

Use of public transport by stroke survivors with persistent disability

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Use of public transport (bus, train, air, ship) by persons disabled after stroke is an expression of autonomy and facilitates social interactions. Based on Riks-Stroke, the Swedish stroke register, 882 persons with persistent, moderate or severe physical disability (mean age 71 years) responded to a questionnaire 12–28 months after stroke. A minority of the respondents had travelled by bus (21%), train (9%), air (14%) or ship (12%) during the last year. Barriers perceived by persons that had abstained from travelling were dominated by physical constraints, but there were also frequent cognitive constraints. Fear of travelling was not perceived as a major constraint. The majority of persons who had actually used public transport did not report any negative experiences. Air and ship journeys were generally perceived as somewhat less troublesome than journeys by bus or train. Thus, public transport is used infrequently in people moderately or severely disabled after stroke. Anticipated cognitive constraints contribute importantly to non-use of public transport. Disabled stroke survivors who have not used public transport may overestimate the actual barriers to use of public transport.

Keywords: stroke; disability; public transport

Introduction

Disability after stroke encompasses not only difficulties with basic and instrumental activities of daily living, but also role activities, social activities, and leisure activities (Jette 2006). The ability to participate in social activities is highly dependent on mobility outside home. Most previous studies on stroke survivors' mobility have focused on driving performance (Legh-Smith, Wade and Hewer 1986; Poole, Chaudry and Jay 2008). Driving may be regarded as an expression of autonomy and contributes considerably to quality of life by allowing recreational activities and social relationship to be maintained (Legh-Smith, Wade and Hewer 1986). Many stroke survivors have, however, physical, perceptual and cognitive impairments that limit their ability to drive (Finestone et al. 2009).

Much less attention has been paid to the use of public transport by persons who are disabled after stroke. Post-stroke depression (Eriksson et al. 2004; Kouwenhoven et al. 2011), anxiety (Åström 1996; Ferro, Caeiro and Santos 2007) and a profound role change (Vanhook 2009) are factors that may limit the use of public transport in people with disabling stroke. In addition, the actual risk of falling during public

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transportation is increased among the elderly, even if they are not disabled (Broome et al. 2009).

Being able to travel by bus, train, air or ship is, like driving a car, an expression of autonomy and facilitates social interactions. The same impairments – physical, perceptual and cognitive – may limit the ability to use public transport. Applying the International Classification of Functioning, Disability and Health (ICF) conceptual framework, the limitations may involve both activities and participation.

As reviewed by Broome et al. (2009), transport is an integral precursor to engaging in many social relationships, hobbies, and leisure pursuits contributing to older people's quality of life. Transactional models focusing on person–environment relationships in the use of transport and other participation in societal activities emphasize that people, their activities and roles, and the environments in which they live, work and play over their lifespan are in dynamic interaction (Iwarsson and Ståhl 1999). A salient feature of 'personal' is the presence of disability, and a disability–environment approach is essential in efforts to improve participation and autonomy of disabled persons (Stucki, Cieza and Melvin 2007; White et al. 2010). In support of this contention, the presence of public transport in the neighbourhood has been shown to be associated with a considerably better chance of not feeling limited in social, leisure, and work role activities, and instrumental activities of daily living (White et al. 2010). Differences in access to public transport in urban compared with rural areas may be related to the experience of being disabled (Clarke and George 2005).

In the Scandinavian countries, most elderly people use public transport; thus, only 7% of the general population in the 65–74 year age range and 17% of people 75 years or above in Norway reported physical barriers to the use of public transport (Nordbakke 2011). Few studies, in Scandinavia or elsewhere, have been published on the use of public transport by people disabled by stroke. In a study of 77 stroke survivors in Sweden, more than a third reported decreased (or ceased) use of bus and train transport compared with before stroke; the decline was associated with physical constraints and depression (Wendel et al. 2009). In a British survey of transport use in 42 consecutive patients 1 year after stroke, 50% had used transport on their own. The use was closely related to other extended activities of daily living (Logan, Gladman and Radford 2001). A qualitative study of 24 stroke patients identified fear of injury or embarrassment from falling, an associated lack of confidence, and inadequate information about transport services as barriers to travelling (Logan, Dyas and Gladman 2004).

