

Towards an Autonomy-Based Approach to Design and Develop Mobility Assistive Technologies for Spinal Cord Injury Populations

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INTRODUCTION

Mobility impairment is the most prevalent type of disability in the United States and the third most common in Canada [1], [2]. A large number of people with mobility impairments rely on wheeled mobility assistive devices (WMADs) to perform activities of daily living. Specific recent design characteristics of existing WMADs make it possible to perform certain types of activities that they could not have performed without the use of these devices, such as reaching from elevated seats or navigating difficult terrains with the Freewheel™. Technological growth has enabled the design and development of advanced WMAD concepts such as self-balancing, stair-climbing, and self-navigating wheelchairs. However, due to the diversity of users' needs, use of even the most advanced WMADs might not fully satisfy users' desires and demands. WMADs restrict the user to perform activities in a specific manner or under certain conditions only. In many cases, restrictions imposed by the device can prevent users from performing what they want to do.

Having control over what one wants to do and how to do it is related to the notion of personal *Autonomy*, which has major significance in everyone's life. For assistive device users specifically, perception of autonomy is directly influenced by the type of device they are using and the type of activity they are performing. Accordingly, it is essential for mobility assistive technology (MAT) developers to recognize the extended dimensions of autonomy among WMAD users. In this paper, the authors reviewed the existing literature to identify the main contributing factors to perceived autonomy of WMAD users. The authors then compared the design, characteristics, and performance of commonly used WMADs based on these identified factors. This led to the identification of existing gaps between what WMAD users want to do and what their mobility device allows them to do. This knowledge can form the basis of an autonomy-based framework to be used in the development of mobility assistive technologies in the future. In this paper, we specifically focused on the spinal cord injury (SCI) population as a model system for people with mobility impairment. The findings of our work are not limited to the SCI population and can be used in the development of mobility assistive technologies for other mobility impaired groups as well.

BACKGROUND

Mobility impairments have several physical and psychosocial consequences that significantly impact life satisfaction and quality of life (QoL) of people with SCI [3], [4]. Research has shown that participation, defined as involvement in a life situation, is one of the major determinants of life satisfaction among the SCI population [5], [6]. Autonomy is one of the major components of participation [7]. The International Classification of Impairments, Activities, and Participation (ICIDH) describes autonomy as having decisional and executional control over what, how, when, where, and in what manner activities are done [8]. According to previous research, there is a significant correlation between autonomy and mobility of people with SCI [9]. In this regard, assistive technologies and WMADs in particular are among the most influential factors on the perceived autonomy of the SCI population [10], [11].

Perception of autonomy varies among different individuals and in different contexts. There are a few subjective and objective outcome measures that are used to assess the perceived autonomy of people with disability. These outcome measures include a subset of these questionnaires: "Impact on Participation and Autonomy (IPA)", "Participation Survey/Mobility (PARTS/M)", and the "Psychosocial Impact of Assistive Devices Scale (PIADS)". IPA evaluates the impact of disability conditions on autonomy indoors and outdoors [12]. PARTS/M examines mobility-impaired individuals' choices and control when performing certain activities (e.g., leaving home, active recreation, leisure activities, taking vacations, etc.) [13]. PIADS is a self-report questionnaire that assesses the effects of an assistive device on functional independence, well-being, and quality of life. A subset of this questionnaires evaluates assistive device users' sense of power and control [14]. Other methods such as using investigator-developed questionnaires, as well as performing interviews and focus group studies have been used to obtain information on personal autonomy of people with SCI.

Depending on the level of impairment, the type of desired activities, and environments of use, people with SCI use different types of WMADs. Manual wheelchairs (MWCs) are the most commonly used WMADs among the SCI population. MWC users rely on their upper extremity strength to move themselves and the chair. MWCs are relatively lightweight, maneuverable, and portable, but are also physically demanding to use. Power wheelchairs (PWCs) are the second most commonly used WMADs among the SCI population. In these devices, batteries and electric motors provide all the required power to move the chair, allowing the users to easily navigate with minimal effort (e.g., use of joystick, touchpad, etc.). PWCs provide a less physically taxing alternative to MWCs. However, since PWCs are bulky and difficult to transport, users often face more environmental and social barriers. Consequently, several power-assist devices have been developed that can be attached to MWCs and provide extra power assistance based on the demands of users. Some examples of these devices include pushrim-activated power-assist wheels (PAPAWs), front-end attachment power units (e.g., Firefly from Rio Mobility), and rear-end attachment power units (e.g., SmartDrive from Max Mobility Inc.). In this paper, we will explain how the design and characteristics of the abovementioned devices influence the perceived autonomy of WMAD users.

