# Quality assessments of ADL instrument and evaluation of ADL ability in individuals with cervical spinal cord injury after reconstructive hand surgery

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*"To someone who has nothing, a little is a lot"*

Sterling Bunnell

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## ABSTRACT

**Background:** A spinal cord injury (SCI) leads to dramatic changes in an individual's life and the rehabilitation after the injury is a lifelong process. For persons with cervical spinal cord injury (SCI), the loss of both sensory and motor function in the upper extremities poses a functional deficit and an impairment in activities of daily living (ADL). Reconstructive hand surgery has the potential to restore loss of motor function and can therefore influence both capacity, i.e. grip function, and activity performance.

**Methods:** One cross-sectional study, one mixed study and two longitudinal studies were performed. The study participants consisted of individuals with cervical spinal cord injury with no prior reconstructive hand surgery before September 1994. Data were collected by face-to-face semi-structured interviews and by connecting the Klein-Bell ADL (KB) Scale to the ICF.

**Results:** The KB Scale linkage to the ICF made it possible to interpret, detect and quantify concepts in the scale and thus highlighted and clarified the scale structure. Comparison between the KB Scale and ICF core sets and have corroborated that the scale can measure basic ADL in individuals with cervical SCI. The KB Scale can be used to assess and discriminate cervical SCI individuals' basic ADL from lesser to greater independence before surgery. Improvements in basic ADL can also be measured after reconstructive hand surgery. Individuals undergoing grip reconstruction became more independent in dimension hygiene, whereas individuals undergoing reconstructive elbow extension and grip surgery increased their independence in dimension mobility.

**Conclusions:** The ICF provided an external reference to identify and quantify concepts in the KB Scale. The KB Scale linkage to ICF provided a systematic overview how the items are constructed from body movements to basic ADL activities. The KB Scale can be used to assess basic ADL, and discriminate and measure changes in self-care in cervical SCI individuals in connection with reconstructive hand surgery. To become a useful tool, selected parts of the KB Scale's structural properties must be further investigated.

**Keywords**: Klein–Bell ADL Scale, tetraplegia, reconstructive hand surgery outcome measurement, ADL, ICF

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# SAMMANFATTNING PÅ SVENSKA

**Bakgrund:** En ryggmärgsskada leder till dramatiska förändringar i en persons liv och rehabilitering efter skadan är en livslång process. En halsryggmärgsskada innebär att en person förlorar både sensorisk och motorisk funktion i armar och händer vilket innebär nedsatt funktion och en oförmåga att utföra i aktiviteter i det dagliga livet (ADL). Rekonstruktiv arm och handkirurgi har potential att återställa förlust av motorisk funktion och kan därför påverka både kapacitet, d.v.s. greppfunktion och daglig aktivitet.

**Metod:** Ett flertal studier har genomförts; en tvärsnittsstudie, en mixad studie och två longitudinella studier. Studiedeltagarna bestod av individer med halsryggmärgsskada som inte genomgått rekonstruktiv handkirurgi före september 1994. Data samlades in dels genom en semi-strukturerad intervju och dels länka Klein-Bell ADL (KB) Skala till ICF.

**Resultat:** KB Skalan länkning till ICF gjorde det möjligt att tolka, identifiera och kvantifiera begrepp i ADL skalan och därmed kunde man betona och klargöra skalans strukturella uppbyggnad. Jämförelse mellan KB Skala och ICF core sets har bekräftat att KB skalan kan mäta bas ADL hos personer med halsryggmärgsskada. KB Skalan kan användas för att bedöma och diskriminera bas ADL hos individer halsryggmärgsskada självständighet före operationen. Förbättringar i bas ADL kan också mätas efter rekonstruktiv handkirurgi. Individer som genomgår rekonstruktion av greppfunktion blev mer självständiga i dimension hygien, medans individer som genomgår rekonstruktion av armbågssträckning och greppfunktion får ökad självständighet i dimension förflyttning.

**Konklusion:** ICF kan via länkning användas som extern referens för att identifiera och kvantifiera begreppen i KB Skalan. KB Skalan länkning till ICF gav en systematisk översikt hur item är konstruerade från funktion till bas ADL aktiviteter. Med KB Skalan kan man  bedöma bas ADL och diskriminera och mäta förändringar i personlig vård för halsryggmärgsskada individer i samband med rekonstruktiv handkirurgi . För att bli ett användbart instrument, måste valda delar av KB Skalan strukturella uppbyggnad undersökas ytterligare.

# LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals. The publisher are reprinted with permission from the publishers[1,2]

I. Dahlgren A, Karlsson AK, Lundgren-Nilsson A, Friden J, Claesson L. Activity performance and upper extremity function in cervical spinal cord injury patients according to the Klein-Bell ADL Scale. *Spinal Cord. 2007;45(7):475-84.*

II. Dahlgren A, Sand A, Larsson A, Karlsson AK, Claesson L. Linking the Klein-Bell Activities of Daily Living Scale to the International Classification of Functioning, Disability and Health. *Journal of Rehabilitation Medicine. 2013;45(4):351-7.*

III. Dahlgren A, Karlsson AK, Claesson L. Long-term follow-up in ADL performance in individuals with cervical spinal cord injury after grip reconstruction. *In manuscript.*

IV. Dahlgren A, Karlsson AK, Claesson L. ADL performance in individuals with tetraplegia after reconstructive elbow extension and hand surgery with a long term follow-up. *In manuscript.*

# CONTENT

# ABBREVIATIONS

| | |
|---|---|
| ADL | Activities of Daily Living |
| ASIA | American Spinal Injury Association |
| BADL | Basic Activities of Daily Living |
| CAT | Computer Adaptive testing |
| CI | Confidence interval |
| FIM | Functional Independence Measure |
| IADL | Instrumental Activities of Daily Living |
| ICF | International Classification of Functioning, Disability and Health |
| IC | International Classification of Hand Surgery |
| KB Scale | Klein-Bell ADL Scale |
| MMT | Manual Muscle Test |
| MRC | British Medical Research Council |
| O | Ocular impulses; depends on vision |
| OCu | OculoCutaneous impulses; both vision and tactile gnosis. |
| OT | Occupational therapist |
| PA | Percentage Agreement |
| PADL | Personal Activities of Daily Living |
| PEO | Person-Environment-Occupation Model |
| PCC | Person-Centered Care |
| PT | Physical Therapist |
| ROC | Relative Operating Characteristic Curve |
| ROM | Range of Motion |
| SCI | Spinal Cord Injury |
| SCIM | Spinal Cord Independence Measure |
| VMA | World Medical Association |
| QIF | Quadraplegia Index of Function |
| UEMS | Upper Extremity Motor Score |
| 2PD | Two Point Discrimination |
| SCIM | Spinal Cord Independence Measure |

# PREFACE

In Gothenburg, Professor Erik Moberg during the early 1970s developed hand surgery in order to improve the function of the upper limb of individuals injured in the cervical spinal cord. Since then, reconstructive hand surgery has been a part of the rehabilitation of these individuals. The team involved in reconstructive hand surgery for individuals with an injured cervical spinal cord were centralised to the Spinal Cord Injury Unit in 1993. These individuals were able to regain elbow extension and grip function by reconstructive surgery. Evaluations connected with these interventions had heretofore mainly been to evaluate functional variables. In this group, there was an interest in broadening the view of which variables could be assessed in connection with these interventions. Variables that the group was interested in including in the evaluation, in addition to function, were quality of life and daily activities. During 1993, an application was therefore written with the title "patient's functional capacity, quality of life and assistance needs", and research funding was applied for and granted by the National Board of Health and Welfare. The current study is one part of the main study and evaluates basic daily activities in individuals with cervical spinal cord injuries in connection with reconstructive hand surgery.

# INTRODUCTION

This thesis includes quality assessments of the Klein-Bell ADL Scale and evaluations of activities of daily living (ADL) in individuals with cervical spinal cord injury after reconstructive hand surgery. These two aspects were chosen because few ADL instruments are designed to measure detailed changes in daily activity. For individuals with cervical SCI undergoing reconstructive hand surgery, it is important to use an ADL instrument where it is possible to examine these changes at this level of detail. In this thesis, a generic ADL instrument, the Klein Bell ADL Scale, was chosen because the structure of the scale makes it possible to show changes at a detailed level in ADL. The Klein Bell ADL Scale has been tested for validity and reliability for persons with cervical spinal cord injury. However, in earlier studies the SCI individuals level of injury either remain unclear (1) or include few cervical SCI individuals (2) .Therefore, examined paper I and paper II the structural properties in the Klein-Bell ADL Scale. In study III and study IV, the Klein-Bell ADL Scale was thereafter used to evaluate ADL in connection with after reconstructive hand surgery.

# 1 BACKGROUND

## 1.1 Epidemiology and rehabilitation after Spinal cord injury

The incidence of traumatic spinal cord injuries (SCI) in Western Europe is 16 cases per million inhabitants per year (3). In Sweden the incidence of SCI is approximately ten to 15 cases per million inhabitants per year. Thus, about 120 persons sustain a traumatic SCI every year in Sweden (4). Internationally and nationally, the mean age at injury has risen during recent years from 30 years (4) to over 40 years (5, 6). Today, life expectancy for individuals with spinal cord injuries is approaching the general population, but it is lower for individuals with cervical SCI compared to those with paraplegia (4). More men (70-80%) than women sustain a traumatic SCI. However, the proportion of women sustaining a traumatic SCI has increased in recent years (7). In Sweden the most common cause of SCI injuries (40-50%) is motor vehicle accidents (4). In Europe, falls are a common cause of SCI injuries, and this is increasing due to an aging population (3, 5). Approximately 50% of all traumatic SCI affects the cervical portion of the spinal cord both in Sweden and in Western Europe (3).

Rehabilitation after SCI is a lifelong process that requires a reorientation in nearly every aspect of daily life (8). Rehabilitation is defined as the management of disease consequences, which include impairment, functional limitation and disability (9). Rehabilitation uses a multidisciplinary approach; the goals are to reduce symptoms, and restore, substitute, and modify function in order to minimize disability and return the individual with SCI to the community (9, 10). Clinically, rehabilitation can be seen as a learning process, aimed at the acquisition of novel skills or the reacquisition of old skills, with its main goal to optimize activity and participation (11, 12). The consequences after a spinal cord injury are reflected in the extent of loss of motor and sensory function. Autonomic disturbances affect for instance loss of urinary bladder control and bowel control (13) which has an impact on the ability of individuals with cervical SCI to carry out ADL (14). Important prerequisites for ADL are upper extremity function (15-17) and physical capacity (18). Other important factors are age, gender, body mass (19), physical fitness (17, 19), motivation, psychosocial status, medical complications (17) and socio-cultural background (20). In many cervical SCI individuals, the level and the extent of the lesion have a great impact on arm and hand function. The rehabilitation of the upper extremities is thus of the utmost importance, and the therapist's aim is to maintain flexible, supple hands that are free from deformity. Rehabilitation can be divided into three different phases, the acute, the subacute and the restorative (reconstructive) phases (21, 22). Conservatively this could be achieved by maximising the individual's function through strengthening voluntary upper extremity muscles, using splints to position and preserve arm and hand function, and training activities of daily living (ADL), including the prescription of assistive devices (23).

## 1.2 Reflections on occupation and spinal cord injury

Sustaining a spinal cord injury is a devastating event and, to describe it with the occupational therapy core concept of occupation, it means that everything a person does in everyday life is disrupted and perhaps changed forever (24, 25). Occupation is a concept and it is visualised through performance of daily activities (26, 27). How persons with SCI carry out these occupations can vary from person to person, between occupations and within an occupation (28). Each individual develops and has numerous ways of performing occupations depending on a complex interaction between internal factors (20, 29) and external factors, which makes them unique for the individual (30). These occupations can be performed alone, in close conjunction with others or together with other persons (26, 31-33). In addition, one has to take into account the context of the occupation and how internal factors and external factors influence what individuals do and why they do it in such diversity (34). By listening and observing them in the context of the occupation, we might understand what they need, want, are expected or choose to do (26, 32, 35). Moreover, an occupation is also time related and occurs within a time frame that has a past, a present and a future (26, 33). Everyday occupations are influenced by habits and routines that form patterns that influence how individuals make use of their time (36). These daily activity patterns are results of complex interactions residing both within and outside of the individuals in their environment (26, 33, 37). Occupation can be performed in a multitude of environments, either naturally occurring or constructed. The environment is comprised of physical, social, cultural and institutional factors that greatly influence occupational performance. Individuals with SCI live within a variety of environments, and these can influence occupations which in turn can shape the environment. In reality, the different environmental factors do not exist in isolation but interact with one another. These factors can either facilitate or limit occupational performance for these individuals (26, 38). Occupation can thus be described as a relationship between the environment that has a physical and socio-cultural dimension (occupational form) related to meaning and as the active doing of individuals (occupational performance) related to the purpose (39, 40). Several studies (26, 41-43) have suggested that the concept of occupation includes occupational performance areas such as activities of daily living (ADL), instrumental activities of daily living (IADL), rest and sleep, education, work, play, leisure and social participation that contribute to health and well-being. In addition to this, the term activity will henceforth be used as equivalent to the term occupation (44). The focus in this thesis has been on occupational performance and activities of daily living, particularly personal ADL (PADL). Activity performance is influenced by many different aspects for persons with SCI, which is made visible by the concept of activity (occupation) (26, 27). Activity performance is unique to the person and therefore is a client-centred approach in rehabilitation of individuals with SCI central (45).

Client-centred practice became during the 80’s and 90’s an integral part of occupational therapy (46). In client-centred practice/ rehabilitation, the occupational therapists’ (OT) or other health professionals’ roles are to work in partnership with the patient, here referred to as the client (12, 45). The clients are recognised as being unique, expert on how their cervical SCI affects everyday life (47). The OTs should provide information and support and facilitate the client’s decision-making, to make informed choices and set achievable goals (48). During the new century, a new perspective has emerged and is termed person-centred care (PCC), which highlights the importance of knowing the person behind the patient to be able to engage the person as an active partner in his/her care and treatment (49). The two perspectives (49, 50) recognise the person as a partner during rehabilitation. However, in this thesis, the client-centred perspective has been used, where individuals with cervical SCI were recognised as occupational beings.

