

## Facilitators for traveling with local public transport among people with mild cognitive limitations after stroke

Ståhl, Agneta; Månsson Lexell, Eva

Published in:

Scandinavian Journal of Occupational Therapy

10.1080/11038128.2017.1280533

2018

Document Version: Peer reviewed version (aka post-print)

Link to publication

Citation for published version (APA):

Ståhl, A., & Månsson Lexell, E. (2018). Facilitators for traveling with local public transport among people with mild cognitive limitations after stroke. Scandinavian Journal of Occupational Therapy, 25(2), 108-118. https://doi.org/10.1080/11038128.2017.1280533

Total number of authors:

General rights

Unless other specific re-use rights are stated the following general rights apply: Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights

- Users may download and print one copy of any publication from the public portal for the purpose of private study
- You may not further distribute the material or use it for any profit-making activity or commercial gain
  You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: https://creativecommons.org/licenses/

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

**LUND UNIVERSITY** 

Download date: 17. Dec. 2025

**Facilitators for Travelling with Local Public Transport** among people with Mild Cognitive Limitations after **Stroke** 

Agneta Ståhl, Professor, PhD  $^1$  and Eva Månsson Lexell, PhD, Reg OT  $^{2,3}$ 

<sup>1</sup>Department of Technology and Society, Faculty of Engineering, Lund University, Lund,

Sweden

<sup>2</sup>Department of Health Sciences, Lund University, Lund, Sweden

<sup>3</sup>Department of Neurology and Rehabilitation Medicine, Skåne University Hospital, Lund-

Malmö, Sweden

Corresponding author: Eva Månsson Lexell, Department of Health Sciences, Lund University,

22100 Lund, Sweden. Tel: +46 46 2228995;

email: Eva.Mansson\_Lexell@med.lu.se

## **KEY WORDS**

Cerebrovascular accident, cognition, mixed-methods, transportation, case study

Length of main manuscript: 7768 words

### **Abstract**

Introduction: Previous research of how people with stroke manage public transport has mainly focused on barriers due to physical limitations whereas the influence of cognitive limitations is scarce. There is also a lack of knowledge of facilitators that can help to overcome these barriers. The aim of this study was to describe facilitators for travelling with public transport, e.g., local buses, among people with mild cognitive limitations after stroke. Methods: A multiple case study research design was used, where quantitative and qualitative data was utilized, and analysed according to a mixed methods design.

*Findings*: The case descriptions reveal how people with mild cognitive limitations after stroke manage their trips but constantly have to be prepared to solve problems to unexpected events. Personal characteristics and other individual strategies together with support and solutions from society were important facilitators for travelling with bus.

*Discussion*: This study takes a new approach by specifically describing facilitators for travelling with public transport among people with mild cognitive limitations after stroke. To facilitate participation in society for this particular traveler group, occupational therapists have an important role when new technology and interventions that target bus travels, and other modes of transport are developed.

### **/197 words**

### Introduction

Many people who have survived a stroke have remaining physical, cognitive and psychological limitations [1-3], where the two latter can be difficult to detect, especially if they are mild [4]. Despite receiving good care, and early rehabilitation services during the initial stroke phase, many still experience activity limitations and participation restrictions. Most commonly, these problems don't become evident until the person is discharged from hospital and try to participate in activities in the society as before, especially among those with cognitive limitations, also when these are mild [5].

Being able to participate independently in activities outside home and in society requires that a person can get around in society, and handle different modes of transport to and from where the different activities take place [6]. Many people with stroke have their driver's license withdrawn as a consequence of their stroke [7], and have to rely on friends or relatives for transports or use other modes of transport, such as Special Transport Services or public transport. However, in line with the sharpened regulation of Special Transport Services in Sweden [8]) from the late 1990s, many municipalities today are more restricted when people with disabilities are assessment eligible for STS. During the latest decade there is a clear decrease in the number of people eligible to STS and there is a reason to believe that this tendency also has affected people with stroke [9]. Instead it is common to rely on friends or relatives for transports or use other modes of transport, i.e., public transport, by themselves. However, travelling with public transport, e.g., bus, includes many different tasks such as deciding which trip to take, walking to the bus stop, buying the ticket, getting on the correct bus etc. Hence, travelling with public transport is a complex activity, where all tasks in the travel chain [10, 11] need to be considered during assessments as well as interventions. This can be particularly difficult for people with stroke.

Around 50 % of people with stroke state they have difficulties moving around in society [12], including travelling with public transport. In Sweden, a survey with over 800 people with stroke showed that a minority had travelled with public transport after their stroke [6], and among those with cognitive limitations, one third reported reduced or no use of public transport compared to their use before stroke [13]. Also a mild stroke, with no evident cognitive limitation, can lead to difficulties, e.g., orientation difficulties that can influence the ability to travel with public transport [14]. Moreover, many anticipate they will experience barriers in relation to travelling with public transport, and together with a reduced level of self-confidence or feelings of inferiority, several cease to travel with public transport [15, 16]. Other barriers in relation to obtaining necessary information prior to their travel, having to

interact with traffic, and having difficulties communicating with the bus driver have also been mentioned [15]. Still, previous research has mainly focused on those who ceased to use public transport [16] or categorized barriers in relation to individual characteristics, transport mode, infrastructure, societal structures or communication between road users [15]. Knowledge of how people with cognitive limitations, who still travel with public transport, reason in relation to overcoming barriers during the travel chain is therefore lacking [17]. To our knowledge, there is no study that has described facilitators for travelling with public transport. This is important when public transport interventions are developed. Today, there is a lack of rehabilitation interventions that focus on the ability to use different types of public transport for people with stroke, especially for those with cognitive limitations. Thus, the aim of this study was to describe facilitators for travelling with public transport, e.g., local buses, among people with mild cognitive limitations after stroke.

