1. Fitness to drive of drivers with cognitive impairment

1.1. Introduction

Individuals with cognitive impairment, their spouses and other family members may struggle with doubts about fitness to drive (Adler, 2010). This corresponds with results from multiple studies which have shown that many patients with cognitive impairment drive less safely than healthy older drivers (Dubinsky, Stein, & Lyons, 2000; Duchek et al., 2003; Fox, Bowden, Bashford, & Smith, 1997; Frittelli et al., 2009; Withaar, Brouwer, & van Zomeren, 2000). Driving errors may occur especially in traffic situations with time pressure or when attention must be divided, for example when turning across traffic at complex intersections (Uc, Rizzo, Anderson, Shi, & Dawson, 2004). Driving errors may also occur in traffic conditions that are not typically regarded as difficult (Barco et al., 2015). The accident risk of patients with cognitive impairment is two to eight times higher than in age-matched controls (Dubinsky et al., 2000), and patients with cognitive impairment are also more often "at fault" in accidents (Cooper, Tallman, Tuokko, & Beattie, 1993; Lucas-Blaustein, Filipp, Dungan, & Tune, 1988). Clearly, patients with cognitive impairment are an at-risk group for unsafe driving. Moreover, patients with cognitive impairment are usually older drivers who are at increased risk for serious injury due to an accident (Michel Bédard, Guyatt, Stones, & Hirdes, 2002). However, this does not mean that all patients with cognitive impairment should cease driving immediately, because a significant proportion of patients with dementia is still able to drive safely at the time of diagnosis (Papageorgiou et al., 2016). Premature driving cessation is undesirable, because driving is important for many patients (and healthy individuals) for social participation, independence, and well-being (Davis & Ohman, 2016; Persson, 1993). In discussions about driving continuation the benefits of driving and the safety risks involved should be carefully weighed.

The benefits of driving may outweigh the risks when cognitive impairments due to normal or pathological ageing are still mild. In line with this, individuals with mild dementia (Clinical Dementia Rating (CDR) ≤ 1) are allowed to drive in the Netherlands if they pass an on-road driving assessment at the Dutch driving licence authority (Netelenbos, 2000). Although

these on-road driving assessments are very representative driving tests (i.e. have high face validity) administered by well-trained experts on practical fitness to drive from the Dutch driving licence authority, they are not standardized with regard to specific road and traffic situations. Usually, patients drive their own car in their own residential area during the on-road driving assessment. As a rule, individuals with dementia who pass the on-road driving assessment renew their driving licence for no more than one year. This is because dementia has a progressive course, hence cognitive impairments increase over time and at some point driving becomes too risky (Liddle et al., 2016). Patients know that they lose their driving licence if they fail the on-road assessment, which can be a reason for patients to not inform the Dutch driving licence authority about their dementia diagnosis. Patients with cognitive impairment and their family members may consult a physician for advice, but also for physicians it is difficult to evaluate fitness to drive at the individual level (Bixby, Davis, & Ott, 2015; Davis et al., 2012; Dobbs, Carr, & Morris, 2002; Jones, Beveridge, & Schattner, 2012; Omer, Dolan, Dimitrov, Langan, & McCarthy, 2014; Ott et al., 2005). Previous studies with on-road driving assessments revealed large individual differences in practical fitness to drive, which are difficult to explain on the basis of clinical characteristics and judgments from patients, family members and caregivers (Barco et al., 2015; Bixby, Davis, & Ott, 2015; Fitten et al., 1995).

Meanwhile, we have an ageing population, therefore the number of patients with cognitive impairment is rapidly increasing and so is the number of older drivers. In the Netherlands, there are more older people with a car, driving more kilometres than ever before (Kampert, Nijenhuis, van der Spoel, & Molnár-in 't Veld, 2017). With the increasing number of older drivers, the number of patients with cognitive impairment with a wish to continue driving will also rise. The Dutch government stimulates 'ageing in place', i.e. older people should live independently for as long as possible (Rijksoverheid, 2015). An important prerequisite for independence and participation in society is sustained mobility (Davis & Ohman, 2016). However, transport should be safe, safe for patients with cognitive impairment and for other road users. In order to determine which patients can continue driving, fitness to drive should be assessed on a patient-by-patient basis (Papageorgiou et al., 2016). For evaluations of fitness to drive, many tools have been and are being used, however, up to this day there is no generally accepted standardized procedure to assess fitness to drive in the clinical setting (Bennett, Chekaluk, & Batchelor, 2016; Carr & Ott, 2010;

Dickerson, 2013, 2014; Jang et al., 2007; Korner-Bitensky, Bitensky, Sofer, Man-Son-Hing, & Gelinas, 2006).