METHODS

We reviewed the existing literature to identify the contributing factors to the WMAD users' perception of their autonomy with regard to their device use. We searched three databases including: Medline (Source PubMed), Google Scholar, and ProQuest. We used different combinations of the following keywords: "mobility assistive technology", "wheeled mobility assistive device", "wheelchair power add-on", "manual wheelchair add-on", "autonomy", "choice", "control", "participation", "quality of life", "Impact on Participation and Autonomy", "Participation Survey/Mobility", and "Psychosocial Impact of Assistive Devices Scale". We excluded the literature in which autonomy of assistive devices, and not the personal autonomy of assistive device users, were discussed and assessed. The population focus of our research is on active and independent wheelchair users and we excluded studies with the following target population: cognitively-impaired, pediatric, and institutional-bound wheelchair users.

RESULTS

Autonomy and Associated Contextual Factors

Perceived level of autonomy among WMAD users was shown to be related to personal, environmental, and activity-related factors. MAT users in general, and wheelchair users specifically, described that the use of their assistive device improved their autonomy [15]. The improved autonomy of wheelchair users was shown to be related to their increased sense of independence and self-reliance [11], [16] as well as their ability to perform desired activities [17]. Perception of autonomy of PWC users was associated with the environment the device was being used in. As an example, PWCs provided higher levels of autonomy to users only when they were used in accessible spaces such as accessible entrances, washrooms, or public transportation [18]. The findings of studies in which the IPA questionnaire was used revealed that WMAD users perceived more restrictions in autonomy outdoors than indoors [9]. In the context of activity performance, perceived autonomy of people with SCI was rated the lowest when visiting family and friends and going on trips and holidays [19].

WMAD Use and Contributing Factors to Autonomy

After synthesizing the data in the literature, we identified that there are six main contributors to the autonomy of WMAD users that are related to the use of their assistive device. These factors are: (1) *device transportability* (e.g., accessibility of private/public transport to WMAD users) [20], [21]; (2) *rough, soft, uneven terrain and ramped surfaces accessibility* (e.g., surfaces covered with snow, sand, and grass) [22]; (3) *curb or step negotiation* [19]; (4) *distance traveled* (e.g., how far WMAD users can go with their device) [23], [24]; (5) *users' health conditions as related to their device use* (e.g., user's joint pain, fatigue, and muscle condition) [23]; and (6) *standing height accessibility* [19].

Autonomy Comparison for Commonly Used WMADs

Design and performance characteristics of WMADs play an important role in the experience of users with each of the abovementioned contributing factors to autonomy. We synthesized the related data to each of these factors and ranked the perceived autonomy of MWC, PWC, and PAPAW users along each of the six factors. A radar chart for these rankings are shown in Figure 1. In terms of device transportability, MWCs provide a higher sense of autonomy compared to PWCs and PAPAWs. Similarly, in terms of curb negotiation, MWCs are ranked the highest. In terms of distance travelled with the device and accessibility of uneven surfaces, PWCs provide the highest perception of autonomy, PAPAWs are ranked second, and MWCs third. Fatigue after long use of an MWC

and inaccessibility of some rough and soft terrains are the main reasons for this ranking. In terms of users' health conditions that are related to the use of WMAD, PAPAWs can provide a more balanced sense of autonomy. High potential risks of upper extremity joint pain and muscle atrophy are some of the consequences of MWC and PWC use, respectively.

