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## Mobility in Public Environments and Use of Public Transport : exploring the situation for people with acquired cognitive functional limitations

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# Mobility in Public Environments and Use of Public Transport

Exploring the situation for people with  
acquired cognitive functional limitations

Jenny Rosenkvist

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Department of Technology and Society  
Lund Institute of Technology  
Lund University, 2008



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### **Keywords**

Accessibility, usability, travel-chain, focus group interviews, expert interviews, semi-structured interviews, user perspective, acquired cognitive disabilities

### **Abstract:**

The aim of this thesis was to explore and gain deeper insight into and understanding of mobility in public environments for people with acquired cognitive functional limitations (target group of this thesis) and of reasons why some of them do not use public transport. Using an explorative approach, the target group's mobility was firstly discussed by experts in focus group interviews. Secondly the reasons for not using public transport anymore after acquiring cognitive functional limitations was described by the target group themselves. The results of this thesis show that mobility and especially use of public transport is not an unproblematic activity for the target group. They face usability problems such as difficulties to manage the serial tasks, the complexity and dynamic in traffic environments. Further, other people's acts and decisions as well as how the target group dealt with feelings, such as anxiety and fear, play a role for their mobility and use of public transport. Reasons for not using public transport could be that the target group did not consider public transport usable or it could be that they considered use of public transport as completely out of the question. Planning for mobility and usability in public transport for people with acquired cognitive functional limitations would mean to completely integrate a travel-chain perspective, to make sure that information is available on beforehand, to offer routes with calmer surroundings parallel with ordinary public transport used by for example commuters.

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## *List of papers*

This thesis is based on the following publications:

### Study 1:

Rosenkvist Jenny, Risser Ralf, Iwarsson Susanne, Ståhl Agneta. A Picture of Mobility in Public Environments – The Situation for People with Cognitive Functional Limitations. Manuscript submitted 2008.

### Study 2:

Rosenkvist Jenny, Risser, Ralf, Iwarsson Susanne, Wendel Kerstin, Ståhl Agneta. The Use of Public Transport: A Challenging Activity either Under Consideration or Out of the Question – Descriptions by People Living with Cognitive Functional Limitations. Manuscript submitted 2008.

## *Introduction*

To be able to move about in the community, i.e. mobility, is a practical necessity in everyday life in order to reach community facilities, go to the working place or to school. To have the possibility to everyday mobility is also a question about social integration and equality. One of several modes of transport is public transport, which should be accessible for everybody; however, people with functional limitations face restrictions in the use of public transport. The needs of people with functional limitations have to be taken into consideration when planning for public transport. Planning for an accessible public transport system must start in the users' perspective and employ a travel chain perspective, i.e. make sure that each part of the travel chain from door to door is accessible.

Until now, reports on mobility and the situation in public transport among people with functional limitations have mostly included only people with certain kinds of functional limitations such as vision hearing and physical functional limitations (see for instance, Carlsson, 2002; Ståhl and Iwarsson, 2007; Waara, 2001; Golledge, Marin-Lemellet, 2001; Marston et al., 1997; Wretstrand A, 2003). There are some studies published 10-15 years ago focusing on cognitive functional limitations related to accessibility in buses and in public transit in general, and they offered proposals for how to solve potential problems (Carpenter, 1994; Hunter-Zaworski and Hron, 1993; Hunter-Zaworski and Hron, 1999; Koppa et al., 1998; McNery et al., 1992). A case study demonstrated that a stepwise method for training people living with brain injuries would have some potential to assist them appropriately to start using the bus again (Newbigging and Laskey, 1995). Focusing not only on the bus, but public transport in general, Logan et al. (2004) made a qualitative approach to study attitudes and barriers to use of public transport by persons who had had a stroke. However, most of those studies are not up to date, meaning that they do not take into consideration the development that has happened during the latest decade.

Within the field of traffic planning, one reason why cognitive functional limitations have been excluded could be that they are more difficult to define as they are not as obvious as physical functional limitations (Grönvall et al., 2004). It could also be that they may have been considered factors that “disturb” research work dealing with the effects of

functional limitation, by producing confounding variables that cannot be appropriately addressed (Andersson et al., 2000). Another problem with existing reports on mobility and accessibility in public transport is that quantitative reports on experience of travelling among persons living with functional limitations have deliberately excluded certain functional limitations such as dyslexia and cognitive functional limitations as individuals living with such limitations are considered by some not to constitute a big enough amount of the population to be included (Davidson, 2003). That means that methods on how to study mobility and use of public transport for people with cognitive functional limitations have to be carefully and systematically developed.

In Europe, the MAPLE project (2003) emphasized that the needs of people with cognitive functional limitations are largely neglected. There is no systematic planning in public transport for users with cognitive functional limitations, and the majority of the transport providers in Europe have no operational definition for this group of users. Consequently, existing schemes and projects are scattered. Thus, there is a lack of scientific knowledge about mobility and especially the current public transport situation for people with cognitive functional limitations.

As this field of research has many angles to be considered, an interdisciplinary research project involving co-operation between researchers with various competences such as traffic planning, occupational therapy, neuropsychology, social psychology, psychology and sociology was initiated. The results of this thesis are part of such co-operation, bridging research in technology, medicine and social sciences.

## ***Background***

### ***Transport planning and policies in Sweden***

The overall goal of Swedish transport policy is to contribute to an environmentally, economically, culturally and socially sustainable transport system for public and industry. In the long run, the transport system should fulfil six particular objectives, of which an accessible transport system is one (Prop 1997/98:56; Prop 2001/02:20). In an international perspective, access conditions to public transport services,

streets and other outdoor environments are some of the target areas for equal participation in society according to The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993). UN member states should ensure access by developing standards and guidelines and eventually legislation. In line with the standard rules, planning for public transport accessible to all is a generally agreed necessity both in Sweden (Prop 1999/2000:79; SOU 2003:67) and in many other countries (CEMT, 2004). According to Swedish law, the public transport has to be accessible for everybody before 2010 (SFS, 1979:558). One type of community-provided transport is Special Transport Service, i.e. a door-to-door service with very high assistance for individuals with so serious functional limitations so they are not able to use other community provided public transport (Ståhl, 1995). There is a common wish from society and users with functional limitations to make public transport accessible for all. Since 1997/1998 efforts have been made to shift as many people as possible from Special Transport Service to ordinary public transport to reduce the costs to society (SOU 1997/98:56). That means it is important to adapt public transport to meet the needs of various user groups. The needs of people with functional limitations must be taken into account when planning for public transport, and vehicles used in public transport must, as far as possible, be adapted to their needs and this must be a natural part of planning for public transport (Prop. 1999/2000:79).

When it comes to public outdoor environments and built public environments, which are environments that also have to be taken into account from a travel chain perspective, the Swedish building and planning legislation requires that those environments must be accessible to and usable by people with restricted mobility or restricted sense of locality (SFS, 187:10). In existing places open to the public, such as public buildings and public outdoor places, the National Board of Housing, Building and Planning has published directions on easily removable obstacles (BFS, 2003:19). In the same way, they have published directions to include accessibility and usability for persons with functional limitations when public environments and areas for constructions other than buildings are put in order (BFS, 2004:15).

## The current accessibility situation in public transport

Accessibility to community provided public transport has been improved during recent years, but there remain differences in the progress of accessibility efforts around the country (SOU 2003:67). Following the principles of the travel chain perspective, land-based public transport, here referring to train and bus transport, is arranged in various ways to suit the needs of various user groups in Sweden.

The Swedish Rail Administration has the regional responsibility for train transport, including assuring that the accessibility perspective permeates the rail transport system – its premises, information system and personnel. According to their action plan for making the train sector open and accessible for individuals with functional limitations, they emphasise, for example, that in buildings easily removable obstacles must be dealt with. Further, the action plan stresses that personnel must have training in understanding for, and how to receive, users with certain needs (Fahlgren and Lindqvist, 2004). “In general” vehicles within train transport have been designed to meet the needs of users with functional limitations. The infrastructure that passengers meet when using the train, i.e. station buildings, platforms, connections to platforms and walking paths accessibility is realised in the form of levelling out differences in height, installing automatic door-openers and elevators, and offering possibilities to have companions (Vägverket, 2005).

Local bus transport in Sweden is provided in differentiated systems in order to suit various user needs. For commuters frequent and fast networks are provided, while for older people and people with various functional limitations networks with more service and shorter distances to the bus-stops are provided. When planning for usable public transport from a perspective of people with functional limitations, a differentiated public transport system can be seen as consisting of three parts; ordinary public transport, intermediate solutions, and Special Transport Service (Ståhl, 1995).

The **ordinary routes** are most often planned in order to quickly link various areas. The buses often operate during peak hours and the time at the bus stops is short (Petzäll, 1996). The distances between the bus stops are longer, and consequently the walking distances to the bus stops are longer (Svensson, 2003). The **intermediate solutions** offer lower environmental demands, i.e. more time and service in connection with

the transport for older people and for individuals with functional limitations (Ståhl, 1995). In general there are two variants of intermediate solutions: routed or demand responsive (Ståhl, 1997). The difference is that the routed ones have ordinary bus stops but with shorter distances between them than ordinary routes, while the demand responsive ones are characterised by the certain meeting points where someone in advance has called to get on or to get off the vehicle (Carlsson and Ståhl, 2006). ***Special Transport Service***, which was described earlier, can only be used by those who are entitled to it. Every municipality individually determine the criteria for a person to be entitled. When an individual's capacity is even too low to manage the environmental demands of intermediate solutions, Special Transport Service can be a solution. But this varies among municipalities, including what types of intermediate solutions are available.

Studies on intermediate solutions showed that the routed one is a network that primarily meets the needs for the group of individuals with insufficient capacity to manage ordinary public transport, but who are not entitled to Special Transport Service, i.e. mainly older people, while the demand responsive one, i.e. flex traffic, has possibilities to relieve the pressure on Special Transport Service (Carlsson and Ståhl, 2006).

## ***Theoretical considerations***

### ***Everyday mobility in public environments***

Mobility is a many-faceted concept. Within health sciences, such as physiotherapy or occupational therapy, it can refer to body movement, that is for example bending an arm or turn the head (Socialstyrelsen, 2003). Other ways to understand mobility are movement of people; movement of objects; imaginative movement i.e. watching television; or virtual movement, i.e. interacting with others who are not spatially present for example by use of the Internet (Urry, 2000). In this thesis mobility refers to people's actual movement in time and space, i.e. moving from one point to another (SIZE, 2003). Such movement can, for example, refer to migration, travel (i.e. tourism) or daily mobility (Kaufmann, 2004). The aspect of mobility in focus of this thesis is everyday mobility. Mobility in this sense is often perceived as synonymous with using various modes of transport, while in this thesis it

refers to all ways of moving from one point to another, also including walking, for example. Much is pointing in the direction that mobility is an important part of our Western society. During recent years, areas for housing, areas for service or other facilities have been separated from each other, i.e. distances between them have grown (SOU, 2003:67). Mobility that allows to cover these distances becomes more and more important and is also a necessity for societal participation (see for example Mollenkopf et al., 2004; Carlsson, 2002).

Studies of mobility most often focus the actual movement (Beckmann, 2003) without taking into account the individual who actually is the actor of his/her mobility. In other words, too much attention has been paid to the movement itself, instead of people's intentions or reasons for being mobile, i.e. *motility* (Kaufmann, 2005). Opposite to actual movement i.e. mobility, motility refers to an individual's capacity to be mobile: "***the way in which an individual appropriates what is possible in the domain of mobility and puts this potential to use for his or her activities***" (Ibid, page 37). In this thesis, supplementing the consideration of actual movement from one point to another, the thoughts, intentions and ideas of individuals undertaking the movement are taken into account in order to achieve a better picture of the mobility of people with acquired cognitive functional limitations.

The term public environment refers to settings away from home that are available for the public, regardless of ownership. Mobility in public environments consequently refers to movement from one place to another in settings that are available for everybody. Mainly mobility in public outdoor environments is focused upon. However, as mobility can occur in different settings, to some extent this also involves indoor public environments, such as train stations.

### ***People with acquired cognitive functional limitations***

Cognition denotes the acquisition, storage, transformation and use of knowledge and includes a range of mental processes that operate when an individual acquires new information (Matlin, 2003). Having a brain injury, either innate or acquired, implies that the mental processes show less capacity to acquire, store, transform and use information. The mental processes are not employed automatically, as is happening when the brain is not injured. For the adult population areas that are critical to

be affected by a brain injury are orientation and insight; attention; motor planning; visual processing; cognition. If some of the areas are affected by brain injury, this can result in difficulties to remember, to orientate in time and space, to solve co-ordination problems, to express oneself verbally, etc (Abreu and Toglia, 1987), i.e. in cognitive **functional limitations**. One could say that functional limitations are restrictions in an individual's ability to perform basic physical or mental actions in daily life (Verbrügge and Jette, 1994). People with acquired cognitive functional limitations are in the focus of this thesis. People with acquired cognitive functional limitations often live with other functional limitations, such as physical or visual, in combination (Abreu and Toglia, 1987). Sometimes the term cognitive **disability** is used to describe the target group's consequences of having an acquired brain injury: however, when using this term it refers to difficulties with activities in daily life, for example, work, personal care, trips (e.g. using public transport) or socialising with friends. The two concepts **functional limitation** and **disability** separate an individual's capabilities from his/her ultimate pattern of behaviour in real life situations, that is, functional limitation refer to what an individual "can do", while disability refers to what an individual "does do" (Verbrügge and Jette, 1994). When using the two terms in this thesis, they refer to the same group of people, i.e. the target group, but they refer to different consequences of having a brain injury. The characteristics of cognitive functional limitations imply that there are difficulties in communication with the target group. When it comes to research, it is essential to carefully develop research methods taking into account eventual difficulties in communication with the target group.

### ***Accessibility, usability and the travel chain***

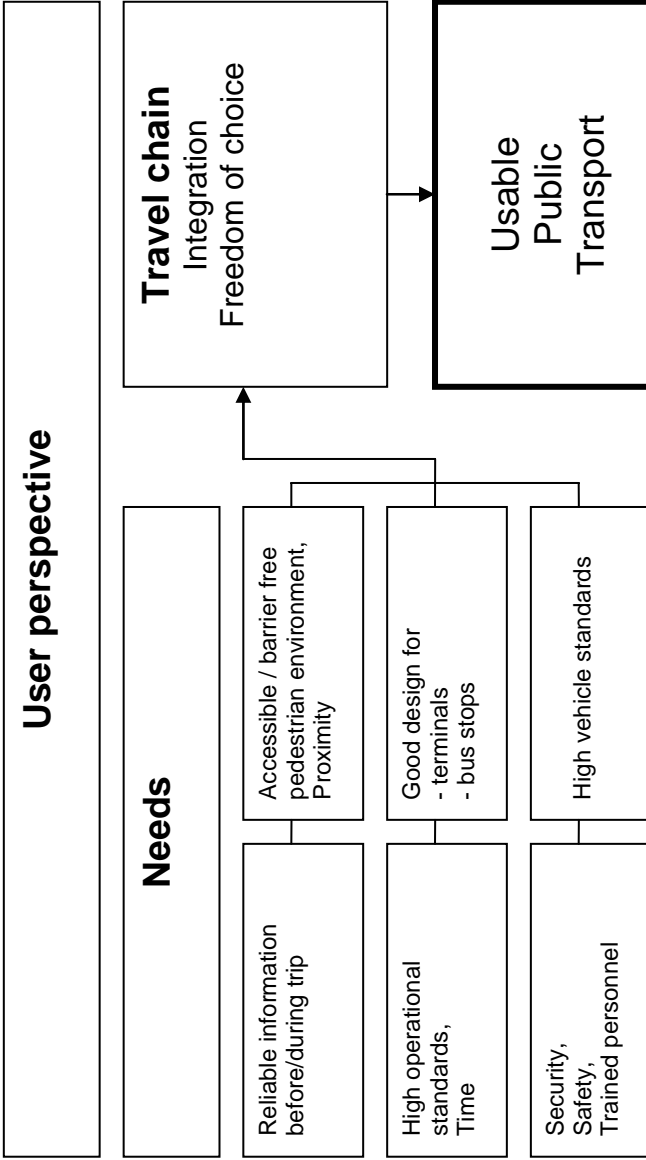
Accessibility is a concept describing the encounter of an individual's or group's functional capacity and the demands of the physical environment (Iwarsson and Ståhl, 2003). This concept is based on one of several interactional models (Steinfeld and Danford, 1999), namely the ecological theory of aging, including the docility hypothesis (Lawton and Nahemow, 1973), meaning that that the relationship between a person's functional capacity and an environment's demand implies restrictions and opportunities for behaviour. Mismatch between the environmental press and the individual's capacity occurs when the environmental press exceeds the individual's competence, or when challenges are far below an individual's competence. The local bus transport provided in a



differentiated system can be described using the terminology of Lawton and Nahemow (1973), i.e. that the environmental press is as greatest in ordinary public transport, meaning that the individual's functional capacity has to be quite high. However, when the individual grows older or acquires functional limitations, his or her functional capacity declines and intermediate solutions offer environments with lower demands. According to Iwarsson and Ståhl (2003), accessibility is a result of the analysis of the relation between the personal component and the environmental component, i.e. information on both the individual's capacity (or limitations) and the characteristics of the environment are needed. Most important, accessibility is mainly objective in character, i.e. both components are assessed professionally and the environmental component is assessed based on official guidelines and norms.

In addition to accessibility, the Swedish building and planning legislation requires public buildings and public outdoor places to be *usable*. Usability is a concept often used similarly to accessibility. However, while accessibility is mainly objective in nature, usability refers to the users' *perceived evaluations* (Iwarsson and Ståhl, 2003:62). In addition to the personal and environmental components, usability integrates an activity component, which contains a description of the activity that is to be performed by an individual or group in a certain environment. An accessible environment is not necessarily a usable environment, because even if an environment is accessible, individuals still may assess the environment impossible to use, i.e. nobody use it. On the other hand, a usable environment is always accessible.

From this perspective the whole travel chain does not only have to be accessible, but it has to be usable (Figure 1). The importance of having a the travel-chain perspective when planning for a public transport system that includes the needs of various user groups has been emphasised in several studies (Ståhl, 1993; Ståhl, 1997; Olsson, 2003). The travel chain perspective stresses the importance of not separating the stay onboard the vehicle from the other parts of the journey; the search for information regarding transport possibilities, the way to and from the vehicle, changes at terminals etc. If one link in the chain is missing, the whole chain will be broken (Ståhl, 1997). From an individual's perspective the use of public transport contains a complex chain of events and each part of the chain has to be usable per se as well as the whole travel as such.



**Figure 1** The need for public transport from the user's perspective. Adapted from Ståhl, 1997.

## *Aims*

The overall aim of this work was to explore and gain deeper insight into and understanding of mobility in public environments among people living with acquired cognitive functional limitations and of reasons why some of them do not use public transport. More specifically there were two aims.

The first aim was to explore, from experts' perspectives, mobility in public environments among people living with acquired cognitive functional limitations. Did these people leave their homes in order to spend time in public outdoor environments? What were the limitations and barriers for their mobility, and what given elements and facilities did enhance/support their mobility? How did they move about in public outdoor environments? How suitable were various modes of transport for them?

The second aim was to gain deeper insight into and understanding for the reasons behind the decision by people with acquired cognitive functional limitations not to use public transport anymore, from their own perspective. What was the decision to stop using public transport based upon? What were the reasons for not using public transport any more? What kind of obstacles they met, or they assumed to be there, had been decisive in this respect?