## 1.3 The Person-Environment-Occupation Model

The Person-Environment-Occupation Model (PEO) model (51, 52) takes into consideration the transactional dynamics or interplay between the *person*, the *occupation* (activity/participation) and the *environment*. The PEO model provides a theoretical framework and an outcome between the three components, the *person*, the *environment* and the *occupation* (Figure 1.). The interplay between these components is believed to be dynamic over time and space, and this overlap is presented as *occupational performance* and is identified as the fit between the three components. Before performing reconstructive hand surgery, the occupational challenges are clinically to understand the lack of fit or poor congruence between the *person*, the *environment* and the *occupation* and thereafter to identify the potential source(s) for change to develop a plan that enables occupation (*activity*).

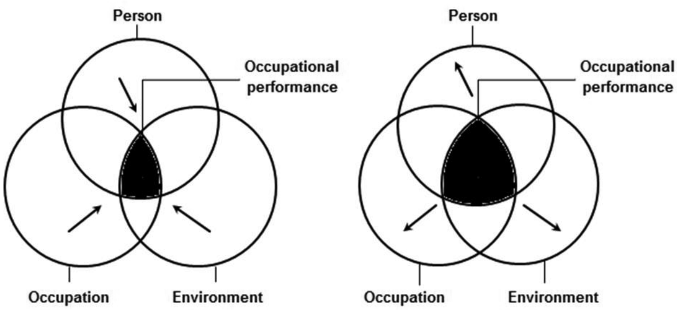


*Figure 1. Person-Environment-Occupation Model of Occupational Performance (PEO) illustrating hypothetical changes in minimal and maximal fit in occupational performance at two different time points. (adapted from Law M Can J Occup Ther. 1996;63(1):9-23)*

Furthermore, the person's sensorimotor, cognitive, and psychosocial components and life experience must be taken into account as these also influence the transaction between the three components. The *environment* is defined broadly in the model to give equal importance so all aspects can be considered that may either support or hinder the individuals' *occupational performance*. The model is therefore used in the thesis to assist the OT to identify several options to make changes in *occupational performance* by using strategies concerning what the person with cervical SCI wanted to do, needed to do and was capable of doing that targets the three components of *person, environment and occupation*. Because human beings are occupational beings, participation in activities (occupation) is essential for health and wellbeing (32).

## 1.4 The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial model (50) and provides a unified, international and standardised language to describe and classify functioning, disability and health in persons with all kinds of health conditions, including SCI. The model has gained worldwide acceptance (53, 54). The ICF is a dynamic interactive framework. The problems that an individual with a spinal cord injury may experience include both health components of body functions and body structures as well as problems with activities and participation, in the ICF termed functioning. The interactions between these problems are direct consequences of the spinal cord injury and the features in the individual's life situation. In the ICF, these are termed contextual factors and include both components of environmental and personal factors (53, 55). These components in the ICF are intertwined as they form and act on a human life during the whole lifespan (53, 54). The ICF can also serve as a tool for education and communication between health care professionals (56) as a reference standard to already existing instruments by linkage (57, 58) and thereby as a reference standard to report functioning across a wide range of measures used in clinical settings or in research. It can also serve as building blocks to develop new instruments (53). ICF has therefore the potential to be the interface through linkage, which can verify activity problems in ADL in individuals with SCI (57, 58). In the ICF, activity is defined "as the execution of a task or action by an individual", whereas participation "is the person's involvement in a daily life situation" (53). The ICF recognises disability as a multidimensional experience for a person where activity and participation are viewed as components of health rather than a consequence of disease (54). Furthermore, it acknowledges that the relationship between impairment and body structure/body function and activity limitation/participation restrictions is complex, which means that a change in any of these components may not limit or enhance people's daily activities (59). Occupational therapists can intervene on all three levels in the ICF and use different perspectives to carry out evaluations (60). Two of these perspectives are the bottom-up and the top-down approaches (61). These two approaches can be used separately but can also be used as a mixed method (62) as they both have their strengths and weaknesses depending on the goal of treatment (63). Both approaches are suggested to focus on different domains in the ICF: bottom-up on the level of body function and body structure and top-down on the level of activity and participation (64). During the acute phase of rehabilitation after an individual sustains a cervical SCI or after the restorative (reconstructive) phase, the bottom-up approach is used as it focuses on the functional deficits or functional gains to obtain an understanding of the individual's impairments (61). When the acute phase merges into the subacute phase during rehabilitation or in late restorative (reconstructive) phase, the focus changes toward a top-down approach as it focuses on whether or not daily activities have been disrupted (65) or whether daily activities can change due to reconstructive hand surgery in their day-to-day real life contexts (62). The ICF has brought attention to the connection between health and occupation as it incorporates a relationship between people's daily life and health in their natural environment (66, 67). The concept of occupation also includes this connection but, in addition to this, occupation also includes the person's subjective experience of the meaning of the activity (occupational form), the output occupational performance (the interaction between occupational form and person) and the context of time

(66). Although several studies (66-68) have revealed shortcomings in the ICF, it can be used in conjunction with conceptual models in occupational therapy, as these models might add valuable occupational perspectives in addition to the ICF. This is even more important, as OTs often work in a multidisciplinary team and, in order not to lose sight of the occupational therapy perspective when planning an intervention, using the ICF in clinical settings is important (66-68). This thesis has been based on the ICF definition of activity that describes what a person does in his or her current environment.

## 1.5 Evaluation of daily activities

Evaluation of people's functional ability, especially their performance in ADL, is one of the oldest and most common methods of measuring the severity of disability and outcome of different interventions in disabling conditions (69, 70). ADL measurements can conceptually be recognised to have items that do not pose the same amount of difficulty in every item; instead they contain items that represent more or less of the demands and complexity to carry out ADL. For example, for individuals with cervical SCI, dressing the lower body involves more body movement and grip function than brushing teeth. This means that every individual with cervical SCI has a level of ability on the attribute being measured, i.e. ADL, and every item used to measure that attribute, i.e. ADL performance, has a level of difficulty from easy to hard items. The measurement of ADL is most efficient if the items in an ADL scale can measure and match the individuals in terms of having less or more ability to carry out ADL (71).

It is important to determine a standardised instrument development method, the psychometric properties of the instrument (72) and the area in which it will be used (73) before evaluation. However, assessment of ADL is accepted as an essential part of outcome research (74) and it offers a method for discriminating, predicting or evaluating patients' functional outcome (75). An important part of occupational therapy evaluation is ADL, where the purpose is to determine present and potential levels of functional ability in individuals with SCI (76, 77). To do this, the OT must learn about the individuals, their repertoire of activities, and any difficulties they have in performing the activities they need, want, or are expected to do (78). The ability to perform different everyday tasks in ordinary life is integrated with environmental demands (physical, social and cultural) and individual capacity, interest and motivation (79). Conceptually, ADL could apply to all tasks an individual routinely performs (80). It includes both basic ADL (BADL), i.e. take care of your own body, and instrumental ADL (IADL), i.e. activities that support daily life within the home and in community. However, the term ADL is generally

restricted to tasks involving functional mobility and personal care. Basic ADL is a very personal part of every person's daily routines. The term BADL is synonymous with self-care and personal ADL (PADL). It includes mobility, feeding, grooming, dressing, bathing, and personal hygiene and toileting (81). These tasks are necessary to maintain health and are universal (82).
The importance of the context of evaluation of daily activities includes the physical environment, social environment and attitudinal world (53, 83). In the early 1990s, when this study was planned, there was a clinical discussion of what concepts could be used in the measurement of basic ADL. The concept of capacity is what a person can do in a defined situation apart from real life (can/cannot) and the concept of performance can be understood as the "involvement in a life situation" or "the lived experience" and is what a person does do in the usual circumstances of his/her everyday life (do/do not). To delineate capacity and performance, the former term has been defined as a concept describing a person's ability to execute a task in a standardized, controlled environment and the latter term as a concept focusing on a person's ability to execute a task in his/her daily environment (53). In this thesis, the concept of performance was chosen to reflect what the persons actually do in basic ADL in their real life surroundings. To be able to make these comparisons in ADL performance over time, there is need to measure the concept in a such a manner to adequately capture changes in basic ADL among individuals with cervical SCI (84).

## 1.6 Assessment with standardised ADL Scale

Using a standardised assessment with an ADL scale means that individuals with cervical SCI answer the same questions in the same way, and the results are scored in a standardised manner and thus comparable in the group (71, 85). Measurement is a process of assigning numbers according to a set of specified rules (86) to represent quantities of a trait, attribute or characteristic, or to classify objects (72, 87), in this study, the use of categories to assess cervical SCI ADL performance. The numbers or categories are results of the measurement and are used to understand and describe aspects of function, abilities or personal characteristics, but not the persons themselves (72). The rules are an important concept of the measurement procedure because they determine the quality of the measurement. The researcher must understand the conceptual background of a particular measurement, in this case an ADL instrument, to understand how the rules for the measurement can be applied and interpreted. Four different levels of measurement have been identified: nominal, ordinal, interval and ratio levels, where the ratio level is the highest level (88-90). Thus, the statistical operations that are permissible depend on the measurement level of the data collected (88). Tools used to measure outcome must be reliable, valid and discriminative. Reliability assesses whether an instrument measures a concept in a reproducible way. However, to be able to determine whether the instrument measures what it is intended to measure, we need to show that the instrument is valid for the group and context under investigation (90). It is essential to investigate content validity to ensure that an instrument measures all the relevant aspects as an outcome measure and appears appropriate for the intended purpose of the study (90). Outcome may be specified in a variety of levels, including disease, impairments, activity limitations or participation restrictions (91). When selecting a specific measurement or overall measurement strategy, it is important to consider the purpose for which the measurement information is gathered and how the results or the measurement might be analysed and used. To measure an individual, measurements can be placed into four main groups: evaluative, descriptive, predictive and discriminative. These are issues to consider when reviewing a measurement in terms of the purpose of the study. It is important when examining a measure's discriminative ability to ensure that the chosen outcome measure is able to differentiate within the cervical SCI group and that it identifies meaningful differences in an individual's abilities (92). In this thesis, the KB Scale was examined for its validity and discrimination before the scale was used as an evaluation tool in connection with reconstructive hand surgery. Both reliability and validity was investigated through linking the KB Scale to the ICF and at the same time investigating if arm/grip function could be detected in the ADL scale.

## 1.7 Klein-Bell ADL Scale

Today the use of standardised instruments (93) has become increasingly important for analysing how different interventions can affect different areas of life and environmental factors and improve ADL performance (94). Standardised ADL instruments are useful for capturing any changes in activities in daily life over time in individuals with cervical SCI (95). ADL instruments have the potential to measure functional gains on the activity level since the activity limitations cannot be inferred from the underlying impairment in itself (53). Over the years, a few studies have included an ADL check list (96, 97), a generic ADL instrument called the Functional Independence Measure (FIM$^{TM}$) (98). In more recent years, studies have included diagnosis-specific instruments such as the Spinal Cord Independence Measure (SCIM) (99) and the Quadriplegia Index of Function (QIF) (100). These ADL instruments measure improvements in ADL in whole basic activities (101-103) rather than in any greater detail within these activities.

Individuals with cervical SCI often make small but significant functional gains, to a greater extent within an activity than in an entire activity (100). The Klein-Bell (KB) Scale can compared to the above mentioned ADL instruments measure ADL in more detail and is therefore more sensitive to detecting problematic activities in ADL in cervical SCI individuals. The KB Scale (1, 104) is a generic instrument that can be applied in persons with or without disability and is constructed to measure basic ADL in detail. The activities are divided into essential components (items), and each component can be scored separately. These attributes make the KB Scale a better tool for evaluating interventions in ADL for cervical SCI individuals. Therefore was chosen the KB Scale as the evaluation instrument in this study.

## 1.8 Linking ADL instruments to the ICF

Today a diversity of ADL instruments exists with different purposes and methods of use, and it can be difficult to gather knowledge about the content of these instruments (71). As both a clinician and researcher, one is required to have the ability to be able to judge which of these instruments is the most appropriate for a particular clinical setting or a specific clinical research question. To facilitate this selection process, an external reference can be used that can systematically identify similarities and differences on the item level in ADL instruments. The International Classification of Functioning, Disability and Health (ICF), a dynamic interactive framework (53), offers such a comparative interface between all instruments. Therefore was chosen the ICF in this thesis as an interface to investigate which levels the KB scale could be linked to in the classification.

## 1.9 Arm and hand function vis à vis ADL

Individuals with cervical SCI vary largely in residual motor and sensory function (105, 106). Spasticity is a common secondary condition in cervical SCI and can limit range of motion, cause pain and/or cause additional stress to muscles and joints. Typically, spasticity can interfere with various body functions such as hand and upper limb control and has been reported to significantly impact activities of daily living (107, 108). Besides the loss of hand function, the individual also suffers from instability in the trunk. This loss of function influences the individual's performance in ADL activities that require sitting balance (105, 109, 110), weight-lifting, trunk support (111-113), reaching (16, 114, 115), and grasping and holding objects (105, 116-118). Even the most basic ADL tasks can become a challenge and can render the individual dependent upon assistance in many areas of daily living (31, 119).

The ability to perform ADL ranges from total dependence to independence in ADL in individuals with different levels of cervical SCI (105, 106, 120). Earlier studies (16, 111, 121) have suggested that cervical levels of C6 and C7 are critical levels for achieving independence in daily activities. Several studies (122-125) have suggested that the ability to transfer is decisive in the process of gaining independence in ADL.

