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# Driving ability among people with stroke:

Developing assessments and exploring the livedexperience

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#### ABSTRACT

The overall aim of this thesis was to explore and describe methods for assessing driving ability and awareness of driving disability following stroke, and to explore and describe the lived-experience of driving ability in the process of a driving evaluation.

The thesis included four studies. In **Study I** people with stroke drove in a driving simulator and the focus was to investigate aspects of validity and stability of a newly developed assessment tool, P-Drive, using Rasch statistics. In **Study II** people with stroke who had previously conducted a driving test in a driving simulator and had difficulties driving safely participated. The aim was to investigate awareness of driving disability. In **Study III** four men with stroke were interviewed during their driving evaluations. The aim was to explore and describe the lived-experience of driving ability in the context of being in the process of a driving evaluation using a phenomenological approach. In **Study IV** participants were people with stroke, dementia and mild cognitive impairments. The participants took an on-road driving test and the aim was to determine aspects of validity and reliability of P-Drive (on-road version), using Rasch statistics.

In conclusion, the results of **Studies I and IV** indicated that P-Drive (two new versions) was an assessment tool that was valid and reliable for assessing driving ability in people with stroke in a driving simulator or on-road, respectively. Both versions of P-Drive demonstrated evidence of internal scale validity, person response validity and also acceptable levels of person separation reliability. In **Study II** lack of awareness of driving disability was evident since the majority of the drivers who failed the simulator test also had limited awareness of their disability. **In Study III** the participants experienced their driving ability as unaffected by the onset of stroke, and driving ability was taken for granted. Limited awareness of disability was indicated since participants were driving despite recommendations not to drive. The results (Study III) also increased our knowledge about the negative feelings that could be aroused by driving cessation and evaluation.

Key words: Occupational therapy, Automobile Driving, Stroke, Awareness of Disability, Rasch, Phenomenology

# LIST OF PUBLICATIONS

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

- Patomella, A-H., Tham, K. & Kottorp, A. (2006) P-Drive: An assessment of driving performance after stroke. *Journal of Rehabilitation Medicine*, 38(5):273-9
- II. Patomella, A-H., Kottorp, A. & Tham, K. (2008) Awareness of driving disability in people with stroke tested in a simulator. *Scandinavian Journal* of Occupational Therapy, 15:3,184-192
- III. Patomella, A-H., Johansson, K. & Tham, K. Lived-experience of driving ability following stroke. *Journal of Disability and Rehabilitation* (in press).
- IV. Patomella, A-H., Tham, K., Johansson, K. & Kottorp, A. P-Drive, an assessment of on-road driving performance of people with neurological disorders. *Submitted*.

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# LIST OF ABBREVIATIONS

AAD Assessment of Awareness of Disability

CI Confidence Intervals

DIF Differential Item Functioning

EPP Empirical Phenomenological Psychology

MCI Mild Cognitive Impairment

MnSq Mean Square

NorSDSA Nordic Stroke Driver Screening Assessment

PCA Principal Components Analysis

P-Drive Performance Analysis of Driving Ability

SE Standard Error

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#### INTRODUCTION

"Lord, I have been driving since 1959 and also abroad...as much as we have been driving, and never have I had trouble with the traffic police, never, no fine, nothing like that. As I can see it, I've never had any problem in traffic or in the car."

(Quote from a participant in Study III)

In this quote we hear the voice of a person who has had several decades of driving experience, which he experiences as good years. Now he is at risk of losing his driving licence following stroke he had last year; he is also at risk of losing much more than just the licence. Driving a car is something that we seem to take for granted, but after stroke there can be more or less obvious obstacles to driving safely. As an occupational therapist, everyday occupations are at the core of my interest. Driving a car is an everyday occupation that is valued by many people for its own sake and for its facilitation of opportunities to engage in other occupations. Driving is one of the everyday occupations that form our lifestyle. For Swedish occupational therapists to conduct driving evaluations has not been a very common task before, but is something that is becoming more and more necessary; it is highlighted as important in the rehabilitation process of people with stroke.

# Driving a car – an occupation in everyday life

The car and driving are parts of the Western culture that shape both public and private spaces and are important in many people's lives, affecting areas like competence and social inclusion. The car and driving can arouse many emotions like comfort, enjoyment and excitement (Sheller, 2004). In Sweden most adults (82%) have a driving licence (SCB, 2007; Vägverket, 2007), but driving is a double-edged occupation (Heikkinen, 2008; Sheller, 2004). It offers mobility and freedom, but on the other hand is connected to crashes, personal injury and risk of death. These two edges need to be balanced: people who are now safe drivers should have the possibility to continue driving for as long as possible, keeping their freedom and mobility. On the other hand, people that are unsafe as drivers due to injury or illness need to be prevented from driving. The American Occupational Therapy Association (AOTA) has identified driving as one of the top ten emerging practice areas for occupational therapists in the new millennium (Johansson, 2000). In countries like the USA and Canada (Korner-Bitensky, Bitensky, Sofer, Man-Song-Hing, & Gelinas, 2006; Korner-Bitensky, Sofer, Gelinas, & Mazer, 1998), United Kingdom (Brooks & Hawley, 2005) and Australia

(Unsworth, 2007) it is common that occupational therapists are actively involved in driving evaluations. In the UK there are 15 Mobility Centres employing multidisciplinary teams working with driving evaluations, and occupational therapists are employed at a majority of the centres. Several different services are provided in the driving evaluations at the centres, including on-road tests, simulator tests and cognitive screening (Brooks & Hawley, 2005). In Melbourne, Australia, occupational therapists have been conducting driving evaluation for the licensing authority for more than 20 years (Unsworth, 2007). The Australian occupational therapists assessing driving ability have been trained and specialized at university to be able to make standardised driving evaluations by following national guidelines and standards. In Sweden there is no official training or national guidelines for occupational therapists, but a recent survey of Swedish occupational therapists indicates that many occupational therapists (57%) are involved in assessing driving ability (Larsson, Lundberg, Falkmer, & Johansson, 2007).

In this thesis the focus is on driving. It explores driving ability and develops and validates assessment tools to measure driving ability and awareness of disability. It also seeks to increase our understanding of how driving ability is experienced while in the process of a driving evaluation. An occupational perspective is used throughout the thesis and theoretical assumptions about instrument development using a Rasch rating scale models are applied.

# An occupational perspective on driving

Driving a car is a dynamic and complex everyday occupation and demands a lot of the driver. As occupational therapists our focus is in the everyday occupations of our clients. Occupations are activities that have unique value and purpose to the person. How we see ourselves (our identities) and how we spend our time and make decisions is influenced by our engagement and participation in these occupations (AOTA, 2002). Occupation is the doing that the person wants and needs or is expected to do in the society (Fisher, 2006). Driving a car can be assumed to be an occupation that many people want and need to do in their everyday lives.

The Model of Human Occupation (MoHO) offers one way to understand how people go about their everyday occupations (Kielhofner, 2008). The MoHO is based on a dynamical systems theory and in the model the components of the person and the environment interact and influence occupation into a dynamic whole. The person is made up of three interrelated

components, volition, habituation and performance capacity, influencing occupation (Kielhofner, 2008). Volition is the motivation for occupation and is about awareness of one's capacity of doing, what one finds important to do and what one finds enjoyable and satisfying to do. Habituation is patterns and routines of occupations and is reflected in our roles. Performance capacities are the physical and mental capacities we have to perform the occupation (Kielhofner, 2008). Driving is an occupation that may give satisfaction and be important for the person to perform. Driving can be part of one's routines and roles in life and the ability to drive is affected by the physical and mental capacities of the person. In addition, human occupation can only be understood if we understand the environment in which it takes place. The environment can be defined as the social and physical, cultural, economic and political dimensions that impact the performance of occupations (Kielhofner, 2008). Driving a car is an occupation performed within a context that comprises several dimensions, including the space where the occupation is taking place (e.g. city traffic), the objects that are used to do things (e.g. the car), the forms of the occupation that are available, expected and/or required (e.g. driving to work), the social groups encountered (e.g. fellow road users), the culture that affects the physical and social aspects of the environment (e.g. the roles as a driver) and the political and economical contexts that affect the freedom and resources relevant for the occupation (e.g. medical requirements for driving). A change in any one of the components in the dynamic whole can alter the total dynamic of the occupation (Kielhofner, 2008).

# Occupational performance of driving

In this thesis the performance of driving a car is studied as the performance of an everyday occupation. Occupational performance occurs in a complex set of interactions between the individual and his/her environment and is a meaningful sequence of actions used to complete a specified occupation (Fisher, 2006, Kielhofner, 2002). These actions are goal-directed, observable and can be seen as discrete behavioural elements of the performance.

Occupational performance is a meaningful sequence of actions in which the person enacts and completes a specified task that is relevant to his/her culture and daily life roles (Fisher, 2006).

Michon's model of driving (1985) is commonly used in the traffic psychology literature to describe driver behaviour. Driver behaviour is defined as what humans actually do when exposed to various traffic environments. The model emphasizes the cognitive components of driver behaviour and driving is seen as a cognitive process, a problem-solving task producing rational behaviour. The model is based on a productions system that is knowledge- and rule-

based and can be statements of action goals. For example a simple goal could be that IF: traffic light is red, THEN: stop. The model is hierarchical with three interdependent levels of skills and control of behaviour during driving (see Figure 1). At the operational level the driver makes decisions about the basic manoeuvring of the car, such as steering and braking; at the tactical level the driver makes decisions to better master and adapt to different traffic situations like adjusting speed and planning ahead. At the highest level of the hierarchy, the strategic level, the driver makes general plans and decisions before entering the car, decisions about the risks and costs involved in driving (Michon, 1985). Michon's model offers a way to understand the levels of decisions made by the driver (see Figure 1). In this thesis an assessment tool (P-Drive, Studies I and IV) is assumed to cover the tactical and operational level of control in relation to the actual performance in a driving simulator or on-road.

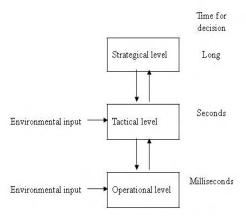


Figure 1: The hierarchical structure of the driving task (Figure freely drawn after Michon, 1985).

