

# Mobility of stroke survivors with cognitive disabilities

Exploring changes in the mobility stroke survivors with cognitive disabilities experience by the means of three different transport types.

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## Summary:

**BACKGROUND:** Stroke survivors can experience a multitude of disabilities, varying from physical to cognitive disabilities. A lot of research has been conducted on the physical disabilities and their relation to the mobility of the stroke survivors, yet few research has conducted on cognitive survivors.

**AIM:** The aim of this thesis is to tap into this lack of knowledge to get a better understanding of the difficulties stroke survivors with cognitive disabilities experience when traveling between two places within the Netherlands. The thesis will focus on a wide array of transportation methods, being car use, bicycle use, walking and public transportation.

**METHODS:** Six semi-constructed interviews were conducted along with a mind-map, to gather more insights about the everyday mobility. A set of two mind-maps was made to compare the mobility prior to the stroke with the post stroke mobility.

**CONCLUSION:** Evident was the increase in physical forms of transportation like walking or cycling for participants living in rural areas. While these participants saw improvement in their condition, participants in the city saw a decline mainly due to fatigue. The fatigue proved to be a crucial factor for all forms of mobility. It was mainly the product of two factors, i.e. overstimulation due to auditive and visual stimuli, and cognitive impairment such as shorter attention spans and reduced concentration. This caused a downward spiral inducing exponentially more fatigue, which reportedly was present while driving. Due to overstimulation the participants reported not using public transport, since it induced extensive amounts of fatigue caused by overcrowded stations, buses and trains.

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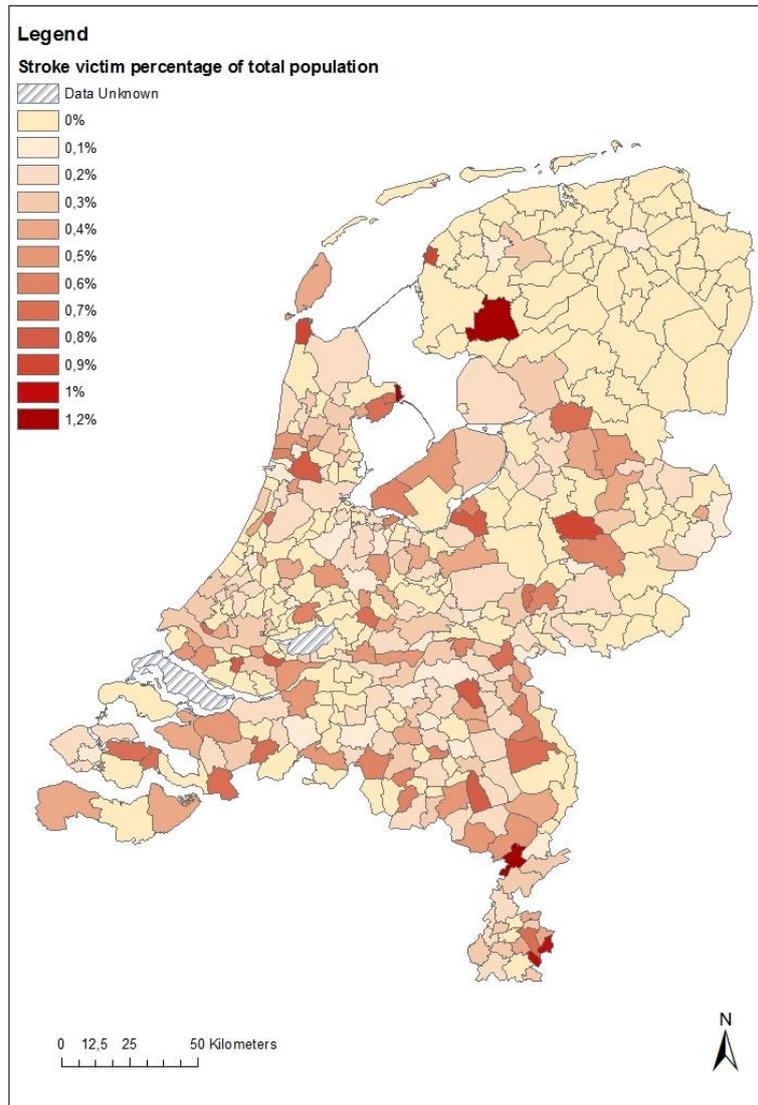
## Background:

In 2016, 0,5 percent of the population experienced a stroke in the Netherlands (CBS, 2016), and for individuals over 50 years the rate is five percent (CBS, 2014). A stroke can have an enormous impact on the life of the stroke survivor itself, but also on his or her family, due to the physical and cognitive effects of a stroke. After rehabilitation stroke survivors can encounter tremendous difficulties managing their changed body and minds into their everyday life (Meijering, Nanninga, & Lettinga 2016). Simple tasks that were effortlessly being conducted before can become a struggle after the event of a stroke. One of the prime examples of difficulties stroke survivors often encounter is a decrease in mobility. Over half of the stroke survivors have difficulties with their mobility after the event of a stroke (Van Wijk, Algra, Van De Port, Bevaart, & Lindeman, 2006). Most research on this field has focused on stroke survivors with physical disabilities, while research on stroke survivors with cognitive disabilities is currently lacking (Risser, Iwarsson, & Ståhl, 2012). Where physical disabilities, such as difficulties with walking or the use of one dominant limb, are more obvious, cognitive difficulties are much less visible (Lock, Jordan, Bryan, Maxim, & House, 2005; Wolfenden & Grace, 2009). Cognitive changes in the brain induced by a stroke may result in clinically significant disabilities which may not be clearly visible. However, these disabilities may be considered as impairing life satisfaction by stroke survivors (Edwards, Hahn, Baum, & Dromerick, 2006). Cognitive changes can cause a huge variety of different disabilities including slower information processing, literacy difficulties and memory lapses (Kersten, Low, Ashburn, George, & McLellan, 2002). These changes can severely affect the mobility of a stroke survivor and even result in isolation (Baum et al., 2008; Lock et al., 2005).

