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Cognitive impairment and its consequences in everyday life

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ABSTRACT

The overall aim was to improve knowledge of the consequences of cognitive dysfunction in everyday life and of instruments to make these assessments. The thesis contains four studies each of different design using different populations.

In **study I**, the relationship between cognitive function, ability to perform activities of daily living and perceived health-related quality of life were investigated in a population of 85-year-old individuals in the community of Linköping ($n = 373$). The study was part of the Elderly in Linköping Screening Assessment 85 (ELSA 85). Even mild cognitive dysfunction correlated with impaired ability to perform activities of daily living and lower health-related quality of life.

In **study II**, the diagnostic accuracy and clinical utility of Cognistat, a cognitive screening instrument, were evaluated for identifying individuals with cognitive impairment in a primary care population. Cognistat has relatively good diagnostic accuracy with a sensitivity of 0.85, a specificity of 0.79 and a Clinical Utility Index (CUI) of 0.72. The corresponding values were 0.59, 0.91 and 0.53 for the Mini Mental State Examination (MMSE), and 0.26, 0.88 and 0.20 for the Clock Drawing Test (CDT).

In **study III**, the aim was to develop an instrument measuring self-perceived or caregiver reported ability to perform everyday life activities in persons with suspected cognitive impairment or dementia and to perform psychometric testing of this instrument, named the Cognitive Impairment in Daily Life (CID). The CID was found to have good content validity.

In **study IV**, experiences of cognitive impairment, its consequences in everyday life and the need for support in persons with mild cognitive impairment (MCI) or mild dementia and their relatives were explored. Interviews were performed with five people with MCI, eight people with mild dementia and their relatives ($n = 13$). The main finding was that persons with MCI and dementia experienced cognitive changes that could be burdensome and result in changed activity patterns.

In conclusion, the findings support earlier research and show that cognitive dysfunction even at mild stages has an impact on everyday life and reduces perceived quality of life. To improve interventions for persons with cognitive impairment, it is important to assess not only cognitive function but also its consequences in everyday life activities.

Key words: activities of daily living, assessment, dementia, mild cognitive impairment, occupational therapy, quality of life.

SAMMANFATTNING

Det övergripande syftet med avhandlingen är att öka kunskapen om konsekvenser av kognitiv dysfunktion i vardagliga livet och kring instrument för att göra dessa bedömningar. Avhandlingen omfattar fyra studier med olika design och olika populationer.

I **studie I** undersöktes sambandet mellan kognitiva funktioner, aktiviteter i dagliga livet (ADL), och upplevd hälsorelaterad livskvalitet hos 85-åriga individer i Linköpings kommun (n = 373). Studien var en del av Elderly in Linköping Screening Assessment 85 (ELSA 85). Resultaten visade att även mild kognitiv funktionsnedsättning korrelerar med nedsatt förmåga att utföra ADL och lägre skattad hälsorelaterad livskvalitet.

I **studie II** utvärderades den diagnostiska noggrannheten och kliniska användbarheten av Cognistat, ett kognitiv screeninginstrument, för att identifiera personer med kognitiv nedsättning i en primärvårdspopulation. Studien visar att Cognistat har en relativt god diagnostisk noggrannhet med en sensitivitet på 0.85 och en specificitet på 0.79 och ett Clinical Utility Index (CUI) på 0.72. Motsvarande värden för Mini Mental State Examination (MMSE) var 0.59, 0.91 och 0.53 och för Clock Drawing Test (CDT) 0.26, 0.88 och 0.20.

I **studie III** utvecklades ett instrument, Cognitive Impairment in Daily Life (CID), som mäter förmågan att utföra aktiviteter i dagliga livet hos personer med misstänkt kognitiv svikt eller demens och instrumentet prövades psykometriskt gällande innehållsvaliditet. Instrumentet kan användas genom intervju med personen själv eller skattas av en anhörig. Studien visar att instrumentet har god innehållsvaliditet.

I **studie IV** var syftet att undersöka upplevelsen av kognitiv funktionsnedsättning och dess konsekvenser i vardagen och behovet av stöd hos personer med lindrig kognitiv svikt (MCI) eller mild demens och deras anhöriga. Kvalitativa intervjuer gjordes med fem personer med MCI och åtta personer med mild demens och med deras anhöriga (n = 13). Resultatet visade att personer med MCI och demens upplevde kognitiva förändringar som kunde vara betungande och resulterade i förändrat aktivitetsmönster.

Sammanfattningsvis stödjer resultaten tidigare forskning och visar att kognitiv funktionsnedsättning även i mild grad påverkar vardagen och leder till minskad livskvalitet. För att förbättra insatserna för personer med kognitiv funktionsnedsättning, är det viktigt att inte bara bedöma kognitiva funktioner, utan även dess konsekvenser i vardagen.

List of publications

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

- I. Johansson MM, Marcusson J, Wressle E: **Cognition, daily living, and health-related quality of life in 85-year-olds in Sweden.** *Aging, Neuropsychology, and Cognition* 2012, 19(3):421-432.
- II. Johansson MM, Kvitting AS, Wressle E, Marcusson J: **Clinical utility of Cognistat in multiprofessional team evaluations of patients with cognitive impairment in Swedish primary care.** *International Journal of Family Medicine* 2014, Article ID 649253, doi:10.1155/2014/649253.
- III. Johansson MM, Marcusson J, Wressle E: **Development and testing of an instrument for measuring activity in daily life in persons with cognitive impairment or dementia.** *Scandinavian Journal of Occupational Therapy*. Resubmitted, Feb 2015.
- IV. Johansson MM, Marcusson J, Wressle E: **Cognitive impairment and its consequences in everyday life: experiences from people with mild cognitive impairment or mild dementia and their relatives.** *International Psychogeriatrics*, doi:10.1017/S1041610215000058.

ABBREVIATIONS

AD	Alzheimer disease
ADL	Activities of daily living
AUC	Area under the curve
CADL	Complex activities of daily living
CID	Cognitive Impairment in Daily Life
CDT	Clock Drawing Test
CUI	Clinical Utility Index
CVI	Content Validity Index
DSM IV	Diagnostic and Statistical Manual of Mental Disorders
ELSA 85	Elderly in Linköping Screening Assessment
GP	General Practitioner
HRQoL	Health-related quality of life
IADL	Instrumental activities of daily living
IAM	Instrumental Activity Measure
ICD	International Classification of Diseases
<i>J</i>	Youden Index
MCI	Mild cognitive impairment
MMSE	Mini Mental State Examination
MMSE-SR	Mini Mental State Examination Swedish revision
NPV	Negative predictive value
PADL	Personal activities of daily living
PHC	Primary health care
PPV	Positive predictive value
ROC	Receiver operating characteristic
SD	Standard deviation
SES	Socioeconomic status
VaD	Vascular dementia

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INTRODUCTION

Cognitive impairment and dementia affect the daily life of people (and their relatives) in a significant way. Tools to support early diagnosis might facilitate actions that might affect the progress and impact of different interventions. Since age is the main risk factor for the development of cognitive impairment and dementia, it is important to find reliable and valid ways to support the diagnosis and its implications for everyday life in the elderly population. Cognitive impairment or dementia can, however, affect younger people of working age, which requires relevant assessment instruments. Dementia is the largest cause of disability in older people and the dependency on others that often follows has been found to have a significant negative effect on people's health-related quality of life (HRQoL). This thesis aims to provide more evidence in this field; in the following introduction some of the existing knowledge in the field is presented and some concepts are explained.

Cognitive function

Cognition is about the processes behind human thinking and experiences. Cognition refers to “a process of identifying, selecting, interpreting, storing, and using information to make sense of and interact with the physical and social world, to conduct one's everyday activities, and to plan and enact the course of one's occupational life” (Kielhofner, 2009, p. 85). In the literature on cognitive function, authors often refer to different cognitive domains such as perception, attention, memory, language, executive function (initiating, planning, organizing, controlling and evaluation of thinking and acting) and psychomotor speed (Wahlund et al., 2011). Some of those cognitive functions decrease within normal aging; for example, short-term memory and the way we learn new skills, mental speed, logical thinking and spatial problem solving (Rönnlund et al., 2005, Fastbom et al., 2014). However, most of our language processes are intact throughout aging (Shafto and Tyler, 2014). Today, we know that there are some risk factors for the development of cognitive impairment; among these, age is the greatest risk factor (Blennow et al., 2006). However, there are also several favourable factors for keeping cognition intact for longer such as physical activity, social participation and engagement, education and intellectual ac-

tivity. Diet is also mentioned as an important factor (Wahlund et al., 2011).