Occupational performances (of driving) and driver behaviour are overlapping but not interchangeable concepts having different theoretical bases. In contemporary traffic psychology the theoretical models are based on cognitive processes and production systems (Michon, 1985) while the occupational therapy model used in this thesis is based on dynamic systems theory (Kielhofner, 2008) and further, the thesis has adopted a top-down-approach to occupational performance (Fisher, 2006). The dynamic systems theory has a holistic view of the interaction between the individual and the environment as a means for occupation (driving), while Michon's model has a more reductionistic view of the production of behaviour (bottom-up approach). It views the environment (traffic environment) as impacting behaviour, not as being integrated as a part of the system of human occupation. In dynamic systems theory all parts of the system interact in ways that depend on the situation and all

components contribute to the total dynamics (Kielhofner, 2002). During driving the driver is exposed to different situations that vary in complexity and dynamics. The traffic environment can change very rapidly and the driver has to face a new and different situation within seconds, which demands good flexibility in the driver. Driving as an occupation has not been specifically described in the theoretical models of occupational therapy and although Michon's model is a way to understand driver behaviour, it is limited to the cognitive aspects of behaviour. This thesis is based on the theoretical foundation of occupational therapy (Fisher, 2006; Kielhofner, 2008) but also applies the hierarchical model of driver behaviour as developed by Michon (1985) in Studies I and IV to develop an assessment tool for measuring driving ability.

# Experiences of not being able to drive

A primary assumption in occupational therapy is that "occupation is a basic human need" and that without the possibility of engaging in occupation there is a risk that the individual's health and well-being might be affected negatively. Another assumption is that "occupation brings meaning to life", allowing us to explore and learn about the environment, use our competence, express our individuality and manage our lives (Townsend & Polatajko, 2007). Without the possibility of engaging in driving any longer, mobility, health, identity and life might be negatively affected. Research has found that elderly former drivers decreased their participation in out-of-home activities (Marottoli et al., 2000) and reported higher levels of depression than active drivers (Ragland, Satariano, & MacLeod, 2005) following their driving cessation.

There are few qualitative studies that have investigated experiences of driving cessation following illness or old age and there is a need to increase our understanding to better meet and support the individual. A study investigating older women's experiences and challenges related to driving cessation (Bonnel, 1999) found that the women experienced a loss of everyday activities – e.g. participating in social activities, going to restaurants and shopping. These women had to find other ways to manage the activities that had previously been facilitated by driving. The women decided to give up their cars for a variety of reasons. However, after stroke, giving up the car may be the decision of a health professional (physician) based on a driving evaluation and not the client's free will. In a study exploring how elderly people with stroke experienced the initial impact of a driver licence cancellation (Lister, 1999), the author found that the loss had negative psychological, social and functional

implications. Loss of the licence was experienced as out of the individuals' control and had a direct effect on their lifestyles. These participants had not been considered for a driving evaluation and had lost their licenses due to the severity of their stroke. Another study exploring older people's experiences of driver licence cancellation after a driving evaluation, revealed the cancellation to be a traumatic and shocking experience, and the driving evaluation was experienced as unjustly executed (Whitehead, Howie & Lovell, 2006). In a case study (Vrkljan & Miller-Polgar, 2007) that investigated the transition from being an active driver to a non-driver by following an older couple in which the man was restricted from driving, the results indicate that the ability to participate in occupations that have meaning seem to be critical for how individuals perceive themselves. Summating, earlier studies have found that driving cessation limited participation in everyday activities, was experienced as traumatic and life changing and could effect the health and the sense of self of the individual. There is a lack of knowledge about the lived-experiences of driving ability during the process of a driving evaluation.

# The lived-experience of driving ability

In phenomenological research the aim is to find out what characterizes a phenomenon and describe the meaning structure of the lived-experience of the phenomenon (Karlsson, 1995). Phenomenological research concerns life-world experiences; the life-world is the subjective and culturally meaningful world we live in and that we first encounter (Karlsson, 1995). The life-world is always pre-given, taken for granted and all-inclusive. Life-world research expands our understanding of human experience and understanding of meaning in everyday life (Dahlberg, Drew, & Nyström, 2001). According to Husserl (1970), in the life-world we take for granted that the world is as we perceive it, and we do not critically reflect upon or criticize our perceptions. Everyday occupations like self-care (Guidetti, Asaba & Tham 2007) or driving a car appear obvious and are taken for granted. By examining the lived-experience in everyday life, we gain access to the person's experienced reality. In Study III in this thesis, phenomenology is used as a method to open up for us to better understand how driving ability is experienced following stroke. The lived-experience (subjective aspects) of ability or occupational performance can also complement the objective approach (measuring and observing performance). By giving attention to the subjective experience we can better understand the occupational performance of the individual (Kielhofner, Tham, Baz & Hutson, 2008).

# Stroke and driving ability

People who are recovering from stroke and participating in rehabilitation are often interested in returning to their everyday occupations as they were before the disease, and driving is one occupation that is desired by many. On the other hand, the ability to drive safely may be reduced following stroke (Akinwuntan et al., 2002; Heikkilä, Korpelainen, Turkka, Kallanranta, & Summala, 1999; Lundqvist, Gerdle, & Rönnberg, 2000; Mazer, Korner-Bitensky, & Sofer, 1998; Wilson & Smith, 1983) and therefore needs to be evaluated.

Stroke is a common cause of brain injury in the world, and in most European countries is ranked as the third most frequent cause of death (Brainin, Bornstein, Boysen, & Demarin, 2000). Each year in Sweden about 30,000 people sustain stroke with an annual incident value of approximately 300 per 100,000 population (Brainin et al., 2000; Socialstyrelsen, 2006). Stroke is caused by disruption of the blood supply to the brain tissue and may result from either blockage (embolus), ischemic stroke, (thrombosis) or rupture of a blood vessel, haemorrhagic either, intracerebral or subarchnoidal. Motor and cognitive impairments are common after stroke with frequently reported symptoms of spasticity, reduced memory, attention, communication and visuospatial functioning (Socialstyrelsen, 2006). Minor symptoms may exist before stroke due to atherosclerotic blood vessels. Everyday occupations might also be challenged following stroke. In a sample of people with acquired brain injuries (subarachnoidal haemorrhage and traumatic brain injury) gaps were experienced in several everyday occupations when comparing status before and after injury (Eriksson, Tham, & Borg, 2006). Transportation (driving not specified) was one occupation that differed significantly, 99 % of the sample engaged in transportation before the injury, but only 76% afterwards.

In research drivers with stroke have been shown to have limited abilities to drive safely. In a sample of drivers referred for a clinical driving evaluation 61% were either judged as unsuitable or not immediately suitable to continue driving (Ackinwuntan et al., 2002). Results from a small study comparing drivers with stroke and healthy drivers in a short on-road test (20 min) showed that drivers with stroke had difficulties with awareness of other vehicles, reversing, doing two things at the same time and positioning the car in the lane (Wilson & Smith, 1983).

In this thesis participants were not only people with stroke; in Study IV drivers with dementia or mild cognitive impairment were also assessed. Research has shown that the level of dementia is related to performance on an on-road test (Hunt et al., 1997); in the group of drivers with mild dementia, 41% failed while in the group of very mild dementia only 19% failed the on-road test.

# Regulations for driving after stroke

Most countries have medical requirements for having a driving license, requirements that might no longer be fulfilled after a brain injury like stroke. The Council of the European Community's directives states that "driving licences shall not be renewed for drivers suffering from a serious neurological disease unless the application is supported by authorized medical opinion" (EU, 1991). However, the interpretation of the directives varies between the European countries (White & O'Neill, 2000) and in several (e.g. United Kingdom, Germany), the physician is not obliged to report drivers who are medically unfit to drive. In Sweden the statutes state that the physician should report to the licensing authorities the fact that a client is obviously unfit to drive due to a medical condition such as stroke (Vägverket, 2008). A diagnosis of dementia should lead to the cancellation of the driving license although in mild stages of dementia holding a license for a passenger car could be allowed, according to the statute (Vägverket, 2008). There are no national guidelines in Sweden for how to evaluate the ability of a person with stroke to continue driving; there is just a brief statement:

"disturbances in judgement, the ability to perceive and process visual input and also mental flexibility, memory, executive functioning and psychomotor tempo shall be taken into special consideration when making the medical assessment. The presence of emotional lability and increased fatigue shall also be taken into consideration. Apraxia and neglect need special attention" (Vägverket, 2008).

In the statute, the medical assessment should be based on a neuropsychological evaluation done preferably by a neuropsychologist, psychologist or occupational therapist with good knowledge of traffic medicine. If the medical assessment results in a doubtful outcome, the statute recommends a practical driving test to complement the evaluation. In Sweden national standards or routines for driving evaluations are not established and there is diversity in methods used at different clinics. Australia might be the country that has the most developed routines for conducting driving evaluations; there occupational therapists conduct both off-

and on-road assessments following national standards (Unsworth, 2007). Criticism of the driving evaluation in Australia includes their lack of use of validated assessment tools.

# Assessing driving ability after stroke

In this thesis driving ability is defined as the safe and competent performance during a practical driving test. A top-down approach, starting with the actual doing of the driver (Fisher, 2006), has been adopted to assess driving performance. The focus is on the quality of the person's performance using an occupational performance analysis. In the analysis the individual's quality of performing an occupation is observed to identify discrepancies between the demands of the occupation and the skills of the person. In the present top-down approach the person's difficulties and strengths are described and measured in terms of goal-directed actions that comprise the occupational performance and not on underlying impairments like cognition. In this thesis the top-down approach starts at the actual performance of a driving test in a simulator (Studies I, II) or on-road (Studies III and IV).

Neuropsychological testing of off-road driving assessments is a method that is used to evaluate underlying cognitive capacities needed for driving safely. Most research has been aimed at finding a neuropsychological test battery that can best predict the outcome of an onroad driving test (Mazer, Gelinas, & Benoit, 2004). One of the neuropsychological test batteries that have a good predictive value towards an on-road test is the Nordic Stroke Driver Screening Assessment (NorSDSA, Lundberg, Caneman, Samuelsson, Hakamies-Blomqvist, & Almkvist, 2003). It has been shown to correctly classify 78% of drivers with stroke when using the on-road test result as the outcome. However, when examining sensitivity and specificity the sensitivity of the test was low; NorSDSA only identified 19 out of 33 participants who later failed the on-road test. The on-road test is viewed as the gold standard of driving tests (Christie, 1996). The result of an on-road test has been found to be the most important determinant of the multi-professional team decision in a driving evaluation (Akinwuntan et al., 2002). However, in the research literature there are few standardised assessments for measuring driving ability on-road and among those that are used in research few have been sufficiently evaluated for their psychometric properties. The TRIP-protocol (Test Ride for Investigating Practical Fitness to Drive) had moderate results of inter-rater reliability, while observing a video of on-road tests of clients with stroke (n=30) (Akinwuntan et al., 2003). In the TRIP, three of the 17 items (18%) were not considered as reliable (De

Raedt & Ponjaert-Kristoffersen, 2001). The global raw score of the Washington University Road Test (WURT) protocol indicated evidence of inter-rater (Hunt et al., 1997, Odenheimer et al., 1994) and test-retest (Hunt et al, 1997) reliability when used in a sample of clients with dementia of the Alzheimer type. These assessment tools are both ordinal scales and their unidimensionality is unknown; there is a lack of unidimensional interval scales to measure driving ability.

