

Measuring self-perceived satisfaction and independence of wheelchair users

Abstract

Background: Following receipt of a wheeled mobility device, outcomes can be measured using subjective (self/proxy report) or objective (performance-based observation at clinic and home) measures. These measures can be used together and can be complementary. There is currently a lack of available outcome measures related to functioning with the use of a wheelchair. In response to the need for more comprehensive outcome measures to document function for third-party payers, and evaluate the efficacy of wheeled mobility interventions, in 2001, a team of researchers at the University of Pittsburgh developed the FEW (a self-report measure), the FEW-Capacity (FEW-C, a performance-based measure for the clinic), and the FEW-Performance (FEW-P, a performance-based measure for the home) outcome measurement instruments. The FEW tools have been used in research and proved to be reliable, valid, and useful. Currently, only a handful of research studies have focused on measuring level of satisfaction and functional independence for wheelchair users using their wheelchairs for everyday functional performance. Therefore, the FEW instrument was used in this study to measure self-perceived satisfaction and functional independence of wheelchair users.

Keywords: satisfaction, rehabilitation, performance, wheelchair

Introduction

The wheelchair is viewed as one of the most important assistive technology devices used in rehabilitation.¹ Wheelchairs, both manual and powered, are enablers of community participation, are used to enhance function, to improve independence, and to enable a person to successfully live at home and in the community.² Wheelchair evaluation is a continuous process requiring re-assessment of wheelchair fit as users age and their functional conditions change.³ Research has shown that during this process, clinicians need to take factors into consideration that are associated with functional performance, such as wheelchair characteristics and client demographics. It is the dynamic interactions between these factors that pose the challenge for clinicians and wheelchair users as they decide on the best wheeled mobility interventions.⁴ Although clients seeking a wheeled mobility device are assessed before a device is prescribed, research has not focused on the everyday functional performance of the clients with their wheelchairs. Rather, instead of focusing on the ability of the device to enable activities and participation, research has focused on wheelchair skills, propulsion, abandonment, cost, policy, and wheelchair design.⁵ Following receipt of a wheeled mobility device, outcomes can be measured using subjective (self/proxy report) or objective (performance-based observation at clinic and home) methods. These assessment methods do not always yield equivalent results with clinical samples, and therefore the level of association among functional subjective and objective methods among clients being assessed for, and receiving, wheeled mobility devices is unclear.⁶ There is currently a lack of comprehensive outcome measures that focus on everyday functioning with a wheelchair. The Wheelchair Physical Functional Performance (WC-PFP), the Wheelchair Skills Test (WST), and the Wheelchair Users Functional Assessment (WUFA) are valid and reliable performance measures used to assess client's skills or function while using a manual wheelchair.^{7,8} None of these measures address the quality of functional performance or provide individual scores for independence and safety for both manual and power wheelchair users. Furthermore, these measures do not fully represent all the important

tasks wheelchair users identified as important to perform in a seating-mobility device, such as Comfort Needs, Reach for multiple levels, Transfers to/from multiple levels, and Transportation.^{6,9} In response to the need for more comprehensive outcome measures to document function for third-party payers, and evaluate the efficacy of wheeled mobility interventions, a team of researchers at the University of Pittsburgh developed the FEW (a self-report measure), the FEW-Capacity (FEW-C, a performance-based measure for the clinic), and the FEW-Performance (FEW-P, a performance-based measure for the home) outcome measurement instruments. The trio of FEW tools has been used in research and proved to be reliable, valid, and useful.^{6,9-11} A study of 25 subjects showed that both the self-report FEW and FEW-C were able to detect significant changes in function over time following the provision of a new wheeled mobility and seating device. However, the FEW often significantly underestimated function compared to the FEW-C, and therefore documented greater changes in function over time⁶. Underestimation may have occurred because it is not unusual for individuals who are seeking interventions to underestimate their capabilities to obtain services or products.¹² The FEW tools have been used in tele rehabilitation studies and also proved to be reliable and effective in that venue.¹¹ Although there are several assessments of wheelchair skills, none address independence, safety and adequacy of performance of everyday tasks with a wheelchair. The FEW, FEW-C and FEW-P were developed to address the need for a more comprehensive assessment and outcomes tool for clients seeking and receiving wheeled mobility devices. Only a handful of research studies focused on measuring level of satisfaction and functional independence for wheelchair users using their current wheelchairs at everyday functional performance.¹³ Therefore, the FEW instrument was selected in this study to measure self-perceived satisfaction and functional independence of wheelchair users. The objectives of this study were to measure self-perceived satisfaction and independence in performing functional activities of individuals who use wheelchair as their primary mobility and seating device, to enable wheelchair users to identify the degree of problems they

have performing functional tasks in their daily lives while using their wheelchairs. We hypothesized that users would underestimate their self-perceived satisfaction and independence with their current means of mobility.