Cognitive impairment

Several diseases can cause cognitive impairment in the elderly such as depression, long-term alcohol abuse, lack of vitamin B₁₂ and folic acid, diabetes, cardiovascular diseases, stress-related diseases, or a combination of different diseases (multimorbidity). Neurodegenerative diseases such as Alzheimer disease (AD), frontotemporal dementia, Parkinson disease, and multiple sclerosis can also cause cognitive impairment (Wahlund et al., 2011, Fastbom et al., 2014). Early detection of cognitive decline could lead to secondary prevention because this information could be used to develop strategies that control risk factors (Gauthier et al., 2006). A substantial acceleration of cognitive decline appears several years before a diagnosis of dementia (Thorvaldsson et al., 2011).

Mild cognitive impairment

Mild cognitive impairment (MCI) is sometimes considered to be a precursor of dementia or as the boundary between normal aging and dementia (Petersen et al., 2014). In a consensus meeting, the following criteria for MCI were determined: (i) the person is neither normal nor demented, (ii) there is evidence of cognitive deterioration shown by either objectively measured decline over time and/or a subjective report of decline by self and/or informant in conjunction with objective cognitive deficits; and (iii) activities of daily living are preserved and complex instrumental functions are either intact or minimally impaired (Winblad et al., 2004). The prevalence of MCI is estimated to be between 10% and 20% among people over 65 years of age (Petersen et al., 2009, Langa and Levine, 2014) but different figures have been mentioned. About 50% of those with MCI progress to dementia within 5 years (Rockwood et al., 1999).

Dementia

Dementia can be defined as a disturbance in intellectual abilities and it is often accompanied by changes in the person's behaviour and personality (Marcusson et al., 2011). Dementia is a syndrome rather than a diagnosis and there are different diagnostic criteria as well as different dementia diagnoses (American Psychiatric Association, 2013). The

most common form of dementia is AD (about 50–60% of all people with dementia) (Blennow et al., 2006). Vascular dementia (VaD) is the second most common disease (10–50% of all people with dementia) (Román, 2003). Mixed dementia refers to a combination of AD and VaD and is particularly common among older people (Langa et al., 2004). Other forms of dementia include Lewy body dementia and frontotemporal dementia. The number of people with dementia in Sweden has been estimated to 160 000 (Wimo et al., 2014) and it is increasing. Dementia is the most common and the most severe cause of cognitive impairment and disability (Marengoni et al., 2008, Ferri et al., 2006). Globally, the prevalence of dementia is estimated to be more than 25 million (Qiu et al., 2009). As life expectancy increases worldwide, so does the prevalence of dementia. In 2050, those figures might have doubled. The total cost for dementia care in Sweden is calculated to be 63 billion SEK (Wimo et al., 2014). The costs for community care are the highest, about 78% of the total costs on society. Besides the high societal costs, dementia causes immense suffering for the individuals and their families. Dementia is the largest cause of disability in the world among older people (Sousa et al., 2009) and the dependency on others for performing activities of daily living (ADL) is the main factor that affects HRQoL negatively (Andersen et al., 2004).

Dementia investigation

It is important to investigate dementia at an early stage to identify any curable conditions, deploy the right medical treatment and provide appropriate support and assistance to patients and relatives (Socialdepartementet, 2003). Today, no single blood sample or test can diagnose a dementia disease. In Sweden, the Swedish National Board of Health and Welfare (Socialstyrelsen, 2010) have defined the requirements that must be included in a dementia investigation. A basal investigation should be based on assessment of cognition using cognitive tests and a structured assessment of function and activity capacity. Both have first priority. The basal investigation should be carried out in primary health care (PHC). The guidelines also recommend a multiprofessional team-based approach. Persons with a dementia illness should have at least a yearly follow-up. This follow-up should include assessment of medication, cognition, and functional capacity, general state of health, behavioural changes and the support that has been agreed on (Socialstyrelsen, 2010).

These guidelines have much improved the work on caring for people with dementia. However, in 2014 an evaluation of the care of people with dementia stated that PHC still needs to improve their investigations and the multiprofessional team work (Socialstyrelsen, 2014).

The tests that are recommended in the guidelines are the Mini Mental State Examination (MMSE) (Folstein et al., 1975) together with the Clock Drawing Test (CDT) (Shulman, 2000) for cognitive screening. No instrument is recommended for structured assessment of function and activity (Socialstyrelsen, 2010). The MMSE is the most commonly used test worldwide for assessing cognitive function (Ismail et al., 2010). The MMSE assesses orientation in time and place, attention, memory, language and visual construction. The MMSE has a maximum of 30 points and higher scores indicate better cognition. It takes about 10 minutes to administer. MMSE has been criticized for having ceiling effects for high premorbid functions and education, and not taking into account the effects of age and sensory impairment (Ismail et al., 2010). In clinical use, it is important to evaluate what subtests failed rather than using the total sum. The MMSE has been seen to be more useful in ruling out dementia in primary care and needs to be supplemented with other tests for best use (Mitchell, 2009). The CDT is a short test and takes 5 minutes to administer. The CDT measures visuospatial and executive functions (Shulman, 2000). A weakness is that different versions and scoring methods exist. There are other cognitive screening tests available but these are not evaluated as much as the MMSE and the CDT.

A test that is mostly administered by occupational therapists in Sweden is Cognistat (formerly known as the Neurobehavioral Status Examination) (Kiernan et al., 1987). In contrast to the MMSE and CDT, the test results are not presented as an overall sum. The results are presented graphically and contain information about the level of impairment (normal/average, mild, moderate, and severe impairment). Cognistat has age-corrected norms and takes about 20 minutes to administer. It includes 10 subtests: orientation, attention, language (comprehension, repetition, and naming), constructional ability, memory, calculation, and reasoning (similarities and judgments). It also includes a more qualitative assessment of word fluency.

Occupational therapist as part of the multiprofessional team

Occupational therapists can contribute to the multiprofessional team with their special focus on occupational performance and how cognitive impairments affect everyday life (AOTA, 2013, Toglia et al., 2009, Wolf and Baum, 2011). When evaluating cognitive impairment and its consequences in everyday life, different methods and approaches are often needed (Hartman-Maeir et al., 2009): interviews or self-reported assessments with the person and others (i.e. relatives, caregivers), observation-based assessments, cognitive screening or more specific cognitive tests. The cognitive evaluation often starts with an interview about the person's own experiences of cognitive problems in everyday life together with an occupational history and screening measurements (Hartman-Maeir et al., 2009). The role and the methods depend on the context where the occupational therapist works. The studies in this thesis involve occupational therapists working in primary care (or community care) and specialist care.

Theoretical framework

Occupational therapy is built on theories explaining human occupation and provides a holistic view of clients (Kielhofner, 2008). Basic assumptions about human occupation are that humans need occupation, occupation affects health and well-being and occupation brings meaning to life and has therapeutic potential (Townsend and Polatajko, 2007). Human occupation plays an important role in a person's well-being, health and development and the body and mind are viewed as integrated aspects of a human being (Kielhofner, 2008). Human occupation refers to the doing of work, play, or ADL within a temporal, physical, and sociocultural context that characterizes much of human life (Kielhofner, 2008, p.5). An easier way to explain this is that human occupation is about the ordinary things that people do in their daily life. However, why and how we do things involves a rather complex interrelationship of different components. The doing means different things to different people. The person's motivation, habits and interests play important roles as well as the person's performance capacity which refers to the physical and cognitive (or mental) abilities that underlies occupational performance. Occupational performance is also greatly affected by the environment. The environment can be supportive or limiting for occupa-

tional performance when a person has impairment (Kielhofner, 2008). If a person suffers from cognitive impairment his performance capacity (cognitive capacity) is reduced and this might lead to limited occupational performance and participation, which leads to decreased health and well-being. The goal of occupational therapy is to support the person's occupational performance and participation in a manner that promotes the possibility of living as full a life as possible (FSA, 2012). The interventions can be directed towards the person or the environment (both physical and psychosocial) and should be client centred.

Activities of daily living

There is no general definition of the concept of ADL although it is commonly used in the literature. ADL is often divided into personal or basic ADL (which includes activities such as personal hygiene, clothing, feeding and toileting) (Katz et al., 1963) and instrumental activities of daily living (IADL) (Lawton and Brody, 1969), which are commonly referred to as independent living abilities. Activities included in this concept are household activities, handling money, shopping and transportation. These activities have a higher demand for cognitive functions than basic ADL and are important for living an independent life in society. Usually, activities such as hobbies or leisure activities or employment are not involved in the concept of IADL. A third ADL concept is described by some authors as advanced activities of daily living (AADL) (Reuben et al., 1990, De Vriendt et al., 2012) or complex activities of daily living (CADL) (Albert et al., 2002), both referring to activities such as employment, leisure and social activities. These three levels of ADL should be evaluated in order to cover all activities in daily life (De Vriendt et al., 2012). In the occupational therapy literature, the ability to perform these three levels of ADL are covered under occupational performance areas of self-care, play/leisure and work (Kielhofner, 2008). Occupations refer to “the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (WFOT, 2010). The Swedish Association of Occupational Therapists defines activity as “execution of a task or action by an individual” (FSA, 2012, p 2).

