

# Understanding the Burden Experienced by Caregivers of Older Adults Who Use a Powered Wheelchair: A Cross-Sectional Study

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## Abstract

**Objective:** In this study, we aimed to describe the burden of family caregivers providing powered wheelchair-related and overall assistance and test the hypotheses that caregiver burden correlates with participation, wheelchair skills capacity, anxiety, depression, and social support. **Methods:** Cross-sectional study. Participants included 35 family caregivers of powered wheelchair users. Caregivers were assessed using the Power Mobility Caregiver Assistive Technology Outcome Measure, Late Life Disability Instrument, Wheelchair Skills Test Questionnaire for caregivers, Hospital Anxiety and Depression Scale, and Interpersonal Support Evaluation List–12. **Results:** The most burdensome powered wheelchair assistance items were providing verbal hints/directions, needing to be nearby, anxiety, and fear that user may be harmed. The most burdensome overall assistance item was feeling limited in recreational/leisure activities. Caregiver burden was significantly correlated with participation limitations, anxiety, depression, and social support. **Discussion:** Caregivers experience burden for wheelchair-related and overall help, especially psychological burden. Such results have implications for the type of resources required to support family caregivers.

## Keywords

caregiver, caregiver burden, cross-sectional study, power wheelchair

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In 2010, there were 23.4 million adults 65 years and older living with a disability in the United States (Brault, 2012). Among them, 2.0 million used a wheelchair to assist with their mobility (Brault, 2012) and approximately 810,000 used powered wheelchairs or scooters (Flagg, 2009). Despite the positive impact of wheelchairs on mobility and participation (Sund, Iwarsson, Anttila, & Brandt, 2015), more than half of all wheelchair users require assistance with activities performed in the wheelchair (Shields, 2004). This assistance is often provided by caregivers (Rushton et al., 2015). Indeed, in 2011, an estimated 14.7 million Americans provided care for daily activities to older adults (Wolff, Spillman, Freedman, & Kasper, 2016).

Caregiving activities may have a direct and indirect impact on caregivers' health and life. A recent study reported that family caregivers who provide 2 hr of caregiving per week report signs of psychological distress such as feeling tired, isolated, irritable, and overwhelmed (Turcotte, 2013). For instance, 60% of those caring for their father or mother, and 74% of those caring for their

spouse, felt worried, or distressed (Turcotte, 2013). According to Darragh and colleagues (2015), 58% of family caregivers of adults with various chronic physical disabilities reported high levels of emotional stress and 38% reported physical stresses associated with providing help. Caregiver burden has also been shown to reduce the social support of caregivers (Losada et al.,

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2010), their participation in meaningful activities (Grigorovich et al., 2015), and their life satisfaction (Losada et al., 2010).

Assistive technologies used by people with disabilities, including but not limited to powered wheelchairs, can reduce caregiver burden (Mortenson et al., 2012). A systematic review conducted on the impact of assistive technologies on the caregivers of older adults with disabilities reported benefits of assistive technology such as reduced time, workload, and burden associated with caregiving activities (Mortenson et al., 2012). Assistive technologies were also seen as reducing caregivers' anxiety and increasing the independence of older adults (Mortenson et al., 2012). However, assistive technologies might not completely eliminate the responsibility and stress of caring for an older adult (Mortenson et al., 2012).

Mixed results have been found regarding the impact of powered wheelchair assistive technology on caregivers. On the positive side, provision of a powered wheelchair has been reported to increase caregivers' sense of freedom and independence (Frank, Neophytou, Frank, & de Souza, 2010; Roberts, Young, Andrew, McAlpine, & Hogg, 2012) and decrease the physical demands of caring for someone with mobility disability (Frank et al., 2010). Family caregivers of powered wheelchair users were also less likely to experience physical pain and health problems than caregivers of manual wheelchair users (Roberts et al., 2012). On the negative side, a powered wheelchair may increase caregiver burden for tasks such as transporting the powered wheelchair (Frank et al., 2010), negotiating aspects of the physical environment (e.g., curbs and slopes) (Frank et al., 2010), driving the powered wheelchair when the user becomes too fatigued, and clearing crowds in busy areas (Rushton et al., 2015). Concerns regarding the safety of the users have also been expressed by family caregivers (Frank et al., 2010; Roberts et al., 2012).

