

# Traffic Light System-BasicADL (TLS-BasicADL)

Development, reliability, validity, clinical  
utility and patient perspective

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UNIVERSITY OF GOTHENBURG

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Traffic Light System-BasicADL (TLS-BasicADL) - Development, reliability, validity, clinical utility and patient perspective

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To my mother

You are an inspiration to us all

You can relax now

I promise you, I am finished!



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## Development, reliability, validity, clinical utility and patient perspective

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### ABSTRACT

**Aim:** To describe the development of Traffic Light System-BasicADL (TLS-BasicADL), and procedures to establish properties of reliability, validity, clinical utility and patient perspective. TLS-BasicADL measures the patient's ability to perform basic activities of daily living.

**Methods:** Study I describes the development process and testing of inter- and intra-rater reliability in 30 patients (orthopaedic diagnoses). Study II investigates criterion validity in 50 patients (mixed diagnoses), and responsiveness in 106 patients following hip fracture surgery. Study III, evaluation of a coordinated rehabilitation programme with focus on patient participation, including use of TLS-BasicADL and enhanced occupational therapy and physiotherapy in 126 patients after hip fracture. Study IV, to gain a better understanding of patients' experiences of recovery following hip fracture, including use of TLS-BasicADL. Twenty patients were interviewed and the data was analysed using qualitative content analysis.

**Results:** Study I: High inter- and fair intra-rater reliability was reported. Study II: Strong to excellent correlations were found between TLS-BasicADL and modified Functional Independence Measure, and TLS-BasicADL and modified Barthel Index. Responsiveness: Significant differences were found between the assessment time points for each item of TLS-BasicADL, except upper hygiene, dressing and eating. Excellent correlation between TLS-BasicADL and Katz Index between pre-fracture – discharge, and moderate to strong from discharge - one month. Study III: The intervention group reported higher levels of participation and independence in lower body hygiene, and dressing. No statistically significant differences at

discharge and one month post-discharge between groups in functional balance and confidence, performance measures or risk for falls. At one month post-discharge 40-80% of all patients remained at risk for falls. Study IV: Two categories were found: 'Being seen as a person' with subcategories; Interaction affects trust and security; Information is key to understanding; and Encouragement is essential to promote activity. And 'Striving for Independence', with subcategories; Accepting the situation whilst trying to remain positive; The greener the better, but it's up to me; Ask me, I have goals; and Uncertainties concerning future.

**Conclusions:** TLS-BADL provides a simple and practical team instrument for assessing basic ADL in older patients in the acute hospital setting, a visual aid to highlight level of independence and promotes communication between team members and patient. TLS-BasicADL has shown fair to high reliability, strong to excellent concurrent validity and moderate to strong responsiveness.

More intensive training and enhanced collaboration with patients following hip fracture leads to increased patient perceived participation and independence in ADL at discharge. At one month post-discharge, patients continue to experience low levels of balance confidence and remain at risk for future falls, highlighting the need for improved discharge planning and rehabilitation services post-discharge.

Following hip fracture patients experience a need to be taken seriously and seen as a person by the health care personnel. All patients described personal goals, but these were not always identified by the physiotherapists. TLS-BasicADL was described by patients as simple and easy to understand. Monitoring progress through the colour-coding changing was described satisfying and fun to see, as well as stimulating and promoting feelings of increased self-confidence.

**Keywords:** Outcome measures, Physiotherapy, ADL, reliability, validity, hip fracture, patient participation, functional balance, physical performance, patient experience, qualitative content analysis

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# SAMMANFATTNING PÅ SVENSKA

**Syfte:** Beskriva utvecklingen av Traffic Light System-BasicADL (TLS-BasicADL) och efterföljande studier för att fastställa och beskriva tillförlitlighet, validitet, kliniskt användbarhet och patientensperspektiv. TLS-BasicADL är ett instrument för att beskriva patientens förmåga att utföra grundläggande aktiviteter i det dagliga livet inkluderande förflyttning, gång och personlig vård samt patientens rehabiliteringsmål.

**Metod:** Studie I beskriver utvecklingsprocessen och testning av tillförlitlighet. Studie II undersöker validitet hos 50 patienter med blandade diagnoser och förmåga att mäta en förändring över tid hos 106 patienter efter höftfraktur. I studie III deltog 126 patienter med höftfraktur i en utvärdering av ett samordnat rehabiliteringsprogram med fokus på patientdelaktighet inklusive användning av TLS-BasicADL, och mer intensiv arbetsterapi och fysioterapi efter höftfraktur. I studie IV intervjuades 20 patienter mot slutet av sjukhusvistelsen, för att få en bättre förståelse av patienternas upplevelser av återhämtningen efter en höftfraktur. Intervjuerna analyserades med kvalitativ innehållsanalys.

**Resultat:** Studie I: TLS-BasicADL visar hög inter-rater och moderat intrarater tillförlitlighet. Studie II visade starka till utmärkta korrelationer mellan TLS-BasicADL och såväl modifierad Functional Independence Measure som modifierad Barthel Index. Analys av totala poäng visade utmärkta korrelationer mellan instrumenten. Förändring över tid: Signifikanta skillnader fanns mellan de tre olika mät tillfällen i alla aktiviteter av TLS-BasicADL förutom övre hygien, påklädning och att äta. Utmärkt korrelation mellan TLS-BasicADL och Katz Index uppvisades mellan prefraktur och utskrivning, och måttlig till stark mellan utskrivning och en månad. Studie III: Interventionsgruppen upplevde signifikant högre grad av delaktighet och självständighet vid nedre hygien samt påklädning. Det fanns inga statistiska skillnader mellan grupperna fanns vid utskrivning och en månad efter utskrivning i funktionell balans, tilltro till sin egen förmåga, fysisk funktionsförmåga eller risk för fall. Mellan 40-80% av alla patienter i studien hade kvarstående risk för fall en månad efter utskrivning. Studie IV: Analysen av intervjuerna gav två kategorier. "Att ses som en person" med subkategorier; Interaktion påverkar förtroende och säkerhet; Information är nyckeln till förståelse; Uppmuntran är väsentlig för att främja aktivitet. Den andra kategorin "Sträva efter att vara självständig" med subkategorier; Acceptera situationen men försök samtidigt förbli positiv; Ju grönare desto

bättre, men det är upp till mig; Fråga mig, jag har mål; Osäkerhet om framtiden.

**Konklusion:** TLS-BADL är ett enkelt och praktiskt teaminstrument för bedömning av basal ADL hos äldre patienter samt ett visuellt verktyg för att visa behov av hjälp. Det främjar kommunikation mellan teammedlemmar och patient. Instrumentet har visat hög tillförlitlighet när olika personer gör bedömningar av samma patient situation, moderat tillförlitlighet när samma person gör bedömningen på samma patient vid olika tillfällen, stark till utmärkt validitet samt måttlig till stark förmåga att mäta förändring av basal ADL över tid.

Tidig insatt intensiv träning och intensifierat samarbete mellan fysioterapeut/artbetsterapeut och patienter efter höftfraktur ger ökad upplevd delaktighet och självständighet i ADL vid utskrivning. Efter en månad har patienterna fortsatt låg tilltro till sin egen förmåga samt kvarstående hög risk för fall. Detta pekar på behovet av ett förbättrat samarbete i vårdkedjan inkluderande fortsatt uppföljning och rehabilitering efter utskrivning.

TLS-BasicADL beskrivs av patienterna som enkelt och lätt att förstå. Att kunna följa sina framsteg genom färgkodningssystemet upplevs som tillfredsställande, stimulerande och främjar ökat självförtroende.



# LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. **Asplin G**, Kjellby Wendt G, Fagevik Olsén M. TLS-BasicADL: development and reliability of a new assessment scale to measure basic mobility and self-care. *Int J Ther Rehabil* 2014;21(9):421-426.
- II. **Asplin G**, Kjellby Wendt G, Fagevik Olsén M. Concurrent Validity and Responsiveness of Traffic Light System-BasicADL (TLS-BasicADL). *Submitted*.
- III. **Asplin G**, Carlsson G, Zidén L, Kjellby Wendt G. Early coordinated rehabilitation in acute phase after hip fracture – a model for increased participation. *BMC Geriatric* 2017;17:240.
- IV. **Asplin G**, Carlsson G, Fagevik Olsén M, Zidén L. See me, teach me, guide me, but it's up to me! Patients' experiences of recovery during the acute phase after hip fracture. *In manuscript*.



# CONTENT

ABBREVIATIONS .....	V
1 INTRODUCTION .....	1
2 BACKGROUND .....	2
2.1 The Ageing Population, Frailty and Osteoporosis .....	2
2.2 Physiotherapy .....	3
2.3 Rehabilitation .....	3
2.3.1 Multidisciplinary Teams .....	4
2.3.2 Importance of involving the patient .....	4
2.3.3 Standardized measurement instruments .....	5
2.3.4 The International Classification of Functioning, Disability and Health (ICF) .....	5
2.4 Assessing Activities of Daily Living .....	6
2.5 Development of Traffic Light System-BasicADL .....	7
2.6 Principles of Assessment and Outcome Measurement .....	10
2.6.1 Assessment .....	10
2.6.2 Evaluation .....	10
2.6.3 Measurement tools to collect data .....	10
2.6.4 Outcome .....	11
2.6.5 Measurement .....	11
2.6.6 Outcome measure and Outcome measurement .....	11
2.7 Measurement Properties .....	12
2.7.1 Reliability .....	12
2.7.2 Validity .....	15
2.7.3 Responsiveness .....	18
2.7.4 Clinical Utility .....	19
3 RATIONALE FOR THE THESIS .....	21
4 AIM .....	22
5 METHODS .....	23
5.1 Design .....	23

5.2	Study Samples.....	23
5.2.1	Drop-outs.....	25
5.3	Ethics.....	25
5.4	Procedure .....	25
5.5	Outcome measures .....	28
5.5.1	Main outcome measure .....	28
5.5.2	Secondary Outcome Measures .....	28
5.6	Analysis methods .....	31
5.6.1	Statistical analysis .....	31
6	RESULTS .....	36
6.1	Study I.....	36
6.2	Study II.....	37
6.3	Study III .....	42
6.4	Study IV .....	47
7	DISCUSSION.....	51
7.1	Methodological considerations .....	51
7.2	Discussion of the results .....	55
8	CONCLUSION .....	62
9	FUTURE PERSPECTIVES.....	63
	ACKNOWLEDGEMENT.....	64
	REFERENCES.....	66
	APPENDIX .....	76

# ABBREVIATIONS

ADL	Activities of daily living
BBS	Bergs Balance Scale
BI	Barthel Index
FES-S	Falls Efficacy Scale (Swedish version)
FIM	Functional Independence Measure
ICF	International Classification of Functioning
I-ADL	Instrumental activities of daily living
OT	Occupational Therapist
PT	Physiotherapist
P-ADL	Personal activities of daily living
SPSS	Statistical Package for Social Sciences
SPPB	Short Physical Performance Battery
TUG	Timed Up and Go



# 1 INTRODUCTION

If you had asked me sixteen years ago, if a piece of paper with colour-coded markers highlighting patient's level of independence in activities of daily living (ADL) would become the subject of a PhD thesis, I would have laughed! Yet, here I am today describing the processes and procedures behind developing a new instrument. It has been incredibly stimulating and rewarding working with a team of likeminded colleagues to develop this new concept to help improve routines and co-ordinate resources concerning ADL and functional outcomes for the older hospitalized person.

One of my first and perhaps strongest memories of working with older people was while training to become a physiotherapist. My grandfather had suffered a stroke resulting in a hemiparesis and aphasia. When I used to visit him, although he wasn't able to communicate verbally, he was able to use body language to make himself understood. He would always signal to me that he wanted to go out for a walk; after all I was soon to become a physiotherapist! At first, we could only go a few meters, but after several weeks he was able to manage up and down stairs and could walk about 100 m. I could see in his eyes, and tell by the gestures he made, how important it was for him to be able to come outdoors, something that was meaningful for him, something that made him smile! His smile is still with me today, and what I learnt from him was not to underestimate the power of communication, to see the person and not their disabilities, and that improvements in function no matter how small, can mean so much to someone whose life has been pulled from underneath them.

I have almost 30 years' experience of working with older people, and during this period I have been party to several changes in the healthcare systems, both here in Sweden as well as the UK. Patients are becoming older and older, and it's not uncommon to be treating people who are in their late 90's or early centenarians. Length of hospital stay has decreased considerably from months, to weeks, to days while the tempo of inpatient care has increased with the introduction of care pathways, early mobilisation and onset of discharge planning. These changes put greater demands on the healthcare system to provide an optimal service that is both effective while still catering for the older person's needs. Healthcare professionals need to adapt to these organisational changes by overseeing their routines and treatment methods to ensure they are following best clinical practices.

## 2 BACKGROUND

### 2.1 THE AGEING POPULATION, FRAILITY AND OSTEOPOROSIS

The fastest growing population worldwide is that of older adults. Within Europe alone the number of people aged 85 years and older is estimated to increase from 14 to 19 million by 2020 and to 40 million by 2050 (WHO, 2017a). The process of ageing can lead to increased vulnerability to various chronic conditions, functional limitations, disability and comorbidity, which in turn can result in decline in physical, social and psychological well-being and quality of life for the older person (Roaldsen, Halvarsson, Sarlija, Franzen, & Ståhle, 2014). These demographic changes and their consequences put greater demands on healthcare services to accommodate and provide optimal care and rehabilitation services for the ageing population.

The process of ageing is individual and not only related to the persons chronological age, but also to genetic and contextual factors including disease and level of activity. A minor illness or change in medication can result in a change in health status that may be sufficient to cause deterioration in health and functional status. The concept of frailty is associated with these consequences, and has been defined as ‘a state of increased vulnerability to poor resolution of homeostasis after a stressor event, which increases the risk for adverse outcomes, including falls, delirium and disability (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013).

Alongside the growing ageing population, the worldwide prevalence of frailty is increasing, with a prevalence of 10.7% in community dwelling adults aged  $\geq 65$  years (Collard, Boter, Schoevers, & Oude Voshaar, 2012), and an estimated 25-50% in adults aged  $\geq 85$  years (Clegg et al., 2013). The concept of frailty is associated with osteoporosis, a condition characterised by loss of bone mass and deterioration of the microarchitecture of bone tissue, which in turn leads to bone fragility and an increased fracture risk (van den Bergh, van Geel, & Geusens, 2012).

One of the most serious and common consequences of frailty is falls, with one in three older people falling at least once during a year. The number of older adults experiencing a fall increases with age, resulting in a corresponding increase in fall-related injuries. Furthermore, falling can also induce fear of falling, which can lead to further falls, avoidance of or



restricting daily activities, losing autonomy, diminishing social activity, depression and deterioration of quality of life (Delbaere, Close, Brodaty, Sachdev, & Lord, 2010; Legters, 2002).

Recent research has shown that fall prevention programs consisting of single, multiple and multifactorial interventions have great potential to counteract age-related decline of physical functioning in older people (Eggenberger, 2015; Iliffe, 2014). Outcome measures commonly used to assess functional balance, physical performance and fear of falling in older people include: Bergs Balance Scale (BBS) (Berg, 1989), Short Performance Physical Battery (SPPB) (Guralnik et al., 1994), Timed Up and Go (TUG) (Podsiadlo, 1992) and Falls Efficacy Scale-International (FES-I) (Yardley et al., 2005).