### **Material and Method**

# Study design

A multiple case study [18], with a mixed-methods design [19] was used. Initially, data gathered from assessments was merged together with interviews and observations, all collected from the same participant, to a narrative which characterized and described each case and his/her bus travels. Later, a cross-case analysis [18] among all the cases was performed where data from all the interviews and observations were used to describe facilitators for travelling with bus.

## Sample

The participants in this study were selected among participants in a larger project, comprising originally 84 participants with stroke [20] included in a local part of the national quality register of stroke incidents (Riks-Stroke), reported by Skåne University Hospital (SUS), Sweden. It included people with stroke with different types of functional limitations, and different experiences in relation to travelling with public transport. Of the 84 participants, six people (two men and four women) who had mild cognitive limitations due to their stroke, were still travelling with public transport, and therefore participated in a more comprehensive data collection. In table 1, the six participants' characteristics are further described. The study was approved by the Regional Ethical Review Board in Lund, Sweden.

Insert Table 1 about here

### Data collection

The comprehensive data collections comprised assessments with different tools, interviews pre and post a bus trip as well as an observation during a bus trip. The data collection started by performing the assessment, and proceeded with the introductory interview, the observation during the bus trip, and ended with the follow-up interview.

Assessments tools - The assessments gave an overview of the participants' physical and cognitive limitations as well as frequency of participation in daily activities. Data on physical limitations were collected by using the personal component of the Housing Enabler (HE) instrument [21]. This version comprised 15 items but one item was excluded (difficulty interpreting information) since this was covered by the other data collection. Cognition was assessed by means of the Cognistat screening instrument [22], comprising three general areas (consciousness, orientation, and attention), and another five major areas (language, visual constructive skills, memory, calculation, and reasoning) of which two are divided into subareas (language and reasoning). Each area/sub-area is scored as average or mild/ moderate/severe. Self-evaluated cognition was measured by a study-specific questionnaire, developed in a previous study [20]. The questionnaire consisted of 18 questions with three response alternatives (yes, no or do not know), where each yes-answer was considered a cognitive limitation. Frequency of participation in daily activities was captured by means of an extended and modified version of the Frenchay Activity Index (E-FAI) [23] with 22 items, where items concerning use of mode of transport, and telephone use were added to the original version of the instrument [24]. The sum score of the new version ranges between 0-66, where a higher number indicate a higher frequency of participation in daily activities.

Interviews and observations - This part of the data collection was performed in a procedural sequence in three steps: i) An introductory interview; ii) an observation of a bus trip; and iii) a follow-up interview, and was performed by two PhD students in sociology, and occupational therapy. All introductory interviews included questions of limitations in relation to the stroke, how each of the participants experienced their outdoor environment, and possibilities to handle outdoor mobility in relation to travelling with bus. Each participant also undertook a trip with public transport to a familiar destination they were motivated to travel to, using local bus. During the trip the observational data collection took place. All participants made this local bus trip during day-time in the urban area of Malmö, Sweden, though to different destinations. The length of the trips varied and so did the time spent on the buses. Some of the

trips included changes of buses, at different bus terminals. These facts are described it the case studies accordingly. During the trip, one PhD student made notes regarding critical incidents [25] that occurred during the trip, and comments made by the participant were tape-recorded. Each participant was asked to, continuously, 'think aloud', i.e. to comment on the performance itself and experiences in relation to the performance. The other PhD student walked beside each participant as a safety precaution, ready to assist if needed. Directly after the trip, a follow-up interview based on the notes was made with each participant. Questions were posed in relation to the different parts of trip, and each participant was given the opportunity to comment and clarify on events that had emerged. Interviews pre and post the trip and comments as well as conversations during the trip were tape-recorded and transcribed verbatim.

# Data analysis

Initially, the data collected from the assessment tools was summarized and analysed for each case (Table 1). Then each case was analysed individually, in a "within-case analysis" [18], using all the descriptive data together with the transcribed data from the interviews, notes, critical incidents as well as the participant's own comments during the bus trips. All data for each case was initially read several times to get a sense of the whole material. Statements and incidents regarding barriers, and possible solutions from each case's bus travel was inductively analysed, using a travel chain perspective. Next, all descriptive data was merged in this analysis [19] which resulted in a narrative description of each case's bus trip. All narrative descriptions were discussed, and modified in an iterative process among the two authors.