Cognition in relation to ADL

In the dementia and geriatric literature, the ability to perform ADL is often referred to as functional ability and as a measurement of disability (Abhilash et al., 2004, Reppermund et al., 2011). Dementia affects people's ability to perform activities of daily life, initially in complex activities but progressing to more basic activities such as the ability to cope with dressing and toileting later in the disease course (Armanius Björlin et al., 2004). Younger people sometimes experience the first changes at work (Öhman et al., 2001).

Previous research shows that activities that are affected by cognitive decline include use of telephones and public transportation and management of medications and finances (Avlund and Fromholt, 1998, Barberger-Gateau et al., 1999, Triebel et al., 2009). Problems with these activities together with cognitive deficits can be seen even before individuals develop dementia (Barberger-Gateau et al., 1999). MCI negatively influences an individual's ability to perform complex ADL (Altaire et al., 2009, Aretouli and Brandt, 2009, Burton et al., 2009, Pernecky et al., 2006b) and increases the risk for dementia (Palmer et al., 2003). The ability to perform basic ADL is preserved when the first symptoms of cognitive deterioration occur, whereas the ability to perform complex ADL is more likely to decrease when memory, attention, and executive functions deteriorate (Pernecky et al., 2006a). Performing tasks at a slower speed might be an early indicator of functional change in MCI (Wadley et al., 2007). Cognitive decline affects performance in IADL, whereas ADL is affected when a certain degree of cognitive dysfunction is reached (Aguero-Torres et al., 2002).

Thus, early detection of cognitive dysfunction is of great importance in PHC. In addition, assessment of everyday life activities should be performed in order to know when and how to intervene. The relationship between cognitive dysfunction and the ability to perform everyday life activities is an important issue in clinical practice. Cognitive functions such as executive functions, memory and attention have been shown to correlate with impaired functional status (Pereira et al., 2008, Aretouli and Brandt, 2009, Farias et al., 2009). It is important to assess not only cognitive functions but also the ability to perform complex

ADL in dementia investigations (Nygård et al., 1998, Pernecky et al., 2006a).

Assessment instruments and methods

Several authors have suggested that more sensitive measures of the ability to perform everyday life activities would be helpful in discriminating between elderly persons with no cognitive impairment and persons with MCI who have an increased risk of developing dementia (Pérès et al., 2006, Nygård, 2003, Gold, 2011). Separating the motor and process aspects of functional ability and incorporating the new technology now available in society and in our everyday lives are important aspects (Nygård, 2003). Generic ADL instruments tend to be less sensitive than disease-specific instruments (Abhilash et al., 2004). Assessment of AADL should also be included when evaluating ADL in the elderly to cover all everyday life activities (De Vriendt et al., 2012). Furthermore, the perceived difficulties of using everyday technology among people with cognitive impairment must be taken into consideration when evaluating function (Rosenberg et al., 2009). However, during the literature research no instrument was found to include all relevant ADL areas and existing instruments lacked validity and reliability (Sikkes et al., 2009, Demers et al., 2000).

There are different methods of assessing activities in daily life: self-reporting, informant-based (i.e. relative, close friend, proxy reported) and performance- or observation-based assessments (Sikkes et al., 2009, Loewenstein and Acevedo, 2010). Self-reporting is an important part of the evaluation. However, in most cases, it has to be combined with another assessment such as an informant-based or performance-based assessment because persons with cognitive impairment may have some insight or awareness impairment (Mårdh et al., 2013, Loewenstein, 2010, p 96). Earlier research indicates that when there is discrepancy between the patient's and the informant's report, the person is more likely to progress from MCI to AD (Tabert et al., 2002), thus it is recommended that both assessments should be included in the investigation.

RATIONALE FOR THE THESIS

As the population in the world grows older, the number of people with cognitive impairment increases. More knowledge is needed about how cognitive impairment influences peoples everyday life and their perceived quality of life.

When planning for and evaluating interventions for these people, it is a prerequisite to use psychometrically tested measurements. With clinically useful measurements, it might be easier for health professionals to fulfil the intentions of the requirements of the Swedish National Board of Health and Welfare and help more people.

When assessing or evaluating cognitive impairment and its effect on everyday life, different methods and instruments are used. Some instruments used today have not been sufficiently evaluated and some may not be sensitive enough to capture the problems that people with cognitive impairment might have. In an attempt to fill this gap and improve knowledge, we evaluated the Cognistat for screening for cognitive impairment and developed the Cognitive Impairment in Daily Life (CID) instrument. The CID instrument (for self-reported and informant-based assessments) has been developed in several phases and is an attempt to measure everyday life activities from a cognitive standpoint, focusing on cognitive causations and changes in the person's ability to perform each activity.

AIM

The overall aim of this thesis was to improve knowledge of the consequences of cognitive dysfunction in relation to everyday life and of instruments to make these assessments.

The specific aims were to:

- investigate the relationships between cognitive function, ability to perform ADL, and perceived HRQoL in 85-year-old individuals in Linköping, Sweden;
- investigate the diagnostic accuracy and clinical utility of Cognistat for identifying individuals with cognitive impairment in a primary health care population. In addition, this study investigated the diagnostic accuracy of Cognistat compared with MMSE and CDT;
- develop an instrument measuring self-perceived and/or caregiver reported ability of everyday life activities in persons with suspected cognitive impairment or dementia and perform psychometric testing of this instrument, the Cognitive Impairment in Daily Life (CID);
- explore experiences of cognitive impairment, its consequences in everyday life and the need for support experienced by persons with MCI or mild dementia and their relatives.

METHODS

This thesis includes both quantitative and qualitative research methods as well as instrument development. The four studies each involved separate populations. An overview of the four studies with the aims, description of the population sample and study design are presented in Table 1.

Table 1. Overview of the aim, sample and study design in study I–IV

Study	Aim	Sample	Design
I	Investigate the relationships between cognitive function, ability to perform ADL, and perceived HRQoL in 85-year-old individuals in Sweden	Persons born in 1922 ($n = 373$)	Quantitative cross-sectional study
II	Investigate the diagnostic accuracy and clinical utility of Cognistat in a primary care population and compare it with MMSE and CDT	Patients and controls in four primary health care settings ($n = 52 + 29$)	Quantitative cross-sectional study
III	Develop an instrument measuring self-perceived and/or caregiver reported ability to perform ADL in persons with suspected cognitive impairment or dementia and to perform psychometric testing of this instrument, the CID	Patients in a primary health care setting and in a specialist memory investigation unit and their relatives ($n = 51 + 49$)	Instrument development
IV	Explore experiences of cognitive impairment, its consequences in everyday life and the need for support experienced by persons with MCI or mild dementia and their relatives	Patients and relatives in memory investigation unit ($n = 13 + 13$)	Qualitative interviews

Participants

In **study I** all persons born in 1922 and living in Linköping municipality in Sweden ($n = 650$) were invited to take part in the study by post. Of these 650 individuals, 586 (90%) replied and 496 (76%) provided written informed consent and answered a postal questionnaire which was the first part of the study. Drop outs included 52 individuals who could not be contacted by post or by telephone. Twelve individuals had died. In total, 380 of those who filled in the questionnaire were willing to take part in the next phase of the study, a home visit by an occupational therapist. At the home visit, the occupational therapist interviewed the participants to gather information about their ADL abilities and performed a cognitive assessment using the MMSE (Folstein et al., 1975). An internal drop out of seven cases occurred because the MMSE was not completed. Thus, the results are calculated on 373 individuals (Figure 1). A larger proportion of men than women participated. The majority were living in ordinary housing (92%).