## Research problem:

A stroke can manifest itself in a huge variety of physical and cognitive functions (Edwards et al., 2006). Both physical and cognitive disabilities can result in a decrease in the mobility a stroke survivor experiences. Risser et al. (2012) explore what difficulties and opportunities stroke survivors with cognitive disabilities encounter when moving from origin to destination while making use of the public transport in Sweden. Most problems identified in this thesis are the feeling of being 'stupid', slower information processing and bad public infrastructural planning. The study presents the lack of research conducted in this field and shows that we only know little about the considerable difficulties stroke survivors with cognitive disabilities experience while traveling on an everyday basis. This thesis will tap into this lack of knowledge to get a better understanding of the difficulties stroke survivors with cognitive disabilities experience when traveling between two places within the Netherlands. The thesis will focus on a broad spectrum of transportation, including private means of transport, being car use, bicycle use, walking and public transportation.

Figure 1. percentage of stroke victims of the total population of the municipality in the Netherlands in 2012 (CBS, 2012).



## Structure of the thesis:

In the following part of the thesis I will present my theoretical framework which is derived from existing research. The theoretical framework will be concluded with the conceptual model in which the links derived from the research will be visually presented. In the methodology I will discuss the research methods, data collection tools and the quality of the acquired data. In the following part I will structure my results, along with striking findings and quotes along with the existing literature linking back to the conceptual model. The findings will be discussed for each mode of transport individually. There is some correlation between the means of transport which will be accounted for in the appropriate sections. At last I will conclude my results in the conclusion, reflect on the thesis as a whole and list my recommendations for further research

## Theoretical framework:

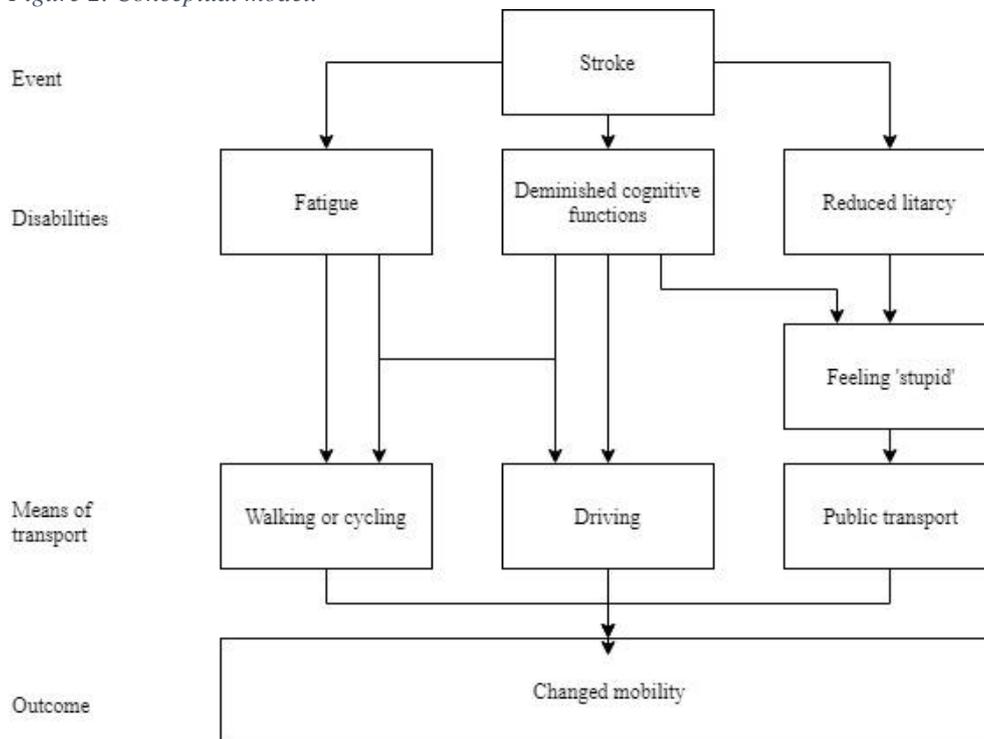
The effects of a stroke which results in cognitive disabilities can have an enormous impact on the daily lives of stroke survivors (Kersten et al., 2002). The disabilities differ for almost every case: some experience literacy difficulties or memory lapses, while others face reduced attention and concentration (Edwards et al., 2006). One of the most prevalent effects among stroke survivors with cognitive disabilities is fatigue, which can limit the mobility and everyday life of a stroke survivor to a great extent (Alaszewski, Alaszewski, Potter, & Penhale, 2007; Koch, 2005; Wolfenden & Grace, 2009). Over 80% of stroke survivors experience fatigue. This includes stroke survivors with physical and cognitive functions (Alaszewski et al., 2007). In most cases this fatigue can be contributed to psychological impairments rather than physical ones, even when those physical impairments are present (Edwards et al., 2006). Stroke survivors will try to avoid being fatigued by dropping intensive activities such as biking or walking, resulting in more inactivity and therefore a decrease in mobility. Like a vicious cycle, inactivity may worsen the fatigue and can lead to physical problems (De Groot, Phillips, & Eskes, 2003).