Hip fracture is considered the most serious osteoporotic fracture in the elderly with a 20%-30% mortality rate within a year and only approximately 50% regaining previous levels of autonomy and mobility (Kanis et al., 2012; Marks, 2010). The world-wide age-standardized incidence of hip fracture varies considerably with the highest incidence found in northern Europe, with 574, 563 and 539 per 100 000 in Denmark, Norway and Sweden respectively (Kanis et al., 2012).

## 2.2 PHYSIOTHERAPY

After nurses and physicians, physiotherapists form the third largest healthcare profession in the Western world (Broberg, 2009). According to the World Confederation for Physical Therapy, the prime purpose of physiotherapists working with older people is to provide rehabilitation services that enable people to, maintain and/or restore function, activity and independence (WCPT, 2016). An integral component of physiotherapy is the interaction between the physiotherapist and the patient/client/family or caregiver to gain a mutual understanding of the individual's needs and preferences. This requires a person-centred, collaborative, and inter-professional approach to meet the often complex needs of the older person (WCPT, 2015).

## 2.3 REHABILITATION

Rehabilitation, has been defined as "a set of *measures* that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments", and is instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and participate in

education, the labour market and civic life (WHO, 2017b). In this context, measures as in “a set of *measures...*” refers to interventions or procedures adopted and not just to the instruments used to measure a person’s ability, trait or behaviour.

The rehabilitation process has been described in terms of a cyclic process comprising four stages: assessment, goal setting, intervention and re-assessment (Derick T Wade, 2005), and a problem solving and educational process that requires the use of assessments to identify relevant problems (Küçükdeveci, Tennant, Grimby, & Franchignoni, 2011).

The process involves identifying the presence and severity of the patient’s problems (including impairments, activity limitations, and participation restrictions) as well as their wishes and expectations. Goal setting involves establishing short and long-term goals together with the patient and thereafter introduction of relevant interventions in accordance with the goals set. The effects of these interventions are then evaluated in the re-assessment phase. When problems remain, the cyclic process continues until goals are met and/or new goals are set (Derick T Wade, 2005).

### **2.3.1 MULTIDISCIPLINARY TEAMS**

Following hip fracture multi- or interdisciplinary teams are commonly used to coordinate resources around the patient use of patient outcome data have shown greater functional gains, improvements in mortality, reductions in costs and improved quality of life (Cameron, 2002; Gillespie et al., 2012; WHO, 2015). It is important that the care pathways used adopt a holistic approach to meet the complex medical, physical, social and psychological needs of the individual. The care pathway following hip fracture is a complex process, however, one of the components that concerns all members of the multidisciplinary team is physical function and ability to perform activities of daily living (ADL) (Roaldsen et al., 2014). Instruments for the assessment of ADL capacity are therefore regarded central in geriatric rehabilitation (Randall, 2000; Sangha et al., 2005).

### **2.3.2 IMPORTANCE OF INVOLVING THE PATIENT**

In order to provide rehabilitation of high quality it is recognised that the patient should be involved throughout the entire process (CAOT, 1997). There is increasing agreement that the measured goals of therapy should relate to functional limitations and disabilities that are individually meaningful to patients (Lohmann, 2011; Miller, 2011; Persson, 1999). Perhaps the most important reason for writing person-centered functional

goals is that patients are more likely to make the greatest gains (Lohmann, 2011; Miller, 2011; Randall, 2000). By adopting a person-centred and functional approach to goal setting, and applying it to all patients, physiotherapists will be consistent with current trends in health care, accreditation, and rehabilitation theories. It is also advocated that such goals will make physiotherapy more effective and meaningful for patients and perhaps for the physiotherapist as well (Randall, 2000).

### **2.3.3 STANDARDIZED MEASUREMENT INSTRUMENTS**

Within rehabilitation settings, routine use of measurement tools is widely advocated in clinical guidelines and standards of practice as an essential component of evidence-based practice, and a means of improving patient outcomes. Rehabilitation teams can through the use of measurement tools more systematically determine the presence and severity of impairment, plan suitable interventions, monitor progress as well as predict recovery and discharge planning (Streiner, 2008; van der Putten, 1999). Although reliability, validity and other psychometric properties are important qualities of assessment tools aimed for clinical use, practicality is a fundamental quality that may determine whether an assessment tool is used or not. Practical aspects such as ease of administration, minimal education, the degree of simplicity of the scoring system and meaningfulness both from the patients' and the professionals' point of view are all of paramount importance when constructing and developing an assessment tool (Aberg, 2003).

### **2.3.4 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)**

Information collected from assessments can be organised using the framework developed by the World Health Organisation (WHO), the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The ICF systematically classifies health and health-related states into two components: 1) body functions and structures, and 2) activities and participation. The term *functioning* is used as an umbrella term that includes all body functions (physiology) and structures (anatomy), activities (individual functioning) and participation (social functioning). In contrast, the term *disability* is the umbrella term including impairments (physiological and anatomical), activity limitations (individual) and participation restrictions (societal). The classifications concerning activity and participation are further divided into capacity (can perform in a standardized environment) and

performance (can actually do in usual environment). The conceptual model for functioning according to ICF is shown in fig 1.

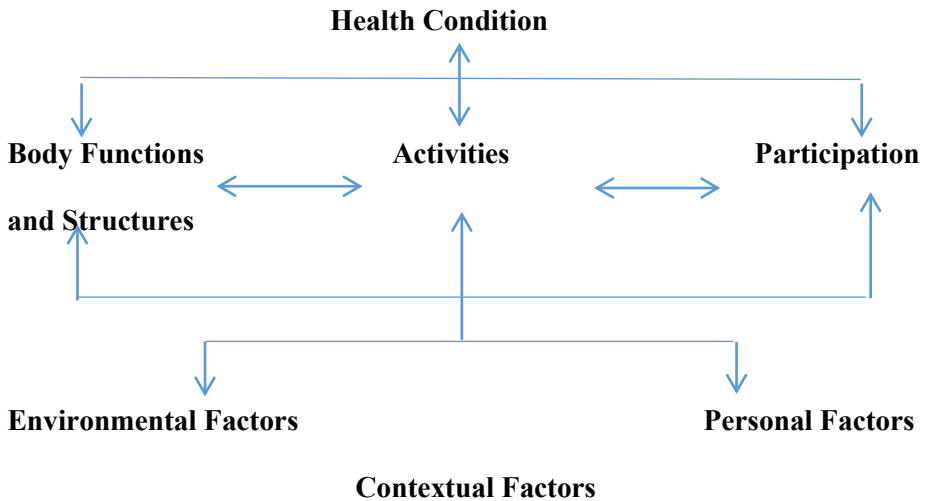


Figure 1. Basic elements of the International Classification of Functioning, Disability and Health (ICF)

## 2.4 ASSESSING ACTIVITIES OF DAILY LIVING

Activities of daily living are commonly referred to as either personal ADL (P-ADL), also known as basic ADL or physical ADL, which includes the basic actions of personal self-care, mobility and eating or instrumental ADL (I-ADL) involving more complex activities associated with community living, e.g. cooking, cleaning, shopping, transport, finances (Asberg, 1989; Mlinac & Feng, 2016). Three of the most frequently used scales are for assessing P-ADL are the Barthel Index (BI) (Mahoney FI, 1965), the Functional Independence Measure (FIM) (Granger, 1986) and Katz Index (Katz, 1963). All three measurements are similar in that they measure P-ADL, however they vary in the number of items included, and scoring procedures.

The BI is comprised of 10 different activities, providing a tool for measuring functional status and can be applied through observation, interview and/or telephone follow up. The items are weighted according to level of difficulty, with 2 to 4 responses (0,5,10,15), giving a total score of 100. The FIM was derived in part from BI and created to be a more comprehensive and

responsive disability assessment than its predecessor. FIM includes 18 different activities and measures in per cent the level of activity the patient can perform (van der Putten, 1999). At individual person level, FIM has been shown to be a more responsive rating scale in comparison to BI (Hobart, 2010) however FIM takes longer to administer, is more complex and requires special certification (Sangha et al., 2005). The Katz Index of ADL summarizes the persons overall performance in six basic P-ADL functions: hygiene, dressing/undressing, ability to go to toilet, mobility, bowel and bladder control and food intake (Katz, 1963). Each function is graded as independent, partly independent or dependent. Before calculation of the total score, each item is dichotomized (dependent/independent) and the degree of dependency is estimated and graded from A (independent) to G (dependent in all 6 activities) or as O (dependent in at least two activities but do not follow the specific hierarchical order).

## 2.5 DEVELOPMENT OF TRAFFIC LIGHT SYSTEM-BASICADL















































While the above instruments all measure P-ADL, they provide information concerning the person's ability in terms of a total score (FIM, BI), or letter (Katz). This information can be utilised by healthcare professionals (HCPs) to assess, monitor progress and evaluate outcomes of treatment by seeing changes in the respective scoring systems. However, they are less practical as total scores are not always easily translated into a language that is readily understood by all team members including the older person. There was a need for another type of instrument, one that was simple for both HCPs and patients to understand, that could be administered in a quick and straightforward manner, giving a visual picture of the patient's functional status and providing a baseline for goal setting. It was felt that a simple visual aid, highlighting level of dependence in individual basic activities, including transfers, gait and personal care, could help HCPs clarify and improve communication concerning key areas regarding the patients' functional status and rehabilitation needs and goal setting.

This resulted in the development of Traffic Light System-BasicADL (TLS-BasicADL), a 13 item instrument comprising transfers, gait and activities concerning personal care, see fig 2. The 13 different activities included in TLS-BasicADL were specifically chosen to give a more detailed description of the patients' ability. The reasoning behind this was to be able to show, patients and staff, more specifically the activities they were able to perform independently and areas where intervention was needed. To address the

aspect of patient safety, when assistance is required, the number of staff required, walking aids and assistive devices used are noted. A simple colour-coding system is used to highlight level of dependence in each activity: red=physical help of one or more persons, yellow=supervision or verbal guiding, and green independent.

The instrument is a dynamic document; as the patients' ability to perform the activities changes, the colour coding markers are changed accordingly. This gives the patient and members of staff an update of level of assistance, aids presently in use and a basis for discussion regarding eventual changes in goal setting. This systematic way of assessing and communicating with the patient follows the cyclic steps of the rehabilitation process, with the aim being for the patient to be well informed and actively participate in decision making regarding their healthcare and rehabilitation (Derick T Wade, 2005).

The time taken to administer TLS-BasicADL varies depending if information is collected by interview, self-report or direct observation. Interview and self-report can take less than 5 minutes, with direct observation varying depending on patients' level of function, and may take up to 20-30 minutes.

		TLS-Basic ADL			
Previous		Present Nr people	Assisting Aids	GOAL	
		LYING – SITTING	 1		
		SITTING – LYING	 2		
		SITTING – STAND			
		BED – CHAIR	 Zimmer		
		CHAIR – BED	 Zimmer		
None		WALK/WHEELCHAIR	 Zimmer		 Zimmer /rollator
<hr/>					
		HYGIENE UPPER			
		HYGIENE LOWER	 1		
Bath board		SHOWER/BATH	 1		
		DRESSING UPPER			
		DRESSING LOWER	 1	Stocking aid	
Raised seat		TOILET			
		EATING			
<hr/>					
Stick		STAIRS	 2	Stick	 Stick
Wheel-chair		WALK/WHEELCHAIR			 Wheel-chair

Physiotherapist: Gill      Occupational Therapist : Anna      Latest assessment

26/5

Gillian Asplin Sjukgymnastikavd SU/Mölndal 2012-08-28

Figure 2. Example of TLS-BasicADL protocol

## 2.6 PRINCIPLES OF ASSESSMENT AND OUTCOME MEASUREMENT

It can be confusing when reading the literature to differentiate between the different terms referred to in the rehabilitation process, the types of instruments used, psychometric properties and testing methods. In order to avoid misunderstanding and be able to communicate effectively about the assessment process and the results with patients, carers, HCPs, referral systems, managers and policy developers, it is important for therapists to have a clear understanding of commonly used terminology (Fawcett, 2007). An overview of common terms and processes is given in the following text to help clarify important aspects.

### 2.6.1 ASSESSMENT

Assessment has been defined as: “The overall process of selecting and using multiple data-collection tools and various sources of information to inform decisions required for guiding therapeutic intervention during the whole therapy process. It involves interpreting information collected to make clinical decisions related to the needs of the person and the appropriateness and nature of their therapy. Assessment involves the *evaluation* of the outcomes of therapeutic interventions“(Fawcett, 2007) .

### 2.6.2 EVALUATION

“Evaluation is a component of the broader assessment process. It involves the collection of data to enable the therapist to make a judgement about the amount of a specific construct of interest (such as degree of range of movement or level of independence in an ADL) or to make a judgement about the value of an intervention for delivering outcomes of relevance to the client population. Evaluation often involves data being collected at two time points in order to *measure* effect and also involve the translation of observations to numerical scores”(Fawcett, 2007).

### 2.6.3 MEASUREMENT TOOLS TO COLLECT DATA

The measurement tools developed for use by therapists to collect data are given a wide range of names including; instrument, scale, index, and profile in their titles. ‘Test’ has been described as a useful umbrella term that includes in its meaning ‘critical examination...of a person’s or things qualities’, a ‘means of examining, standard for comparison’ and ‘ground for admission or rejection’ (Sykes, 1983).



The data collected during the assessment process can be collected using measurement tools and recorded in terms of levels, amounts or degrees. HCPs can rate the presence or severity of impairment or level of independence in an activity or task. There are different tools depending on the type of data to be collected. These tools or tests can be categorized into one of four *levels of measurement*: nominal, ordinal, interval and ratio (Küçükdeveci et al., 2011).

## **2.6.4 OUTCOME**

Outcome is another term commonly used in health, social care, and therapy and rehabilitation literature. Outcome has been defined as ‘the observed or measured consequence of an action or occurrence. In a therapeutic process, the outcome is the end result of the therapeutic intervention’ (Fawcett, 2007).

## **2.6.5 MEASUREMENT**

Assessment has been described as the process of understanding the *measurement within a specific context*’ (Stokes, 1999). A measurement is the data obtained by measuring. Measuring is undertaken by therapists to ascertain the dimensions (size), quantity (amount) or capacity of a trait, attribute or characteristic of a person that is required by the therapist to develop an accurate picture of the person’s needs and problems to form a baseline for therapeutic intervention and/or to provide a measure of outcome. A measurement is obtained by applying a *standard scale* to variables, thus translating direct observations or client/proxy reports to a numerical scoring system (Fawcett, 2007).

## **2.6.6 OUTCOME MEASURE AND OUTCOME MEASUREMENT**

An outcome measure is a *standardised instrument* used by therapists to establish whether the desired therapeutic outcomes have been achieved. Outcome measurement on the other hand is the process undertaken to establish the effects of an intervention on an individual or the effectiveness of a service on a defined aspect of the health or well-being of a specified population. Outcome measurement is achieved by administering an outcome measure on at least two occasions to document change over time in one or more trait/attribute/characteristic that has been influenced by the intervention to the anticipated degree to achieve the desired outcome.