An important potential for improving in function and independence in cervical SCI individuals lies in a proper rehabilitation of the upper extremities. The level of independence among these individuals relies heavily on their ability to use the upper extremities in daily activities. Activities such as feeding, dressing, bathing, making transfers and propelling a wheelchair require the ability to use the arms and hands in purposeful and precise movements (126, 127). The first two phases in upper extremity rehabilitation, acute and subacute, have the aim to prevent complications, achieve optimal function within the limits of the neurologic deficit (128-130) and create optimal conditions for the restorative (reconstructive ) phase (22, 131).

## 1.10 Reconstructive hand surgery

Reconstructive hand surgery is an alternative for individuals with higher cervical lesions to restore motor function and regain the functional levels related to the ability to perform self-care (97, 132, 133). A team approach is essential in undertaking reconstructive hand surgery in persons with cervical SCI (134, 135). A key factor during the planning process before surgery is to be client-centred (48). This means incorporating the individual's needs, expectations and priorities (136), setting realistic goals (137) and identifying the best surgical options to provide the best possible functional outcome (23). A prerequisite for achieving this is that the individual is well informed and involved throughout the process, which involves both planning, training and follow-up after surgery to enhance the person's possibilities to use the newly acquired arm and grip functions in daily activities (134, 138).

In tendon transfer surgery for individuals with cervical SCI, the attachment site is generally firmer and has less risk of rupture because of the significant tendon-to-tendon overlap compared to end-to-end repair in flexor tendon surgery (139). A new treatment regimen for grip reconstruction was therefore introduced in the late 1990's with a rehabilitation strategy that focused on retraining the donor muscles directly after surgery with high tendon excursion and low tendon force (140) and, over time, a progressive increase of wrist extension together with a slow increase of tendon load (141, 142). During the first training period, the individual focused on relearning the movement pattern of the donor muscles in an individually tailored training program. To get the best possible recruitment pattern of muscle activation, the individual used sensory feedback during the retraining period (143). The individuals used the best of their senses in relation to their level of injury; this might involve vision, sensibility and hearing or a combination of all senses. Splints were used during training to maximize a safe zone for tendon excursion (144) and during the night to prevent extensive stretching in the tendon transfers and postoperative oedema (139). During the second training period, the focus shifted towards reintegrating the new grip functions in daily activity. The group who underwent grip reconstruction will henceforth be named as hand group except in the method section in the thesis.

Elbow extension is required not only to extend against gravity but to adequately position the hand for activities of daily living (145). Although gravity may assist elbow extension, it may also cause it to buckle, allowing the hand to suddenly strike the face or forehead when the arm is positioned over shoulder level (101). Many individuals with cervical SCI lack active control of elbow extension and therefore have reduced upper extremity strength and stability (145, 146), which influences their ability for weight shift manoeuvres, wheelchair propulsion and daily activities requiring reaching movements (16, 123, 147). The posterior deltoid muscle is the most commonly used transfer to restore voluntary elbow extension (148, 149). Restoration of triceps function through posterior deltoid tendon transfer has been deemed the "fundamental intervention" (149). This tendon transfer has been shown to influence not only the elbow but also the shoulder during free movements of the upper limb (150). Previous studies (132, 151) have shown that immobilisation of the shoulder and elbow movement positively influenced the outcome after surgery. The postoperative treatment was therefore revised in the mid-1990's. All individuals used an electric wheelchair and a special armrest as a postoperative regime for three months (Figure 2.) (152). A stepwise rehabilitation program for 12 weeks was introduced. It included a circumferential plaster for four weeks to maintain immobilisation in order to permit adequate strength recovery of the surgical sites of the tendon transfer. An adjustable elbow orthosis during the daytime was thereafter used for eight weeks (Figure 3.) (96, 153) to gradually increase the load during training (10° every second week). During night time, a static splint with 10° of flexion in the elbow was used with the arm positioned slightly abducted to protect tendon transfers (154). The postoperative training focused on activating the donor muscle without any external resistance with an adjustable elbow orthosis. After 12 weeks, the individuals were able to gradually start to use the arm/hand in activities of daily living. The group who underwent elbow extension and grip reconstruction will henceforth be named as elbow and hand group except in the method section in the thesis.

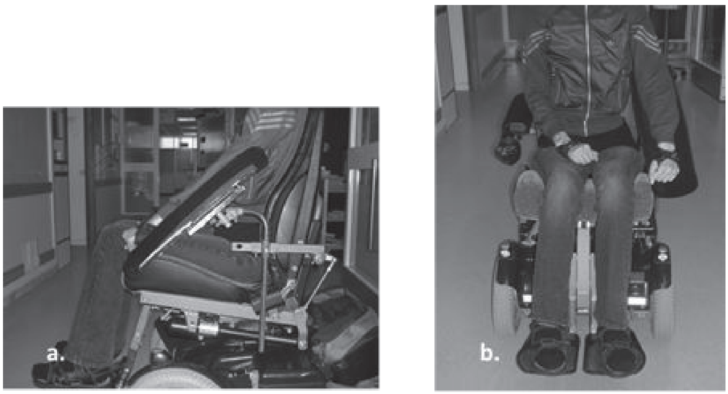


*Figure 2. (a) The arm support attached to the electric wheelchair. (b) Not only is the elbow motion restricted, the shoulder is also restricted from becoming adducted.*

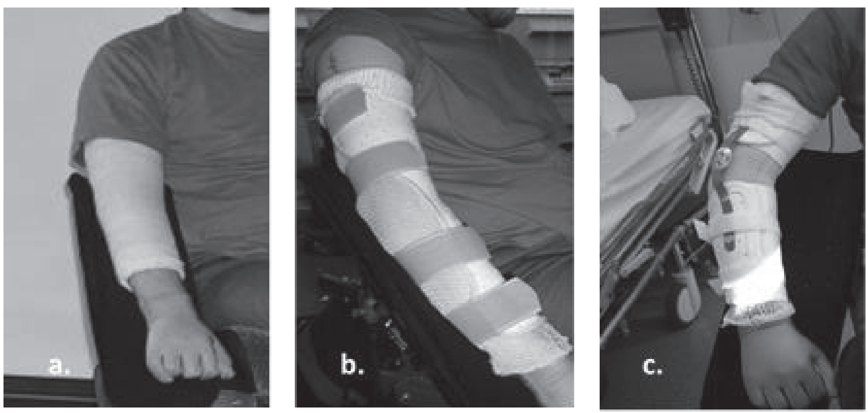


*Figure 3. (a) The patient was immobilised for four weeks in a circumferential plaster. (b) A static splint was thereafter used during the night. (c) An adjustable orthosis was used during the day.*

Earlier studies have shown that most individuals with cervical SCI prefer recovery of hand function to that of urinal bladder, bowel or even sexual function (155, 156). Evaluations after reconstructive elbow extension and grip function (157, 158) have shown that individuals' level of activity can be influenced. However, the outcome of reconstructive elbow extension and grip function has up until recent years focused on evaluation at the impairment level (53) (e.g. range of motion, grip strength, cutaneous sensation, dexterity) (139, 152, 159-161) rather than on the activity level (28, 97, 101-103, 162) . Moreover, the activity domain cannot be inferred from the underlying impairment itself; it must be measured with appropriate scales (59). The activity domain in ICF (53) envisions human activities as the purposeful, integrated use of body functions. This approach might be used to better understand the link between demands for arm and hand function and performance in basic ADL (57).

The challenges after reconstructive elbow extension and grip function must be studied to understand the lack of fit between the person, the environment and the occupation that enables a change in how the individuals with cervical SCI perform basic ADL after surgery. This also allows building a scientific understanding and thereafter integrating the results in clinical practice.

# 2 AIM OF THE STUDY

The general aim of the thesis were to examine the applicability of the KB Scale and to connect (link) the KB Scale to the ICF to validate the scale in terms of content and to examine the association between upper extremity function and basic ADL, and to explore if the KB Scale included basic ADL important for cervical SCI persons. Further aims was to evaluate if basic daily activities changed after reconstructive hand surgery in individuals with injuries in the cervical spinal cord.

Specific aims

- To examine whether the Klein-Bell ADL Scale discriminates cervical spinal cord injury individuals in basic daily activities and to explore its applicability in this group of individuals. Secondly, to examine the association between basic ADL and upper extremity function. Thirdly, to investigate whether grip ability can be detected in the scale (paper I).

- To determine whether all the concepts of the Klein-Bell ADL Scale can be linked to the ICF. Secondly, to identify and explore whether the linked concepts were covered by the ICF Core Sets and, thirdly, to identify and explore the categories of the ICF Core Sets not covered by the scale (paper II).

- To evaluate whether regained grip function changes the use of assistive devices and activity performance in basic ADL in individuals with cervical SCI and, secondly, to investigate whether specific items can be associated with the individual's ability to grasp and execute fine motor tasks in single-handed and bimanual activities after surgery (study III).

- To evaluate whether activity performance in individuals with a cervical spinal cord injury level between C5 and C7 changes in basic ADL after reconstruction of elbow extension and subsequent grip reconstruction. Secondly, to investigate whether specific items can be associated with the individual's ability to stabilize the elbow and use grip ability in basic daily activities after surgery (study IV).

# 3 METHODS

## 3.1 Study group

In this study, three different study designs were used: a cross-sectional, a mixed method and a longitudinal. These were chosen to complement each other. The first two papers examined content validity in the KB Scale and examined reliability between the KB Scale and the ICF but also examined the consistency between the KB scale and ICF core sets. The final studies examined whether the KB Scale over time could provide accurate, consistent and meaningful measurements for individuals with tetraplegia who underwent either grip reconstruction or a combination of elbow extension and grip reconstructions.

The inclusion criteria in three of the four studies were (a) persons with traumatic cervical spinal cord injuries or acute vascular injury in the cervical level of the spinal cord and (b) no prior reconstructive hand surgery before September 1994 (Figure 4.).

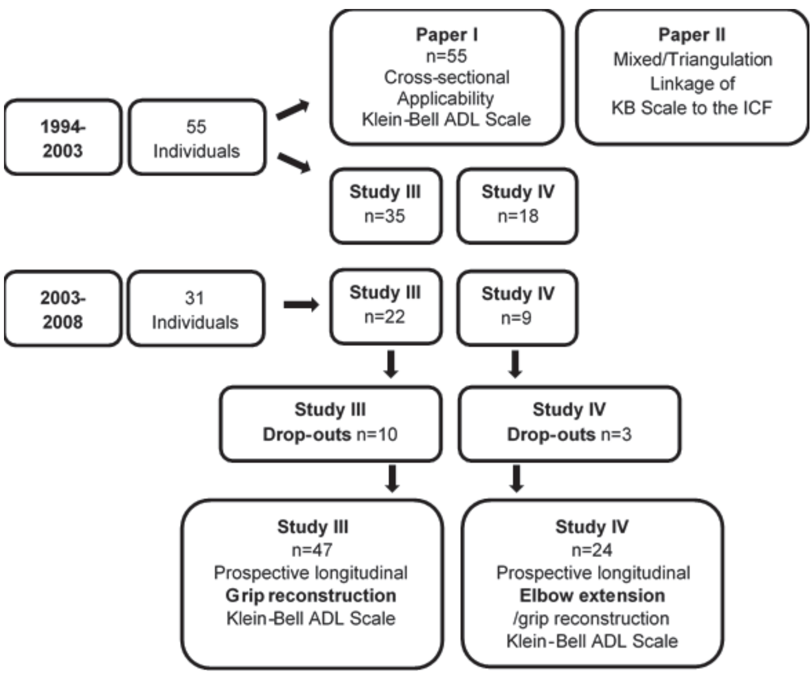


*Figure 4. Flowchart describing the individual's participation in paper I, Study III and Study IV.*

## 3.2 Study participants

Study I included 55 participants. Study III included 57 participants, of whom 47 completed the study, and study IV included 27 participants, of whom 24 completed the study (Table 1).

*Table 1. Baseline characteristics of participants and drop-outs for Study III and Study IV.*

| | Study III | | | Study IV | | |
|---|---|---|---|---|---|---|
| | Participants n=47 (%) | Drop-outs n=10 | All n=57 (%) | Participants n=24 (%) | Drop-outs n=3 | All n=27 (%) |
| **Injury time** (years) | 1-37 | 2-29 | 1-37 | 1-10 | 4-13 | 1-13 |
| Mean | 6 | 7 | 6 | 3 | 9 | 4 |
| **Age**, (years) | | | | | | |
| **- Men** | **33** (70) | 8 | **41** (72) | **21** (88) | 2 | **23** (85) |
| Mean (±SD) | 39 | 49 | 41 (14) | 27 | 30 | 27 (9) |
| Median | 36 | 45 | 39 | 25 | 30 | 25 |
| Range | 20-64 | 33-69 | 20-69 | 18-63 | 29-31 | 18-63 |
| **- Female** | **14** (30) | 2 | **16** (28) | **3** (12) | **1** | **4** (15) |
| Mean (±SD) | 53 | 48 | 53 (14) | 34 | - | 34 (8) |
| Median | 56 | 48 | 56 | 33 | - | 34 |
| Range | 27-72 | 31-65 | 27-72 | 25-44 | - | 25-44 |
| **Social status** | | | | | | |
| - Living together with Partners | 26 (55) | 5 | 31 (54) | 11 (46) | 1 | 12 (45) |
| - Single | 17 (36) | 5 | 22 (39) | 7 (29) | 2 | 9 (33) |
| - living with parents | 4 (8) | - | 4 (7) | 6 (25) | - | 6 (22) |
| **Mobility** | | | | | | |
| - Wheelchair | 36 (77) | 8 | 44 (77) | 24 (100) | 3 | 27 (100) |
| - Ambulation | 8 (17) | 1 | 9 (16) | - | - | - |
| - Part-time wheelchair/ ambulatory | 3 (6) | 1 | 4 (7) | - | - | - |

To discern the motor level and sensory level of the participants, the MMT (163) and 2PD (164) were recorded using the International Classification of Hand Surgery in Tetraplegia (IC) (165). Ocular impulse is denoted O and depends on vision for sensory impulses and OculoCutaneous denotes OCu impulses and depends on both vision and tactile gnosis for sensory function tested with 2 point discrimination (2PD) (164). The data were thereafter translated to the American Spinal Injury Association (ASIA) (14). In ASIA dermatomes C6, C7 and C8 were used only during sensory testing in all three studies; it is therefore not possible to give an accurate ASIA grading of injury. A specialist in neurology classified the individuals according to the ASIA motor level and ASIA sensory level. The data were derived from the MMT test and the 2PD test. In paper I, the ASIA motor levels showed that 33 individuals (60%) had the same motor level in both arms and 20 individuals (36%) showed an asymmetric pattern. Two individuals (2%) were not included owing to a lack of data in the MMT test (Figure 5.).