#### Assessing driving ability in different contexts

In this thesis driving ability is assessed using a driving simulator and on-road driving. The most common way to investigate a person's fitness to drive is by conducting cognitive screening. These three methods differ in the contexts of conducting the assessments as well as in ecological validity. Ecological validity is the relationship between real-world phenomena and the investigation of these phenomena in experimental contexts (Schmuckler, 2001). Ecological validity can be divided into three dimensions – the nature of the research context, the nature of the stimuli used in the experiment and the response or behaviour required by the experimental participant. To reach ecological validity the context must be a true and natural context in which actors take part on a regular basis (Schmuckler, 2001). In many ways the work in this thesis is ecologically valid, examining naturalistic behaviour (actual driving) in naturalistic context (real traffic or a realistic and technically advanced driving simulator) and employing rich stimuli (traffic situations). As a driving simulator may not be a context that is natural for most people, the simulator could be a context that is very stressful for the individual and this could then affect the performance. Driving in real traffic is part of our lifeworld that we take for granted and driving in real traffic is something a driver is used to. However, to drive an unfamiliar car on an unfamiliar route while being in the process of an evaluation of one's driving ability could be stressful and the pressure could influence the occupational performance of the driver. A study comparing the vehicles used for driving tests in older drivers revealed that driving an unfamiliar car made it easier to fail compared to driving your own car (Lundberg & Hakamies-Blomqvist, 2003). Although driving in a simulator is very close to driving in real traffic, the ecological validity of conducting a driving evaluation in real traffic is higher than in the simulator. The advantage of simulators is the possibility to standardise the route, while driving in real traffic can never be totally standardised and unexpected events can never be controlled. Most occupational therapists in Sweden use cognitive tests to assess driving ability (Larsson et al., 2007), tests that have low

ecological validity for assessing driving ability since the nature of the context and responses required is not ecological (paper-pencil tasks in an office).

# Developing assessment tools on an interval scale

In rehabilitation it is of clinical interest to investigate, evaluate and measure complex phenomena that might have many dimensions and layers, for example the ability to perform everyday occupations like driving, while a measure or scale can only target one dimension at a time. The Rasch measurement model can transform observed ordinal data into linear interval measures and be used to develop new assessment tools (Merbitz, Morris, & Grip, 1989). Two of the theoretical requirements of measurement have been stated to be unidimensionality and additivity (Tesio, 2003). In an ordinal rating scale the distance or space between the scoring (1-2, 2-3, etc.) is unknown. The distance between the scores of 1 and 2 might not be the same as that between 2 and 3. Furthermore it is unknown whether the spacing is replicable across different items. Ordinal scales are commonly used at rehabilitation clinics for assessing activities of daily living. Driving ability has been assessed using ordinal scales, and in research studies summed up into raw scores (De Raedt & Ponjaert-Kristoffersen, 2001; Duchek et al., 2003; Hunt et al., 1997; Mazer et al., 1998; Odenheimer et al., 1994). An ordinal scale should not be treated as a continuous scale by adding, dividing etc. By adding up item scores into a total score or raw score the result could be misleading and in the worst case cause a false outcome (Merbitz et al., 1989; Tesio, 2003). By using ordinal scales in the context of driving evaluations there is a risk of passing someone who might not be safe as a driver. It has been pointed out that there it is a need for ratio or interval scales to improve measurement, inference and prediction in rehabilitation medicine (Merbitz et al., 1989; Tesio, 2003).

#### Using the Rasch model to develop new assessment tools

The Rasch model can be used to evaluate and develop new assessment tools, using the quality parameters attained in the data analysis to decide if items should be included, rejected or modified, as well as to investigate strengths and weaknesses of the scale. The assertions of the simple Rasch model is that the easier the item, the more likely it is to be passed by any person and the more able the person, the more likely he or she is to pass harder items than a person who is less able (Fisher, 1993; Wright & Stone, 1979). Statistics attained in the Rasch analysis can be used to perform confirmatory construct validity analyses of the developed scale based on expectations of what should happen when a group of people take the test and

also confirm whether the items fit to the modelled expectations (Fisher, 1993). Several aspects of validity and reliability can be investigated using Rasch analysis.

The Rasch rating scale model used in this thesis considers item difficulty and person ability on the same continuous line (Linacre & Wright, 2004). Person ability and item difficulty measures are expressed in equal interval units that are additive. These are called logits (logodds probability units) and are the natural logarithm of the odds of success or failure. The Rasch rating scale model asserts that at the threshold the likelihood of success (above the threshold) at a given score is equal to the likelihood of failure (below the threshold) (Wright & Mok, 2004). For example for a person with a 3.5 logit ability measure the odds of passing or failing an item (or a threshold of an item) that has a difficulty at 3.5 logit level are equal (50:50).

In a unidimensional scale all items measure the same underlying latent trait on a continuous line (Wright & Stone, 1979). The Rasch programs generated goodness-of-fit statistics in the form of mean square residuals (MnSq), and indicates the extent to which the data fits the Rasch measurement models expectation of unidimensionality. MnSq is the squared mean of the difference (residual) between what was observed and what the model expected. The infit MnSq is weighted and therefore sensitive to unexpected behaviour closer to the score and the outfit MnSq is unweighted and more sensitive to outlying scores. The standardised *z* value is a transformation of the MnSq into a *t* statistic (Bond & Fox, 2001). A MnSq value of 1 indicates that the overall scoring demonstrated an expected pattern of responses; values below 1 indicate that the responses are too predictable and show less variation than the model expected and values above 1 indicate a pattern that is too unpredictable (Tesio, 2003). When the goodness-of-fit statistics for the item and persons are acceptable, they provide evidence of internal scale validity and person response validity (Fisher, 1993).

#### Starting to develop a linear assessment of driving ability

The Rasch measurement analysis has earlier been used to develop assessment tools within occupational therapy (Fisher, 1993; Tham, Bernspång, & Fisher, 1999) and was used to develop P-Drive (Performance Analysis of Driving Ability), a linear assessment tool for measuring driving ability. The aim of developing P-Drive was to create a useful tool for clinical evaluations when assessing people with stroke in a simulator (Patomella, Caneman, Kottorp & Tham, 2004). The development of P-Drive was based on a theoretical frame of

reference with the intention of measuring driving ability in performance in actions rather than underlying capacities using an approach focusing on the actual doing (Fisher, 1998; Kielhofner, 2002). A theory-focused activity analysis (Crepeau, 2003) of driving in a technically interactive driving simulator was conducted, identifying actions needed to drive safely and competently. The activity analysis resulted in a number of identifiable and observable actions that arose during a session of safe driving in the simulator. From this activity analysis potential items were formulated and placed along the line according to their presumed level of difficulty. Items (actions) requiring attention and fast information processing were assumed to be more challenging than other items, based on an earlier study (Lundqvist et al., 2000). Furthermore, items (actions) requiring a high level of control (Michon, 1985) were assumed to be more challenging for the drivers than items requiring less control. The results from a first pilot study (*n*=31) of P-Drive using Rasch analysis, revealed evidence of validity in terms of both item and person goodness-of-fit statistics indicating unidimensionality and person response validity (Patomella et al., 2004). The encouraging results of the pilot study motivated further research to investigate and develop P-Drive.

# Awareness of driving disability

Performing everyday occupations can be problematic after stroke and the disability is evident when the performance of occupation is unsafe and incompetent. After stroke it is common that the person is not aware of his/her disability, showing a limited awareness of disability (McGlynn & Schacter, 1989). A person with limited awareness of disability might continue to perform everyday occupations that are no longer safe (Golisz & Toglia, 2005) and to be unaware of an unsafe and incompetent driving ability could have serious consequences for the individual as well as for family and fellow road users. Limited awareness of driving disability might result in a person driving despite not being safe and competent; furthermore he/she might not follow the advice of a physician not to drive due to stroke. In rehabilitation there is a need to investigate awareness of disability to better design interventions for each individual (Simmond & Fleming, 2003). It is important to assess if persons are aware of their driving disability in order to individually tailor the rehabilitation interventions, especially for those who have limited awareness that they are no longer safe drivers.

Awareness might be seen as a mental process requiring information both from internal thoughts and from the new experiences gained by being confronted with the external reality (Prigatano & Schacter, 1991). Lack of awareness of deficits implies inability to recognize

deficits caused by neurological illness (McGlynn & Schacter, 1989). In this thesis awareness of disability has been investigated (Study II) and is defined as the individual's awareness of his/her limitations of performance in an everyday occupation operationalized as the discrepancy between the self-reported and the observed limitations in performing a self-chosen activity (Tham et al., 1999).

#### Measuring awareness of disability

In this thesis awareness is measured in relation to occupational performance rather than to underlying cognitive and psychological capacities (awareness of deficits). This top-down occupation-based approach (Fisher, 2006) to awareness of disability has a unique occupational therapy perspective with the focus on awareness of performing an everyday occupation. The approach allows the client to reflect on his/her performance of a familiar and meaningful everyday occupation by asking well-timed questions (Simmond & Fleming, 2003). The standardised Assessment of Awareness of Disability (AAD) (Kottorp, 2006; Tham et al., 1999) is a tool that measures awareness when individuals are confronted after experiencing their limitations of performance in a relevant and self-chosen everyday occupation using the Assessment of Motor and Process Skills (Fisher, 2006). The AAD consists of interview questions that focus on different aspects of a recently finalized performance and measure the discrepancy between the person's observed disability to perform an everyday occupation and the person's self-reported disability to perform the occupation (Kottorp, 2006; Tham et al., 1999). This way of measuring awareness, using a well-timed structured interview (questions closely related to a recent doing) is considered a strong method of capturing awareness of disability (Fleming, Strong, & Ashton, 1996).

