

EXPERIENCES AND NEEDS OF CAREGIVERS' OF OLDER POWER WHEELCHAIR USERS

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ABSTRACT

The objective of this study was to improve our understanding of the needs and experiences of family caregivers who assist older power wheelchair (PWC) users. This was a multi-center cross-sectional qualitative study. The project was approved by the research ethics boards of the participating institutions and all participants provided written informed consent. Twenty caregivers who provided at least 2 hours per week of care completed the Power Mobility Caregiver Assistive Technology Outcome Measure (PM-CATOM) measuring wheelchair-related and overall caregiver burden. A semi-structured interview was also conducted with caregivers, which explored the types of assistance given, the barriers encountered, the burdens experienced regarding PWC assistance, caregivers' needs, and the resources provided to the caregivers, such as PWC training. Caregivers experienced moderate burden as measured by the PM-CATOM (means: 52.7 ± 0.5 and 16.1 ± 0.4 respectively). The caregivers experienced burden and their concerns were related to safety issues and risk of injuries. The participants reported receiving resources and support from their relatives and from the PWC users themselves. Regarding PWC training, some participants clearly stated that they would prefer to have access to support and knowledge when a problem occurs with the PWC, while others indicated that training regarding the usage (e.g. putting it in manual mode) or the maintenance (e.g. what to do in case of a battery failure) of the PWC should be given when the PWC is provided. These findings assist in answering how caregivers provide mobility assistance to the older PWC users, and how this help has an impact on their daily

activities. Focusing on the resources and the positive dimension of caregiving, brings new perspective on how to support family caregivers.

INTRODUCTION

Family caregivers are the most important source of assistance for older adults, especially for individuals with more severe disabilities, such as power wheelchair (PWC) users.¹ However, there is limited knowledge about the experiences and needs of caregivers who assist older PWC users.

Existing evidence suggests benefits for the caregivers, such as an increased sense of independence or freedom,² and less health problems,³ but also downsides such as increased stress when navigating in the community³⁻⁵ or concerns about the PWC users' safety^{3,6}. Studies also suggested that caregiving responsibilities for PWC affect the caregivers' participation in community activities. Some Recent research also highlights the importance of addressing the needs of caregivers, in terms of resources such as training on how to use a PWC⁸ and the positive aspects of providing help to a family members⁻¹⁰.

The objective of this study was to gain a better understanding of the needs and experiences of family caregivers who assist older power wheelchair users, including the specific burden in providing wheelchair assistance and the environmental barriers and facilitators.

METHODS

This study presents qualitative data from a larger mixed-methods, multi-centre (n = 69),

the main findings of which are reported elsewhere.¹¹ The project was approved by the research ethics boards of the participating institutions. All participants provided written informed consent.

The potential participants were caregivers providing care to a PWC user. To be included, the caregiver had to be ≥ 18 years of age, able to communicate in English and/or French (depending upon the site), live within 50 km of the research center, want to participate, be able to set a scheduled time for the study visit and provide informed consent. Each caregiver participant had to be an unpaid caregiver and have spent an average total of at least 2 hours per week with the powered wheelchair user that included powered wheelchair mobility. Caregiver participants were excluded if they had unstable medical conditions that might have made the use of a powered wheelchair dangerous, and/or emotional problems that might have made participation unsafe or unpleasant.

Demographic data regarding the caregiver participants was obtained in the interview of the larger cross-sectional study — age, sex, primary language, health concerns, relationship to the wheelchair user, average total number of hours per week spent with the wheelchair user that included powered wheelchair mobility, and whether the caregiver has received any formal training related to wheelchair skills.

The qualitative semi-structured interviews included multiple questions, in order to cover the different dimensions of caregiver experiences. These dimensions were: the type of assistance the caregiver provided; the barriers encountered; caregiver needs; caregiver burden related to wheelchair assistance; resources (personal and social) used and needed by the caregivers; and training. The questions regarding burden experienced by caregivers were based on the answers given to the Power Mobility Caregiver Assistive Technology Outcome Measure (PM-CATOM). The PM-CATOM is an 18-item outcome measure designed to assess power wheelchair-related (Part 1) and overall burden (Part 2) experienced by informal caregivers¹². Frequency of burden was rated using a 5-point ordinal scale.

The assessments took place at locations most convenient for participants, such as the participants' place of residence.

The interviews were transcribed verbatim and we performed a thematic content analysis used to identify the emergent themes from the discourse of the participant. Procedures were established to ensure issues of trustworthiness were considered; for instance, to ensure credibility, the analysis followed an iterative process involving a back-and-forth movement between the transcriptions and the codes.

RESULTS

We interviewed 20 caregivers. The mean (SD) age of the participants was 56.1 (± 11.8) years. The majority of caregivers were family members, and 8 (40.0%) were male. Only 2 (10.0%) of the caregivers had ever received any formal training related to wheelchair skills.

The PM-CATOM Part 1 and Part 2 scores were 52.7 ± 0.5 and 16.1 ± 0.4 respectively, which meant that caregivers experienced moderate burden. In the interviews, the caregivers reported concerns regarding safety and the risk of injuries for both themselves and PWC users. Few caregivers mentioned that helping PWC users created back problems. Some caregivers shared stories of accidents regarding the use of the PWC, which in turn increased caregiver anxiety when the PWC users were using their device alone. Most caregivers mentioned that helping with the PWC allowed them to spend quality time with the PWC users and to enjoy activities together. The majority of caregivers received support regarding the PWC users, mostly from other family members and friends. Few participants used resources from disability or community organizations. Regarding PWC training, participants expressed mixed feelings. Some clearly stated that they would prefer to have access to support and knowledge when a problem occurs with the PWC, while others indicated that training regarding the usage (e.g. putting it in manual mode) or the maintenance (e.g. what to do in case of a battery failure) of the PWC should be given when the PWC is provided. Most of the caregivers mentioned that the PWC users were great resources of

knowledge for them regarding the PWC functioning and manipulation.

DISCUSSION

The caregivers experienced moderate wheelchair-related and overall burden when providing assistance to older PWC users. Their concerns were primarily related to safety issues and risk of injuries as a result of past experiences with the PWC, which confirms the results of existing literature.³⁻⁶ Regarding the positive dimension of caregiving experiences, the participants reported receiving resources and support from their relatives. Additionally, caregivers felt that the PWC users themselves were a great source of knowledge on how to manage the PWCs. Future studies should investigate how the PWC users and their family caregivers work together to improve the usage and maintenance of the PWCs.

CONCLUSIONS

These findings assist in answering how caregivers provide mobility assistance to older PWC users, and how this has an impact on their daily activities. Focusing on the resources and the positive dimension of caregiving brings a new perspective on how to support family caregivers.

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