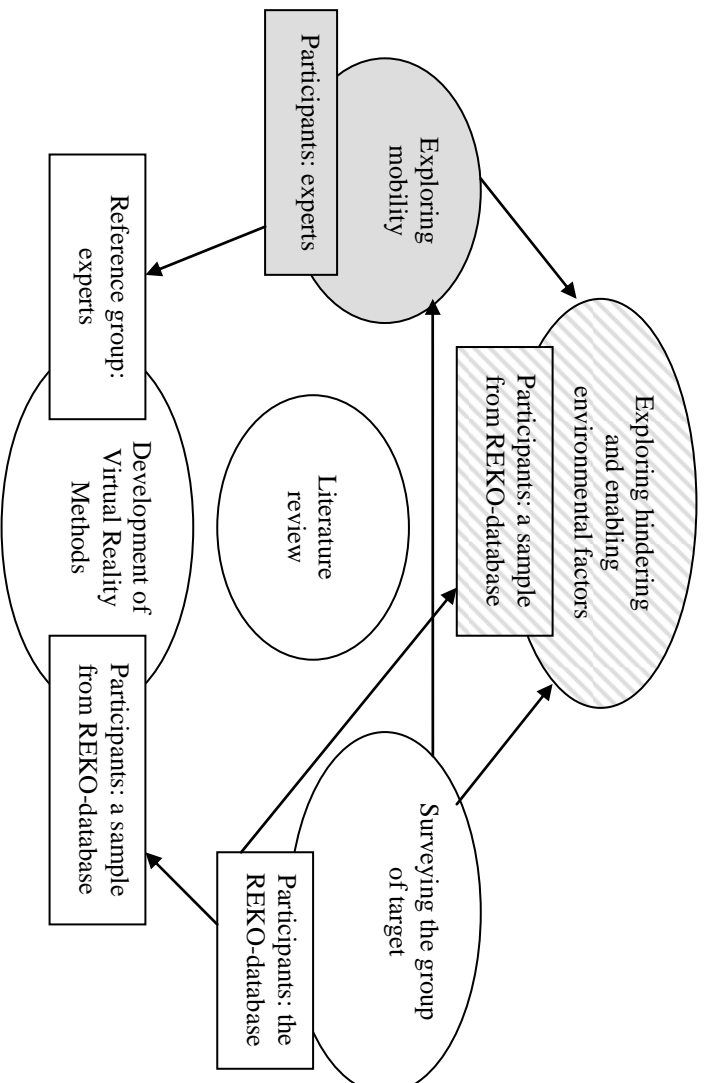
# *Methods*

## *Project context*

This thesis is based on two studies accomplished within the large-scale interdisciplinary research project called “Accessibility in public transport for persons with cognitive impairments – survey, method development and innovative IT-solutions” (VINNOVA dnr 2001-06707). The overall aim of the research project was to provide knowledge on accessibility problems in public transport environments for people with acquired cognitive functional limitations. Further aims were to develop methods for studying accessibility and usability problems among people living with acquired cognitive functional limitations and to come up with innovative solutions.

The research project involved close co-operation among three different departments at Lund University, Sweden: Department of Health Sciences, Faculty of Medicine; Department of Technology and Society and Department of Design Sciences both within the Faculty of Engineering. It engaged three doctoral or licentiate students who represented occupational therapy, traffic planning, and design sciences, and of their respective supervisors. Scientific expertise from the fields of gerontology, psychology, social psychology, sociology, neurology, rehabilitation medicine and design sciences was represented in the project group.

The studies presented in this thesis are two among several sub-studies accomplished within the research project (Figure 2). They explore mobility, from experts' perspective, among people living with acquired cognitive functional limitations and focus on reasons behind the decision by people with acquired cognitive functional limitations not to use public transport anymore. In parallel to this thesis, Wendel (2008) presents her thesis surveying the targeted group with regard to functional limitations, symptoms of depression and use of modes of transport. In addition a thesis for doctoral degree focusing on development of virtual reality methods has been presented (Wallergård, 2007).



**Figure 2** Overview of the various studies within the research project “Accessibility in public transport for persons with cognitive impairments – survey, method development and innovative IT-solutions” and their relationships. A version close to the one presented here was originally presented in 2007 by Rosenkvist, Wallergård and Wendel.

## *Study design*

An overview of the studies in this thesis is presented in Table 1. Two methods were used; focus group interviews (Wibeck, 2000; Krueger and Casey, 2000), and semi-structured interviews (Berg, 2004). The decision to use these methods was based on the nature of the research question, which is exploratory. Overall the procedure can be considered a grounded-theory-based one, as our approach implies openness to the field (Kvale, 1997) and that the method can be modified, e.g. whenever the interviews provide new insights.

The information gained in both studies has a subjective character in two different ways. In Study 1 the individuals we communicated with were “informants” in the sense of Kvale (1997), i.e. they provided information about the target group’ mobility. They were called “experts” as they had professional knowledge about individuals living with acquired cognitive difficulties because of systematic communication and interaction with the target group in the frame of, for example, their profession. The experts’ answers were based on their (professional) experiences with the target group. On the other hand, the participants in Study 2 were “respondents” in the sense of Kvale. According to Kvale’s definition, the respondents’ answers were based on their own personal experience (in this case: experience concerning their own use of public transport).

**Table 1** Overview of Study 1 and Study 2

	<b>Study 1</b>	<b>Study 2</b>
Aim	Explore mobility in public outdoor environments among persons living with acquired cognitive functional limitations from an expert perspective	Gain deeper understanding of choosing not to use public transport anymore when living with acquired cognitive functional limitations
Perspective	Subjective: informants	Subjective: respondents
Method	Focus group interviews	Semi-structured interviews
Participants	Experts, i.e. people who knew about the situation for people with acquired cognitive functional limitations	People with acquired cognitive functional limitations
Analysis	Qualitative content analysis	Qualitative content analysis

### ***Selection of and description of participants***

In qualitative research sampling strategies that are not based on any probabilities are used. Examples are purposive sampling, snowball sampling and quota samples (Berg, 2004). Purposive sampling implies identifying people who possess certain attributes that are relevant for the purpose of the study. Snowball sampling is similar to purposive sampling by way of introduction, but after people with certain characteristics have been identified, they are asked for names of other people who possess the same attributes as they themselves have. Quota samples begin with a matrix or a table where the researcher fills in attributes of individuals who are interesting in relation to the research question(s). The researchers use the matrix to locate individuals who fulfil the criteria. All three sampling strategies were used in Study 1, while a purposive sample was used in Study 2.

## The experts (Study 1)

In this study the participants were called “experts” because they possessed a general knowledge about everyday mobility among people living with cognitive functional limitations. This was interesting for the purpose of the study as they could contribute to improved understanding of individuals with acquired cognitive functional limitations within society.

A framework – or a matrix – for the variety of experts was developed (Table 2) based on an overview of which types of experts people with cognitive functional limitations meet. Individuals with cognitive functional limitations often come in contact with experts within health and rehabilitation services, public authorities and special interest organisations on both an institutional and non-institutional context, but in many cases also when taking care of relatives or friends. It should be noted that some of the experts both had knowledge from a professional perspective as well as they also lived with acquired cognitive functional limitations themselves.

**Table 2** Framework for the sampling of experts in Study 1

### Different categories of experts in contact with individuals with acquired cognitive functional limitations

<i>Health and rehabilitation services</i>	<i>Public authorities</i>	<i>Political work</i>	<i>Special interest organisations</i>	<i>Informal care and support</i>
Occupational therapist	Welfare officer	Lay assessor	Representative from special interest organisation	Relatives
Physiotherapist	Handling officer	Participant in political committees		Friends
Psychologist				
District nurse				
Social worker				
Personal assistant				

On the basis of this framework, lists of names of potential participants were produced. The local telephone directory as well as web site



references to municipalities, county councils and public authorities provided these names of these people to contact. The potential participants were asked to reply positively if they felt that they fulfilled the criteria specified for being an expert. Thereafter snowball sampling was used in order to reach people in public authorities and special interest organisations. A total of 27 experts between 30 and 60 years old participated, three of whom were men. Four focus groups interviews were carried out and in all the groups different kinds of experts were represented:

**Focus group 1:** lay assessors, welfare officer, handling officers and special interest organisation were represented.

**Focus group 2:** occupational therapists, handling officers and physiotherapist were represented.

**Focus group 3:** occupational therapists and special interest organisation were represented.

**Focus group 4:** welfare officer, handling officers, occupational therapist, physiotherapist and special interest organisation were represented.

### **The individuals with acquired cognitive functional limitations (Study 2)**

Two inclusion criteria were set up for the selection of the participants. Firstly, the participants had to have acquired cognitive functional limitations and secondly, they had to have been public transport travellers before acquiring their cognitive functional limitations. Taking into account these two inclusion criteria, participants were selected from a database (Wendel et al. in press 2008) within the research project (Figure 2). This database comprises individuals with stroke and contains quantitative data on professionally assessed and self-reported acquired cognitive functional limitations, physical functional limitations and use of mobility devices, depression symptoms and activity performance.

The participants selected from the database were those who had reported that they do not use public transport (bus or train) post-stroke (Wendel, et al., submitted). A systematic variation with respect to cognitive functional limitations, gender and age was strived for by compiling a maximum variation sample according to Patton (1990). Also, in order to generate information about problems related to cognitive functional

limitations, the portion of physical functional limitations among the participants should be as low as possible.

The resulting group of participants comprised seven women and two men, aged 45-90 years. The two men lived with their spouses in apartments close to the city centre. Five of the women lived alone in apartments, and the remaining two lived with their spouses in houses with gardens; one of them had children still living at home. The group showed a variation of types of cognitive functional limitations for each cognitive area and sub-area according to the screening instrument Cognistat (Wendel, et al. in press 2008). However, among the resulting group of participants, nobody had memory and judgement difficulties (Table 3). Despite the ambition to keep down the portion of physical functional limitations, especially difficulties in bending and kneeling, and dependence on mobility devices were present among the participants (Figure 4). The mobility devices in use were walking sticks or rollators (a walking frame, typical for Nordic countries, see Brandt, et al. 2008). At the time for the data collection of Study 2, the actual use of walking aids in the sample appeared to be more common than at the time of the quantitative data collection for Wendel et al. (in press 2008). Turning to emotional aspects, according to the database information five of the participants had six or more depression symptoms.

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*Professionally assessed acquired cognitive functional limitations*

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*Cognistat area/sub-area*

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	Orientation	Attention	Comprehensio	Repetition	Naming	Construction	Memory	Calculation	Similarities	Judgment
<i>Mild</i>	0	3	2	1	2	3	0	1	1	0
<i>Moderate</i>	0	3	3	1	0	0	0	0	0	0
<i>Severe</i>	1	0	0	0	0	0	0	1	3	0

<sup>a</sup> (Kiernan et al. 1987, Mueller et al. 2001)

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**Table 3** Number of participants, having professionally-assessed acquired cognitive functional limitations, divided into areas and sub-areas within Cognistat<sup>a</sup>

Physical functional limitations and dependency on mobility devices

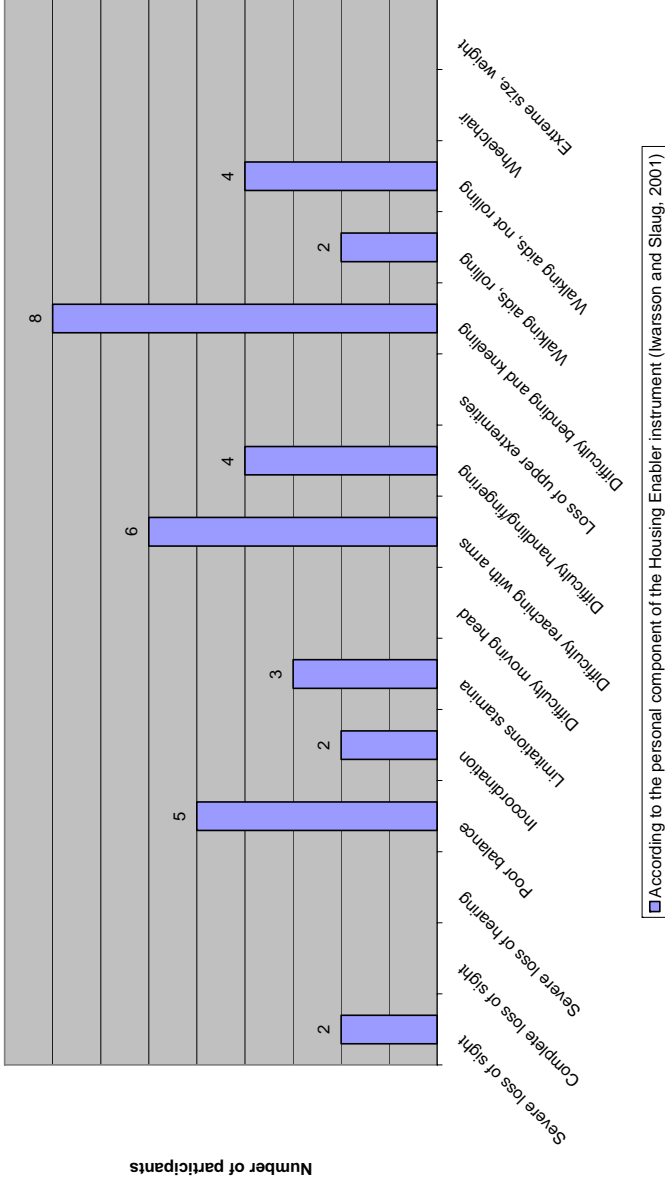


Figure 4 Description of the participants' physical functional limitations and dependency of mobility devices

## ***Study districts***

The participants in both studies (1 and 2) lived in the region of Scania in Sweden. The experts came from the whole region of Scania (Study 1), while all the participants in Study 2, except for one, lived in the city of Malmö; the largest city in Scania. Thus, the participants in both studies may have experience of public transport in other geographical areas.

### **Study 1**

Scania is the southern-most county of Sweden, where 1,170,000 of Sweden's 9 million inhabitants live. The authority responsible for public transport in Scania is Skånetrafiken, which is part of the regional public body. In Scania, where Study 1 and 2 were carried out, the efforts to make adaptations in public transport in order to increase accessibility has come long way in comparison with other parts of Sweden. About 25% of bus stops have been adapted, especially in heavily trafficked districts. Buses are gradually being adapted as the bus fleets are renewed, for instance with low floors and entry steps and room for wheelchairs and rollators. All of the city buses in Scania are of low-floor type (Skånetrafiken, 2008).

### **Study 2**

Malmö is the third largest city in Sweden with an urban population of 280 801 inhabitants (as of January 1, 2008). The public transport system is differentiated, with fast trunk bus routes where buses run very quickly and frequently (every 5 minutes) to and from important destinations in the city, and more local routes that take care of more restricted travel needs that do not run that frequently (they leave every 30 minutes). Most of the city area (82%) is regarded as being covered by public transport. Regarding accessibility to the public transport system in Malmö, the situation is as follows: the average distance to bus stops is 240 metres, more than half of the bus stops (56%) are sheltered and all buses are low entrance buses, i.e. there are no steps into the buses and the buses can kneel down to a height of 230 mm from the ground. No intermediate solutions specifically designed to meet the needs of people with functional limitations are available. Special Transport Service is provided for those who qualify, which is decided by the municipality.

## ***Methods and procedures for data collection***

As already has been said above, focus group interviews and semi-structured interviews have been carried out in the two studies referred to in this thesis:

### **Focus group interviews (Study 1)**

Focus group interviews involve small groups of people who talk about a certain topic. The participants of a focus group interview have certain characteristics in common that relate to the topic under study. Carrying out a focus group interview is a way to understand how people think about an issue (Wibeck, 2000; Krueger and Casey, 2000). The group has to be small enough for everyone to be able to express their opinions and perspectives but at the same time large enough to provide diversity of perspectives (Krueger and Casey, 2000). The number of focus group interviews is not determined beforehand, but, according to literature, a saturation point is reached when qualitative focus group interviews do not provide any more new information and when there consequently is no point in conducting any more focus group interviews (Wibeck, 2000).

In Study 1 two focus groups were initially composed. As the saturation point had not been reached after two focus group interviews, another two focus group sessions were scheduled. In all, four focus group interviews were conducted during a five-month period, each focus group interview contained six to eight (6, 7, 6, 8) people.

Focus group interviews can be structured either strongly or weakly. Weakly structured interviews are preferable for explorative research, which was the case in Study 1. The order of questions in the interview was inspired by Morgan's funnel-based interview, which begins "with a less structured approach that emphasises free discussion and then moves towards a more structured discussion of specific questions" (Morgan, 1997:41). The first question in the focus group interviews concerned everyday life of the people with acquired cognitive functional limitations in general, followed by questions that increasingly zoomed in on mobility and the use of different transport modes. The central themes were mobility and transport styles. The following four topical questions

were formulated: “What does a normal day look like for a person with acquired cognitive functional limitations?”, “What does this group’s mobility look like?”, “How does it work for a person with acquired cognitive functional limitations to walk or to travel by bicycle, train or bus or by car?” and, finally, “What is a good way and a bad way of moving about?, and why?”.

The task for the interviewer/moderator in a focus group interview is to pose the questions and to support the discussion by encouraging the participants to use their own words and categorisations (Stewart and Shamdasani, 1990). The interviewer/moderator also makes sure that the focus group interview is not dominated by one or two participants.

The moderating team in Study 1 consisted of an interviewer/moderator and an assistant. The author and an experienced focus group moderator moderated and assisted all four focus groups, and they thereby alternated in their respective roles.

The first contact with the potential participants in Study 1 was established by means of an introductory letter briefly presenting the project and the aim of the focus group interviews. Each focus group session began with a reminder of the purpose of the project, followed by the interview. The questions to be dealt with had been written down on a flip chart in advance. As the moderator posed each question, he/she displayed the relevant flip chart page to the group. The assistant made notes and sometimes asked questions for further clarification. Each focus group interview took about two hours. The interviews were electronically recorded and subsequently transcribed.

### **Semi-structured interviews (Study 2)**

Semi-structured interviews consist of a number of predetermined questions and special topics, but the interviewer is free to ask the interviewed individual to evolve his/her description (Berg, 2004).

The semi-structured interviews in Study 2 were performed as conversations with open-ended questions, thereby following an interview guide that had been developed on the basis of the findings in Study 1 and of results of previous research on acquired cognitive functional limitations and the use of public transport (see for example Hunter-

Zaworski and Hron, 1993; Hunter-Zaworski and Hron, 1999; Koppa et al., 1998). The themes in the interview guide were 1) mobility in general, 2) hindering and enabling environmental factors when using public transport, 3) strategies if one wanted to use public transport, 4) future use of public transport, and 5) ideal public transport. The intention was first of all to understand the perspective of the participants. The questions about the second theme, namely hindering and enabling environmental factors when using public transport, were the essential ones (Berg, 2004). The standardised questions have to be formulated so that the words used are familiar to the people being interviewed. Therefore the question formulation was pre-tested on several occasions both within the project group as well as with outside individuals followed by revisions of the interview guide until it reached an optimal format.

The first contact with the potential participants was by a telephone call during which the research project was briefly presented and the person was asked to consider participation. This was followed up by a letter with extended information. About a week later, a second telephone contact was made to set a date for an interview. The interview was carried out in the participant's home by the first and fourth authors of Study 2. During the visit the participant was asked to sign an agreement of consent, and the interviewers explained that the information gathered was to be treated as confidential. The repeated contacts with the participant before the interview were supposed to establish confidence between them and the interviewers. To establish confidence is important, especially for this group, as, by experience, they often hesitate to encounter new persons and events outside of their routine life.