In summary, with this thesis I wish to contribute to the knowledge and methods of conducting driving evaluations after stroke, more specifically the driving test conducted in a driving simulator or on-road. There is a lack of valid assessment tools that can capture driving ability on an interval scale. To improve the clinical driving evaluation and conduct research on driving in people with stroke we need to have assessment tools that can give a valid measure of a person's driving ability and awareness of driving disability. The research literature regarding how driving ability is experienced following stroke is sparse and it is of importance to understand how driving ability is experienced following stroke and during the driving evaluation. To be able to improve the clinical progress from having sustained a stroke,

being advised not to drive and then being in the process of a driving evaluation, we need to understand the lived-experience of being in the process of a driving evaluation. The intention is also to generate new theoretical knowledge and describe driving ability in people with stroke, in order to better understand what is needed for driving safely and competent.

#### AIM

# General Aim

The general aim of the thesis was to explore and describe methods for assessing driving ability and awareness of driving disability in people with stroke. It was also to explore and describe the lived-experience of driving ability in the process of a driving evaluation following stroke.

# Specific Aims

- To investigate aspects of validity and stability of P-Drive for people with stroke, when used in a driving simulator (Study I).
- To explore and describe awareness of driving disability in people with driving difficulties after stroke (Study II).
- -To explore and describe the lived-experience of driving ability after stroke in the context of being in the process of a driving evaluation (Study III).
- To determine aspects of validity and reliability of P-Drive by observing on-road driving performance among people with neurological disorders (Study IV).

#### **METHODS**

The research in the thesis is aimed at developing new assessment tools and knowledge to improve and standardise the driving evaluation of people with stroke. The first study focused on developing P-Drive for evaluating driving ability in a technically advanced driving simulator in persons with stroke. In the second study awareness of driving disability was explored in a sample of persons with stroke who made substantial mistakes during the simulator driving. In the third study the lived-experiences of persons with stroke undergoing a driving evaluation with an on-road test were investigated using in-depth interviews. The last study focused on developing P-Drive for the on-road context for evaluating driving ability in persons with stroke and other neurological disorders (dementia and mild cognitive impairment- MCI). An overview of the studies and methods used in the thesis are presented in Table I.

Table I: An overview of the four studies included in the thesis.

	Study I	Study II	Study III	Study IV
Design/research approach	Cross-sectional, instrument development	Cross-sectional, quantitative, explorative	Qualitative, process, explorative, phenomenological	Cross-sectional, instrument development
Study context	Driving simulator	Driving simulator	In the process of a driving evaluation, real traffic	Real traffic
Methods of data collection, (instruments)	Observation, (P-Drive)	Observation, (P-Drive), interview, (mod. AAD)	Open-ended in- depth interviews (interview guide)	Observation, (P- Drive on-road)
Methods of data analysis	Rasch rating scale model	Rasch rating scale model, General Linear Model analysis, descriptive statistics	Empirical Phenomenological Psychological method	Rasch rating scale model

# **Participants**

The participants in Studies I-III had the diagnosis of stroke, while Study IV also included participants with dementia and mild cognitive impairment (MCI). A consecutive sampling method was used in Studies I, II and IV, and in Study III a purposive sampling method was used to receive a variation in the sample. All studies included persons referred for a driving evaluation, who fulfilled the inclusion criteria of that specific study. In Studies I and II

participants from the Stockholm Stroke Registry were also included. The gender distribution of the thesis was due to the distribution in the referrals and a majority of the participants were men. The ages of the participants in the thesis ranged between 33 and 86. An overview of the participants in the four studies is presented in Table II.

Table II: Clinical characteristics of the participants in the thesis

	Study I	Study II	Study III	Study IV
Sample size	101	38	4	205
_		(from Study I)	(from Study IV)	
Gender:				
male/female (%)	88/13 (87/13)	34/4 (89/11)	4/0 (100/0)	178/27 (87/13)
Age, years:				
Mean, range	62, (37-84)	64 (49-84)	64 (46-83)	69 (33-86)
Diagnoses	Stroke	Stroke	Stroke	Stroke (n=128)
				Dementia (n=34)
				MCI (n=43)

#### Study I

The participants were recruited for the study from the referrals for a driving evaluation made by physicians in the Stockholm area to the Unit of Traffic Neurology, Karolinska Hospital during 2002–2003. In addition, all people with stroke on the Stockholm Stroke Registry during the period who had reported being active drivers before the onset of stroke were invited to participate. The study included a consecutive series of 101 participants with stroke (29 from the Stroke Registry). Inclusion criteria for the study were: a) having a diagnosis of stroke, b) not becoming nauseous during the practising in the simulator, c) holding a driving license and having been an active driver before the stroke and d) having given informal consent for participation in the study.

#### Study II

The participants in Study II also participated in Study I. All participants from Study I who meet the inclusion criteria for this study were included. The inclusion criteria for Study II were that the participants: a) had sufficient verbal ability to understand instructions/questions and to give answers to questions, b) gave informed consent for participation in the study (II), c) had completed a test drive in the simulator, d) had made one or several mistakes during the test drive resulting in an incident that clearly impacted on the safety of driving and had clear consequences for the continuation of the test drive.

# Study III

Four men with stroke participated in Study III. They were recruited from the Traffic Medicine Centre (TrMC) in Stockholm, Sweden. The inclusion criteria were a) the diagnosis of first-ever stroke, b) being referred for a driving evaluation, c) finishing the first part of the driving evaluation (medical examination and neuropsychological testing), d) planning to undergo an on-road driving test, and e) being able to understand interview questions and describe their experiences in Swedish. From the beginning six participants were selected using purposive sampling to make sure that the persons included in the study showed variation according to age and gender. There were two drop-outs in the study: one man who had an epileptic seizure (which entails a two-year prohibition on driving in Sweden) during the course of the driving evaluation and one woman who cancelled participation because she lacked the time for interviewing.

#### Study IV

The study included a consecutive series of 205 drivers with neurological disorders of stroke, dementia (including vascular dementia, Alzheimer and mixed forms) or MCI. Inclusion criteria for the study were that the subjects: a) had a neurological disorder: stroke, dementia or MCI, b) held a driving license, c) had given written consent for participation in the study. The drivers were referred to three different rehabilitation clinics (five different occupational therapists) for an on-road driving test. The on-road test was preceded by different clinical tests of medical fitness to drive including visual acuity and cognitive screening.

#### Data collection and instruments

#### Contexts of data collection

Data for the thesis were collected in different contexts. In Studies I and II data were collected in a driving simulator. The interactive, realistic and technically-advanced simulator used was situated at the Karolinska University Hospital (Stockholm, Sweden). The simulator was designed and used by occupational therapists to observe driving performance after stroke. The simulator consisted of a real, but truncated car (see Fig 2). As in real driving, the driver had to operate the pedals, turn the steering-wheel, etc. When required the car could be adapted with technical devices such as a spinner-knob and automatic gearshift. The driving program was projected onto three big screens with a total field-of-view of 135 degrees. An audio system generated synchronised sounds, such as the engine running and radio messages. All of the

participants started the driving in the simulator in a special practice-program, to get used to the car. The participant decided when no more practice was needed (usually after 15–30 min). The test program consisted of 70 traffic situations, each presenting a different challenge. The drive took about 40–60 min, depending on the speed and the number of mistakes made. The simulator required the driver to deal with the type of situations that one would frequently encounter when driving a car and also challenges that were less common.



Figure 2: Argus driving simulator

In Study III the interviews were done in places chosen by the participants, most often in the participants' homes. In Study IV data were collected in real traffic in the context of an onroad driving test on standardised routes set in three different cities in Sweden. The data for Studies I-III were collected by Ann-Helen Patomella, and in Study IV five other occupational therapists, trained in the use of P-Drive for on-road test, collected data.

#### *P-Drive (Performance Analysis of Driving Ability)*

To observe and measure driving ability two versions of P-Drive were used in the thesis. In Studies I and II the original version of P-Drive developed for assessing driving ability in a driving simulator was used (Patomella et al., 2004) and for Study IV a modified version for the context of real traffic evaluations was developed. The original version of P-Drive consists of 20 items and in the version for on-road tests 7 more items were developed to improve the scale and better fit the context of driving in real traffic. The new items were: Organising, Attending straight ahead, Solving problems, Focusing, Keeping distance, Attending to mirrors and also one item that was divided into two: Controlling speed at low pace and Controlling speed at high pace. These new items were developed with a new activity analysis together with clinical occupational therapists that started to use the original version in real traffic. The items are rated on a 4-point rating scale based on the safety and quality of performance: 4 =

competent driving ability, 3 = questionable, 2 = problem and 1 = incompetent driving ability. An extensive manual for both versions was written.

In Study I, the participants got a chance to practise in the simulator using a special practise-program that allowed the participant to get used to the car, that is, to the pedals, gearshift and steering. Thereafter, the participants underwent a driving evaluation using the test program in the simulator. An occupational therapist (A-H P) with previous experience of performing driving evaluations scored each participant's driving performance using P-Drive. The occupational therapist scored the P-Drive protocol directly after the test drive, following the instructions in the manual.

In Study IV, the drivers' performance was observed in an on-road test on a set route (set using different criteria in the manual and lasting approximately 60 min). A car with a dual-control system was used and an experienced driving instructor sitting beside the client could use the dual controls if necessary. The instructor gave instructions for the ride and was responsible for the safety of the ride together with the driver. The occupational therapist sat in the back seat (diagonally behind the driver) observing and taking notes on the driver's actions during the on-road test. After the on-road test's completion the occupational therapist scored the driver's ability in the P-Drive on-road protocol, following the instructions in the manual.

#### Assessment of Awareness of Disability (modified version for driving)

Assessment of Awareness of Disability (AAD) was modified for Study II and the original questions were rewritten to measure awareness of driving disability, i.e. by linking the questions to the actions measured in P-Drive. This modification was close to the wording of the original version of AAD and was done in collaboration with the developers of AAD (Tham and Kottorp, personal communication). Twelve questions measuring awareness of driving disability were asked and scored using a criterion-referenced rating scale based on the discrepancy between the self-reported and the observed limitations in driving ability, on a scale from 4 to 1 where 4 = no discrepancy, 3 =minimal discrepancy, 2 = moderate discrepancy and 1 = major discrepancy. The scoring of AAD has been more thoroughly explained elsewhere (Kottorp, 2006; Tham et al., 1999). An example of how the modified version of AAD was used in Study II is displayed in Table III, reproducing interview data from a driver with stroke who showed major performance difficulties during the simulator driving. The failure to yield resulted in a crash with another vehicle, and he also had

difficulties obeying regulations concerning stopping at stop signs and giving right-of-way (see scoring in the first column). When interviewed, the driver did not report any difficulties (second column) and the discrepancy between the performance and the self-report was therefore considered major (third column). The lower the score of the item, the greater the discrepancy, and the more limited the awareness related to the specific driving actions addressed in the question.

