Preliminary case series description of power standing wheelchair users

J. Borin[1], R. Schein[1], G. Pramana[1], M. Schmeler[1]

[1]*University of Pittsburgh, Department of Rehabilitation Science and Technology*

INTRODUCTION

Standing systems, incorporated within a power or manual wheelchair, allows an individual to transition from a seated position to a standing position without the need of a wheelchair transfer. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) published a position paper on the application of wheelchair standing devices defined as "A standing feature integrated into a wheelchair base that allows the user to obtain a standing position without the need to transfer from the wheelchair. A mechanical or electromechanical system manipulated via levers or the wheelchair's controller moves the seat surface from horizontal into a vertical or anteriorly sloping position while maintaining vertical position of the leg rests and backrest, thus extending the hip and knee joints." [1]

Standing is an essential component in the medical and rehabilitative management of some individuals. [2] The benefits of standing have been reported as a clinical consensus statement in RESNA's previous position on the application of wheelchair standing devices. [3] The ability to access vertical environments is not only reasonable and necessary for performance of activities of daily living but medically necessary and vital for: medical benefits such as reduced pressure on internal organs and improved lung volume [4,5]; improved bone density [6]; and to relieve pressure. [7,8]

Current policy within the Centers for Medicare and Medicaid Services (CMS) views standing features on a wheelchair as not a covered item within the durable medical equipment benefit and defines it as a as a convenience item therefore not medical in nature. [9] In addition, many insurances follow CMS coverage criteria. To promote change and request CMS to open a National Coverage Determination decision on power standing, individualized comments and voices must be heard. The purpose of this paper is to provide a characterization through a case series of individuals who use standing wheelchairs from the Functional Mobility Assessment (FMA) Registry.

MATERIALS AND METHODS

Data for this study was retrieved from the Functional Mobility Assessment/Uniform Data Set (FMA/UDS) Registry. [10] The FMA/UDS Registry contains data spanning 4+ years with over 10,000 unique mobility device users, collected through an exempt Institutional Review Board protocol and a vetted Collaborative Corporate Research Agreement with the Van G. Miller Group, Inc. (VGM). VGM is a national leader in the health care industry and provides business solutions to an expanding number of businesses and industries, working with nearly 400 independent complex rehabilitation providers and has nearly 1400 provider locations within the United States. The FMA/UDS was administered by over 20 supplier companies to individuals at the time of initial evaluation for a new mobility intervention (baseline) and follow-up at set times after provision of new mobility assistive equipment (MAE) device. [10]

The FMA contains 10 statements about satisfaction with operation of the device, using the device for carrying out daily routines and personal care tasks, meeting comfort or health needs, reaching objects, transferring, moving indoors and outdoors, and using transportation. When the FMA is administered, a client needs to respond by rating each statement from 1 to 6 (1-completely disagree, 2-mostly disagree, 3-slightly disagree, 4-slightly agree, 5-mostly agree, and 6-completely agree). [11]

A case series study design was implemented to describe the characteristics and outcomes from individuals 18 and older, using a standing wheelchair for one year after receiving their new MAE.

Measures

In addition to the total FMA score, the following variables were extracted from the FMA/UDS Registry for analysis:

- Client age (Self-identified in years)
- Gender (Self-identified by the client)
- Primary diagnosis (Self-identified reason for disability, categorized by 31 groups in the UDS)
- Years since disability onset (Number of years that the client has been living with their primary diagnosis)

- Device type (The UDS defines primary device type by 17 categories based on the CMS Healthcare Common Procedure Classification System.)
- Device use (The UDS measures device use in terms of hours of use per day, broken down into increments.)
- Employment (The UDS defines employment in terms of 3 categories.
- Wheelchair manufacturer (The UDS defines wheelchair manufacturer as the producer of the mobility device.)
- Funding (The UDS defines funding as the payer source of the mobility device. In this case, the database only allowed for one payer source to be listed.)

RESULTS

The registry yielded 7 cases. All were male and all used power wheelchairs. There were no cases of manual standing wheelchair users. Each are described as follows;

Participant 1

Participant 1 is a 26-year-old male with cerebral palsy. He is 5'9" and weighed 127 pounds at baseline (BMI = 19.21). He previously used a Permobil group 4 power wheelchair with standing and currently uses a Permobil group 4 power wheelchair with standing with Medicaid as the funding source. He resides in the community and his employment status changed throughout the course of the study. His initial FMA score was 52 and his FMA score 21 days post-delivery was 54.

Participant 2

Participant 2 is a 46-year-old male with a spinal cord injury (paraplegia). He is 5'9" and weighed 142 pounds at baseline (BMI = 21.47). He previously used no mobility device and currently uses a Permobil group 4 power wheelchair with standing with an unknown funding source. He resides in the community and was employed throughout the course of the study. His initial FMA score was 10 and his FMA score 21 days post-delivery was 60. His reported daily use of his previous mobility device at baseline is unknown.