The two interviewers were present during all but one interview, which was advantageous because they represented different experiences with people with acquired cognitive functional limitations as well as different scientific fields, i.e. traffic planning and occupational therapy. The doctoral student from the Department of Health Sciences (fourth author in Study 2) led the conversation, but interviewers posed questions and encouraged the participant to describe his/her thoughts by probing questions (Berg, 2004). During the interviews the answers were played back to the participant to make sure that his/her own perspectives had been understood correctly, in order to strengthen the internal validity of the data (Persson, 2006). Both interviewers made notes during the interviews and they made summary notes after each interview. When



carrying out the interviews, an iterative process was followed; information given in one interview was taken into account and amended in the following interviews. The interviews were tape-recorded and transcribed word by word.

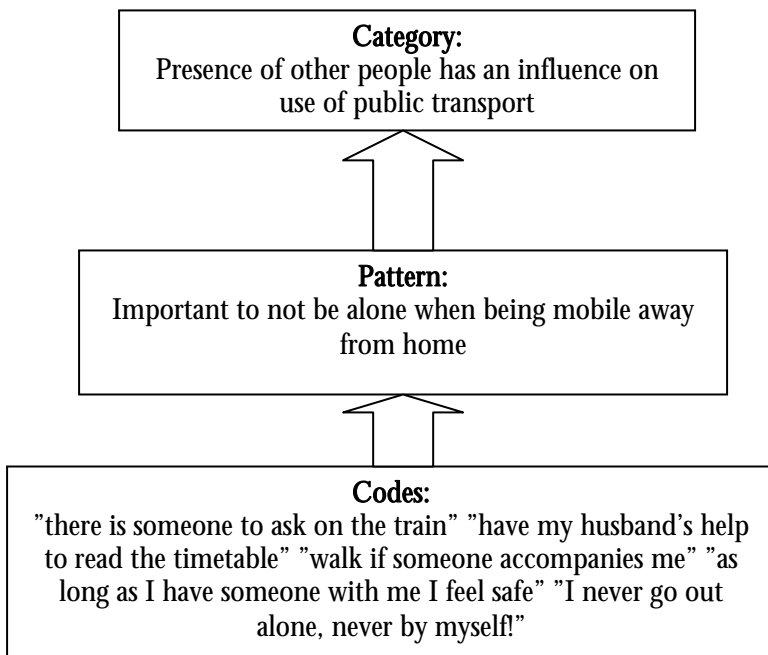
## *Analyses*

An inductive analysis (Patton, 1990) was carried out. This means that patterns, themes and categories appear from the material, so there is not a pre-determined/certain theory that steers the analysis process. In such a process, research starts from being as independent as possible. Then successively, the data gained during the research process constitute basis for building a theory. Both the focus group interviews (Study 1) and the semi-structured interviews (Study 2) were analysed by means of content analysis (Patton, 1990; Flick, 2002), striving to understand *what* the participants were talking about.

The interviews were firstly read through with the intention of grasping an overall picture of what they were about. This was followed by an open coding<sup>1</sup>, line by line, constantly comparing the codes. The codes were written on small post-it notes and organized and re-organised on notice board. After a while there appeared to be similarities and a number of codes showed a common pattern (Figure 5). The computer software MindManager® 2002 Enterprise Edition was used to produce the first raw draft of the structure of the categories in Study 1.

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<sup>1</sup> Coding means giving a name to a phenomenon or event. (Starrin, 1996)



**Figure 5** Example of the analysis process where a number of codes show a pattern that becomes part of a category. Model adapted from Starrin, 1996.

### ***Ethical issues (Study 2)***

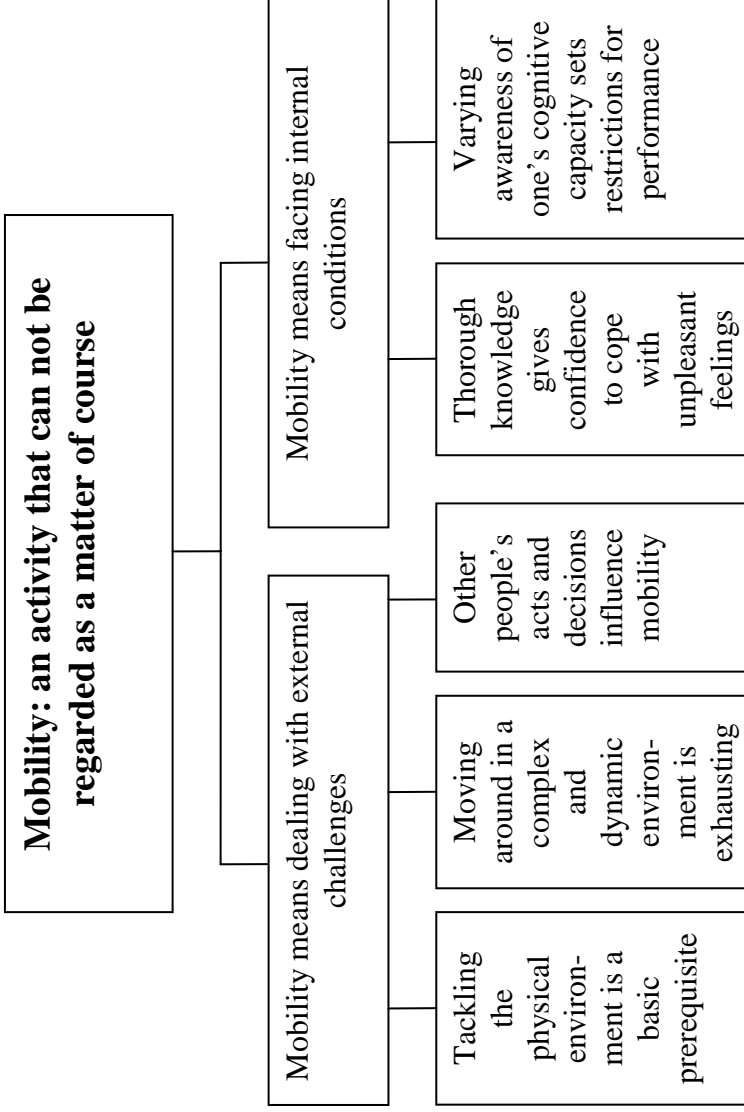
Before the semi-structured interviews took place, the participants signed a consent agreement, and the information was treated confidentially. The study was approved by the regional ethical review board in Lund, Sweden.

## ***Findings***

The analysis of the focus group interviews and the semi-structured interviews resulted in a deeper understanding for mobility among persons living with acquired cognitive functional limitations seen through the eyes of experts and of reasons for not using public transport after having a stroke as described by the members of the target group themselves. The focus group interviews in Study 1 resulted in a core category called “Mobility: an activity that can not be regarded as a matter of course”, and the semi-structured interviews in Study 2 resulted in the core category “The use of public transport: A challenging activity, either under consideration or out of the question”.

### ***Mobility: an activity that can not be regarded as a matter of course (Study 1)***

The experts had different views of the mobility situation for people with acquired cognitive functional limitations. According to the experts, the level of mobility in public outdoor environments varied considerably within the target group: there were those who maintained mobility and left their homes regularly and those who stayed at home most of the time. Those who wanted to maintain mobility and made efforts to do so had to deal with external challenges in the public environment, they also had to face internal conditions that either promoted or restricted mobility, according to the experts. A core category “Mobility: an activity that can not be regarded as a matter of course” appeared, with two main categories: “Mobility means dealing with external challenges” and “Mobility means facing internal conditions” (see Figure 6).



**Figure 6** Overview of the main category “Mobility: an activity that can not be regarded as a matter of course” and its sub-categories.

## **Mobility means dealing with external challenges**

According to the experts, public environments brought forth external challenges that people with acquired cognitive functional limitations were more or less able to manage. If they coped with the challenges they could maintain mobility. However, the experts' descriptions illustrated situations when the target group interacted inappropriately with the external environment, and facing the external environment became difficult and problematic, in words reflecting that ***tackling the physical environment is a basic prerequisite***. The most concrete and basic precondition for mobility was the design of the physical environment, both with respect to the public outdoor environment such as pavements and to vehicles (design, ergonomic etc.).

Cognitive functional limitations appear to be more subtle than and different from physical functional limitations: experts indicated that dimensions such as time pressure, and the complexity of traffic environments constitute serious external challenges, in words reflecting that ***moving around in a complex and dynamic environment is exhausting***. Cars, cyclists and pedestrians are constantly moving, traffic lights are changing, buses and trains have tight schedules to follow, etc. In order to manage eventful contexts, the user is forced to quickly sort out the most important parts of the large amount of information given. For individuals with acquired cognitive functional limitations, the experts made clear that this could be an almost impossible task, since this group of people requires calmness to cope with decision-making on the basis of a lot of information. One of the experts described a possible scenario for one of her patients who:

“...doesn't look to the side and doesn't notice the traffic. And what can happen – and it's relevant in all contexts...if there's too much information and so on, – then patients panic if there's too much at one time. So they need a bit of peace and quiet.”

Another example of complexity, mentioned by the experts, was when a bus trip includes changes from one bus or train to the other, forcing the user to be alert all the time. For an individual with acquired cognitive functional limitations who easily gets mentally exhausted, it is a challenge to handle several tasks one after another. A situation that

requires change of vehicle in public transport could cause exhaustion or even chaos.

The experts also meant that if other people do not see any obvious reason why individuals with acquired cognitive functional limitations behave in a certain way, they may not have patience with their sometimes differing behaviour, in words reflecting that ***mobility is influenced by other people's acts and decisions***. Other people may react to their behaviour and the reaction is taken notice of by the person with acquired cognitive functional limitations, thus influencing the situation in a negative way. However, individuals living with acquired cognitive functional limitations do not want to exhibit their functional limitations; according to the experts they want to be treated "just like everybody else". On the other hand, the experts described that some individuals living with acquired cognitive functional limitations use other people's, such as relatives', friends' or individual assistants' support in order to maintain mobility. It could be that a relative drives the car or that an employee of the public transport company assists in order to manage a change from one bus or train to another one.

### **Mobility means facing internal conditions**

The experts also described that people with acquired cognitive functional limitations have to deal with internal conditions in order to maintain mobility, such as feelings of anxiety, uncertainty, stress or fear. Mobility depends upon how individuals with acquired cognitive functional limitations coped with such feelings, one solution being reflected in the wording ***thorough knowledge gives confidence to cope with unpleasant feelings***. An overwhelming amount of information given at the same time in traffic environments can cause unpleasant feelings, such as stress, anxiety and fear: one important way to deal with such feelings in order to enable mobility is to reach certainty/confidence about a situation and what activities are about to happen. For example, in order to deal with internal struggles of uncertainty, the experts mentioned that the target group needs to know what is going to happen when travelling somewhere away from home already before leaving home. They have to prepare the trip mentally. Further, they prefer spending time in familiar environments, where they often have strict instructions, experiences and routines for managing situations that arise.

Another kind of internal condition that have implications for the target group's mobility was, according to the experts, the target group's varying awareness of their cognitive capacity, in words reflecting that ***varying awareness of one's cognitive capacity sets restrictions for performance***. There were those who knew for certain what they could or could not manage because they had an appropriate sense of their abilities, but there were also those who had lost their ability to sense what their cognitive capacity actually allowed them to do. One expert, herself living with acquired cognitive functional limitations, explained:

“I sometimes overestimate myself, and sometimes I underestimate myself. There is no general solution. Either do this or that. Sometimes you should have done this, and sometimes you should have done that – so you get confused.”

Those who underestimated their capabilities did not leave home very much since they did not think that they could manage. But if they really have tried, the experts said that some of them might have found that they could perform adequately. Since there are people with different personalities in the target group, there are also some who do not hesitate to try. Some of them are prepared to accept a failure, while others are afraid of, and want to avoid, failures, and still others who are not aware that their abilities are inadequate and who thus are not prepared for failure.

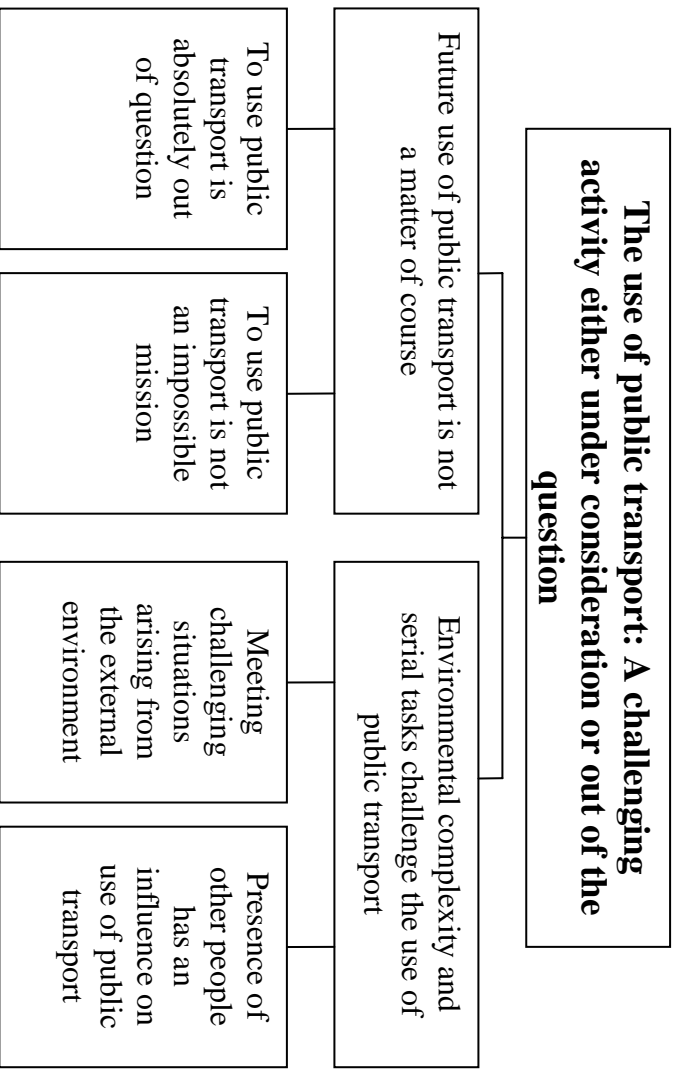
### ***The use of public transport: A challenging activity under consideration or out of the question (Study 2)***

The interviews with the target group revealed that the participants' thoughts related to the present and future use of public transport varied. Some had distanced themselves from the very thought of travel by bus or train while others were prepared to consider using public transport now or at some time in the future. The participants' descriptions of public transport originated, for example, from their imaginations or from what they had heard from friends, or read in newspapers. Further, their descriptions originated from their experiences from using public transport before having a stroke and experiences from actual journeys with public transport after they had had a stroke. There had been occasions when the participants had tested public transport after the stroke, together with friends or relatives in order to see whether they could cope or not. However, the participants no longer viewed

themselves as public transport users, as such use was not at all frequent, nor did they use public transport on their own, at the time of the interview.

As can be seen in Figure 7, the core category emerging from the interviews was ***The use of public transport: a challenging activity either under consideration or out of the question.*** It comprised two main categories, each with two sub-categories: ***Future us of public transport is not a matter of course*** and ***Environmental complexity and serial tasks challenge the use of public transport.***





**Figure 7** Categorisation of the results from semi-structured interviews with people with acquired cognitive functional limitations

## Future use of public transport is not a matter of course

There were statements that revealed how thoughts of using public transport were far away in the participants' minds' – for example one participant noted that she did neither use public transport nor would she like to, in words reflecting that *to use public transport is absolutely out of the question*. The interviews enlightened explanations as to why it was completely out of the question to use a bus or train. It could be due to the consequences of the stroke, which was exemplified by a woman who said that her loss of memory had made her forget how to use a bus or a train:

”the mere thought of leaving where we live and then all that travelling and then having to board the train [cleared her throat] ehm ehm oh, I don't know, I don't know anymore what you're supposed to do. I do not know how to handle objects. I have lost it all!”

Other decisions to not use public transport anymore were attributed to the aging process:

”No, no, I'll never do that again, old as I am, I don't believe any bus would take me onboard, I'll be running on these legs before I ride [laughs]”.

Other modes of transport had replaced the participants' need for buses or trains, for example by being entitled to the Special Transport Service or being given a lift by their children, friends or partners.

There were also statements that revealed that ideas of using public transport were present in the participants' minds, i.e. to use public transport was an activity that the participants thought they were to be able to manage to the same extent as they did before their stroke, in words reflecting that *to use public transport is not an impossible mission*. The statements that revealed thoughts about start using public transport again showed that in the minds of the participants public transport was a present issue. One woman explained that she was prepared to make an attempt to use public transport, on her own, again. Her plan was firstly to try the train by herself, as taking the train was not as stressful for her as

taking a bus. Then her daughter would meet her at the railway station and join her on the bus to their final destination. To start to take the bus from the railway station by herself would be a later mission.

### **Environmental complexity and serial tasks challenge the use of public transport**

The participants described their ideas of what it would be like if they were to use public transport today as persons having had a stroke. They described situations they considered as challenging and in what way such situations had an influence on them, in words reflecting *meeting challenging situations arising from the external environment*. It was experienced as demanding to handle an external environment that was characterised by complexity and constituted situations with serial tasks to be performed within a short amount of time. An example was the situation that arose when getting on and off a bus, such as standing in a queue, managing the payment process, finding a seat, and in addition in some cases bringing a rollator onboard. One woman described this situation:

"I can't board with my rollator and I can't put the rollator aside and go up front and pay and then go back and find a seat, 'cause you can't sit on your rollator because you'll fall off."

A male participant pointed at the difficulty in performing serial tasks in a short time, even though he was able to perform them one by one. His solution was that his wife assisted him. When he only had to handle a few tasks by himself, one at a time, he found it much easier.

According to the statements, the bus was regarded a greater challenge to handle than the train. This was exemplified by one woman who considered the bus problematic as she was unsure about when and where to push the stop button in order to make the bus stop. She felt that it was easier to use the train as the train comes to a standstill at every designated stop, which diminished the risk of getting off at the wrong station.

Further, the statements revealed that challenging situations in the external environment could be caused by the design of the physical environment, such as differences in level which can be especially difficult

when using a rollator. Finally, some statements implied that the participants were not able to point out specific situations that they considered themselves unable to handle. Rather the statements demonstrated a general fear and anxiety about “everything” related to using buses and trains. One woman described it as a blurred anxiety – everything scared her. For her it was not the lack of practical help in order to manage the environmental conditions that made her hesitate to use public transport, but rather her negative feelings and anticipations.

The statements made it obvious that the participants considered the presence of other people as influencing their use of public transport, in words reflecting that ***presence of other people has an influence on the use of public transport***. For example the participants described that they did not want to disturb or irritate other passengers, nor would they want to be disturbed by others. In order to avoid situations where the participants experienced themselves as disturbing others, they considered using public transport at other times than rush hours, if possible. The statements also revealed that trust in other people was an important issue. For example, one woman said that for her it was no problem to move about in her neighbourhood because she knew that there were people there in whom she could trust if anything should happen to her. Other participants had different experiences, namely that people out on the streets do not offer help if one falls. According to the statements, the availability of other people to help, for example a partner, a friend or the driver from the Special Transport Service implies safety and support when it is time to leave the home environment. However, some also had the wish not to be accompanied when leaving home.

