ORİJİNAL ARAŞTIRMA ORIGINAL RESEARCH

DOI: 10.31609/jpmrs.2020-78832

Self-Reported Difficulties and Related Factors in Wheelchair Users in Turkey

Türkiye'de Tekerlekli Sandalye Kullanıcılarının Karşılaştıkları Sorunlar ve İlişkili Faktörler

İlkay KARABAY[a], Mehpare FIRAT[b], Hüma BÖLÜK ŞENLİKÇİ[c], Murat ERSÖZ[d], Selami AKKUŞ[d]

[a]Clinic of Physical Medicine and Rehabilitation, Gaziler Physical Medicine and Rehabilitation Training and Research Hospital, Ankara, TURKEY
[b]Clinic of Physical Medicine and Rehabilitation, Etimesgut Şehit Sait Ertürk Government Hospital, Ankara, TURKEY
[c]Department of Physical Medicine and Rehabilitation, Başkent University Faculty of Medicine, Ankara, TURKEY
[d]Department of Physcial Medicine and Rehabilitation, Yıldırım Beyazıt University Faculty of Medicine, Ankara, TURKEY

ABSTRACTObjective: To investigate the difficulties experienced by wheelchair users and to determine the relative impact of environmental barriers compared with demographic data and disability. **Material and Methods:** The study included 92 individuals who had received initial rehabilitation between January 2015 and January 2017 at Ankara Physical Medicine and Rehabilitation Training and Research Hospital, Turkey for wheelchair use because of multiple sclerosis, spastic paraparesis, cerebral palsy and transverse myelitis diagnoses. Face-to-face interviews were conducted and the extent of the disability was measured using the Craig Handicap Assessment and Reporting Technique-Short Form, functional independence was assessed with the Functional Independence Measurement and the Beck Depression Inventory was completed by all participants. **Results:** Age, gender, marital status and presence of social support did not seem to be associated with functional independence, handicap and depression scores. The type of wheelchair and duration of wheelchair use were found to be associated with handicap scores. In the comparison of two groups who had difficulty at home or not, a significant difference was determined in the functional independence scores, and in wheelchair use outside the home, a significant difference was determined between the groups in respect of functional independence, depression and handicap scores. **Conclusion:** Most of the difficulties experienced were related to handicap and functional independence scores and the vast majority of the participants reported that there was a need for architectural changes in the place where they lived. Further efforts to eliminate environmental barriers will help to make life easier for wheelchair users.

Keywords: Disability; wheelchair; handicap

ÖZET Amaç: Çalışmanın amacı, tekerlekli sandalye kullanıcılarının yaşadıkları zorlukları ve etkileyen çevresel faktörleri, demografik özellikler ve özürlülük ile birlikte ortaya koymaktır. **Gereç ve Yöntemler:** Çalışmaya, Ocak 2015-Ocak 2017 tarihleri arasında Türkiye Ankara Fizik Tedavi ve Rehabilitasyon Eğitim ve Araştırma Hastanesinde, rehabilitasyon programına alınan ve multipl skleroz, spastik paraparezi, serebral palsi ve transvers miyelit tanıları nedeniyle tekerlekli iskemle kullanan 92 hasta dâhil edilmiştir. Tüm katılımcılara, Craig Handikap Değerlendirme ve Bildirme Teknik Kısa Formu, Fonksiyonel Bağımsızlık Ölçeği ve Beck Depresyon Ölçeği yüz yüze görüşmelerle uygulanmıştır. **Bulgular:** Yaş, cinsiyet, medeni durum ve sosyal destek varlığı; fonksiyonel bağımsızlık, handikap ve depresyon skorlarıyla ilişkili bulunmamıştır. Tekerlekli sandalye tipi, kullanma süresi, handikap skorları ile ilişkili bulunmuştur. Evde zorluk yaşayanlar ile yaşamayanlar arasında fonksiyonel bağımsızlık skorları açısından farklılık saptanmıştır. Dışarıda tekerlekli iskemle kullanımı açısından ise zorluk yaşayan ve zorluk yaşamayan gruplar arasında fonksiyonel bağımsızlık, depresyon ve handikap skorları açısından farklılık saptanmıştır. **Sonuç:** Hastaların yaşadıkları birçok zorluk, handikap ve fonksiyonel bağımsızlık skorları ile ilişkilidir. Birçok hasta, yaşadıkları ortamda mimari değişiklik gereksiniminden bahsetmişlerdir. Geleceğe yönelik çabalar ile çevresel engeller ortadan kaldırılıp, tekerlekli sandalye kullanıcılarının hayatı kolaylaştırılabilir.