Given the current dearth of knowledge regarding the burden associated with caring for a powered wheelchair user, the primary objective of this study was to describe the burden experienced by informal caregivers of powered wheelchair users. The secondary objective was to test the hypotheses that caregiver burden would correlate with wheelchair skills capacity, participation frequency, limitations of participation, anxiety, depression, and social support.

## Method

### Study Design

This project used a multicenter, cross-sectional study design. The study was conducted in six Canadian cities: Vancouver, British Columbia; London, Ontario; Toronto, Ontario; Montréal, Quebec; Quebec City, Quebec; and Halifax, Nova Scotia. The data were collected as the first time point in a larger 2-year longitudinal study that

was designed to describe the variation in power mobility use among power wheelchair users and caregivers, using a power wheelchair outcome tool kit (reported elsewhere; Rushton, Demers, Miller, & CanWheel Research Team, 2012).

### Ethical Issues

The institutional research ethics boards of all participating sites approved the project. All participants provided written informed consent.

### Recruitment and Screening

A volunteer sample of participants was recruited through a variety of sources including disease and caregiver support organizations (e.g., the Multiple Sclerosis Society, Alzheimer's Society, Parkinson's Society), rehabilitation centers, long-term care facilities, hospitals, community care organizations, wheelchair seating programs, and wheelchair equipment vendors. Recruitment strategies included distribution of the study letter of information, posting of advertisements (electronically and in buildings), and circulation of pamphlets. Snowball recruitment was promoted through recruited participants and wheelchair users who participated in the larger longitudinal study.

### Inclusion/Exclusion Criteria

Eligible participants consisted of family caregivers (e.g., spouse, family member, or friend), who were at least 19 years old, provided at least 1 hr of any type of care (powered wheelchair-related or otherwise) per week for a powered wheelchair user who was 50 years of age or older and spoke English or French. Formal, paid caregivers (e.g., individuals who were hired from external agencies and who provided caregiving services as a source of employment) were excluded.

### Primary Outcome Measure

**Power Mobility Caregiver Assistive Technology Outcome Measure (PM-CATOM).** The PM-CATOM is an 18-item outcome measure designed to assess device-specific and overall burden experienced by family caregivers of powered wheelchair users (Mortenson et al., 2016). It is administered via semistructured interview and is composed of two parts. In Part 1, caregivers identify the powered wheelchair-related activities with which they help the wheelchair user and then rate how frequently they experience burden in 14 different aspects of powered wheelchair-related caregiver activities (e.g., physical demands, worry, time demands). In Part 2, caregivers identify all activities (with the exception of the powered wheelchair-specific activities identified in Part 1) with which they help the wheelchair user and then rate how frequently they experience an overall sense of burden

related to all of their caregiving activities in four different areas (e.g., recreational activities, work, relationships). Frequency of burden is rated using a 5-point ordinal scale where 1 = *nearly always*, 2 = *frequently*, 3 = *sometimes*, 4 = *rarely*, and 5 = *never*. Scores for Part 1 (range 14-70) and Part 2 (4-20) are calculated by adding the score for each item. Higher PM-CATOM scores indicate less burden. The PM-CATOM has demonstrated good measurement properties among caregivers of older adult powered wheelchair users (Mortenson et al., 2016).