Left hand

| Right hand | C4 | C5 | C6 | C7 | C8 | >C8 | NT |
|---|---|---|---|---|---|---|---|
| C4 | | 1 | | | | | |
| C5 | | 5 | 6 | | | | |
| C6 | 1 | 3 | 13 | 2 | | | |
| C7 | 1 | 1 | | 12 | 2 | | 1 |
| C8 | | | | 1 | 2 | 1 | |
| >C8 | | | | | | 1 | |
| NT | | | | | | | |

Paper I

*Figure 5. Paper I ASIA motor level divided into the participants right and left hand (n=53)*

In study III, the ASIA motor levels for the 47 participants were heterogeneous and ranged from C4 to C8; 25 individuals (53%) were found to have the same motor level in both arms, whereas 20 individuals (43%) showed an asymmetric pattern (Figure 6.). Two individuals (4%) were only tested in one hand. All ten drop-outs but one had the same motor level in both arms and ranged from C5 to C7. In study IV, the ASIA motor levels for the 27 participants were heterogeneous and ranged from C5 to C7 (Figure 7.). The individuals' upper extremity function ranged from O:0 to OCu5 according to the IC (165). Three individuals did not continue the study and were recorded as drop-outs.

Left hand

| Right hand | C4 | C5 | C6 | C7 | C8 | >C8 | NT |
|---|---|---|---|---|---|---|---|
| C4 | | 1 | | | | | |
| C5 | | 1 | 1 | | | | |
| C6 | 1 | | 7 | 6 | | | |
| C7 | 3 | 1 | | 12 | 3 | | 1 |
| C8 | | | | 2 | 4 | 1 | |
| >C8 | | | | 1 | | 1 | |
| NT | | 1 | | | | | |

Study III

*Figure 6. Study III ASIA motor level in hand operations divided into the participant's right hand and left hand operations, three persons excluded due to lack of MMT test (n=47)*

Left hand

| Right hand | C4 | C5 | C6 | C7 | C8 | >C8 | NT |
|---|---|---|---|---|---|---|---|
| C4 | | | | | | | |
| C5 | | 3 | 6 | | | | |
| C6 | | 6 | 8 | 1 | | | |
| C7 | | | | | | | |
| C8 | | | | | | | |
| >C8 | | | | | | | |
| NT | | | | | | | |

Study IV

*Figure 7. Study IV ASIA motor level in arm and hand operations divided into the participant's right hand and left hand operations tested with MMT (n=24)*

## 3.3 Surgical procedures

The training regimen after hand surgery included both functional training and training to reintegrate the newly acquired grip function in daily life (134).

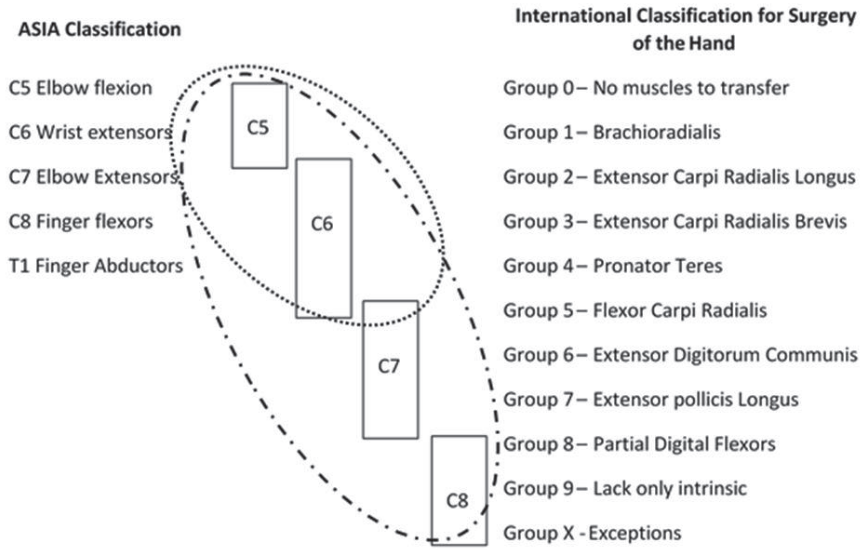


*Figure 8. The motor components in the ASIA motor classification and the motor components of the International Classification of Hand Surgery in Tetraplegia (IC). (Adapted from Bryden AM. et al, Topics in Spinal Cord Injury Rehabilitation 2005; 10: 75-93.) Footnotes: ASIA Classification (14) motor levels denote key muscles with a muscle strength of grade 3 or greater that are expected to be functioning at corresponding spinal segments. The International Classification for Surgery of the Hand (166) provides information about the number of voluntary muscles depending on the level of injury for individuals with tetraplegia. Group denotes number of muscles with minimum grade 4 (MRC).*

In Study III, the majority of individuals in the hand group, 30 (64%) and 13 (28%), underwent one and two operations, respectively, three (6%) and one (2%) individuals underwent three and four operations, respectively. The individuals underwent grip reconstruction with a transfer of brachioradialis to thumb flexion and some also got a transfer of extensor carpi radialis longus to finger flexion, i.e. improvements of grip function, which was the major surgical procedure. In the dropout group, seven individuals underwent one operation whilst three individuals underwent two operations. Grip reconstruction including thumb flexion with finger flexion was the major surgical procedure. In Study IV, all 24 individuals underwent a tendon transfer of the posterior part of the deltoid muscle to reconstruct elbow extension, 15 (63%) underwent surgery to regain elbow extension in one arm whilst nine (37%) underwent surgery to regain elbow extension in both arms. Of the 24 individuals, five (21%) only reconstructed elbow extension. Twenty-one individuals also underwent hand surgical procedures to enhance their grip function. The majority got either active thumb flexion via transfer of brachioradialis or a grip reconstruction including both thumb flexion via brachioradialis and finger flexion via extensor carpi radialis longus (Figure 8.).

## 3.4 Measurement - KB ADL Scale

The Klein-Bell ADL Scale (1, 104) is a generic instrument and has been translated into Swedish (167). It has in previous studies demonstrated reliability (1, 168, 169) and validity (1, 169) as well as sensitivity toward small changes in ADL (168, 170). The KB Scale (1, 104) operationalises the concept of functional independence in terms of an individual's level of independence into six dimensions: dressing, elimination, mobility, bathing and hygiene, eating and emergency telephone use. The KB Scale (1, 104) can be applied in persons with or without disability, and the item definitions are constructed regardless of the methods used by the individual to achieve the item. The KB Scale measures basic ADL in detail, and the domains are divided into essential components (items). Each component is scored separately with either a raw sum score or with a weight score in 170 items (1, 104). The majority of items (162 items) measure activities of daily living (dressing, bladder and bowel management, mobility, hygiene, eating and drinking and using the telephone) while eight items measure body function (bladder and bowel emptying, bladder and bowel incontinence, chewing and swallowing food, swallowing liquids, verbalizing telephone messages). Thirteen items are gender specific items; eight items are gender specific items for women and five items are gender specific items for men. The KB Scale includes six categories: totally dependent [1], takes more than ten minutes [2], refuses to do [3], partly dependent[4] , use of assistive devices [5] and independent [6] (167).

A weight score was developed in 159 out of the 170 items (1, 104). The 159 items in the KB Scale have been rated in an empirical manner by rehabilitation professionals (OTs, PTs and nurses) on four criteria with a five-point scale (1):

1. How difficult is it for average able-bodied persons?
2. How difficult is it for the average able-bodied person to perform this activity for someone else (to provide maximum assistance)?

3. How much time does it take to perform this activity?

4. How injurious to one's health would it be if the activity could not be performed?

Each rater obtained a mean rating; a frequency distribution was thereafter calculated for each item and the 159 items were divided into three segments.

- All items whose mean rating fell within one standard deviation above and below the grand mean were given two points.
- All items greater than one standard deviation below the grand mean received one point.
- All items greater than one standard deviation above the grand mean received three points.

The developers of the KB Scale argued that the weight scheme was reasonably simple yet allowed for basic weighting since some items are more difficult, time consuming etc. than others (1, 171). In paper I, the points or weights were then given a weight score from 1 to 3, where weight 3 is given to the most complex items based on the argument of the developers of the KB Scale that some items are more difficult to perform and take a longer time to perform (172).

In paper I, Study III and Study IV, the assessment of a participant's level of independence in basic ADL was made via a semi-structured interview conducted by one health professional (AD). The KB Scale was presented verbally to the individual prior to the interview, and the interview time ranged between 35 and 45 minutes. All interviews were conducted at the SCI Unit. The individuals in the study were asked what they in fact do or carry out on a regular basis in order to assess the actual activity level in the person's real life surroundings (53, 173). Category takes more than ten minutes [2]and refuse to do [3] were not used by the individuals during the interview. Gender specific items for the opposite gender and diagnosis specific items were registered as not applicable items. Diagnosis specific questions were used to verify uncertain answers during the interview and to include more information, such as the use of assistive devices and car and house adaptations.

### 3.4.1 Investigation of item weights versus raw sum score in KB Scale (paper I)

Paper I included three different analyses. The first two analyses included: the items' weight system and raw sum score in the scale. Item weights 1, 2 and 3 were used in the first analysis and were referred to as simple, average complex and complex, respectively (104). The weight scheme was divided into 29 simple items, 108 average complex items and 22 complex items (1, 104).

- **Weight 1 – Simple items** (n=29):

Grasp clothes, grasp and rip off toilet paper, flush toilet, operate doorknob, grasp and release toothbrush, comb, shaving device, grasp and replace telephone.

- **Weight 2 – Average items** (n=108):

Dress underwear to outer garment, reach to wipe after emptying bladder/bowel and dress clothes after toileting, transfer in / out of bed, in / out of the car, transfers through doors, showering (except wash front and back body), brush teeth, brush hair, shave, cut and use cutlery to eat.

- **Weight 3 – Complex items** (n=22):

Bladder / bowel emptying and continence, transfers in bed, walk up and down stairs, mobility on an uneven surface, transfer from floor to standing or wheelchair, load and unload car, achieve bathing position, wash front and back body, chew/swallow food and swallow drink.

As 11 items in the KB Scale lack an individual weight score in the weight scheme (104),only 159 items were included in the analysis of the weight scheme. The categories in 159 items in the KB Scale were thereafter dichotomised in each item and were used to analyse the individuals' independence in basic ADL (1, 104):

- Independent and independent with assistive devices (**3 points**)
- Category partly dependent and totally dependent (**0 points**)

A data program called the ADL diagram © (174) was developed to compile the raw sum score to recommendations in the KB Scale manual (1, 104, 171). The analyses made with the ADL diagram © showed each item per individual and raw sum score:

- An individual who carries out an item independently received a raw score of 3 points.
- An individual who was unable to carry out the item received a raw score of 0 points.

The raw sum score ranges from 0 (dependence) to 510 points (independence) in the KB Scale (171).

### 3.4.2 Linking KB ADL Scale to the ICF (paper I & II)

Connecting (linking) the KB Scale to the International Classification of Functioning, Disability and Health included two parts (57). In part one, which is included in paper I, the linking procedure was carried out to better understand the relationship between individuals with cervical SCI function and activity performance (175). In part two, which is included in paper II, the linking process (53) investigated the structural properties of the Klein-Bell ADL Scale (1, 104). In both papers, the Swedish version of the KB Scale (167) was used and, during the linking procedure, an individual perspective was used and was coded as activity (a), defined as "the execution of a task or action by an individual" (53). In paper I, the linking procedure was carried out by one health professional (AD) according to ten linking rules (57) developed to link the health status instrument to the ICF. In paper II, the linking procedure (57,58) was carried out by four senior OTs with clinical experience in spinal cord injury rehabilitation, reconstructive arm and hand surgery and research. The OTs were divided into two groups. In the case of disagreement, discussions within the groups and between the groups continued until consensus was achieved (176).

### 3.4.3 Investigating arm/grip function and health domains in the ICF (paper I)

In paper I, the linkage procedure (57) between the KB Scale and the ICF (53) included two analyses:

- The first investigated which health domains the KB Scale covered.
- The second examined whether arm and grip function could be detected in the KB Scale items' operational criteria while using both Napier's (177) definition of precision and power grips together with Bendz's (178) description of grip ability from the opening phase to the terminal opening phase in the grip procedure. Bendz (178) described in more detail the hand as an organ which comprises four capabilities:
    1. To grip
    2. Use of arm and trunk support
    3. To manipulate, i.e. separate use of the fingers
    4. To sense for identification of shapes and forms.
- Napier (177) suggested that the intended activity rather than the shape of the object governed the grip, introducing a dynamic aspect to grip function. In functional terms, grip capabilities can be described in different phases in the grip procedure:

1. Initial opening phase
2. Purposeful closing
3. Stabilisation phase, i.e. the actual grip
4. Final or terminal opening phase in which the hand opens and releases its grip on an object.

With this view, Napier could reduce the functional demands to two different factors: precision and power. With a precision grip, it is possible to manipulate the object with the fingers while, with a power grip, the object is held against the palm to be able to use it with the aggregated power of the hand and arm.