### ***The expert perspective and the user perspective***

Summing up the two studies, the expert perspective and the perspective of people with acquired cognitive functional limitations, i.e. the user perspective, both had similarities and differences. To the similarities, were the categories related to the influence of the external environment both on their mobility in general and use of public transport. For example, both the experts and the users pointed at the difficulties caused by the design of the physical environment, complexity and eventfulness in traffic environments and the influence of other people. Turning to the differences, the experts’ descriptions had a more objective (in the sense of experience from several types and individuals with cognitive functional

limitations) perspective, while members of the target group themselves gave more personal and detailed descriptions. Another difference was that, the experts easily focused cognitive functional limitations in relation to mobility. On the other hand, for the participants in Study 2 it seemed to be easier to describe their physical functional limitations as impeding their use of public transport whereas more difficult to pronounce the consequences of their cognitive functional limitations. A reason might be that it is easier to talk about what is visible, while their cognitive functional limitations were not that obvious. From a planning perspective it is important to be aware of the different perspectives of experts and users, combine and take hold of both of them (Iwarsson and Ståhl, 2003) in order to be able to plan for both an accessible and usable public transport.

## *Discussion*

The findings of the two studies building up this thesis constituted useful insights into mobility in public environments from an expert perspective as well as from the perspective of people living with acquired cognitive functional limitations themselves. From the user perspective, the findings also provided a deeper understanding of why people choose not to use public transport any longer after acquiring cognitive functional limitations.

The results of this thesis showed that the external environment created various challenges both for mobility in general and for use of public transport. The individuals' cognitive competence had decreased and they were more vulnerable to the environmental demands (Lawton and Nahmow, 1973) of traffic environments, which meant that activity involving mobility in general and/or use of public transport in particular did not take place anymore or took place in somehow changed ways. This is supported by Wendel et al (submitted), showing that among individuals with decreased or ceased user of public transport post-stroke, 26 of 28 persons declared the reason to be changes in physical or cognitive functioning. Thus, the results indicated that there were usability problems (Iwarsson and Ståhl, 2003) in public transport for people with acquired cognitive functional limitations. That is, the participants expressed problems perceived in person-environment-activity transactions. Turning to the occurrence of accessibility problems, in Study 2 the information at hand on the personal component was professionally assessed (see Wendel et al, in press), while we lack such data on the environmental component of accessibility. That is, based on the studies building up this thesis, we do not have any information about the occurrence of environmental problems expressed in terms of official norms and guidelines in the areas the target group moved around. Still, a noteworthy quality of Study 2 was that the sample was defined and selected based on valid and reliable professional assessment of the participants' functional limitations. In this respect the results of this study differ from other studies within the field of traffic planning, as they often lack a detailed description on the personal component, which is required in order to be able to verdict on accessibility and usability (Iwarsson and Ståhl, 2003).

The descriptions given by the experts in Study 1 focused on the **preconditions** for the mobility of people with acquired cognitive functional limitations. Thus, it is relevant to say that experts' empathetic descriptions were aspects of motility (Kaufmann, 2005). From this perspective it was not merely the cognitive functional limitation per se that determined the individual's level of mobility, alternatively it could be the individual's interpretations of his/her situation, needs and wishes for mobility that were decisive for how and to what degree mobility would actually take place. The findings in Study 2 illustrated that the target group's motility was in many respects determined in the participants' minds – the environmental pressure was thought of as being too high. In other words, the usability problem may only exist in the participant's mind, i.e. the "actual" environment may not imply an insurmountable usability problem.

The findings of this thesis showed that the frequency of mobility was experienced in various ways as well as there was both a desire to be able to use public transport and, at the same time, resistance to using it. In other words, absent mobility did not per se mean dissatisfaction, which was also the fact in Wendel et al. (submitted) as there were no difference in self-reported satisfaction among individuals who used public transport post stroke and those who did not. According to Kaufmann (2005), dissatisfaction arises when motility does not correspond to mobility, for example when an individual wants more mobility than he/she already has. The fact that there are individuals within the target group who seem to be pleased with a low level of mobility indicates that low level of mobility does not per se mean dissatisfaction (SIZE, 2003). If the individuals showed dissatisfaction, i.e. motility did not correspond to mobility, the acquired cognitive difficulties then meant acquired cognitive disabilities, i.e. restricted behaviour in everyday life (Verbrügge and Jette, 1994) from an individual perspective. When motility corresponded to mobility, even if the level of mobility was low, the acquired cognitive difficulties should be referred to as acquired cognitive functional limitations, as they only caused restrictions in activities that the individuals could do, but did not do (Verbrügge and Jette, 1994). The findings in Study 2 referred to behaviour that the participants only **could do**, but **did not** do in their everyday life. However, from a structural perspective, motility can be seen as a ("Bourdieuian") capital that can be exchanged for other kinds of capitals such as social, cultural or economic (Kaufmann, 2005). In other words, a high level of motility meant better

opportunities to gain access to various parts of society. A low level of motility caused by acquired cognitive disabilities thus meant fewer opportunities to gain access to various parts of society. Consequently, opportunities to be mobile and the usability of public transport are important fields to focus on in order to achieve equal opportunities for everybody.

The findings that showed that the participants would avoid using buses at rush hours in order not to disturb other passengers implied that the participants' behaviour was a result of an interaction with their environment. From the interaction perspective, people usually resign themselves to the environment, but if the environmental demands exceed an individual's level of tolerance, the desire to make a change in their situation increases. For example, it may cause people to make changes in their own environment; for instance, they might move to another area (Steinfeld and Danford, 1999). The participants who had replaced their use of buses and trains with the use of other modes of transport, such as the Special Transport Service, can be interpreted as having changed their environment in order to be able to deal with it appropriately. Another way people deal with a situation where the environmental demands exceeds their individual level of tolerance is to adjust themselves to their new situation psychologically by altering their expectations and values (ibid). The statements in Study 2, showing that to use public transport is absolutely out of the question can be interpreted as a psychological adjustment to the situation where people protected themselves from psychological dissonance (Festinger, 1962). Thoughts of using public transport and at the same time not being able to do so brought about psychological dissonance. Since people strive to avoid psychological dissonance, the participants consequently avoided thinking about public transport as that would increase psychological dissonance. That was understandable in the light of the findings in the sub-study (Figure 2) of people's use of public transport post stroke (Wendel, et al., submitted), which showed that individuals with decreased use of public transport, or individuals who no longer use it at all, also had more professionally assessed and self-reported cognitive functional limitations than individuals who continued to use public transport. In addition they also showed a decreased frequency of social activities outside of their homes than individuals whose pattern of the use of public transport was unchanged. When having more cognitive functional limitations and activity restrictions it is possible to assume that our target group preferred



to avoid thinking about public transport in order to avoid psychological dissonance. It could, of course, be attributable to a natural process of ageing, when people tend to lower their expectations (Tornstam, 2005) just as some statements in Study 2 revealed. However, it could also be that there is a concealed need for public transport, the experts descriptions provided some indications that that could be the case.

Turning to planning implications, the results of this thesis gave some ideas on how to plan for mobility, based on the motility of the target group, i.e. planning for individuals' actual needs and wishes for mobility (Beckmann, 2001). That kind of planning could increase mobility, for example by means of public transport, for people living with acquired cognitive functional limitations. Planning for mobility on the basis on motility of the target group, mean to utilize the usability problems defined by the users as a basis for development of more efficient rehabilitation programs, and production of information and educational material directed towards people with acquired cognitive functional limitations. In other words to take measures to show them in beforehand how to use public transport in real environments which, when put in practise, has shown good results (Newbigging and Laskey, 1995). It is especially important for the group at target in Study 2 as individuals with decreased or ceased use of public transport post stroke show more cognitive functional limitations concerning the ability to cope with new environments and situations, i.e. abilities that are crucial for navigating in outdoor environments (Wendel et al., submitted).

Another aspect to take into account when planning for usability in public transport for people with acquired cognitive functional limitations are that the fewer the tasks that demanded attention during the travel chain, the more usable it was. It was noteworthy that tasks that might not cause any usability problems per se constituted hindrances if they appeared simultaneously, frequently or in longer sequences. This underscores the value of the studies presented in this thesis, i.e. importance of adopting a travel chain perspective when studying and planning for people with acquired cognitive functional limitations, while earlier studies only focused in the vehicle per se (Hunter-Zaworski and Hron (1999); Koppa et al., 1998). Even small difficulties, manageable per se, when combined can result in a major hindrance (Stahl, 1997). Adopting the travel chain perspective, accessibility and usability measures targeting people with physical functional limitations are also supportive for people with

acquired cognitive functional limitations, as demonstrated by the findings in both studies. That means, if the accessibility measures already implemented work, they reduce the amount of tasks to be performed in the travel chain, and consequently increase usability also for the target group of this thesis.

The findings that revealed that routes that offered calmer surroundings were preferable and the findings showing that traffic environments were experienced as complex implied that there is a need for intermediate solutions for public transport or Special Transport Service where the environmental pressure is lower (Stähl, 1997) for people with acquired cognitive functional limitations. This suggests that municipalities that have chosen to implement intermediate solutions have taken a step forward towards making public transport more usable for people with acquired cognitive functional limitations. At the same time, it is important to realise that Special Transport Service may be the only option for people with certain kinds and degrees of cognitive functional limitations, e.g. people with very advanced orientation difficulties. However, in addition to lower environmental pressure the results of this thesis show that intermediate solutions have to be experienced as part of the ordinary public transport as the group of target do not want to be treated differently.

The findings also indicated the positive effects of the presence of other people were supported by results in previous studies (Hunter-Zaworski and Hron, 1993). Personal interaction with public transport personnel provided flexible assistance in unique situations. However, in addition to the flexibility that the presence of other people provides, especially the findings in Study 1 indicated that it was important that other people, such as bus or train personnel not only were present, but that they also showed understanding and were experienced in the target groups' special needs, enabling them to give proper assistance. In other words, knowledge about individuals with acquired cognitive functional limitations should be part of the education programme for personnel at trains and buses, which for example is the case in the plan of action for increasing accessibility in train transport (Fahlgren and Lindqvist, 2004). Equally important is that the users know that the personnel have this knowledge. This is an aspect that should be included in information and educational material directed towards people with acquired cognitive functional limitations, which were mentioned above.

Turning to some methodological reflections, as this is a novel and largely understudied field of research, the decision to use an explorative approach, starting from experts' perspective going to users' perspective was fruitful. The studies complement each other as the results obtained in Study 1 were based on an "outside" perspective while study 2 provides an "inside" perspective.

Mixed groups of experts representing diverse professions were advantageous as they triggered each other's ideas and knowledge about areas of discussion that a researcher new to the field would not be aware of (Wibeck, 2000). It was useful to let the focus group interviews with experts begin our approach as their comprehensive experiences of everyday life for the target group, resulted in a comprehensive picture of mobility to start from. Focusing the user perspective, by semi-structured interviews in a second step, gave in deep descriptions of details in the experts' comprehensive picture. For example, the focus groups with experts provided that certainty gave confidence to cope with unpleasant feelings in general such as stress, fear or anxiety. However, the semi-structured interviews with the target group provided deep and detailed descriptions on what it felt like in certain situations with using public transport. In other words, the methods used were complimentary.

As the intention was to explore the situation for people with acquired cognitive functional limitations, it could be considered as disadvantageous to not begin by directing the target group themselves, i.e. in the very end it is the people with acquired cognitive functional limitations who are the specialist on their own situation. However, due to the shortages in previous studies, where often this group of people is excluded (Grönvall et al., 2004; Andersson et al. 2000; Davidsson, 2003; MAPLE, 2003), and due to the potential communication problems with people with acquired cognitive functional limitations, it was helpful to begin learning about the situation for this group via experts. The focus group interviews in Study 1 revealed potential challenges in communication with the target group, and ideas on how to deal with such challenges in forthcoming studies.

It was advantageous to have valid data on the individuals' functional limitations in Study 2 based on both professionally assessed and self-reported data (Wendel et al., in press 2008). This is very unusual in

research on public transport; however, it was possible thanks to the interdisciplinary co-operation in the research project (VINNOVA dnr 2001-06707). At the same time, it was not possible to use this data more specifically in the kind of analysis applied in the studies presented in this thesis. That is the interviews with the experts as well as with the target group intended to grasp subjective experiences. In particular the target group described their use of public transport as a transaction between person-environment-activity in a very integrated way. It is neither possible nor desirable to separate the components of usability, i.e. based on the two studies presented it is not possible to verdict on which types of cognitive functional limitations that are most negative for use of public transport. However, in another study within the research project (Wendel et al., submitted) it has been studied more. One important limitation in Study 2 is that only people with stroke were interviewed as representatives for people with acquired cognitive functional limitations, i.e. we can not know anything about people living with acquired cognitive functional limitations due to e.g. learning disabilities or dementia. However, functional limitations of the same kind can appear as consequences of a range of different diagnoses, and therefore the findings presented might be transferable to other user groups, while this remains to be further studied.

## *Future research*

Compared to earlier studies, often excluding persons with acquired cognitive functional limitations, the results of the studies, presented in this thesis, constitute sound knowledge for future research on the public transport situation for this group of people. Future studies must focus the usability in real environments. By the use of participant observations in combination with semi-structured interviews, material on usability for people with acquired cognitive functional limitations, still using public transport after having had a stroke, have been collected within the research project (Figure 2). However, the analysis of this material should also focus environmental aspects.

The studies have showed that, from the perspective of people with acquired cognitive functional limitations, it is important to plan public transport from a travel-chain perspective. However, still there is still a need for further research on what possibilities there are to simplify or reduce tasks in the travel chain. This is intimately connected to the need to further investigate what kind of needs this group of people has, when it comes to assistance from public transport personnel, and how this is possible to implement. Finally, especially the participants in Study 2, were homogeneous and that implies a need to, in future research, focus on and develop, methods to study the situation for groups of people with acquired cognitive functional limitations that have not been included here. This could for example be people with communication problems due to aphasia, people with problems with the Swedish language and younger people with cognitive functional limitations, as their needs and wishes for public transport can be different from the group focused especially in Study 2.

## *Conclusions*

The results of the two studies complement each other and constitute useful insights into mobility and reasons for not using public transport among persons living with cognitive functional limitations. The main conclusions are:

Mobility in public environments and use of public transport are activities that are difficult to manage for people with acquired cognitive functional limitations, and consequently activities that they might not do very frequently. Within the target group, people handle those difficulties and low frequency mobility differently. When some psychologically adapt to a low frequency of mobility, i.e. they say that they have no use for public transport; others change their environment to be able to maintain mobility and to maintain use of public transport, for example they decide to use Special Transport Service instead of using ordinary public transport.

The environment provides challenges for mobility and use of public transport for people with acquired cognitive functional limitations. They are particularly vulnerable to the complexity in traffic environments. Therefore, for supporting mobility for them, it is important to understand how they consider their own possibilities for mobility. For those who are not able to increase their mobility in the sense of public transport, but still express a need for mobility, Special Transport Service must stay as an alternative.

Regarding accessibility and usability of the public transport system our first conclusion is that implementations that facilitate use of public transport for people with physical functional limitations also facilitate use of public transport for people with acquired cognitive functional limitations. Therefore, for people with acquired cognitive functional limitations it also is of importance to plan public transport system applying a travel chain perspective. For this group of people, every extra task imposed in a travel chain constitutes a potential obstacle even if each single task is manageable by itself. Of particular importance is the information given on beforehand about the public transport system – the journey starts already at home. The members of the target group need this kind of information in order to decrease uncertainties, which can be

decisive for whether they take the step to use public transport or not. Further, people with acquired cognitive functional limitations are very dependent on that personnel at trains and buses are supportive, offer flexibility and have knowledge about and understanding for how to support user groups with various needs, or in other words, that they give individual support to different users. Taking this into account, one further conclusion is that intermediate solutions are good solutions to enable use of public transport for people with acquired cognitive functional limitations. They want to live independent lives and many of them would like to use public transport, but ordinary public transport environments are often too demanding related to their functional capacity.

Going outside the field of public transport planning, within other disciplines the development of efficient rehabilitation programs and providing information and educational material directed to people with acquired cognitive functional limitations are essential if one wants to support their use of public transport. For some persons within the target group, the very thought of public transport constitutes a hindrance.

Compared to earlier studies, that often excludes persons with acquired cognitive functional limitations the results of the studies, presented in this thesis, constitute an improved knowledge base for future studies dealing with this special group.

## *Summary*

Mobility, in the sense of people's everyday movement from one point to another, for example, walking or using bus/car/train, is a practical necessity in everyday life in order to reach community facilities, go to the working place or to school. As areas for housing, areas for service or work have been separated from each other, mobility that allows people to cover these distances becomes more and more important. In order to understand people's actual mobility it is important to understand their intentions or reasons for being mobile.

One type of mobility is use of public transport. Planning for public transport accessible to all is a generally agreed necessity both according to Swedish policy as well as many other countries' policies. Accessibility is a concept describing the encounter of an individual's or group's functional capacity and the demands of the physical environment, and implies restrictions and opportunities for behaviour. While accessibility is mainly objective in nature as it refers to fulfilment of official norms and standards, the concept usability is primarily subjective in nature, as it refers to the user's subjective evaluations. Usability integrates an activity component, which contains a description of the activity that is to be performed by an individual or group in a certain environment. An accessible environment it is not necessarily a usable environment, but a usable environment is always accessible. Including a travel chain perspective in planning for a usable public transport system is of importance. The travel chain perspective stresses the importance of not separating the stay onboard the vehicle from the other parts of the journey; the search for information regarding transport possibilities, the way to and from the vehicle, changes at terminals etc. If one link in the chain is missing, the whole chain will be broken.

Even though the arrangement of land-based public transport Sweden, here referring to train and bus transport, follows the principles of travel chain perspective and is arranged in various ways to suit the needs of various user groups, still people with functional limitations face restrictions in their use of public transport. However, most often research on accessibility issues has focused on individuals with physical functional limitations and older people, while the situation of people with acquired cognitive functional limitations is generally overlooked. Apparently there



is a need to investigate mobility and especially the situation in public transport for persons living with acquired cognitive functional limitations.

The overall aim of this work was to explore and gain deeper insight into and understanding for mobility in public environments among people living with acquired cognitive functional limitations and reasons why they not use public transport.

The studies presented in this thesis are two among several sub-studies accomplished within a large-scale interdisciplinary research project. Methods used in those two studies were focus group interviews and semi-structured interviews. In Study 1, focus group interviews were performed with *experts* here referred to people who possessed knowledge about everyday mobility in general among people living with acquired cognitive functional limitations, such as handling officers, occupational therapists, people representing special interest organisations etc. In Study 2 the users' perspective was focused, using semi-structured interviews. The participants were selected from a database created within the interdisciplinary research project. The database comprised individuals with stroke and contained quantitative data on professionally assessed and self-reported acquired cognitive functional limitations, physical functional limitations and use of mobility devices, depression symptoms and activity performance. Individuals who, according information in the database, had cognitive functional limitations and had been public transport travellers before they got their stroke were asked for participation.

The central themes for the focus group interviews (Study 1) were mobility and transport styles. The first question concerned everyday life of the people with acquired cognitive functional limitations in general, followed by questions that increasingly zoomed in on mobility and the use of different transport modes. The findings from the focus group interviews constituted a basis for the interview guide developed in Study 2, i.e. the semi structured interviews. The themes in the interview guide were mobility in general; hindering and enabling environmental factors when using public transport; strategies if one wanted to use public transport; future use of public transport; and ideal public transport. The semi-structured interviews were performed as conversations with open-ended questions.