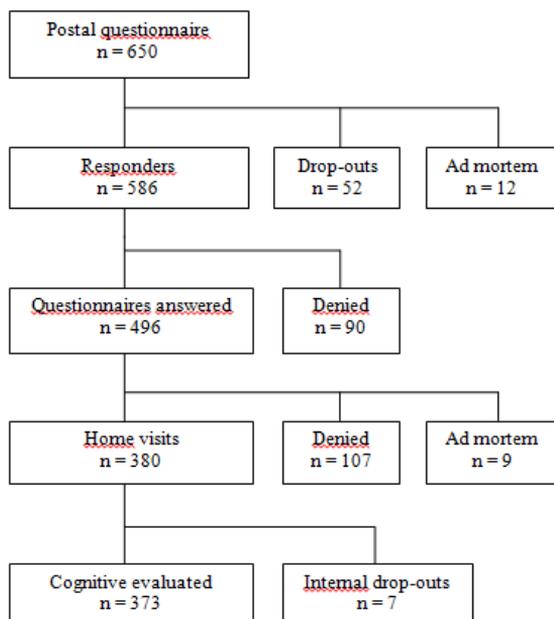


Figure 1. Flowchart study I

The participants in **study II** were systematically recruited from four PHC centres between 2007 and 2009. The participants were asked to take part in the study during an appointment with a general practitioner (GP). The inclusion criteria were: older than 65 years, any complaint or suspicion of cognitive symptoms expressed either by the patient, an informant, or primary care staff. In all, 52 people met these criteria. During the same period, patients visiting the GP for medical reasons other than possible cognitive symptoms were asked to participate in a clinical control group. Those participants extended the study group to assure its clinical relevance. Inclusion criteria for the comparison group were as follows: age older than 65 years and no complaint or suspicion of cognitive symptoms expressed either by the patient, an informant, or a GP. Twenty-nine people met the criteria and were willing to participate. Exclusion criteria for all participants were a medical record of recent stroke, brain tumour, brain-related infection, head trauma, ongoing verified psychiatric illness, a previous dementia investigation, or a known dementia diagnosis.

The participants in **study III** were patients with suspected cognitive impairment and their relatives. These patients were referred to an occupational therapist for cognitive evaluation between August 2012 and February 2013 as part of an ongoing dementia investigation. Inclusion criteria were ability to speak and understand the Swedish language and to have a relative involved in the investigation. In total, 62 patients were invited to participate. Eleven patients and two relatives declined and 51 patients and 49 relatives participated.

The participants in **study IV** were recruited at a geriatric memory clinic. Five people with MCI and eight people with mild dementia and their relatives (2 children and 11 spouses) participated, in total 26 participants. They were diagnosed according to the diagnostic criteria from a key symposium for MCI (Winblad et al., 2004) or DSM IV criteria for dementia (APA, 2004) and were at level 3 or 4 according to the Global Deterioration Scale (Reisberg et al., 1982). A heterogeneous sample regarding gender, age and time since diagnoses was chosen.

Data collection

Postal questionnaire

The postal questionnaire included questions about demographics; education, socioeconomic status (SES), occupation, social network, and use of assistive technology and was sent to all participants in **study I**. SES, referring to the person's previous occupation, was classified into the following categories: low (blue collar); intermediate (white collar); and high (self-employed or academic profession) (Dutton, 1989).

The EQ-5D

The EQ-5D (Brooks, 1996, EuroQol Group, 1990, Rabin and Charro, 2001) was used for measuring HRQoL in **study I**. The instrument was attached to the postal questionnaire. This is a generic instrument that assesses HRQoL in terms of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D response alternatives are no problems, moderate problems, or extreme problems. The scores on the five EQ-5D items were converted into a single summary index value generated by means of the Time-Trade-Off (TTO) method (Dolan, 1997, Rabin and Charro, 2001). The EQ-5D index value ranges from -0.594 to $+1$, where $+1$ represents perfect health, 0 is a state equivalent to death, and -0.594 is worse than death (Dolan, 1997). A visual analogue scale (VAS) recording the individual's self-rated valuation of health is included, ranging from 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-5D is considered to be a practical and easy to administer tool for assessing the elderly population (Holland et al., 2004), valid in a general population (Johnson and Pickard, 2000), and effective in persons with cognitive impairments (Wolfs et al., 2007).

Assessment of PADL

In **study I**, the ability to perform PADL was assessed using four questions that addressed the participant's ability to perform the following activities: dressing and undressing; bathing; toileting; and eating. Answer alternatives were independent, need of some help, or need of much help. This assessment was done at the home visit.

Assessment of IADL

In **study I**, the Instrumental Activity Measure (IAM) (Andrén et al., 1997, Andrén and Grimby, 2004, Daving et al., 2009) was used to assess dependence and perceived difficulty in IADL for eight items (locomotion outdoors, simple meals, cooking, public transportation, small-scale shopping, large-scale shopping, cleaning, and washing) with the following scoring alternatives: 4 = no problems; 3 = some problems; 2 = great problems; and 1 = impossible.

Cognitive screening tests

The MMSE (Folstein et al., 1975) was used to assess cognitive function in **studies I, II, III and IV**. The MMSE assesses orientation in time and place, attention, memory, and language and visual construction. The MMSE has a maximum of 30 points where higher scores indicate better cognition. The cut-off levels used in this study were: ≥ 27 = no impairment; 21–26 = mild; 11–20 = moderate; and ≤ 10 = severe impairment (Folstein et al., 2001). A cut-off of ≥ 23 was used in study II for comparison.

The CDT was used in the **study II**. The CDT is a short cognitive test that measures visuospatial and executive functions with an administration time of 5 minutes (Shulman, 2000). The CDT was administered by asking the participants to perform the following task on a blank sheet of paper: “Draw the face of a clock, put the numbers in the right place, and set the time to 10 past 11.” A five-point scoring scale was used whereby a perfectly drawn clock scored 5 points (Shulman, 2000). A minor visuospatial error scored 4 points. If an inaccurate representation of “10 past 11” is drawn but the visuospatial organization is well done, the score is 3 points. If the visuospatial disorganization of the numbers is moderate, the score is 2 points. If the visuospatial disorganization is severe, the score is 1 point. If there is no reasonable representation of a clock, the score is 0. A cut-off of 4 or less is used for cognitive impairment in the analyses.

The Cognistat was evaluated in **study II**. This test includes 10 subtests: orientation, attention, language (comprehension, repetition, and naming), constructional ability, memory, calculation, and reasoning (similarities and judgments) (Kiernan et al., 1987). Each subtest, with the exception of memory and orientation, has a screening test. If the

patient fails the screening item, a metric section is administered. A higher score indicates a higher level of function in each domain. The result is presented graphically and contains information about the level of impairment (normal/average, mild, moderate, and severe impairment). The test results are not presented as a global sum. Cognistat has age-corrected norms and takes about 20 minutes to administer. In this study, Cognistat was administered in accordance with standardized instructions provided in the Swedish manual (Caneman, 2001). When analysing against diagnoses, a cut-off required one or more subtests to be in the impaired range for the participant to be considered cognitively impaired. Analyses were also made using a cut-off of two or more subtests within the impaired range as comparison.

Instrument development

The CID instrument is a self-reported and/or relatives/caregiver-rated measure of the ability to perform ADL in people with suspected cognitive impairment. The first steps in developing the CID are described in **study III** (Figure 2). Phases 1–3 are presented in the thesis; phases 4 and 5 are ongoing. The development process follows *A Guide for Instrument Development and Validation* by Benson and Clark (1982) and the *Standards of Educational and Psychological Testing* (1999).

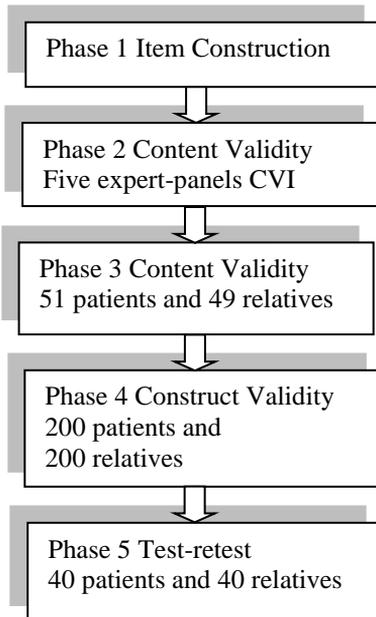


Figure 2. Instrument development chart

Item construction (phase 1): As a start the 12 activities with 47 actions in the Swedish ADL taxonomy (Törnquist and Sonn, 1994) were included. As a result of the literature research and clinical experience, 7 activities with 28 actions were added. To ensure face validity, the first version was presented to a group of experienced occupational therapists working with dementia in primary care or in specialist care; 9 occupational therapists participated (years of experience 7–22 years). A group discussion was held and changes were suggested so that the items more clearly reflected the cognitive aspects of activity performance. The items were then revised in discussions with the last author and an experienced occupational therapist colleague on several occasions. This modified version included 23 activities and 95 items.

Content validity (phase 2): This modified version was examined by five expert panels to ensure content validity. Five different investigative units (geriatric departments) in southeast Sweden were asked to participate in the expert panel. Twenty-six professionals in different categories participated. A Content Validity Index (CVI) was used and analysed as suggested by McGartland et al. (2003). The results from all five expert

panels resulted in adjustments and a reduction in the number of items. After revision, the second version contained 23 activities and 58 items.