## Secondary Outcome Measures

**Wheelchair Skills Test Questionnaire (WST-Q) for caregivers.** The WST-Q for caregivers of powered wheelchair users, Version 4.1, is a subjective, self-report test that evaluates 29 wheelchair skills ranging from turning the powered wheelchair on/off to ascending/descending a 5-cm-level change (Kirby et al., 2016). It can be used to measure capacity (what the individual *can* do) and performance (what the individual *does* do) (World Health Organization, 2001). In this study, it was only used to measure capacity. Specifically, it was used to measure the caregivers' capacity to either handle the wheelchair themselves or assist the wheelchair user when needed. Each skill was scored using a dichotomous pass/fail response format according to the scoring criteria outlined in the Wheelchair Skills Test Manual (Kirby et al., 2016). Total WST-Q percentage scores were calculated (number of passed skills / number of possible skills  $\times$  100%). The WST-Q for powered wheelchair users has demonstrated reliability and validity (Rushton, Kirby, Routhier, & Smith, 2016). Based on the existing literature, that describes the role of caregivers related to negotiating aspects of the physical environment (Frank et al., 2010) and controlling the powered wheelchair (Rushton et al., 2015), a negative, low correlation between the PM-CATOM Part 1 and WST-Q was expected.

**Late Life Disability Instrument (LLDI).** The LLDI is a 16-item self-report measure of frequency and perceived limitation in life tasks such as visiting friends and family in their homes, providing care or assistance to others, and taking part in organized social activities (Jette et al., 2002). In this study, the total score for both the frequency and the limitation domains was used. The raw scores are reported in this article, with higher scores representative of better levels of functioning. A recent systematic review reported moderate to high test-retest reliability for the LLDI and moderate correlations between the LLDI and both the London Handicap Scale and the RAND-36 among community-dwelling older adults (Beauchamp, Schmidt, Pedersen, Bean, & Jette, 2014). Given the reported increased freedom and independence by caregivers of powered wheelchair users (Frank et al., 2010), positive moderate correlations between the PM-CATOM

Part 1 and 2 and both the LLDI frequency and limitations domains were expected.

**Hospital Anxiety and Depression Scale (HADS).** The HADS is a 14-item, self-report measure of anxiety (seven items) and depression (seven items) using a 4-point scale (0-3) (Zigmond & Snaith, 1983). Higher scores indicate higher symptom frequency. The HADS correlates with the Beck Depression Inventory (Lis-pers, Nygren, & Soderman, 1997) and the State-Trait Anxiety Inventory (Millar, Jelcic, Bonke, & Asbury, 1995). The HADS has good internal consistency and factor structure among caregivers of older adults (Sánchez-López, Limiñana-Gras, Colodro-Conde, & Cuéllar-Flores, 2015). Based on the concerns regarding the safety of powered wheelchair users by caregivers and the increased burden reported, negative moderate correlations between the PM-CATOM Part 1 and anxiety and the PM-CATOM Part 2 and depression were anticipated.

**Interpersonal Support Evaluation List-12 (ISEL-12).** The ISEL is a 12-item measure used to assess social support using a 4-point scale ranging from 0 (*definitely false*) to 3 (*definitely true*) (Cohen & Hoberman, 1983). Higher scores indicate more social support. The ISEL correlates with the Sense of Support Scale (Dolbier & Steinhardt, 2000) and has been used to assess the social support of caregivers (Perrin et al., 2015). A positive moderate correlation was expected between the PM-CATOM Parts 1 and 2 and social support, given the reported increased caregiver burden related to powered wheelchairs (Frank et al., 2010).

## Demographic Data

Participant demographic data for the caregivers were collected using a study-specific demographic questionnaire. Data collected included age, primary language, sex, marital status, education, employment status, income, relationship to wheelchair user, frequency of care provision, hours of care provision, receipt of formal care provision training, and receipt of formal wheelchair skills training.

## Procedure

The data collection included administration of a sociodemographic questionnaire, followed by administration of the outcome measures, in the following order: PM-CATOM, WST-Q caregiver version, LLDI, HADS, and ISEL. For the convenience of the participant, the researchers offered to collect the data at either the testing site or a location of the participant's preference (e.g., at or close to the home). To further minimize the potential for study burden, the participants were offered alternative options, outside of the in-person data collection session, for completing the LLDI, HADS, and ISEL.

These options were phone administration or self-administration and return via mail.

### Data Analysis

The Statistical Package for the Social Sciences, Version 22.0, was used for the data analyses (IBM Corp, Armonk, New York). Descriptive statistics were calculated to describe the sample and outcome measures. Associations between the PM-CATOM and the secondary outcome measures were calculated using Spearman's correlation. A correlation of .5 or less was considered low, a correlation between .5 and .8 was considered moderate, and a correlation greater than .8 was considered strong (Zou, Tuncali, & Silverman, 2003).