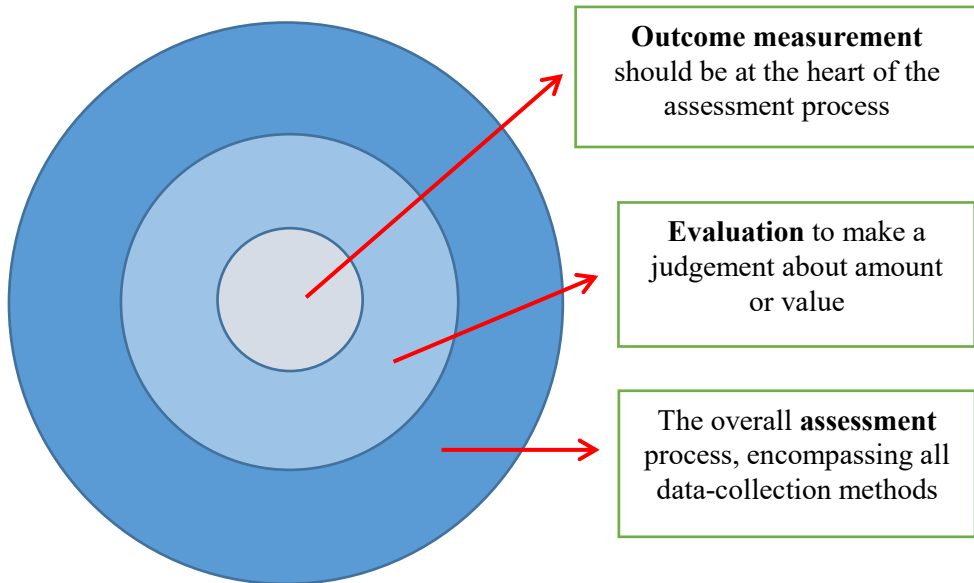


Figure 3. *Relationship between Assessment, Evaluation and Outcome Measurement (Fawcett, 2007)*

Figure 3 highlights the overarching assessment process, which encompasses the complete data-gathering and interpreting process, within which evaluation and outcome measurement components are included. The assessment process can be regarded as a broad, holistic analysis using multiple types of data, a process which becomes narrower during evaluation, with a greater need for specificity, to outcome measurement which requires clearly defined and robust *standardised measures*.

## 2.7 MEASUREMENT PROPERTIES

When using outcome measures regardless of the type of data to be measured it is important that the instrument fulfils certain basic standards, called psychometric properties which are principally related to reliability and validity.

### 2.7.1 RELIABILITY

Reliability involves the extent to which an instrument can estimate a person's symptoms, level of trait or ability in a consistent manner. It reveals how stable the test scores remain over time and across different examiners

(Küçükdeveci et al., 2011). The reliability of a test has been described as the amount of error both random and systematic that is inherent in any measurement (Streiner, 2008). In other words it not only reflects the degree of correlation but also agreement between measurements.

According to Streiner and Norman, reliability is the ratio of variability between patients to the total variability (the sum of patient variability and measurement error). This gives a ratio between zero and one, with zero indicating no reliability and one perfect reliability with no measurement error (Streiner, 2008).

$$\text{Reliability} = \frac{\text{Subject variability}}{\text{Subject variability} + \text{Measurement Error}}$$

There are a number of different types of reliability, which can be investigated depending on the type of instrument under investigation and the aim of the study e.g. inter-rater, intra-rater, test-retest, parallel form, split-half, and internal consistency. However, for the purpose of this thesis only a description of the types of reliability that have been examined will be given.

## **Inter-rater reliability**

Inter-rater reliability refers to the degree of agreement between different raters/observers. It is important to ensure that a person's test score is consistent when being assessed by different raters i.e. when a person is being assessed by different raters during hospital stay or when transferred between services i.e. from inpatient to outpatient setting (Fawcett, 2007).

## **Intra-rater reliability**

Intra-rater reliability refers to the consistency of the assessments made by the same rater over a period of time. Here it is important to know that differences in results collected for different patients is not the result of inconsistencies in the rater's method of administering or scoring the test, but due to a true difference between patients scores (Fawcett, 2007). The time period between testing must be carefully considered: to avoid learning or memory loss and for the persons condition or ability to have changed and should be clearly documented when describing test procedures (Streiner, 2008).

As with types of reliability, there are different reliability coefficients that can be used. These include Pearson's correlation, Cohen's kappa (Cohen, 1960), the Bland-Altman method (Bland & Altman, 2010) and the Intraclass Correlation Coefficient (ICC) (Fisher, 1925). There is however debate as to which coefficient is the most appropriate to use (Carter RE, 2016).

Pearson's correlation is a measure of the linear correlation between two variables based on regression analysis. This pairwise correlation can be beneficial when it is of interest to identify outliers. However, it can also be a disadvantage when analysing multiple observers, as it can give a considerable numbers of correlations depending on the number of observers and there is no agreed way to average or combine them. When there is no interest in individual observers, an ICC is more suitable giving a single correlation representing the average correlations between any two observers (Streiner, 2008).

The kappa coefficient can be used to calculate the proportion of agreement when one of two levels of response are given (e.g. when a trait is present or absent, person is dependent or independent in an activity). The overall agreement as well as the standard error can be obtained using a 2 x 2 contingency table. In situations where more than two responses for a given observation may be given a weighted kappa can be used, which takes into account disagreement. According to Fleiss and Cohen, a weighted kappa is exactly identical to the ICC (Fleiss, 1973) .

If the researcher wishes to report their reliability coefficient results graphically, the Bland - Altman approach may be used. This method involves plotting the pairs of observations against the mean of the observation. The average difference in observations and the standard deviation are calculated and thereafter the limits of agreement, which are equal to the mean difference  $\pm$  two times the standard deviation. However, according to Streiner and Norman if graphical reporting is not required, these results are comparable to those given by an ICC, with mean differences related to the observer variance calculated in the ICC and the standard deviation of differences to the error variance.

The ICC is one of the most commonly-used statistics for assessing IRR for ordinal, interval, and ratio variables and has been described as having the advantage of reporting both the degree of correlation and agreement (Hallgren, 2012). However it is important to ensure the correct form of ICC has been adopted as this varies depending on the design of the study

(McGraw, 1996 ; Shrout, 1979 ), and documentation of the ICC used follows one of two methods.

McGraw and Wong defined 10 forms of ICC (an extension to the Shrout and Fleiss model described below) based on the model (1-way random effects, 2-way random effects, or 2-way fixed effects), the type (single rater/measurement or the mean of k raters/measurements), and the definition of relationship considered to be important (consistency or absolute agreement) (McGraw, 1996 ). Shrout and Fleiss defined 6 forms of ICC, which are presented as two numbers in parentheses [eg, ICC (2,1)]. The first number refers to the model (1, 2, or 3), and the second number refers to the type, which is either a single rater/measurement (1) or the mean of k raters/measurements (k) (Shrout, 1979 ). A useful flowchart describing the selection process for determining the correct form of ICC based on the experimental design of the study can be found in an article by Koo and Li, 2016 (Koo & Li, 2016).

## **2.7.2 VALIDITY**

Validity describes the ability of an instrument to measure the trait it is intended to measure. Traditionally validity has been described using three separate types of validity: the 3 c's, content, criterion and construct validity. A more modern approach when constructing and testing an instrument has been described by Streiner and Norman who refer to 'validity' as a unitary construct, but then states the different types of validity testing. They use the term 'validation' to describe the process adopted to establish the property of the instrument and 'validity' to the outcome. They state that "validating a scale is really a process whereby we determine the degree of confidence we can place on the inferences we make about people based on the scores from that scale". In other words we cannot say that "this scale is valid" as it is not the scale that is being validated, but what can be concluded is "this scale has been shown to be valid with this group of people and in this context". It is therefore important to question the validity and use of a scale in different populations and circumstances as the results from the original study may not be related, requiring further studies with the new population (Streiner, 2008).

As for reliability there are a number of different types of validity that can be investigated. These include content, criterion (concurrent and/or predictive), and construct (convergent and/or discriminant) validity. In order to be able to differentiate and better understand the reasoning behind the validity examined in this thesis, a brief description of the different types is given.

## **Content validation**

The terms of content validity and face validity have been referred to as technical descriptions showing that an instrument looks reasonable for its' proposed purpose (Streiner, 2008). Content validity remains as in traditional approaches, an essential first step in the development of assessment measures, revealing the extent to which the items of the instrument cover the construct to be measured. This is performed using systematic, qualitative methods including focus groups and/or consensus of an expert panel (de Morton, Davidson, & Keating, 2010). The instrument should be evaluated by knowledgeable peers or tested in natural settings as part of the pilot testing. This is important as it may lead to addition or deletion of irrelevant items (Carter RE, 2016). Face validity on the other hand, simply states whether the items appear, on the surface, to be measuring the construct of interest (Streiner, 2008).

Instruments that include items representative of the trait or behaviour being examined are more likely to give more accurate inferences in a wider range of circumstances. Thereby, the higher the content validity of an instrument, the greater are the inferences that can be validly made about the person being assessed under a variety of conditions and situations.

The process of content validation differs from other forms of validity testing in that it is not based on scores from the scale, or performance differences between people, or changes based on some intervention. It is only based on the judgement of experts regarding the content of the items (Streiner, 2008).

## **Criterion validation**

Criterion validation has been defined as the correlation of a scale with some other measure of the trait or disorder under study, ideally a 'gold standard' which has been used and accepted in the field. Two types of validation are commonly referred to depending on the situation: concurrent validation and predictive validation. Concurrent validation studies are one of the most frequently reported types of validation studies in therapy literature, correlating the new scale with one or more criterion measures (gold standards), all of which are given at the same time (Fawcett, 2007). Predictive validation on the other hand is the process of determining the ability of a scale to predict an outcome in the future, e.g. Timed Up an Go to predict risk for future falls 6 months after hip fracture (Kristensen, Foss, & Kehlet, 2007).

Constructing and testing a new instrument is a time consuming and laborious task. It is therefore important to be clear why a new instrument needs to be developed when there is already an existing gold standard. Reasons can include that existing measures are expensive, invasive, dangerous, or time consuming (concurrent validation) or the outcome may not be known until too late (predictive validation). More descriptive terminology to better clarify the purpose of testing have been suggested but as yet are not widely used in the literature. These include: diagnostic utility or substitutability for concurrent validation, and predictive utility for predictive validation (Fawcett, 2007); Messick (1980).

The most commonly used analysis method used in criterion validation is the correlation co-efficient. By testing the new instrument with a gold standard measuring the same trait or behaviour the developer is hoping to show sufficient correlation between the two tests. However, if the test correlates too highly and does not show practical advantages over the gold standard (e.g. easier to use, shorter time to administer) it may be difficult to motivate continued investigation and be seen as simply reinventing the wheel (Anastasia, 1988) (Fawcett, 2007).

## **Construct Validation**

Construct validation has been defined as the process of evaluating a new instrument where there is no existing instrument measuring that particular construct (no available gold standard) or there is dissatisfaction with the existing instrument and a need for improvement (Streiner, 2008). They describe a construct as a “mini-theory that can explain the relationships among various behaviours or attitudes” (Streiner, 2008). While content and criterion validity can generally be established with one or two studies, construct validation is an on-going process. A single correlation is not enough to unequivocally support construct validity. It involves learning more about the construct, making new predictions or hypotheses and there after testing them. A well designed study reporting negative findings can put the validity of the instrument and its construct into question.

Three mandatory steps that involve assessing both the theory and the measure at the same time should be followed in construct validation. These include explicitly stating the theoretical concepts and how they are related to each other; developing scales to measure these hypothetical constructs; and testing the relationship among these constructs and their observable manifestations (Cronbach LJ, 1955)

Construct validity is described in terms of convergent and discriminant validity. Convergent validation is the process of testing how closely the new scale is related to other variables and other measures of the same construct to which it should be related. Discriminant validation also known as divergent validation is in contrast, the process of testing the new scale with measures that are dissimilar and unrelated (Streiner, 2008).

A further method known as the multi-trait-multimethod matrix is described as a powerful technique for analysing both convergent and discriminant validation simultaneously (Campbell and Fiske 1959). Two or more different, usually unrelated, traits are measured by two or more methods at the same time. While this may address a number of validity issues simultaneously it may not be possible as it demands more time on the subject's part and it may be difficult to find suitable methods for assessing the same trait.

Unlike criterion validation, there is no one experimental design or statistic which is common to construct validation studies as it depends on the hypothesis. When testing the new instrument against others with a similar construct a correlation coefficient can be analysed as with criterion validation, however if the purpose is to assess the new instruments with two groups with different behaviours or traits then differences between the means can be used to assess and compare.

It is important to note when developing a new instrument where there is no known gold standard but is one measuring a hypothetical construct, the process is on-going. When new hypotheses are made new studies are required. Also if the instrument is to be used on different groups not initially validated on, it must be tested to determine if the inferences are as valid as for the original article. Modifications of an existing instrument may require revalidation e.g. changing period of recall or changing from Likert scale to VAS. However minor changes such as in wording which do not change the meaning do not require retesting.

For the purpose of this thesis criterion validation was performed to investigate the concurrent validity of TLS-BasicADL by correlating TLS-BasicADL with the gold standard FIM and BI.

### **2.7.3 RESPONSIVENESS**

Over and above reliability and validity is the property of responsiveness. Responsiveness of an instrument has been defined as the instruments ability to detect changes over time, and the degree to which it can detect a meaningful change (Guyatt, Osoba, Wu, Wyrwich, & Norman, 2002;



Mokkink et al., 2010). Responsiveness is related to both the reliability and validity of a measure. In situations where a measure shows poorer levels of reliability with a larger standard error of measure (SEM) then the changes in status or score of the patient or participant must be even larger to represent more than the measurement error. In contrast when an instrument is very reliable with a small SEM, smaller changes are required indicating the instrument more responsive to change (Carter RE, 2016).

The number of values in a scale can also affect responsiveness. The greater the number of grades, the smaller the change in score required to detect change. Therefore for scales with a smaller number of grades e.g. dependent, supervision and independent then larger changes in status is required to show change on the scale. Ceiling and floor effects also affect responsiveness. A floor effect occurs when individuals score at the bottom of the scale and no further deterioration can be recorded. A ceiling effect in contrast occurs when individuals score at the top of the scale and no further improvement can be registered. A maximum of 15% for any given sample has been proposed as the reasonable limit of ceiling or floor effects (Fieo, Austin, Starr, & Deary, 2011). However in circumstances when the goal of treatment is to regain independence in ADL, a ceiling effect will occur when the person becomes independent in all activities. In situations where there is a need for continued monitoring, complementary outcomes measures may be adopted to detect further change, for example balance tests or gait speed (D. T. Wade, 1992).

As with validity, there is no consensus regarding the methods for measuring responsiveness (Guyatt et al., 2002; Streiner, 2008). Two of the methods that have been described are internal responsiveness that characterises the ability of a measure to change over a particular time frame, such as before and after an intervention. External responsiveness on the other hand reflects the degree to which changes in a measure are associated with a criterion measure. This can be professionals perceptions of change or an instrument measuring the same construct (Husted, Cook, Farewell, & Gladman, 2000).