Methods

This was a descriptive quantitative research study design. The Functioning Everyday with a Wheelchair (FEW, Self-report Version) was used for this study. The FEW Beta Version 2.0 is a 10 item structured self-report outcome measurement tool (Table 1) that was developed based on input and validation from wheelchair users. The FEW can be self-administered, administered as an interview or administered by telephone. Items 2-10 of the FEW measure perceived functional independence of individuals who use a wheelchair or scooter as their primary mobility and seating device and have progressive or non-progressive conditions. For example, the OPERATE item is “The size, fit, postural support and functional features of my wheelchair/scooter allow me to operate it as independently... as possible: (e.g., do what I want it to do when and where I want to do it). The items are scored using a 6 point scale of 6=completely agree to 1=completely disagree, and a score of 0=does not apply. The FEW enables clients to identify the degree of problems they have performing 9 functional tasks in their daily lives while using their wheelchairs (manual/power wheelchair/scooter). It has excellent test-retest reliability (ICC=0.92). In addition, the FEW has excellent content validity because it was generated by input from both consumers and clinicians, validated by several samples of wheelchair/scooter users, and shown to be capable of detecting users' perceived function with a wheelchair over time.^{9,10,14} Approval to conduct this study was obtained from the Deanship of Academic Research for the University of Jordan. The inclusion criteria for participants recruited for this study were (a) existing manual/power wheelchair or scooter user, who had experienced a change in functional status; (b) 16 years of age or older; and (c) adequate cognitive and language status, that is participants would be able to understand and verbally respond to questions in the FEW. Individuals with cognition and language impairments were excluded. Informed consents were obtained from 26 participants who had completed the FEW instrument, and therefore the analyses were conducted with data from those 26 participants. Participants were recruited from the University of Jordan, University of Jordan hospital, and Al-Bashir hospital in Amman. All participants were seen and interviewed at the three sites.

Table 1 Items of the FEW, FEW-C, and FEW-P

Items/tasks
1. Stability, Durability, Dependability
2. Comfort Needs
3. Health Needs
4. Operate
5. Reach
6. Transfer
7. Personal Care
8. Indoor Mobility
9. Outdoor Mobility
10. Transportation

Results

Demographics of participants (n=26)

Our study sample consisted of 26 wheelchair users with progressive or non-progressive conditions: 13 were male and 13 were female. The average participant was 37.6 years old, mostly Jordanians, and had used a wheelchair for 5.7 years. Participants with muscular dystrophy, spinal cord injuries, and traumatic brain injuries comprised over half of the sample (Table 2).

Table 2 Study participants' demographics at baseline (n=26)

Demographics	Mean (SD) [range]	n
Age (mean, SD) [range]	37.67 (±20.21) [16.3–75]	
Gender		
Male (n)		13
Female (n)		13
Race		
Jordanian (n)		25
Non-Jordanian (n)		1
Years using a wheelchair (mean, SD) [range]	5.761 (±6.753) [0.2–20]	
Primary medical condition		
Above Knee Amputation (n)		1
Cardiac Disease (n)		0
Cerebral Palsy (n)		2
Cerebral Vascular Accident (n)		4
Lupus (n)		0
Muscular Dystrophy (n)		6
Multiple Sclerosis (n)		0
Orthopedic Disorder (n)		3
Parkinson Disease (n)		0
Traumatic Brain Injury (n)		0
Spinal Cord Injury (n)		5
Other (n)		5

Characteristics of participant's wheelchairs (n=26)

Seventeen of the wheelchairs were manual and nine were power, and on average of 1.8 years old. The manual wheelchairs used by the participants were either with sling foldable seats or rigid frames with no seat functions. The power wheelchairs were either basic or with seat functions (Table 3).