## Results

### Participants

The demographic characteristics of the sample are presented in Table 1. The sample of 35 caregivers ranged in age from 35 to 82 years and was mostly women who provided wheelchair-related assistance to their spouses with whom they lived. The majority of caregivers provided wheelchair-related care several times a week. Almost no caregivers had received any formal training in caregiving or wheelchair skills.

### Study Measures

The median scores and interquartile range (IQR) for the PM-CATOM Part 1, PM-CATOM Part 2, PM-CATOM Total, WST-Q, LLDI-frequency domain (LLDI-F), LLDI-limitation domain (LLDI-L), HADS anxiety, HADS depression, and ISEL were 55 (IQR: 13), 14 (IQR: 7), 69 (IQR: 21), 85.7 (22.2), 57 (IQR: 9), 60 (IQR: 18.5), 7 (IQR: 5), 4 (IQR: 5), 13 (IQR: 6), respectively.

### Caregiver Burden

Table 2 describes the specific activities with which the caregivers provided assistance to the wheelchair users. It specifies whether the caregiver helped the wheelchair user or performed the activity on behalf of the wheelchair user (substitute). In terms of wheelchair-related help, the caregivers assisted mostly with transfers and wheelchair maintenance. Regarding overall help, the caregivers helped the wheelchair users mainly with dressing and instrumental activities of daily living (i.e., housekeeping, meal preparation, shopping, and laundry).

Table 3 describes the frequency of burden for each item on the PM-CATOM for this sample of caregivers. The items that were the most burdensome were needing to provide verbal hints or directions, needing to be nearby, feeling anxious, and feeling that the user may be harmed. The overall assistance item that was most burdensome was feeling limited in recreational and leisure activities.

**Table 1.** Participants' Demographic Characteristics (N = 35).

Characteristics	Value
Age in years, mean (SD)	63.7 (10.2)
Range	35-82
Primary language, n (%)	
English	25 (71.4)
French	6 (17.1)
Other	4 (11.5)
Sex, n (%)	
Female	23 (65.7)
Marital status, n (%)	
Common-law/married	26 (74.3)
Separated/divorced/widowed	5 (14.3)
Single	4 (11.4)
Highest level of education, n (%)	
High school or less	12 (34.3)
College or trade school	11 (31.4)
University	11 (31.4)
Other	1 (2.9)
Employment status, n (%)	
Employed	8 (22.9)
Unemployed/retired	27 (77.1)
Other (student, volunteer)	8 (22.9)
Relationship to wheelchair user, n (%)	
Spouse	26 (74.3)
Other (friend/employee)	7 (20.0)
Parent/sibling	2 (5.7)
Live in same residence as wheelchair user, n (%)	27 (77.1)
Frequency of provision of overall help, n (%)	
Daily	31 (88.6)
Weekly	4 (11.4)
Frequency of provision of wheelchair-related help, n (%)	
Never	3 (8.6)
Monthly	1 (2.9)
Once a week	3 (8.6)
Several times a week	7 (20.0)
Once a day	9 (25.7)
Several times a day	12 (34.3)
Formal care training, n (%)	1 (2.9)
Formal wheelchair skills training, n (%)	1 (2.9)

### Correlations Between PM-CATOM and Secondary Outcome Measures

The correlations between the PM-CATOM and the secondary outcome measures are presented in Table 4. All correlations were in the directions hypothesized, although not all as strong as expected (i.e., LLDI frequency domain and ISEL). Statistically significant correlations were found between the PM-CATOM and the ISEL, LLDI-L, and HADS.