Anahtar Kelimeler: Özürlülük; tekerlekli sandalye; handikap

Mobility is one the most important parts of daily life for patients with motor disabilities. Wheelchairs (WCs) play a significant role in mobilization, independence and social participation.[1,2] Mobilization affects community integration, and contributes to personal development in many ways, thereby improving

Correspondence: Hüma BÖLÜK ŞENLİKÇİ
Department of Physical Medicine and Rehabilitation, Başkent University Faculty of Medicine, Ankara, TURKEY/TÜRKİYE
E-mail: humaboluk@gmail.com

Peer review under responsibility of Journal of Physical Medicine and Rehabilitation Science.

Received: 10 Sep 2020 ***Received in revised form:*** 07 Oct 2020 ***Accepted:*** 19 Oct 2020 ***Available online:*** 18 Jan 2021

quality of life. Social participation includes all educational, leisure, family and home activities. The crucial focus of the rehabilitation process is to provide community participation for patients with functional disability. Although the WC is considered to be the leading mobility device, WC users report decreased social participation.[3]

When the World Health Organization developed the international classification of functioning disability and health, well-being was included with components not only related to health (body functions and structures) but also health-related components such as activities, participation, environmental and personal factors.[4] To achieve well-being equivalent to the definiton of health, all parts of these domains should be complete, although it has previously been reported that WC users deal with both motor disabilities, and environmental and social restrictions.[5,6] Few studies have assessed the relationship between the self-reported experienced difficulties and functionality and handicap. The aim of this study was to present the sociodemographic characteristics of WC users and the relationship between functionality and handicaps and the difficulties experienced.

MATERIAL AND METHODS

STUDY DESIGN AND PARTICIPANTS

This cross-sectional study included patients who were administered a neurological rehabilitation program in the Physical Medicine and Rehabilitation Department of Ankara Training and Research Hospital, between January 2015-January 2017. The patients included were those with lower extremity motor dysfunction due to multiple sclerosis, diplegic cerebral palsy, hereditary spastic paraparesis and transverse myelitis who had been using a WC for >4 hours per day for at least one month. The patients were aged between 15-81 years and permanently resident in Turkey. Except for the non-traumatic spinal cord injury patients mentioned above, patients with traumatic spinal cord injury and cognitive dysfunction (<23 points in the assessment of mini mental test) were not included in the study.

Data were collected from interviews conducted face-to-face by the same physician. Variables included in the study were grouped into the following 5 categories. Sociodemographic factors, including age, gender, marital, educational and occupational status, time since injury and type of WC used. Activity level was measured using the Functional Independence Measurement (FIM). Environmental factors were questioned in the face-to-face interviews. Social limitation was evaluated with the Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF) and depression symptoms were evaluated using the Beck Depression Inventory (BDI).

The study protocol was approved by the Ethics Committee of Ankara Physical Medicine and Rehabilitation Training and Research Hospital, in 04-09-2009. The study was performed in accordance with the principles of the Declaration of Helsinki.

EVALUATION

Sociodemographic Evaluation

The same physician communicated separately with each of the 95 participants who met the inclusion criteria. First, they were informed about the study and a total of 92 agreed to participate in the study and provided signed informed consent. The participants were questioned about sociodemographic characteristics.

Interview

All the interviews were conducted by the same investigator in a quiet and separate room. Questions were designed as both open-ended and yes-no responses. The interview was divided into two sections. In the first section, environmental conditions were examined such as where they live, what kind of house they live in, the number of floors, the presence of an elevator and whether they think there is a need for architectural changes.

The second section consisted of questions with regards to difficulties they experienced in social or home life. First, it was emphasized that “If you are having any difficulties in any of the activities I am going to describe, you can answer ‘yes’ or ‘no’”. The first question was about home life: “Do you have any difficulties at home/in the kitchen/in the bathroom/in the toilet?”. Questions continued in the following order: “Do you have any difficulties doing house-

work?", "Do you have difficulty using the WC outside the home? When you are going shopping or sightseeing?", "Do you experience any difficulties accessing health care?", "Do you have any difficulties in your social life, when you are going out with your friends or visiting relatives?", "If you have a car, do you have any difficulties parking your car?" and "Does the WC constitute an obstacle to exercising political rights?". The participants were divided into two groups according to the responses to the questions; having difficulty (a) at home, (b) doing housework, (c) outside the home, (d) accessing health care, (e) social life, (f) parking car, (g) exercising political rights. Each interview took about 30 minutes.

Functional Independence Measurement

The FIM is an 18-item scale used to assess physical, cognitive, and social functioning, with a focus on disability. The FIM motor subscale includes self-care, sphincter control, locomotion, and transfer information. The FIM cognitive subscale collects information about communication and social functioning. In addition, the FIM can be used to assess development at discharge.[7]

Craig Handicap Assessment and Reporting Technique-Short Form

The CHART-SF evaluates handicaps in 6 different dimensions: physical independence, cognitive independence, mobility, occupation, social integration and economic self-sufficiency. These domains are used to assess disabilities resulting in handicap. The questionnaire consists of 27 items to provide objective measurement and is designed to be applied by a physician in a face-to-face interview. High scores represent a low level of handicap.[8]