Another effect stroke survivors with cognitive disabilities often experience, is the feeling of being 'stupid'. This feeling might sound unscientific but conveys the feelings stroke survivors experience accurately due multiple and mostly invisible disabilities caused by the stroke like slower processing times and reduced literacy (Röding, Lindström, Malm, & Öhman, 2003; Wolfenden & Grace, 2009). The feeling of being 'stupid' can manifest itself in particular while travelling or while interacting with strangers. It is usually caused by the stroke survivor itself and is likely based on one's own assumptions instead of others (Risser et al., 2012). On the other hand, some stroke survivors experience intolerance from others, which might also result in embarrassment and frustration (Röding et al., 2003). This results in the stroke survivor feeling powerless and humiliated while being in public places. As individuals naturally attempt to avoid these feelings, it is common for stroke survivors to avoid some interactions when travelling, such as talking to the bus driver or buying tickets for a train ride (Risser et al., 2012).

However, for stroke survivors with cognitive disabilities is it not always possible to avoid interactions in public space. When covering large distances, one might choose to travel by means of public transport, although many individuals choose using their own car. The ability to drive is usually considered to be an important source of independence and quality of life (Freund, 2006). Nevertheless, for many stroke survivors with cognitive disabilities this is impossible due to disabilities such as shorter attention spans and visual-spatial delay (Leśniak, Bak, Czepiel, Seniów, & Członkowska, 2008). About two thirds of stroke survivors do not return to driving after the event of a stroke (Fisk, Owsley, & Pulley, 1997).

## Conceptual model:

Figure 2. Conceptual model.



There can be a great amount of disabilities stroke survivors can experience after the event of a stroke (Edwards et al., 2006). Those disabilities directly influence one's mobility (Kersten et al., 2002). In the conceptual model above those disabilities and their relation to means of transport are shown. At the top of the model we can see the event of a stroke. The stroke can cause a variety of different disabilities, some of these disabilities are displayed in the layer below. There are allot more possible disabilities after the event of a stroke, I however chose to display those three disabilities derived from the literature. First of all are all those disabilities a cognitive nature. Secondly are those disabilities and their link to the layer below the most reoccurring in the existing literature.

At last I would like to clarify the 'Diminished cognitive functions' box. This is an aggregation of multiple cognitive disabilities such as a decrease in concentration, attention, visual spatial delay and memory lapses. Literature seems to suggest that all of those disabilities affect every mean of transport and are therefore linked to all boxes in the layer below (Edwards et al., 2006; Leśniak et al., 2008; Risser et al., 2012). In the last layer are all means of transportation displayed which will be further discussed in this thesis. There can be seen a direct link between the disabilities and the means of transportation. This is link implies there is a negative effect from the layer above which inflicts an inconvenience on a certain transport mode. Reduced literacy and 'Diminished cognitive function' generate the feeling of being 'stupid' for stroke survivors, this is shown in the model with the link (Risser et al., 2012).

## Methodology:

Stroke survivors with cognitive disabilities are a diverse study group, due to the wide variety of different disabilities. To create a more heterogeneous study population, the following criteria were formulated:

### Inclusion criteria:

- Stroke survivors with cognitive disabilities (and minor physical disabilities)
- Age of >18 years
- Employed before stroke

### Exclusion criteria:

- Unable to verbally communicate
- Use of walking aid (e.g. wheelchair, zimmer frame, crutches)
- Immobile before stroke

The first inclusion criterion is the most obvious criterion of all due to this thesis being aimed at the mobility of stroke survivors with cognitive disabilities. I also included stroke survivors with minor physical disabilities since many stroke survivors do experience both physical and cognitive disabilities after the event of a stroke (Risser et al., 2012). This criterion is further explained in the exclusion criteria where I chose to exclude stroke survivors who made use of walking aids in the everyday life. This decision was made to have a clear understanding of the changes which were induced by the cognitive disabilities. Furthermore, I chose to exclude stroke survivors whom were under the age of 18 years. Together with the inclusion criterion of employed before the event of the stroke, would this help me to create a more heterogeneous study population. At last I excluded participants whom were not able to verbally communicate, this would ensure all participants would be able to take part in an interview with me. Several participants in this thesis suffered from aphasia. This was a mild obstacle for the thesis, yet it did not hold back the inclusion of those participants. While sometimes having trouble with finding the right words, those participants were able to properly communicate their mobility. When transcribing I was able to listen to the interviews at any pace, this ensured me in transcribing the interview in detail while the speech may be difficult to comprehend.

The experience of travelling after the event of a stroke is very subjective. Therefore, it is necessary to concretize the outcomes, using a series of semi-structured interviews to describe cognitive functional limitations. Semi-structured interviews are excellent when working with a diverse group such as stroke survivors with cognitive disabilities. All interviews, except for one interview were conducted at the home of the participant, therefore contributing to a calm and informal setting (Clifford, French, & Valentine, 2013). This was especially necessary for a sensitive group such as stroke survivors. Interviewing the participants at their own homes would also make sure there would be minimal nuisance of background noise. In the case of one interview this would prove to be wrong. When construction workers began drilling and mowing the grass the interview was made difficult for the participant. The interview continued, yet I felt rushed and I accelerated the interview.