## **2.7.4 CLINICAL UTILITY**

While properties of reliability and validity are important in the development of a standardised measure, it does not necessarily follow that the measure will be chosen by practitioners for use in the clinical setting. It is therefore important to investigate the overall usefulness of a measure known as the clinical utility. This includes studying factors of: appropriateness, accessibility, practicability and acceptability (Smart, 2006). Appropriateness refers to both the relevance and effectiveness of the measure, does the

measure 'fit' into the existing care pathway and how meaningful is it in clinical decision making. Cost comes under the component of accessibility, will the use of the measure involve more resources, how much will it cost to purchase, is training involved prior to use. Practicability covers aspects such as ease and time to administer, minimal education, the degree of simplicity of the scoring system. The fourth component, acceptability, involves the willingness of the practitioner to use the measure, are there any ethical issues which may require attention, what are the views of the patient, how do they experience using the instrument, is it beneficial and meaningful or do they find it difficult, stressful or offensive (Aberg, 2003; Fawcett, 2007; Smart, 2006).

### 3 RATIONALE FOR THE THESIS

The fastest growing population worldwide is that of older adults (WHO, 2017a). The process of ageing can lead to increased vulnerability to various chronic conditions, functional limitations, disability and comorbidity, which in turn can result in decline in physical, social and psychological well-being and quality of life for the older person (Roaldsen et al., 2014). These demographic changes and their consequences put greater demands on healthcare services to accommodate and provide optimal care and rehabilitation services for the ageing population (WHO, 2017b). Multi- or interdisciplinary teams are commonly used to coordinate resources around the patient (Neumann et al., 2010; Strasser et al., 2005; Derick T. Wade, 1999). Advantages of structured teams that make use of patient outcome data have shown greater functional gains, improvements in mortality, reductions in costs and improved quality of life (Cameron, 2002; Gillespie et al., 2012; WHO, 2015). A key component of care and rehabilitation of the older person that concerns all members of the team is the person's level of physical function and ability to perform ADL (Roaldsen et al., 2014). Instruments for the assessment of ADL capacity are therefore regarded central in geriatric rehabilitation (Randall, 2000; Sangha et al., 2005). Furthermore, there is increasing interest in the aspect of patient participation, with evidence that care pathways encouraging patient participation show improved outcomes, increased motivation and a greater likelihood of the patient achieving their rehabilitation goals (Sahlsten, Larsson, Sjöström, & Plos, 2009). While a variety of instruments are available for assessing ADL there is a lack of a simple and clinically useful instrument that measures both basic ADL and encourages more active patient participation. TLS-BasicADL was therefore developed for this purpose. It is important when developing a new instrument for clinical use that it is both reliable and valid for the patient group being assessed and suitable in the setting it is being used. Over and above these issues, practicality is a fundamental quality that may determine whether an assessment tool is used or not. Practical aspects such as ease of administration, minimal education, the degree of simplicity of the scoring system and meaningfulness both from the patients' and the professionals' point of view are all of paramount importance (Aberg, 2003). While structured care pathways and appropriate outcome measures should continue to be adopted, further improvements can be made by gaining a better understanding of patient experiences and views of what is important and meaningful in order to better meet their needs.

## 4 AIM

The overall aim of this thesis was to describe the development process of Traffic Light System-BasicADL (TLS-BasicADL), to investigate the psychometric properties of reliability, validity, clinical utility and feasibility in the inpatient setting and to explore patients' perspectives.

### Specific Aims

- Study I** To describe the development process of TLS-BasicADL and investigate properties of inter- and intra-rater reliability.
- Study II** To investigate if TLS-BasicADL is a valid and responsive measure when tested against other internationally used instruments assessing physical function and ADL (Functional Independence Measure, Barthel Index and Katz Index).
- Study III** In a clinical trial, the primary aim was to evaluate a modified rehabilitation programme, with focus on patients' perceived participation. Secondary aims were to investigate effect on ADL, functional balance and confidence, and physical performance. A further aim was to investigate level of recovery at one month including risk for future falls. TLS-BasicADL was included in the intervention to promote patient participation as well as a measure to assess ADL outcome.
- Study IV** To investigate patients' experiences of recovery and use of TLS-BasicADL during in-patient rehabilitation after hip fracture surgery

## 5 METHODS

### 5.1 DESIGN

This thesis includes data from four studies with various methodological approaches resulting in four papers. Three of the studies follow quantitative research methods with the fourth study adopting a qualitative approach. An overview of the study design, samples, and data collection are seen in table 1.

*Table 1. Overview of design, samples, and data collection included in this thesis*

	<b>Paper I</b>	<b>Paper II</b>	<b>Paper III</b>	<b>Paper IV</b>
<b>Study design</b>	<b>Scale development Reliability testing</b>	<b>Validity testing Responsiveness</b>	<b>Prospective controlled trial</b>	<b>Qualitative explorative design</b>
<b>Study samples</b>	<b>n= 30</b>	<b>Validity n=50 Responsiveness n=106</b>	<b>n=126</b>	<b>n=20</b>
<b>Data collection</b>	<b>Performance based</b>	<b>Performance based</b>	<b>Performance based and questionnaires</b>	<b>Semi-structured interviews</b>

### 5.2 STUDY SAMPLES

All of the studies were conducted at Sahlgrenska University Hospital, Gothenburg, Sweden. Participants in all four studies were recruited from geriatric wards specialised in treating patients with orthopaedic conditions. In study II participants were also recruited from an oncology ward, which is under same organisation but cares for patients from 18+ years.

Inclusion criteria for the four studies:

Study I, III and IV: Men and women  $\geq 65$  years who were able to understand and communicate in Swedish and with intact cognition.

Study II: Men and women  $\geq 18$  years for the testing of concurrent validity and  $\geq 65$  years and admitted due to hip fracture for responsiveness. All patients were able to understand and communicate in Swedish and with intact cognition.

Study III: Men and women presenting with hip fracture, community dwelling prior to fracture, independent walking indoors with or without walking aid and in personal care with exception of bathing/showering. Exclusion criteria: severe drug or alcohol abuse, mental illness or documented cognitive impairment  $\leq 6$  according to the Short Portable Mental Status Questionnaire (Pfeiffer, 1975 ).

Study IV: Presenting with hip fracture, community dwelling prior to fracture.

An overview of demographic characteristics of participants is presented in table 2.

*Table 2. Overview of demographic characteristics of participants included in studies I - IV.*

	Study I, Reliability		Study II		Study III		Study IV
	Inter-rater n=30	Intra-rater n=5	Concurrent validity n=50	Responsiveness n=106	Intervention group n=63	Control group n=63	Interview group n=20
Age: Years, mean (SD) range	82.5 (6.6) 71–97	83 (9.3) 72–97	74.3 (13.4) 33-91	81.2 (7.9) 65–98	82.0 (8.0) 65–97	80.5 (7.7) 65–98	82.3 (7.9) 66–94
Gender: female, n (%)	27 (90)	5 (100)	34 (68)	96 (76)	47 (75)	49 (78)	14 (70)
Main diagnosis:							
Orthopaedic	30	5	6	106	63	63	20
Cancer	-	-	30	-	-	-	-
Cardio	-	-	4	-	-	-	-
Neuro	-	-	3	-	-	-	-
Respiratory	-	-	2	-	-	-	-
Other	-	-	5	-	-	-	-

## 5.2.1 DROP-OUTS

In study I, of the 39 patients who agreed to participate, 9 patients dropped out: 5 chose to withdraw when the occupational therapists (OT) came to assess ADL, three patients were already washed and dressed, and one patient had been discharged before the assessment could be performed. In study III, of the 126 patients recruited, 8 patients had dropped out prior to discharge from hospital, with a further 12 patients at one month follow up leaving a total of 106 patients completing the follow-up assessment, 52 patients in the intervention group and 54 in the control group respectively. Reasons for drop-out prior to discharge included; partial weight-bearing (2), new fracture (3), medical reasons (1), discharged before measurements could be performed (1) and declined (1). Prior to one month follow-up; declined (6), deceased (5), and admitted to hospital (1).

In study II there were no drop-outs in the testing of concurrent validity. The data used to investigate responsiveness was collected from the 106 patients who completed one month follow-up in study III. The reasons for drop-out are therefore the same as described above. There were no drop-outs in study IV.

## 5.3 ETHICS

All of the studies were approved by the Regional Ethical Review Board in Gothenburg, Sweden (Dnr 537-06, Dnr 351-10 and Dnr 541-13). Written and oral information about the study was given and informed written consent was obtained from all participants. Patients were informed that they could withdraw from the study at any point without having to give a reason, and without affecting future care.

## 5.4 PROCEDURE

**Study I:** Development of Traffic Light System-BasicADL and the processes undertaken to investigate inter- and intra-rater reliability.

**Scale development:** Members of the multidisciplinary team agreed upon suitable items, instrument protocol and user manual by means of the consensus method. Regular team meetings were held where feedback was given from both staff and patients with revision of protocol and manual made accordingly. This resulted in an instrument consisting of 13 basic ADL items and user manual.

**Inter-rater reliability:** Inter-rater reliability (between two raters): the 30 patients were assessed firstly in ADL by two OTs (7 ADL items ) and then later on the same day by two PTs (testing the remaining 6 items of physical function). Which therapist should observe or perform the assessment was randomised. Seven OTs and eleven PTs with varying levels of clinical experience (1- 35 years) participated in the study. Prior to commencing the study all therapists were given information regarding the aims of the study, how to assess patients following the user manual and to fill in the protocol. After assessment the test protocols were filled in individually without discussion.

**Intra-rater reliability** (same rater at two time points). The six items of physical function were filmed on the same occasion the two PTs assessed/observed the patients for inter-rater testing. A total of 27 patients were filmed; three of the 30 patients agreed to participate in the inter-rater study but declined being filmed. Five films were thereafter randomly chosen from the 12 patients where there had been disagreement in the inter-rater testing. Twenty-five therapists participated in this part of the study; 19 physiotherapists and 6 occupational therapists. The time lapse between the time points was approximately four weeks.

**Study II:** To test concurrent validity and responsiveness of Traffic Light System- BasicADL (TLS-BasicADL).

**Concurrent validation:** The 50 patients were assessed on one occasion during their hospital admission using three different instruments: TLS-BasicADL, Functional Independence Measure (FIM) [13] and Barthel Index (BI). The assessments were performed by a physiotherapist who received training in how to use TLS-BasicADL and BI and licensed in the use of FIM.

**Responsiveness:** The 106 patients were assessed according to TLS-BasicADL for four time-periods; pre-fracture, post-operatively, discharge and one month follow-up. Data according to modified Katz Index were also collected for pre-fracture, discharge and one month follow-up for the same study sample. Information regarding pre-fracture status and one month follow-up was obtained through interview, with post-operative and discharge status collected through observational assessment. All data were collected by a research group during evaluation of an intervention study of hip fracture patients. Three physiotherapists and two occupational therapists performed the assessments. They had no treatment association with the patients. All therapists received training in both TLS-BasicADL and Katz Index prior to data collection.



**Study III:** Evaluation of early coordinated rehabilitation in acute phase after hip fracture.

Both groups of patients received inpatient rehabilitation and were assessed with a battery of outcome measures to collect data concerning pre-fracture status, post-operatively, at discharge and at one month follow-up.

***The control group:*** received standard rehabilitation following surgery.

***The intervention group:*** received a more coordinated rehabilitation programme, which included enhanced collaboration with the OT and PT, with more active discussions concerning goal setting using TLS-BasicADL. The patients also received treatment from the OT and/or PT three times a day (Monday-Friday), and were provided with a training kit to promote self-training, self-efficacy and participation in their rehabilitation process.

#### **Study IV**

Participants were invited by the treating occupational therapist or physiotherapist on the ward, if they would be interested in participating in an interview towards the end of their hospital stay. Participants were thereafter given verbal and written information concerning the study. The patient's written consent was obtained and an interview was scheduled. Semi-structured interviews were conducted with each of the 20 patients between April and September 2016 prior to discharge from hospital. The 20 interviews were performed by two of the researchers, 19 interviews by the first author and 1 by the last author. All interviews were performed in a quiet room where disturbances were kept to a minimum, they were recorded using a dictaphone, and lasted between 25 and 67 minutes and thereafter transcribed verbatim. The interview commenced with asking the patients to give a brief description of the fall event and subsequent hospital admission. A semi-structured interview guide was thereafter used, which included questions concerning the following areas; experiences of recovery and participation in their rehabilitation process including the use of TLS-BasicADL.

## 5.5 OUTCOME MEASURES

### 5.5.1 MAIN OUTCOME MEASURE

#### Traffic Light System-BasicADL (TLS-BasicADL)

TLS-BasicADL is the instrument under investigation in this thesis. The instrument highlights the patient's level of independence in basic ADL, comprising of 15 different activities; 6 items showing ability to transfer and walk indoors, 7 P-ADL items and 2 additional items; negotiating stairs and walking outdoors. Three colour-coded markers indicate level of dependence; green=independent, yellow=supervision and red=dependent on physical help of others. TLS-BasicADL does not form a composite score but shows through the colour-coding, level of dependence with regard to the patient's; 1) *previous* ability and assistive aids prior to admission to hospital, 2) *present* ability and assistive aids used and 3) *goals* which the patient aims to achieve during inpatient treatment. As the patient's ability to perform activities changes during in-patient rehabilitation, the colour-coded markers are changed correspondingly. This is done in collaboration with the patient with the aim of promoting increased participation. TLS-BasicADL is also used as a tool for discussion regarding future rehabilitation needs/goals after discharge with the patient.

### 5.5.2 SECONDARY OUTCOME MEASURES

#### Functional Independence Measure (FIM)

The Functional Independence Measure (FIM) is an 18-item performance-based instrument (13 motor, 5 cognition) that are rated on a 7-level ordinal scale (Granger, 1986). They describe levels of complete dependence (1) to complete independence (7) in performing basic activities of daily living. Total scores range from 18 (lowest) to 126 (highest) level of independence.

#### Barthel Index (BI)

The Barthel Index (BI) is a 10-item instrument also describing level of independence in basic activities of daily living (Mahoney FI, 1965). The items are weighted for degree of difficulty ranging from 2-4 intervals: 0-5, 0-5-10, and 0-5-10-15. Total scores range from 0 (lowest) to 100 (highest) level of independence.

## Katz Index

The Katz index of ADL summarizes the persons overall performance in six basic P-ADL functions: hygiene, dressing/undressing, ability to go to toilet, mobility, bowel and bladder control and food intake (Katz, 1963). Each function is graded as independent, partly independent or dependent. Before calculation of the total score, each item is dichotomized and the degree of dependency is estimated and graded from A to G or as O, in a specific hierarchical order.

## ADL staircase

The ADL staircase is an expansion of Katz ADL Index of personal activities of daily living, with the addition of four I-ADL items; cooking, shopping, cleaning, and transportation (Asberg, 1989). The ADL staircase uses only two levels; dependent or independent and can be administered through interview and/or observation. The ADL-staircase has shown good validity and reliability , and is considered a stable and clinically relevant when used in studied of older people (Ekerstad, 2017; Jakobsson & Karlsson, 2011).

## Bergs Balance Scale (BBS)

Functional balance and fall risk was assessed using Bergs Balance Scale (BBS) (Berg, 1989). BBS assesses 14 activities of varying difficulty with a scoring range from 0-4 (0 unable to perform to 4 able to perform completely). The item scores are summed giving a score of 0-56, with 56 showing indicating normal functional balance. BBS has shown excellent test-retest reliability and validity in older adults (Berg, 1989; Shumway-Cook, Baldwin, Polissar, & Gruber, 1997). To determine clinical significance, minimal detectable change (MDC) scores (Donoghue, 2009) were used, ranging from 4-7 points depending on baseline score. To discriminate those at risk for falls, a cut-off score of 47 was defined (Chiu, Au-Yeung, & Lo, 2003).