Table III: Example of scoring awareness of driving ability, question 11.

Table III. Example of cooling awareness of anying ability, question 11.				
Actions scored in P-	How was it for you to act upon traffic rules	Discrepancy between driving		
Drive and judged as	and road laws? Did you experience any	performance and self-reported		
limited (item score <sup>1</sup> )	difficulties? Can you describe?	performance		
Yields (1)	"I did not have any problems, everything	Major differences i.e. limited		
Gives right-of-way (2)	went OK"	awareness, scored 1 <sup>2</sup>		
Stop sign (1)				

<sup>&</sup>lt;sup>1</sup> Lower score indicates less competent driving ability.

The procedures of the data collection in Study II consisted of both the driving test (no new test drive was required for this study) and an interview. The participants had been driving in a simulator and their driving performance been observed and scored using P-Drive. A semi-structured awareness interview using 12 questions in the modified version of AAD was done directly after the test drive had been scored. The interview took approximately five to ten minutes to complete. After the interview, the scoring of the items in the modified version of AAD was done by comparing driving performance as measured with P-Drive with the answers to the questions.

# Nordic Stroke Driver Screening Assessment (NorSDSA)

NorSDSA was used in Study II and is the Nordic version (modified for the traffic conditions of the Nordic countries) of the Stroke Driver Screening Assessment (Nouri & Lincoln, 1992). NorSDSA is a cognitive screening test and consists of four subtests that together capture several cognitive capacities that can be related to driving such as divided and selective attention, visuospatial orientation, mental speed, executive functioning, reasoning and working memory (Lundberg et al., 2003). A mathematical model summates and weights the four subtests into pass, borderline or fail.

<sup>&</sup>lt;sup>2</sup> Lower score indicates less awareness of driving disability.

#### Interview

The phenomenon under exploration in Study III was the lived-experience of driving ability in the context of being in the process of a driving evaluation because of stroke. The interviews were done on three occasions. The first interview was held in the midst of the driving evaluation, after the medical and cognitive examination, one week before the on-road test; the second interview was held one week after the on-road test and the physician's decision of the outcome, and the third interview was held three months after the second interview. The interview guides focused on the participants' experiences of driving and ability to drive. The questions were open-ended and the guides were specific to the different interview sessions. The interviews were designed to gather rich descriptions of the participants' lived-experiences of their own driving abilities to capture the participants' spontaneous and immediate lived-experiences (Kvale, 2007). The interviews were recorded and lasted between 22 and 38 minutes. All interviews were transcribed verbatim.

# Data analyses

#### Rasch analysis

Rasch analysis was used to investigate psychometric properties in Studies I, II and IV and also for a new analysis of a healthy sample of drivers (presented in the Results section). Two different computer programs, FACETS (Linacre, 2006) and WINSTEPS (Linacre, 2005), were used in the analysis and the selection of program was based on the possible applications of each program to answer different research questions.

#### Rating scale functioning (Studies I, IV)

In order to determine the functioning and the effectiveness of the rating scale used in P-Drive the distribution of the observations for each category in the scale was investigated. Inspecting whether disordered categories (thresholds) occurred also confirmed by the randomness of the choice of categories. The criteria used when determining randomness were outfit MnSq for the categories of less than 2.0 (Linacre, 1997).

# Internal scale validity (Studies I, II, IV, Healthy sample)

To investigate unidimensionality or internal scale validity, goodness-of-fit statistics for the items were analysed. Infit and outfit MnSq between 0.6 and 1.4, associated with z values higher than -2 and lower than 2, were set as criteria for an acceptable goodness-of-fit for items

(Wright & Linacre, 1994). In accordance with other studies (Kottorp, Bernspång, & Fisher, 2003; Tham et al., 1999), it is generally expected that 5% of the items may fail to meet these criteria by chance. A principal components analysis of standardised residuals (PCA) was used to further investigate unidimensionality, i.e. if any additional dimensions were present in the scale (Linacre, 1998; Smith, 2002). A rule of thumb is that the dimension of the scale (the first component) should explain at least 60% of the variance (Linacre, 2008); other criteria suggest that it should explain at least 20% (Reckase, 1979). The second component should explain less than 5% of the variance in order for the scale to be considered unidimensional (Smith, 2002).

#### Person response validity (Studies I, II, IV, Healthy sample)

To investigate the validity of the ability measures of the participants (person response validity), goodness-of-fit statistics for the persons were analysed. Infit and outfit MnSq between 0.6 and 1.4, associated with z values higher than -2 and lower than 2, were set as criteria for an acceptable goodness-of-fit of persons. It is generally expected that 5% of the persons may fail to meet these criteria by chance.

#### Standard Error (Study I)

The Rasch program calculated standard error (SE) for each person and item and was used to describe the degree of precision of the estimated ability of the person or difficulty of the item. SE is a measure of how well the data fit the model's expectations and how well targeted the difficulty of the items are to the abilities of the persons (Wright, 1977). A guiding principle for the SE in the person measures had previously been set at  $\leq 0.30$  logit (Tham et al., 1999).

# Person separation reliability (Studies I, II, IV, Healthy sample)

In order to investigate if the scale was able to separate the persons taking the test, so that more able persons are separated from less able persons, the person separation reliability was analysed (Wright, 1996). For a scale to be able to distinguish between two or more groups in the sample, the reliability should be at least 0.7 (Fisher, 1992).

# Differential item functioning (Studies I, IV)

In order to investigate if the item calibrations remained statistically stable across different subgroups (side of lesion, age group, ability (Study I) and diagnosis (Study IV)) an analysis of differential item functioning (DIF) was conducted. DIF analysis investigates the stability of

the item hierarchy (Wright & Stone, 1979). DIF was plotted with 95% confidence interval (CI). An item outside the CI would indicate that this item was relatively harder or easier to perform for drivers in different subgroups, considering the SE of each item's difficulty measure (Wright & Stone, 1979). For the scale to be considered as stable across different diagnoses we expected that there should be no more than 5% of the items outside the CI.

# Statistical analyses

All other statistical analyses (Study II, healthy sample) were done using SPSS for Windows (version 15.0.0., 2006, Chicago: SPSS Inc.). Descriptive statistics were used to describe the characteristics of the participants. In Study II proportions of item scores were calculated. General Linear Models (GLM) using a backward stepwise ANCOVA (Analysis of Covariance) was applied to identify which variables could explain the variation in driving ability (dependent variable). The least significant available variable was eliminated at each step (*p*-value for removal >0.05). The independent variables that were investigated included Age, Gender, Time since onset, Side of lesion, Cognitive screening outcome (NorSDSA pass/borderline/fail) and Awareness of driving disability. Adjusted R² was used as a measure of the variance, explained by the independent variables. In the healthy sample, independent samples t-tests were used to compare levels of driving ability to a sample of drivers with stroke.

#### The Empirical, Phenomenological, Psychological method

Interview data for Study III were analysed using a qualitative method, the EPP (Empirical, Phenomenological, Psychological) method as developed by Karlsson (Karlsson, 1995). The EPP traces the meaning structure of the lived-experience related to a phenomenon (Karlsson, 1995; Tham, Borell, & Gustavsson, 2000). In the study an occupational perspective was used which has been adopted in previous studies (Guidetti et al., 2007, Tham et al., 2000). Following the EPP method, five steps in the analysis were used, and the interviews were analysed separately until step five where all interviews for the four participants were analysed together. As a start the author thoroughly read all three interviews for all four participants to get a good comprehension and to understand each participant's original experience (Karlsson, 1995). After reading all the interview material, each interview was analysed separately in steps one to four. In step one, the interview was read until the researcher felt confident that the content was familiar. The attitude of the researcher was open and the reading of the texts was done with conscious bracketing of theoretical knowledge not in agreement with

phenomenology, for example knowledge based in bio-medicine. In the second step, the researcher divided the interview into meaning units each time there was a shift in meaning. In the third step, each meaning unit was analysed and interpreted in the light of the whole interview in order to describe the implicit and explicit meaning embedded in the facts relating to the phenomenon under study. In the fourth step, the described meaning units were synthesised and organised into a summarised and preliminary situated structure, and each interview was presented in a synopsis with different themes describing the phenomenon under investigation. In the fifth step, the researcher explored and compared the situated structure of all the protocols, i.e. the change between the different interviews over time within each participant and across the four participants. In this final step, there was a move from the situated structure of each interview to a general structure of the phenomenon for all four participants and across all interviews.

#### RESULTS

P-Drive, a valid assessment tool for measuring driving ability in people with stroke, in a driving simulator and on-road

Driving simulator (Study I)

The study investigated aspects of validity and stability of P-Drive for people with stroke. Of the 101 participants, 98 demonstrated acceptable goodness-of-fit (97%) to the Rasch model, indicating acceptable person response validity. Nineteen of the 20 items demonstrated acceptable goodness-of-fit (95%) and the scale could be viewed as unidimensional and holding evidence of internal scale validity. When examining the categories of the rating scale no step disordering was found in the scale category measures, indicating that the scale categories was randomly chosen and functioned as intended. The person separation reliability of the participants was 0.84 indicating that P-Drive was able to separate the participants' driving ability into different strata. The mean SE for the participants was larger (M=0.42) than the criteria set. Further investigation of the SE revealed that participants with a good driving ability had higher SE than drivers in the middle and lower end of the scale, suggesting that P-Drive was able to more precisely estimate the abilities of moderate to poor drivers than more able drivers. No DIF was found between the samples with right and left stroke (CVA) and only minor differences could be detected between older and younger drivers, respectively drivers with high and low ability to drive, the conclusion was that the overall item hierarchy was stable across the subgroups.

Further, the results indicated that the item hierarchy (Table IV) of P-Drive was in line with the theoretical model used. Items needing tactical decisions were more challenging than those only concerning operational decisions.