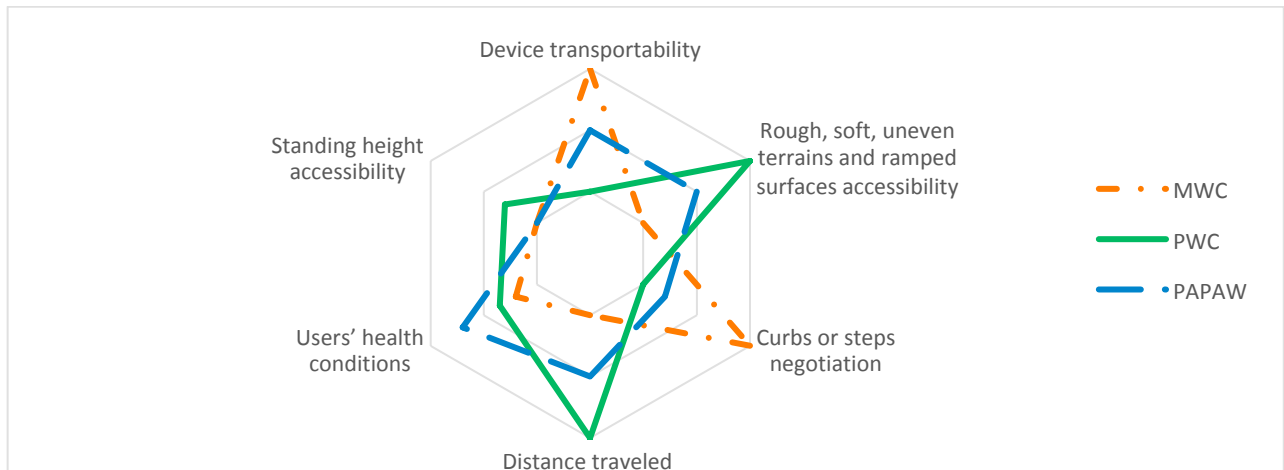


Figure 1. Autonomy evaluation of WMADs

DISCUSSION

Autonomy of WMAD users has a direct impact on life satisfaction and participation in life activities. Therefore, it is crucial to consider and address the autonomy-related needs and challenges of WMAD users. To achieve this goal, it is important to know the most influential contributing factors to autonomy and their importance to WMAD users. At the same time, it is crucial to recognize the impact of each factor for different user groups and in different contexts of device use (e.g., when performing different activities and in different environments). Analysis of the literature revealed that the design and development of different WMADs are focused on certain dimensions of autonomy only. Therefore, there is still a gap between what WMAD users want to do and what the design of currently available WMADs lets them do.

The comparison between MWCs, PWCs, and PAPAWs across the identified six contributing factors to autonomy, shows that: (1) MWCs and PWCs have high rankings in some (but different) factors, and (2) PAPAWs have a more uniformly distributed ranking among all the factors. This may be because power-assist units for MWCs can provide unique characteristics and different capabilities for different users and in different contexts of device use. Previous studies suggested this by demonstrating the PAPAWs' potential to improve certain aspects of autonomy for both manual and power wheelchair users [22]. However, the current design of existing power-assist devices hasn't significantly changed the life satisfaction of users [25]. This is again related to the restrictions imposed by the device that reduces users' flexible interaction with the environment [26].

The identified gaps between autonomy-related needs of WMAD users and the solutions offered by existing devices can be reduced through a user-centered approach in conjunction with an autonomy-based design framework. Taking into account the advantages provided by power-assist devices, we hypothesize that adoption of a modular-based approach can further improve the individualized aspects of autonomy-related design components.

CONCLUSION

In conclusion, the use of WMADs provide benefits and impose some restrictions to users that directly influence their autonomy [26]. Currently, there is a need for a new generation of mobility assistive technologies that can provide a more balanced sense of autonomy to users to significantly improve their QoL and life satisfaction. The first step to achieve this goal is to both objectively and subjectively assess WMAD users' perceptions of their autonomy when using their WMADs. Also, further research can be done with other types of power-assist devices (e.g., front-end attachments and rear-end attachments) to explore the autonomy-related potential provided by the use of these devices. The results of this research can then provide the basis for an autonomy-based design framework for mobility AT developers and influence new innovations in WMADs.

