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Needs for mobility devices, home modifications and personal assistance among Canadians with disabilities

by Edward M. Giesbrecht, Emma M. Smith, W. Ben Mortenson and William C. Miller

Abstract

Background: People with disabilities often require assistive devices, modifications to their home environment, and physical assistance to facilitate mobility. This study examines self-reported met and unmet needs of people with disabilities who use wheeled mobility devices, compared with non-users.

Data and methods: The 2012 Canadian Survey on Disability followed up with 45,442 individuals who reported a disability on the 2011 National Household Survey, and obtained a 75% response rate. Descriptive statistics with variance estimates and 95% confidence intervals were used to compare wheeled mobility device users and non-users.

Results: Nearly 10% of wheeled mobility device users identified an unmet need for an additional mobility device. Compared with non-users, they were twice as likely to modify their home with a ramp and three times as likely to install a lift. The prevalence of unmet need for each type of residence adaptation among wheeled mobility device users was at least double that of non-users. Wheeled mobility device users received assistance with an average of 4.4 activities, compared with 2.0 for non-users, and reported an average of 1.9 activities for which assistance was needed but not received. About one in three relied on paid assistance; for 14% of those who paid for assistance, out-of-pocket expenses amounted to $10,000 or more annually, compared with 2% among non-users.

Interpretation: Wheeled mobility device users reported a higher prevalence of met and unmet needs for residence modifications than did non-users. They required help with more activities of life on a more frequent basis, with greater dependence on paid individuals, resulting in higher out-of-pocket expenses. Power and manual wheelchair users reported greater needs than did mobility scooter users.

Key words: Activities of daily living, architectural accessibility, assistive devices, ramps, social participation, wheelchairs

Mobility limitations affect many Canadians, but all types of impairment do not have a comparable impact on activity performance or contribute to the same degree of disability. In a national survey, 13.7% of Canadians reported having a disability, which was defined as a health problem or condition that created difficulty in performing activities of living at least some of the time.[1] Mobility was the third most common impairment, and in 96% of cases, was accompanied by at least one other type of disability.[1]

Bizier et al.[1] found that nearly 90% of Canadians with a mobility impairment required assistance with at least one activity of daily living, and around 60% reported needing, but not receiving, assistance with other activities.[1] More than 8 in 10 with a disability used some type of assistive aid.[2]

For people with mobility limitations, a variety of assistive devices are available. Ambulation aids such as canes, crutches, and walkers are fairly inexpensive, highly portable, lightweight, and can be used in environments of varying accessibility. Wheeled mobility devices such as manual and power wheelchairs and mobility scooters provide more support for people with strength, endurance, and postural issues, but are heavier, more expensive, and can be used only in more accessible areas. In addition, individuals with a mobility impairment often require environmental accommodations and assistance (human and technology-based). For example, building a ramp and widening doorways can make the home more accessible. Provision of and funding for these resources may be available through public and private health insurance or may fall to the individual.

In 2012, an estimated 288,800 community-dwelling Canadians aged 15 or older were wheeled mobility device users—about 1.0% of the total population. An estimated 197,950 used a manual wheelchair; 108,550, a mobility scooter; and 42,360, a power wheelchair.[3]

The specific needs of wheeled mobility device users are unknown and likely to be different and more substantial than those of the general population with a disability. A better understanding of the met and unmet needs of this group could assist in anticipating accessibility and human support needs of individuals using and transitioning to wheeled mobility devices, and in turn, inform resource allocation and prioritization of services.

This study examines the met and unmet needs for environmental accommodations and assistance among wheeled mobility device users, compared with individuals with a disability who do not use a wheeled mobility device. Estimates are presented by type of device. The analysis investigates met and unmet needs for a wheeled mobility device (acquired and still needed); residence modifications (completed and still needed); and assistance with activities (received and still needed). The examination of personal assistance covers number and type of activities, providers, frequency, and out-of-pocket expenses.

Methods

Data source

The data are from the 2012 Canadian Survey on Disability (CSD), a cross-sectional survey of community-dwelling individuals aged 15 or older who reported an activity limitation to the 2011 National Household Survey (NHS). The NHS sampled about one in three Canadian dwellings, followed by a subsample of non-respondent dwellings.