# On-road (Study IV)

The study investigated aspects of validity and reliability of P-Drive among people with neurological disorders (stroke, dementia, MCI). The results indicated that the scale categories increased in difficulty as intended and that there was randomness in the choice of categories. Ninety-five percent of the drivers demonstrated goodness-of-fit to the model, indicating acceptable person response validity. The person separation reliability was 0.90, indicating that P-Drive was able to separate the clients' driving ability. Of the 27 items, three items did not comply with the Rasch model's expectations. The items of *Obeying stop regulation* and

Steering had a higher MnSq and z than the criteria set. Organising had an infit and outfit MnSq (Infit=0.57) and z (infit z=-5.4) that were marginally too low according to the criteria, indicating that this item showed too little variation and was over-predictable, although not necessarily a threat to the validity of the scale.

Table IV: Item hierarchies for the two different P-Drive versions. Harder items at the top and easier items at the end of the table. Items are numbered according to the numbering in the protocol. Classification of the items according to Michon's (1985) levels: Tactical (T) and Operational (O).

	the items according to Michon's (1985) levels: P-Drive simulator item hierarchy	P-Drive on-road item hierarchy
Harder item	11. Attending to fellow road users (T)	10. Positioning on the road (T)
	4. Controlling speed (T)	12. Organising (T)
	6. Attending to the left (T)	16. Follow speed regulation (T)
	14. Giving way (T)	18. Attending to the right (T)
	13. Giving right-of-way (T)	19. Attending to the left (T)
	7. Attending to the right (T)	23. Heeding information sign (T)
	20. Positioning on the road (T)	24. Attending to fellow road users (T)
	8. Heeding warning/prohibition sign (T)	8. Following instructions (T)
	9. Heeding regulation sign (T)	13. Giving right-of-way (T)
	19. Reversing the car (O)	17. Attending straight ahead (T)
	10. Heeding information sign (T)	21. Heeding warning/probation sign (T)
	18. Finding the way (T)	27. Solving problem (T)
	1. Steering (O)	5. Contr. speed, high pace (T)
	2. Changing gears (O)	20. Attending to mirrors (T)
	17. Following instructions (T)	25. Reacting and responding (O)
	12. Reacting and responding (O)	26. Focusing (T)
	5. Using indicator (O)	6. Using indicator (O)
	3. Using pedals (O)	9. Finding the way (T)
	16. Following speed regulation (O)	14. Yielding (T)
	15. Obeying stop regulation (O)	15. Obeying stop regulation (O)
		4. Controlling speed, low pace (T)
		11. Keeping distance (T)
		2. Changing gears (O)
		3. Using pedals (O)
		22. Heeding regulation sign (T)
		7. Reversing the car (O)
Easier item		1. Steering (O)

The principal components analysis (PCA) revealed that the scale (first component) explained 59.1% of the variance of the residuals and that the second component explained 4.9% of the

variance, which indicates that the items formed a unidimensional scale. Most items seem to be stable across different diagnostic groups, although four items clearly differentiated in challenge between the diagnoses of stroke and MCI. The items of *Giving right-of-way* (item 13), *Keeping distance* (item 11) and *Heeding regulation signs* (item 22) were relatively more challenging for drivers with stroke than for drivers with MCI. One item, *Finding the way* (item 9), was relatively harder for clients with dementia and MCI than for those with stroke.

The item hierarchy of P-drive on-road complies with a hierarchical model of driver behaviour. In the present hierarchy, items needing tactical decisions were more challenging than items concerning operational decisions like manoeuvring (Table IV).

## Preliminary analysis of driving ability in a healthy sample of drivers

For this thesis another analysis (not part of Studies I and IV) was done to complement the psychometric analyses of P-Drive. In order to investigate driving ability in a sample of healthy elderly people a preliminary analysis was conducted from an unpublished research study. Eighty-eight persons were included in a study and the participants were recruited using the driver license register of Stockholm's southern suburbs. The mean age of the participants was 72 years (SD 5.4, range 64-84) and 42 were women. The participants drove a set on-road test that took about one hour to complete (the same route as used at one of the clinics in Study IV). Their driving ability was scored using P-Drive on-road. The occupational therapist who conducted the on-road test also set a clinical judgement of pass or fail based on the on-road test performance, and 21 of the participants would have failed the on-road test if it had been a clinical test. In this preliminary analysis two research questions were asked: a) Are there any significant differences between the healthy sample and a sample of people with stroke? b) What are the psychometric properties of P-Drive when the healthy sample is included in a larger sample of drivers with neurological disorders?

a) When comparing the healthy sample with a sample of 128 drivers with stroke (from Study IV) the two samples differed greatly in gender distribution. In the sample of drivers with stroke there were only 14 women (11%) participating while in the sample of healthy drivers there were 48% women. Furthermore, the sample of drivers with stroke (mean age 67, SD 11) was younger than the healthy sample (Mean age 72, SD 5) (p<0.001). We decided to match the samples according to gender and age (women  $\pm$  5 years, men  $\pm$  2 years). For some women

in the sample of drivers with stroke there were several healthy women that matched and a lottery method was used to select one. The matched samples constituted of 52 healthy drivers and 52 drivers with stroke, both groups with a mean age of 73. When comparing the matched groups there were significant differences in driving ability (t=2.4, df= 102, p=0.02), indicating that P-Drive could differentiate between a healthy sample of elderly and drivers with stroke on a group level (when matched for gender and age). The results of these analyses indicate that participants in the healthy sample, consisting of more or less able drivers, also demonstrated driving difficulties and the two groups were overlapping in driving ability. However, when matched according to age and gender, healthy drivers (Mean measure on P-Drive was 1.4, SD 0.7) were more safe and competent than drivers with stroke (Mean measure on P-Drive was 0.9, SD 1.1).

b) In the Rasch analysis the healthy sample was included in the whole sample of people with stroke, dementia and MCI (from Study IV) and the results revealed that the psychometric properties remained acceptable. Person separation reliability was at 0.9 and with a person response validity of 95%. Two items did not demonstrate goodness-of-fit to the model's expectations (in Study IV there were 3 items that did not fit) and *Obeying stop regulation* was still the item that had the highest infit and outfit MnSq and z (Infit MnSq= 1.9, z= 8.5).

# Awareness of driving disability in people with driving difficulties following stroke

Study II explored and described awareness of disability in people with driving difficulties after stroke. In 60% of all the ratings in the sample there was either a major (score 1) or moderate (score 2) discrepancy between how the participant performed and what he or she reported. In 28% of all the ratings there were major discrepancies between self-reported and observed driving performances (score 1). Twenty-nine (76%) of the participants had at least one of the questions scored 1 (a major discrepancy) indicating that during the driving evaluation at least one serious mistake or incident occurred of which the participant was not aware. The majority of the participants demonstrated unsafe and incompetent driving ability (36 had P-Drive measures under the cut-off criterion and were considered as "fail" and two were within the at-risk zone) and also limited awareness of driving disability, since they showed a major or moderate discrepancy in the scoring of the items in the modified version of AAD.

Awareness of driving disability and Cognitive screening outcome (NorSDSA) were significantly associated with driving ability (P-Drive) and could explain 74% (adjusted  $R^2$ ) of the total variance in driving ability in the sample. The results from a psychometric analysis using Rasch revealed that all 12 items in the modified version of AAD generated acceptable goodness-of-fit supporting unidimensionality and internal scale validity in the test. The PCA of the residuals revealed a variance explained by the test (the first component) to be 77%, which was higher than the general criterion, suggesting further evidence of unidimensionality in the items used to measure awareness of driving disability. The items generated a person separation reliability of 0.8.

## Lived-experience of driving ability following stroke

The phenomenon being explored in Study III was the lived-experience of driving ability in the context of being in the process of a driving evaluation because of stroke, and the findings revealed five main characteristics

## The meaning of driving remained throughout life

Driving was a matter of course; it was something permanent that the individual took for granted and did not reflect upon. The advice from the physician not to drive was unexpected and surprising. Driving and driving ability had been taken for granted even after stroke. All the participants described themselves as competent and safe drivers both in retrospect and at present, and their beliefs that they were competent and safe drivers seemed to be incorporated as a part of self. The meaning of driving did not change with the onset of stroke and, after the driving cessation, driving still remained an important activity.

## Being questioned and advised not to drive – an untenable situation

The advice from the physician not to drive due to stroke was surprising and questioned the participants' competence and ability to drive and to make rational judgements and decisions. Feelings of being unfortunate and treated unjustly followed the advice and not driving was experienced as an untenable situation. Three of the four participants decided to drive despite the advice from the physician. These participants experienced that the advice was not valid in their case.

## Being out of control and violated by the driving evaluation

The participants described that the driving evaluation was perceived as a violation of the right of self-determination, a situation that they had not chosen, but one that had been inflicted on them on top of the onset of stroke and made them feel powerless. The neuropsychological testing was experienced as something they were forced to do. The purpose of the testing was unclear and the on-road test was seen as a way to show one's true competence as a safe driver.

## Driving safely (as usual) during the on-road test

Despite the fact that they all had different driving abilities and evaluation outcomes, all participants (even those who failed) experienced that the on-road test had gone well, that they had been driving in a safe manner, and that they performed the same way they had performed before their stroke.

#### Perceiving consequences in everyday living

The advice not to drive and later the outcome of the driving evaluation had consequences on everyday life and led to new routines. After finishing the driving evaluation, everyday routines were either re-established or a permanent loss was evident. The inability to drive was experienced as a hard blow and a great loss. Two of the participants still experienced the evaluation as a violation and experienced anger, sadness, and anxiety as a result of the reminder. They both had difficulties accepting the results and moving on with their lives after the evaluation, and their futures with or without driving were unknown to them.

#### CONCLUSIONS

The results from Studies I and IV indicated that P-Drive (both versions) is an assessment tool that is valid for assessing driving ability in people with stroke in a technically advanced driving simulator or on-road, respectively. P-Drive showed evidence of scale validity meaning that the scale steps and items worked as intended. P-Drive was able to give a valid linear measure on the persons' driving ability (person response validity). The scale was also able to separate the abilities of the persons, the less able from the more able. The item hierarchies in the two P-Drive versions were both theoretically logical and in line with a (behavioural) model of the driver. Further, the results of a preliminary analysis indicate that P-Drive was able to detect differences between a healthy sample of drivers and drivers with stroke, when matched for age and gender healthy drivers were more safe and competent than drivers with stroke.