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REFERENCES

- [1] E. A. Courtney-Long, D. D. Carroll, Q. C. Zhang, A. C. Stevens, S. Griffin-Blake, B. S. Armour, and V. A. Campbell, "Prevalence of disability and disability type among adults — United States, 2013," *MMWR. Morb. Mortal. Wkly. Rep.*, vol. 64, no. 29, pp. 784–792, 2015.
- [2] Stats Canada, "Disability in Canada: Initial findings from the Canadian survey on disability fact sheet," 2013. [Online]. Available: <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.htm>.
- [3] M. P. J. M. Dijkers, "Correlates of life satisfaction among persons with spinal cord injury," *Arch. Phys. Med. Rehabil.*, vol. 80, no. 8, pp. 867–876, 1999.
- [4] N. Sezer, "Chronic complications of spinal cord injury," *World J. Orthop.*, vol. 6, no. 1, p. 24, 2015.
- [5] World Health Organization, "Towards a Common Language for Functioning , Disability and Health ICF," *Int. Classif.*, vol. 1149, pp. 1–22, 2002.
- [6] M. L. Lund, A. Nordlund, B. Bernspång, and J. Lexell, "Perceived participation and problems in participation are determinants of life satisfaction in people with spinal cord injury," *Disabil. Rehabil.*, vol. 29, no. 18, pp. 1417–1422, 2007.
- [7] J. Hammel, S. Magasi, A. Heinemann, G. Whiteneck, J. Bogner, and E. Rodriguez, "What does participation mean? An insider perspective from people with disabilities," *Disabil. Rehabil.*, vol. 30, no. 19, pp. 1445–60, 2008.
- [8] M. Cardol, R. J. de Haan, G. A. M. van den Bos, B. A. de Jong, and I. J. M. de Groot, "The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA)," *Clin. Rehabil.*, vol. 13, no. 5, pp. 411–419, 1999.
- [9] M. L. Lund, A. Nordlund, L. Nygård, J. Lexell, and B. Bernspång, "Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury," *J. Rehabil. Med.*, vol. 37, no. 1, pp. 3–8, 2005.
- [10] J. Wee and R. Lysaght, "Factors affecting measures of activities and participation in persons with mobility impairment," *Disabil. Rehabil.*, vol. 31, no. 20, pp. 1633–1642, 2009.
- [11] J. A. Lenker, F. Harris, M. Taugher, and R. O. Smith, "Consumer perspectives on assistive technology outcomes," *Disabil. Rehabil. Assist. Technol.*, vol. 8, no. 5, pp. 373–380, 2013.
- [12] de G. I. Cardol M, de Haan RJ, van den Bos GA, de Jong BA, "Impact on Participation and Autonomy-E (IPA)," *Clin. Rehabil.*, vol. 13, pp. 411–419, 1999.
- [13] D. B. Gray, H. H. Hollingsworth, S. L. Stark, and K. A. Morgan, "Participation Survey / Mobility," pp. 1–13, 2006.
- [14] J. W. Jutai and H. Day, "Psychosocial Impact of Assistive Devices Scale (PIADS)," *Technol. Disabil.*, no. JANUARY 2002, pp. 107–111, 2002.
- [15] A. Martins, J. Pinheiro, B. Farias, and J. Jutai, "Psychosocial Impact of Assistive Technologies for Mobility and Their Implications for Active Ageing," *Technologies*, vol. 4, no. 3, p. 28, 2016.
- [16] R. Fomiatti, J. Richmond, L. Moir, and J. Millsted, "A Systematic Review of the Impact of Powered Mobility Devices on Older Adults' Activity Engagement," *Phys. Occup. Ther. Geriatr.*, vol. 31, no. 4, pp. 297–309, 2013.
- [17] M. J. Scherer and R. Glueckauf, "Assessing the Benefits of Assistive Technologies for Activities and Participation.," *Rehabil. Psychol.*, vol. 50, no. 2, pp. 132–141, 2005.
- [18] A. Korotchenko, L. Hurd Clarke, L. H. Clarke, and L. Hurd Clarke, "Power mobility and the built environment: the experiences of older Canadians," *Disabil. Soc.*, vol. 29, no. 3, pp. 431–443, 2013.
- [19] C. Pettersson, Å. Brandt, E. M. Lexell, and S. Iwarsson, "Autonomy and housing accessibility among powered mobility device users," *Am. J. Occup. Ther.*, vol. 69, no. 5, pp. 1–9, 2015.
- [20] M. Pyer and F. Tucker, "“With us, we, like, physically can’t”: Transport, Mobility and the Leisure Experiences of Teenage Wheelchair Users," *Mobilities*, vol. 12, no. 1, pp. 36–52, 2017.
- [21] B. Collins and P. O’Mahony, "Physically disabled adults' perceptions of personal autonomy: Impact on occupational engagement," *OTJR Occup. Particip. Heal.*, vol. 35, no. 3, pp. 160–168, 2015.
- [22] E. M. Giesbrecht, J. D. Ripat, J. E. Cooper, and A. O. Quanbury, "Experiences with using a pushrim-activated power-assisted wheelchair for community-based occupations: a qualitative exploration.," *Can. J. Occup. Ther.*, vol. 78, no. April, pp. 127–136, 2011.
- [23] P. R. Giacobbi, C. E. Levy, F. D. Dietrich, S. H. Winkler, M. D. Tillman, and J. W. Chow, "Wheelchair Users' Perceptions of and Experiences with Power Assist Wheels," *Am. J. Phys. Med. Rehabil.*, vol. 89, no. 3, pp. 225–234, 2010.

- [24] D. Pradon, E. Garrec, I. Vaugier, T. Weissland, C. Hugeron, and B. Guillon, "Effect of the use of electric assistance on the propulsion of the manual wheelchair Smartdrive on the biomechanical parameters of the propulsion in ecological situation," *Ann. Phys. Rehabil. Med.*, vol. 60, p. e12, 2017.
- [25] M. G. Kloosterman, G. J. Snoek, L. H. van der Woude, J. H. Buurke, and J. S. Rietman, "A systematic review on the pros and cons of using a pushrim-activated power-assisted wheelchair," *Clin. Rehabil.*, vol. 27, no. 4, pp. 299–313, 2013.
- [26] M. Cardol, B. a De Jong, and C. D. Ward, "On autonomy and participation in rehabilitation," *Disabil. Rehabil.*, vol. 24, no. 18, pp. 970–974, 2002.