To have a better understanding of the changed mobility of the stroke survivors the interview was accompanied with a mind-map. Research proved the effective use of this technique and concluded it could assist the participants to frame their experiences better and therefore help researchers with their data collection (Wheeldon & Faubert, 2009). After a short introduction a mind-map was

made for everyday journeys undertaken before the event of the stroke. Those everyday journeys included journeys to: Friends and family, work, everyday activities (Grocery shopping, sporting etc.) and recreational journeys. To get a clear understanding of the mobility before the event of the stroke the frequency and means of transport was documented. This mind-map was followed up by post stroke mind-map intended to compare the mobility before, and after the event of the stroke. This mind-map was conducted in the same fashion as the first mind-map. After having conducted two mind-maps the interview would presume semi-structured, while referring to the journeys and changes observed by the mind-maps. An example of a mind map can be found in the attachments, as is the interview guide.

All participants were recruited through an advertisement posted on Facebook. The advertisement was posted by an experiential expert I came in contact with through my supervisor. The advertisement was posted in a closed Facebook group for patients whom experienced a stroke. I planned to conduct 8 interviews, yet some participants did not respond after initial contact, and one interview did prove to not be suitable for inclusion. The interviews were roughly within the intended time limit of 1 hour.

The interviews were digitally recorded and transcribed with the use of ATLAS.TI, a software to conduct analyses on qualitative data. With the use of ATLAS.TI I wrote a great variety of codes to help me analyse the transcribed interviews. The codes branched from the three-general means of transport to codes about certain details of those means. Before the interviews were conducted I deductively created 30 codes which found their origin in existing literature. Besides the deductive codes I also formulated a set of 12 inductive codes which arose while interviewing and transcribing. A network overview of the formulated codes can be found in the attachments. Within this network there has been made a distinction between inductive and deductive codes.

All data is anonymized and stored at a safe data storage at the Rijksuniversiteit of Groningen (RUG). To ensure full anonymity the participants were given a pseudonym. Furthermore was the research conducted in accordance with the ethical guidelines of the University of Groningen (University of Groningen, 2012). Participants were asked to sign an informed consent form to ensure full disclosure, a copy of this can be found in the attachments. In the table below are the participants listed, accompanied with some basic characteristics.

*Table 1*

	<b>Age</b>	<b>Relation</b>	<b>Able to drive?</b>	<b>Revalidation time</b>	<b>Time since event of stroke</b>
<b>Tim</b>	44	Not married	Yes	3 months	9 years
<b>Patrick</b>	70	Married	Yes	6 months	7 years
<b>Deborah</b>	50	Married	Yes	No revalidation	7 years
<b>Simon</b>	42	Not married	Yes	12 months	6 years
<b>Kevin</b>	63	Married	No	3 months	10 years
<b>David</b>	46	Not married	Yes	6 months	7 years

## Results

### Car use:

At the time of interviewing, 5 of the 6 participants were able to drive. Most participants did need reassessment of their driver's license by the Centraal Bureau Rijvaardigheidsbewijzen (CBR) after the event of their stroke. The CBR is a driving agency which, among other tasks, assesses the 'mental and physical capability of drivers to ensure safe driving' (CBR, 2018). There is great public backlash to the CBR in the Netherlands due to the agency presumably being slow, expensive, and hard to contact for people with medical conditions who need their driver's licenses reassessed (NOS,2018). The interviewed participants supported this statement. Out of the 6 participants, 3 had to have their driver's license reassessed, 1 participant decided himself to retake driving lessons, and 2 participants did not have to reassess their driver's license.

One of the participants, Kevin, has unfortunately lost the ability to drive due to hemianopsia (i.e. partial loss of eyesight due to damage of the optical nerves) caused by the stroke. After 10 years, Kevin is still experiencing frustration, especially being a front seat passenger next to his wife when traveling large distances. This feeling of frustration is well covered in literature, especially by Röding et al., (2003) who published about this frustration and embarrassment, which Kevin also expressed to have on not being able to drive. Although he is currently not driving anymore, Kevin is one of the two participants still in possession of a driver's license, without it having to be reassessed by the CBR.

*Kevin: 'Doctors said, 'Well Kevin, driving is not allowed anymore'. But the CBR remained silent. I received a new driver's license two weeks ago because mine had expired. I just applied for a new driving license.'*

Despite medical advice Kevin is still able to possess a driver's license and participate in traffic. Kevin however chose not to drive his car anymore, due to his poor eyesight. He chose to keep his license, just in case there would be technological breakthroughs which could improve his eyesight.

While Kevin did not need to have his driver's license to be reassessed, Tim, who has mild physical and cognitive disabilities, was subjected to a driving test. Although he completed the driving test with success, he still had to be assessed by a neurologist, for which he was charged 100 Euros. Other participants were also assessed by a neurologist for varying costs.

*Patrick: 'They question everything, the health of your heart, your blood pressure, your eyes, epilepsy. Which is stupid, because they do not know anything about my case. My own doctor does know everything about me.'*

Tim and Patrick confirmed the recent news article by the NOS concluding the CBR was 'slow' and 'bureaucratic'.