Finally, a cross-case analysis [18] was performed where all interviews and observations from all cases were utilized, and analysed according to a directed content analysis [26]. This type of analysis is guided by a theory, a model or specific key concepts. In the present study, the analysis focused on individual facilitators as well as societal facilitators. That is, initially all relevant text was read again, and thereafter sorted into meaning units that was given a preliminary code. All preliminary codes were compared and collapsed until a set of codes were present that could be categorized either as an individual facilitator or as a societal facilitator. The codes within each of the categories were further scrutinized, and categorized until a set of subcategories within each of the two main categories was present. This process was first performed separately for each case, and then the results from all cases were merged, until a final set of subcategories emerged for each predefined main category.

Finally, the titles of the predefined main categories were adjusted to better represent the content in the subcategories. Both authors, an experienced occupational therapist (EML) and an experienced researcher in traffic planning especially in relation to people with disabilities (AS) were involved in the data analysis. The second author performed all the initial steps of the analysis, which was validated by the first author.

#### **Results**

# Narrative descriptions

**Axel** - had a right-sided stroke, and is left with decreased balance and stamina. He uses a stick during walking. He has mild problems with attention, comprehension, and judgment, and perceives problems with fatigue and poor concentration. Axel states he performs more heavy household activities, but less outdoor and social acitivities compared to before the stroke. He does not drive a car anymore, is eligible for and uses Special Transport Service, and travels as a passenger in a private car. He travels less with public transport than before the stroke, and always with the support from his wife. He is satisfied with being a car passenger, yet misses being able to manage to travel independently.

Before the trip, his wife helped him to prepare the bus trip. She talked him through the different steps of the trip, i.e., how to choose the appropriate bus routes and pay for the bus trip. He made careful notes of the trip to ensure he would remember all trip details, and also brought extra money in case he had to use Special Transport Services. He needed some physical support by the observers during the walk to the different bus stops, i.e. one observer walked arm-in-arm beside him, whereas he managed to orientate to and from the bus stops independently. At the first bus stop, he was late noticing the arrival of the bus. Since he made no attempt to approach or make a sign to the bus driver, the bus drove away, and he had to wait for the next bus. When this arrived, he got on the bus, payed the fee with the discount card without any problems, and hurried to take a seat before the bus took off. Still, during the trip he asked several questions to the observers regarding which bus he was on, but also regarding other aspects in relation to the bus trip. Later he explained that asking questions is a strategy he uses to manage different types of tasks. He also concluded that his ability to memorize helped him to manage many tasks, i.e. finding the correct bus.

*Brita* - had a left-sided stroke but do not use any mobility device, even if she has poor balance and stamina. She has mild difficulties with attention and repetition, and also confirms that she has problems with fatigue, poor concentration, and doing things simultaneously. Brita states

she performs most of the daily activities as before the stroke. Still, she is dissatisified with performing less social activities than before the stroke. She walks outdoors as previously, but due to safety reasons, she no longer walks alone during evenings. Generally, she does not find it difficult to travel with bus, only when she has to carry groceries, and when she has to take a big step when the bus is not kneeling.

Brita wanted to take the bus to the churchyard to plant flowers on her husbands' grave, and she had planned the whole trip by herself. She walked to and from the bus stops independently, and without any problems. At one point she was late at the bus stop. Since the bus was about to leave, she ran over the zebra-crossing and made a sign to the driver that she wanted to get on the bus. She had no problems to enter, pay or find a seat. She recognized the stop where to get off, signaled in advance and got off without any problems. Afterwards, when she reflected on her trip with the observers, she said she had more problems to travel with bus immediately after her stroke but since she was an experienced bus traveler she had overcome her problems fast. She did not experience any anxiety in relation to travel with bus either.

*Christer* - has a hearing aid but no physical limitations. Ha has moderate problems with attention, and mild problems with construction, but does not experience any cognitive limitations himself. He has a low participation in daily activities, but says he performs most of the daily activities as before the stroke. He mainly performs gardening whereas his wife takes care of other household activities. He drives a car as previously, and despite the fact that he travels less with bus/train than before, mainly to familiar places, he is satisified with his travel possibilities. He says he chooses transport mode depending on the errand or activity he is pursuing.

When Christer planned the trip, he wanted to go into the city and back. He was aware of the timeschedule and the destinated traveltime, and made sure he had his mobile phone with him if something unpredictable happened. During the walk to the bus stop, his body kept on drifting to the right, and on the returntrip he walked into a bike on his right side, and stumbled. Afterwards, he said these types of situations sometimes happens when he is tired. Yet, he didn't think it was a problem. When the bus arrived, he got on the correct bus, paid with the discount card, but didn't manage to find a seat before the bus took off. He walked further to the back of the bus, and held on to the other seats while looking for a seat. He knew when to get off, and orientated independently in the surroundings. On one occasion he took

the wrong turn but he corrected himself when he noticed he was walking in the wrong direction.

*Disa* - lives together with her husband, who has an illness. Disa has several physical limitations in her upper and lower extremity. She has moderate problems with calculation, whereas she experiences more cognitive problems herself e.g., orientation to room, fatigue and poor concentration, doing things simultansously, talking and expressing herself, remembering planned activities as well as things heard, read or seen, planning, doing mental calculations, and writing. She is dissatisfied with performing household activities more seldom than before her stroke, and she participates less in social and leisure activities. Sometimes they receive help with household activities from one of their grandchildren. Disa uses a rollator for walking indoors and outdoors, but she doesn't drive a car. She travels more seldom with public transport, and wants to be accompanied by another person. Not because she needs any help, but because she feels insecure to travel alone. Despite this, she is satisfied with her travelling.