- During the linkage process, the KB Scale was linked to components and thereafter to the codes or categories in the ICF (53).
- If more than one ICF category was used per item definition, the categories appear marked in italics in sequence in the text.
- If the content of an item was not explicitly named in the corresponding ICF category, then "other specified" option was linked at the third and the fourth coding levels of the ICF classification.
- When ICF categories were too general, the additional information in the item definitions was coded to keep the level of detail of the KB Scale intact (57).

### 3.4.4 Linking procedure with directed content analysis (paper II)

In paper II, a qualitative approach with triangulation was used with a directed content analysis (179), which makes it possible to analyse written or oral communication in a systematic way. The items in the KB Scale were analysed using two different types of analyses (180), manifest and latent content analysis, which differ in depth and level of abstraction (181). Both were used as they are considered to be complementary (180).

Several steps are included in the content analysis (182):

- The first step was to read through the ADL scale unconditionally and repeatedly in order to get an overall impression of the items.
- In step two, the two groups of OTs separately identified sentences or phrases that contained information and were referred to as meaningful units or meaningful concepts. These concepts can consist of several words, sentences or paragraphs whose content is related to each other by their content and context. These meaningful concepts should convey a single

theme and were based on the rater's judgement and expertise in ADL performance. The surrounding text in the items should however remain intact and should not be edited out to retain the context of the items.

- In the third step, the meaningful concepts were condensed in order to shorten the text but still retain the content; thereafter, the condensed meaningful concepts were linked to the ICF separately by the two groups of OTs. If a single item was found to include several meaningful concepts, each concept was linked to the most precisely corresponding categories in the ICF. The ICF categories were linked on the third level when possible in order to maintain the level of detail in the KB Scale (104). The linking procedure was carried out according to established rules (57, 58).
- In the fourth step, differences and similarities in the condensed concepts now identified as linked ICF categories were compared between the two groups that carried out the linkage. Discussions in the two groups were based on how the activity was carried out in each item in the scale. To illustrate the process, item 13 *pull sock over right foot with heel to heel* is used as an example where two meaningful concepts were identified that could be linked to two different ICF categories.
    - o Concept 1: Pull linked to a445 (arm and hand use)
    - o Concept 2: Sock linked to a5402 (putting on footwear)
- In the fifth step, the linked ICF categories were compiled and presented in a model by Escorpizo (183) developed further by one health professional (AD): in total, second level and third level categories of the ICF (Figure 9.).

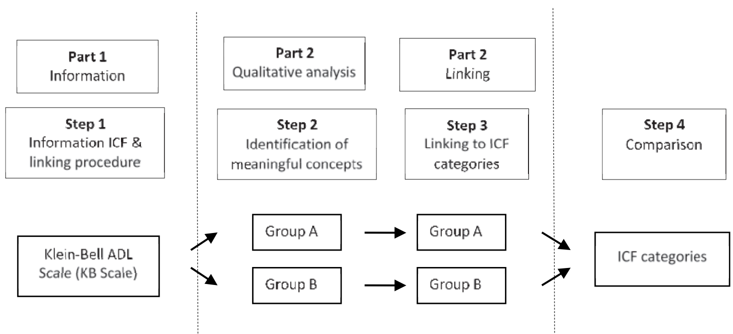


*Figure 9. Linking process of meaningful concepts into ICF categories. (Adapted from Escorpizo, R. et al., Journal of occupational rehabilitation. 2009;19(4):382-97.).*

- After the linkage procedure, each linked category was examined and compared as to whether the category was covered in the Core Sets for SCI (17, 18) that include self-care.
- Thereafter, was each linked category examined and compared with categories that included self-care that reached a cut-off point of 75% or more in the Core Sets for SCI from the perspective of OTs (10).
- The number of items in the KB Scale, concepts identified in the KB Scale, and the numbers of ICF categories were thereafter counted and separated by component. Content density and content diversity were calculated using Stamm's definitions (27). Content density is defined as the mean number of meaningful concepts per item. Content diversity is identified as the number of ICF categories per concept. A value of 1 means that each concept is linked to another ICF category.

### 3.4.5 Study III and Study IV

In Study III and Study IV, descriptions of demographic data, mean, median, range and standard deviation (SD) were calculated. Statistical analysis for descriptive data was carried out using statistical software Statistical Package for Social Services (SPSS©) computer program (SPSS 19.0 for Windows®). In Study III and Study IV, a raw data analysis was first carried out on the dimensional, sub dimensional and item level in the KB Scale to evaluate cervical SCI individuals changes in basic ADL, use of assistive devices and category differences after reconstructive hand surgery.

A Rank invariant method (184, 185) called Svensson's method was then used to evaluate changes in basic ADL assessed with the KB Scale after surgery. The analysis included 159 items of 170 items. Eleven items that measured extra devices were not included in the analysis. The comprehensive analysis was carried out on both individual items and item groups. The analysis of item groups was based on clinical knowledge of how persons with cervical SCI carried out the components of activities (items) (1, 104), as these are often crucial to the performance of an entire activity (186). It was possible to measure different levels of difficulty in the KB Scale items due to the level of detail (172, 187); for example, item group putting on shoes was analysed separately from item tying shoe laces for left and right foot. Median values were calculated when more than one item were included in the analysis.

The evaluation with the non-parametric statistical method included measures for systematic group change common for the group, relative position (RP), relative concentration (RC) and measure of individual variability, relative rank variance (RV).

- Relative position (RP)

  Possible values for RP range between -1 and 1; for RP, a zero value means a lack of systematic change in the ability to perform basic ADL for the group. In this study, RP >0.1 was considered a cut-off value for change (184). A non-zero RP means that the second assessment has systematically higher or lower ratings, i.e. showed a higher or lower change, i.e. positive or negative change, to perform basic ADL in common for the group.

- Relative concentration (RC)

  Possible values for RC range between -1 and 1; for RC, a zero value means a lack of systematic concentration, i.e. no shift in the scale's category distribution in the group between the two assessments. In this study, RC >0.1 was considered a cut-off value for how the individuals used the different categories (184). A non-zero RC means a shift in category distribution toward one part of the scale (184), i.e. the group used a limited number of categories after as compared to before surgery.

- Relative rank variance (RV)

  Relative rank variance (RV) measures individual variability and was used to interpret changes that are not explained by a systematic group change. This measure takes into account the number of disagreeing assessments and the distances between the assessments in the same individual. Possible values for RV range from RV=0, lack of individual change, to RV ≤ 1, total additional individual change. Four categories were used in this study, and this influences the upper limit value for RV, which changes the maximum from RV≤ 1 to RV≤ 0.53 (184). The smaller the RV, the more homogeneous the measurable change for the group; the higher the RV, the more heterogeneous the measurable change for individuals in basic ADL (184). In this study, RV >0.1 was considered a cut-off value for heterogeneity in the group (184).

In order to handle the amount of data from the analysis, a decision was made that items and item groups for group change, or individual variability that included at least five individuals, who changed their activity level, should be included in the results. Exceptions to this were made when an item showed statistical significance with four individuals or an item showed a limit value above 0.1 for three individuals. The results are presented in tables on the dimensional level and sub dimensional level in the KB Scale. The frequency distributions for KB Scale items were used to illustrate the presence of a systematic group change, i.e. relative position and relative concentration using a square contingency table where the main diagonal of unchanged categorical assessments is oriented from the lower-left to the upper-right corner. The group change, i.e. relative position and relative concentration is graphically shown by plotting the cumulative proportions of the two marginal distributions together yielding a relative operating characteristic curve (ROC) curve. The measures and the 95% confidence intervals (CI) of the measures were calculated by means of a free interactive software program (188). Statistically significant RP, RC and RV values on at least the 5% level are indicated by 95% confidence intervals that do not cover zero values of the measures.

# 4 ETHICAL CONSIDERATIONS

The study was guided by the World Medical Association (VMA) Declaration of the Helsinki ethical principles for medical research involving human subjects (34). In paper I and Studies III and IV, the participants were recruited at the first visit to the team after they had accepted undergoing reconstructive hand surgery. The study was approved by the Regional Ethical Review Board in Gothenburg, Sweden (ref.nr 377-06).

Important aspects of the Declaration of Helsinki were considered in the study, where the benefits of the research should exceed the risks for the individual. The individuals received only verbal information about participation in the study. They then gave their approval if they agreed to participate. They were also informed that they, at any time and without explanation, could discontinue participation in the study. If they withdrew from further participation in the study, this would not influence their continuing rehabilitation after the surgery. The gain for the individual in participating in the study was assessed as greater than the risks.

# 5 RESULTS

## 5.1 Paper I

### 5.1.1 Discrimination and applicability of the KB ADL Scale

The level of independence in the investigated individuals ranged from 42 to 456 points according to the raw sum score in the KB Scale. Thirty-two of 55 individuals had less than 50 % of the raw sum score. The individuals' activity level varied in the six dimensions. The dimension of use of telephone included more individuals who were independent whereas, in the dimension of elimination, more individuals were dependent. The individuals with cervical SCI were more dependent in items including grip function visualised through linking the KB Scale to the ICF and analyses with Napier's and Bendz's definition of grip function. Eighty-two percent of the 159 items required grip function and, of these items, 22% required precision grip. In these items where precision grip is a prerequisite, the individuals were more dependent in specific items, for example button trousers, tie shoelaces, do buttons in buttonholes and cuffs, put on bra, fasten and zip zippers. Assistive devices could compensate for the loss of grip function in 57% of 159 items. Both assistive devices and car and house adaptations made the individuals more independent in ADL.

### 5.1.2 Linking the KB Scale to investigate grip function

The results have shown that the need for arm and hand function is included in all three levels in the KB Scale's weight scheme during the linking process using Napier's definition and Bendz's description of grip function. Precision grips or power grips or a combination of both could be detected in the items' operational criteria. Simple items include those that either prepare for or terminate an activity whereas average complex items and complex items involve performing or continuing an activity with a static or a dynamic grasp pattern. Precision grip (manipulation), a dynamic grasp ability, was more common in average hard items.

### 5.1.3 Correlation between the KB Scale and upper extremity function

ASIA motor score and ASIA sensory score showed that individuals with cervical spinal cord injury were heterogeneous in terms of both motor function and sensory function. There was a moderate correlation between the raw sum score in the KB Scale and the UEMS for shoulder muscles to intrinsic muscles, rs = 0,63 (P<0,01). The individuals' sensibility ranged from no sensory function in all fingers to full sensory function in all fingers according to the 2PD test. There was a moderate correlation between the raw sum score in the KB Scale and the 2PD test with ≤ 10 mm in number of fingers, rs = 0,68 (P<0,01).

### 5.1.4 Analysis of the weight scheme in the KB Scale

The proportion of individuals who carried out the item independently was calculated for each item. These proportions were grouped according to the KB weight scheme: simple, average complex and complex. The proportions of items in the KB Scale performed independently by the individuals were calculated for each of the three weight levels and tested with regard to differences between the weight levels in the KB Scale. The mean percentage units in the groups were 64% in the simple items, 55% in the average complex items and 61% in the complex items. The comparison between the weight levels showed that there was a difference in complexity between simple items and average complex items of 8.5 percentage units. There was an inverted difference in complexity between average complex items and complex items of 5.6 percentage units, i.e. this means that average complex items were more difficult to carry out for the individuals with cervical SCI than complex items. Both the abovementioned comparisons between the weight levels were statistically significant. The comparison between simple items and complex items was 2.9 percentage units and showed no statistically significant difference.

### 5.1.5 Analyses of structural properties in the KB Scale

Forty-six (27%) of 170 items in the KB Scale showed problems concerning the structural properties during the measurement process. Thirty-four (20%) of these items made it impossible to assess any differences in functional limitations owing to the formulation of the items' operational definition. The majority of the 34 items were found in the dimensions of elimination and mobility. Seven (4%) items that included assessment of extra devices were not relevant for cervical SCI individuals. Five (3%) functional items (bladder and bowel incontinence, chewing and swallowing food and swallowing liquids) showed a ceiling effect, i.e. all individuals were assessed as independent.

# 5.2 Paper II

## 5.2.1 Results of the linking procedure

The results of the linking procedure showed that 385 concepts were identified in 170 items in the KB Scale. Of these, 384 concepts in 169 items could be linked to categories in the ICF. In one item, the meaningful concept that was identified could not be linked to any category in the ICF and was therefore linked as not covered (nc) in the classification. The linked concepts displayed a span of categories included in all the components in the ICF: body function, activity and participation and environmental factors.