Both the focus group interviews and the semi-structured interviews were analysed using qualitative content analysis. The analysis of the focus group interviews (Study 1) resulted in the core category “Mobility: an activity that can not be regarded as a matter of course”, and the semi-structured interviews in Study 2 resulted in the core category “The use of public transport: A challenging activity, either under consideration or out of the question”.

The findings in Study 1 showed that mobility in public environments among persons living with acquired cognitive functional limitations varied considerably. To maintain mobility meant facing external challenges. For example, managing the complexity of traffic environment was described as constituting serious external challenges. Further, people with acquired cognitive functional limitations had to deal with internal struggles, such as feelings of anxiety, uncertainty, stress or fear in order to maintain mobility. One important way of dealing with such feelings was, according to the experts, to reach certainty/confidence about a situation and what activities were about to happen. Lastly, the findings in Study 1 showed that within the group of people with acquired cognitive functional limitations, there were those who choose a low level of mobility and those to whom a low level of mobility was not a choice but they strongly expressed a wish to leave home every now and then, even though it was difficult.

The findings in Study 2 showed that some individuals with acquired cognitive functional limitations had distanced themselves from the very thought of travel by bus or train again after having stroke, while others were prepared to consider using public transport now or at some time in the future. The participants in Study 2 considered some environments as challenging if to use public transport. Especially environments that set up serial tasks to perform in a short amount, was expressed as too demanding. An example was the situation that arouse when getting on and off a bus, such as standing in a queue, managing the payment process, finding a seat, and in addition in some cases bringing a rollator onboard. Additionally the participants in Study 2 considered the presence of other people as influencing their use of public transport. For example they did not want to disturb or irritate other passengers, nor would they want to be disturbed by others. In order to avoid situations where the participants experienced themselves as disturbing others, they

considered using public transport at other times than rush hours, if possible.

The results of this thesis showed that the external environment created various challenges both for mobility in general and for use of public transport for people with acquired cognitive functional limitations. The findings indicated usability problems in public transport for people with acquired cognitive functional limitations. Turning to the occurrence of accessibility problems, in Study 2 the information at hand on the personal component was professionally assessed, while we lack such data on the environmental component of accessibility. That is, based on the current study, we do not have any information about the occurrence of environmental problems expressed in terms of official norms and guidelines. Anyway, it is a noteworthy quality of Study 2 that the sample was defined and selected based on assessment of the participants' functional limitations. For that reason the results of this study differ from other studies within the field of traffic planning as they are often lacking a detailed description on the personal component, which is required in order to be able to verdict on accessibility or usability.

The findings in both studies implied that it was not always the cognitive functional limitations per se that determined the individual's mobility. Alternatively it could be the individual's interpretations of his/her situation, needs and wishes for mobility that were decisive for how and to what degree mobility would actually take place. In order to reach a more comprehensive picture of mobility of people with acquired cognitive functional limitations, it is important not only to study their real mobility, but also their intentions or reasons for being mobile.

Further the findings in Study 2 demonstrated that environments, which set up serial tasks, were especially challenging. Every extra task imposed in a travel chain constituted an obstacle even if each task was manageable. The fewer the tasks that demanded attention during the travel chain, the more usable it was. That means, for people with acquired cognitive functional limitations it is of importance that the public transport system is planned in a travel chain perspective.

The findings in both studies that indicated the positive effects of the presence of other people, such as personnel at buses and trains, is supported by earlier studies showing that technical solutions were not the

best solution for this group of people. Rather personnel offer flexible assistance in unique situations. In addition, especially the findings in Study 1 indicated that it was important that other people, such as bus or train personnel not only were present, but that they also showed understanding and were experienced in the target groups' special needs, enabling them to give proper assistance. Equally important the target group experienced them as cognisant and thus could trust them.

This work contributes to understanding of the present situation in public transport for individuals with acquired cognitive functional limitations. Further, compared to earlier studies, often excluding persons with acquired cognitive functional limitations, the results of the studies, presented in this thesis, constitute sound knowledge as a basis for future studies.

## *Summary in Swedish / Svensk sammanfattning*

Mobilitet är ett mångfacetterat begrepp, men definieras här som människors vardagliga förflyttning från en plats till en annan, till exempel, genom att gå eller att använda buss/bil/tåg. Mobilitet är en praktiskt nödvändigt för att få vardagen att gå ihop, d.v.s. för att nå samhällets faciliteter, för att komma till arbete eller skola. Eftersom bostadsområden, service och arbetsplatser separeras från varandra, måste människor vara mobila för att kunna förflytta sig mellan dessa platser. För att förstå den mobilitet som människor verkligen utför är det viktigt att också förstå deras intentioner och anledningar till varför de valt att organisera sin mobilitet på det sättet.

En typ av mobilitet är att använda kollektivtrafik. Att ta hänsyn till tillgänglighet i planeringsprocessen för kollektivtrafik är en självklarhet både i Sverige och i många andra länder. Tillgänglighet är ett begrepp som beskriver mötet mellan en individs eller grups funktionella kapacitet och kraven från den fysiska miljön. Tillgänglighet framförallt är en objektiv beskrivning då det refererar till officiella normer och standards. Å andra sidan är begreppet användbarhet till största del subjektivt, då det refererar till användarens subjektiva bedömningar. Användbarhet integrerar en aktivitetskomponent, d.v.s. en beskrivning av aktiviteten som ska utföras av en individ eller grupp i en viss miljö. En tillgänglig miljö är inte nödvändigtvis en användbar miljö, men en användbar miljö är alltid tillgänglig. Att inkludera ett reskedjersperspektiv i planering för att göra kollektivtrafiksystemet användbart är viktigt. Reskedjersperspektivet betonar vikten av att inte skilja vistelsen ombord på fordonet från andra delar av resan; informationsökning om transportmöjligheter, vägen till och från fordonet, byten o.s.v. Om en länk i kedjan inte fungerar så kommer hela kedjan att brytas.

Även om planeringen av markbunden kollektivtrafik i Sverige, här åsyftas buss och tåg, följer principerna för reskedjersperspektivet och är utformat på olika sätt för att passa olika användargrupperns behov, så möter personer med funktionella begränsningar restriktioner när de använder kollektivtrafik. Det finns mycket forskning om tillgänghetsläget i kollektivtrafiken för personer med fysiska funktionella begränsningar och

äldre människor men situationen för personer med förvärvade kognitiva funktionella begränsningar är generellt förbisedd. Uppenbarligen finns det ett behov att utforska mobilitet och speciellt situationen i kollektivtrafiken för personer med förvärvade kognitiva funktionella begränsningar.

Det övergripande syftet med detta arbete var att utforska och få djupare insikt i och förståelse för mobilitet i offentliga miljöer för personer med förvärvade kognitiva funktionella begränsningar och anledningar till varför de inte använder kollektivtrafik.

De studier som presenteras i detta arbete är två av flera delstudier som genomfördes inom ramarna för ett stort interdisciplinärt forskningsprojekt. Metoder som användes i dessa två studier var fokusgruppsintervjuer och semistrukturerade intervjuer. I Studie 1 genomfördes fokusgruppsintervjuer med *experter*; med andra ord personer som hade kunskap om vardagsmobilitet generellt för personer med kognitiva funktionella begränsningar såsom bl.a. biståndshandläggare, arbetsterapeuter och representanter från handikapporganisationer. I Studie 2 fokuserades användarperspektivet via semistrukturerade intervjuer. Deltagarna valdes ut från en databas som skapats i en annan delstudie inom det interdisciplinära forskningsprojektet. Databasen bestod av personer med stroke och innehöll kvantitativa data om professionellt och egenbedömda kognitiva funktionella begränsningar, fysiska funktionella begränsningar och användning av förflyttningshjälpmedel, depressionssymptom och aktivitetsutförande. Personer som, enligt informationen i databasen, hade kognitiva funktionella begränsningar och hade varit kollektivtrafik användare innan de fick stroke tillfrågades om deltagande i studien.

De centrala temana i fokusgruppsintervjuerna (Studie 1) var mobilitet och transportsätt. Den första frågan handlade om vardagslivet och sedan följde stegvis fokus mot mobilitet och användning av olika transportsätt. Resultaten från fokusgruppsintervjuerna utgjorde ett underlag för utvecklingen av intervjuguiden som användes i Studie 2, d.v.s. de semistrukturerade intervjuerna. Intervjutemana i intervjuguiden var: generell mobilitet; hindrande och underlättande omgivningsfaktorer vid användning av kollektivtrafik; strategier för att använda kollektivtrafik;

framtida användning av kollektivtrafik; och ideal kollektivtrafik. De semistrukturerade intervjuerna liknade samtal med öppna frågor.

Analysen av både fokusgruppsintervjuerna och de semistrukturerade intervjuerna skedde i form av kvalitativ innehållsanalys. Analysen av fokusgruppsintervjuerna i Studie 1 resulterade i huvudkategorin "Mobilitet: en aktivitet som inte kan betraktas som en självklarhet" och de semistrukturerade intervjuerna i Studie 2 resulterade i huvudkategorin "Användning av kollektivtrafik: En utmanande aktivitet som är nära eller långt ifrån i tanken".

Resultaten i Studie 1 visade att förekomsten av mobilitet i offentliga miljöer varierade bland personer med förvärvade kognitiva funktionella begränsningar. För att hålla igång sin mobilitet möttes personer med förvärvade kognitiva funktionella begränsningar av yttre utmaningar. En speciell yttre utmaning utgjordes t.ex. av komplexiteten i trafikmiljöer. Vidare måste personer med förvärvade kognitiva funktionella begränsningar övervinna inre strider, såsom oros känslor, osäkerhet, stress och rädsla för att behålla sin mobilitet. Ett viktigt sätt att hantera sådana känslor var, enligt experterna, att skaffa sig vetskap om vad som kommer att hända under ren hel resa för att känna säkerhet inför situationen. Slutligen, visade resultaten i Studie 1 att bland gruppen personer med förvärvade kognitiva funktionella begränsningar fanns det de som valde att inte vara så mobila, medan andra kämpade för att kunna ta sig hemifrån då och då även om det var svårt.

Resultaten i Studie 2 visade att det, bland gruppen personer med förvärvade kognitiva funktionella begränsningar, både fanns de som hade distanserat sig själv från tanken på att använda buss eller tåg igen efter att de fått stroke; och det fanns de som övervägde att börja använda buss eller tåg igen ganska snart eller längre fram. Deltagarna i Studie 2 ansåg att delar av miljön var en utmaning att hantera ifall de skulle använda kollektivtrafik. Speciellt miljöer som gav upphov till situationer där man skulle utföra flera saker under en mycket kort tid beskrevs som krävande. Ett exempel som gavs var påstigning och avstigning på en buss, d.v.s. stå i kö, hantera betalningsprocessen, hitta ett säte och dessutom i vissa fall ta ombord sin rollator. Dessutom menade deltagarna i Studie 2 att närvaron av andra människor påverkade deras användning av kollektivtrafik. Till exempel ville de inte störa eller irritera andra passagerare, inte heller ville de själva bli störda av andra. För att undvika

situationer där deltagarna upplevde att de störde andra människor, så övervägde de möjligheten att använda kollektivtrafik på andra tider än rusningstider om det var möjligt.

Resultaten i detta arbete visade att den yttre miljön skapade olika utmaningar både för deras mobilitet generellt och om det skulle använda kollektivtrafik. Resultaten indikerar användbarhetsproblem i kollektivtrafiken för personer med förvärvade kognitiva funktionella begränsningar. Om vi ser till förekomsten av tillgänglighetsproblem, finns det i Studie 2 professionellt bedömd information om personkomponenten, medan det saknas sådan information om miljökomponenten. Det betyder att studien inte ger någon information om förekomsten av miljöproblem uttryckt i termer av officiella normer och riktlinjer. Ändå finns det en anmärkningsvärd kvalitet i Studie 2 eftersom urvalet definierades och valdes på basis av bedömningar av deras funktionella begränsningar. Därför skiljer sig resultaten i denna studie från andra studier inom trafikplaneringsområdet eftersom de ofta saknar en ordentlig beskrivning av personkomponenten, som är nödvändigt för att kunna uttala sig om tillgänglighet eller användbarhet.

Resultaten i båda studierna indikerar att det inte alltid är de kognitiva funktionella begränsningarna i sig som avgör individens mobilitet. Det kan istället vara individens tolkningar av sin situation, sina behov och önskemål om mobilitet som är avgörande för om och i vilken omfattning deras mobilitet tar form. För att få en mer komplett bild av mobilitet för personer med förvärvade kognitiva funktionella begränsningar, är det viktigt att inte bara fokusera den mobilitet som faktiskt sker, utan också vilka intentioner och anledningar det finns till att den tar form eller inte.

Vidare visade resultaten i Studie 2 att miljöer, som ger upphov till många uppgifter på samma gång var speciellt utmanande. Varje extra uppgift som reskedjan framkallade utgjorde ett hinder även om varje uppgift i sig var möjlig att hantera. Ju färre uppgifter som krävde uppmärksamhet under reskedjan, desto mer användbar var den. Det innebar att för personer med förvärvade kognitiva funktionella begränsningar var det av extra vikt att kollektivtrafiken är planerad med ett reskedjeperspektiv.

Resultaten i båda studierna indikerade att närvaro av andra människor, såsom personal på bussar och tåg, får stöd i tidigare studier som visade att tekniska lösningar inte var den bästa lösningen för denna grupp. Personal



var bättre då det kunde ge flexibel assistans i unika situationer. Vidare visade resultaten, speciellt i Studie 1, att personal inte bara skulle finnas utan även visa förståelse och ha erfarenhet av de speciella behov som personer med förvärvade kognitiva funktionella begränsningar har, så att de kunde ge rätt sorts assistans. Lika viktigt var det att personer med förvärvade kognitiva funktionella begränsningar också visste att personalen hade den kunskapen så att de kunde lita på dem.

Detta arbete bidrar till förståelse för den nuvarande situationen i kollektivtrafiken för personer med förvärvade kognitiva funktionella begränsningar. Vidare, jämfört med andra studier som ofta exkluderar personer med förvärvade kognitiva funktionella begränsningar, så utgör resultaten i studierna som presenteras i detta arbete en gedigen kunskapsbas för vidare studier.

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Computer software:  
MindManager® 2002 Enterprise Edition



# Paper 1

# A picture of mobility in public environments

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## The situation for people with cognitive functional limitations

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## ***ABSTRACT***

This paper is based on a study aiming to explore, from experts' perspectives, mobility in public environments among people with acquired cognitive functional limitations (target group). Focus group interviews were performed with experts, i.e. individuals who were experienced in the everyday life of the target group. According to the experts, mobility for the target group meant that they had to keep external and internal critical challenges at a manageable level, and that mobility varied from those who were mobile to those who preferred, or had to accept, a sedentary situation. From a planning perspective it is important to learn how the members of the target group consider their possibilities for mobility.

## ***Introduction***

Mobility is most often thought of as a natural part of our everyday life; nonetheless, mobility is limited for people with functional limitations. Mobility limitations among individuals with functional limitations receive more and more attention in society, although mostly the mobility situation among people with physical and visual functional limitations is highlighted, while the situation for individuals with cognitive functional limitations has not received much attention. In the present study, a qualitative approach was adopted in order to explore mobility among people with acquired cognitive functional limitations, hereafter referred to as the target group. This study is part of an ongoing interdisciplinary research project at Lund University in Sweden (VINNOVA dnr 2001-06707).

## ***Background***

Mobility in the sense of moving about in different places, i.e. an observable physical, spatiotemporal process of moving from one point to another (SIZE, 2003), for example to walk, to use a bicycle, or travel by train, bus or car, is most often seen as a natural and important part of people's everyday life. We need to go to work, to school, visit friends or go shopping. Much is pointing in the direction that mobility is an important part of our Western society as areas for housing, areas for service or other facilities have been separated from each other, i.e. distances between them have grown during recent years (SOU, 2003:67). Mobility that permits one to cover these distances becomes more and more important and is also a necessity for societal participation (see for example Mollenkopf et al., 2004; Carlsson, 2002). Whether spatiotemporal mobility takes place or not can be a consequence of the interaction between individual competence and the environment (SIZE, 2003), as described by Lawton and Nahemow (1973). From this perspective, an activity (in this case mobility) can only be performed when an individual's capacity and environmental pressure are balanced, i.e. the adaptation level is reached. When the individual capacity decreases and the environmental pressure becomes too high, negative consequences may occur, and conversely, if the environmental pressure is too low an individual may experience deprivation.

To live with functional limitations often means limited mobility (Imrie, 2000; Ståhl, 1993). Although societal efforts to promote mobility, in the sense of transport, among individuals with functional limitations are evident (see for example Carlsson, 2002; CEMT, 2004; Delén and Magnusson, 2002; Statskontoret, 2000; Wretstrand, 2003), major challenges remain. To date, most interventions have focused on physical functional limitations, while people living with cognitive functional limitations are seldom mentioned as a target group for efforts to promote mobility (MAPLE, 2003).

Cognition denotes the acquisition, storage, transformation and use of knowledge and includes a range of mental processes that operate when an individual acquires new information (Matlin, 2003). Having a brain injury, either innate or acquired, implies that the mental processes have less capacity to acquire, store, transform and use information. A brain injury can result in difficulties to remember, to orientate in time and space, to solve co-ordination problems, to express oneself verbally, etc (Abreu and Togliola, 1987), i.e. cognitive functional limitations. Functional limitations are restrictions in an individual's ability to perform basic physical or mental actions in daily life (Verbrügge and Jette, 1994). People with cognitive functional limitations often live with other functional limitations, such as physical or visual, in combination (Abreu and Togliola, 1987). Due to the difficulties that cognitive functional limitations may entail, it is a challenge to develop research methods suitable for studies involving individuals with cognitive functional limitations. For example, there may be uncertainties about how to communicate with an individual who has difficulties expressing him/herself verbally, i.e. it is essential to carefully develop research methods taking into account eventual difficulties in communication with the target group.

On the international arena there are reports from North America focusing on cognitive functional limitations related to the use of buses and in public transport in general that offer suggestions for how to solve potential problems (Hunter-Zaworski et al., 1999; Koppa et al., 1998). However, the results and guidelines of the reports rest upon the situation more than 10 to 15 years ago. Over ten years ago a case study demonstrated that a stepwise method for training people living with brain injuries had some potential to assist them to start using buses again

(Newbigging, et al., 1995). Other literature (Logan et al., 2004) focused on attitudes and barriers in public transport experienced by individuals who have had a stroke. As public transport is changing over time, for example as a consequence of the advances in technology, the results and guidelines from older studies may not correspond to the present situation.

## ***Aim of the study***

The aim of this study was to explore, from experts' perspectives, mobility in public environments among people with acquired cognitive functional limitations.

## ***Method***

The method used in this study was focus group interviews with individuals who had systematic contact with people living with cognitive functional limitations, employing a qualitative approach. Focus group interviews (Wibeck, 2003; Krueger, et al., 2000) are interviews with small groups of people who talk about a certain topic. Focus group interviews can be structured either strongly or weakly. Weakly structured interviews are preferable for explorative research, which was the case for this study.