Descriptive of participant's total FEW scores (n=26)

Descriptive statistics of participants' total FEW scores and descriptive of total mean FEW item scores were used. Over one third (almost 40%) of our participants scored less than 40/60 on the total FEW scores. For all subjects, the lowest total FEW score for the 10 items was 16/60, while the highest total FEW score for the 10 items was 58/60 (Table 4).

Descriptive of the FEW item means (n=26)

For all FEW items, participants' answers were between slightly agree and slightly disagree: The lowest total score was 3.5/6 for “outdoor mobility” item, while the highest total score was 4.57/6 for the “Health needs” item. Outdoor mobility, reach, and transportation

items had the lowest total scores respectively for all subjects, while Health needs, comfort needs, and personal care items had the highest total scores, respectively, for all subjects (Table 5).

Table 3 Characteristics of participants' current wheelchairs at baseline (n=26)

Demographics	n
Type of wheelchair	
Manual	17
Power	9
Scooter	0
Age of current wheelchair	1.8 (± 1.7)
Mean (SD) [range]	[2 weeks–7 years]
Number of wheelchairs owned currently	
1 (n)	11
2 (n)	12
3 (n)	2
4 (n)	1

Table 4 Descriptive of participants' total FEW scores at baseline (n=26)

Participant ID	Total FEW score
R.A01	40
R.B02	46
H.N03	57
L.S04	38
H.K05	41
H.Q06	42
H.A07	33
A.T08	29
H.M09	42
A.M010	33
R.SH011	16
S.A012	46
M.J013	41
M.M014	44
A.S015	36
I.S016	37
M.I017	27
F.A018	50
Y.A019	35
T.T020	37
H.I021	57
S.J022	53
A.A023	58
M.A024	49
M.Y025	44
I.M026	42
Total FEW scores for all participants (mean, SD) [range]	(41.27, ± 10.0) [16-58]

Table 5 Descriptive of FEW item means at baseline (n=26)

FEW Item	Baseline
Stability, Durability, Dependability (mean, SD)[range]	4.26 ± 1.25 (1.00–6.00)
Comfort	4.53 ± 1.24 (2.00–6.00)
Health	4.57 ± 1.74 (0.00–6.00)
Operate	4.34 ± 1.49 (1.00–6.00)
Reach	3.57 ± 1.50 (0.00–6.00)
Transfer	4.07 ± 1.49 (1.00–6.00)
Personal Care	4.50 ± 1.44 (1.00–6.00)
Indoor	4.30 ± 1.54 (1.00–6.00)
Outdoor	3.50 ± 1.67 (0.00–6.00)
Transportation	3.61 ± 2.49 (0.00–6.00)

Discussion

Our hypothesis that there would be relatively an overall underestimation of self-perceived satisfaction and independence using the FEW self-report instruments was partially confirmed. 40% of participants tended to underestimate their capabilities on the self-report FEW may be because of their desire to obtain new wheelchairs. It is not unusual for individuals who are seeking interventions to obtain health services or a new product and/or equipment.^{6,12} The underestimation evident in the FEW could suggest that participants perceived greater disability, some wheelchairs provided from donors and charitable agencies and not prescribed by expert clinicians were not properly fitted, and not having adequate training to deal with the complexity of power wheelchairs. Perceptions of their function as indicated on the FEW may have been worse than their actual performance. Self-reports do not always agree with performance-based measures among wheelchair users.^{6,15} Clinically, rehabilitation clinicians may get a more accurate estimation of actual performance using combination of subjective and objective measures.¹³

Low scores of Outdoor mobility, Reach, and Transportation items reflected low satisfaction and independence levels. Environmental restrictions and poor accessibility standards for indoor and outdoor places and means of transportation may have led to relatively lower scores. High scores on Health needs, Comfort needs, and Personal care items reflected high satisfaction and independence levels. Familiarity with health, comfort and personal care routines with their current wheelchairs may have led to relatively higher scores on these items.