Two intervention studies have indicated that it may be possible to influence the use of public transport in persons with disability after stroke. Thus, in a randomized controlled trial involving 168 community-dwelling people with a clinical diagnosis of stroke in the previous 36 months, Logan, Gladman et al. (2004) targeted occupational therapy intervention at home; this increased outdoor mobility. In a small before-and-after study, travelling increased among people who had had a stroke when a behavioural intervention programme was introduced in community rehabilitation teams (McCluskey and Middleton 2010).

In view of the very limited scientific information available on the use of public transport by disabled survivors of stroke, we undertook a large-scale quantitative exploratory study. The use of public transport by 822 persons with moderate and severe disability late after stroke is reported by mode of public transport (bus, train, air and ship). In those who used public transport, we explored their experiences, and

in those who did not use it, we asked for the barriers they anticipated. We hypothesized that not only physical constraints but also cognitive constraints and fear of travelling would contribute importantly to perceived barriers against use of public transport. The results are of relevance for national and local transport authorities in planning of a more disability- and elderly-friendly environment.

Methods

Riks-Stroke, the Swedish stroke register, was established to support quality improvement in stroke services. It covers all 76 hospitals in the country that admit patients with acute stroke and validations have shown that at least 85% of all hospital admissions for acute stroke are included in the register (Asplund et al. 2011). In addition to data collected during the acute phase of stroke, Riks-Stroke includes a three-month follow-up by questionnaire, including patient-reported outcomes and rehabilitation after stroke. Case record forms are available on Riks-Stroke’s website (www.riks-stroke.org).

Patients eligible for the present study were those who were hospitalized for acute stroke during the period August 2007–September 2008, were recorded in Riks-Stroke and who reported that they were dependent on other persons for their physical mobility at the three-month follow-up. As shown in Figure 1, both random and strategic selections of patients were used. To include an adequate number of younger individuals, all eligible stroke patients below the age of 50 years were selected. Older subjects were randomly selected in two strata; 50–64 years and ≥65 years. In order to reach a sufficient number of persons with experience of transport by ship, all stroke patients on the island of Gotland (served by ferry-boats) were selected.

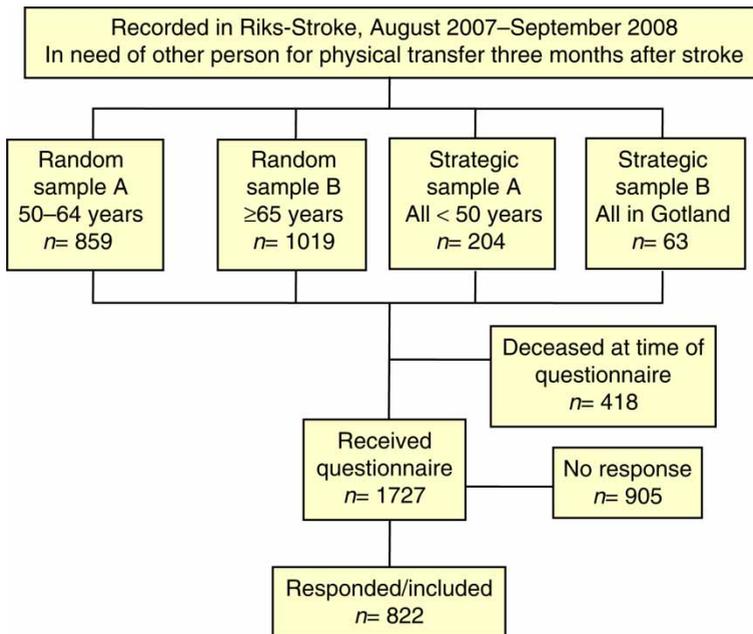


Figure 1. Flow chart showing selection of participants in the survey, responders and non-responders.