Disa planned the trip by herself, but on the day of the departure she changed the destination because she needed to run an errand. This resulted in a longer wait for the bus. Afterwards, she said she had gathered information regarding the trip by using the timetable booklet. During the walk to and from the different bus stops she had problems pushing the rollator on two occasions. At one time she pushed it into a kerbstone she didn't pay attention to, and the other time she had to use a lot of effort to lift the rollator over a kerbstone because she did not notice the ramp to the right. She had to lift the rollator when getting on and off the bus, because the driver did not kneel the bus. On the bus, Disa had no problem to buy the ticket with her discount card but checked if someone came behind her on the bus. Afterwards she explained that she asks them to wait to drive off until she is seated if she is the last person to enter. She said she avoids having to do too many things under time pressure since she is easily stressed. On the returntrip she asked one of the observers to push the signal button to notifiy the driver she wanted to get off at the next stop. Later, she said there was no signal button near her seat, and she did not want to stand up to reach another button further away because she was afraid she would loose her balance and fall. She also explained that she often worry she will not find a seat or that she may stumble or fall, which is why she does not like to travel alone.

*Ebba* - has several physical limitations in her upper and lower extremities. She relies on a stick for indoor as well as outdoor walking. Ebba has mild problems with memory and similarities, but experiences more cognitive problems herself in relation to fatigue and poor concentration, do things simultansously, verbal comprehension, talk and express herself, handle new environments and situations, remember planned activities as well as things heard, read or seen, write and read. Ebba said she is less involved in social actitivites compared to before the stroke. She also used to travel a lot before, mostly by car and sometimes with train or bus. Because she can no longer drive, she now travels less frequent. Still, she is satisfied with how she manages her travelling, i.e., local bus trips and occasional taxi rides.

Ebba uses a magnifying glass to read the timetable booklet, and therefore she has to prepare her trips in advance. She decided to take a certain bus route in order to reduce the waiting time at the bus-stop, and as a consequence she had to change buses to reach her final destination. She said she prefers to travel familiar routes so she can recognize herself in the surroundings. She had no orientation problems during the walk to and from the bus-stops. When she entered the bus, the bus kneeled, and she held on to the handrails with one hand, and the stick in the other without any problem. Before the trip, she described how she uses her discount card to pay the bus fee. She walked past the driver without validating her card and was called back by the driver. She did not manage to turn the card in the correct position, and eventually the bus driver took the card and validated the trip for her. The driver then started to drive away before she had the chance to get seated. She lost her balance but nevertheless managed to take a seat without any incident. Later, she explained how the whole situation had become too much for her to handle at the same time. When she was about to change buses, she hesitated, and therefore did not get off at the right place Therefore she missed the connecting bus and had to wait for the next to arrive. She also lost her balance and fell back in her seat, when the bus driver made a quick break. Furthermore, prior to the trip she pointed out that due to her poor eyesight she has to be attentive to traffic. Still, when she got off the bus, she didn't pay attention to a car that came up from behind and the car had to pull the breaks.

*Frida* - uses a stick for walking indoor. She has few physical limitations related to stamina, bending and kneeling. She has mild cognitive problems with attention and similarites, but also expressed self-perceived cognitive limitations in relation to fatigue and poor concentration, remember things heard, read or seen and with planning ahead. Frida has a decreased level of participation, but is satisfied with the fact that she can perform activities as before. Still, she

finds it difficult to accept that she is only half the person she used to be, referring to how her reduced memory and difficulty with calculation influence her ability to cook and bake. Furthermore, high anxiety and stress have made her afraid to get out alone. Because she feels she cannot rely on her abilities as before, and is easily stressed, she says she travels less often with bus or train than before the stroke.

When she planned the trip, Frida knew which route she wanted to take, but she had to have assistance by the observers to find the time of departure. The trip included several bus transfers, and during the trip she struggled to find the correct bus several times. She did not pay attention to the information signs, and later she said she never reflected on them at all. Instead, she made several attempts to ask the bus driver or other travellers, before, during as well as after the trip. Later she confirmed that posing questions to people was a strategy she used to manage different types of situations. At the same time she expressed she finds it difficult to remember, and thereby follow verbal instructions. She said she felt she should have been better prepared for the trip, and planned the different bus routes and time for departures etc on beforehand. On the other hand, she expressed how she normally did not have any problems when she travelled by bus together with her husband, and yet she did not find they normally planned their trips much in advance.

## Cross-case findings

The cross-case findings resulted in two main categories that represent facilitators related to either individual strategies or to support and solutions needed from the society. These are futher presented below, together with quotations from the participants (Figure 1).

# Insert Figure 1 about here

Facilitators in terms of personal characteristics and individual strategies - This main category comprised four sub-categories pertaining to personal characteristics and individual strategies; Making use of personal characteristics, Planning the trip in advance; Maintaining control and finding safe solutions; and Communicating with other people.