Content validity (phase 3): To further evaluate the content, a pilot study was performed. Participants included both patients and their relatives. Nine occupational therapists working at one PHC facility or at a specialist memory clinic collected the data. They interviewed the patients and documented their answers in the instrument using a four-point scale. Directly after this interview, the patients were asked four questions by the same occupational therapist about the content of the instrument. The same instrument was rated by a relative who also answered four additional questions regarding the content of the instrument.

The occupational therapists who took part in data collection were asked to take notes regarding the use and content of the instrument and they also participated in a group discussion when the data collection was finished.

Qualitative interviews, Grounded Theory

Qualitative interviews with a focus on people's experiences of cognitive decline and its consequences in everyday life were performed either in the participants' home or at a memory clinic depending on the participants' preference. An interview guide with topics covering different occupational areas (work, leisure, social participation, relations and communication, household activities and personal activities) and need for support was used. The purpose of the guide was to generate conversation and questions were added if and when new areas of interest arose. All participants were interviewed separately except for one person who wanted the relative present as a support during the interview. The interviews lasted between 40 and 95 minutes and all participants were able to express themselves and were willing to share their stories. They were given time to gain trust in the interviewer both by phone and before and after the interview.

Statistical and qualitative analysis

An overview of the statistical methods used in the different papers is shown in Table 2.

Table 2. Overview of the statistical methods in papers I–IV

	I	II	III	IV
<i>Descriptive data</i>				
Number (%)	x	x	x	x
Mean \pm SD	x	x	x	x
Range	x	x	x	x
<i>Parametric test</i>				
Student <i>t</i> test	x	x		
<i>Non-parametric test</i>				
Chi-squared test or the Fisher exact test	x	x		
Mann-Whitney <i>U</i> test	x			
Spearman rank correlation	x			
<i>Diagnostic test</i>				
Sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV)		x		
Area under the receiver operating characteristic curve (AUC)		x		
Clinical Utility Index (CUI) and Youden Index (<i>J</i>)		x		
<i>Kappa agreement</i>			x	

In **study I**, statistical non-parametric analyses were performed using the PASW 18.0 statistical package. The results from the EQ-5D items were dichotomized into two categories: being independent/having no problems, no pain/discomfort, no anxiety/depression or being in need of help/having problems, pain, worries. The PADL items were dichotomized into two categories: being independent or being in need of help. The IAM items were dichotomized into two categories: having problems or having no problems. For comparative analyses, participants were divided into three groups according to MMSE scores: se-

vere/moderate impairment (0–20); mild impairment (21–26); and no impairment (27–30). Comparisons were also performed between participants with cognitive impairment (MMSE 0–26) and participants without cognitive impairment (MMSE 27–30). Regarding differences between the groups based on MMSE scores, the chi-squared test was used for categorical data. The Mann-Whitney *U* test was used for ordinal scales (MMSE and EQ-5D items) as well as for the EQ-5D index value and VAS as the data were not normally distributed. A *P* value <0.05 was considered statistically significant. Spearman's rank-order correlation was used for analyses of associations between cognition revealed by the MMSE, years of education, and HRQoL as found for the EQ-5D VAS and EQ-5D index value.

In the **study II**, quantitative analysis of the data was performed using SPSS for Windows 19.0 (SPSS, Inc., Chicago, IL). The chi-squared and Fisher exact tests were used to compare differences in gender, native language, medical history, and medical drugs between the groups. Age, education, duration of symptoms, and test scores for MMSE, CDT, and Cognistat, and the neuropsychologist test battery were compared using the *t* test. A *P* value <0.05 was considered statistically significant throughout the analysis. Sensitivity, specificity, PPV, and NPV, and the area under the receiver operating characteristic (ROC) curve (AUC) with 95% confidence intervals were calculated using the final diagnoses as the standard. The CUI+ ((sensitivity × PPV) – 1) (Mitchell, 2011) and the Youden index (*J*) ((sensitivity + specificity) – 1) were calculated (Youden, 1950). Analysis of the MMSE and the CDT combined was also done (the results of the two tests were analysed as one test and if participants scored under the cut-off in at least one of the tests, they were considered positive). The AUC was also analysed for each subtest of Cognistat. A power calculation indicated that that a sample size of about 30 patients per group was sufficient.

In **study III**, descriptive analyses were performed using IBM SPSS Statistics for Windows, version 21.0 (IBM Corp, Armonk, NY). The result from the four-point scale in the pilot study was dichotomized into two categories: difficulties or no difficulties. If any difficulties were found (i.e. some difficulties, severe difficulties or impossible) in the activity area, it was categorized as difficulties. Items that were left blank by occupational therapists or relatives were considered as internal drop

outs. The agreement level between patients' and relatives' answers was analysed using kappa statistics. Reliability in terms of internal consistency for the instrument was calculated by Cronbach alpha on both patients' and relatives' answers for the instrument.

In **study IV**, some descriptive statistics for demographics was calculated using SPSS Statistics for Windows, version 21.0 (IBM Corp, Armonk, NY). The qualitative analysis was inspired by the Grounded theory methodology (Strauss and Corbin, 1990). The interviews were read through repeatedly to get a thorough understanding of the narrative; thereafter, a process of open coding was applied. Codes that seemed to pertain to the same phenomena were categorized together, compared and revised. The codes were then put together in a new way as in axial coding, categorized and named (Strauss and Corbin, 1990). Data collection and analyses were done in parallel until the final categories were set and no new data emerged (saturation was reached). The first author did the analysis, which was then discussed with and checked by the third author (EW) to ensure the quality and credibility.

ETHICAL CONSIDERATIONS

Ethical approval was obtained for all four studies from the Regional Ethical Review Board in Linköping, Sweden (dnr 2006/141-06 for paper I, dnr 2007/137-07 for paper II, dnr 2012/160-31 for paper III, and dnr 2012/307-31 for paper IV). Written informed consent was obtained from all participants and they were informed that participation was completely voluntary and could be withdrawn at any time. All data were analysed on a group level.

In studies III and IV, both patients and relatives received oral and written information about the study and written informed consent was obtained from both parties. The patient had to give their approval that a relative could be contacted and participate.

When doing research that includes people with cognitive impairment, it is important to take into consideration that these people might have a limited understanding of the aim of the research. Therefore, we put extra effort into informing about the fourth study: that it was not part of the treatment in the clinic and that none of the individual results were revealed to the professionals that the people met during their treatment at the clinic. However, we did inform them that if something came up during the interviews; we could arrange contact with a member of the team for further treatment if participants wanted this.

SUMMARY OF THE FINDINGS

Paper I

The aim of this paper was to investigate the relationships between cognitive function, ability to perform ADL, and perceived HRQoL in 85-year-old individuals in Linköping, Sweden.

Main results

The mean value for the MMSE was 27 (SD = 3.4) for all participants, ranging from 6 to 30, and no difference was found with respect to gender. When using the cut-off of <27 points, 108 (29%) individuals had cognitive impairment. Perceived health assessed by EQ-5D showed that 50% of all participants had no mobility problems, 85% were independent in self-care, and 74% managed their usual activities, 67% perceived pain/discomfort and 35% had anxiety/depression. The mean score on the EQ-5D VAS for perceived health was 67 (SD = 19.8) and the index value was 0.72 (SD 0.24). The majority of the participants were independent in the four PADL items (84–99%). Participants with impaired cognition reported more problems with bathing and dressing compared with the group without cognitive impairment. Among all eight IADL items, a larger proportion of participants with cognitive impairment reported the need for assistance compared with the group without cognitive impairment. Divided into three MMSE groups, all IADL items except locomotion outdoors showed significant differences between groups.

There were significant but low correlation coefficients between the EQ-5D index value and the MMSE score ($r = 0.145$, $P < 0.001$) and between EQ-5D VAS and MMSE score ($r = 0.178$, $P = 0.001$), higher ratings on perceived quality of life correlated with higher results on MMSE. Higher cognitive function was associated with better ability to perform in all IADL items measured by IAM. There was also a significant relationship between education years and MMSE score ($r = 0.192$, $P < 0.001$), indicating that more education years correlates with better cognitive function. The correlation coefficient between SES and MMSE was $r = 0.259$ ($P < 0.001$).

Conclusions

There seems to be a relationship between cognition, ADL and quality of life. Early detection of cognitive impairment is vital for establishing interventions aimed at reducing inactivity and sustaining or improving a person's activity level and thus quality of life.

Paper II

The aim of this study was to investigate the diagnostic accuracy and clinical utility of Cognistat for identifying individuals with cognitive impairment in a primary care population. In addition, this study investigated the diagnostic accuracy of Cognistat compared with MMSE and CDT.