All participants that were able to drive described this ability as a tremendous freedom, which is in line with research conducted by Freund (2006). Deborah described the car as a 'safe-haven' while attending meetings or other intensive activities, despite the occurrence of her stroke in the car. She described the feeling of being able to leave from activities as a vital addition of her journeys:

*Deborah: 'I prefer to travel alone if I have events going on. I don't like to travel with someone else. I like being able to leave when I need to, which is a very nice feeling.'*

She described the car as a safe-haven not only because she could choose her own time of departure, but also because she 'could choose her own stimuli'. Whenever she felt energetic, she could turn on the radio or even sing along, and whenever she felt tired or overstimulated, she could enjoy the absolute silence in 'her own bubble'. This is also one of the reasons she prefers to travel alone when making use of the car. When traveling with a fellow passenger, she would often get overstimulated either due to the radio or due to a conversation. The 'always present fatigue' as Deborah and Alaszewski et al., (2007) described was exaggerated by this overstimulation. Both of those factors had a negative impact on cognitive functions like concentration and attention, thus on further progression of the fatigue.

Having difficulties with fellow passengers while making use of the car is a problem most participants have. It has proven to be very difficult for most participants to concentrate on driving whilst conversating with fellow passengers. Multiple participants described having problems with having fellow passengers or co-drivers, either due to the combination of auditive stimuli from the radio and actively participating in a conversation, or even just the conversation on itself. Tim and Patrick both described how they would isolate themselves with a headset while traveling with fellow passengers. Patrick described how a friend with whom he would hike would travel with him on several occasions:

*Patrick: 'There was this lady with whom I travelled about 4 times. [...] She kept on talking, and I would say 'Please stop talking, I'm tired, I have to pay attention to traffic', but after two minutes she began talking again. I concluded that we couldn't travel together anymore.'*

Besides expressing difficulties while driving with fellow passengers, all participants who were able to drive expressed difficulties when covering large distances by car. The main cause of these difficulties was the occurring fatigue during a long journey. The participants concluded that most fatigue is caused by long concentration spans, especially in combination with energy draining activities at arrival. The participants expressed a vast progression of their fatigue when being subjected to a noisy or stressful activity. The participants tackled this by frequently stopping along the journey to rest and restore their energy levels. Another precautionary measure consisted of proper planning of their journey. They made sure planned activities would not quickly drain energy levels if they would need to travel back, and did ensure to not travel too far, as was also described by De Groot et al., (2003). Most participants had a limited maximum travelling time of 2 hours. Exceeding their maximum travelling time would result in severe fatigue and high levels of discomfort.

Besides fatigue induced by the length of the journey and a noisy or stressful activity, participants acknowledged several other predisposing factors. One of the most striking factors was the difficulty participants expressed to have while driving in the dark. Especially when Deborah and Simon were already tired, they described tremendous difficulties with driving at night. 'The [car] lights shine right through you' Deborah stated, when she described the overstimulation induced by the intensity of halogen car lights. Simon stated he preferred to sleep over at his friend's house when visiting instead of returning home at night. All participants shared this disturbance while traveling in the dark, and stated they only did so if they absolutely had to.

Another predisposing factor was the effect of driving in crowded city centres, or busy roads. While driving on the freeway is considered by all participants as the most comfortable, driving within city centres was seen as less favourable. Especially the presence of cyclists in the city centres caused a lot of stress, resulting in a drop in energy levels. All participants mentioned the high density of cyclists in city centre of Groningen accountable for a constant state of alertness and stress. Due to diminished sensory perceptions, the participants had problems processing the buzz, in line with research by (Leśniak et al., 2008). The opposite applies to freeways, which participants described as rather relaxing due to the paucity of stressful factors.

*Tim: '[The freeway] I find the easiest. If it gets too fast for me, I will just drive behind a truck and ride along'*

Since the event of their stroke, all participants have seen a decrease in their driving speed. For most participants, the legal speed on the freeways is comfortable and they do not desire to go any faster. Moreover, most participants add there is no motivation to go any faster anymore, and that they are being more cautious due to the event of the stroke. Regardless of the universal appreciation of the freeway, Tim and Deborah stated that they disfavoured congestions more after the event of the stroke. This was caused by the constant stopping and pulling up, contributing to the fatigue.

Altered navigation while driving was also assessed during the interview. The participants explained the importance and ease of navigational devices such as a TomTom or Google Maps. Deborah explained how she did not have to worry about taking a wrong turn, as the navigational device would automatically redirect her route. Therefore Deborah could now focus solely on driving, which was less energy draining.

### Walking & Bicycle use:

Four participants expressed walking or using their bicycle substantially more compared to prior to the event of their stroke. Many participants moreover acknowledge the vital importance of being physically active, as was formerly discussed by De Groot et al., (2003). Most participants therefore chose to engage in a great variety of physical activities to remain in good mental and physical condition.

*Simon: 'I have to move, otherwise I won't feel good. The more I move, the better I feel. I walk, swim, and cycle a lot.'*

Some participants replaced the car in certain short to medium distance journeys with biking, others used the bicycle to stay physically active, thus feeling mentally healthy. However, two participants expressed to walk or cycle less while moving from place to place, compared to before their stroke. Walking or biking caused too much stress and overstimulation for these two participants. An important note is that these two participants both live in somewhat larger cities, while the other four participants live in rural towns. The participants who live in the rural towns did also express their aversion of walking or biking within city centres due to sensory overstimulation. Participants proclaimed having trouble navigating through the noisy and crowded city due to a combination of reduced attention and concentration on one hand, and increased fatigue on the other hand, which is in line with Edwards et al., (2006). When they had to, they would stop after travelling in

the city centre to rest, or even avoid the city centre entirely by planning out the journey ahead. Where the two participants living in cities had no direct access to calm and silent environments, the participants in the rural towns could ride or walk out of their homes and enjoy those environments almost immediately. The four rural residential participants described the surrounding areas around their houses as comfortable, lush and pleasant. All of them walked or cycled almost daily in those surrounding areas, even when the weather was less favourable. Some stated walking daily for about 20 minutes, while others would easily cycle over 10 thousand kilometres a year.