The questionnaire was distributed in September 2009 – i.e. 12–28 months after their index stroke – to a total of 1727 persons.

The questionnaire was designed in close collaboration with experts at the Swedish Transport Agency, the governmental administration concerned, which commissioned the present study. Key questions had been used by the agency in previous similar mappings of access for disabled persons to public transport. Representatives of the national patient organization Stroke-Riksförbundet reviewed the relevance of the questions.

In a non-responder analysis, data obtained during the acute phase of stroke and at the three-month follow-up were used. The study was designed to permit subgroup analyses; the study permitted detection of an absolute percentage difference of 15 in subgroups of 80 patients or more with an alpha error of 5% and a power of 80%. Statistical analyses were performed using SPSS version 19.

Results

Characteristics of responders

From the 1727 persons to whom the questionnaire was distributed, 822 responses were received (response rate 47.8%). The questionnaire had been answered by the disabled person without assistance in 263 instances (32.8%), the disabled person with assistance by another person in 303 instances (37.8%), by a family member in 175 instances (21.8%) and by another person in 61 instances (7.6%).

Mean age among responders was 71 years, 51% of them were women and 31% had had a recurrent stroke as the index event. Comparisons between responders and non-responders showed that the two groups were similar with respect to mean age, sex distribution and distribution of first-ever vs. recurrent stroke (Table 1). The proportion of cohabitant persons was significantly larger among responders compared with non-responders.

The selection criteria included impaired mobility after stroke, as reported by the patient at the Riks-Stroke three-month follow-up. At the time of the questionnaire (12–28 months after stroke), nearly all respondents had remaining mobility impairment, and the majority needed assistance of another person for transfer outdoors (Table 2). However, 26% stated that they managed transfers outdoors

Table 1. Comparison of basal characteristics in responders and non-responders.

Items		Responders (<i>n</i> = 822)	Non-responders (<i>n</i> = 905)	<i>p</i> -value
Age in years, mean (95% CI)		70.6 (69.7–71.5)	69.4 (68.4–70.4)	
Sex, <i>n</i> (%)	Men	401 (49%)	448 (50%)	0.765
	Women	421 (51%)	457 (50%)	
Previous stroke, <i>n</i> (%)	Yes	249 (31%)	263 (30%)	0.510
	No	550 (69%)	623 (70%)	
Living conditions three months after stroke, <i>n</i> (%)	Living alone	309 (38%)	449 (51%)	< 0.001
	Cohabitant	460 (56%)	438 (49%)	

Table 2. Disability and self-perceived health in responders 12–28 months after stroke.

Question	Response alternatives	n (%)
Do you have any of the following disabilities?	Impaired mobility	795 (97%)
	Difficulties in understanding or interpreting information	185 (23%)
	Impaired vision	151 (18%)
	Impaired hearing	108 (13%)
	Other	203 (25%)
How is your physical mobility?	Can transfer without assistance of another person indoors and outdoors	216 (26%)
	Can transfer without assistance of another person indoors but not outdoors	239 (29%)
	Need assistance by another person for all transfers	335 (41%)
	No response	32 (4%)
Do you use a walking aid or wheelchair?	No walking aid	80 (10%)
	Walking stick/crutches	180 (22%)
	Walker	260 (32%)
	Manual wheelchair	411 (50%)
	Electric wheelchair	124 (15%)
How do you assess your general health?	Very good	24 (3%)
	Rather good	411 (50%)
	Rather poor	258 (31%)
	Very poor	70 (9%)
	Do not know/no response	59 (8%)

without personal assistance. A substantial proportion (23%) had difficulties in understanding or interpreting information; they had usually had assistance when responding to the questionnaire. Most of the responders selected intermediate alternatives (rather good/rather poor) for their self-perceived health.

Use of public transport

The great majority of the responders had not used public transport during the last year. Bus had been used by 166 responders (21%), train by 72 (9%), air transport by 108 (14%) and ship by 99 (12%; it should be noted that a strategic sampling of Gotland islanders resulted in over-representation of potential ship users). Of those who had travelled by bus, nearly half (46%) had used regular local buses, whereas half had travelled with long distance, charter or special handicap-adjusted buses. The proportion in need of another person for all transfers was similar in persons using bus (46%), air (44%) and ship transport (43%) but significantly lower in people who had travelled by train (28%) ($p < 0.05$ by Fisher's exact test, two-tailed).