Main results

Among the group who visited PHC for reasons other than cognitive symptoms ($n = 29$), two participants had a medical history and obvious clinical signs that indicated undiagnosed cognitive decline when evaluated by the occupational therapist at the PHC and verified at the specialist memory clinic. These two participants were considered drop outs from the cognitively healthy group and their results were not analysed as part of the study. Of the 52 participants who visited a primary care facility primarily for suspected cognitive impairment, six were diagnosed as cognitively healthy. Thus, 46 participants has a final diagnosis of cognitive impairment and 33 participants did not. Of the 46 participants with a final diagnosis of cognitive impairment based on the criteria used in this study, 16 had MCI (35%), 12 had AD (26%), 5 had VaD (11%), 6 had mixed dementia (13%), 2 had unspecified dementia (4%), 1 had Lewy body dementia (2%), 1 had dementia from Parkinson disease (2%), and 3 had a comorbidity with depressive disorders (7%).

The results for all three tests were significantly lower in the group with cognitive impairment. The most prominent scores for the Cognistat subtests were found for memory and construction.

The Cognistat had good diagnostic accuracy with the best sensitivity of the three tests (Table 3). However, the specificity and PPV for Cognistat were slightly lower than for the MMSE, although they seemed to be acceptable. When using the cut-off of at least two subtests within the range of impairment, Cognistat's specificity and PPV increased to 0.97 and 0.96, respectively, but the sensitivity decreased to 0.57. When comparing Cognistat with MMSE and CDT combined, Cognistat showed better results than the combined tests. With a Clinical Utility Index (CUI+) of 0.72, Cognistat was classified as good (Mitchell, 2011), whereas the MMSE was satisfactory. This classification remains the same when the CDT is added.

Table 3. Diagnostic accuracy of the tests

Test cut-off	Sensitivity	Specificity	PPV	NPV	CUI+
Cognistat ≥1 subtest	0.85	0.79	0.85	0.79	0.72 (good)
Cognistat ≥2 subtests	0.57	0.97	0.96	0.62	0.55 (satisfactory)
MMSE ≤26	0.59	0.91	0.90	0.61	0.53 (satisfactory)
MMSE ≤23	0.26	1.00	1.00	0.49	0.26 (poor)
CDT ≤4	0.26	0.88	0.75	0.46	0.20 (poor)
MMSE/CDT ≤26 and ≤4	0.70	0.79	0.82	0.65	0.57 (satisfactory)
MMSE/CDT ≤23 and ≤4	0.46	0.88	0.84	0.54	0.39 (poor)

CDT, Clock Drawing Test; CUI, Clinical Utility Index; MMSE, Mini Mental State Examination; NPV, negative predictive value; PPV, positive predictive value.

The results illustrated in ROC curves for the tests with the highest cut-off are presented in Figure 3.

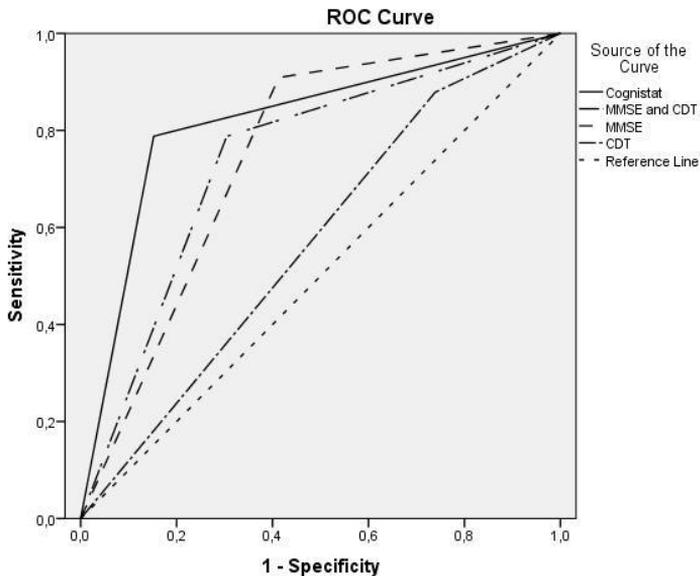


Figure. 3. The ROC curves for Cognistat ≥ 1 subtest, MMSE ≤ 26 , CDT ≤ 4 , and combined MMSE and CDT ≤ 26 or ≤ 4 .

Memory and construction were the most prominent findings with an AUC of 0.84 and 0.73, respectively. The AUCs for other subtests of Cognistat were less than 0.70.

Conclusions

Cognistat can be used as a first screening for cognitive impairment in PHC. It is more sensitive than both the MMSE and the CDT and still specific and can be helpful to determine who needs to be evaluated further.

Paper III

The aim of the third study was to develop and test the psychometric properties of the CID instrument measuring self-perceived and/or care-giver reported ability of everyday life activities in persons with suspected cognitive impairment.

Main results

The results of the CVI by expert panels were good with a total score of 0.83. The CVI was used and analysed as suggested by McGartland et al. (2003). According to the group discussions, some adjustments were made, resulting in a reduced number of items under each activity.

The result of the pilot study showed that the majority of the patients (84%) did not miss any activity. Nine patients mentioned missing items e.g. difficulties getting started, needing to take more notes, looking for belongings and putting them in the right place, and a fear of missing appointments. No one thought the questions during the interview were difficult to answer but a couple of patients had difficulties answering the four questions on the content due to their memory problems (as reported by themselves). Most relatives (88%) thought that the instrument included relevant activities and no one thought that any activity should be removed. Thirty-four relatives (70%) agreed largely or completely that the instrument captured the difficulties their relatives' had. Some general suggestions were: it can be difficult sometimes to separate cognitive symptoms from others; the patient's interest has great impact; some items might need to be separated; and more explanations about the items might be needed. An answer alternative for "I don't know/can't be assessed" was suggested as a complement.

All activities except eating and drinking were perceived as difficult by at least some of the patients; only a few patients had problems with personal activities. Activities most frequently scored by the patients ($n = 51$) as causing difficulties were social contacts (53%), telephone (53%), medication (49%), conversation (67%) and orientation in space (55%). Not applicable was used more frequently in the patient interviews, for example, with regard to computer use (24 patients/16 relatives) and laundry (17 patients/9 relatives). Internal consistency was good with a Cronbach alpha for the total instrument of 0.79 for the patients' answers. A value above 0.70 is recommended (Streiner & Norman, 1994).

Relatives' responses ($n = 49$) indicated difficulties more often than the patients' responses, including personal activities: telephone (67%), shopping (61%), reading (63%), conversation (71%) and orientation in space (73%). There were also fewer internal dropouts (items left unan-

swered) by relatives and not applicable was used less frequently by relatives. Cronbach's alpha for the total instrument scored by relatives' was 0.80.

A couple of occupational therapists commented that the order of the activities did not come naturally and that they wanted more space for making notes. There were some comments on the scoring and how to separate between the four scoring alternatives. A suggestion was to have only three rates.

During the different development phases of the instrument, the cognitive aspects of occupational performance became clearer and separated in the instrument. In order to arrange the activities in a more natural order, the activities were sorted into groups of complex activities, technical activities, household activities, personal activities and relations/communication. The rating scale was adjusted to a three-point scale: no difficulty (the person is completely independent, performing the activity as before); some difficulty (the person can perform the activity in whole or in part but needs extra time or some assistance and the performance is slightly different from the person's previous ability); severe difficulty (the person has great difficulty performing the task, performs the task incorrectly or poses a risk to himself or the environment; a clear difference from the person's previous ability is evident) and an additional score for "do not know/cannot judge (the person or relative does not have enough information to rate this)". The items for each activity were adjusted and sorted into cognitive functions, i.e. initiating, planning, performance, attention, memory and time perception under each activity where appropriate (see example in Table 4). Some cognitive domains were not suitable for all activities (Table 5). This meant that the number of items increased giving a total of 92 items for the 23 activities.