Some mainly used their bicycle for recreational purposes, others used it as a primary mean of transport. Kevin was not able to drive a car due to his poor eyesight, and therefore conducted all of his journeys by bicycle. At first, this proved some difficulties, as his employer was a mere 25 kilometres away from his home. This led to frustration, exhaustion and fatigue, ultimately resulting in him retiring his old job. This so called disruption can also be seen in the research on 'biographical disruption' by Bury M (1982), where, in this case, the stroke can be identified as the disruptive event. Besides the exhaustion caused by the bike ride, Kevin also experienced sensory overstimulation at his work due to his cognitive disabilities. After 3 years of riding his bike for 25 kilometres back and forth to work, Kevin quit. Although he first saw his bicycle dependence as inconvenient, several years and adaptations later he began to like cycling:

*Kevin: 'I really like it [Cycling], but it is sometimes also just out of necessity. To get groceries, for example.'*

The other 4 participants who saw an increase in walking and biking also obtained more affinity with those activities, and therefore gained tremendous improvement in their physical condition. The participants confirmed to have more spare time now opposed to prior to the stroke, resulting in more time to exercise and conduct recreational trips. A striking example was Kevin. At the time of the interview Kevin was preparing for a biking trip to Maastricht, which spanned over 340 kilometres on his own. Many participants admitted to engage in high intensity physical tasks, sometimes as a way to prove themselves to either their surroundings or themselves.

Three of the participants used a tricycle for adults, as their stroke had an impact on their balance. Even though this alleviated the struggles of cycling on a bicycle, the attitude towards these types of aid were divided. Simon saw his tricycle as a stunning assistance in increasing his mobility, while David despised his. While Simon was positive about the tricycle, he rejected the recumbent trike:

*Simon: 'I prefer not to cycle on that recumbent trike'... 'That's a disabled bicycle, you do not want to be seen with that'*

This statement was supported among other participants, who would wish not to be seen as disabled. Tim described how people would give him 'strange looks' when he would dismount his tricycle and walk normally. In the beginning it did bother him, but eventually he has grown to accept it. The embarrassment and frustration is in line with the findings of Röding et al., (2003) who established this sentiment among younger stroke survivors.

### Use of public transport (Bus & Train):

Most participants refrained from using the bus or train altogether. Only one of the participants had strong affection with the bus and would occasionally travel with it. This participant also travelled by train, with the addition that he would always plan some extra time to catch another train. The current use of public transport was also compared to prior to the stroke. Unfortunately, merely two participants actually used public transport before their stroke, one of which was Tim, who is currently still travelling by public transport. Comparison of pre- and post-stroke use of public transport was therefore hard to obtain during this thesis. However, although this comparison could not be made, some striking insights on the post-stroke use of public transports did arise.

Unlike the study conducted by Risser et al., (2012), the interviews suggested that participants did not express the feeling of being ‘stupid’ when using public transportation. The main obstacle participants expressed to encounter when using public transport was sensory overstimulation due to crowded environments. Besides Tim, all participants preferred to travel by private means, such as their car. Deborah explained how she tried to use public transport to travel to work shortly after her stroke. She identified two major obstacles she encountered when doing so. First of all, the entire process of traveling by public transport exhausted her extremely, causing her to not being able to function normally at the destination of the journey.

*Deborah: ‘Here at home I can just walk out the back door and walk straight to the car, but with public transport, I have to walk all the way to the station, and wait for a bus or take and change trains. Those kinds of activities wear me out.’*

Secondly, Deborah indicated another obstacle being the overly crowded stations, buses and trains. Due to the constant auditive and visual stimuli present in public transport Deborah’s energy levels easily drained. Other participants also recognised these obstacles as well while using public transport. Pre-departure planning of the journey has also proven to be an obstacle for some participants.

As stated before, Kevin was unable to drive and therefore preferred to travel with his bicycle. He stated that he rode his bike weekly to visit his daughter that was living 25 kilometres from his home. Although he expressed being able to ride his bike for over 100 kilometres a day, Kevin also stated that he would ‘love to travel by bus’, but he lacked the confidence and experience to travel by bus.

*Kevin: ‘You have to complete a lot of tasks to be able to take the bus to the city. First you have to know what time the bus is going. You need a public transport pass, or you need to pay the bus driver, and I have no idea how any of that works.’*

Using conventional public transport was not an option for most participants, yet there was a striking alternative: the regional taxi. The WMO-Taxi is available for everyone, but is regionally funded for individuals with mobility restrictions. The service is intended for journeys within a radius of 25 kilometres from the home address of the customer (WMO-Vervoer, 2018). Many participants made use of this WMO-Taxi service, but did express some criticism. Sometimes, the taxi would arrive fifteen minutes early to the reserved time, or even fifteen minutes late, David pointed out. ‘Which makes showing up on time for an appointment very hard, when the service is unreliable,’ David added when explaining the difficulties he faced. Another inconvenience for Simon is the fact that the regional taxi often

deviates from the intended route to pick up another customer, as this further lengthens the journey. For crossing long distances, David relied on another WMO-taxi service called Valys, which is a transport service for longer distances for individuals with mobility restrictions.