Conclusion

This study was the first study that examined self-perceived satisfaction and perceived independence of wheelchair users in Jordan. Also, it was the first to apply the FEW self-report tool for this purpose among wheelchair users in Jordan. The FEW self-report tool is useful and could bring unique information to wheeled mobility and seating assessments. The FEW is helpful in measuring self-perceived satisfaction and perceived functional independence. It requires little time to complete (10-15 minutes) and is a key component of a comprehensive wheelchair assessments workup. Properly fitted wheelchairs prescribed from expert clinicians have been shown to enhance users' satisfaction and functional independence. In addition, FEW could help wheelchair users to identify problems

they have performing functional tasks in their daily lives while using their wheelchairs. Furthermore, the FEW may suggest priorities and focus areas of wheeled mobility and seating interventions. Typically, subjective and objective measures have complementary relationship and the application of both is recommended to get more comprehensive and accurate estimates of functional performance for wheelchair users.^{6,9,15} This study may provide a better understanding of an assessment for measuring wheelchair users perceptions, enable practitioners to better understand the person-wheelchair-environment match, and improve the clinical practice for future wheeled mobility and seating interventions. Use of the self-report and performance-based FEW tools has the potential to yield data that will have a positive impact on wheelchair users, practitioners and suppliers.

This study also had limitations. It had a small sample size and a relatively homogeneous sample of experienced wheelchair users with good cognitive and language skills. Additionally, this study used a subjective measure only (FEW). For future studies, it is recommended that the study have a larger sample, inclusion of non-experienced wheelchair users, inclusion of clients with cognitive and language deficits, inclusion of more diagnoses, and the inclusion of objective measures to further investigate concordance and confirm results (FEW-C and FEW-P).

Acknowledgements

I would like to thank all wheelchair users for their active participation and cooperation.

Conflict of interests

Author declares that there is no conflict of interest.

References

1. Kirby RL, Swuste J, Dupuis DJ, et al. The Wheelchair Skills Test: A pilot study of a new outcome measure. *Arch Phys Med Rehabil.* 2002;83(1):10–18.
2. Wee J, Lysaght R. Factors affecting measures of activities and participation in persons with mobility impairment. *Disabil Rehabil.* 2009;31(20):1633–1642.
3. Karmarkar AM, Collins DM, Kelleher A, et al. Satisfaction related to wheelchair use in older adults in both nursing homes and community dwelling. *Disabil Rehabil Assist Technol.* 2009;4(5):337–343.
4. Oyster ML, Karmarkar AM, Patrick M, et al. Investigation of factors associated with manual wheelchair mobility in persons with spinal cord injury. *Arch Phys Med Rehabil.* 2011;92(3):484–490.
5. World Health Organization. International classification of functioning, disability, and health. Geneva; 2001.
6. Schmeler MR. *Development and testing of a clinical outcome measurement tool to assess wheeled mobility and seating interventions.* University of Pittsburgh: 2005.
7. Rushton PW, Kirby RL, Miller WC. Manual Wheelchair Skills: Objective testing versus subjective questionnaire. *Arch Phys Med Rehabil.* 2012;93(12):2313–2318.
8. Stanley RK, Stafford DJ, Rasch E, et al. Development of a functional assessment measure for manual wheelchair users. *J Rehabil Res Dev.* 2003;40(4):301–308.
9. Mills TL. *Functioning EveryDay with a Wheelchair (FEW): Development and validation of self-report and performance-based observation instruments to measure functional outcomes of seating-mobility interventions.* University of Pittsburgh; 2003.
10. Mills TL, Holm MB, Schmeler M. Test-retest reliability and cross validation of the Functioning Everyday with a Wheelchair instrument. *Assist Technol.* 2007;19(2):61–77.
11. Schein RM, Schmeler MR, Holm MB, et al. Telerehabilitation assessment using the Functioning Everyday with a Wheelchair-Capacity instrument. *J Rehabil Res Dev.* 2011;48(2):115–124.
12. Cress ME, Schechtman KB, Mulrow CD, et al. Relationship between physical performance and self-perceived physical function. *J Am Geriatr Soc.* 1995;43(2):93–101.
13. Sarsak HI. *Functional assessment of wheeled mobility and seating interventions: Relationship of self-report and performance-based assessments.* University of Pittsburgh; 2013.
14. Mills T, Holm MB, Trefler E, et al. Development and consumer validation of the Functional Evaluation in a Wheelchair (FEW) instrument. *Disabil Rehabil.* 2002;24(1–3):38–46.
15. Warms CA, Whitney JD, Belza B. Measurement and description of physical activity in adult manual wheelchair users. *Disabil Health J.* 2008;1(4):236–244.