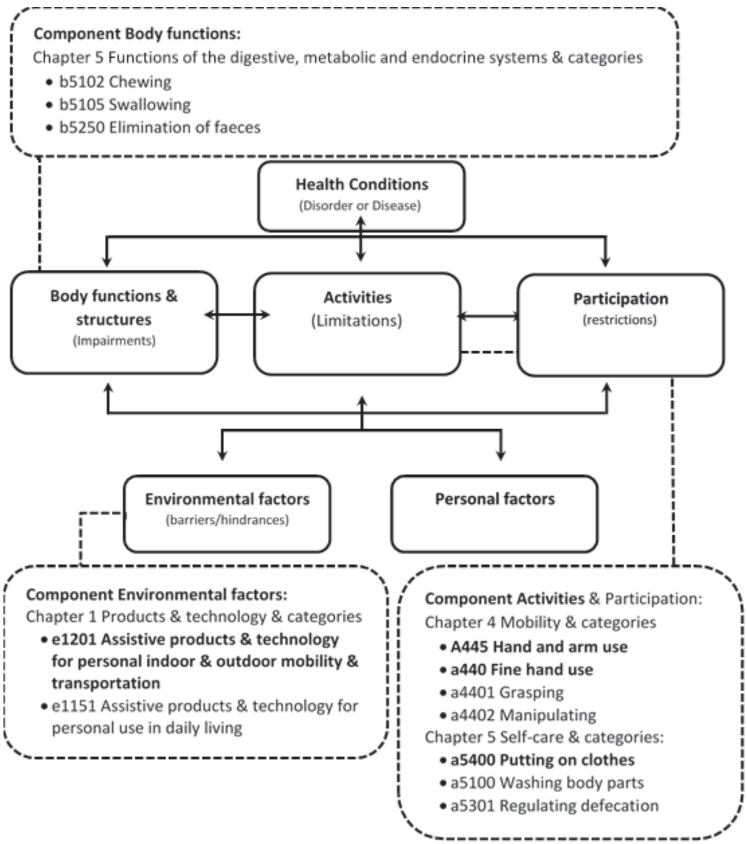


*Figure 10. The model of the ICF with its interactive relationship between its components, chaptersand categories.*

*Footnote: In the dashed boxes, components are included that were identified in the linkage procedure of the KB scale to ICF and examples from chapters and categories within the different components. (Adapted from Stamm T. et al. Rheumatol 2006; 45: 1534-1541)*

The majority of concepts were linked to the ICF component activity and participation, n=345 (90%), and environmental factors, n=31 (8%), and a few concepts were linked to body functions, n=9 (2%). The most frequently used categories are shown in bold writing in Figure 10 in the component of activity and participation and in the component of environmental factors. The 384 concepts identified in the KB Scale items were linked to 58 different ICF categories on the second and third levels. One concept could not be linked to any ICF category. Third level categories in the ICF could be used in 81% when linking meaningful concepts to the KB Scale. The chapter most used during linkage was mobility: this was followed by the chapter self-care, and the number of linked categories can be seen in Figure 11 and Figure 12.

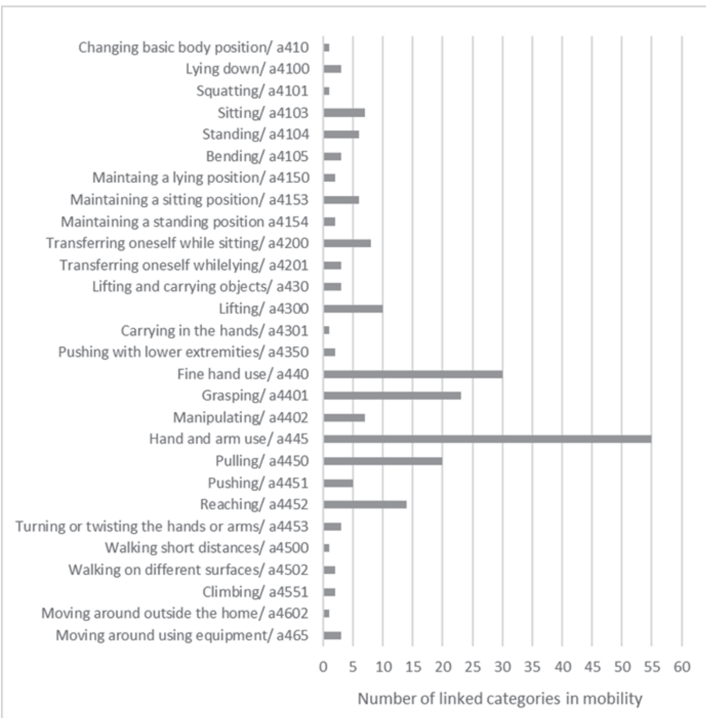


*Figure 11. Number of linked categories in the chapter mobility in the ICF*

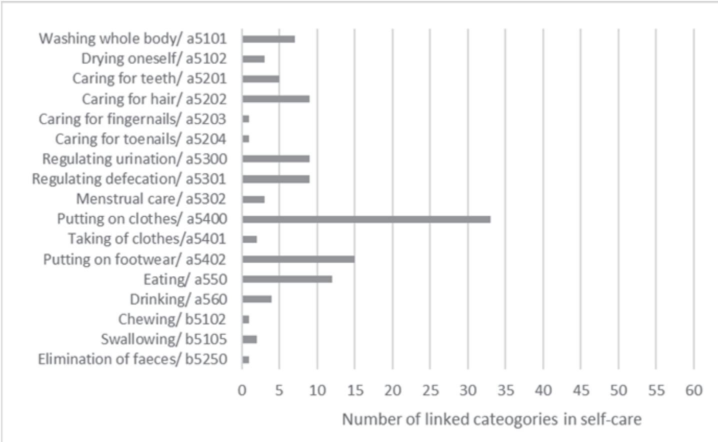


*Figure 12. Number of linked categories in the chapter self-care in the ICF*

### 5.2.2 Comparison between linked categories and SCI core sets

The results showed that the comparison of linked categories on the same level in the KB Scale and the core sets for SCI post-acute and long term care and for the core sets for SCI from the perspective of OTs showed that more categories were matched between the core sets of OTs than the core sets of SCI. This difference between the core sets for SCI and OTs became even more apparent when a comparison was made between the categories that were linked to a less detailed level and categories. The core sets for OTs lacked fewer categories that were included in the linking of the KB Scale than the core sets for SCI.

### 5.2.3 Frequencies, KB Scale items and concepts and ICF categories

The results showed that all the dimensions had the high density ratio of over 1.0, indicating that, in most items, more than one concept was identified and linked. A density ratio with a value of 1.0 indicates that one concept is identified in the item. The diversity ratio ranged between 0.10 and 0.53 in the different dimensions. The dimensions of hygiene (0.28) and use of telephone (0.53) showed the highest diversity ratio, indicating that most concepts were linked to different ICF categories.

### 5.2.4 Statistical test

The results showed that the percentage agreement (PA) ranged from 0.33 to 0.69 and the estimated Kappa values ranged from 0.25 to 0.62, a range from a level of fair to substantial level agreement. Five of the six dimensions in the

KB Scale and the overall KB Scale showed statistical significant differences, while the dimension of mobility showed no statistical significant difference. After splitting the dimension of dressing into the sub-dimensions of dressing and additional devices, a second calculation resulted in PA values of 0.31 to 0.81, Kappa values of 0.75 and 0.29 and non-parametric bootstrapped CI values of (0.21 to 0.82) and (-0.09 to 0.41) for each sub-dimension.

## 5.3 Study III and Study IV

### 5.3.1 KB Scale measure changes in basic ADL

The KB Scale can discriminate and measure small changes in basic ADL over time in individuals with cervical SCI who underwent grip reconstruction or elbow extension with or including grip reconstruction. This was seen even though the last group includes fewer individuals and, as a group, was heterogeneous in terms of how the individuals carried out basic ADL. The individuals in both the hand group and the elbow/hand group stopped using assistive devices after surgery(s); the change was more prominent in the hand group than in the elbow/hand group. The hand group began instead to grasp and execute fine motor tasks in single-handed and bimanual activities such as in items grasp soap, grasp/release toothbrush and shaving device, use suppository when emptying bowel, button trousers and fasten and zip zippers in jacket. The elbow/hand group began instead to use the increased reach and stability in the regained elbow extension coupled with grasp in items such as mobility on uneven surface, open and close car doors, wash and dry back body and put on shirt/jacket.

### 5.3.2 Changes in basic ADL in individuals with SCI

The hand group in Study III improved after the hand surgery procedure(s) and became more independent and the results are shown according to improvement in each dimension: hygiene, dressing, mobility, eating and elimination. The elbow/hand group in Study IV also became more independent, but in three dimensions, dressing, hygiene and eating, and, in these dimensions, the improvement was almost as large as in the hand group. Both groups became also less able to carry out basic ADL after the surgery(s). These deteriorations was numerically far lower than the improvements in basic ADL for both groups. The groups deteriorated in the same dimensions, dressing, hygiene, mobility and elimination, but the deterioration was greater in the elbow/hand group compared with the hand group. The deterioration meant that the groups became more dependent on assistance to carry out basic ADL in these dimensions.

### 5.3.3 Non-use of assistive devices in sub dimensions after surgery

The analysis of the raw data showed that the hand group in Study III improved their grip function and discontinued use of assistive devices after the surgery(s). The largest improvement could be seen in items in the sub dimensions of bladder, brush teeth, brush hair, shave, eat and drink. The elbow/hand group also improved their grip function and discontinued use of assistive devices in items in the sub dimensions of put on socks, brush teeth and eat. Both groups had the greatest change in the dimension of eating because they began to use cutlery without assistive devices. Items that had statistical significance showed that individuals in the hand group could handle both the knife and fork to eat (Figure 13-14) while the individuals in the elbow/hand group could handle fork and eat after the surgery (Figure 15-16). However, the elbow/hand group in Study IV had a need to use assistive devices to a greater extent than the hand group, even after surgery(s). This was clearly seen in items included in the sub dimensions of transfer in and out of car and transfer in and out doors.

### 5.3.4 Svensson's method – to evaluate basic ADL

The results have shown that the evaluation with a Rank invariant method called Svensson's method (184) can measure changes in basic ADL to identify and measure changes on the group level separately from individual change assessed with the KB Scale after surgery(s). In Study III and Study IV, the results are shown in both individual items and item groups. The hand group had more statistically significant items, 25 items and five item groups which included 28 items, than the elbow/hand group. The elbow/hand group had 11 items and three item groups which included ten items that were statistically significant. The hand group included ten items that were over the limit value of 0.1, and the elbow/hand group included 41 items and three item groups that were above the limit value of 0.1.The number of individuals who were included in each group differed; the hand group included 47 persons and the elbow/hand group included 24 persons.

The contingency table shows the distribution of categories in the item grasp knife in the KB Scale (1=totally dependent, 2=partly dependent (not chosen by the individuals in this item), 5=assistive devices, 6=independent) before and after surgery (Figure 13-14.).

| | | Before 6 | Before 5 | Before 1 | | |
|---|---|---|---|---|---|---|
| After | 1 | | | 14 | 14 | 1 |
| | 5 | | 4 | 1 | 5 | 0.70 |
| | 6 | 21 | 1 | 6 | 28 | 0.60 |
| | | 12 | 8 | 25 | 47 | |
| | | 0.45 | 0.55 | 1 | | |

*Figure 13*

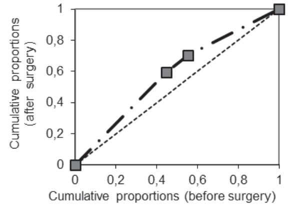


*Figure 14.*

*Figure 13-14. The hand group had a positive statistically significant change in how they used the item grasp knife in the KB Scale, RP = -0.1648 (n=47).*

The diagonal of unchanged assessments in the contingency table is indicated in grey. Twenty-one (45%) of the individuals with SCI could use a knife while eating before as well as after the intervention. Fourteen (30%) of the individuals were unable to use a knife both before and after the surgery(s). The results in the contingency table indicate a positive systematic group change, i.e. after surgery, seven individuals could independently use the knife while eating and one individual could, with a assistive device, handle the knife while eating. This result could also be visualised by plotting the cumulative relative frequencies of marginal distribution in the ROC, which showed a systematic positive group change between before and after surgery(s), RP = -0.1648. This means that there was a 16% chance for individuals with SCI to be able to use a knife while eating after the surgery(s).

The contingency table shows the distribution of categories in the item grasp fork/spoon in the KB Scale (1=totally dependent, 2=partly dependent, 5=assistive devices, 6=independent) before and after surgery(s) (Figure 15-16.).

| | | Before 6 | Before 5 | Before 4 | Before 1 | | |
|---|---|---|---|---|---|---|---|
| After | 1 | | | | | 0 | 0 |
| | 4 | | | | | 0 | 0 |
| | 5 | 1 | 8 | | | 9 | 1 |
| | 6 | 9 | 6 | | | 15 | 0.63 |
| | | 10 | 14 | 0 | 0 | 24 | |
| | | 0.42 | 1 | 0 | 0 | | |

*Figure 15*

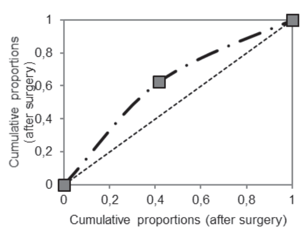


*Figure 16.*

*Figure 15-16. The elbow/hand group had a positive statistically significant change in how they used the item grasp fork/spoon in the KB Scale, RP = -0.2083 (n=24).*

The diagonal of unchanged assessments in the contingency table is indicated in grey. Nine (38%) of the individuals with SCI could use a fork or a spoon while eating before as well as after the intervention. No individual was unable to use a fork or a spoon before or after the surgery(s). The results in the contingency table indicate a positive systematic group change, i.e. six individuals could independently use the fork or the spoon while eating. One individual could independently handle a fork or a spoon before the surgery but, after the surgery, needed to use an assistive device to be able to handle a fork or a spoon while eating. This result could also be visualised by plotting the cumulative relative frequencies of marginal distribution in the ROC, which showed a systematic positive group change before and after surgery, RP = -0.2083. This means that, after the surgery(s), there was a 21% chance for individuals in the elbow/hand group to be able to handle a fork or a spoon without using an assistive device when eating.

# 6 DISCUSSION

Research on clinical practice after reconstructive grip function and elbow extension surgery is important to gain knowledge about function and effects of the interventions (71, 189). Proper measurement instruments are a prerequisite. While the KB Scale seems to fulfil this requirement, papers I and II together with the final studies III and IV have also shown that, to become a useful tool for measuring basic ADL in individuals with tetraplegia, selected parts of the structural properties of the KB Scale must be further investigated.

## 6.1 Independence and functional mobility before surgery

Functional mobility (transfers and wheelchair propulsion) in individuals with tetraplegia represents a significant factor in overall independence in ADL (113, 190). With the KB Scale, this could be shown in paper I, where a small sample showed the same combination between being able to make transfers and overall independence. One of the greatest barriers to independence is the inability to support and lift the upper body using the upper limbs (i.e. performing a weight-relief manoeuvre) (123, 191). A number of studies have reported that upper extremity function and movement, that is, in transfer and push-up motions, is decisive in the process of gaining and maintaining independence (111, 123, 124, 192). Without these skills, individuals are not able to transfer, which influences their independence in other activities necessary for mobility and self-care (123, 191). The more independent individuals in paper I could make bed transfers by themselves, which also made them independent in getting clothes and dressing the lower body. However, the individual's physical characteristics, such as height and weight, were not taken into account, which might have further explained why these individuals were more independent than the rest of the study group.