A sample of NHS respondents who identified an activity limitation (n = 45,442) were contacted to participate in the CSD; the response rate was 74.6%.[4] Additional CSD screening ques-

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tions asked about type of disability, level of difficulty experienced (no difficulty, some difficulty, a lot of difficulty, cannot do), and frequency of activity limitation (never, rarely, sometimes, often, always). Respondents were included in the CSD if the frequency of activity limitation was at least "sometimes," or "rarely" if they also experienced at least "some difficulty." The CSD was conducted using computer-assisted telephone interviews and in-person paper and pencil formats. Information collected included disability type and severity, assistance received and required, and use of assistive devices.[4] Details of the weighting calculations are described elsewhere.[4]

What is already known on this subject?

- Mobility limitation is the third most common type of disability.
- Wheelchair users experience additional barriers.
- The number and percentage of Canadians using wheelchairs is growing.

What does this study add?

- People with disabilities who use wheeled mobility devices identify more needs, both met and unmet, for residence adaptation and assistance with activities of daily life than do non-users.
- Needs for mobility devices and dwelling modifications are unmet primarily because of cost.
- Wheeled mobility device users are more reliant on people outside of their social network and spend more money to obtain this help.
- Wheelchair users had greater needs than did mobility scooter users.

Residence adaptation and wheeled mobility devices

Respondents were asked, "Because of your condition do you have" (met need) and "Do you need, but do not have" (unmet need) six residence modifications: walk-in bath/shower; access ramp or ground-level access; widened doorways/hallways; lift device/elevator; automatic/easy-to-open doors; and lower kitchen/bathroom counters. Similar questions about met and unmet needs were asked about manual wheelchairs, power wheelchairs, and mobility scooters. For affirmative responses to "Need but do not have," follow-up questions asked "why not?": cost; not covered by insurance; not willing/able to upgrade; don't know how/where to get; not available locally; on a waiting list; cannot be adapted for their situation; and no reason stated.

Assistance with activities of daily living

Respondents were asked, "Do you receive help?" (met need) and "Do you think you need help?" (unmet need) with nine activities of daily living: preparing meals; everyday housework; heavy household chores; getting to appointments/errands; personal finances; personal care; basic medical care at home; moving around in the house; and childcare. Because of small sample sizes, assistance with childcare is not reported.

Respondents who reported receiving help were asked, "Who helps with everyday activities?": family member living with you; family not living with you; friend/neighbour; organization/individual you pay; organization/individual you don't pay; and other. A follow-up question asked, "How often do you usually receive help?": daily; at least once a week; at least once a month; and less than once a month.

Respondents were asked, "Did you have any out-of-pocket/direct expenses for help received?" Those who replied affirmatively were asked, "How much did you pay out-of-pocket in the past 12 months?": less than $500; $500 to less than $1,000; $1,000 to less than $2,000; $2,000 to less than $5,000; $5,000 to less than $7,500; $7,500 to less than $10,000; or $10,000 or more. Because of small sample sizes, three adjacent categories were collapsed into a single category—$2,000 to less than $10,000.

Analyses

The full dataset consists of individuals who reported a disability (identified by activity limitation). Results are shown for wheeled mobility device users (by type of device when cell size was sufficient) and for individuals with a disability who did not use a wheeled mobility device (non-users). Frequency counts rounded to the nearest 10, point estimates, and standard

Table 1
Prevalence of modifications to residence, by type of modification and use of wheeled mobility device, household population aged 15 or older with a disability, Canada, 2012