## ***Selection of participants***

The participants in this study were informants, i.e. they provided information about a phenomenon rather than their personal thoughts about it (Kvale, 1997). In this study the information-rich individuals chosen (Patton, 1990) were called "experts", here referring to people who have a general view of everyday life for people living with cognitive functional limitations based on experiences of systematic communication and interaction with the target group. The participants should, in a broad sense, contribute to the understanding of people with cognitive functional limitations within society.

The selection procedure aimed at achieving as comprehensive a perspective as possible so, inspired by what Berg (2004) called a quota

sample, a framework for the variety of experts the target group meets was developed (see Table 1). Such experts are, either due to their professional or private interest, in contact with the target group within health and rehabilitation services, including both institutional and non-institutional level; public authorities; political work; or special interest organisations. In addition, relatives and friends were defined as experts as in many cases they take care of individuals with cognitive functional limitations in their daily context.

**Table 1** Framework for the sampling of experts

<b>Different categories of experts in contact with individuals with cognitive functional limitations</b>				
<b><i>Health and rehabilitation services</i></b>	<b><i>Public authorities</i></b>	<b><i>Political work</i></b>	<b><i>Special interest organisations</i></b>	<b><i>Informal care and support</i></b>
Occupational therapist	Welfare officer	Lay assessor	Representative from special interest organisation	Relatives
Physiotherapist	Handling officer	Participant in political committees		Friends
Psychologist				
District nurse				
Social worker				
Personal assistant				

On the basis of the framework, lists of names of potential participants were produced. The local telephone directory as well as web site references to municipalities, county councils and public authorities in Scania County, South Sweden, were used to identify contact persons. In addition, snowball sampling was used to reach people in public authorities and special interest organisations. Snowball sampling means that individuals with relevant characteristics for the aim of the study are asked to identify people who possess the same attributes (Berg, 2004).

Potential participants were asked to reply positively if they felt that they fulfilled the criteria for being an expert, namely to have a general view of everyday life for people living with cognitive functional limitations thanks to experiences of daily communication and interaction with the target group.

A total of 27 experts between 30 and 60 years of age participated, three of whom were men. Eleven experts represented health and rehabilitation services, seven represented public authorities and nine represented special interest organisations and lay assessors.

### *Themes for the focus group interviews*

The questions for the focus group interviews were inspired by Morgan's funnel-based interview, which begins "with a less structured approach that emphasises free discussion and then moves towards a more structured discussion of specific questions" (Morgan, 1997:41). The first question concerned the everyday life of the target group in general, followed by questions that increasingly zoomed in on mobility in public outdoor environments and the use of different transport modes. The central themes were mobility, transport modes used and evaluation of various transport modes related to the difficulties caused by cognitive functional limitations. Four topical questions were formulated: 1) "What does a normal day look like for an individual with cognitive functional limitations?" 2) "What does this group's mobility look like?" 3) "How does it work for an individual with cognitive functional limitations to walk, use a bicycle or travel by train, bus or car?" and, finally, 4) "What is a good way and a bad way of moving around, and why?"

### *Procedure*

The first contact with the potential participants was made by means of an introductory letter with a short presentation of the project and the aim of the focus group interviews. Two focus groups were initially shaped. According to the literature, a saturation point is reached when the qualitative interviews do not provide any more new information and there is consequently no point in conducting any more interviews (Wibeck, 2002). As the moderating team (the first and second authors) considered that the saturation point had not been reached after two focus



group interviews, another two focus group sessions were conducted. Four focus group interviews were conducted during a five-month period.

The moderating team consisted of a moderator and an assistant who alternated in their respective roles. The task for the moderator was to pose the questions and to support the discussion by encouraging the participants to use their own words and categorisations (Stewart and Shamdasani, 1990). The moderating team also made sure that the focus group interview was not dominated by one or two participants.

Each focus group session began with a reminder of the purpose of the project, followed by the interview. The four topical questions had been written down on a flip chart in advance. As the moderator posed each question, he/she displayed the relevant flip chart page to the group. The assistant made notes and sometimes asked questions for further clarification. In addition, the interviews were recorded and subsequently transcribed. Each focus group interview took about two hours.

## *Analysis*

The focus group interviews were analysed by means of content analysis (Patton, 1990; Flick, 2002), striving to understand what the participants were talking about. It was an inductive analysis process (Patton, 1990), i.e. the patterns, themes and categories appeared from the material, so there is not a pre-determined/certain theory that steers the analysis process. In such as process, research starts from being as little dependent as possible, then successively, the data gained during the research process constitute basis for building a theory.

The transcribed interviews were firstly read though with the intention of grasping an overall picture of what they were about. This was followed by an open coding<sup>3</sup>, line by line, constantly comparing the codes. The codes were written on post-it notes and organised and re-organised on a notice board, resulting in identification of similarities and a number of codes showing a common pattern. The computer software MindManager® 2002 Enterprise Edition was used to sort the first raw draft of the structure of the categories. In accordance with the qualitative approach, the analysis process introduced theoretical angles from which

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<sup>3</sup> Coding means giving a name to a phenomenon or event. (Starrin, 1996)

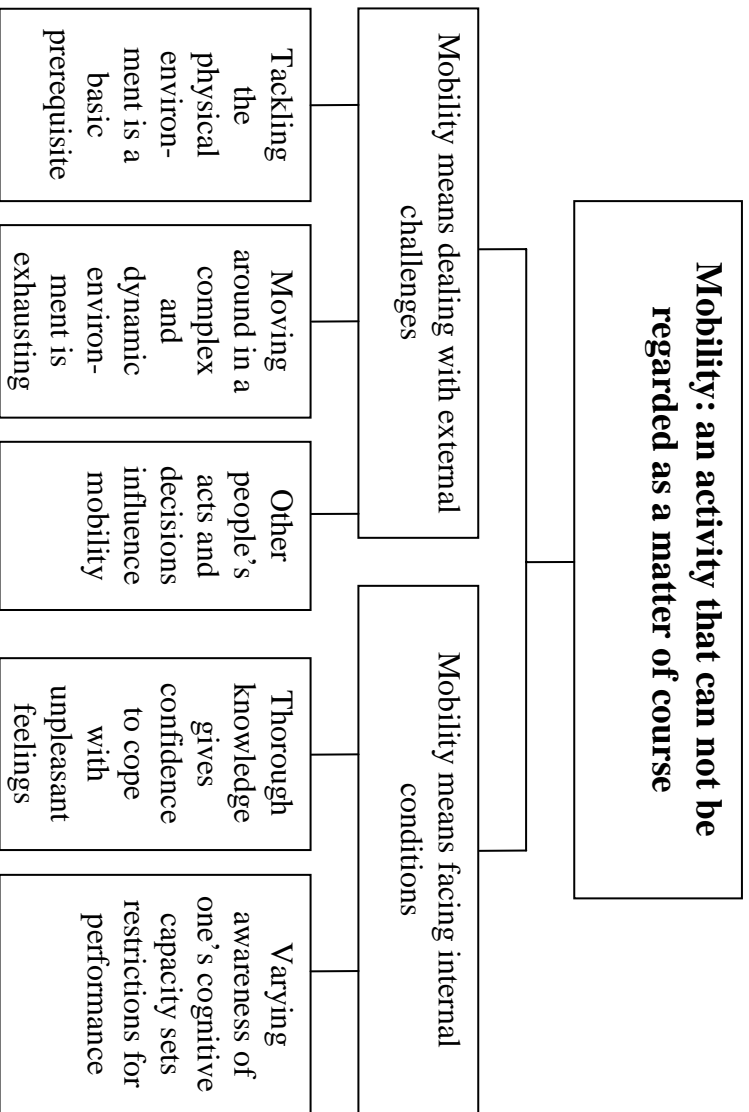
to view the results, complementary to those reflected upon at the prospect of the study.

## *Findings*

The experts had different views of the mobility situation for people with acquired cognitive functional limitations. According to the experts, the level of mobility in public outdoor environments varied considerably within the target group. The experts had met individuals who had chosen a low level of mobility and who saw it as an opportunity to slow down or to spend more time together with the family. However, the experts also had met individuals to whom low mobility was not an active choice, but who had accepted a sedentary situation. Contrary to the individuals who accepted a low level of mobility, the experts emphasised that there were those who strongly expressed a wish to leave home every now and then, even though it was difficult:

“... this is an individual who has contacted me and that means that he thinks that he can not manage on his own – he wants help with some things, and it is mostly about being able to go out”.

Those who wanted to maintain mobility and made efforts to do so had to deal with external challenges in the public environment, they also had to face internal conditions that either promoted or restricted mobility, according to the experts. A core category “Mobility: an activity that can not be regarded as a matter of course” appeared, with two main categories: “Mobility means dealing with external challenges” and “Mobility means facing internal conditions” (see Figure 1).



**Figure 1** Overview of the main category “Mobility: an activity that can not be regarded as a matter of course” and its subcategories

## ***Mobility means dealing with external challenges***

According to the experts, public environments bring forth external challenges that people with cognitive functional limitations are more or less able to manage. In addition, cognitive functional limitations can mean that strength and stamina vary from one day to another. Consequently, people with cognitive functional limitations can cope with external challenges and maintain mobility one day but perhaps not the other. The different types of external challenges that the target group faces are reflected in three sub-categories: “Tackling the physical environment is a basic prerequisite”, “Moving around in a complex and dynamic environment is exhausting” and “Mobility is influenced by other people’s acts and decisions”.

### **Tackling the physical environment is a basic prerequisite**

Since physical functional limitations often appear in combination with cognitive functional limitations, the most basic condition for maintaining mobility was, according to the experts, well designed physical environments – both public outdoor environment such as pavements as well as in vehicles. The experts mentioned that individuals living with cognitive functional limitations might bump into high pavements when they are out walking, or they may encounter problems when trying to board a bus with high steps. For example, brain injury may give paralysis in either the right or left half of the body. An individual living with this kind of paralysis can only control the other half of the body, and that makes it difficult to lift the paralysed part of the body over levelled surfaces. Further, powered wheelchairs are often used by individuals with cognitive functional limitations. For example the experts described that using powered wheelchair every second day was a strategy to keep up mobility in spite of the fact that their stamina could vary from day to day. Wheelchair ramps to board buses are thus a prerequisite if the bus is to be an alternative mode of transport and thereby support mobility:

“Bus – if it’s possible to take a wheelchair onboard, then one or two could go by bus. Train – if you have a wheelchair ramp and assistance, then you can manage.”

## **Moving around in a complex and dynamic environment is exhausting**

The experts meant that other types of external challenges, i.e. complexity, dynamic and narrow time margins in traffic contexts, constituted very problematic situations for the target group. Cars, cyclists and pedestrians are constantly moving, traffic lights are changing, buses and trains have tight schedules to keep to, etc. In order to manage eventful contexts, the user is forced to quickly sort out the most important information from the large amount of information given. For individuals with cognitive functional limitations, the experts made clear that this could be an almost impossible task, since this group of people requires calmness to cope with decision-making on the basis of a lot of information.

One type of dynamic environment with narrow time margins, which the target group may encounter, was large bus terminals where several buses were gathered at the same spot at the same time. One expert described the situation for a man living with cognitive functional limitations who got confused when several buses appeared. He tried to find out which one to take by running from one bus to the other, asking on each bus about its direction. He did not manage this challenge, so he missed his bus. Further, the experts considered how suitable it is for individuals with cognitive functional limitations to drive a car or bike in traffic environments. The experts concluded that if the user can manage only one task at a time, such as keeping track of red and green lights, he/she may not be able to control a vehicle with great speed and power and at the same time pay attention to what is happening around him/her in traffic. One of the experts described a possible scenario for one of her patients who:

“...doesn't look to the side and doesn't notice the traffic. And what can happen – and it's relevant in all contexts...if there's too much information and so on, – then patients panic if there's too much at one time. So they need a bit of peace and quiet.”

One example of complexity mentioned by the experts was when a bus trip includes changes from one bus or train to the other, forcing the user to be alert all the time. For an individual with cognitive functional limitations who easily gets mentally exhausted, it is a challenge to handle several tasks one after another. A situation that requires change of vehicle in public transport could cause exhaustion or chaos:

“What is bad [when travelling] is if you need to make a change. If it’s possible to go from A to B without interruption, whether it’s by bus or taxi or train, things are ok, but what gives trouble is the change, because this is where it gets sticky.”

From this perspective, the experts concluded that use of transport modes such as private car, taxi, Special Transport Service or public transport that goes from door to door facilitates mobility. However, the experts emphasised that in many cases the target group actually can manage each task per se, but each task takes energy and decreases the capacity for managing the next. A consequence of this may be that an individual with cognitive functional limitations may not be able to take part in the activity that was the purpose of the journey as he/she will be too exhausted by the journey itself.

### **Mobility is influenced by other people’s acts and decisions**

The experts pointed at the aspect of facing other people in public environments as an external challenge for mobility. They meant that people do not know about, and consequently do not respect, the special prerequisites for mobility for people living with cognitive functional limitations. If other people do not see any obvious reason why individuals with cognitive functional limitations behave in a certain way, the experts meant that they may not have patience with their sometimes differing behaviour. Other people may react to their behaviour and the reaction is taken notice of by the person with cognitive functional limitations, thus influencing the situation in a negative way. However, individuals living with cognitive functional limitations do not want to expose their functional limitations; according to the experts they want to be just like everybody else. An example mentioned by the experts is an individual with cognitive functional limitations who has difficulties buying a bus ticket (understanding and handling money) and needs more time than others to accomplish this task. Then this individual may experience a growing irritation from people standing in the queue behind waiting to board the bus. The experts said that even the bus driver can show impatience. The experts concluded that these are challenging situations for an individual living with cognitive functional limitations, partly because the irritation and impatience from other individuals may raise the level of stress and affect the ability to manage buying the bus ticket negatively, partly as it is a situation that distinguishes this individual from the other passengers.

On the other hand, the experts described that some individuals living with cognitive functional limitations use other people such as relatives, friends or individual assistants in order to maintain mobility. It could be that a relative drives the car or that an employee of the public transport company assists in order to manage a change from one bus or train to another. Assistance is offered as a service by train companies to people with certain needs. One expert gave the example of individuals being guided by others, using a mobile telephone in order to find the way:

“...otherwise I think that the mobile telephone is a good aid. I know a boy who could not find the way at all. He was piloted by a relative to go by bus, also short distances, he was connected all the time: ‘now we pass this and now we pass that’. He was worried all the time. But with the support he could manage.”

This boy described the surroundings to the relative and the relative could explain to him where and how to proceed in order to reach his destination. According to the experts, in contrast to using other individuals as tools for maintaining mobility, this is a strategy that hampers spontaneous mobility, since accompanying individuals are not always available. Furthermore, a great deal of the help that is available in order to compensate for what the individual cannot do because of his/her cognitive functional limitations also functions as a signal of “being different”. An example given by the experts is the option for assistance from some transport companies. However, one of the experts, herself living with cognitive functional limitations, said that such assistance may trigger feelings of not being able to manage independently. She explained that personnel on trains and at train stations are supposed to be available for everybody, without distinguishing between the target group and other people. It is important to not be treated differently or to experience oneself as deviating from everybody else. In the end, the experts thought that people living with cognitive functional limitations are just like everybody else. For example one of them, herself living with cognitive functional limitations, described herself as any mother who needs to meet her children at school. The best thing is if

“it’s possible to be handicapped without being a ‘special case’”

In some cases, other people such as relatives or friends directly determine the level and kind of mobility for the target group. For example, the

experts explained that relatives may not find it appropriate for an individual living with cognitive functional limitations to leave home and thus prevent him/her from doing so, or advise him/her to use only certain modes of transport.

### ***Mobility means facing internal conditions***

The experts also described that people with cognitive functional limitations have to deal with internal conditions in order to maintain mobility, elucidated in the two sub-categories: “Thorough knowledge gives confidence to cope with unpleasant feelings” and “varying awareness of cognitive capacity sets restrictions for performance.

#### **Thorough knowledge gives confidence to cope with unpleasant feelings**

An overwhelming amount of information given at the same time in traffic environments can cause unpleasant feelings, such as stress, anxiety and fear. As the experts pointed out, stress and other unpleasant feelings make the target group’s possibilities to manage the situation even more difficult. One important way to deal with such feelings in order to enable mobility is to reach certainty/confidence about a situation and what activities are about to happen. For example, in order to deal with internal struggles of uncertainty, the experts mentioned that the target group needs to know what is going to happen when travelling somewhere away from home already before leaving home. Further, they prefer spending time in familiar environments, where they often have strict instructions and routines for managing situations that arise. One of the experts gave an example of a man who was going to meet her at her office who had made a walk by himself to her office the day before the day for their meeting. She further explained that he had done this in order to learn the way to her office beforehand in order to be sure about the way the day when their meeting was going to take place. If they know in advance what the environment looks like and what situations may arise, people with cognitive functional limitations are better prepared to deal with certain situations that may appear. In other words, advanced knowledge facilitates their mobility. The experts emphasised that feeling certainty before the trip is not the only facilitator for mobility; it is also important to feel certainty during the trip. For example, if there is a need for a change of vehicle during a trip it is important that the personnel provide



adequate information to understand and react to. Just as important as knowing what is happening is to have the possibility to get confirmation during the trip, for example to ask other people whether one is heading in the right direction. One example given by the experts was when there are bus stops on both sides of the street. An individual with cognitive functional limitations may feel uncertain about which side of the street to stand on to catch the right bus. This may cause the individual to run from one bus stop to the other to find out which is the right one. This uncertainty may be overcome if there is someone to ask who can confirm which of the bus stops to stand at.

### **Varying awareness of one's cognitive capacity set restrictions for performance**

Another kind of internal condition that have implications for the target group's mobility is, according to the experts, the target group's varying awareness of their cognitive capacity. There are those who know for certain what they can or cannot manage because they have a sense of their abilities, but there are also those who have lost their ability to sense what their cognitive capacity actually allows them to do. One expert, herself living with cognitive functional limitations explained:

“I sometimes overestimate myself, and sometimes I underestimate myself. There is no general solution. Either do this or that. Sometimes you should have done this, and sometimes you should have done that – so you get confused.”

Those who underestimate their capabilities do not leave home very much since they do not think that they can manage. But if they really have tried, the experts said that some of them might find that they can perform adequately. Since there are people with different personalities in the target group, there are also some who do not hesitate to try. Some of them are prepared to accept a failure, while there are others who are not aware that their abilities are inadequate and who thus are not prepared for failure.

## ***Discussion***

In line with the aim of this article, the results presented give a picture of mobility in public outdoor environments among people living with acquired cognitive functional limitations.

The results pointed to the fact that cognitive functional limitations definitely play a role for the target group's mobility in public outdoor environments. The individuals' competence has decreased, and they are more vulnerable to the demands (Lawton and Nahmow, 1973) of traffic environments, which means that they do not reach the adaptation level in mobility. On the other hand, sometimes the barriers to mobility for people with cognitive functional limitations are similar as for individuals with solely physical functional limitations (Carlsson, 2003), one reason being that they often live with a combination of functional limitations. For example, the experts several times mentioned problems among the target group caused by high pavements and high steps into buses, i.e. environmental barriers often problematic also for people with physical or visual functional limitations (Carlsson, 2004).