## 6.2 ADL activity in relation to body function

The study group in paper I included a heterogeneous group regarding both motor and sensory function. This might explain the moderate correlation in paper I between motor and sensory function in the upper extremities and the individual's level of independence in ADL (193). Another explanation for the results in paper I might be that measurements of body function do not allow a direct translation to basic daily activities, hence the moderate correlation in paper I because measurements of body function level are based on capacity and not on actual doing (performance) as the ADL is (102). Earlier studies (29, 194) have however suggested that the functional gains at each level of the cervical spinal cord have a major impact on an individual's ability to carry out ADL. Yet other studies (16, 111, 192, 195) have stated that there exists a specific relationship between critical levels or key muscle groups and independence in certain ADL activities. Furthermore, earlier studies (196-198) have also suggested that differences in ADL abilities among cervical SCI individuals with a similar motor level could be attributed to differences in sensory function.

## 6.3 Change in basic ADL after reconstructive hand surgery

The results in Studies III and IV confirm our clinical experience that individuals with cervical SCI could change their level of activity in basic ADL after reconstruction of elbow extension and grip function measured by KB Scale (199, 200). Studies III and IV showed that individuals in both studies had statistically significant changes in activity level in five out of six dimensions. However, the change in the KB Scale dimensions showed that individuals who reconstructed grip function had more statistically significant items, i.e. changed more in how they carried out basic ADL, than individuals who reconstructed elbow extension and grip function (199). Individuals who underwent reconstructive hand surgery had the majority of statistically significant items in the dimension of hygiene. The individuals in Study III (199) changed activity level more in items that included parts of the activities than in whole activities. It was therefore possible to detect whether the different phases in the grip procedure (178) had changed after hand surgery. These results offer OTs a tool to measure BADL that has the potential to be more sensitive to changes in activity in individuals with tetraplegia than most commonly used ADL instruments today (98, 99). Individuals who underwent reconstructive elbow and grip function had the majority of statistically significant items in dimension mobility. The individuals in Study IV changed more in items where shoulder function and stabilisation of the elbow are needed coupled with a hand grip. These types of changes in activity level in items were most clearly seen in the dimensions of mobility and hygiene. However, the individuals also changed activity level, albeit in fewer items, that included parts of the activities but not whole activities (1, 104). The individuals in Study III showed no individual change (variability) in activity level in the items, while the individuals in Study IV showed an individual change in activity level in items that was both statistically significant and over the limit value in the KB Scale (199, 200).

This difference in the results in the studies may be because they included different numbers of individuals and individuals with different levels of cervical SCI. However, the difference between the groups in BADL may also be due to the fact that the individuals who gained elbow extension and grip function improved in other activities that they found meaningful such as writing, reach for a book and stretching out the arm when lying down (201), which could not be assessed with the KB Scale. However, there were individuals from both studies who became more dependent in BADL after surgery and needed help from persons in their immediate environment. This means that surgery not only influences the individual who undergoes it but also those who are closest to the individual.

The deterioration may be due to several reasons. It had been strenuous for the individuals to reach their level of independence before surgery. Furthermore, they might have had too high expectations of what they could accomplish after surgery. Another reason may be that it takes time to change how to carry out activities in BADL. Individuals have established routines and habits after the SCI in terms of how they carry out activities. These routines and habits might make it hard for the individual to make a change, which means that the functional benefits of elbow extension and grip function might not be translated for the individuals to become more independent in BADL after surgery. Furthermore, the difference in activity level in BADL between the groups may also be due to different immobilisation times, since the type of surgery controls when training in ADL can begin after surgery (152). Earlier studies (152, 161) have shown that a combination of armrest and electric wheelchair has a positive impact on the surgical results after reconstruction of elbow extension. However, it has been suggested in an earlier study (202) that the lengthy period of immobilisation is too cumbersome because it restricts the individual’s ability to be mobile and active in daily life (203). Nowadays, the individuals are involved early after surgery to train the newly acquired elbow extension, but the length of the overall restrictions is almost the same as in this study (204).

## 6.4 Factors influencing basic ADL before and after surgery

The results in Study I and the final studies suggest that individuals’ activity in BADL is not just a function of muscle strength or sensory ability. It also depends on the individuals’ physical characteristics, such as age (29), gender (205), body weight (206) and the SCI individuals’ skill and motivation (192). Additional factors that may influence the outcome after surgery is the type of rehabilitation (77, 207) they received after their cervical SCI and how much time elapsed between rehabilitation and the reconstructive hand surgery. Could it be that some of the individuals' improvement in BADL after the surgery(s) can be attributed to an unexploited capacity and therefore not be seen as improvements after arm and hand surgery? This would support the need to use one and the same ADL instrument that can measure changes in BADL deemed important by the individuals with cervical SCI (156) throughout the rehabilitation continuum from the primary rehabilitation to restorative (reconstructive) rehabilitation. This may provide the information needed to clarify which improvements in BADL are due to the recovery of function after a cervical SCI or are the result of reconstructive hand surgery procedures.

## 6.5 Functional mobility and measurement

The results of paper I and in the final studies highlight inherent problems in the dimension of mobility in the KB Scale because assistive devices are included in some of the item definitions. For this reason, the items are not sensitive to change in function; neither do the items distinguish between individuals with different levels of injury. Despite the existence of these problems, a degree of skill difficulty could be discerned between the different transfer modalities, and this has been corroborated by other studies (192, 208). The individuals in paper I were most dependent in climbing stairs, followed by transfer from floor to wheelchair, and thereafter transfer to toilet, shower, chair and bed.

The results in Studies III and IV have shown that the KB Scale can measure different modalities of mobility in finer detail than the Functional Independence Measure (FIM™). This is despite the fact that an earlier study (208) suggested that five additional mobility items (move about in bed, transfer floor to wheelchair, push a manual wheelchair over level ground, ramps and kerbs) should be included in the FIM™ to capture important factors influencing mobility and to distinguish important functional differences among the SCI population. However, the item definition of these five items suggests testing in a standardised environment, and the assessment seems to be based on capacity, and not performance. However, capacity (can do) is a different phenomenon than actual performance (does do). Measures of capacity establish the limits of performance but are generally poor indicators of actual behaviour. A crucial distinction between measures of capacity and of actual doing (performance) is where the behaviour occurs (53). Clinically, getting up from a supine position on a gymnastic plinth (hard surface) does not necessarily mean that the individual can do the same procedure in a bed on a soft surface. Actual performance can, compared to capacity, only be measured in places where the persons conduct their day-to-day living (53, 209). Therefore, in paper I and in the final studies, the individual's actual doing (performance) was assessed in the KB Scale in an attempt to capture what the individuals did on a regular basis in their real life surroundings. That is, a person's ability to carry out activities should be seen as an interaction between the person, the activity and the environment (51-53). However, the actual performance was not observed but relied on the description of the individual, given during the semi-structured interview.

## 6.6 Impairment-specific dimensions

Impairment-specific dimensions have been suggested in earlier studies (210, 211) to be identified and measurable in ADL scales. In paper I, a connection between function and activity was established using Napier's definition (177) and Bendz's description of grip function (178) during the linkage of the KB Scale to the ICF. The KB Scale can compare to FIM™ not only in being divided into upper and lower body but also being divided into impairment-specific items for arm and hand function. In its present form, however, the KB Scale cannot differentiate the quality or types of grip function needed to carry out ADL. Evaluation tests of body functions and structure and dexterity level must be included to measure this, preferably on the level of performance not based on capacity (102). However, the focus on body structure/body function is only appropriate as long as the assessment of abilities is related to how these abilities interact with the environment and daily activities to create activity limitations.

## 6.7 Reason for using ADL as an outcome measures

Outcome of reconstructive hand surgery may be measured as muscle strength, sensation or grip ability (212). However, it is crucial that functional gains after a surgical intervention also have an impact and meaning in real life (71). Connecting basic movement in the upper extremities to basic ADL in papers I and II gives an understanding of the arm and grasp abilities needed to perform an activity (172, 187). This has also given a greater understanding of what is required to be able to change activity patterns in basic ADL in Study III and Study IV after undergoing reconstructive grip function and elbow extension surgery (199, 200). These studies have shown that it is therefore important to select appropriate outcome measures on all levels, from body function and structure to activity and participation, to capture these functional gains and real-life benefit after an intervention (53). The KB Scale has the potential to capture these real life benefits in BADL in a way in which a person's abilities may be enhanced, activities be modified or the environment be adapted to improve the person's activity or participation in daily life (60, 213).

However, BADL is only a part of the concept of occupation, which includes everything a person with cervical SCI does in everyday life (24, 25). The evaluation of BADL was based on how individuals with SCI carried out the items in the KB Scale at home. If questions concerning routines or habits had been included in the study, the individuals could have described how the routines and habits influenced their use of time and it would perhaps have provided a greater understanding of why some individuals changed more or less in BADL. In addition, if a goal attainment scale had been used in the study to complement the KB Scale, it would have provided more information about the activities that individuals deemed important and meaningful in BADL and in activities not measurable in the KB Scale. Finally, in the future, categories that measure degree of difficulty should preferably be included in the assessment with the KB Scale. This way of assessing BADL in individuals with cervical SCI could then provide information on why individuals choose to perform activities that are difficult to carry out and perhaps why they still choose to do these activities by themselves.

# 7 METHODOLOGICAL CONSIDERATIONS

By using a combination of quantitative and qualitative methods in the studies, the researcher was able to take advantage of each specific method in collecting and / or interpreting and analysing the data. Still, each method has its strengths and limitations. The different methods used in the study are discussed below.

## 7.1 Quantitative and qualitative methods

The major advantage of a cross-sectional design is that it is relatively easy to conduct, does not take a long time to execute and is less expensive than a study with a longitudinal design (71). However, a cross-sectional study gives a snapshot of a single sample measured at one time point, for example in examining the health behaviour or conditions that exist in a group (89). Paper I is a cross-sectional study derived from an interest in finding and evaluating the KB Scale for its measurement qualities and for its ability in the subsequent studies to measure changes in basic ADL in connection with reconstructive hand surgery. The limitations of this type of study are that it cannot distinguish the temporal sequence of cause and effect, and it only gives a snapshot of a person's status at a given time point, which might falsely classify a person as being more dependent or independent in ADL. A third limitation in paper I is that, although it is a cross-sectional study, the data were collected over several years and the care and rehabilitation the patients received might have changed over time. This might have influenced the results of paper I.

In a study with a mixed method design, the qualitative and quantitative methods complement each other, that is, the OT/ researcher utilises their strengths to get the breadth and depth that give additional insights (71, 214). Paper II is a mixed method study that incorporates elements of both qualitative and quantitative methods. One of the two methods is chosen to be the core method: in this study, the direct content analysis of the KB Scale linkage to the ICF (57, 58, 179). Triangulation was used in the qualitative part of the study, which is a process where concepts are confirmed using different strategies, such as more than one researcher, more than one data source or more than one collection method. These strategies represent a major opportunity to increase the accuracy with the goal of strengthening the validity (content validity) and thus being able to minimize the bias that affects the results of a study (71, 89, 215). To achieve this, the underlying assumption in the qualitative core method must be given priority and be visible in the purpose, methodological decisions and overall analytical approach. These assumptions should not be violated when analysis is performed in the secondary method, in this study the quantitative part, which includes both calculations of the content density, content diversity and evaluation of reliability of the two independent linkage versions in the study (71, 214). The core method in the mixed method provided the theoretical basis; in this study, the purpose was inductive: to investigate whether the KB Scale could be linked to the ICF systematic coding system. However, the limitation in this study is that it also includes a deductive part, which was testing of the two independent linkage versions made by the two groups, as suggested by the developers of the linking rules (57, 58). This might have violated the assumptions in the core method (71, 214).

In longitudinal studies, the OT / researcher can gain a detailed understanding of how and why patterns of change in BADL occur over time (71). However, longitudinal studies are expensive to perform, take a long time and pose the risk of losing participants over time, which can affect the final outcome of the study (216). Before Studies III and IV, a cross-sectional study was conducted, which showed that the KB Scale could measure the intended variable, BADL in individuals with cervical spinal cord injury (172). In longitudinal studies, it is possible to collect data at different time points, which makes it possible to describe and analyse the direction of change and the magnitude of change over time (217). In Studies III and IV, data were collected before and after the reconstructive hand surgery, which made it possible to examine and analyse basic ADL measured by the KB Scale ADL in individuals with cervical SCI. Although Studies III and IV had well-defined time points to evaluate basic ADL with the KB Scale after reconstructive hand surgery, there are limitations in the studies since it is unclear how long after completing the surgical procedures it is possible to measure relevant changes in ADL ability in individuals with cervical SCI. Perhaps a follow-up two years after the last surgery would show whether the individuals perceived that they reached as far as they can in independence in BADL. However, this follow-up may also show that, when individuals do not get the full attention of health professionals, they do not continue to carry out certain activities that perhaps took too much time or were at the limit of what they could carry out in BADL. This may seem negative from a professional point of view, given that they do fewer activities in BADL after surgery, but, on the other hand, it might show that the individuals have chosen what they want to do and what they think is important to do and integrated these activities into their everyday lives.