	Wheeled mobility device users (n = 288,800)						All persons with a disability (n = 2,917,530)		
	Total			Wheelchair					
		95% confidence interval						95% confidence interval	
Type of modification	%	from	to	Manual	Power	Mobility scooter	%	from	to
				%					
Ramp/Ground-level access	49.4	47.2	51.1	46.7	67.6	56.8	19.1	18.7	19.4
Widen doors	36.8	35.0	38.5	40.3	51.2	32.6[E]	11.9	11.5	12.3
Walk-in bath/shower	30.7	29.0	32.0	32.7	38.5[E]	29.6	19.8	19.4	20.2
Easy-open doors	28.1	26.9	29.5	28.8	34.7[E]	28.0[E]	14.1	13.8	14.4
Lift/Elevator	27.1	25.7	28.5	28.0	40.8[E]	24.8[E]	9.0	8.7	9.3
Lower counters	11.4	10.7	12.2	12.3	25.0[E]	10.8[E]	4.5	4.3	4.6

[E] use with caution
Source: 2012 Canadian Survey on Disability.

errors were calculated using STATA (version 12), adjusting for person-weight (representative at the national level) and bootstrapping with 1,000 replications for variance estimates and 95% confidence intervals, where possible (correction for sampling design).

Results

Wheeled mobility devices

In 2012, among the estimated 3,775,920 individuals with a disability, 288,800 (8%) used a wheeled mobility device (data not shown in tables). As well, 10% of the latter reported an unmet need for an *additional device*: a power wheelchair (5%), a mobility scooter (4%), or a manual wheelchair (1%).

For non-users who needed a wheeled mobility device, the most common was a mobility scooter (60%), followed by a power wheelchair (21%), and a manual wheelchair (19%).

The leading reason for not obtaining the device was cost (77%); lack of insurance to cover the expense (17%) and not knowing how or where to obtain the device (6%) were reported less often.

Residence modification

The most common residence modification that wheeled mobility device users had made was a ramp or ground level access (49%) (Table 1). For each of the six modifications (walk-in bath/shower; access ramp/ground-level access; widened doorways/hallways; lift device/elevator; automatic/easy-to-open doors; lower kitchen/bathroom counters), power wheelchair users had higher rates of completion than did manual wheelchair and mobility scooter users.

The most prevalent *unmet* needs for residence modification were for a walk-in bath/shower, a lift/elevator, and a ramp/ground-level access (Table 2). The primary reason for not having made the renovations was cost (76%); no insurance (13%) and not knowing how or where to obtain it (11%) were cited less frequently.

Assistance with activities of daily living

Almost all (94%) wheeled mobility device users received help with at least one activity of daily living. The average number of activities with which they were assisted was 4.37 (95% CI: 4.30, 4.44) (Table 3); getting to appointments/errands was the most common (Table 4). Manual wheelchair users reported assistance with the highest average number of activities (4.97; CI: 4.87, 5.07), followed closely by power wheelchair users (4.83; CI: 4.66, 5.00); the average for mobility scooter users was much lower (2.68; CI: 2.58, 2.77).

About two-thirds (66%) of people with disabilities who did not use a wheeled mobility device received assistance with activities of daily living; the mean number of activities was 1.76.

Table 2
Prevalence of unmet needs for modifications to residence, by type of modification and use of wheeled mobility device, household population aged 15 or older with a disability, Canada, 2012

	Wheeled mobility device users (n = 288,800)						All persons with a disability (n = 2,919,620)		
	Total			Wheelchair					
		95% confidence interval		Manual (n = 54,050)	Power (n = 16,530)	Mobility scooter (n = 28,520)		95% confidence interval	
Type of modification	%†	from	to	%			%†	from	to
Ramp/Ground-level access	2.8[E]	2.4	3.3	3.2[E]	x	x	0.9[E]	0.8	1.0
Widen doors	1.9[E]	1.6	2.3	F	x	x	0.3[E]	0.3	0.4
Walk-in bath/shower	7.0[E]	6.3	7.8	6.6[E]	F	F	2.9	2.7	3.0
Easy-open doors	0.8[E]	0.7	0.9	F	x	x	0.4	0.4	0.5
Lift/Elevator	5.7[E]	5.0	6.3	7.4[E]	F	F	1.2[E]	1.2	1.3
Lower counters	2.0[E]	1.6	2.3	F	x	x	0.5[E]	0.4	0.5

x suppressed to meet confidentiality requirements of *Statistics Act*
[E] use with caution
F too unreliable to be published
† percentage of total number of survey respondents in category
Source: 2012 Canadian Survey on Disability.