## Discussion

This is one of only a few studies that looked at the burden of caregivers of older powered wheelchair users. This study accomplished its goals of describing the



**Table 2.** Activities With Which the Caregivers Provide Assistance.

Activities	Give help n (%)	Substitute n (%)
<b>Part 1: Wheelchair-related help</b>		
Transfers to and from the wheelchair	27 (77.1)	6 (17.1)
Wheelchair maintenance	25 (71.4)	16 (45.7)
Propelling a wheelchair inside	16 (45.7)	1 (2.9)
Transporting wheelchair (up/down stairs/ into/ out of vehicle)	18 (51.4)	5 (14.3)
Getting around outside with wheelchair	12 (34.3)	N/A
Operating special wheelchair features (tilt in space, elevating leg rest, recline)	14 (40.0)	4 (11.4)
<b>Part 2: Overall help</b>		
Eating	13 (37.1)	2 (5.7)
Washing	19 (54.3)	9 (25.7)
Dressing	32 (91.4)	10 (28.6)
Grooming	18 (51.4)	5 (14.3)
Toileting (getting on/off toilet, wiping, managing clothing)	21 (60.0)	8 (22.9)
Transfers (not toilet or wheelchair)	20 (57.1)	4 (11.4)
Walking inside	3 (8.6)	N/A
Negotiating stairs	4 (11.4)	1 (2.9)
Getting around outside without wheelchair	8 (22.9)	N/A
Installing prosthesis or orthosis	4 (11.4)	3 (8.6)
Housekeeping	33 (94.3)	24 (68.6)
Meal preparation	33 (94.3)	23 (65.7)
Shopping	34 (97.1)	19 (54.3)
Laundry	32 (91.4)	28 (80.0)
Telephone	8 (22.9)	2 (5.7)
Transport	22 (62.9)	7 (20.0)
Medication use	19 (54.3)	5 (14.3)
Budgeting	20 (57.1)	14 (40.0)
Leisure	19 (54.3)	4 (11.4)
Work activities	4 (11.4)	N/A

burden experienced by family caregivers in relation to powered wheelchair-related assistance and overall assistance, and it tested the hypotheses of a relationship between burden and relevant outcomes. The caregivers in this study, mostly nonworking females who were the spouses of and living with the wheelchair users, provided assistance for a wide range of activities. The powered wheelchair-specific activities with which the family caregivers helped were consistent with the literature such as transportation of the devices (Frank et al., 2010) and getting around inside (Rushton et al., 2015) and outside (Frank et al., 2010) with the wheelchair.

The participants experienced moderate caregiver burden for both wheelchair-related and overall help. This result is consistent with findings of recent studies that showed that family caregivers of people with various physical disabilities report low to moderate burden (Giesbrecht, Miller, & Woodgate, 2015; Roth, Fredman, & Haley, 2015). The moderate (rather than high) level of burden of caregivers in this study could be associated with the benefits of powered wheelchair provision reported in previous research such as an increased sense of freedom and independence (Frank et al., 2010) and decreased physical demands (Roberts et al., 2012). It is also possible that caregiving may have a positive impact

on the family caregivers of powered wheelchair users. Recent studies have suggested that caregivers use personal resources such as positive emotions, self-efficacy, or sense of coherence to cope with their burdens and even reduce them (Roth et al., 2015). The interaction between the caregiver and the person cared for was also identified as a protective factor (Roth et al., 2015). Further research is needed to understand the factors that may positively affect the experience of caregivers of powered wheelchair users.

Interestingly, the PM-CATOM wheelchair-specific items (Part 1) that were most burdensome for the caregivers were related to the psychological burden, such as needing to provide verbal hints, needing to be nearby, feeling the wheelchair user may be harmed, and feeling anxious, rather than physical burden. These findings are consistent with concerns regarding safety found in previous studies with powered wheelchairs (Frank et al., 2010; Roberts et al., 2012) and the notion that, despite provision of assistive technologies, caregiver responsibility and stress remains (Mortenson et al., 2012). Furthermore, the PM-CATOM items that represent overall burden (Part 2) suggest that these caregivers experienced limited recreational and leisure activities, providing support for the idea that caregiver