## Conclusion:

The aim of this thesis was to get a better understanding of the difficulties stroke survivors with cognitive disabilities experienced after their stroke. The fatigue proved to be the most influencing factor contributing to obstacles within their mobility. Journeys beyond a travelling time of 2 hours were not possible for most participants without serious sacrifices of energy levels. The fatigue was indirectly induced through the diminished filter of sensory perceptions. Due to the sensory overstimulation caused by auditive and visual stimuli the participants noticed a reduction in their cognitive functions. Continuous concentration and having to pay attention to the road, while being subjected to sensory overstimulation further induced fatigue, initiating a downward spiral of progression of fatigue and decline of concentration levels. As a result of this increased fatigue, participants who still had the ability to drive could not drive for long distances without taking breaks. Moreover, the presence of fellow passengers in the car has shown to have an additive negative effect on energy levels.

The city centre proved to be difficult for most participants, due to the high amount of stimulation induced in this environment caused by cyclists and crowded and noisy streets. This again contributed to the downward spiral combined with the reduced filter of sensory perceptions. Short journeys were beneficial compared to longer distances by car due to less fatigue.

Participants living in rural areas chose to walk or bike considerably more compared to participants living in the city, who saw a decline in those means of transport. The participants in cities acted as was suggested by literature, moving less to avoid being drained of energy by the crowded city environment, resulting in further decrease of their physical condition and energy levels. For participants who had access to rural environments the opposite was true, as they felt more physically healthy, and moreover felt an increase in cognitive condition. These participants especially made a conscious decision to use their bicycle to stay active while traveling short distances.

Although most participants saw an increase of biking, walking or driving as means of transport after their stroke, they universally noticed a steady decline in the use of public transport. Unlike earlier studies suggested, this decline was not due to the participant feeling 'stupid', but rather due to the participants not feeling comfortable in public transport. This was likewise correlated to the constant fatigue experienced by the participants and the downward spiral confounded by sensory overstimulation. Especially in public transport there is a wide array of auditive and visual stimuli, which were described as fatigue inducing factors.

## Reflection:

While conducting this research some problems arose. First of all it proved to be tremendously difficult to acquire participants who only experienced cognitive disabilities after their stroke. Some participants included in this thesis did also experience mild physical disabilities. I have been able to make a clear distinction between cognitive and physical disabilities, yet it would be more ideal for research purposes to only have stroke survivors with cognitive disabilities. Furthermore, literature on this particular subject was sparse and often medical of nature, which made it difficult to construct a proper conceptual model. Eventually this was solved by combining multiple different studies and articles, and further delving into medical knowledge.

## Recommendations:

Further research is definitely needed in this field of mobility. There is a serious knowledge gap for this specific group of disabilities. I would recommend conducting this research with a larger group of participants with only cognitive disabilities. Due to the short time available and the sparse resources at hand for this study, I was not able to conduct walk-along interviews, which are necessary for providing further insights in the difficulties the participants experience. I would definitely recommend conducting these walk-along interviews, to acquire those insights. Furthermore, I would recommend to further analyse the actual impact of the disabilities caused by the stroke on the perception and use of public transport, as only few of my included participants used this mean of transport prior to the stroke. To make an accurate comparison of the impact, larger numbers of participants that used to travel by public transport prior to their stroke are critical.

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## Attachment 1. Interview guide:

Ik ben Sofiane Ghenam en studeer aan de Rijksuniversiteit Groningen. Hier schrijf ik mijn bachelor scriptie over de mobiliteit van mensen met een niet aangeboren hersenletsel. In de scriptie onderzoek ik hoe mensen met een aangeboren hersenletsel bewegen tussen plekken in het dagelijks leven, welke vervoersmiddelen ze gebruiken en in welke mate de mobiliteit is veranderd na het aangeboren hersenletsel. Daarom zal ik u graag willen interviewen aan de hand van een aantal vragen. Het interview zal ongeveer een uur duren. Bij het interviewen zou ik graag audio willen opnemen. Dit helpt mij ook om zo nauwkeurig mogelijk uw bevindingen over te zetten in tekst. Meer informatie hierover is terug te vinden op het consentformulier. Hebt u hier bezwaar tegen?

Als u gedurende het interview bepaalde vragen niet wil beantwoorden of het interview in zijn geheel wil stoppen kunt u dat op elk moment doen. Verder zal alle data die in dit gesprek is verkregen worden geanonimiseerd. Dit wil zeggen dat uw naam nergens in het onderzoek gebruikt zal worden, er zal gebruik worden gemaakt van pseudoniem, om uw anonimiteit te waarborgen. Hebt u nog vragen voor we het interview beginnen?

### **Algemeen:**

- Kunt u meer over uzelf vertellen?

*Optionele vragen: Leeftijd, Woonsituatie, relatie, kinderen*

- Wanneer hebt u uw hersenletsel gehad?

- Wat zijn de gevolgen van uw hersenletsel?

*Optionele vragen: Last met lezen, praten, opnemen, vermoeidheid of dergelijke*

- Hoelang hebt u gerevalideerd?

- Waar hebt u gerevalideerd?

- Revalideerde u in de kliniek of woonde u thuis?

- Zijn de gevolgen tijdens het revalideren afgenomen?

- Als u kijkt naar uw mobiliteit voor en na het hersenletsel, ervaart u dan verschillen?

*Optionele vragen: Negatieve en positieve verschillen*

- Kunt u uw beweegpatronen schetsen voor het hersenletsel?