Table 4. Two activities and the associated items assessing specific cognitive functions in the final version of CID

	No diffi- culties	Some difficul- ties	Severe difficul- ties	Don't know/can not judge
Work (paid professional employment)				
Initiative: takes on duties at work				
Planning for tasks during the day and week				
Performance: perform tasks as previously				
Attention: can focus on what you do at work without being disturbed by environmental factors; can handle stress as previously				
Memory recall: routines, times, meetings at work				
Transport/travel (transportation service, bus, train or longer trips, specify in notes what is applicable)				
Initiative: takes trips as previously				
Planning for the trip, packing, reading timetables, buying tickets, order the travel/journey				
Performance: manage the actual trip itself, manage tickets				
Memory: recall times for travel				

Table 5. Overview of activities and cognitive functions in the CID

Activity areas	Activities (cognitive function) ¹
Complex activities	Work (I, PL, PF, A, M)
	Leisure (I, PF, A, M)
	Transportation (I, PL, PF, M)
	Car driving (I, PF, A, M)
	Economy (I, PL, PF, M)
Technology-related activities	Computer (I, PE, M)
	Television (I, PL, PF, A, M, T)
	Telephone (I, PF, M, T)
Household activities	Cooking (I, PL, PE, A, M, T)
	Shopping (I, PL, PF, M)
	Cleaning (I, PL, PF)
	Washing (I, PL, PF, M)
Personal activities	Medication (I, PL, PF, M, T)
	Mobility (I, PF, A, M, T)
	Clothing (I, PL, PF, T)
	Personal hygiene (I, PL, PF, M, T)
	Toilet visits (I, PF)
	Eating/drinking (I, PL, PF, M, T)
Relationships/communication	Contacts with society (I, PF, M)
	Contacts with family and friends (I, PF, M)
	Conversation (I, PF, A, M)
	Reading (I, A, M)
	Writing/notes (I, PF)

¹I, initiative; PL, planning; PF, performance; M, memory; A, attention; T, time perception.

Conclusions

The CID instrument is a self-reported and/or relatives/caregiver-rated measure of ability to perform ADL in people with suspected cognitive impairment. The ability to perform ADL is assessed from a cognitive standpoint and the CID aims to capture changes in the person's abilities. The instrument has been developed in several phases and has been adjusted after each step. The CID has good content validity; however, further testing of reliability (test-retest and internal consistency) and construct validity is ongoing.

Paper IV

The aim of the fourth study was to explore experiences of cognitive impairment, its consequences in everyday life and the need for support experienced by persons with MCI or mild dementia and their relatives.

Main results

The categories that emerged were noticing cognitive change, changed activity pattern, uncertainty of own ability and environmental reactions, coping strategies, support in everyday life, support from health care system, consequences in everyday life for relatives, and support for relatives. All categories except for the last two involve the individuals and their relatives.

Conclusions

Perceived cognitive impairment and its consequences in everyday life were individual and differed among people with MCI or dementia and their relatives. Thus, health care professionals must listen to both the person with cognitive impairment and their relatives for optimal individual care planning. Support such as education groups and day care could be more tailored towards the early stages of dementia.

DISCUSSION

Main findings

In our first study, the main finding in this general population was that IADL functions are negatively affected by cognitive impairment in participants, even with mild impairment, while the capacity to perform PADL is less affected. This is shown in previous studies on MCI (Nygård et al., 1998, Nygård, 2003, Allaire et al., 2009, Wadley et al., 2007, Avlund and Fromholt, 1998), in a cross-sectional study in Belgium (Kurz et al., 2003) and in community-dwelling elders in Japan (Dodge et al., 2005). The results confirm that not only cognition has to be assessed in dementia investigations; ADL and especially IADL should also be considered. Structured assessments of both IADL and cognition could be performed as a screening in primary care in order to detect small cognitive deficits at an early stage so that interventions can be initiated with the aim of improving and/or retaining a person's activity level and thus quality of life. Another important finding was that cognitive impairment, even mild, was related to lower HRQoL. A Danish study in patients with dementia found that being dependent on others in ADL had a negative effect on quality of life (Andersen et al., 2004). Quality of life and ability to perform ADL are shown to be associated with subjective memory complaints, thus, this should be borne in mind by health workers in daily consultations (Montejo et al., 2012). Waldorff et al. (2008) confirms the importance of asking patients about memory problems; a cross-sectional study revealed that quality of life was the only predictor of self-reported memory problems.

In the second study, we found that Cognistat has relatively good sensitivity and PPV for detecting cognitive impairment and an acceptable specificity and NPV in a primary care population. The high sensitivity in combination with acceptable specificity and the high PPV indicates that the test is useful in primary care. The negative aspect of a test with high sensitivity and low specificity is the risk of overdiagnosis. On the other hand, tests with low sensitivity and high specificity increase the risk of underdiagnosis, with the added risk that patients and relatives do not receive adequate social support and medical treatment. This study investigated a population with a high proportion of patients with cognitive impairment; therefore the predictive values should be interpreted

with this in mind. To evaluate the test in the whole primary care population, it would have been necessary to include all patients over the age of 65 years at the time of inclusion, a condition that was not feasible. On the other hand, we do not recommend screening all patients over the age of 65 years for cognitive impairment; this study investigated the clinical utility of Cognistat in primary care patients in whom some sort of cognitive decline was suspected.

The results indicate that Cognistat is more sensitive than the MMSE and yet still specific. Earlier research (Johansson and Wressle, 2012, Lamarre and Patten, 1994, Fields et al., 1992) supports our finding that the sensitivity of Cognistat was higher than that of the MMSE, but the relatively high specificity is more prominent in this study group than in earlier research, which suggests that Cognistat would be useful in primary care settings. In comparison with MMSE and CDT combined, Cognistat is more sensitive with the same specificity and a slightly higher PPV. The MMSE and CDT combined was second best. Our results show that the MMSE and the CDT not are the ideal tests for detection of cognitive impairment. The study confirms earlier research suggesting that the MMSE is better at ruling out dementia than detecting it (Mitchell, 2009). The MMSE and CDT are recommended in the national guidelines but our results indicate that there is a need for better cognitive instruments and that it is important to continue evaluating the tests in use today. One improvement is the standardized Swedish version of the MMSE (MMSE-SR).

Cognistat is appealing as a cognitive instrument for primary care because it includes several cognitive subtests but is still easily administered. The multidomain perspective adds valuable information in a clinically applicable way with the possibility of presenting the results graphically and providing information about the level of impairment. DSM IV requires that memory and another cognitive domain is impaired for a diagnosis of dementia and a test that includes more cognitive domains than memory might help the GP to determine a diagnosis. The screening and metric procedure in Cognistat is appealing and some qualitative data are provided during the test that is not presented in these figures. However, the test might be improved and be even more sensitive with the addition of a short subtest of executive function.

The time it takes to perform the tests is important, especially in a PHC setting. The Cognistat takes more time to administer than the MMSE, in some cases twice as long, but compared with other multidomain instruments, 20 minutes is acceptable. The economic cost must also be considered. The Cognistat has to be purchased unlike the MMSE and the CDT, which are free of charge. The extra time it takes to perform Cognistat has to be considered as a limited cost if the test can lead to an early correct diagnosis and treatment with the benefit of lower social cost. In Sweden, the use of a multiprofessional team is recommended in the investigation and care of people with dementia (Socialstyrelsen, 2010).

It is not possible for the GP to administer more than a short test at the first appointment but other team members such as an occupational therapist or a nurse can administer other tests during another appointment and then discuss the results with the GP. The study results indicate that Cognistat, instead of or as a complement to the MMSE and the CDT, can be used in primary care as an initial instrument to evaluate cognitive impairment.

A disadvantage of Cognistat might be that it does not include tests that measure processing speed or more demanding frontal or executive functions (some subtests, however, do incorporate measures of executive functions). An earlier study pointed out that psychomotor speed and executive function together with verbal memory might predict dementia (Tabert et al., 2006). In Sweden, Cognistat is administered by occupational therapists. In addition to evaluating cognitive function, the occupational therapist can estimate the consequences of impairment in daily living and plan for further interventions that aim to restore or improve the functioning, activities and participation of patients with cognitive impairment. The results of the test always need to be interpreted within the patient's daily life situation. A weakness of this study was that no instrument covering ADL was used.

The third study showed that the CID instrument has good content validity and is considered to have clinical usefulness in dementia investigations. The content has been thoroughly examined in different ways both by professionals and by patients and relatives. As a result of the expert panels, the number of items decreased in an attempt to have a more feasible instrument; however, the outcome of the pilot study did

point to the fact that relatives needed more items. Relatives suggested separating items and clarifying different aspects such as initiative and planning and memory. This led to the idea of separating items on the basis of different cognitive functions in order to have a clearer distinction between issues with initiating, planning, and performing tasks or problems related to memory.

One important aspect was to develop an instrument that could be used in different ways, i.e. with the patient, with a relative or with the patient and a relative together. In clinical reality, different individuals have different needs. Some patients do not wish to include a relative in the evaluation and some patients do not wish to be assessed through observation. Some patients might prefer to fill in the instrument together with a relative, however, in this study, individual assessment was chosen in order to compare their results. An investigation often starts with an interview with the patient and then information from a relative, and by observations performed by an occupational therapist. By asking about both the patients' and the relatives' perceptions of everyday problems, we can get a better picture of the problems occurring in occupational performance, which helps us to plan relevant interventions. As the literature shows, lower cognition is associated with more difficulties in IADL and people can have difficulties in daily life even in MCI (Reppermund et al., 2011). This instrument will hopefully be helpful in capturing these difficulties.