**Table 3.** Frequency of Caregiver Burden per CATOM Item.

CATOM item	n (%)				
	Nearly always	Frequently	Sometimes	Rarely	Never
<b>Part 1</b>					
1. Does the wheelchair user ever require the caregiver's help to use his or her wheelchair?	3 (8.6)	8 (22.9)	10 (28.6)	5 (14.3)	9 (25.7)
2. Do you physically help (your relative) to use his (or her) wheelchair?	5 (14.3)	5 (14.3)	4 (11.4)	10 (28.6)	11 (31.4)
3. Do you ever feel that you must be nearby when (your relative) is using his (or her) wheelchair (to make sure that everything is OK)?	7 (20.0)	5 (14.3)	7 (20.0)	3 (8.6)	13 (37.1)
4. Do you ever provide verbal hints or directions to help (your relative) use his (or her) wheelchair?	2 (5.7)	8 (22.9)	13 (37.1)	6 (17.1)	6 (17.1)
5. Do you ever feel that helping (your relative) with his (or her) wheelchair requires too much of your time?	0 (0.0)	2 (5.7)	2 (5.7)	6 (17.1)	25 (71.4)
6. Do you ever feel that (your relative) may be harmed when he (or she) is using his (or her) wheelchair?	2 (5.7)	5 (14.3)	10 (28.6)	6 (17.1)	12 (34.3)
7. Do you ever feel you may be harmed when you are helping (your relative) to use his (or her) wheelchair?	0 (0.0)	0 (0.0)	7 (20.0)	14 (40.0)	14 (40.0)
8. Do you ever feel (physically) tired after helping (your relative) with his (or her) wheelchair?	1 (2.9)	4 (11.8)	8 (23.5)	2 (5.9)	19 (55.9)
9. Does the help you are providing to (your relative) with his (or her) wheelchair ever result in pain or physical strain?	1 (2.9)	1 (2.9)	8 (23.5)	4 (11.8)	20 (58.8)
10. Do you ever miss having free time for yourself because you help (your relative) with his (or her) wheelchair?	0 (0.0)	1 (2.9)	11 (32.4)	3 (8.8)	19 (55.9)
11. Do you ever feel anxious while (your relative) is using his (or her) wheelchair (whether you're there to help or not)?	0 (0.0)	3 (8.8)	13 (38.2)	6 (17.6)	12 (35.3)
12. Do you ever feel annoyed about having to help (your relative) with his (or her) wheelchair?	0 (0.0)	1 (2.9)	9 (26.5)	6 (17.6)	18 (52.9)
13. Do you ever feel overwhelmed by the help (your relative) needs with his (or her) wheelchair?	0 (0.0)	2 (5.7)	6 (17.1)	2 (5.7)	25 (71.4)
14. Do you ever feel that the wheelchair limits the use of space within your home (or somewhere else)?	4 (11.4)	0 (0.0)	8 (22.9)	5 (14.3)	18 (51.4)
<b>Part 2</b>					
15. When you consider all of the help you are providing to (your relative), do you ever feel that you have more to do than you can handle?	4 (11.4)	10 (28.6)	10 (28.6)	2 (5.7)	9 (25.7)
16. Do you ever feel that all of the help you are providing to (your relative) limits your recreational and leisure activities?	6 (17.1)	10 (28.6)	9 (25.7)	1 (2.9)	9 (25.7)
17. Do you ever feel that all of the help that you are providing to (your relative) limits your work or volunteer activities?	4 (11.8)	3 (8.8)	10 (29.4)	0 (0.0)	17 (50.0)
18. Do you ever feel that all of the help you are providing to (your relative) strains your social and family relationships?	3 (8.8)	2 (5.9)	11 (32.4)	1 (2.9)	17 (50.0)

Note. CATOM = Caregiver Assistive Technology Outcome Measure.

burden impacts participation in meaningful activities (Grigorovich et al., 2015). For example, caregivers' perceptions of their leisure time has been shown to be significantly, negatively associated with burden, after controlling for the carers' functional status and other caregiver sociodemographic variables (Losada et al., 2010).

The results of this study corroborate the hypotheses regarding caregiver burden and other relevant outcomes.