One interesting result was that preparation for a journey beforehand was used as a strategy to improve mobility in public outdoor environments, for example to become acquainted with an environment in advance. In public transport it is important to stress that a journey starts by preparation already at the traveller's home, as emphasised in the travel chain perspective (Stahl, 1997). The travel chain perspective stresses the importance of not only concentrating on the design of the vehicle itself, which has been focused on by Carpenter (1994), Hunter-Zaworski and Hron (1999), Koppa et al. (1998), for example. Instead, all elements must be included, such being onboard the vehicle, the search for information about transport, the way to and from the vehicle, transfers at terminals etc. This was confirmed by the experts' opinion that people with cognitive functional limitations need to experience their trip as coherent. That is, if any link of the travel chain cannot be coped with, the whole trip might become impossible to carry out. Feeling that the trip is not divided into small segments is especially important for people with cognitive functional limitations, because the trip itself must not be too exhausting at the expense of the reason for the trip.

The descriptions of the experts had a considerable focus on the preconditions for the target group's mobility. That makes it relevant to say that aspects of motility, i.e. the degrees of freedom for an individual to move around if he/she wants to (SIZE, 2003), were underscored in the experts' empathetic descriptions. Their statements demonstrated that members of the target group do consider their own abilities after

acquiring a brain injury. In some situations, they seem to overestimate and in other situations they seem to underestimate themselves. The results also demonstrated that there are various opinions within the target group about absent mobility. Hence, a priori it is not the cognitive functional limitation per se that is the cause of mobility or of a sedentary situation. It is rather the individual's interpretations of his/her situation, needs and wishes for mobility – namely motility – that is decisive for how and to what degree mobility will actually take place. According to Kaufmann (2005), part of an individual's motility has its base in experiences related to factors that are valid for everybody, for example gender, generation, cultural heritage, education, etc. This is of course true also for individuals with cognitive functional limitations as exemplified by the expert, herself living with cognitive functional limitations, who expressed a wish – just like any mother – to meet her children at school. In addition, part of the target group's motility is based on aspects valid especially for them, such as being uncertain about one's own abilities or having uncomfortable feelings such as anxiety. Planning for motility means planning that depicts possible mobility (motility) instead of realized mobility (Beckmann, 2001). Taking such an approach, planning for mobility would be planning from what planners think is needed – that is planning for those who are already mobile – while planning for motility would be planning for individuals' (such as individuals with cognitive functional limitations) actual needs and wishes for mobility. As motility determines whether mobility takes place or not for members of the target group, the concept of planning for motility can be used instead of planning for mobility. This perspective highlights that it is necessary to communicate with members of this target group, because the phenomena one has to deal with cannot be observed but understood only on the basis of what is said by individuals. If carried out appropriately, planning for motility would mean an increase of de-facto-mobility among some people with low or no mobility today, while this has to be investigated in studies designed to capture such effects.

The results showed that absent mobility is experienced in various ways. According to Kaufmann (2005), dissatisfaction arises when motility does not correspond to mobility, for example when an individual wants more mobility even though he/she is reduced to a sedentary situation. The fact that there are persons who seem to be pleased with their sedentary situation shows that low mobility does not per se mean dissatisfaction (SIZE, 2003); it may be that their need for mobility is expressed in other

forms such as telecommunications, etc. (Kaufmann et al., 2004). However, questions of other forms of communication were not addressed in this study, and the experts did not mention those issues spontaneously.

Based on our results it seems to be challenging to develop a general plan for making mobility correspond to motility for people living with cognitive functional limitations, not least due to the heterogeneity of the group. Their heterogeneity is illustrated by various preferences for strategies to conquer immobility and different attitudes to a mobile or a sedentary situation. In addition, a varied set of difficulties produced by cognitive functional limitations, as also described in /less recent studies (McInery et al., 1992), is evident. Solutions to increase congruence between motility and mobility also necessitate individual support. In public transport, this implies interaction between personnel or other passengers and members of the target group (Hunter-Zaworski and Hron, 1992).

As this is a novel field of research, the decision to use an explorative approach, beginning with focus group interviews with experts, was fruitful for three reasons. Firstly, it was useful because the results elucidate the target group's complexity of preconditions for mobility that might not have been possible to come to terms with by means of conventional methods applied directly with the representatives of the target group. The qualitative approach applied in this study made that possible. Secondly, becoming acquainted with the situation of individuals living with cognitive functional limitations via experts also revealed potential challenges in communicating with them, and ideas on how to deal with challenges that might appear when meeting individuals who live with cognitive functional limitations. Lastly, it was an advantage to have mixed groups of experts representing various professions, as they were spokespersons for diverse definitions of cognitive functional limitations and could trigger each other's ideas and knowledge about areas of discussion with which a researcher new to the field would not be aware (Wibeck, 2000).

The results of the focus group interviews conducted in this study constitute useful insights into the target group's mobility. It should be kept in mind that the results were based on an "outside" perspective, and

that the perspective provided by people with cognitive functional limitations themselves should be concentrated on in future studies. However, compared to earlier studies often excluding individuals with cognitive functional limitations, our approach is an advantageous beginning of gaining fruitful insights. It is also an important contribution to this field of research where knowledge on the mobility situation for people with cognitive functional limitations is scarce.

In conclusion, within the group of individuals living with cognitive functional limitations there are those with a high level of mobility, while there are also those who are more sedentary, according to expert opinions. Their mobility, according to experts, involves keeping external and internal critical challenges at a manageable level. To live with cognitive functional limitations means consequences for mobility of both practical and social nature. The cognitive functional limitations per se influence spatial mobility as they decrease the individual's capacity to handle external environmental demands, and a low level of mobility may lead to limited participation in societal activities. The cognitive functional limitations also influence how the target group form an opinion about their possibilities to mobility, namely motility. From this perspective, low level of mobility can mean satisfaction as well as dissatisfaction; however, a low level of motility always means dissatisfaction. That is why a potentially useful starting point for promoting mobility among people with cognitive functional limitations would be to aspire to motility rather than mobility in societal planning. More research, such as focusing on the perspective of people who themselves live with cognitive functional limitations, is necessary in order to learn how to improve mobility within this group.

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# Paper 2

# The use of public transport: A challenging activity either under consideration or out of the question

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## Descriptions by people living with cognitive functional limitations

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## ***ABSTRACT***

This paper is based on a study aiming to achieve deeper insight into and understanding for reasons not to use public transport from the perspective of people living with cognitive functional limitations (participants). Semi-structured interviews in combination with a qualitative content analysis were performed with nine participants. The results showed that reasons not to use public transport were to some degree a usability-problem – both real and imagined. Other reasons were that participants with intent had changed from buses or trains to other modes of transport or they had psychologically adapted themselves to a new situation which meant that they did not miss using public transport.

## *Introduction*

Accessibility to public transport for older people and people with functional limitations has been a subject of great interest during recent years (CEMT, 2004). However, the specific problems for people with *cognitive* functional limitations have not been sufficiently studied in this respect. Consequently, we have sparse knowledge about this group as users of public transport. In the study reported in this paper an explorative approach was taken in order to investigate major barriers to the use of public transport for this group. It deals with the question of how people with cognitive functional limitations regard public transport and, in the case of this study, especially why they have stopped using it. This study was part of an ongoing interdisciplinary research project at Lund University in Sweden (VINNOVA dnr 2001-06707).

## *Background*

Planning for an accessible public transport system for all is a generally agreed necessity (CEMT, 2004; Prop. 1999/2000; SOU 2003:67) but at the same time it is a challenge. In Sweden, urban public transport is provided in a differentiated system in order to suit various user groups. The system includes, for example, trunk route traffic for use by commuters; service route traffic with a higher level of service from the driver and shorter distances to bus-stops for use by older people and people with functional limitations; and the Special Transport Service which is a door-to-door service for which special entitlement is required (Svensson, 2003). For a long time, both research and governmental evaluations in Sweden have emphasized the importance of the user perspective and the travel chain perspective when planning for various transport user groups (Olsson, 2003; Ståhl, 1997). However, both internationally and nationally, planning for accessibility to public transport predominantly focuses on people with visual- or physical functional limitations (see for example Carlsson, 2002; Davidson, 2001; Marin-Lemellet et al., 2001; Ståhl, 2007; Waara, 2001), while the situation for people with cognitive functional limitations is generally overlooked (Grönvall et al., 2004; Davidson, 2001).

Cognitive functional limitations imply a more varied set of difficulties than, e.g., vision and hearing functional limitations. Cognition can be

defined as the "technique" the central nervous system uses in order to process information, which includes the ability to distinguish, organize and assimilate information. Brain injuries can cause for e.g. difficulties in structuring and organizing information. Hence, people with cognitive functional limitations can have difficulties orientating themselves in time and space, to solve co-ordination problems, to express themselves verbally, to remember etc. Brain injuries can be innate or acquired, for example by a stroke. Often people with cognitive functional limitations also have additional functional limitations such as physical or visual (Abreu and Toglia, 1987).

**Accessibility** is a concept describing the encounter between an individual's or a group's functional capacity, and the design and demands of the physical environment (Iwarsson and Ståhl, 2003). Defined in this way, the concept is based on the ecological theory of aging (Lawton and Nahemow, 1973), meaning that the relationship between a person's functional capacity and environmental demands set both restrictions and possibilities for behavior. If one of the components is changing a balance can be maintained if one or more of the other components change as well (Lawton and Nahemow, 1973). For instance, an individual's functional capacity can be altered due to a brain injury, e.g. leading to difficulties in understanding directional abstract concepts like North, South, East or West. This can be compensated for by offering information that gives directions showing concrete significant landmarks in order to support their orientation (Hunter-Zaworski and Hron, 1993).

While few recent studies have been published in this research field, some results elucidating the challenge of investigating the public transport situation for people with cognitive functional limitations have been presented. From a technical perspective, some reports have focused on barriers at transport terminals (McInerney et al. 1992) and attempts have been made to specify operation guidelines, to give suggestions on technological changes, and to develop appropriate operation policies and training programs (Hunter-Zaworski and Hron, 1993; Hunter-Zaworski and Hron, 1999; Koppa et al. 1998). From a rehabilitation perspective, one case study demonstrated a step by step method for training people with brain injuries to start to use buses (Newbigging and Laskey, 1995). Overall, most of the studies found are not up to date, meaning that they do not take into consideration the rapid technological development within the field of public transport that has taken place during recent

years. In a more recent study, Logan et al. (2004) used semi-structured interviews looking at attitudes and barriers for using transport in general among people who have had a stroke, their findings indicated that the use of public transport was experienced as difficult. In Europe, the MAPLE project (2003) emphasized that the needs of persons living with cognitive functional limitations are largely neglected, since there is no systematic planning for users with cognitive functional limitations, and the majority of the transport providers in Europe have no operational definition for this group of users. Consequently, existing schemes and projects are scattered. Thus, there is a lack of scientific knowledge on the current public transport situation for the user group targeted in this study.

## *Aim of the study*

The aim of this study was to gain deeper insight into and understanding for the reasons behind the decision by people with cognitive functional limitations not to use public transport anymore.

## *Method*

### *Sample*

The participants were selected among individuals from a database created in another sub-study within the research project mentioned above. In the database, the individuals were taken from a national quality assessment register of stroke incidents (Riksstroke) at the Department of Neurology, Malmö University Hospital, Sweden. To be included in the database the individuals had to 1) have had a stroke sometime between January 1:st 2002 and June 30:th 2003, 2) be able to move about independently, at least indoors, three months after their stroke and 3) live in ordinary housing three months after their stroke. Details of the sampling procedure are described elsewhere (Wendel, et al., in press 2008). The database contains information from 84 individuals concerning their professional and self-evaluated cognitive functional limitations, physical functional limitations and use of mobility devices, depression symptoms and activity performance. Cognitive functional limitations were professionally assessed by an experienced occupational therapist using

Cognitstat, a rapid and sensitive measure of cognition (Kiernan et al., 1987; Mueller et al. 2001). Five major areas were assessed: language (three sub-sections), visual constructive skills, memory, calculation and reasoning (two sub-sections) and three general areas covering consciousness, orientation and attention. Each area or sub-section was scored as; average, mild, moderate or severe. Self-reported cognitive functional limitations were examined by a study-specific questionnaire with 18 questions on cognitive tasks used in daily activities. It should correspond to the Cognitstat, however, it was based on relevant literature, ICF (UN, 2003) and the clinical experience of the authors' (Wendel, et al., in press 2008). Physical functional limitations and use of mobility devices were collected by means of the personal component in the Housing Enabler instrument (Iwarsson and Slaug, 2001). Depression symptoms were self-rated by use of the Geriatric Depression Scale (Gottfries et al., 1997), where a score between 6 and 20 implied a depression. Activity performance (in-house, outdoor mobility, leisure/social activities and work), was examined using the Frenchay Activity Index (FAI) (Dijkers et al. 2000; Turnbull et al., 2000). The FAI-instrument was extended with questions about the modes of transport used and the use of telephones. Based on their frequencies of the use of buses or trains after a stroke, the participants from the database were divided into subgroups where 14 individuals reported that since having a stroke they now never travel by bus or train, while 41 individuals reported that, post stroke, they continue to use buses or trains, either with reduced, unchanged or increased frequency.

A strategic sampling strategy (Patton, 1990) was used to select the participants for this study. The two basic criteria were that the participants:

had cognitive functional limitations *and*

had been public transport travellers before they got cognitive functional limitations.

The 14 individuals not using buses or trains anymore fulfilled the criteria, and were primarily asked to participate. However, due to the time that had passed between the information in the above mentioned database being collected, and the point in time when contact was made with the individuals inviting them to take part in the study, a number of the 41 participants who had reported a continued use of public transport in the database, had now ended their use of public transport and consequently fulfilled the criteria for participation in this study. In



addition a *maximum variation sample* was strived for (Patton, 1983), i.e. a selection of people with a maximum variation of cognitive functional limitations, both men and women and different age groups. Also the portion of physical functional limitations among the participants should be as low as possible. Finally nine individuals were positive towards participating in this study, and are hereafter referred to as the *target group* or the *participants*

### Participants' characteristics

The target group comprised of seven women and two men, aged from 45 to 90. The two men lived with their spouses in apartments close to the city centre. Five of the women lived alone in apartments, and the remaining two lived with their spouses in houses with gardens; one of them had children still living at home.

Within the target group there is a variation of types of cognitive functional limitations for each area and sub-area in Cognistat, however, among the ones who were positive for participation, nobody had memory and judgement difficulties (table 1.). Physical functional limitations, especially difficulty in bending and kneeling, and dependency on mobility devices were present in the target group (figure 1). The mobility devices could be a walking stick or a rollator, which is a walking frame with wheels; it has handlebars with brakes and in some cases a seat, a basket or a shelf. The use of walking aids appeared to be more common within the target group during the period in which this study was executed than at the time of the data-collection to the database mentioned above. Five of the participants had six or more depression symptoms indicating a depression.

**Table 1** Number of participants, having professionally assessed cognitive functional limitations, divided into areas and sub-areas within Cognistat

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*Professionally assessed acquired cognitive functional limitations*

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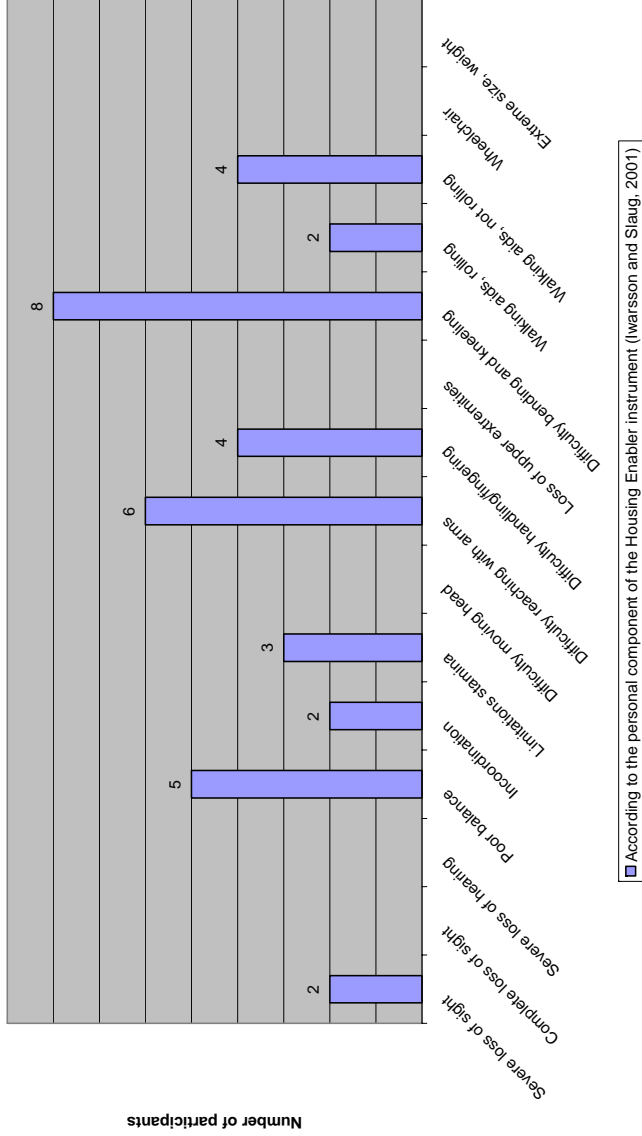
*Cognistat area/sub-area*

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Orientation	0	3	2	1	2	3	0	1	1	0
Attention	0	3	3	1	0	0	0	0	0	0
Comprehension	1	0	0	0	0	0	0	1	3	0
Repetition										
Naming										
Construction										
Memory										
Calculation										
Similarities										
Judgment										
<i>Mild</i>	0	3	2	1	2	3	0	1	1	0
<i>Moderate</i>	0	3	3	1	0	0	0	0	0	0
<i>Severe</i>	1	0	0	0	0	0	0	1	3	0

<sup>a</sup> (Kiernan et al. 1987, Mueller et al. 2001)

Physical functional limitations and dependency on mobility devices



**Figure 1** Description of the participants' physical functional limitations and dependency of mobility devices

## *Study district*

The target group lived in Malmö, Sweden, or in the adjacent environment of the city. Malmö is the third largest city in Sweden with an urban population of 270,000 inhabitants. The public transport system is differentiated, with fast trunk bus routes where buses run fast and often (every 5 minutes) to and from important destinations within the city, and in addition local routes that take care of more restricted travel needs. These buses do not run so frequently (about every 30 minutes). Most of the city area (82%) is considered to be covered by public transport. The average distance between bus stops, in the central area, is more than 500 meters, more than half of the bus stops (56%) are sheltered and all buses are low entrance buses, i.e. there are no steps up to into the buses and can kneel down to a height of 230 mm above ground. There are no so-called intermediate solutions specifically designed to meet the needs of older people and people with functional limitations – service route traffic or flex rout traffic (Carlsson and Ståhl, 2006). The Special Transport Service (Svensson, 2003) is provided for those who qualify, which is decided by the municipality.

## *Semi-structured interviews*

The guide for the semi-structured interviews was developed on the basis of the results of another sub-study of the project Rosenkvist et al. (submitted) as well as those reported earlier by others (see for example Hunter-Zaworski and Hron, 1993; Hunter-Zaworski and Hron, 1999; Koppa, et al., 1998). The themes in the interview guides were:

Mobility in general

Environmental factors that hinder or enable the use of public transport

Strategies when desiring to use public transport

Future use of public transport

Ideal public transport

The question formulation was tested on several occasions, both within the project group and on persons not initiated into the project, before the interviews with the target group took place, in order to avoid complicated words or phrases. The interviews were performed as conversations with open-ended questions about the themes described

above. The intention was first of all to grasp the words of the participants. Starting out from open-ended questions, interviewers went on to encourage the participant to embellish on his/her statements by the use of probing questions (Berg, 2007). During the interview the answers were played back to the participant to make sure that the participant's own perspective was understood, in order to strengthen credibility or internal validity (Persson, 2006). The second theme, environmental factors that hinder or enable when using public transport, was the most essential. Information given in one interview was taken into account and amended in the following interviews.