Table 3
Number of activities of daily living for which assistance was received, by use of wheeled mobility device, household population aged 15 or older with a disability, Canada, 2012

	Wheeled mobility device users (n = 288,800)						Non-users of wheeled mobility device (n = 3,487,110)		
	Total			Wheelchair					
		95% confidence interval		Manual (n = 197,560)	Power (n = 42,360)	Mobility scooter (n = 108,550)		95% confidence interval	
Number of activities	%	from	to	%			%	from	to
0	5.7[E]	3.8	6.3	5.0[E]		9.9[E]	34.4	33.9	34.8
1	11.3[E]	7.7	12.2	7.3[E]	9.8†[E]	16.6[E]	22.1	21.7	22.6
2	9.8	6.7	10.6	7.3[E]	3.6[E]	14.4[E]	14.9	14.5	15.1
3	10.2	7.0	11.0	8.3	8.5[E]	13.7[E]	10.1	9.8	10.4
4	12.5	8.6	13.5	11.2[E]	13.3[E]	15.7[E]	8.0	7.7	11.1
5	13.2	9.2	14.1	13.9	25.9[E]	11.5[E]	4.5	4.3	4.6
6	10.7	7.5	11.4	13.5	7.8[E]	8.9[E]	3.7	3.5	3.8
7	16.7	11.5	17.8	20.4	20.6[E]	8.2[E]	1.8	1.7	1.9
8-9	9.8[E]	6.5	10.9	13.1[E]	F	F	0.7[E]	0.6	0.8
Mean	4.37	4.30	4.44	4.97	4.83	2.68	1.76	1.75	1.78

[E] use with caution
F too unreliable to be published
† 0 and 1 combined to meet confidentiality requirements of *Statistics Act*
Source: 2012 Canadian Survey on Disability.

The majority of wheeled mobility device users who received assistance got help every day—the figure ranged from about 50% of those with mobility scooters to more than 70% of those with wheelchairs (Figure 1). Two-thirds (65%) reported help from family members in the same household, and 44% reported help from family who lived elsewhere (Table 5). A third (35%) were assisted by unpaid organizations/individuals, and a quarter (27%) paid for assistance. For 14% of wheeled mobility device users who paid for assistance, out-of-pocket expenses in the previous 12 months amounted to $10,000 or more; among non-users who paid for assistance, the comparable figure was 2% (Figure 2).

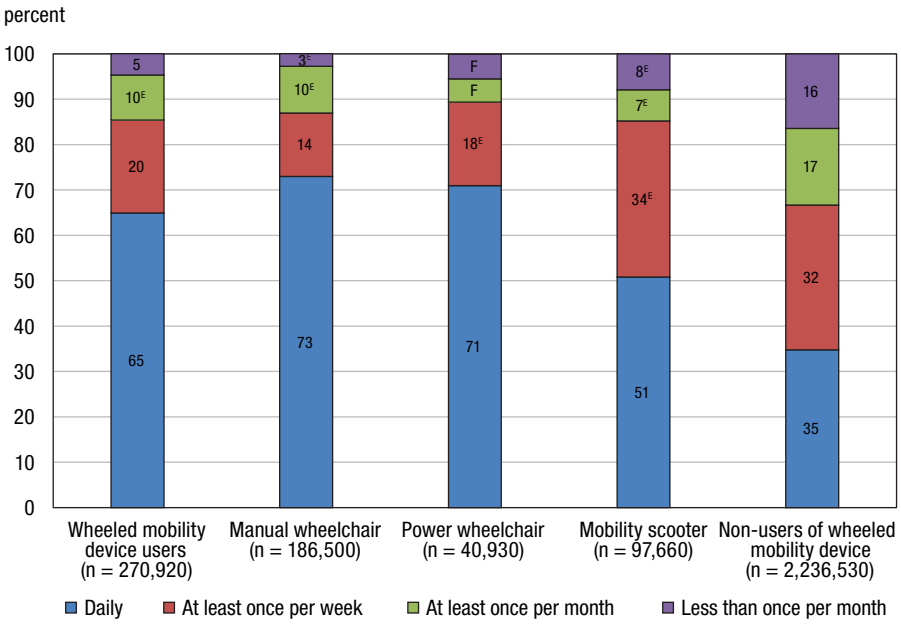
Wheeled mobility device users identified an average of 1.85 additional activities with which they required, but did not receive, assistance (unmet need) (data not shown in tables). Power wheelchair users reported 2.50 activities (CI: 2.28, 2.73); manual wheelchair users, 1.96 (CI: 1.88, 2.04); and mobility scooter users, 1.00 (CI: 0.94, 1.06).