Making use of personal characteristics - Participants described how personal characteristics, such as being stubborn and courageous, was used as facilitators for managing bus travels. They argued that those who could make use of these characteristics could suppress feelings of low self-confidence or self-esteem, and get out in society and travel with bus on a regular

basis, crucial for maintaining their skills. On the other hand, they described how it had also become necessary for them to work on their personal characteristics in order to facilitate bus travelling, e.g., learn to handle upset feelings if they missed a bus, and practice how to handle stressful situations.

Planning the trip in advance - Participants shared how they planned their trips in advance to decrease feelings of stress. For instance, they did not travel with bus on days with bad weather conditions, if roads were icy or slippery. They also kept track of possible hassles during the route, including all parts of the travel chain such as construction work during the route. Hence, they tried to stay to already known routes, and sometimes they chose not to travel at all. The planning also included writing down all the stops at the current route, possible departure times as well as type of errands, shops etc. Some described how they found it difficult to carry things with them, including having to remember and handle many bags. Therefore, they closely planned what they needed to bring, and some also said they tried to manage without any bag at all.

They planned for unexpected events, for instance by bringing extra money and a mobile phone if they needed to reach for help. Some always planned their bus travels together with a travelling companion, either a family member or a friend. This made them feel more secure, not necessarily because they needed help from this person. As one participants said: "We help each other [to lift the rollators]... and stick together. I don't know but I get nervous when I travel alone and it can happen anytime anywhere. It is very important for me [to travel with a companion].

Maintaining control and finding safe solutions - Participants shared several actions they undertook to maintain control and find safe solutions during their trips. They made sure they moved safely and avoided to expose themselves to any risk. They always kept an eye on the ground to avoid falls, made sure to turn their head to compensate for any visual field loss, and never walked in traffic if fatigued. When they were on the bus they always held on to the rails or seats, and placed themselves close to the windows to compensate for poor balance.

They tried to avoid stress, because it exposed them to more problems. They made sure they had plenty of time to get on the bus, find a seat, and if they missed getting on or getting off a bus in time they persuaded themselves that they were in no hurry and could wait for the next opportunity. Moreover, they avoided stress by neglecting to get on a bus if the bus

was crowded. Otherwise, there was a risk they may not get a seat, and they also found it difficult to manage the limited space etc. As one person shared: "...if there is a lot of people already on the bus, then I wait until the next bus arrives...I might have to wait a couple of minutes but then I don't have to handle all the noice and hullabaloo."

Another action they undertook to maintain control during bus trips, was to constantly stay orientated to where the bus was on the route. This could be challenging if the bus windows were dirty, if the text screen announcing the different bus stops was out of order, or if the text screen and the automatic voice machine gave contradictory information. They said they did not trust the automatic information and used all information simultaneously to make sure they stayed orientated.

Communicating with other people - They used different strategies to communicate their needs with other people – passengers, people they met on the street and drivers – during their travels. Some emphasized how they made sure their assistive devices were noticed by other people. Others described how they payed certain attention to the bus drivers, so they did not drive off before the participants had found a seat or got off the bus safely.

Another strategy was to pose questions directly to other people, for instance how to find their way to the correct bus stop or if they could give them their seat, if there were no other comfortable seats available.

Facilitators in terms of support and solutions from the society - This main category comprised three sub-categories pertaining to support and solutions from the society: Having different transport modes to choose between; Having an accessible travel chain, and Receiving support from others.

Having different transport modes to choose between - Participants described how many people after stroke experience fatigue, anxiety and feel insecure, which could explain why many find it difficult to manage bus travels, and prefer to take a taxi. They said the opportunity to choose between different modes of transport could be a facilitator for getting out in society, and argued that if it was possible to combine bus travels with Special Transport Services in a more flexible way, travelling with bus would probably increase among people with stroke.

They also emphasized how the possibility to choose direct buses or buses with fewer stops would decrease the number of possible hassle during a trip. Hence, travelers would worry less about their limitations, and feel more confident they could manage bus travels.

Having an accessible travel chain - Participants described how the possibility to travel independently with local buses not only require accessible buses but an accessible travel chain. That is, public buildings and outdoor environments also need to be accessible. They gave examples of how automatized door-openers facilitated access to buildings, and how an even surface on walking pathways and pavements could decrease stumbles and falls. In turn, they said this would also decrease anxiety connected to fear of falls.

Another aspect they pinpointed was how clear markings at the bus stops as well as on the buses were called for in order to facilitate orientation to the buses. They preferred digital signs to other type of signs, since only relevant information would be present. In turn, this could facilitate the possibility to find and comprehend information. They also suggested loud speakers at the bus stops stating which bus that was leaving and from where, as well as their current departure time. Digital signs on the front of the buses, and use of colours instead of letters or numbers to identify the buses and their destination were also called for. As one participant narrated: "...it can be green or purple or whatever colour as long as the buses are marked the same way as the bus stops. It would be more logical and easier to find it [the correct bus]."

Different facilitators in relation to getting on and off the bus in a safe manner were described. For instance, buses with pull out ramps and technical equipment that made it possible to get close to the pavement, and facilitated kneeling of the bus. Other examples were better contrast markings inside the buses to decrease the risk of falls, something that happened fairly frequent according to the participants.