## Falls Efficacy Scale (Swedish version) (FES-S)

Balance confidence was measured using the Swedish version of the Falls Efficacy Scale (FES-S) (Hellström & Lindmark, 1999). This version is modified from the original 10-degree scale (1-10) where 1 represents 'very confident, no fear of falling' and 10 'not confident at all, very afraid of falling', into an 11-degree scale (0–10) with a reversed answering alternative (0 not confident at all and 10 totally confident). For the purpose of this study the aspect of confidence rather than fear has been assessed. FES-S includes

13 items, comprising three parts, six items measuring self-care, one item stair walking, and six items instrumental activities. The maximum score is 130. Test–retest reliability of the Swedish version of the scale was found to be acceptable by Hellstrom et al (Hellström & Lindmark, 1999).

## Short Physical Performance Battery (SPPB)

Short Physical Performance Battery (SPPB) (Guralnik et al., 1994) consists of three components: standing balance, walking speed, timed 4 m walk, and ability to rise from chair. The sum of the three components comprises the final SPPB score with a possible range from 0 to 12 (12 indicating the highest degree of lower extremity functioning). According to Perera et al [37] a small meaningful change is 0.5 and a substantial meaningful change 1.0 point respectively (Perera, Mody, Woodman, & Studenski, 2006). For analysis of risk for falls a score of  $\leq 6$  is associated with a higher fall rate (Veronese et al., 2014) .

## Timed Up and Go (TUG)

Timed Up and Go (TUG) test measures ability to perform basic everyday movements. TUG assesses total time for standing up from a standard chair, walking 3m, turning 180 degrees, returning and sitting down (Podsiadlo, 1992). According to recommendations by Podsiadlo and Richardson, TUG was performed twice in each test session, one trial and one timed performance, with a brief seated rest in between. The participants were instructed to walk at a comfortable, safe speed. TUG has good inter-rater and intra-rater reliability and is a reliable and valid measure of functional mobility (Podsiadlo, 1992). A TUG score  $>24$  seconds at discharge, was used for analysis of risk for falls, which is a predictor for falls at 6 months in hip fracture patients (Kristensen et al., 2007). An overview of the outcome measures used in the studies I-III is given in table 3.

Table 3. Overview of outcome measures used in studies I-III

Outcome measure	Study I	Study II	Study III
<b>TLS-BasicADL</b>	<b>X</b>	<b>X</b>	<b>X</b>
<b>Functional Independence Measure</b>		<b>X</b>	
<b>Barthel Index</b>		<b>X</b>	
<b>Katz Index</b>		<b>X</b>	
<b>ADL Staircase</b>			<b>X</b>
<b>Bergs Balance Scale</b>			<b>X</b>
<b>Falls Efficacy Scale</b>			<b>X</b>
<b>Short Physical Performance Battery</b>			<b>X</b>
<b>Timed Up and Go</b>			<b>X</b>

## 5.6 ANALYSIS METHODS

### 5.6.1 STATISTICAL ANALYSIS

Descriptive statistics are reported as means and standard deviations (SD), median (min-max) or n (%) as appropriate.

#### Study I

Inter-rater reliability was calculated using percentage agreement (agreement between each pair of scores) and a one way random effects model (referred to as Intra-Class Correlation 1, ICC 1), which according to Shrout and Fleiss is suitable when different raters are assessing the patients using average measures (Shrout, 1979). The ICC result is equivalent to a weighted kappa (Fleiss, 1973). An ICC value  $\geq 0.90$  was regarded as high reliability, 0.80-0.89 good, 0.70-0.79 fair and  $\leq 0.69$  poor reliability (Currier, 1990).

For intra-rater reliability, percentage agreement was calculated for scores between therapists, within patients and for each individual item scored. Calculations were made in Microsoft Office Excel ® 2003 and in SPSS ® Statistics, v18 (IBM, USA).

#### Study II

Analysis of both concurrent validity and responsiveness, Spearman's rho coefficient ( $r_s$ ) was used. For concurrent validity, correlation was calculated at both item level and for total scores of TLS-BasicADL, modified FIM and modified BI respectively.

TLS-BasicADL items were for the purpose of the correlation analyses of total scores, given scores 1-3: 1=dependent, 2=supervision and 3= independent giving a score of 13-39. Modified FIM: A modified version of the motor FIM was used by excluding the items concerning bladder, bowel and stairs, as these items are not included in TLS-BasicADL. This gave a total of 10 items with range 10-70. The 7-level scoring system was modified to three levels for correlation with TLS-BasicADL: level 1 (1-2), level 2 (3-5) and level 3 (6-7). Modified BI: BI was also modified by the removal of bladder, bowel and stairs, giving a 7-item total score from 0- 70. For correlation analyses the scores for all three instruments were adjusted to give scores out of 100.

The internal responsiveness was examined in a group of patients following hip fracture surgery where it is recognised that change in function and ADL occurs during hospital stay. The following time points were chosen 1) pre-fracture, 2) post-op, 3) discharge and 4) one month follow-up. The results are presented graphically showing the percentage of change in level of independence, supervision and active help for the individual activities between the different time points. Sign test has been used to analyse if the percentage of change was significant.

For external responsiveness Katz ADL Index has been used, an instrument measuring the same construct, also modified with the exclusion of the item bowel and bladder control. Correlation of the differences in scores of TLS-BasicADL and modified Katz Index for the time periods: a) pre-fracture status and discharge and b) discharge and one month follow-up were also calculated for each item and for total scores. Values used to describe the strength of the correlations were 0-0.19 (very weak), 0.20-0.39 (weak), 0.40-0.59 (moderate), 0.60-0.79 (strong) and 0.80-1.0 (excellent) (Statstutor, Accessed 13-12-2017). Analyses were performed with SPSS 20 (SPSS Inc., Chicago, IL, USA).

### Study III

It was not possible to calculate power from the primary outcome, patient perceived participation, as the questionnaire was formulated specifically for the purpose of the study and has not previously been tested. The power was hence based on FES, which measures patients' balance confidence and is closely related to participation (Allison, 2013). Therefore, on clinical assumptions and the results of previous studies (Hellström, Lindmark, Wahlberg, & Fugl-Meyer, 2003; Petrella, Payne, Myers, Overend, & Chesworth, 2000) assuming a power of 80% and  $\alpha$  of 0.05, and a difference between groups of 13 points in Falls Efficacy Scale with SD = 20, a total

sample size of  $n = 76$  was estimated. With an approximated drop-out rate of 20% a total sample size of  $n = 92$  was necessary. Descriptive statistics are reported as means and standard deviations (SD) or median (min-max) as appropriate. The questions included in self-rated degree of participation were dichotomised. For comparison between the groups at discharge and at one month, Chi-square was used for analysis of self-rated degree of participation, and P- and I-ADL. Mann-Whitney U Test was used for the analysis of BBS, FES, SPPB and TUG. For comparison within groups over time Sign test was used for analysis of P-and I-ADL and Wilcoxon Signed Ranks Test for the analysis of BBS, FES, SPPB and TUG. Level of significance was defined as  $p < 0.05$ . Analyses were performed using SPSS 21 (SPSS Inc., Chicago, IL, USA).

## Study IV

In Study IV the method of qualitative content analysis described by Graneheim and Lundman was followed (U. H. Graneheim & Lundman, 2004). This method focuses on the subject and context and emphasizes variation, e.g. similarities within and differences between parts of the text. It gives the opportunity to analyse manifest and descriptive content (components that are visible and obvious), as well as latent and interpretative content. An inductive, deductive or abductive approach may be used to analyse the data (Krippendorff, 2013). An inductive approach, also known as text-driven, involves looking for patterns, similarities and differences in the data, and forming categories and/or themes on varying levels of abstraction and interpretation. Here the researcher forms a theoretical understanding from the data, moving from the concrete and specific to the abstract and general. The deductive method also known as concept-driven (Schreier, 2012) differs to inductive by analysing the data against existing theories or explanatory models about the phenomenon being studied. Here the researcher analyses the data from a more abstract and general level, to a more concrete and specific level. A risk with this technique is that the researcher formulates the categories solely on the previously recognised theory or model. The third method, known as an abductive approach, is not commonly expressed in the literature but has been described as a method giving a more complete understanding (U. Graneheim, Lindgren, & Lundman, 2017). It involves the researcher moving between an inductive and a deductive approach during the different stages of the analysis.

No matter the approach adopted, the main challenge with qualitative content analysis is to demonstrate the trustworthiness of the study. The researcher

must give a clear account of the entire process, from planning, to recruiting, methods used, integrity of findings, discussion and conclusion (U. Graneheim et al., 2017). The overall trustworthiness of the study is described through aspects of credibility, dependability, confirmability, transferability, and authenticity (Lincoln, 1985; Polit, 2012).

To achieve credibility, the participants recruited must have experience and be able to express themselves concerning the phenomenon under investigation. Also, there must be a sufficient number of patients included to give variation in the content of data. The number required is study specific i.e. when the quality and richness of data is high then fewer patients may be required. Also by accurately describing the participants included improves the aspect of transferability of the findings.

A challenge to dependability involves the interaction between the participant and the researcher as well as between the data and the researcher during the analysis. The process of creating categories, and deciding which codes and supporting quotes to be included can also affect dependability. Ways to overcome this is for more than one researcher to be involved in the interviewing and/or analysis process to provide varying interpretations and through discussion form a consensus concerning the results. Varying levels of abstraction and interpretation during the creation of categories and themes can affect not only credibility and authenticity but the overall trustworthiness of the findings. This may be dealt with by providing representative citations giving the reader the opportunity to view and judge the participants voice over that of the results presented by the researcher/s (U. Graneheim et al., 2017).

The transcribed interviews constituting the unit of analysis were first read several times in order to gain a sense of the whole. Analysis began by finding meaning units, which included words, sentences or paragraphs that were related to each other by content or context with regard to patients' experiences of their recovery, rehabilitation and TLS-BasicADL. Thereafter these units were condensed, abstracted and labelled with a code while still preserving the core meaning. The codes were then compared based on differences and similarities and sorted into categories and subcategories to highlight nuances of the essential sense of each category. The first, third and last author were all involved in the coding and creation of categories throughout the analysis process with the final categories and subcategories agreed upon through a consensus approach. Citations have been used throughout the results section to give the reader a better understanding of the results. The number after each citation shows the participant who has



provided it and the use of ‘...’ refers to words or sentences that have been omitted. An overview of the analysis methods used is given in table 4.

*Table 4. Overview of analysis methods used in the studies*

Methods	Study I	Study II	Study III	Study IV
Descriptive statistics				
<b>Mean</b>	X	X	X	
<b>Median (Min-Max) (Range)</b>	X	X	X	
<b>Numbers (Percent)</b>	X	X	X	
Reliability				
<b>Percentage agreement (PA)</b>	X			
<b>Intraclass Correlation (ICC)</b>	X			
Concurrent Validity				
<b>Spearman's rho coefficient</b>		X		
Responsiveness				
<b>Spearman's rho coefficient</b>		X		
<b>Sign test</b>		X		
<b>Comparison between the groups at discharge and at 1 month</b>				
<b>Chi-square</b>			X	
<b>Mann-Whitney U Test</b>			X	
<b>Comparison within groups over time</b>				
<b>Sign test</b>			X	
<b>Wilcoxon Signed Ranks Test</b>			X	
Patient experiences				
<b>Qualitative content analysis</b>				X

## 6 RESULTS

### 6.1 STUDY I

#### Inter-rater reliability

The results of the analysis of the inter-rater reliability showed an ICC of 0.90 (95% CI 0.74-1.0) indicating excellent agreement (Table 5). The overall mean percentage agreement for all 13 items was 86%. When analysing item for item, the activity of washing and grooming the upper body revealed the lowest ICC value of 0.74, the percentage agreement was however 90%. The three items; sitting to standing and transfers between bed to chair and back showed the lowest percentage agreement, 70%, 73% and 73% respectively.

*Table 5. Inter-rater reliability. Percentage agreement (PA), ICC for each individual item and mean for all items.*

Items	PA %	ICC
1. Lying to sitting	100	0.86
2. Sitting to lying	100	1.00
3. Sitting to standing	70	0.86
4. Bed to chair	73	0.87
5. Chair to bed	73	0.88
6. Gait/wheelchair	87	0.94
7. Upper hygiene	90	0.74
8. Upper dressing	80	0.91
9. Showering	90	0.95
10. Lower hygiene	80	0.86
11. Lower dressing	87	0.93
12. Toileting	92	0.93
13. Feeding	100	1.00
Mean for all items	86	0.90

#### Intra-rater reliability

Intra-rater data collected from the 25 therapists who assessed the 5 filmed patients on two test occasions was analysed for percentage agreement, and range (min-max) at three different levels; for each individual therapist, within each individual patient and for each of the 6 items for the whole group. Percentage agreement for each individual therapist ranged from 43-93 %,

mean PA  $73.2 \pm 12.7$ . The PA for each individual patient ranged from 60-83.3 %, mean  $73.7 \pm 6.8$  and the PA item for item for whole group, ranged from 68.8-80%, mean  $72.6 \pm 7.8$ , table 6.

*Table 6. Intra-rater reliability. PA and 95% CI, within patient (II) and per item (III).*

		Percentage of Agreement (PA) (Mean $\pm$ SD)	Median Range (min-max)
<b>Within patient (II)</b>	<b>Patient nr 1</b>	<b>72.7<math>\pm</math>7.1</b>	<b>72 (60-80)</b>
	<b>2</b>	<b>76.7<math>\pm</math>6.8</b>	<b>76 (64-92)</b>
	<b>3</b>	<b>76.0<math>\pm</math>6.9</b>	<b>74 (64-96)</b>
	<b>4</b>	<b>83.3<math>\pm</math>6.0</b>	<b>86 (60-92)</b>
	<b>5</b>	<b>60.0<math>\pm</math>7.3</b>	<b>54 (48-80)</b>
	<b>Total group</b>	<b>73.7<math>\pm</math>6.6</b>	<b>72 (48-96)</b>
<b>Per item for whole group (III)</b>	<b>Lying to sitting</b>	<b>80.0<math>\pm</math>7.0</b>	<b>80 (64-88)</b>
	<b>Sitting to lying</b>	<b>73.6<math>\pm</math>7.7</b>	<b>68 (60-96)</b>
	<b>Sitting to standing</b>	<b>73.0<math>\pm</math>7.8</b>	<b>76 (52-92)</b>
	<b>Bed to chair</b>	<b>69.6<math>\pm</math>8.1</b>	<b>72 (48-80)</b>
	<b>Chair to bed</b>	<b>68.8<math>\pm</math>8.1</b>	<b>68 (48-92)</b>
	<b>Gait/wheelchair</b>	<b>70.4<math>\pm</math>8.0</b>	<b>64 (64-80)</b>
	<b>For all items</b>	<b>72.6<math>\pm</math>7.1</b>	<b>72 (48-96)</b>

When scoring varied it was found that it never differed by more than one level i.e. no one scored dependent or independent first time round and then independent or dependent respectively second time round. The differences found were between the levels; dependent and supervision or supervision and independent.

## 6.2 STUDY II

### Concurrent validity: TLS-BasicADL, modified FIM and BI

Strong to excellent correlations were found between TLS-BasicADL and modified FIM (0.65- 0.95), and between TLS-BasicADL and modified BI (0.77-0.97) for individual items. The highest correlation was found between TLS-BasicADL and modified BI, in 7 of the 13 items, in 5 between TLS-BasicADL and modified FIM. A further analysis of total scores revealed

excellent correlations between the three measurements (0.96-0.98). For further details, see tables 7 and 8.