Table 4
Activities of daily living for which help was received, by use of wheeled mobility device, household population aged 15 or older with a disability, Canada, 2012

	Wheeled mobility device users (n = 288,800)						Non-users of wheeled mobility device (n = 3,484,870)		
	Total			Wheelchair					
		95% confidence interval		Manual (n = 197,110)	Power (n = 42,280)	Mobility scooter (n = 108,470)		95% confidence interval	
Activities	%	from	to	%			%	from	to
Going to appointments and errands	76.8	74.5	79.1	82.6	78.9	67.4	33.4	33.0	33.8
Heavy household chores	70.8	68.1	72.6	71.9	82.0	63.7	47.3	46.7	47.7
Everyday housework	69.9	67.2	71.9	74.4	81.7	62.0	32.3	31.7	32.7
Preparing meals	60.3	58.1	62.3	68.7	77.9	43.7	19.9	19.6	20.3
Personal care	50.5	48.4	52.4	59.8	58.5	34.2	10.8	10.6	11.1
Personal finances	43.7	41.9	45.5	52.8	46.5[E]	23.5	17.9	17.5	18.2
Basic medical care at home	35.8	34.1	37.5	41.5	38.0[E]	26.5	7.2	7.0	7.4
Moving around	28.9	27.4	30.3	37.0	29.7[E]	13.1[E]	6.0	5.8	6.2

[E] use with caution
Source: 2012 Canadian Survey on Disability.

Figure 1
Frequency of assistance with activities of daily living, by use of wheeled mobility device, household population aged 15 or older with a disability who received assistance, Canada, 2012



[E] use with caution
F too unreliable to be published
Source: 2012 Canadian Survey on Disability.

Discussion

This study explores the needs of people with a disability who use wheeled mobility devices and those who do not. Needs were substantial among all individuals with a disability, but wheeled mobility device users reported higher levels of met and unmet need. This is of concern, given the growing number of people who use wheeled mobility devices, particularly in the context of an aging population.

According to results of the CSD, the prevalence of unmet needs is higher among people who *already use a wheeled mobility device*, many of whom require an additional device to enable various activities and facilitate access to different environments. Obtaining a manual wheelchair tends to be least problematic, likely because of lower costs and availability through provincial programs and private insurance. An adjustable, lightweight manual wheelchair can have a positive impact on use, caregiver burden, and level of participation,[5] but owing to cost, many people may have only a basic chair.[6,7] Whether current users' manual wheelchair was optimal, or even satisfactory, is not known.

Those who already had a wheeled mobility device tended to identify an unmet need for a power wheelchair (as an additional device), whereas non-users predominantly reported a need for a mobility scooter. Some manual wheelchair users are limited in their ability to propel long distances or in more challen-

ging environments, and may choose not to engage in certain activities.[8] A worsening health condition or level of impairment might signal the need for a power wheelchair, which can provide better postural support and promote independent use both indoors and outdoors. Mobility scooters are often indicated for outdoor use and for individuals with decreasing endurance but only mild mobility impairment, where some degree of ambulation is still feasible.