For bus and train journeys, the proportions travelling were strongly dependent on the place of living with low proportions in rural areas and small communities and higher proportions in big cities (Figure 2). For journeys by air and ship, there were no significant differences with regards to place of living.

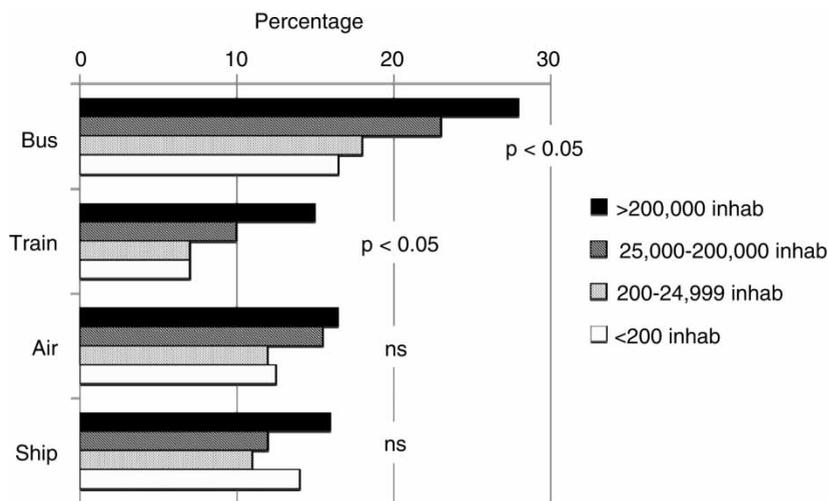


Figure 2. Proportion of disabled stroke survivors that had used different modes of public transport on at least one occasion in the last year, by place of living. Notes: p -values calculated using Fisher's exact test; ns, non-significant.

Experiences of using public transport

Among persons who had experience of travelling by public transport, a majority of those who expressed any opinion reported that they had no problems at various stages of the travel (Table 3). With all means of transport, physical constraints in embarking, moving around on-board and disembarking were perceived as the dominating problems. However, problems with embarkation and disembarkation were significantly fewer with ship travel than with other means of public transport.

As for information, buying tickets and personal services, there were no significant differences between the four modes of transport (Table 3). The most deviant observation was that a large proportion of train passengers had problems with information in terminals. Air and ship travellers seemed have experienced somewhat fewer problems with personal services, but the differences were not statistically significant (Table 3).

Barriers to use of public transport

When asked for reasons for not travelling, many (31–56%, depending on means of transport) responded that they had no need to use public transport. However, substantial proportions (45% for bus; 30% for train; 31% for air; and 28% for ship transport) reported that they may have had a need or a desire to travel by public transport but had not used it.

Their reasons for not travelling were dominated by anticipated physical constraints in transfers to and from buses, trains, airports, and ships and embarking and disembarking (Table 4). The response profiles were very similar for bus and train transport, whereas for air travel considerably lower proportions anticipated problems in getting to and from the airport or embarking/disembarking.

In addition to physical constraints, 29–43% reported anticipated cognitive constraints that involved problems in finding information, making reservations,

Table 3. Number and proportions of stroke survivors using public transport who reported problems when travelling.

