complicated mild" equal to moderate head injury outcome (see also *Methods; Outcome measurements*).

Complex discourse abilities were impaired in all participants, according to parental estimations. The data also indicated the predictive value of the clinical test findings, showing that injury site, language data and IQ results may be prognostic factors of communication outcome after paediatric ABI.

However, the study results also point to the uniqueness of each lived experience of communicative participation, leading to individual rehabilitation interventions to enhance the participation perspective in daily interactions. The important role of the parents in exploring the adolescents' communication barriers and facilitators in real-life contexts is underscored, as they have first-hand knowledge of the adolescents' communication both before and after the occurrence of the head injuries. However, from a communicative participation perspective, the adolescents who are able to make self-evaluations should be invited to do so. As has previously been pointed out, participation has been suggested as the most significant outcome of rehabilitation interventions, indicating that an understanding of the communication disorders in daily surroundings should always rely on descriptions given by the person with the health condition (Baylor et al., 2011).

# CLINICAL IMPLICATIONS AND FURTHER STUDIES

This study highlights the need for a new, more context-sensitive model for the evaluation and planning of interventions after ABI in school-aged participants. The need for development in this area is related to the fact that acquired brain injuries in adolescents frequently result in life-long communication difficulties, severely affecting both social and academic inclusion in adult life. During the last few decades, investigations of the disorders solely through clinical assessments have been increasingly disputed and evaluations of the outcome in other, more personally related contexts appear to be needed.

One interesting continuation of this research would be to further explore how the communicative participation perspective according to the ICF could be further developed in adolescents with ABI.

Based on the results of the five papers included in the present thesis, it was concluded that:

- The inclusion of both TBI and NTBI aetiologies in communication studies is important to provide relevant information about the outcome after ABI.

- Limited cognitive and linguistic skills may affect complex communication interactions in daily life. The results of parental evaluations confirmed that severely injured adolescents, as well as those with moderate/mild injuries, had difficulty communicating in complex communication interactions. The findings point to the important role of the parents in exploring children's everyday communication abilities.
- Evaluations of interventions to improve everyday communication abilities in adolescents with acquired brain injuries benefit from analyses in real-world contexts.
- The participation perspective should be further developed by applying self-assessment procedures to meet subjective needs and strengths. Interviews and video recordings are other suggested methods to meet the need for a contextual evaluation and a participation perspective of communication.
- "Mild is not mild" refers to the lack of predictability of classical neurological models for injury severity. The models could benefit from a more detailed description of differences between moderate and severe injuries, so that the available physiological findings in mild injuries might change the classification of severity from a "mild" to a "moderate" injury, See also *Participants; Inclusion of Participants with Non-Traumatic Brain Injury (NTBI).*
- More research is required in larger populations to develop models for assessment and treatment to enhance participation in children and adolescents with communication impairments after ABI.

# SWEDISH SUMMARY

**Syfte** Övergripande syfte med denna avhandling var att undersöka metoder för att bedöma kommunikativ delaktighet hos barn och tonåringar (hädanefter: tonåringar) med förvärvade hjärnskador (ABI). Undersökningarna genomfördes framför allt genom skattningar med en svensk version av the Communicative Effectiveness Index (CETI) och genom intervjuer med deltagarna. Syftet med avhandlingen var också att belysa viktiga förändringar av den kommunikativa förmågan över tid. Fem delstudier genomfördes som del i avhandlingsarbetet. Dessa presenteras i studie I-V.

**Metod** Studie I: Pragmatiska bedömningar av åtta deltagare med svår ABI gjordes. Den kliniska insamlingen av data utfördes av logoped och rehabiliteringsassistenter i en svensk översättning av en taxonomi för klassificering av pragmatisk förmåga, the Pragmatic Protocol (PP). Studie II: Beskrivande och jämförande metoder användes för att undersöka kommunikativ förmåga hos en tonåring med ABI. Lingvistiska och kognitiva testdata inkluderades samt utvärderingar i CETI av tonåringen själv och föräldrarna av den kommunikativa förmågan, efter skadan och vid ett uppföljningstillfälle. Videoinspelningar av interaktion analyserades genom självskattningar och intervjuer för att undersöka tonåringens kapacitet att hantera kommunikationen i dialoger (Communication Management). Studie III: CETI:s användbarhet undersöktes genom föräldraskattningar av 30 tonåringars vardagskommunikation. Resultaten jämfördes med resultat från undersökningar av lingvistisk förmåga, kognitiv nivå och med data från neurologiska och demografiska undersökningar. Studie IV: Bedömning av daglig kommunikativ förmåga hos åtta ungdomar gjordes av deras föräldrar. Data jämfördes med ungdomarnas egenskattningar. Kvalitativa data från intervjuer med deltagarna analyserades med hjälp av aktivitetsbaserad kommunikationsanalys, ACA, (Allwood, 2013) och en kognitionsvetenskaplig teori: teori för distribuerad kognition (Hutchins, 1995a). Studie V: Data som mäter förändring av kommunikativ förmåga efter hjärnskadan beräknades hos de 30 ungdomar som deltog i studie III, genom att jämföra resultat från den första mätningen med senare, uppföljande analyser.