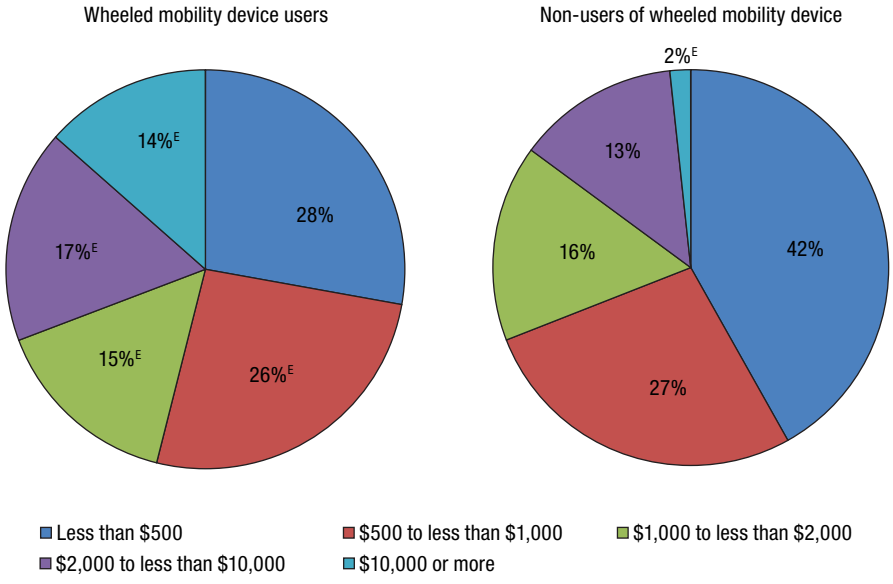
The primary reason for not obtaining a wheeled mobility device was financial. Provincial funding varies across the country. Eligibility for powered devices is typically more restricted and may require applicants to be "full-time" power users; many jurisdictions do not fund mobility scooters.[9-11]

Table 5
Sources of assistance with activities of daily living, by use of wheeled mobility device, household population aged 15 or older with a disability who received assistance, Canada, 2012

	Wheeled mobility device users (n = 272,170)			Non-users of wheeled mobility device (n = 2,269,150)		
		95% confidence interval			95% confidence interval	
Source of assistance	%	from	to	%	from	to
Family in same household	65.3	63.3	67.3	65.6	64.6	66.0
Family not in same household	44.4	42.5	46.3	40.4	39.6	40.8
Friends/Neighbours	30.4	28.8	32.1	25.6	25.0	25.9
Paid organizations/individuals	27.0	25.8	28.2	20.4	19.9	20.7
Unpaid organizations/individuals	35.4	33.5	37.4	11.0	10.5	11.5

Note: Because respondents could report more than one source of assistance, detail sums to more than 100.0%.
Source: 2012 Canadian Survey on Disability.

Figure 2
Annual out-of-pocket expenses for assistance with activities of daily living, by use of wheeled mobility device, household population aged 15 or older with a disability who reported expenditures, Canada, 2012



E use with caution
Source: 2012 Canadian Survey on Disability.

Access to the home and to essential locations inside it is critical for wheeled mobility device users.[10,12] As expected, compared with non-users, they had a much greater need to modify their residence. A large U.S. study reported that wheeled mobility device users were 57% more likely than non-users to require home accessibility modifications.[13] Similarly, according to the CSD, wheeled mobility device users were twice as likely as non-users to have a ramp or ground-level access and three times more likely to have a lift or elevator. Power wheelchair users had the highest rates of each type of modification, a reflection of the difficulty of maneuvering the devices in tight spaces.[11] By contrast, mobility scooter users generally have some ability to transfer and ambulate independently, and tend to use the devices for travelling longer distances and outdoors,[12] which would account for the lower rates of home modification.

Despite a higher prevalence of completed renovations, wheeled mobility device users reported at least twice the rate of *unmet* need for residence modifications, compared with people with a disability overall. Regardless of the device used, the most common unmet need was for a walk-in bath/shower, followed by a lift/elevator, both of which entail substantial expenditures.[14,15] A lift/elevator may be critical for wheeled mobility device users, particularly if their home has multiple levels. The initial cost, installation and on-going maintenance of a lift/elevator have been implicated as barriers to acquisition.[15]

No data were available about how home adaptations were funded. Federal and provincial programs that provide financial assistance and low-cost renovation loans to those with a disability are primarily targeted toward low-income individuals and are reported to involve a time-consuming administrative process.[16,17] Bishop et al.[13] found that 85% of their survey respondents funded home renovations out-of-pocket.