*Table 7. Correlation between individual item scores of TLS-BasicADL, modified Functional Independence Measure and Barthel Index respectively*

Item	TLS/Modified FIM	TLS/Modified BI
Lying to sitting	0.914**	0.925**
Sitting to lying	0.913**	0.929**
Sitting to standing	0.933**	0.936**
Bed to chair	0.933**	0.959**
Chair to bed	0.941**	0.970**
Gait/wheelchair	0.875**	0.818**
Hygiene upper body	0.946**	0.905**
Hygiene lower body	0.879**	0.805**
Bathing/shower	0.637**	0.815**
Dressing upper body	0.908**	0.882**
Dressing lower body	0.825**	0.772**
Toileting	0.908**	0.933**
Eating/drinking	0.649**	1.000**

\*\* Spearman's rho, significant at the 0.01 level (2-tailed).

Traffic Light System-BasicADL(TLS), modified Functional Independence Scale (FIM) and Barthel Index (BI)

*Table 8. Correlation between total scores of Traffic Light System-BasicADL and modified Functional Independence Measure and Barthel Index respectively*

Assessment measures	Spearman's rho correlation	p-value
TLS-BasicADL and modified FIM	0.979	P<0.000
TLS-BasicADL and modified BI	0.965	P<0.000

Traffic Light System-BasicADL(TLS), Functional Independence Scale (FIM), Barthel Index (BI)

## Responsiveness

The correlations of the differences in total scores of TLS-BasicADL and Katz Index showed excellent correlation for the period, pre-fracture status and discharge (0.897) and moderate correlation, for discharge to one month follow-up (0.597). Correlations at item level varied from very weak in upper body hygiene and dressing for both time periods. Excellent correlation was found for items of lower body dressing and toileting from pre-fracture to discharge. The majority of items showed moderate to strong correlations for both time periods, with slightly better results for the pre-fracture to discharge period (see table 9).

*Table 9. Correlations between differences in scores for modified Katz and TLS-BasicADL at both item level and total score for time periods; pre-fracture status to discharge and discharge to one month follow-up.*

ADL Items	Correlations between differences in scores Pre-fracture – discharge Spearman's rho	Correlations between differences in scores Discharge – 1 month Spearman's rho
Katz bathing / TLS upper hygiene TLS lower hygiene TLS bathing	0.134 0.416 *** 0.777 ***	0.157 0.004 0.563 ***
Katz dressing/ TLS upper dressing TLS lower dressing	0.132 0.859 ***	0.048 0.687 ***
Katz toileting / TLS gait TLS toileting	0.662 *** 0.833 ***	0.344 *** 0.632 ***
Katz transfers/ TLS lying to sitting TLS sitting to lying TLS sit to stand TLS bed to chair TLS chair to bed	0.589 *** 0.660 *** 0.703 *** 0.693 *** 0.718 ***	0.389 *** 0.365 *** 0.441 *** 0.420 *** 0.423 ***
Katz food intake/ TLS food intake	0	0
Katz total score/TLS total score	0.897 ***	0.597 ***

Katz Index = Katz, TLS-BasicADL = TLS

\*\*\* Correlation is significant,  $p < 0.001$

The distribution and changes in the patients' ability to transfer and ambulate (figure 4) and activities of daily living (figure 5) in TLS-BasicADL are presented graphically. As can be seen in figure 4, between 5-10% of patients were independent post-operatively in all transfers and walking, however by discharge approximately 80-85% had regained their ability to transfer in/out of bed and 72% were walking independently. By one month follow-up these figures were up to approximately 95%. All changes between the different assessment time points were significant,  $p < 0.001$ .

Figure 5 highlights three activities in particular; bathing, dressing lower body and going to the toilet showing that less than 5% of the study group were independent post-operatively. At discharge just over 25% were independent in bathing, 50% in dressing lower body and approximately 65% going to the toilet. By one month approximately 50%, 80% and 90% were independent respectively showing that bathing and dressing lower body are the two activities that patients are least independent in. All changes between the different assessment time points were significant,  $p < 0.001$  except for eating for all time periods, and upper hygiene and dressing between discharge and one month follow-up due to higher level of retained upper body function in this patient group.

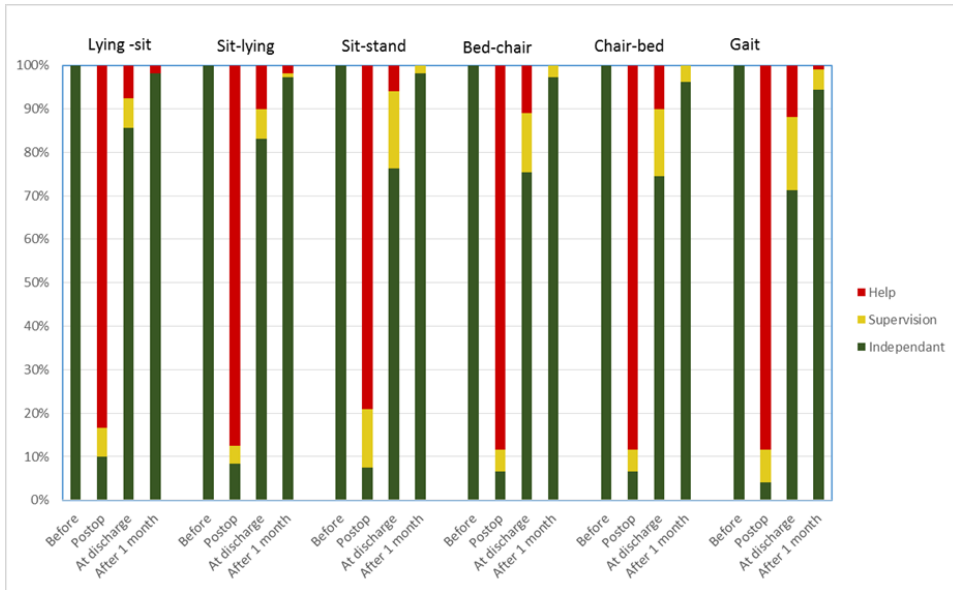


Figure 4. Proportion of patients requiring help, supervision or independent in the individual items of transfers and gait prior to admission, post-op, at discharge and 1 month post-discharge

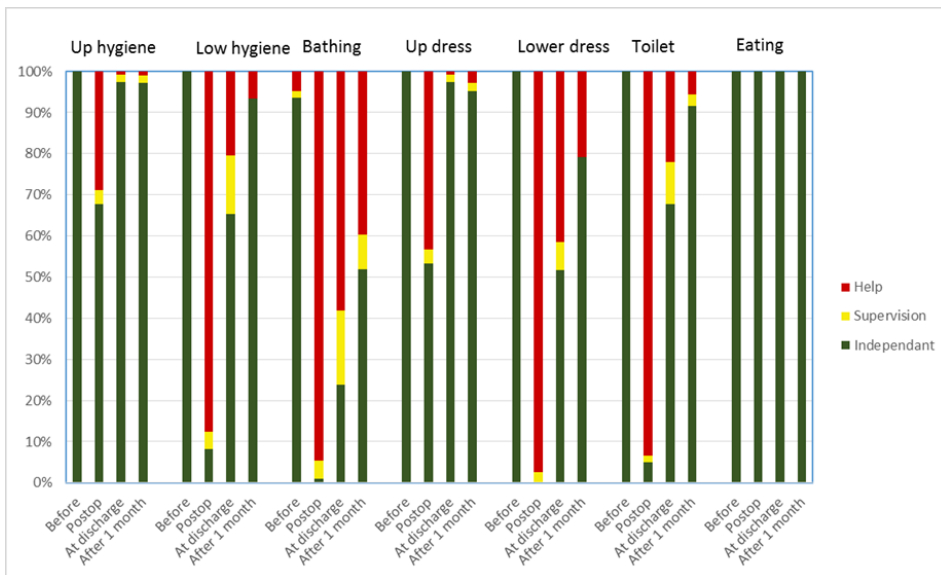


Figure 5. Proportion of patients requiring help, supervision or independent in the individual items of P-ADL prior to admission, post-op, at discharge and 1 month post-discharge

### 6.3 STUDY III

No statistically significant differences were found between the groups at baseline apart for type of surgery, with a higher proportion with a hemiarthroplasty in the IG and in I-ADL cooking, with CG more independent.

#### Primary Outcome Self-rated degree of participation

Statistically significant differences were found between the groups at discharge, with a greater number of patients in the IG reporting higher levels of perceived participation compared to the CG,  $p < 0.05$  in all four domains (table 10). Two patients in the IG and one in the CG did not complete the questionnaire, leaving a total of 58 and 57 patients in the IG and CG respectively.

Table 10. Degree of perceived participation between the groups at discharge. P-value indicates significance for dichotomised values.

Participation questions	Degree of participation	Intervention group n= 58		Control group n=57		p-value
		n	n (%)	n	n (%)	
To what degree do you feel you have participated in your rehabilitation on the ward?	Very high	29	55 (95)	21	44 (77)	p=0.021
	Moderate	26		23		
	Small	3	3 (5)	13	13 (23)	
	Not at all	0		0		
To what degree have you worked together with the OT and PT towards common goals regarding your rehabilitation?	Very high	30	48 (83)	17	36 (63)	p=0.003
	Moderate	18		19		
	Small	10	10 (17)	11	21 (37)	
	Not at all	0		10		
To what degree do you feel you have taken personal responsibility for your rehabilitation?	Very high	37	52 (90)	20	42 (74)	p=0.008
	Moderate	15		22		
	Small	6	6 (10)	11	15 (26)	
	Not at all	0		4		
Have you been involved in making decisions about your care and treatment as much as you wished?	Very high	39	55 (95)	20	45 (79)	p=0.003
	Moderate	16		25		
	Small	2	3 (5)	11	12 (21)	
	Not at all	1		1		



## Secondary Outcomes

### Activities of daily living, P-ADL (TLS-BasicADL)

*Comparison between groups at discharge and one month*

Statistically significant differences were found between the IG and CG in the P-ADL activities of lower body hygiene ( $p=0.025$ ) and dressing ( $p<0.001$ ) at discharge, with the IG reporting greater levels of independence. By one month follow-up these differences had levelled off between the groups. At one month, significant differences were found in the activities of walking up and down stairs and walking outdoors, with a larger proportion of the CG requiring active help than the IG in both activities (Table 11).

*Table 11. Between group differences in levels of dependence at discharge and one month in lower body lower body hygiene and dressing, stairs and walking outdoors. P-values for significant differences marked in bold.*

TLS-BasicADL Activity	Discharge			1 month		
	Intervention group	Control group	p-value	Intervention group	Control group	p-value
Lower body hygiene	n=60	n=58		n=52	n=54	
Independent	41	36	<b>0.025</b>	49	50	<b>0.734</b>
Supervision	12	5		0	0	
Active help	7	17		3	4	
Lower body dressing	n=60	n=58		n=52	n=54	
Independent	39	22	<b>0.000</b>	41	43	<b>0.921</b>
Supervision	7	1		0	0	
Active help	14	35		11	11	
Stairs	n=33	n=27		n=46	n=48	
Independent	4	8		21	21	
Supervision	21	10	<b>0.093</b>	18	8	<b>0.009</b>
Active help	8	9		7	19	
Walking outdoors			n/a as not tested in majority	n=47	n=49	
Independent				22	22	
Supervision				16	7	<b>0.022</b>
Active help				9	20	

### I-ADL (ADL-staircase)

Concerning I-ADL, no statistically significant differences were reported between the groups in any of the I-ADL items at one month follow-up.

#### *Comparison within groups at discharge and one month post-discharge*

Both groups reported statistically significant improvements in the majority of ADL activities between discharge and one month follow-up. Activities where no statistically significant changes were reported included the three activities involving the upper body; upper body hygiene, dressing and eating in which the groups remained highly independent. For all participants at one month, the activities patients were most dependent in were up and down stairs, and walking outdoors (approx. 60%), showering/bathing (approx. 55%) and lower body dressing (approx. 35%). The distribution of levels of dependence in a selection of seven TLS-BasicADL items can be seen in figure 6.

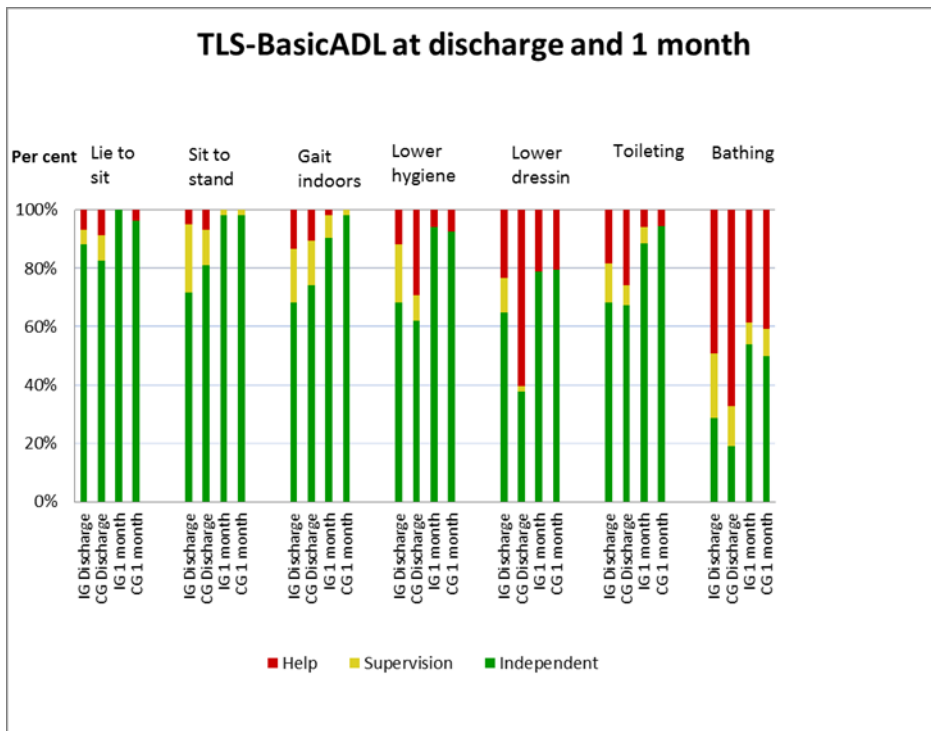


Figure 6. The distribution of levels of dependence in a selection of seven TLS-BasicADL items. IG: Intervention group, CG: Control group

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## **Functional balance (BBS), balance confidence (FES-S), and physical performance (SPPB and TUG)**

### *Comparison between groups at discharge and one month post-discharge*

The results of the outcomes measuring functional balance, balance confidence and physical performance proved to be very similar between the two groups at discharge and 1 month follow-up, with no significant differences between the two groups reported.

### *Comparison within groups at discharge and one month post-discharge*

Statistically significant improvements were reported in both groups for all measures between discharge and one month follow-up. Both groups showed clinically significant differences in BBS and SPPB, with improvements exceeding the recognised MDC scores (Table 12).