**Resultat** Studie I: Sju av åtta deltagare med svåra hjärnskador bedömdes ha en starkt reducerad förmåga att kommunicera inom alla de pragmatiska parametrar där tal och språkförmåga bedömdes. Självskattningar av videoinspelningar i studie II bekräftade svårigheter i hantering av kommunikationen relaterade till nedsatt språkförståelse, högt samtalstempo hos konversationspartnern och även associerade med antalet deltagare som interagerade i dialogerna. Studie III: CETI-data visade att tonåringar som hade större svårigheter att kommunicera enlig föräldrarna också hade signifikant lägre resultat på test som mäter grammatisk förståelse (samma trend vad gäller ordförståelse, dock ej signifikant resultat) och verbal IQ. En majoritet av dem med kommunikationssvårigheter enligt föräldrarnas bedömning hade också nedsatt benämningsförmåga. Komplexa kommunikativa interaktioner, till exempel snabba samtal med flera talare, var dock svåra för alla deltagare enligt föräldraskattningarna, också hos de tonåringar som hade högre resultat i test som mäter grammatisk förståelse och verbal IQ. Studie IV: Hög samstämmighet förekom mellan föräldrar och

tonåringars bedömningar av kommunikativ förmåga men tonåringarnas interaktion i komplexa kommunikativa situationer skattades lägre av föräldrarna jämfört med ungdomarnas egenskattningar. Analyser i ACA och distribuerad kognition samt analyser av intervjudata visade på användbarheten av en systematisk jämförelse i CETI av gemensamma perspektiv på kommunikation efter ABI i tonåren, för att öka medvetenheten om delaktighetsperspektivet i dagliga samtalssituationer. Studie V: Art och grad av kommunikativ förmåga efter ett års tillämpning av strategier av föräldrar i hemmiljön visade en signifikant ökning hos 30 deltagare ($p < .01$). Vissa förmågor förbättrades dock inte så mycket och i några fall såg man en försämring av den bedömda förmågan, enligt föräldrarnas skattningar. Dessutom visade en jämförelse att tonåringar skattade sina förmågor som mer välfungerande, jämfört med föräldrarnas skattning.

I de olika delstudierna återfanns inget samband mellan hjärnskadornas grundorsaker och deltagarnas övriga resultat i tester av kommunikation, lingvistik och kognition. Emellertid hade en majoritet av dem med vänstersidiga skador, oberoende av skadornas orsaker, större kommunikativa svårigheter jämfört med dem med andra skadelokalisationer, enligt föräldrarnas bedömningar.

**Slutsatser** En allmän slutsats av avhandlingens studier är att bedömningar av kommunikationen hos ungdomar med ABI med fördel kan göras utifrån analyser av interaktion i vardagliga miljöer. Kommunikativa bedömningar med CETI-taxonomin identifierade observationerna gjorda av deltagarna i hemmiljön. De data som inhämtades från kliniska undersökningar, särskilt resultat av kognitiva och lingvistiska test och av hjärnskaderelaterade undersökningsdata, förefaller att ha ett visst predicerande värde när det gäller påverkan på den kommunikativa funktionen. Resultaten i studien pekar också på föräldrarnas viktiga roll när det gäller att undersöka tonåringarnas kommunikativa delaktighet i vardagssamtal genom att använda CETI och genom intervjuer där föräldrarna ytterligare kan fördjupa sina synpunkter på kommunikationen. Deltagarperspektivet kan ytterligare tydliggöras av ungdomarna själva, vilket visades i analyser av videoinspelningar och i intervjuer som baserades på analysmetoder från ACA och distribuerad kognition. De kvantitativa och kvalitativa analysmetoderna som tillämpades i denna avhandling kan bidra med resultat som kan vara användbara i utformningen av individuella rehabiliteringsprogram för ungdomar efter ABI.

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