## 7.2 Linking the K-B Scale to the ICF

The use of the ICF (53) as an independent reference has made it possible to interpret, detect and quantify concepts the KB Scale. However, the results in papers I and II have shown that there was a discrepancy in the level of detail between the concepts of self-care identified in KB Scale and its counterpart in the ICF (53), i.e. the categories in self-care in the ICF lacked both breadth and depth in the definitions of their categories. Examples of lack of breadth and depth of ICF categories are evident in the category of dressing, which does not separate upper and lower dressing and undressing, and in the category of toileting, which is seen as one activity and is not divided into parts of an activity. However, in both linkage procedures, arm and hand function could be elucidated and strengthened at the item level by the linking procedure (172, 187). Concepts concerning arm and hand function in the KB Scale could be linked to a higher level of detail in the ICF (53) than what was possible in the linkage of self-care. Even though parts of the linking procedure in papers I and II were problematic, the linkage made it possible to study similarities and differences between the KB Scale and the ICF. However, a limitation in the linking process in paper I was that one person (AD) did the linkage between the KB Scale and the ICF, whereas it is recommended in the linkage rules (57, 58) that at least two persons should be part of the procedure. This means that, if one complies with this recommendation, it will increase the reliability of the linking procedure when instruments are linked to the ICF (57, 58). The result of the linking procedure in paper II could, however, when four OTs participated in the linking process, confirm that arm and hand function could be detected in the items in the KB scale. The core sets for SCI (55, 218, 219) verified and confirmed that the KB Scale includes important concepts and does encompass a majority of problems concerning self-care in individuals with cervical SCI treated by OTs. Furthermore, the linkage has also given an insight into the scale structure, i.e. breadth (content density) and precision (content diversity) (220) in the KB Scale items. The dimension of dressing is the most precise and detailed of all the dimensions, and the dimension of mobility is the most problematic dimension in the KB Scale. However, these results have also made it possible to verify the final linkage version that more than one concept is identified in some items and that several concepts are linked to the same ICF category; both these results have the potential to create problems when assessing basic ADL in individuals with tetraplegia.

The OTs who took part in the linkage procedure had the same amount of experience regarding spinal cord rehabilitation. However, limitations existed with regard to a difference in experience and knowledge of the ICF among the raters. Although the raters have the same professional background and thus applied an occupational therapy perspective during the linkage, the two groups of raters encountered problems linking concepts to the ICF in the dimension of mobility in the KB Scale. When comparing the two linkage versions, five of the six dimensions in the KB Scale could be considered reliable, but not the dimension of mobility.

## 7.3 Measurement qualities in the KB Scale

The results in papers I and II have shown that the KB Scale (1) could discriminate basic ADL along a continuum of skill difficulty for cervical SCI individuals. This investigation was important, although earlier studies have shown the KB Scale to be reliable, valid (1, 168, 169) and sensitive toward small changes in ADL (168). However, in these earlier studies (1, 168, 169), the SCI individual's levels of injury either remain unclear or include few cervical SCI individuals. Therefore, these studies did not provide enough evidence that the KB Scale could be used to assess BADL in individuals with SCI. The measurements depend not only on the KB Scale measurement quality, however, but also on the skills of the persons carrying out the interviews and the group of individuals and their interest in answering the questionnaire (221).

## 7.4 The use of semi-structured interviews

The total number of items in a scale is generally related to precision, i.e. how well a scale can discriminate for example ADL ability among cervical SCI individuals (71). However, the total number of items also affects how much time is needed for the measurement (222). In paper I and the final studies, a semi-structured interview was chosen even though the KB Scale includes many items. This choice of interview technique also meant that the KB Scale could not be used in a standardized way. However, the use of semi-structured interviews allows the interviewer to tailor questions and probe to obtain in-depth and trustworthy information (216). This includes questions concerning what, how, why, where and when certain activities are performed (79). This interview method gave a more thorough understanding of the SCI individuals' ADL ability. It also gave information about environmental factors such as the use of assistive devices and car and house adaptations. However, there must be a balance between how much information is needed and how long an interview can be in order not to burden the individuals too much. The limitation in using a semi-structured interview is that there is always a risk that the respondent might not be telling the truth because his or her ability to carry out BADL has not been observed. Another limitation is that there is always a risk of interviewer bias when the OT (AD) both train the individuals following surgery and evaluate the outcome after surgery (90). One way to lessen the burden to the respondent and at the same time maintain the level of detail in the KB Scale would be to develop a computerized adaptive test (CAT) (223).

## 7.5 Skill difficulty in the items in the KB Scale

The results of paper I confirm previous findings that the highest levels of independence are attained in easier self-care activities for individuals with cervical SCI before and after the surgery(s) (17, 31, 121, 224). The individuals' level of independence in paper I appears to be related to skill difficulty. Eating and using the telephone were the easiest activities, while grooming and dressing upper body were moderately hard activities. Transfers, showering, dressing lower body, and bladder and bowel management were the most difficult activities to carry out because these activities required greater motor ability to achieve proficiency. These results are consistent with a previous study (172) that suggested that ADL activities could have different levels of skill difficulty, i.e. that they can be divided into easier and more difficult activities. This is because some ADL activities require skills and physical ability to balance and maintain a stable position either standing or sitting while using the arms and hands (225).

## 7.6 Categories in the KB Scale

It has been suggested that the minimum number of categories in a scale should be between five and seven (90). Regardless of how many categories are incorporated in a scale, all should be applicable and measurable in all items (226). If the numbers of categories are less than the rater's ability to discriminate, the result will be a loss of information (90). This is clearly seen in paper I, where the use of dichotomized categories of independence and dependence in the KB Scale limit the individuals' choice of response levels, which in turn leads to a loss of efficiency in discriminating individuals' level of independence. Furthermore, the use of dichotomized categories also reduces the correlation with other instruments or measures (90). One of many improvements after reconstructive hand surgery was that individuals either discarded assistive devices or began to use assistive devices that allowed them to be independent without the help of others (199, 200). Clinically these changes in activity pattern are important to the individuals, and it should be possible to measure the utilisation of assistive devices in all items in the KB Scale. The Swedish version of the KB Scale (167) includes a category to measure the use of assistive devices apart from categories that measure independence, partly dependence and total dependence. As the number of categories in a scale defines the sensitivity to change in the individual's ability in an item (222), it is recommended that all these categories should be used in future assessments and evaluations in order to better discriminate individuals with cervical SCI independence in BADL.

## 7.7 Weight scheme in the K-B Scale

The results in paper I have shown that arm and grip function, and not the original weight scheme, are decisive with regard to item complexity for cervical SCI individuals. The most difficult items for the individuals with tetraplegia were those that include precision grips (manipulation). Furthermore, all three weight levels, simple, average complex and complex, in the KB Scale include items that require grasp abilities, power grip or precision grip or a combination of both, using one and two-hand grasps. This makes weighting items obsolete and only creates complexity in scoring the items for cervical SCI individuals (90). The guiding principle for assessment of item complexity should therefore be reflected by the individual's choice of categories in the KB Scale. This change in approach to evaluate basic ADL will also highlight that arm and hand function seems to play a crucial role for ADL independence in cervical SCI individuals, which is supported by earlier studies (15, 16, 111, 123, 124, 227). In addition, the individual's views should be allowed to be taken into consideration in the assessment of BADL measured with KB Scale. This change in perspective means an acknowledgment that the individual's perspective is more informative than the perspective of groups of health professionals (48).

## 7.8 Use of raw sum score in the KB Scale

Only the analysis with the raw sum score was useful in paper I, and it was used according to the recommendations in the original KB Scale (1, 104). However, this made it more difficult to interpret the results since individuals with tetraplegia can have the same scores in spite of different needs of assistance (69). Furthermore, the use of a total score for the degree of independence assumes that the items in the scale have equal disability values, which leads to a questioning of the basic soundness of measures of disability (228). In addition to this, the KB Scale is considered to be an ordinal scale, which means that each successive score does not necessarily represent an equal amount of change (229), which makes the use of the sum score questionable, and interpretations in paper I should therefore be made with statistical caution (216).

## 7.9 Generic vis a vis diagnosis-specific instruments

It might be expected that a diagnosis specific instrument would be more sensitive to changes in ADL in the SCI group. However, paper I showed that the KB Scale, compared to the Spinal Cord Independence Measure (SCIM) (99) and Quadraplegia index of function (QIF) (100), can measure ADL in finer detail since the items in the SCIM and the QIF lack the necessary components to assess important parts of an activity. Paper II (187) confirmed the results in paper I (172), that the KB Scale has the potential to make this distinction, and the scale is therefore more sensitive to detecting items that can both restrict or facilitate the ability to carry out basic ADL in relation to the individual's SCI. These attributes would make the KB Scale a better tool for targeting interventions in ADL for individuals with tetraplegia. However, even though the results of papers I and II showed that the KB Scale can tap into many important areas of ADL for cervical SCI individuals and discriminate them according to BADL, it has all the inherent problems associated with a generic scale. The KB Scale includes items that are both inappropriate and irrelevant for cervical SCI, and these non-useful items only contribute noise when the instrument is used and subsequently analysed. However, generic instruments would provide an opportunity to compare individuals across disorders, diseases and interventions compared to a diagnosis-specific instrument (90).

## 7.10 Measure KB dimensions together or apart

ADL has been suggested to be multidimensional and divided into self-care, bladder and bowel control and mobility, which are relevant to most individuals at all levels of physical disability (210, 225). In papers I and II these dimensions were identified in the KB Scale through the process of linking to the ICF (187, 193). As these dimensions have also been shown to influence independence among cervical SCI individuals in the final studies and in earlier studies (133, 192, 208), all three dimensions should be included in the investigation of independence in cervical SCI individuals. However, as these dimensions measure self-care, physiological function and the ability to be mobile (53) and therefore are distinctly different from each other, they should preferably be investigated as separate dimensions. Being able to delineate these domains allows gaining a more complete picture of a cervical SCI individual's ability in BADL. Clinically, either one or all domains could show change as a result of an intervention. Furthermore, differences in progress among the dimensions at various stages during rehabilitation can be highlighted.

## 7.11 Statistical considerations

Svensson's method (184, 222) used in Studies III and IV made it possible to separate the pattern of change attributed to two components, pattern of changes in a group versus individual changes that cannot be explained by the estimated group changes. In clinical practice, it is important to identify these two types of patterns of change because they can have an impact on how to continue a treatment or an intervention. Furthermore, it also became possible in Studies III and IV to investigate both types of changes in BADL. This knowledge can provide information about individuals who are likely to benefit the most or the least from an intervention. It may also be used to support individuals who need advice and extra training in order to achieve a change in ADL ability after surgery. Furthermore, with Svensson's method, we can investigate whether a surgical intervention is more appropriate for individuals or for groups with cervical SCI. The results showed that the group in Study IV was heterogeneous, i.e. more items were above the limit value than was statistically significant in all three measures (group change, category concentration, individual variation) and thereby perhaps in need of individualised treatment after surgery. However, the group in Study IV included only 24 persons, as compared to the group in Study III that included 47 persons. Fewer participants leads statistically to less precision and an increase in the width of the confidence interval, hence a lower degree of confidence in how the treatment, i.e. the surgery(s), influenced the individuals' activity level in BADL (230). It would have been an advantage if more individuals had been included in Study IV. However, the possibility to measure individual variability, with only four categories, *independent* [6], *assistive devices* [5], *partly dependent* [4] and *totally dependent* [1], may have made it difficult to detect individual changes because the number of categories in the KB Scale influenced the upper limit of individual variation. That is, the fewer the categories a scale includes, the greater the chance of missing measurable individual changes (231). However, the use of a sum score is more common (98, 100) when evaluating ADL ability among individuals with SCI, and this will make it more difficult to interpret the results, both clinically and scientifically. Individuals can have the same sum score, and this may not reflect their actual ADL ability (69). The non-parametric rank-invariant method (184, 222) was therefore chosen in this study as the statistical method because it takes into account the level of measurement in the KB Scale and therefore the non-parametric properties of the studied data.

# 8 CONCLUSION

This study has shown that the KB Scale can measure changes in self-care in individuals with SCI in finer detail in connection with reconstruction of grip function and elbow extension and subsequent grip reconstruction. This is because the KB Scale can measure basic ADL and divide it into essential components (items) of an activity and can therefore discriminate cervical SCI individuals' ability to carry out basic ADL. This applies even though the group with SCI in this study included individuals with a diversity of levels of function, that is, differences in upper extremity function and differences in their ability to be mobile. However, for cervical SCI individuals, only a raw sum score was useful for measuring basic ADL within the KB Scale. However, further studies are needed due to the low number of participants after reconstructive elbow extension surgery to ascertain whether the surgery in itself or in conjunction with hand surgery has the potential to change basic ADL ability among individuals with cervical SCI. The ICF has provided a valuable reference to identify and quantify the concepts in the KB Scale. The comparison between the ICF core sets and the KB Scale has corroborated that the scale can measure basic ADL deemed important for individuals with SCI. In addition, the comparison also provided insights into areas that are covered by these instruments with respect to the breadth and precision of the linked categories. Furthermore, the ICF linkage also provided information about which items in the scale might require more specification in a future revision of the KB Scale.

# 9 FUTURE PERSPECTIVES

The knowledge gained in paper I and II should be used to address the problems in the structural properties in the KB Scale. Items that are not relevant for individuals with cervical SCI should be excluded from the scale. This means rewriting items mostly found in the dimensions of elimination and mobility that include assistive devices in order to exclude them from the items' definition and instead be able to use them as a category during assessment of basic ADL in the future. In addition, the item definitions that include more than one linked meaningful concept concerning basic ADL should be rewritten and, when needed, splitting items to be able to measure one skill difficulty per item during assessment. After the structural change in the KB Scale, it should be investigated whether further items in basic ADL specific to individuals with SCI need to be included in the item bank for basic ADL; thereafter, attempts should be made to develop Computer Adaptive Testing (CAT). This development means reduced time consumption and thereby enables a more detailed assessment of basic ADL since individuals with SCI usually improve within an activity than in a whole activity. This can offer the OTs, both novices and experts, a guiding tool in a clinical environment that can support them and the individuals with cervical SCI to determine which activities, and in what order, should be carried out to train basic ADL during rehabilitation. In addition, it can provide OTs with a scientifically structured and feasible method to detect and evaluate longitudinal changes in basic ADL among cervical spinal cord individuals.

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