### *Procedure*

The first contact with the potential participants was by a telephone call during which the project was briefly presented and the person was asked to consider participation. This was followed up by a letter with extended information. About a week later, a second telephone contact was made to set a date for an interview. The interview was carried out in the participant's home by the first and fourth authors. During the visit the participant was asked to sign an agreement of consent, and the interviewers explained that the information gathered was to be treated as confidential. The repeated contacts with the participant before the interview were supposed to establish confidence between them and the interviewers. To establish confidence is important, especially for this group, as they, by experience, often hesitate to encounter new persons and events outside of their routine life.

Both interviewers were present during all but one interview. The fourth author led the conversation, but as the interviewers represented different experiences together with people with cognitive functional limitations as well as different scientific fields, they both posed questions and encouraged the participant to describe his/her thoughts.

### *Analysis*

When all interviews had been conducted, an open coding was performed in order to more systematically analyse the material. The codes were sorted and subsequently, in an iterative process, categories emerged. The participants' statements were units for analysis. However, for

exemplification of the categories, individuals are exemplified in the description of the results. In accordance with the qualitative approach, the analysis process introduced theoretical angles from which to view the results that were complimentary to the theories and conceptions that existed in the beginning of the study.

### ***Ethical issues***

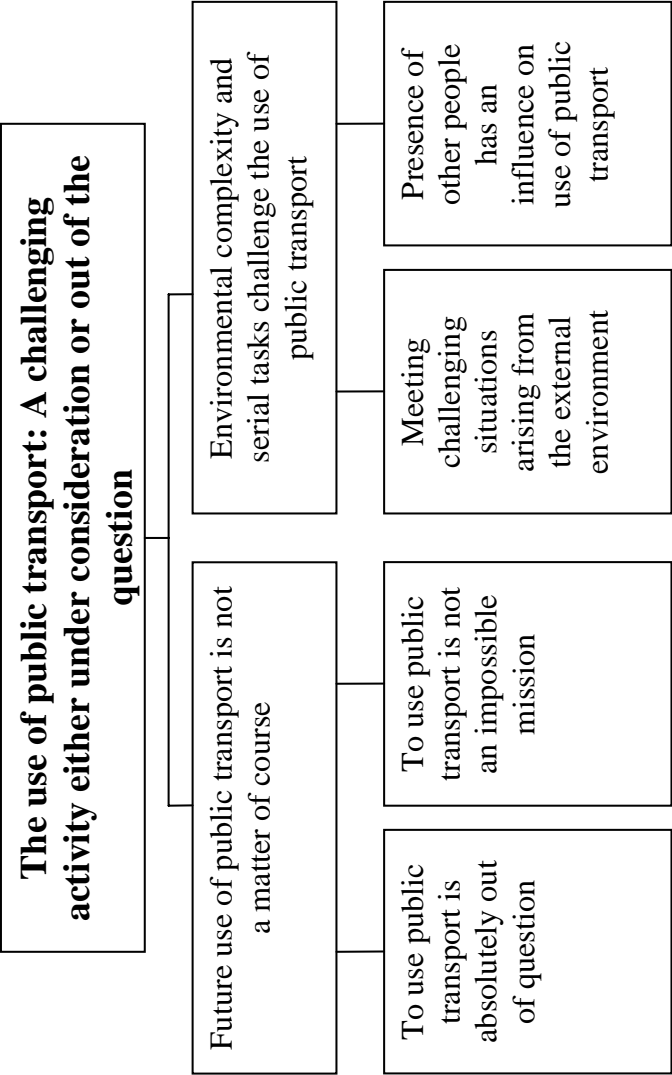
Before the interviews took place, the participants signed a consent agreement, and the information was treated confidentially. The design of the study had previously received approval from the Ethics Committee, Lund University, Sweden.

## ***Results***

The interviews revealed that the participants' thoughts related to the present and future use of public transport varied. Some had distanced themselves from the very thought while others were prepared to consider using public transport now or at sometime in the more distant future. The participants described what it would be like if they were to use public transport today, after having a stroke. The participants' descriptions of public transport originated, for example, from their imaginations or from what they had heard from friends or read in newspapers. Further their descriptions originated from their experiences from using public transport before having a stroke and experiences from actual journeys with public transport after having a stroke. There had been occasions when the participants had tested the use of public transport after having a stroke, together with friends or relatives in order to see whether they could cope or not. However, the participants no longer viewed themselves as public transport users as they neither went by public transport on a daily basis, nor on their own, at the time for the interview.

The core category emerging from the interviews is The use of public transport: a challenging activity either under consideration or out of the question. It comprises two main categories, each with two sub-categories: Future use of public transport is not a matter of course and

Environmental complexity and serial tasks challenge the use of public transport, (see figure 2)



**Figure 2** Categorisation of the results from semi-structured interviews with people with cognitive functional limitations

## **Future use of public transport is not a matter of course**

There were statements that revealed how ideas of using public transport were far away in the participants' minds' – for example one participant noted that she did neither use it nor would like to. There were also statements that revealed that ideas of using public transport were present in the participants' minds. Two sub-categories appeared: *To use public transport is absolutely out of question* and *To use public transport is not an impossible mission*.

### ***To use public transport is absolutely out of the question***

In the statements that revealed idea of public transport as being a distant thought in the participants' minds, the use of public transport was expressed as an activity that belonged to the past or was considered as an activity the participants did not think about nor had to care about. One woman, who was very definite in her answer, emphasised that she does not want to think about activities that she does not judge herself as able to manage – such as, to use public transport. She stated that she gets depressed when thinking about activities that she cannot manage. For her it was better to be grateful for what she can do today and not think about activities that she can not do. She has accepted, and is satisfied with her life-situation as it is.

The interviews enlightened explanations as to why it was completely out of the question to use a bus or train. It could be due to the consequences of the stroke, which was exemplified by a woman who said that her loss of memory had made her forget how to use a bus and train:

”the mere thought of leaving where we live and then all that travelling and then having to board the train [cleared her throat] ehm ehm oh, I don't know, I don't know anymore what you're supposed to do. I do not know how to handle objects. I have lost it all!”

In addition to stroke, heart-trouble, gout or depression were offered as reasons for not using public transport. One woman explained that she would not like to expose herself to the risk of being injured, should she



try to use the bus, as that would worsen her depression. Other decisions to not use public transport anymore were consequences of the aging process:

"No, no, I'll never do that again, old as I am, I don't believe any bus would take me onboard, I'll be running on these legs before I ride [laughs]".

Further, it was told that other modes of transport had replaced the participants' need for buses or trains, for example by being entitled to the Special Transport Service or being given a lift from their children, friends or partners. One man described it as more natural to let his wife drive the car on one of the special parking spaces for the disabled, they then come closer to the entrance.

Some statements implied that the participants had tried to use buses and trains once or several times, after their stroke. Those occasions were described as being the straw that broke the camel's back. These trips had made them make the final decision to not use public transport anymore. One woman said that she came to the conclusion that using the bus was no longer suitable for her following a tryout trip by bus, together with her daughter. She emphasised that her daughter, whom she trusts highly, agreed with her.

### ***To use public transport is not an impossible mission***

In the statements that revealed ideas on the use of public transport as being close in mind, use of public transport was expressed as an activity that the participants were to be able to manage to the same extent as they did before their stroke. The participants' explanations for not using public transport was not their inability to use it, rather their statements revealed that, for example relatives had advised them not to. One example was a man who referred to what other people have told him about having neglect. He meant that, due to his neglect, he might forget to look for cars coming from the left when standing at a pedestrian crossing. At the same time he concluded that if he would really face such a situation, he would probably never forget to look for cars as he considered this as being too important to forget.

The statements that revealed thoughts about start using public transport again, showed that in the minds of the participants public transport was

a present issue. One woman explained that she was prepared to make an attempt to use public transport, on her own, again, taking it one at a time. Her plan was firstly to try the train by herself, as taking the train is not as stressful for her as taking a bus. Then her daughter would meet her at the railway station and join her on the bus to their final destination. To start to take the bus from the railway station by herself would be a later mission. She explained that she was fighting uncomfortable feelings, such as stress, because travel by bus was not a routine for her. However, if it were to become a routine, she said that she would probably not be that nervous.

### **Environmental complexity and serial tasks challenge the use of public transport**

The participants described their ideas of what it would be like if they were to use public transport today as persons having had a stroke. They described situations they considered as challenging and in what way such situations had an influence on them. This category comprised two sub-categories, namely *Meeting challenging situations arising from the external environment* and *The presence of other people has an influence on use of public transport*.

#### ***Meeting challenging situations arising from the external environment***

It was experienced as demanding to handle an external environment that was characterised by complexity and constituted situations with serial tasks to be performed within a short amount of time. An example was the situation that arises when getting on and off a bus, such as standing in a queue, managing the payment process, finding a seat, and in addition in some cases bringing a rollator onboard. One woman described this situation:

”I can’t board with my rollator and I can’t put the rollator aside and go up front and pay and then go back and find a seat, ’cause you can’t sit on your rollator because you’ll fall off.”

A male participant pointed at the difficulty in performing serial tasks in a short time, even though he was able to perform them one by one:

Participant: "I can manage the step up into the bus, but I don't get more than halfway before he starts driving."

Interviewer: "No way?!"

Participant: "I can't take out the...what do you call it...the ticket and then pay when there's a queue and then find a place to sit. Plain impossible when I'm on my own. But, if my wife is along, then she takes care of the fare."

He explained that the complex situation, the serial tasks and in addition, time-pressure made his experience very stressful (he was almost seized by panic) when trying to get off the bus. However, if his wife assisted him and when he only had to handle a few tasks by himself, one at a time, he found it much easier.

According to the statements, the bus was regarded mostly as being a greater challenge to handle than the train. It was noted that onboard a bus it is the passenger's responsibility to know where to get off and when to communicate that to the driver. This was exemplified by one woman who considered this a problem as she was unsure about when and where to push the stop button in order to make the bus stop. She felt that it would be easier to use the train as the train comes to a standstill at every designated stop, which diminished the risk of getting off at the wrong station.

Further, the statements revealed that challenging situations in the external environment could be caused by the design of the physical environment, such as differences in level which can be especially difficult when using a rollator:

"Stairs are not just suitable for people with rollators"

A rollator was the mobility aid for several of the participants, therefore it was considered to be easier to use buses or trains if the step onboard the bus or train was at the same level as the edge of the pavement or platform.

Finally, some statements implied that the participants were not able to point out specific situations that they considered themselves unable to

handle. Rather the statements demonstrated a general fear and anxiety about “everything” related to using buses and trains. One woman described it as a blurred anxiety – everything scared her. She said, that for example, technical aids would not promote her to use the bus because she already was afraid, anxious and worried at the very thought of crossing the street to get to the bus stop. For her it was not the lack of practical help in order to manage the environmental conditions that made her hesitate to use public transport, but rather her negative feelings.

### ***Presence of other people has an influence on use of public transport***

The statements made it obvious that the participants considered the presence of other people as influencing their use of public transport. For example the participants described that they did not want to disturb or irritate other passengers, nor would they want to be disturbed by others. They explained that other people are often stressed and in a hurry, while the participants need more time in order to manage various tasks when, for example, getting on a bus which means that other passengers may therefore be hindered by them. In order to avoid situations where the participants experienced themselves as disturbing others, they considered using public transport at other times than rush hours, if possible. One man even thought that older people and people with functional limitations should arrange their transport in such a way that they are not a hindrance for others to use public transport, for example by using other modes of transport more suitable to individuals with functional limitations.

The statements also revealed that trust in other people was an important issue. For example, one woman said that for her it was no problem to move about in her neighbourhood because she knew that there were people there in whom she could trust. Local people she knew would be there to help if anything should happen to her as they knew of her cognitive functional limitations. Other participants had different experiences, namely that people out on the streets do not offer help if one falls. One participant talked about how he fell on the pavement and everybody passed by without assisting him. As a consequence he no longer expects that people will offer their help if he should fall in a public place.

According to the statements, the availability of other people to help implies safety and support when it is time to leave the home environment. These other people can be a partner, friends or the driver from the Special Transport Service who comes to pick up the participants at their address when they use this service. The participants noted that when using the Special Transport Service or taxis they can be sure to get personal support, which they felt was not the case when using buses where the driver has too many things to do at the same time. It was also mentioned that an accompanying person would most likely have insight into the participant's problems and would be prepared to help when assistance was needed, for example be prepared to catch the participants if they were about to fall. However, for some it was their wish not to be accompanied when leaving home. For instance, one woman said that she preferred to do things on her own, because then she could take her time without being a hindrance to others. She explained that she had become more careless than before. Nowadays she also needed more time to manage things and for that reason she preferred to be alone.

## *Discussion*

In line with the aim of this article, the results presented contribute to a deeper insight into and understanding of persons with cognitive functional limitations following a stroke, taking the decision to no longer use public transport.

The participants' concerns about challenging situations when using public transport reflected their thoughts around their individual competence in relation to environmental pressure (Lawton and Nahemow, 1973) in public transport situations. They pointed at situations where the environmental pressure exceeded their individual competence. With this in mind, one can assume that the findings indicated accessibility problems within public transport or, more specifically, the findings indicated usability problems (Iwarsson and Ståhl, 2003), as the results reflected the participants' subjective evaluations of how the environment restricted their performing an activity in a specific environment. One example of a usability problem was the participants' estimation of the complexity and serial tasks constituted by the external environment that they considered restricted their performance of getting on a bus. However, using buses or trains was

an activity that was no longer a part of the participants' everyday life. The fact that using public transport was not a daily activity for them was visible, for example, in those statements where the participants' descriptions originated from their earlier experiences of boarding a bus before they had a stroke. Consequently, they described usability from the perspective of a person not living with cognitive functional limitations. On the other hand, the situations that the participants mentioned must be expected to have had a certain meaning for them since their awareness of them had increased (Steinfeld and Danford, 1999). Even if they do not constitute usability problems in the "actual" environment, but rather in the participants' minds the environmental pressure was thought of as being too high, so the idea itself was a hinder for them.

It was interesting how the presence of specific other individuals, such as friends or individuals who the participants trust, was experienced as supportive when using public transport. Those findings implied that the participants wanted to know that there were people in the public environment and the public transport system who were cognisant about their cognitive functional limitations and thereby could give proper assistance. Those findings are endorsed by results from a previous study that emphasized the fact that technical solutions are not those most suited for people with cognitive functional limitations (Hunter-Zaworski and Hron, 1993). Rather, personal interaction offered the best solution as it enabled flexible assistance in unique situations. In addition, those studies came to the conclusion that one way to provide opportunity for interaction was to reduce the drivers' tasks, which was also touched upon by the participants in this study.

The findings of this study on user perspectives and the results of another sub-study within the research project (Rosenkvist et al., submitted), where experts give their perspective on prerequisites for mobility for the target group are complementary. The experts emphasized the importance of the travel-chain perspective, which was also touched upon by the woman in this study who said that the mere thought of crossing the street to the bus stop was a hindrance for her. The travel chain perspective stresses the importance of not separating the time spent onboard the vehicle from the other parts of the journey; the search for information regarding transport possibilities, the way to and from the vehicle, changes at terminals etc. If one link in the chain is missing, the whole chain will be broken (Stahl, 1997).

The findings that showed that the participants would avoid using buses at rush hours in order not to disturb other passengers implied that the participants' behaviour was a result of an interaction with their environment. From the interaction perspective, most of the time, people resign themselves to the environment, but if the environmental demands exceed an individual's the level of tolerance, his or her will to make a change in their situation increases. For example, it may cause them to make changes in their own environment, for instance, they might move to another area, or they will adjust themselves to their new situation psychologically by altering their expectations and values (Steinfeld and Danford, 1999). The findings revealed that it was preferable to use such modes of transport where pressure from other passengers was avoided and where one could get more help from the driver. Those statements implied that there is a demand for intermediate solutions of public transport, such as service route traffic or Special Transport Service where the environmental pressure is lower (Ståhl, 1997). Consequently, the participants who had replaced their use of buses and trains by the use of other modes of transport, such as the Special Transport Service, can be interpreted as having changed their environment in order to be able to deal with the environment in a proper manner. The participants' statements based on experiences from using public transport before having a stroke can be interpreted as a psychological adjustment to the situation where they protected themselves from psychological dissonance (Festinger, 1962). Thoughts of using public transport and at the same time not being able to do so brought psychological dissonance. Since people strive to avoid psychological dissonance, the participants consequently avoided thinking about public transport as it would increase psychological dissonance. That was understandable in the light of the findings in a study of people's use of public transport post stroke (Wendel, et al., submitted), that showed that individuals with decreased use, or individuals who no longer use public transport, also had more professionally assessed and self-reported cognitive functional limitations than individuals who continued to use of public transport. In addition they also showed a decreased frequency of social activities outside of their homes than individuals whose pattern of the use of public transport was unchanged. When having more cognitive functional limitations and activity restrictions it is possible to assume that our target group preferred to avoid thinking about public transport in order to avoid psychological dissonance.

As this is a rather novel field of research for traffic planners, there is no certain method available that is well-adapted for studying the public transport situation for those with cognitive functional limitations. The decision to approach the field of research by focusing the ex-users' reasons for not using public transport by means of qualitative interviews was advantageous. When evaluating the statements given by the participants, it is important to emphasise that they reflected the thoughts and ideas they had on using public transport. The descriptions of usability problems might not directly be applied in the "actual" environment, but they might be considered as usability problems in the participants' minds. There is a range of how "actual" or imaginative the statements are, as the participants' descriptions originated both from their imaginations and from experiences of actual journeys.

## *Summary and prospects*

To sum up, understanding the reasons for not using public transport anymore from the perspective of people living with cognitive impairments after having had a stroke, gave a picture of a group to whom public transport in some cases put greater pressure on the group than they have the capacity to handle. This was especially the case when the environment was characterised by serial tasks and complexity. Further, within the target group, there were those who had adapted their environment or themselves to new conditions. Reasons for not using buses or trains were, in those cases, that their use of bus or train had been exchanged for other modes of transport, such as travelling by with relatives or using the Special Transport Service; or alternatively they had psychologically adapted to a sedentary situation, for example by saying that they were now older and therefore they no longer use public transport. To better enable the use of public transport for this group would be to make sure that the whole travel-chain works throughout and that the personnel working on buses or trains should possess sufficient knowledge regarding cognitive functional limitations to be able to show understanding and patience when in contact with individuals in this group. However, what was more important was that in some cases it was not the "actual" environment that constituted a hindrance, but rather the participants' ideas that hindered them. Consequently, in a planning process, the findings of this study may not be a basis for redesigning the public transport environment as such. Nevertheless, the results may



constitute a basis for designing information and education material directed towards people with cognitive functional limitations showing them how to use public transport which, in earlier studies, has been pointed out as a particularly important matter (Hunter-Zaworski and Hron, 1993).

The results of this study constitute a rich basis for further studies on the situation in public transport for people living with cognitive functional limitations. In further studies, the implications for usability issues must be investigated by observations in real environments, connected to interviews with the individuals observed. However, for those, in this group, who are inclined to start using public transport again after having a stroke, the findings of this study are valuable for understanding under which conditions public transport can be brought within their reach again. They can help to point out implications on usability issues that are thought of as being a hinder.

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