Participant 3

Participant 3 is a 38-year-old male with multiple sclerosis. He is 6'0" and weighed 150 pounds at baseline (BMI = 20.83). He previously used an Invacare standard manual wheelchair and currently uses an Invacare group 3 power wheelchair with standing with Medicare as the funding source. He resides in the community and was employed through the course of the study. His initial FMA score was 12 and his FMA score 21 days post-delivery was 57. His reported daily use of his mobility device was 5-8 hours at baseline.

Participant 4

Participant 4 is a 37-year-old male with cerebral palsy. He is 5'5" and weighed 179 pounds at baseline (BMI = 30.50). He previously used a Pride/Quantum group 3 power wheelchair without standing and currently uses a Motion Concepts group 3 power wheelchair with standing with Medicaid Managed Care as the funding source. He resides in the community and was employed for every period after baseline. His initial FMA score was 46 and his FMA score 21 days post-delivery was 60.

Participant 5

Participant 5 is a 68-year-old male with a stroke (CVA). He is 5'9" and weighed 200 pounds at baseline (BMI = 30.25). He previously used a Pride/Quantum group 2 power wheelchair without standing and currently uses a Pride/Quantum group 3 power wheelchair with standing with Medicare as the funding source. He resides in the community and was retired throughout the course of the study. His initial FMA score was 57 and his FMA score 21 days post-delivery was 58.

Participant 6

Participant 6 is a 72-year-old male with a spinal cord injury (paraplegia). He is 5'5" and weighed 235 pounds at baseline (BMI = 40.05). He previously used an Invacare group 3 power chair without standing and currently uses a Pride/Quantum group 3 power wheelchair with standing with Workers' Comp as the funding source. He resides in the community and was employed throughout the course of the study. His initial FMA score was 36 and his FMA score 21 days post-delivery was 53.

Participant 7

Participant 7 is a 67-year-old male with amyotrophic lateral sclerosis/primary lateral sclerosis. He is 6'0" and weighed 243 pounds at baseline (BMI = 33.75). He previously used a cane, walker, and/or crutches and currently uses a Permobil group 4 power wheelchair with standing with Medicare as the funding source. He resides in the community and was retired throughout the course of the study. His initial FMA score was 25 and his FMA score 21 days post-delivery was 60.

DISCUSSION

This retrospective analysis of the FMA/UDS Registry were reviewed, and over the course of 4+ years, 7 individuals had a power standing feature and described as a case series. Investigators descried the cases based on a set of specific variables including funding sources, FMA Score, height, weight, previous MAE, and living situation.

Funding Source

Three out of the seven participants had Medicare as a payer source which does not historically pay for standing wheelchairs. Therefore, it is likely these were covered through other sources such as a secondary payer source not identified in the registry.

Overall changes in FMA score

All participants showed an increase in FMA score with every participant reporting an FMA score above 50 at one year post-delivery. This means all participants rated most statements a 5 or above (indicating satisfaction). However, it is also important to note that the individuals who were using a power wheelchair at baseline had higher FMA scores at baseline than those who used a cane, crutch, walker, or manual wheelchair. Further analysis is needed to see how participants compare with other power wheelchair users in the database without standing.

Diagnoses

There were two participants with congenital diagnoses (cerebral palsy) and the other five had acquired diagnoses. Two of the diagnoses (multiple sclerosis and amyotrophic lateral sclerosis/primary lateral sclerosis) are progressive conditions; this means that the time from diagnosis can impact the progression of the condition in those individuals. Participants 2 and 7 had their diagnoses for the shortest amount of time (1 year and 3 years respectively) and both were receiving their first power wheelchair. From the data these cases were sourced from no details were included about the specifics of any of the diagnoses (i.e., GMFCS level for cerebral palsy or ASIA level of SCI patient) or of any co-morbid conditions. Without this additional information, it is difficult to have a complete clinical picture of these participants.

Strengths and Limitations

This study is the first descriptive case series of users of standing wheelchairs. It is vital to understand the types of users who receive standing wheelchairs and can benefit from them in order to better understand the clinical significance and help to pass policy to fund standing wheelchairs in the future. This case series clearly shows the gaps in the data that remain. Of the thousands of users these cases were pulled from, only 7 users received standing wheelchairs. Even with robust data on wheelchair users and service delivery, data on standing wheelchairs remains limited due to limited funding sources. Multiple points of data were marked as "unknown" within the database these cases were taken from and even still, the data that is recorded is not very descriptive. Diagnoses, payer sources, and previous equipment listed are all relatively vague. In order get more detailed data, it would likely need to be obtained from the health record and other sources however could require more burdensome processes as compared to readily available registry data.

Despite the documented benefits of standing wheelchairs, only 7 cases out of the 10,000+ surveyed received a standing wheelchair.

CONCLUSION

Further analysis will be conducted in a future publication. It will be important to examine additional data such as living situation and reported daily usage of mobility device, and to compare the seven participants in the series with the database averages to see how they compare. There is a need for further research in this area when it comes to long term use of the standing feature. This case series shows the missing component of qualitative data

that is absent from the current knowledge base. Without qualitative data on standing wheelchair users, it is difficult to truly describe these users. The next steps would be to gather more case studies and more in-depth information collectively including secondary payer sources, specifics of diagnosis, demographic information, and details of when and in what setting the chairs are prescribed.

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