Finally, in the fourth study, the aim was to explore experiences of cognitive impairment, its consequences in everyday life and the need for support by using qualitative interviews. The main findings were that people with MCI or dementia experienced cognitive changes that could be burdensome and activity patterns changed. Most considered themselves capable of coping on their own. However, feeling safe when being in the health care system and trusting that relatives would stand up for them when necessary were mentioned. The relatives noticed cognitive changes and disruptions to activities to a greater extent and tried to be supportive in daily life as best they could.

Changed activity patterns covered many different activities in everyday life from work to more personal activities. It was notable that taking care of personal hygiene and appearance was mentioned as changed.

This is not included or mentioned as a symptom in the early stages of dementia (Reisberg et al., 1982, Winblad et al., 2004). However, in another qualitative study with the same target group (people with MCI and mild dementia), relatives also reported that some people neglected their personal appearance, e.g. shaving and washing less frequently (Frank et al., 2006). Normally, a basic ADL measure is not used in clinical investigations in the early stages of the disease and an instrument such as the ADL Index (Katz et al., 1963), which only measures independence or dependence in activities, would probably not have captured these difficulties. The present results, however, show that questions on managing hygiene and more personal activities should be raised at an early stage. The use of an IADL instrument such as the Lawton scale (Lawton and Brody, 1969) in clinical settings might be feasible but still there is a chance of missing activities such as leisure, social activities and communication, which seem to deteriorate in the early stages. There was a discrepancy between the people with MCI and the people with dementia in the way they spontaneously told about the consequences in everyday life. It appeared to be easier for those with MCI, while those with dementia needed more prompting and more follow-up questions. A good method was to go through a normal day and then ask about any shortcomings. This suggests that a checklist or other instrument that covers different areas of activity might be useful when interviewing patients with dementia in clinical settings. This speaks in favour of using an instrument like CID. Most of the activities that emerged as changed are included in the instrument.

People with MCI/dementia gradually decrease their areas of activity and their life space (Chung et al., 2008, Vriendt et al., 2013). An interesting finding in our study was that this was not always experienced as a problem by them, but it was seen as a problem by relatives. This also confirms the need to include a relative when assessing the consequences in daily life for the person and the relative.

There is a need for more public information about dementia and the fact that there are different stages and individual differences. People with dementia seem to be dependent on relatives and friends who can accept their shortcomings and find ways to handle them. Having AD is not the same for everyone and the same applies to the carers who have different experiences of the burden felt (Nay et al., 2014). The benefits

of career support groups have been highlighted (Chien et al., 2011); however, in our study it became clear that it is important to have groups that are matched in terms of age and degree of dementia.

There was a discrepancy between the stories of those with MCI and, in particular, those with dementia, and the stories of the relatives. Awareness differed among people with MCI or dementia. Lack of awareness could lead to problems in everyday life according to the relatives and interfered with the use of external memory strategies. In conclusion, experiences of cognitive impairment and its consequences in everyday life were very individual and varied among the participants and their relatives. Thus, it is important for health care professionals to listen to both the people with MCI or dementia and their relatives when planning optimal individual care. People with MCI or dementia and their relatives might need help with how to communicate about these issues and how to handle things in everyday life. In line with earlier studies, the present results indicate that even people with MCI may have insight problems (Frank et al., 2006) and need support like those with AD (Mårdh et al., 2013).

Methodological considerations

In the first study, the mean value for MMSE was rather high but participants' scores showed a wide range. One limitation is the large proportion of non-participants from the target population of 85 year olds ($n = 650$); more non-participants were living in sheltered housing compared with participants and they probably had cognitive impairments to a greater extent. The cut-off at <27 could be questioned; at the same time we found significant differences between the groups concerning both IADL and HRQoL.

In the second study we used the cut-offs suggested in the Cognistat manual. As a consequence, participants with a high premorbid function could produce false-negative results due to a ceiling effect. Furthermore, the study sample is quite small. A larger study would be of interest to confirm the results. However, a power calculation indicated that a sample size of about 30 patients per group was sufficient. Another limitation is that the cognitively impaired group had a higher mean age and

lower education level than the group with no cognitive impairment. These differences were not very large, but they are statistically significant. Although these characteristics may influence the test results, we used the geriatrician's and psychologist's evaluations as the standard. According to this evaluation, the participants with no impairment were cognitively healthy and were all evaluated in light of their premorbid function.

Some methodological limitations of the third study also need to be discussed. The choice of using only professionals in the expert panels can be questioned. Another option would have been to include expert panels of patients and relatives. However, the pilot study provided valuable information about how to adjust the instrument.

Lincoln and Guba (1985) state that the quality of a study depends on its trustworthiness, criteria of credibility, transferability, dependability and conformability. To enhance the credibility and the dependability of the present study, the data and the interpretation were discussed continuously with the last author in study IV (EW). To be able to judge the transferability of the study as a reader, the procedures must be described thoroughly and this has been done. One participant had some minor problems expressing himself, talking in a fragmented way or paraphrasing and sometimes he had difficulties finding his words. Thus, it was an advantage that the interviewer has long experience of people with similar problems and was secure about how to deal with that. This is important for making the participant feel comfortable during the interview. There is a risk that the cognitive decline of the participants, even when mild, prevented them from expressing everything they experience in everyday life, due to the nature of the disease. Another approach would have been to combine interviews with observation. However, the aim was to gain a deeper understanding of experiences, and interviews were chosen as the best way to capture this. A weakness of the study is that even though saturation was reached, the sample is rather small and was taken from one clinic. This decreases the generalizability.

Implication for future studies

Future research should focus on the development of a model for early detection of cognitive impairment including a vital area such as IADL. A lot of different instruments occur in practice, which makes it problematic to compare individuals or groups of individuals, and thus, it is also difficult to learn what signs you should be looking for. This model for detecting cognitive impairment must be easy to administer, not too time consuming, rely on standardized instruments tested regarding psychometric properties, and be helpful for further investigations step by step when needed.

Follow-up studies on the population used in the first study are planned.

Cognistat has many benefits and larger studies to confirm the results in our second study would be of interest. It may be profitable for future research to compare Cognistat with other newer tests (e.g. the Cognitive Assessment Battery (CAB) (Nordlund et al., 2011) and the Montreal Cognitive Assessment (MoCA) (Smith et al., 2007) to detect MCI and early-stage dementia.

Continuing research and psychometric testing of the CID focusing on test-retest reliability and construct validity are ongoing.

A subject for future study is to see if the CID differs between cognitively healthy persons, persons with MCI and persons with dementia, and to compare it with a comprehensive neuropsychology test battery for evaluating whether the difficulties found correlate with tests measuring cognitive functions.

It would also be of interest to ask patients to fill in the instrument themselves using an electronic device such as an iPad. A short version of CID might be tested in future.

Future studies should also focus on interventions and support for persons in the early stages of dementia.

CONCLUSIONS

Early detection of cognitive impairment is vital to allow interventions aimed at reducing inactivity and improving or retaining a person's activity level and thus quality of life. This is beneficial for the individual as well as for society and health care. The individual's ability to perform everyday life activities should be included in the assessment phase.

Cognistat shows fairly good diagnostic accuracy and clinical utility for detecting cognitive impairment in this primary care population. Memory and construction were the most prominent findings among the subtests. Cognistat should be used for basic primary care evaluations to detect cognitive impairment overall, but it could also complement dementia evaluations in primary care facilities when the MMSE and CDT results are questionable. In addition, Cognistat can help a GP to determine which patients need to be referred to secondary care for further evaluation.

The CID seems to be promising in terms of content validity; however, further testing of reliability (test–retest and internal consistency) and construct validity is needed. The instrument is now under further testing.

Perceived cognitive impairment and its consequences in everyday life are individual and differ among people with MCI or dementia and their relatives. Thus, health care professionals must listen to people with cognitive impairment and their relatives for optimal individual care planning. Support for persons and their relatives needs to be tailored towards the early stages of dementia. The results support the use of an instrument like CID.

CLINICAL IMPLICATIONS

- Questions on memory-related problems experienced and how the person is handling IADL should be raised when health professionals meet older people in primary care.
- Multiprofessional team work should be done at all levels of health care.
- Occupational therapists can make an important contribution to dementia investigations for the diagnostic work and most important for promoting activity and participation.
- Cognitive tests as well as ADL assessments should be included in the investigation.
- Relatives should be included in the investigation and the person with suspected cognitive impairment and the relatives should be listened to when suitable.
- Support for people and their relatives should be adapted for the stages of the disease.

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