Another aspect they mentioned was how the pre-charged validation card for payment had facilitated their independence during bus travels since they no longer had to handle money or manage numbers. This had removed previously stressful situations.

Receiving support from others - Participants shared how the opportunity to get instructions, and being able to practice in real life situations together with a professional, was highly valued. Overall, the possibility to participate in rehabilitation interventions was often mentioned as a facilitator for being able to travel by bus. This applied to more, as well as less complex situations in all parts of the travel chain.

### **Discussion**

This study focused on people with mild cognitive limitations after stroke, and public transport, e.g., local bus travels. Our case descriptions revealed similar barriers as previous studies have presented, especially in relation to when necessary information is obtained, during interaction with traffic, as well as personal barriers, e.g., a lack of self-confidence that a trip can be managed without obstacles. This supports the notion that in order to capture the variety of barriers in relation to travelling with public transport, assessments have to consider all parts of the travel chain [15, 16]. Our results also show that even if our participants managed to travel with bus with only minor difficulties, if unexpected events, or too many incidents occurred momentarily, the situation could become complicated and demanding for them. As a result, they constantly had to be prepared to handle unexpected situations and find solutions to problems. This can put a lot of strain on a person, and be overwhelming for those who experience a lack of self-confidence and a low self-efficacy, common features after stroke [27], and also described in previous studies [15, 16]. In turn, this can lead to an overestimation of anticipated constraints [6, 17] or increase the level of challenge to such an extent that people with these types of limitations cease to travel with public transport, common among people with stroke [13]. However, our study also present facilitators that can help people with cognitive limitations after stroke to overcome experienced barriers, on an individual as well as a societal level.

In the cross-case findings, our participants described several facilitators important for managing bus travels. Personal characteristics such as stubborness and courageousness were described as facilitators since they were thought to compensate for low self-confidence and self-esteem. At the same time, they emphasized the importance of support through rehabilitation interventions that could enable them to regain their ability to manage outdoor mobility, including travelling with bus. Hitherto, only one such intervention – developed by occupational therapists – targeting outdoor mobility for people with stroke has been developed and evaluated [28]. Still, it did not specifically focus on the needs of those with cognitive limitations. Today, interventions that target public transport is an underdeveloped area where occupational therapists can play an important role in developing, evaluating and implementing such interventions. This is particular important since people in general live longer, also those with different limitations. Thus, rehabilitation interventions that target different transport modes as well as general outdoor mobility are not only important for those who have sustained a stroke, but for older people in general [29].

During the last decade, interventions that use self-management strategies have been developed, and used among people with stroke [30]. Self-management is based on social construct theory [31] and aim to increase participants' self-efficacy and their ability to set goals, construct actions plans, and manage problem-solving in their everyday life [32]. This is congruent with Logan et al. [28], who emphasized the importance of teaching strategies with the aim of enhancing self-confidence in relation to managing outdoor mobility. However, self-management interventions for people with stroke have, so far, mainly focused on peoples' ability to handle the consequences, i.e., impairments, after a stroke [30, 33], rather than aspects of participation. Currently, a self-management intervention focusing on public transport and cognitive limitations after stroke has been developed, and results from a feasibility study is under way [34].

Our participants describe several facilitators important for managing bus travels during the travel chain. Access to, and the ability to interpret information were an important facilitator, but can be particular challenging when people with cognitive limitations after stroke travel with public transport [15]. Previous research has shown that people with covert limitations such as pain, speech difficulties or difficulties interpreting have a greater need for information concerning different aspects of travel, beyond aspects related to their limitations, and yet little consideration is usually given these groups in public transport planning [35]. Aspects that could facilitate information provision was surveyed by Asplund et al. [6], but surprisingly, no suggestions of how information in relation to how bus travels could be improved for people with stroke were received. In contrast, our participants emphasized how information in the travel chain could be facilitated by using more simplistic ways of communicating information, e.g., by having identical markings or colours connecting buses with corresponding bus stops, and replacing manual signs with electrical signs in order to provide only updated information. Our findings thereby contribute with important knowledge of how information in relation to public transport can be improved for people with cognitive limitations.

Somewhat surprisingly, new technology was not particularly highlighted as a facilitator by our participants. One explanation may by that our participants experienced difficulties using new technology, and therefore did not utilize e.g. smartphones, even if they said they used a mobile phone. It is also possible that because they were older, and data was collected some years ago, many did not frequently use new technology. Yet, there is reason to believe that new technology will be used more frequently also among the older population in the future. Previous studies have shown that everyday technology, e.g., mobile phones and

gps, can be used to improve performance in different daily activities [36]. Such equipment is also developed by public transport authorities with the aim to facilitate travel information asked for. New technology can be difficult for non-experienced users, and even more complicated for those with cognitive limitations. No application has yet been specifically designed with the purpose of facilitating public transport among people with cognitive limitations. Still, computer-based assisted technology may have a potential to support performance in different activities for people with cognitive limitations after stroke [37], even though public transport was not among any of the targeted activities. Developing technological support for this group is therefore another area where societal input is called for, and where occupational therapists can contribute with substantial knowledge.