Although the literature describes the role of caregivers related to negotiating aspects of the physical environment (Roberts et al., 2012) and controlling the powered wheelchair (Rushton et al., 2015), the positive, low association between burden and wheelchair skill (WST-Q) was expected given the generality of the PM-CATOM items (as opposed to wheelchair-skill-specific). Interestingly, this sample of caregivers scored high on the WST-Q ( $M = 85.7$ ), despite the fact that only one

**Table 4.** Correlations of the PM-CATOM With the Secondary Outcome Measures.

Outcome measures	WST-Q	ISEL	LLDI-F	LLDI-L	HADS-A	HADS-D
PM-CATOM Part 1	.22	.24	.26	.66**	-.53**	-.51**
PM-CATOM Part 2	.07	.37*	.32	.77**	-.59**	-.72**

Note. PM-CATOM = Power Mobility Caregiver Assistive Outcome Measure; WST-Q = Wheelchair Skills Test Questionnaire; ISEL = Interpersonal Support Evaluation List; LLDI-F = Late Life Disability Index–Frequency Domain; LLDI-L = Late Life Disability Index–Limitation Domain; HADS-A = Hospital Anxiety and Depression Scale–Anxiety Domain; HADS-D = Hospital Anxiety and Depression Scale–Depression Domain.

\* $p \leq .05$ . \*\* $p \leq .01$ .

caregiver reported having received formal wheelchair skills training. One possible interpretation of this finding is that caregivers learn how to handle the powered wheelchair “on the job.” A more objective evaluation of caregiver powered wheelchair skills may provide additional insight into this aspect of caregiving.

The associations between the PM-CATOM and the LLDI indicate that there is a higher association between caregiver burden and the extent to which caregivers feel limited in participating in activities (LLDI-L) than their actual frequency of participation in activities (LLDI-F). This finding may be a consequence of the psychological burden associated with caring for a powered wheelchair user, in that the caregivers’ perceptions of their limitations in participation may not have been consistent with the reality of their true participation level.

Based on the concerns regarding the safety of powered wheelchair users by caregivers (Frank et al., 2010; Roberts et al., 2012), the negative moderate correlation between the PM-CATOM Part 1 and anxiety was anticipated. The negative moderate correlation between the PM-CATOM Part 2 and depression was also expected, given the previously reported association between burden and higher levels of depression (Darragh et al., 2015; Turcotte, 2013). For example, Losada and colleagues (2010) found that a lower level of mental health was positively correlated to perceptions of burden in family elderly caregivers.

The moderate correlation between overall caregiver burden and social support was also as expected. As described above, caregivers may experience a limitation in their recreational and leisure activities, thus potentially reducing their support networks. This notion is supported by a recent study that reported that the social circle of caregivers of new manual wheelchair users decreases with the introduction of the wheelchair (Giesbrecht et al., 2015). However, this reduction of social support may be offset by the development of interpersonal relationships with the care recipient’s family members and friends (Giesbrecht et al., 2015; Losada et al., 2010).

### Limitations and Future Directions

This study had a number of limitations. First, the sample size was small, a reflection of the difficulties inherent in recruiting from an already overburdened population. However, the caregivers represented six different cities in four provinces across Canada, thus representing caregiver

experiences in a variety of Canadian contexts. Second, the sample was one of convenience. Thus, the results may portray only the experiences of caregivers of powered wheelchair users that were interested in participating in the study and able to integrate the study into their schedule of caregiving duties. Third, although caregiving involves a caregiver and a care recipient, with the experience of one individual dependent on the other, in this study, only the caregiver was studied. An understanding of caregiver burden may be enhanced in future studies by considering the caregiver and powered wheelchair user dyad. Fourth, as the sample size did not allow the researchers to perform regression analyses, this study is unable to identify which variables are independent predictors. However, these data can inform the selection of variables for inclusion in larger studies. Finally, while the findings of this study serve to improve understanding of the burden of caregivers of powered wheelchair users, knowledge of this domain would be enhanced with a longitudinal perspective of how caregiver burden changes over time, including the burden associated with caring for a new powered wheelchair user.

Caregivers of powered wheelchair users provide assistance for a wide range of activities and experience moderate burden for both wheelchair-related and overall help, with the psychological burden being more frequent than the physical burden. Such results have implications for the type of resources required to support family caregivers.

### Declaration of Conflicting Interests

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