*Aan de hand van Familie en vrienden, werk, dagelijkse taken, vrijetijd en overig, vragen van welk vervoersmiddel gebruik werd gemaakt, waarheen en hoe vaak.*

*Onderstaand schema is een weergave waarin schematisch de reizen kunnen worden weer gegeven. Tijdens het interview kan de huidige mobiliteit hieraan worden gespiegeld om zodoende te kijken waar veranderingen zijn opgetreden,*

	Familie/vrienden	Werk	Dagelijkse taken	Vrijetijd	Overig
plekken					
Vervoersmiddel					
Frequentie					
Gezamenlijk					

- Kunt u kort de bovengenoemde plekken omschrijven?

*Ligging, drukte, bereikbaarheid enz...*

- Hoe ervaart u de plekken na uw hersenletsel?
- Komt u nog even vaak op de voorheen genoemde plekken na uw hersenletsel?

*Indien niet: waarom niet? Is er misschien een alternatief voor deze plek na het hersenletsel?*

- Bewoog u bij deze reizen alleen, of was dit (soms) met anderen?

*Optionele vragen: Wanneer met anderen?*

- Is hier verandering in gekomen na het hersenletsel?
- Zou u het fijn vinden als u met anderen samen kon reizen, of juist niet?
- Hoe ervaart u contact onderweg? Denk hierbij aan medereizigers of passanten
- Kiest u na uw hersenletsel voor andere vervoersmiddelen dan voorheen?

*Indien wel: kunt u benoemen bij welke bewegingen dit is, waarom en waarmee u zich u nu vervoert?*

**Autogebruik** (indien hier voorheen ook gebruik van werd gemaakt):

- Als u kijkt naar uw autogebruik op het moment, is dit veranderd na het hersenletsel?

*Indien negatief: Hoe gaat u hiermee om? Laat u bv. bepaalde ritten zitten of dergelijke?*

- Kon u direct weer gebruik maken van de auto?
- Is de ervaring bij het gebruik maken van de auto hetzelfde als voorheen?
- Kunt u nog lange afstanden rijden na het hersenletsel?

*Indien niet: waarom niet? Hoe lost u dit op?*

- Hoe ervaart u verschillende wegen na het hersenletsel? Denk hierbij aan de snelweg, stad of het platteland.
- Zijn er bepaalde verkeerssituaties die u als lastig beschouwd na uw hersenletsel?

*Optionele vragen: Hoe gaat het met drukte op de weg?*

- Merkt u een verandering in uw rijstijl?

### **Lopen/fietsen**

- Als we u dan kijkt naar het bewegen met de fiets of al lopend, ziet u een verandering in het gebruik hiervan?
- Hoe is het gesteld met uw conditie? Is uw conditie veranderd na het hersenletsel?

*Optionele vragen: Kunt u nog lange afstanden fietsen en lopen?*

- Is de ervaring bij het gebruik maken van de fiets/lopen hetzelfde als voorheen?
- Zijn er bepaalde verkeerssituaties die u als lastig beschouwd na uw hersenletsel?

*Optionele vragen: Hoe gaat het met drukte op de weg?*

### **Openbaar vervoer:**

- Maakte u voor uw hersenletsel gebruik van het openbaar vervoer? (bus en/of trein)

*Indien beide worden gebruikt zullen bus en trein apart worden bevraagd bij de volgende vragen*

- Maakt u hier nu meer of minder gebruik van dan voorheen?
- Hoe ervaart u het openbaar vervoer na het hersenletsel?

*Optionele vragen: Voelt u zich op uw gemak bij het gebruik?*

- Zijn er veranderingen bij het gebruik van het openbaar vervoer?

*Optionele vragen: Maakt u bijvoorbeeld gebruik van een stiltecoupe of speciale zitplaatsen*

### **Afsluiting**

Ik heb alle vragen gesteld die ik wilde stellen.

- Zijn er nog toevoegingen die u graag zou willen vermelden?

Ik zou u graag willen bedanken voor uw medewerking aan mijn scriptie. Als u interesse hebt in het eindresultaat kunt u mij bereiken via mijn contactgegevens op het consentformulier.

## Attachment 2. Consent form:



**rijksuniversiteit  
 groningen**

**faculteit ruimtelijke  
 wetenschappen**

Ondergetekende:

Naam:

Adres:

Woonplaats:

verklaart als volgt:

In het kader van het opnemen van het interview voor mijn bachelor scriptie op ...  
De opgenomen gesprekken en transcripten zullen uitsluitend beschikbaar zijn voor Sofiane Ghenam en de Bachelor scriptie begeleiders.

De verkregen data zal geanonimiseerd worden om zodoende de identiteit van de ondergetekende te waarborgen. De data zal opgeslagen worden op de beveiligde opslagruimte van Rijksuniversiteit Groningen.

De ondergetekende kan zijn/haar medewerking op elk moment in het proces van het maken van de scriptie terug trekken waarna alle verkregen data zal worden verwijderd. Ondergetekende kan ook aanvraag doen naar de data, de transcripten en/of de bachelor scriptie.

te ... op ...

Deelnemer, naam:

Interesse in opname/ transcript / bachelorscriptie (omcirkelen wat van toepassing is):

Emailadres (in geval van interesse in informatie):

Student-onderzoeker: Sofiane Ghenam  
Sofiane.ghenam@live.nl



### Attachment 4. Mind-Map:

This mind-map is an example due to guaranteeing the privacy of the participants.