*Table 12. Scores of functional balance, balance confidence and physical performance at discharge and one month follow up. Comparisons within groups, between groups, differences within groups between discharge and one month and change over time*

**Bergs Balance Scale (BBS), Short Physical Performance Measure (SPPB), Timed up and Go (TUG) IG-intervention group, CG-control group,\*Mann Whitney U Test, \*\*Wilcoxon Signed Ranks Test**

## Number of falls reported at one month post-discharge

A total of ten patients reported having fallen since discharge; two patients in the IG and eight in the CG, these results were however not statistically significant.

## Risk for falls (BBS, SPPB, TUG)

### *Comparison between groups at discharge and 1 month*

With regard to BBS the majority of the patients in both groups scored considerably lower than the cut-off score of  $\leq 47$ , discriminating those at risk for falls. At discharge 93 and 95 % in the IG and CG respectively had failed to reach above 47 points, while the proportion of patients at risk decreased at one month, 75 and 78% remained at risk for IG and CG respectively.

For SPPB, 91 and 90% in IG and CG respectively failed to score above cut-off value of 6 for fall risk at discharge, which improved to 69 and 66% respectively at one month follow-up.

The results of the TUG scores revealed that 64 and 68% in IG and CG respectively scored above 24 seconds indicating risk of falling at discharge, which improved to 36 and 42 % respectively at 1 month post-discharge (Table 13).

*Table 13. Risk for falls at discharge and one month post-discharge.*

## 6.4 STUDY IV

The participants described their experiences of recovery during the acute phase after hip fracture. The interviews were performed in the hospital prior to discharge. Participants described what started as an accident, a broken leg, resulted in them finding themselves in an unfamiliar situation. They had become dependent on others, and experienced difficulties to perform simple tasks such as reaching for objects from their bedside table to activities previously taken for granted, such as visiting the toilet. Concerns regarding their future after discharge were also voiced. Furthermore participants described how they perceived the rehabilitation on the ward, the use of the TLS-BasicADL and their personal rehabilitation goals.

Two categories were identified: ‘Being seen as a person’ with subcategories; Interaction affects trust and security; Information is key to understanding; and Encouragement is essential to promote activity. And ‘Striving for Independence’, with subcategories; Accepting the situation whilst trying to remain positive; The greener the better, but it’s up to me; Ask me, I have goals; and Uncertainties concerning future. See table 14.

*Table 14. Categories and subcategories*

<b>Categories</b>	<b>Being seen as a person</b>	<b>Striving for independence</b>
<b>Sub-categories</b>	<p><b>Interaction affects trust and security</b></p> <p><b>Information is key to understanding</b></p> <p><b>Encouragement is essential to promote activity</b></p>	<p><b>Accepting the situation whilst trying to remain positive</b></p> <p><b>The greener the better, but it’s up to me</b></p> <p><b>Ask me, I have goals</b></p> <p><b>Uncertainties concerning future</b></p>

## **Being seen as a person**

The experiences described by the participants varied depending on the context, recovery phase, and the patients' perceived degree of dependency on others. For some, the process went quicker, smoother and better than they had envisaged, while for others with more complex needs, recovery was more challenging. They experienced it taking longer to make progress and more of a struggle to get the level of support and encouragement they wished and felt they needed.

### *Interaction gives trust and security*

Sustaining a hip fracture results in dependency and thus having to rely on others for help. The behaviour of those helping was important for the well-being of the person receiving help. Being met and treated by staff that were friendly, compassionate, who informed what was going to happen and gave support was perceived positive by the patients, instilling trust and feelings of security. However, there were times when participants felt helpless, vulnerable and unsure and did not feel that HCPs were seeing them as a person and their individual needs. This was expressed especially in situations when they required help. Patients voiced being reluctant to press their call button as they felt the HCPs were often short staffed, stressed running between patients, and didn't have the time to help them.

### *Information is key to understanding*

Patients emphasized the importance that information should be kept simple and not overwhelming. Information concerning the recovery process (written, verbal and visual) was of value to help participants understand their new situation. However, their ability to process information varied. This was most evident during the early post-operative period, with some patients describing they were unaware that they had been given information, or had forgotten what was said. Others expressed that they were at times aware they had been given information but did not feel able to take in and retain what was said at that point in time.

### *Encouragement is essential to promote activity*

The role of the PTs and OTs was described essential in helping participants regain autonomy. Patients described the encouragement, support and positive feedback given by PT and OT regarding their efforts and progress, were particularly valuable in assisting patients becoming more active and giving

them the strength to continue to strive after increased independence. The use of TLS-BasicADL, giving visual feedback regarding progress, was also described positively and giving patients a boost in self-confidence.

### **Striving for independence**

#### *Accepting the situation whilst trying to remain positive*

Strategies adopted by patients in the transition from dependence to independence varied somewhat depending on the speed and level of recovery. Some patients described being surprised at how well and quickly they were progressing whilst others with more complex needs expressed an understanding that recovery will take time, often referring to their complications and/or decline being caused by the natural ageing process. However, despite it being a struggle, they conveyed the importance of accepting the situation and maintaining a positive attitude in order to move forward.

#### *The greener the better, but it's up to me*

It was important for patients to get feedback and to be made aware of the progress they were making no matter how small, in order for them to continue to feel motivated and to participate in their rehabilitation. Recognising improvements in functional status, was one such area of progress, seen through the changing of the colour coding in TLS-BasicADL, from red (dependent), to yellow (supervision), to green (independent), which was expressed as being stimulating, and motivating patients to continue to strive for independence. While patients valued becoming 'greener', they also described situations when they were apprehensive about changing the colour-coding from supervision to independent in an activity. They referred mainly to the activities: walking and going to the toilet.

Participants were aware that in order to enhance their recovery, they themselves, had to actively participate in their rehabilitation. Taking the initiative and responsibility to participate in their rehabilitation and becoming more active was recognised as essential by participants. However, for those patients who described having limited resources, it was important that HCPs were sensitive to their limitations, and adapted care accordingly to give them time to participate as much as they were able.

*Ask me, I have goals*

The participants expressed their goals clearly during the interviews however, few experienced that they had discussed their goals with the OTs or PTs. The goals most frequently described by the participants were associated with regaining mobility. However, the content and context of mobility goals varied depending on the patients' resources and the recovery phase referred to. For those patients who were dependent on others in basic transfers and ADL, short-term goals including getting back on their feet as soon as possible in order to regain ability to go to the toilet independently were often referred to. Others talked more about long-term goals, including getting back to how they were prior to fracture, returning to a normal life, to be able to cycle, travel, cook, meet friends, and being able to walk outdoors again. The participants who had experience of using TLS-BasicADL for goal setting expressed that they found it easy to understand, well-structured, providing a logical way of thinking and for following progress.

*Uncertainties concerning future*

Participants expressed concern regarding their future after discharge from hospital. They felt unsure how they were going to manage their lives outside of the hospital environment. Despite feeling these concerns, not all patients felt able to talk about them with their significant others, they did not want to be a burden for them and therefore kept their thoughts to themselves. They questioned whether they would be able to return home, will they be able to move about in their homes, will they be able to come out or will they be confined indoors. These questions left them feeling worried and insecure.



## 7 DISCUSSION

This thesis describes the reasoning behind the development of TLS-BasicADL and procedures adopted to investigate the psychometric properties of reliability, validity and responsiveness. Furthermore, the clinical utility of TLS-BasicADL has been described in a clinical trial and patients' experiences of its use in normal clinical practice have been reported in a qualitative interview study.

### 7.1 METHODOLOGICAL CONSIDERATIONS

TLS-BasicADL is an ordinal scale, comprising 13 items with 3 different colour-coding scoring categories. A conscious decision was made during the development process to maintain the colour-coding scoring system and not to use numbers or letters to give a total score. While ordinal scales and sum scores are widely used in rehabilitation, reporting a total score can be misleading, with patients having the same score but requiring assistance/help in different activities (Merbitz, 1989; Stucki, Daltroy, Katz, Johannesson, & Liang, 1996). A further reason for maintaining individual item scoring was to promote communication with staff and patients by being able to show visually, the specific activities of dependence/independence. By helping the patient unnecessarily is both ineffective use of HCP time, and takes away opportunities for active participation from the part of the patient.

Calculating at item level led to limitations in choice of statistical methods for investigating both reliability and validity. Studies reporting on outcome measures often rely on calculation of means, standard deviations, change scores, minimally important difference or effect sizes however, ordinal data does not support the use of these statistical methods (Merbitz, 1989). Here appropriate non-parametric statistics should be adopted, alternatively the data should be converted to interval data through the use of methods such as the Rasch model (C. V. Granger, 2008). For the purpose of this thesis non-parametric statistics have been used, however, it is recognized that further investigation of the properties of the instrument, such as Rasch analysis, are of value to strengthen the results.

Following hip fracture surgery, patients' functional ability can change dramatically between treatment sessions, and is thus not regarded a stable state. The six activities concerning transfers and gait were therefore filmed during the inter-rater testing to ensure stability. The reason for only filming the first 6 items was that it was not considered ethical to film the activities

concerning personal care hence the intra-rater results do not apply to the ADL section.

Concerning responsiveness, the study sample comprised a group previously independent in transfers, ambulation and P-ADL excluding bathing. As can be seen in figures 4 and 5, the differences between ability post-op and at discharge are considerable. The item 'eating' scored high during hospital stay, however, had patients been recruited who were less independent, (with additional co-morbidities) the results would have shown greater variance, both at discharge and one month follow-up. The aim of treatment during hospital stay is to become as independent as possible prior to discharge. However, when using TLS-BasicADL it is not possible at present to differentiate between levels of independence, i.e. how safe a person feels, or the level of difficulty experienced when performing an activity. Methods have been described, which can even apply for TLS-BasicADL, in order to give a 'more diversified and information-rich picture' by adding dimensions such as degree of difficulty with or without assistive aids, and/or satisfaction when performing an activity (Archenholtz, 2008; Iwarsson, 2009). Examples of instruments that have been developed or extended include; ADL staircase that was combined with 'self-rating of difficulty' and Performance and Satisfaction in Activities of daily Living (PS-ADL) developed for patients with RA (Archenholtz, 2008; Iwarsson, 2009).

Although a randomized controlled study would have strengthened the methodology of study III, this was not possible due to different admission routines depending on day of the week, and time of admission. A further reason was that it was not possible to treat patients from the two study groups in the same ward room. The power calculation initially showed that we needed 92 patients. However gender was not stratified, which resulted in a maldistribution towards the end of the inclusion process. To compensate for this, participants continued to be included until a balance was reached between women and men, which resulted in a total of 126 participants.

In study III, there were more patients with cervical fractures, as well as having ASA 1-2 in IG, which in theory could mean participants being less medically compromised early post-operatively. However, our clinical observation was that patients in the IG were in fact less physically able than the CG. With regard to baseline data, a statistically significant difference between groups was found in the one of the I-ADL activities, with more patients in CG independent in cooking. Although not significant, the CG was 1.5 years younger and a greater number of patients were independent walking outdoors, suggesting a slightly higher level of pre-fracture function. These

results are of interest and could partly explain why a higher proportion of the IG was discharged to an intermediary rehab unit and not directly home, 33% versus 18% for the IG and CG respectively.

When performing, and presenting research, using a qualitative approach, the aspect of trustworthiness must be addressed. In qualitative content analysis this is commonly presented using the following five criteria: credibility, dependability, confirmability, transferability, and authenticity (Lincoln, 1985; Polit, 2012).

Credibility was established through identifying and describing the participants accurately which was presented in the text. As we were interested in the patients' experiences of recovery during inpatient care we performed the interviews towards the end of their hospital stay in order for them to have experienced as many stages of inpatient care and rehabilitation as possible. A semi-structured interview protocol was used with examples of open-ended questions concerning the patients' experiences of recovery, participation in rehabilitation including the use of TLS-BasicADL. We performed the interviews in a quiet room in the physiotherapy department rather than on the ward with the aim of allowing the patient to speak more openly about their experiences. Analysis of the data was performed using triangulation; the main author performed the initial analysis with regular consensus meetings with the collaborating authors to ensure the findings were robust and well-developed.

It is reasonable to believe that the patients interviewed represent the group chosen for the study, i.e. community dwelling older persons with relatively high physical performance ability before the fracture. The participants were all independently mobile indoors with or without walking aid prior to fracture, and were cognitively intact, whilst limiting the selection of patients it may increase the dependability of the analysis. Fourteen women and six men were recruited which is also representative for this patient group.

With regard to confirmability, two of the authors are clinicians with experience of working on the wards where the patients were treated, which can lead to bias in the analysis. These two authors read and listened to all interviews, and made separate analyses of the interviews before discussing together. However, to minimise preconceptions and strengthen confirmability, the other authors, who have no experience of the workings on the included wards were involved throughout the analysis.

While the data analysed in this study have been collected from interviews with patients treated for a hip fracture in a geriatric unit, the results of this study are similar to earlier research examining patient experiences of care. This should therefore increase the transferability of the results to other geriatric wards.

To achieve authenticity the results have been presented using two main categories: 'Being seen as a person', describing the patients' experiences of interaction with HCP and 'Striving for independence' referring to experiences affecting their own inner drive in their recovery process. To further improve authenticity, the results of this study were presented and discussed with allied health care staff working with this patient group for feedback regarding chosen categories and subcategories.

Patients were recruited from three wards in the geriatric unit to give a greater variation in our data. Had patients been recruited from other hospitals, the results may have shown varying experiences. The participants were community dwelling, with intact cognition and independent walking indoors prior to fracture, while this is not representative for all patients recovering from hip fracture, the results of this study can be compared with previous research studying similar patient groups (Gesar et al., 2016; Olsson, Nyström, Karlsson, & Ekman, 2007; Zidén, Frandin, & Kreuter, 2008). To further maximize trustworthiness, a description of the analysis procedure has been given in the Methodology section and the data in the Result section, with corresponding citations, to increase transparency. The interviews were performed by two researchers, who are physiotherapists with clinical experience of working on the three wards. This may have led to bias of the results and influenced patients to adapt their descriptions to what they thought they were expected to talk about, i.e. did not talk as freely. To compensate for this and increase confirmability, we performed the interviews out with the ward setting, in civilian clothing and analysed the data using triangulation with the two other authors.

## Ethical considerations

Assessment of physical function and basic ADL is part of standard clinical practice and is routinely assessed throughout hospital stay. For the purpose of this thesis a conscious effort made to keep extra assessments to a minimum. For inter-rater reliability testing the participants were assessed using TLS-BasicADL on one extra occasion by two PTs (first six items) and two OTs (seven P-ADL items) simultaneously. To avoid the patients being subjected to extra assessments for intra-rater reliability testing, filming of the

examination of transfers and ambulation was made during the testing of inter-rater reliability. The seven activities of personal care were however not filmed for ethical reasons. The advantage of using the film sequences for intra-rater testing ensured that the patients' functional ability remained in a stable state between testing.

The participants in study II who took part in the testing of criterion validity were not subjected to any extra assessment situations. The data analysed for establishing responsiveness in TLS-BasicADL was collected from the assessments of ADL made in study III, thereby no further assessment sessions were required.

The participants in Study III were required to perform more intensive exercise, i.e. extra balance and physical performance tests, and fill in the questionnaires concerning perceived participation and falls efficacy at both discharge and one month post-discharge. It was recognised prior to commencing the study that some patients may find the battery of tests challenging to complete in one session. For these patients, the testing was divided up to allow participants periods of rest or the performance tests were alternated with the questionnaires as required.