In Study II lack of awareness of driving disability was evident, as the majority of the persons with stroke who failed the driving evaluation also had limited awareness of their disability. In Study III the participants experienced their driving ability as unaffected by the onset of stroke and driving ability was taken for granted. Limited awareness of disability was indicated since participants were driving despite a recommendation not to drive. In addition, the results from Study III increased our knowledge that the driving evaluation arouses strong negative feelings and losing the driving licence was experienced as traumatic. The participants experienced driving as an important everyday occupation, an occupation the participants took for granted even after stroke.

## GENERAL DISCUSSION

The purpose of this thesis was to explore and describe methods for assessing driving ability from an occupation perspective and also to investigate awareness of driving disability in people with stroke. The purpose was also to describe and gain understanding of the lived-experience of driving ability in people who are in the process of a driving evaluation following stroke. The perspective of the thesis was based in occupational therapy with a focus on the actual performance of the driver. In this section the main findings of the four studies will be discussed, as will limitations and ethical considerations. The discussion will conclude with a summary of clinical implication together with suggestions for future studies.

# Measuring driving ability

To measure a person's ability to drive safely after stroke is a complex task for health care and a task that requires several different methods (both off- and on-road tests). The results from Studies I and IV indicate that P-Drive withholds evidence of internal scale validity and person response validity in both the simulator and real traffic context. The results from Study II indicated that the modified version of AAD seems to hold evidence of internal scale validity and person response validity and could give a valid and reliable measure of a person's awareness of disability. Both assessment tools are based in occupational therapy theory (Fisher, 2006; Kielhofner, 2008) and are unique in the sense that they measure aspects of driving ability with a focus on occupation, the actual performance of the driver and therefore give an important contribution to the driving evaluation. In a recent study the driving evaluation made by a multi-professional team (physician, orthoptist, psychologist, occupational therapist/physiotherapist and driving instructor) seemed to be an effective way to assess drivers with stroke (Ponsford, Viitanen, & Johansson, 2008). The driving evaluation can be viewed as a jigsaw puzzle, a puzzle that needs to be solved by a multi-professional team (Akinwuntan et al., 2002; Heikkilä et al., 1999), using valid and reliable assessment tools to get as full a picture as possible. Cognitive screening batteries are common in the driving evaluation and in this thesis (Study II) NorSDSA was used. NorSDSA captures several cognitive functions (Lundberg et al., 2003), focusing on the underlying capacities of the driver. There is no test or method that can stand on its own and determine whether a person with stroke is able to continue driving. Rather a combination of tests (on and off-road) is recommended (Akinwuntan et al., 2002) and needed to solve the puzzle and help the

physician come to a final outcome, taking several aspects and measures of the driver's ability and capacity into consideration.

Although the assessment tools presented in this thesis produce valid and reliable measures they also have limitations. The on-road driving test is just a snapshot of someone's ability performed during that specific hour, on that day and in that car and therefore it has been questioned whether an on-road test can pick up risky behaviour (Christie, 1996). The development of P-Drive is not by any means finished; future steps in the development need to expand the sample to also include more women and a variety of people with different diagnoses. In order to adjust for and explore the stringency in different raters, there is a need to investigate the effect of multiple raters and rater severity (Engelhard, 1994), as has been done in the Assessment of Motor and Process Skills (Fisher, 2006) and the Assessment of Awareness of Disability (Kottorp, 2006). In Study IV different sites and routes were used that could have different degrees of difficulty. P-Drive measures the person's quality of performing a driving test in a context that is closely related to the "real-life driving context" and according to a definition by Schmucker (2001) is assumed to uphold high value of ecological validity. The neuropsychological testing could be criticized for limited ecological validity since the relationship to real-traffic driving could be questioned; as the participants in Study III expressed, it was not clear what the tests were investigating related to their driving ability.

# Describing driving ability

P-Drive is an assessment tool that aims at measuring driving ability and the items has been operationalized as the safety and quality of performing observable goal-directed actions during a driving test, either in a technically advanced driving simulator or on-road in real traffic. The results from Studies I and IV indicated that the two versions of the scale were unidimensional and that the item hierarchies were logical. The item hierarchies in Studies I and IV give valuable information and can be used to describe the construct of driving ability. They could contribute to describing which actions are easier and harder and which items are needed to be able to perform as a safe and competent driver following stroke. There is little research that describes driving and actions required to drive safely following stroke. Literature and models aiming at describing driving a car have either broken down driving into capacities needed for handling the occupation (cognitive, psychomotor and sensory/perceptual capacities (Mazer et al., 2004), or into models describing the cognitive decision making of the

driver (Michon, 1985). However, driving a car following stroke as actually performed has so far been sparsely described in the literature.

In line with a model of driver behaviour (Michon, 1985) the item hierarchy in Study I showed that items concerning manoeuvring or operating the car were relatively easier than items needing tactical decision like attending and responding to fellow road users and controlling speed to the demands of the traffic situation (see Table IV). In Study IV Positioning on the road and Organising were the hardest items (see Table IV). The scales differ in length (20 and 27 items), context of performing (simulator and on-road) and in the positions of the items, for example Following speed regulations was relatively harder on-road than in the simulator (see Table IV). The demands from the context differ in difficulty (drivers in the simulator have a tendency to drive slower and seldom exceed speed limits). The item hierarchies are both related to the two lower levels in the cognitive driver behavioural model (Michon, 1985), but can be seen as going beyond the model of the driver. P-Drive focuses on the actual doing while the cognitive model focus on underlying decisions related to the behaviour. The items in P-Drive are goal-directed actions – based on theories that occupational performance is a dynamic interaction between the individual and the environment (Fisher, 2006; Kielhofner, 2002). The P-Drive item hierarchy gives a more detailed picture of the actions required for driving safely and the hierarchy of more or less difficult actions performed during driving either in a simulator or on-road. From these hierarchies we can learn more about the patterns of how drivers with stroke perform on-road or in a simulator (although there were also drivers with dementia and MCI included in Study IV). The item hierarchy gives the occupational therapist information of what to be extra attentive to when observing driving and also how to design a test route including actions challenging enough to capture the difficulties that drivers with stroke seem to have during driving.

# Awareness of limited driving ability

Study II indicated that people with stroke who had driving difficulties also had limited awareness of their limited ability to drive safely. The results were in line with a recent study of drivers with brain injury (Lundqvist & Alinder, 2007) in which a group of drivers that failed a driving evaluation were also less aware of their difficulties than the group of drivers that passed. With a limited awareness following stroke the individual may have trouble perceiving why he/she should not be driving any longer or may also be unable to make correct

decisions during driving or take rational decisions about their own driving. The results from Study III also indicate limited awareness of driving disability since the drivers (3 of 4) were driving despite a restriction from their physician. These indications that drivers with stroke have limited awareness of their driving disability could have several consequences, as in Study III where the participants were driving despite restrictions and had difficulties accepting the results. Improving the routines around the advice not to drive will be discussed in the Clinical implications section. Awareness training techniques like video-feedback have been shown to help patients discover their errors themselves and improve awareness of disability (Tham & Tegnér, 1997) and this technique may also be useful in driving evaluations where cameras can be used to videotape the driving test and feedback be given afterwards by showing the film in order to improve awareness. The results from these two studies (II and III) indicate the need for further interventions related to awareness of driving disability.

# Driving an important occupation in everyday life

The findings of Study III revealed that driving was experienced as an important occupation, an occupation and ability taken for granted despite the onset of stroke. The advice not to drive given by the physician and later the driving evaluation was experienced as devastating, and there were similar findings in a study of elderly people who had had their driving licences cancelled (Whitehead, Howie, & Lowell, 2006). Earlier studies have shown that a driving cessation decreased participation in society (Marottoli et al., 2000) and decreased health (Marottoli et al., 1997; Ragland et al., 2005) and confirms the strong reaction of the participants, as there is so much at stake with a driving cessation. Furthermore, one of the participants experienced the outcome of the evaluation, his failure, as a shock. He had trouble accepting and adapting to his new situation. A transition model from an active driver to a nondriver (Vrkljan & Miller-Polgar, 2007) suggests that a disruption in the ability to participate in occupations that bring meaning to life, such as driving, and an inability to adapt to the disruption could lead to a state of occupational deprivation. This deprivation is a state in which the individual is restrained from engagement in activities of necessity and/or meaning because of external factors that are beyond the control of the individual (Wilcock, 2006). As occupational therapists we need to follow up the individual after a failure by offering an intervention that can compensate for the loss (further described under Clinical implications).

# Methodological considerations

In this thesis two main methodological approaches have been used to a) develop assessment tools for evaluating driving ability and explore awareness of driving disability and b) gain better knowledge about the lived-experience of driving ability following stroke. The methods of analysis were Rasch analysis (Studies I, II, IV) and phenomenological analysis (Study III).

## Inclusion of participants

One limitation in this thesis was that the samples for Studies I, II and IV were dominantly male participants (87-89%). The small amount of women included was dependent on the ratios in the referrals coming in to the clinics, but the reason why so few women were referred for a driving evaluation is not clear. We do not know if the results of the studies would have been different if more women had been participating. Research has shown that compared to men, women more often voluntarily give up driving and that women gave up driving at a younger age than men (Hakamies-Blomqvist & Wahlström, 1998). Maybe a part of the answer to why women were not referred is that they had already given up driving or that the onset of stroke made them take the decision to give up driving. Men are slightly more often affected by stroke (50.8%), but this still does not explain the overrepresentation in this thesis. Women receive stroke at a later age than men (Mean age=78.3, Riks-Stroke, 2006) and this could mean that most of the women inflicted by stroke have already given up driving and therefore are not referred. Also the mean age of the participants in the thesis studies is more than 10 years lower (Mean age=64.8) than the mean age of people getting stroke in Sweden (Mean age=75.8, Riks-Stroke, 2006). The samples in the studies in this thesis cannot be said to be representative of the total stroke population in Sweden when it comes to age and gender. However, due to the sampling methods used (Studies I, II and IV) the participants included can be representative of those referred for a driving evaluation. The aim of the purposive sampling that was done in Study III was to get a wide variety of participants who could describe different variations of the phenomenon under investigation. The intention was to include one woman in the study, but this was difficult since so few women with stroke were referred for driving evaluations during the period of the project and the one women who was included eventually dropped out.

In Study IV two more diagnoses were included besides stroke, and healthy elderly people were also analysed to further investigate the psychometric properties and develop P-Drive.

The inclusion gave valuable information and experiences of other samples besides people with stroke, but the samples were small. Research needs to continue investigating other and larger groups of drivers so P-Drive can become more generic.