There are many factors potentially influencing fitness to drive, therefore clinical as well as neuropsychological measures need to be studied thoroughly in relation to on-road driving assessments. In addition, the effects on fitness to drive of individual differences in traffic knowledge (e.g. knowledge of traffic rules), driving skills (e.g. hazard perception), and driving experience should be investigated. For the design of a fitness-to-drive assessment for patients with cognitive impairment, it is important to carefully determine the best approaches and measures. Different sources of information could be useful, such as self-report from patients or interviews with family members (Dobbs et al., 2002), neuropsychological tests for cognitive functions that are important for driving (Aksan, Anderson, Dawson, Uc, & Rizzo, 2015; Lafont, Laumon, Helmer, Dartigues, & Fabrigoule, 2008; Ott & Daiello, 2010; Withaar et al., 2000), driving simulator rides (Devos et al., 2013; Etienne, Marin-Lamellet, & Laurent, 2013; Freund, Gravenstein, Ferris, & Shaheen, 2002), and on-road driving assessments (Hunt et al., 1997; Withaar, 2000). All sources may reveal 'red flags' indicating that driving is no longer safe, or in a more positive sense if there are no indications of 'red flags' from any source, driving may still be safe. However, different sources could also provide contradictory information, therefore it needs to be determined which information is indicating fitness to drive most reliably. Moreover, it is essential to define how different types of information should be combined to make a scientifically and socially arguable decision on fitness to drive. In the end, fitness-to-drive assessments should lead to driving cessation in patients who are no longer fit to drive and promote driving continuation in patients who are fit to drive or could be when adequately supported. The latter implies that the assessments must be rehabilitation oriented: Could this driver with doubtful practical fitness to drive be helped with a restrained licence, technical support and/or driving lessons?

A complicating factor in research on driving with cognitive impairment is the variability between patients. Older drivers with cognitive impairment may be diagnosed with dementia which is an umbrella term for various brain diseases, mainly neurodegenerative disorders (McKhann et al., 2011). Alzheimer's disease is the most common type of dementia, but vascular dementia, frontotemporal dementia, and Lewy body dementia are also frequently seen in clinical practice (Alladi et al., 2011; Goodman et al., 2016; Vieira et al., 2013). These types of dementia are characterized by different

symptoms, impairments and prognoses, which may result in different driving difficulties (Ernst et al., 2010; Fujito et al., 2016; Snyder, 2005). For example, patients with Alzheimer's disease may suffer from strategic difficulties such as finding a route while patients with frontotemporal dementia might be more inclined to make tactical level errors such as ignoring traffic signals (Fujito et al., 2016). In previous studies about fitness-to-drive assessments, patients with different types of dementia were grouped together, but taking the different symptoms and course of disease into consideration, it seems questionable whether one universal strategy can be developed that predicts fitness to drive accurately for all types of dementia.

1.2. Thesis outline

The primary aim of this PhD thesis is to systematically study how different factors contribute to variations in fitness to drive between patients with cognitive impairment. In this PhD research, diagnoses, severity and nature of symptoms are considered, i.e. different types of dementia, CDR scores, and various neuropsychological measures. In addition to classical neuro-psychological tests, traffic-specific knowledge and skills are assessed in computerized tests as well as in a driving simulator. A comprehensive approach incorporating all these types of assessments is used in relation to on-road driving assessments. The on-road driving assessment of the Dutch driving licence authority is the legal standard in the Netherlands, therefore, this assessment is the benchmark against which other assessments of fitness to drive are compared. This research will result in a procedure for the assessment of fitness to drive in patients with cognitive impairment in a clinical setting. Such an assessment procedure may substitute or complement the on-road driving assessment. Importantly, it provides information about strengths and weaknesses of patients with cognitive impairment, which may reveal options for compensation of deficits through the use of corresponding interventions (e.g. in-car support systems, adaptations to road infrastructure, education and training for traffic-specific knowledge and skills).

In addition to the development of a fitness-to-drive assessment strategy, this thesis will address the consequences of fitness-to-drive assessments for individual mobility. It is imperative to examine whether patients with cognitive impairment adhere to driving recommendations given after fitness-to-drive assessments, because reluctance to cease driving has been reported before (Byszewski, Molnar, & Aminzadeh, 2010; Jett, Tappen, & Rosselli, 2005). In this context, another important question is whether patients with

cognitive impairment sustain their independent mobility after a fitness-to-drive assessment or whether they become very dependent on rides of family and friends (Taylor & Tripodes, 2001).

Chapter 2 is a literature review which provides an overview of previous research about driving with different types of dementia. This chapter addresses the question whether different types of dementia have similar potentially detrimental implications for driving. *Chapter 3* describes the development of an assessment strategy to evaluate fitness to drive in a clinical setting. For this study, patients with the most common type of dementia, Alzheimer's disease, were selected. Three different types of assessments, i.e. clinical interviews, neuropsychological assessment, and driving simulator rides, were used to predict on-road driving performance. In total, a large number of predictor variables was tested on a relatively small sample, which poses the risk of finding significant associations due to random error (i.e. capitalization on chance). This emphasizes the need for a validation study, which is reported in *Chapter 4*. In order to externally validate the developed assessment strategy, it was applied on an independent sample of patients with mild cognitive impairment (MCI). A sample of patients with MCI is closely-related to a sample of patients with Alzheimer's disease, because a large proportion of patients with MCI may develop Alzheimer's disease. Notwithstanding, fitness to drive may also be questioned in patients with other types of dementia. In *Chapter 5*, we investigated whether the developed assessment strategy is also predictive of fitness to drive in other types of dementia than Alzheimer's disease. In this study, patients with vascular dementia, frontotemporal dementia and Lewy body dementia were included. In addition to the identification of unsafe drivers with cognitive impairment, one should also evaluate the effectiveness of fitness-to-drive assessments. If patients are deemed unfit to drive, they should adhere to driving cessation advice. This could prevent future car accidents, however, it might also result in a reduction of mobility. A final follow-up study described in *Chapter 6* addresses adherence to the driving recommendation given after the fitness-to-drive assessment and consequences for mobility. *Chapter 7* contains a general discussion in which implications for fitness-to-drive assessments of patients with cognitive impairment will be considered.