The participants recruited to the qualitative study were invited by their treating occupational therapist or physiotherapist on the ward, to participate in an interview towards the end of their hospital stay. This was done to ensure patients met inclusion criteria and that those with moderate to severe cognitive difficulties were not subjected to being interviewed, which may have caused ethical as well as validity problems.

## 7.2 DISCUSSION OF THE RESULTS

TLS-BasicADL was developed and introduced on to a geriatric rehabilitation ward approximately 16 years ago and continues to be used as a simple, practical and informative visual aid for assessing and communicating the patient's ADL ability and needs. The original concept of assessing the patient's ADL ability using the simple 3-graded, colour-coding system has remained. The protocol has however, been given several face-lifts and adapted over the years to better fit the needs of the patient and HCPs, providing more relevant information for promoting communication between team members and patient concerning their rehabilitation process, with the protocol now highlighting the patient's previous and present ability as well as rehabilitation goals concerning basic ADL activities.

## Clinical Utility

The overall goal was to develop a tool that was clinically useful. This has been accomplished, with TLS-BasicADL fulfilling the 4 factors important for clinical utility: appropriateness, accessibility, practicability and acceptability (Smart, 2006). Appropriateness has been achieved by the instrument fitting well into the care pathways, providing meaningful information regarding ADL ability and goal setting for HCPs and patients alike. It is used to monitor and communicate level of ADL progress with patients, at team ward rounds and at case conferences when planning future care. Both practicability and accessibility have also been attained, through the simple format of the protocol, user manual and degree of simplicity of the scoring. The equipment comprises basic stationary items and the new staff can be easily informed and trained in the ward environment. The fourth component, acceptability, the willingness of practitioners to use the instrument, has been shown with the instrument continuing to be used after 16 years. It has been important to consider ethical issues which may require attention when using an instrument in clinical practice. Patients or significant others are informed regarding the use of TLS-BasicADL and asked if they have anything against the protocol being visible at their bedsides. To my knowledge no patient or relative has declined. Participants in study IV were all asked their opinion about the protocol being visible at their bedside, and if they found the use of it offensive in any way. None of the participants were against the protocol being visible on the wardrobe door or found the information included offensive. It was however voiced that the positioning of the protocol was not optimal, as it was not visible for patients when they were lying in bed. Some patients were more interested than others in the use of TLS-BasicADL. Those less interested, expressed that it was perhaps an instrument more useful for therapists and other HCPs than for them.

## Reliability and validity

The purpose of study I was to establish the reliability of TLS-BasicADL, the extent to which different raters can simultaneously estimate a person's ADL ability in a consistent manner, and to show how stable the test scores of raters remain over time (Küçükdeveci et al., 2011). Study II was performed to establish how TLS-BasicADL correlates to other measures of the same construct measuring ADL, modified FIM and BI respectively.

The results show TLS-BasicADL to have a high inter-rater (ICC, 0.90) and fair intra-rater reliability (PA, 72.6-73.3%), and strong to excellent concurrent validity (0.65-0.97) when compared with modified versions of

FIM and BI in a mixed diagnosis group. These results are comparable to previous inter-and intra-rater reliability and validity studies of FIM and BI, with ICCs of between 0.83-0.99 in mixed diagnosis groups, and patients following stroke and MS (Brosseau, 1994; Chau, 1994; Hamilton, 1994 ; Kidd, 1995; Roy, 1988; Sharrack, 1999). Excellent validity has also been reported for FIM and BI in studies of older adults and patients with stroke (Hsueh, Lin, Jeng, & Hsieh, 2002; Pollak, Rheault, & Stoecker, 1996). For the testing of responsiveness of TLS-BasicADL following hip fracture surgery a further ADL index, the Katz Index was used as an anchor, which is another commonly used instrument in older patients following hip fracture (Aarden et al., 2017; Bellelli et al., 2014; Scholtens et al., 2017).

Assessing patients' ability to transfer from: sitting to standing, from bed to chair and from chair to bed were shown to be the three activities with the lowest PA. These results may be due to the use of pairs of raters, who had no previous knowledge of the patients' ability, and who assessed the patient simultaneously. Therapist 1 led the assessment, gave instructions and assisted the patient when required, thus had closer contact with the patient and thereby more control over the assessment than therapist 2 who was observing. Individual rater assessments of the patient may have improved the results, however, this was not a viable option as all the patients were in the acute phase of their rehabilitation after hip fracture surgery. Patient's ability can vary considerably, with improvements and deterioration in function due to pain and/or fatigue being experienced in the same day.

Patients with hip fracture have generally good function in their upper limbs and thereby ability to perform activities of washing and grooming the upper body which can explain the high PA (90%) and lower ICC of 0.74. The results of intra-rater testing for each individual therapist showed that 17 of the 25 raters scored a PA  $\geq 70.0$ , 2 raters  $\geq 60.0-69$ , 4 raters  $\geq 50-59\%$  and a single rater  $< 50\%$ . An explanation for these varying results may be due to the crude nature of the scoring system, with only three categories and/or raters being more or less observant to the content of the film. Furthermore, the five patients included in the intra-rater testing had shown greater variation between raters during the initial inter-rater testing. Had we chosen patients with higher inter-rater reliability, the intra-rater reliability results may also have been higher.

## Enhanced collaboration

It is recognised that multi-disciplinary teams that collaborate well together and involve patients in their care and rehabilitation can result in better

outcomes (Cameron, 2002; Niklas et al., 2017; WHO, 2017b). The results of study III show that improved outcomes related to patient participation and ADL can be achieved by therapists focusing on routines to enhance collaboration together with the patient. These improvements were achieved without increasing OT or PT resources, and show that a more coordinated approach to rehabilitation after hip fracture surgery can benefit the patient.

TLS-BasicADL played a central role as a tool to communicate ADL ability and planning of goals with the patients, as well as an outcome measure to evaluate the effect of the intervention on ADL. While it is not possible to report specifically the effect of TLS-BasicADL on the outcome, we can say that when included in the intervention procedure, positive results in the form of increased levels of patient participation and independence in ADL were reported in comparison with standard care.

No significantly statistical differences were found between the two groups in functional balance, confidence or physical performance at discharge or after one month post-discharge. Improvements were reported for all outcome measures between the time points, however risk for falls at one month was found to be between c.a. 40-80 % and balance confidence continued to be affected in this previously independently mobile group of older adults. There is no standardized follow-up program for patients with hip fracture in Sweden and the rehabilitation services provided after discharge vary considerably. Despite evidence that exercise programs combined with good discharge planning and support in the home environment can improve balance confidence (Zidén et al., 2008) and help prevent future falls (Rapp et al., 2013; Sherrington et al., 2016), this is not included in standard practice.

## Patient experiences

At the time that Study IV was performed no other clinical trial was in operation. The results presented are therefore viewed as mirroring clinical reality, and reflecting patients' experiences under normal clinical practice conditions. The overall findings of this study continue to highlight the complex needs of patients with hip fracture and the challenges that therapists and other HCPs meet in the clinical setting. The variation of experiences expressed by the participants is in accordance with previous research emphasising the heterogenic nature of this patient group, with varying individual needs and preferences (Gesar et al., 2016; Malmgren, 2014; Olsson et al., 2007).



In brief, the experiences described by the participants in this study revealed that; some were more sensitive to how they were received and treated by staff than others; some were more able to take in information, while others were unaware or had forgotten if they had been given information; some patients recovered and regained function more quickly, while others required extended support and rehabilitation; some had a greater inner motivation and self-efficacy, while others required more encouragement and feedback from PTs and OTs; and some developed concerns regarding their future after discharge, while others were more confident.

Sustaining a hip fracture is undoubtedly a traumatic event, with sudden loss of function and subsequent admission to an unfamiliar hospital environment for surgical intervention and rehabilitation. Good supportive interaction between the patient and healthcare teams is essential in order to promote self-confidence and well-being. It is important for HCPs to see the person in front of them, a person with individual needs and not as the disease they have been admitted with (Eldh, Ekman, & Ehnfors, 2006). This may be achieved through dialogue, information and feedback (Rasmussen & Uhrenfeldt, 2016).

Despite these fundamental recommendations the results of study IV showed that patients, particularly those who were frail and with more complex needs continue to experience situations of feeling helpless, vulnerable, and at times, staff insensitive to their needs. This can lead to patients not only feeling frustrated, but may also affect their ability to participate, thus resulting in missed opportunities to exercise and become more physically active (Angel & Frederiksen, 2015). Another important aspect described by Proctor et al for promoting well-being, is for HCPs to have the ability to understand and respect situations when patients capacity or willingness is low, for example, due to illness, pain or lack of energy (Proctor et al., 2008). This was confirmed by participants who experienced at times being overruled, especially those patients with more complex health conditions and/or complications following surgery, who expressed it being more of a struggle to remain positive. This highlights their need for more support and encouragement, in order to understand and accept the situation and to help retain perspective (Schiller et al., 2015). It is essential that the rehabilitation provided is adapted to a level where the patient feels they can participate, where they can recognise improvements, no matter how small, in order to regain self-confidence and an inner belief in recovery (Furstenberg, 1986; Gesar, Hommel, Hedin, & Bååth, 2017; Olsson et al., 2007).

Here, the role of the PT to support and guide, as well as the use of TLS-BasicADL, to monitor progress, was described important and helped motivate patients. This is in accordance with previous work by Proctor et al, who recommend the use of charts to monitor progress to improve self-efficacy and promote continued progress (Proctor et al., 2008).

While some patients felt well-informed concerning their rehabilitation process, including TLS-BasicADL, others reported that they had forgotten or were not aware that they had been given information. This is an issue that has been reported earlier (Malmgren, 2014), with recommendations that information be kept simple, adapted to the individuals' needs, given at appropriate times and in suitable amounts, but most importantly, followed up in order to determine if the patient has understood or not (Malmgren, 2014; Olsson et al., 2007). If the patient has not understood then alternative methods must be adopted, (e.g. re-assessing timing of information, informing relatives or significant other, reinforcing verbal information with written and vice versa). The results show that this is an area requiring attention, as it is apparent from the interviews that patients are either not being given information, or the timing and/or format are not suitable for their varying capabilities and needs.

The potential benefits of goal setting in the rehabilitation process are well documented in the literature and should not be underestimated. Goal setting is recognized as a central component of rehabilitation with improvements reported in self-confidence, motivation, participation, satisfaction, team communication, and the likelihood of patients achieving their goals (Plant, 2016). During the interviews patients were able to express clearly what their goals were, but few had discussed them with therapists or other HCPs. Although goal setting is included in TLS-BasicADL to assist discussion of short-term goals concerning mobility and ADL, this aspect has not been fully utilized. It is, as described above, unclear if OTs and PTs have discussed goal-setting with patients, and if so, at what time point. Organizational barriers including staff perceiving lack of time, lack of co-ordination between staff, staff turn-over and/or pressure to provide 'hands-on therapy' have been described as possible obstacles (Plant, 2016). Further investigation is warranted, to determine and resolve possible barriers, in order to improve goal setting routines.

Regaining stable mobility to be able to participate in valued activities is a goal most commonly expressed by patients following hip fracture surgery (Griffiths et al., 2015). This was also conveyed by participants in this study who all expressed goals related to aspects of mobility. During the initial

phase of dependency post-operatively, they commonly expressed the wish of being able to get up out of bed and going to the toilet independently, without having to rely on staff. While for others who were making progress, more long-term goals were referred to, valued activities they could associate with getting back to normal after discharge. This further emphasises the importance of learning and acknowledging patients goals in order to plan continued rehabilitation.

Concern regarding their future was an issue conveyed by patients. They described how their life situation had changed, they were no longer as independent or mobile as before, and they were worried how they were going to be able to manage after discharge from hospital. Furthermore, the thought for some, who were not able to be discharged home, of having to move to alternative care, was distressing. They also expressed concerns about becoming a burden to significant others (Colleen, Pryor, & Jeeawody, 2009). This highlights that more attention is required to identify and address patients concerns to minimise their worries, and adapt discharge planning to better fit their needs (Olsson et al., 2007). Patients need to be encouraged to express their concerns, which may simply be accomplished by staff regularly showing up in the patient's room, indicating to the patient that they are interested in their situation (van Der Meide, Olthuis, & Leget, 2015). Furthermore, implementation of a supportive discharge team, including an OT and PT, can help decrease the patients' concerns and improve self-confidence (Zidén et al., 2008). A team that assists the patient home from hospital, assessing them in their own environment, and planning need for continued rehabilitation.

The results from study III showed that when a more structured approach to rehabilitation and collaboration between PT, OT and patient was implemented, higher levels of perceived patient participation and independence in ADL were achieved. However, it is apparent from the experiences expressed by the participants in study IV, that these levels of collaboration and patient participation, including goal setting, have not been maintained.

To improve and maintain quality of care and rehabilitation there is continued need for organizations to monitor and reflect over existing practice, and to question routines and procedures. Furthermore, it is essential to continue to investigate and acknowledge the patients' experiences, needs and preferences and make efforts to accommodate these where possible. Physiotherapists and other HCPs must recognise that patients with hip fracture are individuals, with varying needs that change across the continuum of recovery.

## 8 CONCLUSION

TLS-BADL provides a simple and practical multidisciplinary instrument for assessing basic ADL in older patients in the acute hospital setting. It provides a visual aid to highlight level of independence in individual activities and promotes communication between the multidisciplinary team members and patient.

TLS-BADL has shown to have high inter-rater reliability, and fair intra-rater reliability for mobility items. Regarding validity, strong to excellent concurrent validity has been shown in a mixed diagnosis group and moderate to strong responsiveness in a group of patients following hip fracture.

TLS-BasicADL has, in a clinical trial studying patients with hip fracture, provided an outcome measure to assess function and personal care. Furthermore, a visual aid to monitor progress, set rehabilitation goals and promote patient participation. The intervention comprising more enhanced collaboration between OT, PT and patients and more intensive training following hip fracture surgery resulted in increased patient participation and independence in ADL at discharge. Patients at one month post-discharge reported continued low levels of balance confidence, and remain at risk for future falls highlighting the need for improved discharge planning and rehabilitation services post-discharge.

After a hip fracture patients experience a need to be seen as a person with individual needs. Physiotherapists and other HCPs must acknowledge that the patients they meet and treat require varying levels of support and encouragement, no individual is alike. Patients expressed personal goals concerning aspects of mobility; however, these goals were not routinely discussed with the physiotherapists. Monitoring progress using TLS-BasicADL was experienced positively, however, there is a need for therapists to review how the instrument is used in day to day practice to ensure that patients are given, not only information regarding their progress, but the opportunity to discuss present and future goals.

## 9 FUTURE PERSPECTIVES

Several areas and ideas meriting further investigation have arisen during the work on this thesis.

There is a need:

- To further investigate the reliability, validity and clinical utility of TLS-BasicADL For example with other team members and different patient groups and care settings.
- To develop more standardized routines to ensure that the older person is given the opportunity and encouraged to participate in goal setting during inpatient rehabilitation.
- To further develop TLS-BasicADL to include patients' experienced level of safety and difficulty in performing activities in which they are independent.
- To review the information given to older adults concerning their rehabilitation, for both inpatient stay and after discharge. Including the type and content of information, timing and follow-up to ensure patients and/or significant others are receiving pertinent information as well as understanding and retaining the information being given.
- To use the results of this thesis to communicate to community and primary care services the need for supportive discharge planning and continued rehabilitation after discharge from hospital to prevent future falls

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# APPENDIX