Travel element	Bus (<i>n</i> = 166)	Train (<i>n</i> = 72)	Air (<i>n</i> = 108)	Ship (<i>n</i> = 99)
Information (e.g., time schedules, prices), <i>n</i> (%)	17 (11%)	6 (9%)	11 (10%)	5 (5%)
Booking or buying ticket, <i>n</i> (%)	17 (11%)	7 (10%)	9 (9%)	7 (7%)
Information in terminal (or bus stop), <i>n</i> (%)	22 (14%)	16 (24%)	10 (10%) ^a	8 (8%) ^a
Embarking and disembarking, <i>n</i> (%)	49 (27%)	17 (25%)	29 (27%)	18 (18%) ^b
Moving on board, <i>n</i> (%)	59 (38%)	28 (42%)	40 (39%)	26 (26%)
Personal service, <i>n</i> (%)	22 (14%)	10 (15%)	7 (7%)	10 (10%)

Notes: ^a*p* < 0.05 vs. train (Fisher's exact test); ^b*p* < 0.05 vs. bus.

buying tickets and orientation at terminals (Table 4). Less than a fifth of the responders (18–19%) reported that fear of travelling was a constraint; the proportion was independent of mode of public transport.

Suggested areas for improvement

The questionnaire also included open-ended questions and an opportunity to suggest improvements in public transport so as to make it more accessible to disabled people. Table 5 summarizes the most frequently addressed areas. Many of the comments concerned problems with embarking, disembarking and moving around on-board and a request for more space at handicap seats (or cabins on ships). The issue of more and better handicap toilets was frequently addressed.

There were also specific areas of improvement for specific means of transport. Thus, bus passengers often asked for more level-adjustable buses. They also frequently had comments on driving – stopping closer to the pavement, not starting

Table 4. Anticipated constraints to travelling reported by stroke survivors who had not travelled.

Anticipated constraints	Bus (<i>n</i> = 368)	Train (<i>n</i> = 250)	Air (<i>n</i> = 252)	Ship (<i>n</i> = 229)
Physical constraints				
Transfer to and from public transport	310 (84%)	205 (82%)	155 (62%) ^a	184 (80%)
Embarking and/or disembarking	325 (88%)	201 (80%)	152 (60%) ^b	165 (72%) ^c
Cognitive and emotional constraints				
Booking and payment	129 (35%)	92 (37%)	72 (29%)	67 (29%)
Orientation problems	149 (40%)	108 (43%)	80 (32%)	88 (38%)
Fear	66 (18%)	44 (18%)	42 (17%)	42 (18%)
Other	88 (24%)	48 (19%)	50 (20%)	42 (18%)
Do not know	15 (4%)	15 (6%)	22 (9%)	15 (7%)

Notes: Data are presented as *n* (%); ^a*p* < 0.0001 vs. bus, train and ship (Fisher's exact test); ^b*p* < 0.001 vs. bus and train; ^c*p* < 0.05 vs. bus and train.

Table 5. Suggested areas of improvement in response to open-ended questions.

Domain	Suggested areas of improvement	Bus	Train	Air	Ship
Physical/ technical	Improved embarking/disembarking, various suggestions	+++	+++	+++	++
	Better possibilities to bring wheelchair on board (e.g. ramp)	+++	+++	+	0
	More space at handicap seats (or cabins)	+++	++	+++	++
	Handicap toilets	++	++	++	++
Service	More assistance by staff, including help with luggage	+++	+++	+	++
	Reduced pace	++	0	0	+
Information	Improved information on handicap seats, access to ramps and possibility to get assistance	0	+++	+	+
	Simpler booking system	0	+	0	+

Notes: + + +, frequently suggested; + +, moderate number of suggestions; +, occasionally suggested; 0 no responses.

until seated, softer and less stressful driving, etc. Among ship passengers, there were frequent comments on thresholds and carpets making it difficult to manage a wheelchair on board. Ship passengers also frequently asked for more disability-friendly elevators.

Discussion

The present study shows that only a relatively small minority of stroke survivors with extensive functional impairments use public transport, whether by bus, train, air or ship. The anticipated barriers perceived by the disabled persons that had not used public transport were dominated by physical constraints, but there was also a considerable contribution of cognitive constraints. Fear appeared to be considerably less of a concern. In contrast to this rather gloomy picture of using public transport among those who had not used it, persons who had actually used public transport provided a more positive description, though still dominated by physical constraints. It may be that stroke survivors who have not used public transport may overestimate the actual barriers to travelling.