Compared with non-users, people who used wheeled mobility devices reported greater dependence on others. Fewer than

6% required no help at all, lower than the 6% of men and 14% of women estimated in the 2000/2001 Canadian Community Health Survey.[18] This suggests that the prevalence of need for assistance with activities of daily living has increased. Manual and power wheelchair users had comparable rates of assistance; those using mobility scooters were less dependent. The discrepancy likely reflects the greater degree of impairment that necessitates a wheelchair.

At least one-third of wheeled mobility device users required help with *every type of activity*, aside from basic mobility in the home. As well, roughly 35% of manual and power wheelchair users required assistance with basic mobility. The rate appears to have declined since 2000/2001, when 50% were estimated to need help with mobility.[18] One explanation for the apparent decrease may be improved accessibility in the home, as evidenced by the prevalence of residence modifications. As well, rehabilitation services increasingly focus on adapting home and community environments; initiatives such as aging in place[19] and visitability[20] may be contributing to improved dwelling accessibility. Another factor may be wheelchair skill training,[21,22] which, while still not common practice, is increasingly provided in rehabilitation care.[23] Future analyses could examine whether skills training is having an impact on independence and functioning at home.[8]

The type of assistance most commonly needed by wheeled mobility device users was getting to appointments and errands. This is in line with the most prevalent home adaptation—a ramp/ground-level access. Appointments and errands also likely involve some form of transportation, which may mean vehicle adaptation or the use of accessible transit/transportation services,[11] and in turn, additional expenses (not reported in the CSD).

Wheeled mobility device users relied on a more extensive network of care providers and on a more frequent basis than did non-users. For both groups, the most commonly reported source of care was family members, which confirms previous findings about demands on family,[24] whether living with or apart from the person with a disability. However, wheeled mobility device users appear to have greater dependence on individuals outside the family.[25] For example, they were more likely than non-users to report paid assistance and unpaid individuals/organizations.

Wheeled mobility device users were nearly twice as likely as non-users to need help every day. While the frequency of help received was ascertained collectively (from all sources), it is likely that assistance from family members was more frequent, and the overall burden on family increased accordingly.[26,27] In future studies, it would be worthwhile to investigate the frequency and total hours of caregiver support.

Regardless of who provided assistance, wheeled mobility device users incurred higher out-of-pocket expenses than did non-users. Among those who paid directly for help, wheeled mobility device users were eight times more likely to spend $10,000 or more annually. In 2012, the mean annual income of working-age individuals with a mobility limitation was $17,100, about half that of Canadians without a disability.[1] Thus, reliance on paid care may result in substantial out-of-pocket costs for individuals who are already financially disadvantaged.

Limitations

The results of this study should be considered in the context of several limitations. Individuals living in institutions such as residential care facilities or on First Nations reserves were not included in the CSD. Moreover, owing to small sample sizes, some response categories were consolidated, and "don't know" or "not stated" responses were removed. In some cases, particularly where analyses were stratified by device type, data were not releasable.

The sample of wheeled mobility device users was determined by identifying individuals who used a power wheelchair, manual wheelchair, or mobility scooter; however, approximately one in five used a combination of devices. Consequently, where the data were presented by device type, some responses would have been counted more than once. While this might influence interpretation of results pertaining to specific device use, restricting the analysis to exclusive device users would have eliminated a large number of responses and ignored a trend toward multiple device use.[3]

Conclusion

It is well established that the provision of wheelchairs and scooters should consider the specific needs of an individual, the context in which they move, and the activities in which they need and want to engage.[28] Furthermore, those with mobility issues might also require (or desire) multiple devices to enable different activities and facilitate access to different environments.[12]

According to estimates from the 2012 Canadian Survey on Disability, among individuals with a disability, wheeled mobility device users had a higher prevalence of both met and unmet needs. They reported greater needs for residence modifications and additional devices. As well, they required help with more activities on a more frequent basis, and were more dependent on individuals outside of their immediate community for this support. In particular, reliance on paid assistance was more common, and out-of-pocket expenses were higher than for those who did not use wheeled mobility devices. ■

Acknowledgments

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