Regarding methodological considerations, our aim was to provide a rich illustration of facilitators for bus travelling among people with cognitive limitations after stroke. Taking advantage of the fact that data was collected with multiple sources [18], where different methods captured different aspects, and complemented each other, was a strength. That is, through the case descriptions, each participant's barriers could be depicted together with how these problems were solved. At the same time the cross-findings made it possible to give a broader picture of all participants' experiences in relation to facilitators that can enhance bus travels for this group. Because we used a qualitative approach, the findings cannot be generalized to all people with cognitive limitations after stroke. It is possible that if we had included other participants in our study, or if data had been collected on another occasion, this could have influenced the narratives as well as the cross-case findings. The data collection and analysis were carried out by different researchers from different professional backgrounds which is a methodological strength, especially during the data analysis when data was scrutinized from different perspectives.

In conclusion, this study takes a new approach by specifically describing facilitators for travelling with bus. Building on previous research, our findings give an enhanced understanding of how travelling with bus among people with mild cognitive limitations after stroke can be facilitated. For this group, the possibility to find and interpret information during travels are specifically important to consider for transport authorities when designing and planning public transport in the future. It is also important to develop interventions that target self-efficacy during outdoor mobility, in particular local public transport, for people with cognitive limitations. By using self-management strategies or other problem-solving methods such interventions can be developed. Occupational therapists can take a leading role

in this work, co-operating with societal planners, highway departments and public transport authorities, as well as people with stroke.

# Acknowledgements

The authors thank the participants, and the PhD students for performing the data collection, and The Swedish Transport Administration and Vinnova who funded the data collection. This study was prepared within the Centre for Ageing and Supportive Environments [CASE] at Lund University, financed by the Swedish Council for Working Life and Social Research.

#### **Disclosure of interest**

The authors report no conflict of interest.

#### References

- Hachinski V, Iadecola C, Petersen RC, et al. National Institute of Neurological Disorders and Stroke-Canadian Stroke Network vascular cognitive impairment harmonization standards. Stroke. 2006;37:2220-2241.
- Erkinjuntti T. Vascular cognitive deterioration and stroke. Cerebrovasc Dis. 2007;24
   Suppl 1:189-194.
- 3. Claesson L, Linden T, Skoog I, et al. Cognitive impairment after stroke impact on activities of daily living and costs of care for elderly people. The Goteborg 70+ Stroke Study. Cerebrovascular Dis. 2005;19(2):102-109.
- 4. Carlsson GE, Moller A, Blomstrand C. A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in persons <75 years. Disabil Rehabil. 2004;26(23):1373-1380.
- 5. Adamit T, Maeir A, Ben Assayag E, et al. Impact of first-ever mild stroke on participation at 3 and 6 month post-event: the TABASCO study. Disabil Rehabil. 2015;37(8):667-673.
- 6. Asplund K, Wallin S, Jonsson F. Use of public transport by stroke survivors with persistent disability. Scand J Disabil Res. 2012;14(4), 289-299.
- 7. Finestone, HM, Marshall, SC, Rozenberg, D, et al. Differences between poststroke drivers and nondrivers: Demographic characteristics, medical status, and transportation use. Am J Phys Med Rehabil. 2009;88(11):904-923.
- 8. Hälso- och sjukvårdslag (SFS 1982:763). Stockholm: Socialdepartementet.
- 9. Trafikanalys. Färdtjänst och riksfärdtjänst 2015 Statistik 2016:24 [Special transport services and national special transportation services Statistics 2016:24], Stockholm.

- 10. Ståhl, A. Planning for a Community Responsive Public Transport System, The Swedish Model. Broadening our Vision of Housing and Community Care for Older People. 1998:21-28. Anchor Research, England.
- 11. Wretstrand A, Ståhl A. User needs and expectations relative to accessible transport. Framework for mobility planning, EuroAccess WP2-Lund-Deliverable2-v.1.0. 2008. EU:s Sixth Framework Programme.
- 12. Logan PA, Gladman JRF, Radford KA. The use of transport by stroke patients. Br J Occup Ther. 2001;64:261-264.
- 13. Wendel K, Ståhl A, Risberg J, et al. Post-stroke functional limitations and changes in use of mode of transport. Scand J Occup Ther. 2010;17(2):162-174.
- 14. van der Ham IJ, Kant N, Postma A, et al. Is navigation ability a problem in mild stroke patients? Insights from self-reported navigation measures. J Rehabil Med. 2013;45(5):429-433.
- 15. Risser R, Iwarsson S, Ståhl A. How do people with cognitive functional limitations post-stroke manage the use of buses in local public transport? Transp Res Part F, 2012;14F(1):111–118.
- 16. Rosenkvist J, Risser R, Iwarsson S, et al. The challenge of using public transport: Descriptions by people with cognitive functional limitations. J Transp Land Use. 2009;2(1):65-80.
- 17. Barnsley L, McCluskey A, Middleton, S. What people say about travelling outdoors after their stroke: a qualitative study. Aust Occup Ther J. 2012;59(1):71-78.
- 18. Yin RK. Case Study Research Design and Methods [4th ed.]. Thousand Oaks: Sage Publications, Inc, 2008.
- 19. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Thousand Oaks, CA: Sage Publications, Inc, 2011.
- 20. Wendel K, Risberg J, Pessah-Rasmussen H, et al. Long-term cognitive functional limitations post-stroke: Objective assessment compared to self-evaluations and spouse reports. Int J Rehab Res. 2008;31(3),:31-239.
- 21. Iwarsson S, Slaug B. The Housing Enabler. An instrument for assessing and analysing accessibility problems in housing. Nävlinge och Staffanstorp: Veten & Skapen HB & Slaug Data Management AB; 2001.
- 22. Kiernan RJ, Mueller J, Langston JW, et al. The Neurobehavioral Cognitive Status Examination: a brief but quantitative approach to cognitive assessment. Ann Intern Med. 1987;107(4):481-485.