A strength of the present study is its size, permitting subgroup analyses and analyses by different modes of public transport. It is, by far, the largest study performed on the use of public transport after stroke. The combination of random and strategic selection of disabled people invited to the present survey ensured that a broad age spectrum was represented. For the first time, data on the use of public transport by air and ship late after stroke are presented.

The inclusion criteria involved the presence of moderate and severe mobility disability three months after stroke; this resulted in a group of respondents with extensive impairment of mobility, two-thirds of whom used a wheelchair at the time of the survey 12–28 months after stroke. Thus, the respondents represent a group of severely disabled persons, and not the entire spectrum of stroke survivors. The proportion not using public transport was very high in the present study (e.g., 79% for bus use). This is to be compared with 7% of the general population in the 65–74

year age range and 17% of people aged 75 years or above in Norway reporting physical barriers to the use of public transport (Nordbakke 2011).

A definite limitation of the present study was the low response rate (48%). Responders and non-responders were, however, similar with regards to mean age, sex distribution and the distribution of first-ever vs. recurrent stroke. Since a large share of the respondents had had assistance in responding, it is not surprising that stroke survivors that were cohabitant responded more often than people living alone. It is possible that more non-responders than responders felt that a questionnaire on public transport was irrelevant to them. If so, the percentages of use of public transport would be somewhat inflated.

The differences in travelling experience between the means of transport reported here should be interpreted with caution. The relatively negative profile given by bus passengers does not reflect a higher proportion with severe physical disability compared with air and ship passengers. However, assistance for transfer was needed significantly less often among train passengers. It may be that people who perceived that they had particular problems in travelling had not used train transport. Therefore, the constraints during travelling by train may have been underestimated in relation to other modes of public transport.

When the study was designed, we hypothesized that cognitive constraints would be a very significant barrier towards using public transport. In support of this assumption, about one-third of those who had not travelled by public transport reported, irrespective of mode of transport, constraints related to cognition.

In view of the frequent occurrence of anxiety after stroke (Åström 1996; Ferro, Caeiro and Santos 2009), we also presumed that fear of travelling would contribute considerably to non-use of public transport. Indeed, feelings of stress and high pace were frequent responses to open-ended questions on travelling by bus. It is not surprising that disabled persons need more time. Contrary to our expectations, however, a relatively small minority of the respondents reported fear of travelling to be an important constraint to use of public transport.

The variations in use of bus and train transport between cities, towns and rural areas reported here reflect, in all likelihood, differences in access to public transport. No differences between people living in rural and urban areas were present for air and ship transport. Living in rural and suburban areas (compared with urban living) confers a clear public transport disadvantage for elderly people in Sweden (Iwarsson and Ståhl 1999) and other countries (Broome et al. 2009), and there is some evidence that older adults living in urban settings are less likely to be disabled (Clarke and George 2005). It may be speculated that, in disabled stroke survivors living in urban settings, access to and actual use of public transport contribute to a sense of autonomy and participation.

The differences in anticipated barriers in people who had not used public transport and the actual experiences of those who had used it are conspicuous. Disabling stroke often involves a dramatic role change (Vanhook 2009). This, together with post-stroke depression (Eriksson et al. 2004; Kouwenhoven et al. 2011) and anxiety (Åström 1996; Ferro, Caeiro and Santos 2007), may lead to negative expectations and a profound restriction of activities outside home, including non-use of public transport. Although the actual risk of falling during public transportation is increased among elderly, even if they are not disabled (Broome et al. 2009), our results indicate that stroke survivors who have not used public transport may overestimate the actual barriers to travelling.

The present results underscore the importance of both personal components (for example, a very high level of both physical and cognitive anticipated barriers in people who have not used public transport) and environmental factors (for example, urban vs. rural living).

Given the importance of transport in the lives of elderly and disabled people, and the obvious transport disadvantage that disabled people face, improved public transport usability should be a key priority in urban as well as rural planning. The present study was commissioned by national transport authority in Sweden and the intention is that the results will be used in the planning of a more elderly-friendly and disability-friendly environment. They may also be of use in local transport planning.

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