#### Methods for data collection

Studies I and IV are based on data from a driving test and were conducted in the contexts of a technically advanced driving simulator and in real traffic on a set route on-road. Driving simulators have been criticized for being expensive and time-consuming (Evans, 2004). Two recent studies that compared performance in on-road testing and in a simulator (elderly drivers) found that a test in a simulator gives a valid measure of a person's driving ability (Freund, Gravenstein, Ferris, & Shaheen, 2002; Lee, Cameron, & Lee, 2003). The results from Study 1 also indicate that performance in a technically advanced simulator seems to give a valid measure of a driving ability in people with stroke. There are limitations with driving simulators; the initial cost could be high and motion sickness could prevent some drivers from being tested. The main limitation of the on-road test is the inability to standardise the test and test really challenging and hazardous situations (Ponsford et al., 2008). In the onroad test the difficulty of each test varies, i.e. there are no two tests that are equally difficult. The limitation of P-Drive is that the assessment tool was developed to measure driving ability in people with stroke and therefore might need further development in order to assess other diagnoses and healthy drivers as suggested by the DIF-analysis in Study IV. Another limitation with Study IV is that five different occupational therapists were rating the abilities of drivers with neurological disorders, and the severity and stability of the raters needs to be investigated (inter- and intra-rater reliability).

In Study III interviews were done on three occasions using interview guides that focused on the participants' experiences of driving and ability to drive. The questions were open-ended and the interview guides were specific to the different interview occasions. The qualitative interview gives the researcher access to the individual's experience of the life-world (Kvale, 2007). By encouraging the participants to give examples and describe actual situations they found that the data became rich and spontaneous, capturing the immediate lived-experiences. The lived-experience of driving ability in the context of undergoing a driving evaluation began with the advice from the physician not to drive and was described by the participants in retrospect. Future qualitative studies should start interviewing at the time point when the client receives the advice not to drive, in order to provide a deeper understanding of the lived-

experiences right from the time the advice is given. The topic of the interviews was sensitive and could have affected the responses of the participants, although three of the four participants revealed that they were defying the advice and were driving anyway. This could mean that they trusted the researcher and felt that they could be open in their descriptions.

## Methods for analysis

In Studies I, II and IV, Rasch analysis was used to investigate psychometric properties of two newly developed assessment tools, P-Drive and a modified version of AAD. Rasch is a method that can be used to develop new scales and improve or reject existing scales by the transformation of ordinal scales into linear measures (Tesio, 2003; Wright & Linacre, 1989). Rasch can be used to analyse assessment tools measuring clinical variables (like abilities), but the limitation is that the analysis of the results becomes more complicated to handle than for an ordinal scale were scores are summed up. In Winsteps' (Linacre, 2005) Rasch program there are applications (key-forms) that can be used to visualize and more easily interpret clinical data.

In Study III, the EPP method (Karlsson, 1995) was used to analyse the interviews. It is a complicated method in several steps, but one that was well suited to describe the phenomenon of the lived-experience of driving ability in the context of being in the process of a driving evaluation because of stroke. When the aim is to understand and describe the meaning of a phenomenon the use of a phenomenological approach, as opposed to measuring and observing, is needed in order to discover the lived-experience of the individual (Karlsson & Tham, 2006).

#### Generalisation of findings

The samples used in the thesis were mostly clinically referred drivers with stroke (all studies) or other neurological disorders (Study IV) and cannot be considered to be representative of the stroke population, being too young and too dominated by men. However, the results can give a picture of drivers that are referred to driving evaluations following stroke. In Study IV drivers with dementia and MCI were also included and the results from the study do not describe a clear group of drivers with stroke. Nonetheless the variation of diagnoses was included as the authors believe inclusion of different groups enriches the development of P-Drive. The results from Studies I, II and IV indicate internal scale validity for the assessment tools used (P-Drive and the modified version of AAD) and strengthens the validity of the

thesis. The phenomenological approach used in Study III does not aim at generalising, but rather at increasing our knowledge of a specific phenomenon. Phenomenological findings are contextual, but still the results have meaning for other contexts (Dahlberg & Nyström, 2001). In this case our understanding of the lived-experience of driving ability in the context of undergoing a driving evaluation following stroke increased, and this can be used to help us understand other groups of drivers in similar situations.

#### Ethical considerations

All the studies (I-IV) in this thesis were approved by the Ethical Review Board at Karolinska Institutet and all participants in the studies gave both oral and written consent to participate in the studies. The participants were given oral and written information about the study, including information about the aim, methods and procedures of the research and also about the confidentially and their right to end their participation at any time. In the evaluation of the driving abilities of people with stroke there are several ethical dilemmas to be considered and by conducting research in this field these dilemmas are encountered. People with stroke are in a weakened and vulnerable state, and being confronted with advice not to drive is a hard blow, as could be seen in Study III. With the evaluation of someone's driving ability we are conducting an act that the person does not really want to be part of, but feels obligated to participate in to have the chance of keeping the driving licence. The evaluation sets many negative emotions into play (Study III) and the individual might suffer from both anxiety and anger by being forced into the evaluation. However, not to assess the driving ability of a client with stroke is an even larger ethical dilemma since an unfit driver might be then permitted out in traffic. The interviews that were conducted in Study III addressed a sensitive topic and aroused many emotions that may have been negative reminders of the harsh situation of being in the process of a driving evaluation. It could also be a positive experience to have someone that asks and listens to the situation in which these men had been. Finally, the clinical outcome of the participant's driving evaluation was not biased by their participation in any of the studies in this thesis.

# Clinical implications

Stroke has a major impact on a person's health and life, and is often followed by a stay at a rehabilitation clinic. During rehabilitation the person with stroke is often confronted with issues related to driving and advised not to drive due to the medical implications following

the illness. The need for a driving evaluation is stressed following stroke (Akinwuntan et al., 2002; Mazer et al., 1998). Clinical implications supported by the results from this thesis are suggested and discussed below:

- The results from Study III showed that even though all participants had been advised not to drive most of them had started driving again. In Sweden it is the responsibility of the physician to, when necessary, give the advice not to drive (Vägverket, 2008). The results from Study III indicate the need for the delivery of the advice to be improved. The three participants who had started driving re-interpreted the advice in favour of resuming driving. From the descriptions of the participants it could be interpreted that the information given with the advice not to drive was incomplete and unclear in the sense of why the advice were given. To improve this, the oral information could be complemented with written information about the illness and the reasons for not driving afterwards (in the case of stroke, its symptoms and the risk of relapse and seizures).
- The results (Study III) indicate that it could be harsh to receive advice not to drive. The participants reacted with feelings of being insulted. Suggestions for improvement could include a continued discussion at the clinic between the driver, family members and other health care professionals about different ways to cope during the driving cessation and also a therapeutic discussion of consequences in everyday life following the cessation of driving. The occupational therapist could have the role of discussing and training use of alternative methods of transportation during the cessation.
- The experiences of the participants in Study III point out several parts of the driving evaluation that need to be improved, more specifically the information about the tests used. The methods used to measure driving ability and underlying cognitive capacities need to be standardised and validated. The results from Studies I and IV indicate that P-Drive has the potential of becoming a valid tool for assessing driving ability in a driving simulator or on-road. The item hierarchy could be used to inform the occupational therapist conducting the driving test of what to be extra attentive to when observing and be used to design a test route.
- The implementation of a new assessment tool needs serious consideration. In Study
  IV the raters had difficulty rating one of the items equally, thus a certification course
  where raters are calibrated for their severity before becoming licensed raters is needed.

- In Study III the participants described frustration about the neuropsychological tests used during the evaluation. What the test actually could say about their driving ability was questioned; therefore there is a need for information to the person under investigation about the methods used in the evaluation, about why they are used and how they are going to be interpreted. Also, the health care professionals working at a traffic medicine centre must try to understand the stress the person is under during testing and meet the needs of the person.
- The results from Study II indicated that limited awareness of driving disability might be evident in drivers with stroke. There is a need to assess awareness in those drivers with difficulties in performing safely and competently during the driving test. If a limited awareness is evident after a failure, actions to improve the awareness of disability are needed to help the person understand that he or she is no longer a safe driver.
- The work of the occupational therapists does not end with the on-road test, for drivers that have failed the evaluation occupational therapy intervention need to continue.

  (See Figure 3 for a clinical model of driving evaluations including intervention.)

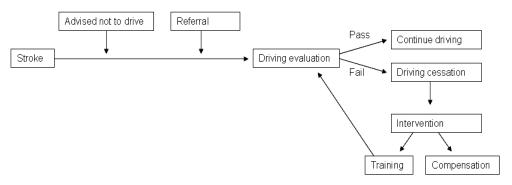


Figure 3: A suggested model for clinical driving evaluations

Fisher (1998) emphasised two different intervention methods for someone who has lost the ability to perform everyday occupations. Intervention with the aim to retrain abilities (called therapeutic occupation) can be done using occupations that are naturalistic and contextual. Training in a simulator seems to improve driving ability following stroke (Akinwuntan et al., 2005) and on-road training at a driving school improved driving ability in a sample of people with stroke who had failed an on-road test (Söderström, Pettersson, & Leppert, 2006). The second intervention method is the

use of adaptive or compensatory occupation to help the person reorganise this new everyday situation and find other or new activities that can bring meaning to life. An example is teaching the person to use other forms of transportation, like public transportation. A study aimed at increasing outdoor mobility in elderly people with stroke using a targeted occupational therapy intervention in the home showed an improved outdoor mobility at four and ten months (Logan et al., 2004).

#### Future research

One suggestion for a future study would be to evaluate the effect of a compensatory intervention. This would be an intervention that takes into consideration the needs and wishes of the person with stroke and the person's continued everyday life without driving. The intervention would be for those persons with stroke who have shown limited driving ability and awareness of disability, who have limited ability to accept being a non-driver, and who are in need of either further therapy or a reorganisation of their lives to be able to cope without driving. The occupational therapist needs to start by giving the person feedback about the disability and the difficulties shown during driving performance. One method that has been used to improve awareness of disability is video-feedback (Tham & Tegnér, 1997) and is a method that could be adopted in driving research. A second step is to investigate what occupations the person wants and needs to be able to do in his/her life and from there target the intervention to help the individual regain meaningful everyday occupation. Research to continue the development of P-Drive is also needed. There is a need to compare different diagnoses, raters, contexts (simulator vs. on-road) and also different routes.

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