- 23. Wendel K, Ståhl A, Iwarsson S. Inter-rater agreement of a modified and extended Swedish version of the Frenchay Activities Index [FAI]. European Journal of Ageing, 2013;10(3):1-9.
- 24. Holbrook M, Skilbeck CE. An activities index for use with stroke patients. Age and Ageing. 1983;12(2):166-170.
- 25. Flanagan JC. The critical incident technique. Psychol Bull. 1954;51(4):327-358.
- 26. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277-1288.
- 27. Horne J, Lincoln NB, Preston J, et al. What does confidence mean to people who have had a stroke? A qualitative interview study. Clin Rehabil. 2014;28(11):1125-1135.
- 28. Logan PA, Armstrong S, Avery TJ, et al. Rehabilitation aimed at improving outdoor mobility for people after stroke: a multicentre randomised controlled study (the Getting out of the House Study). Health Tecknol Assess 2014;18(29):1-113.
- 29. Boome K, McKenna K, Fleming J, et al. Bus use and older people: A literature review applying the Person-Environment-Occupation model in macro practice. Scand J Occup Ther. 2009;16(1):3-12
- 30. Lennon S, McKenna S, Jones F. Self-management programmes for people post stroke: a systematic review. Clin Rehabil. 2013;27(10):867-878.
- 31. Bandura A. Self-efficacy: The exercise of control. Basingstoke, Great Britain: W.H. Freeman & Co Ltd.; 2007.
- 32. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1-7.
- 33. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil. 2006;28(13-14):841-847.
- 34. Carlstedt E, Iwarsson S, Ståhl A, Pessah-Rasmussen H, Lexell EM. Multiple case-study of a new self-management intervention focusing on bus travels for people with cognitive impairment after stroke (In manuscript).
- 35. Waara, N, Brundell-Freij K, Risser R, et al. Feasible provision of targeted traveler information in public transportation: segmentation based on functional limitation. Transp Res Part A. 2015;74:164-173.
- 36. Lindén A, Lexell J, Larsson Lund M. Improvements of task performance in daily life after acquired brain injury using commonly available everyday technology. Disabil Rehabil Assist Technol. 2011;6(3):214-224.

37. Lindqvist E, Borell L. The match between experienced difficulties in everyday activities after stroke and assistive technology for cognitive support. Technol Disabil. 2010:22(3):89-98.

Table 1. Characteristics of the six cases.

Sociodemographics	Axel	Brita	Christer	Disa	Ebba	Frida
Age (years)	79	73	69	64	76	76
Sex (Male/Female)	M	F	M	F	F	F
Living conditions	Partner/family	Alone	Partner/family	Partner/family	Alone	Partner/family
Type of stroke	Right-sided	Left-sided	Left-sided	Rigt-sided	Left-sided	Left-sided
	Infarction	Infarction	Infarction	Infarction	Infarction	Haemorrhage
Housing	Apartment	Apartment	Single-dwelling	Apartment	Apartment	Single-dwelling
Mobility device:						
indoors (i); outdoors (o)	Stick (o)	None	None	Rollator (i/o)	Stick (i/o)	Stick (o)
Disability (sum score)						
Physical limitations <sup>1</sup>	2	2	1	7	6	2
Assessed cognition <sup>2</sup>	3	2	2	1	2	2
Self-evaluated cognition <sup>3</sup>	1	3	0	9	9	3
Extended Frenchay Activity Index <sup>4</sup>	22	33	32	37	34	40

Note: <sup>1</sup>Number of physical limitations according to the Housing Enabler (HE) [19], range 0-12. <sup>2</sup>Number of affected areas according to Cogntistat [20], range 0-10; <sup>3</sup>Number of self-assessed cognitive limitations [18], range 0-18; <sup>4</sup>Extended Frenchay Activity Index (E-FAI) [21], range 0-66, where a higher score denotes a higher level of participation.

Figure 1. An overview of the categories and sub-categories in the findings.					
CATEGORIES	SUB-CATEGORIES				
Facilitators in terms of personal characteristics and individual strategies	Making use of personal characteristics				
	Planning the trip in advance				
	Maintaining control and finding safe solutions				
	Communicating with other people				
Facilitators in terms of support and solutions from the society	Having different transport modes to choose between				
	Having an accessible travel chain				
	Receiving support from others				