BECK DEPRESSION INVENTORY

The BDI is applied to evaluate characteristic attitudes of depression and anxiety, and it consists of 21 items with higher scores indicating a greater severity of depressive symptoms.[9]

STATISTICAL ANALYSIS

Data analysis was performed using IBM SPSS Statistics version 24.0 software (IBM Corporation, Armonk, NY, USA). The Kolmogorov-Smirnov test was used to determine the normality of the distribution of continuous variables. The Levene test was used for the evaluation of homogeneity of variances. Data were shown as mean±standard deviation or median (minimum-maximum) values for continuous variables. Number of cases and percentages were used for categorical data. Data not showing normal distribution were compared between groups using the Mann-Whitney U test, otherwise the Kruskal-Wallis test was applied for comparisons between more than two independent groups. When the p values from the Kruskal-Wallis test were statistically significant, Conover's multiple comparison test was used to determine which group differed from the others. Degrees of association between continuous variables were evaluated with Spearman's Rank correlation analyses.

Stepwise linear regression analyses were performed to determine the best predictor(s) which affected the FIM, BDI and CHART levels. Any variable with a univariable test level of $p<0.10$ was accepted as a candidate for the multivariable model together with all the variables of known clinical importance. The coefficient of regression (B) and 95% confidence intervals (CI) for each independent variable were also calculated. As the data did not show normal distribution, logarithmic transformation was used for FIM, Beck Depression and CHART-SF measurements in the regression analyses. A value of $p<0.05$ was considered statistically significant.

RESULTS

The 92 WC users included in the study comprised 59 males and 33 females with a mean age of 39.8 years. The diagnosis was multiple sclerosis in 56 cases, diplegic cerebral palsy in 14, transverse myelitis in 12 and spastic paraparesis in 10. The sociodemographic characteristics of the patients are given in Table 1. The descriptive statistics of environmental conditions and the difficulties experienced at home and in social life are given in Table 2. Of the whole group, 23.9% were living in a village, 33.7% in a town and 42.4% in a city. Half of the participants were living in a detached house, most were living on the first floor of an apartment block and only 15.2% had an elevator in their place of residence.

TABLE 1: Sociodemographic and clinical characteristics of the participants.

	n=92
Age (years)	39.8±17.0
Age range (years)	15-81
Gender	
Female	33 (35.9%)
Male	59 (64.1%)
Educational status	
None	14 (15.2%)
Elementary school	41 (44.6%)
Middle school	16 (17.4%)
High school	17 (18.5%)
University graduate	4 (4.3%)
Marital status	
Married	51 (55.4%)
Divorced	8 (8.7%)
Single	33 (35.9%)
Employment	
Unemployed	8 (8.7%)
Homemaker	24 (26.1%)
Manual worker	12 (13.0%)
Clerical worker	7 (7.6%)
Retired	7 (7.6%)
Self-employed	24 (26.1%)
Student	10 (10.9%)
Presence of social support	30 (32.6%)
Type of wheelchair	
Powered	14 (16.9%)
Manual	69 (83.1%)
Duration of wheelchair use (months)	5 (1-192)
FIM (median)	68 (19-130)
Beck Depression Inventory score (median)	21 (4-50)
CHART-SF (median)	207.5 (120-386)

FIM: Functional Independence Measurement;
CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form.

No statistically significant relationships were determined between age and FIM, BDI and CHART-SF scores ($p>0.05$), or between educational status and BDI and CHART-SF scores ($p>0.05$). A statistically significant positive correlation was determined between educational status and FIM scores ($r=0.224$, $p=0.032$) (Table 3).

As the duration of WC use increased, so there was seen to be a statistically significant increase in FIM and CHART-SF scores ($r=0.298$, $p=0.004$; $r=0.424$, $p<0.001$, respectively). A negative correlation was found between time since injury and BDI scores ($r=-0.236$, $p=0.023$) (Table 3).

The comparisons of the sociodemographic characteristics and FIM, CHART-SF, BDI scores are shown in Table 4. There were no significant differences between gender, marital status, presence of social support and type of WC and FIM, BDI scores ($p>0.05$).

Gender, marital status and presence of social support did not show any significant difference in the CHART-SF scores ($p>0.05$). The median CHART-SF score was significantly lower in those using a manual WC than in those using a powered WC ($p=0.008$).

The participants were divided into two groups as those who did or did not experience difficulty in the parameters were examined (Table 5). There was a significant difference between the groups in respect of using the WC at home according to the FIM scores ($p=0.006$), but no significant difference was determined according to the CHART-SF and BDI scores ($p>0.05$). No significant difference was determined in the median FIM level between the group who had or did not have difficulty in doing housework ($p=0.057$), whereas a significant difference was determined between these two groups in respect of the median BDI and CHART-SF scores ($p=0.044$, $p=0.16$, respectively).

TABLE 2: Other sociodemographic characteristics and difficulties experienced in daily living.

	n=92
Place of residence	
Village	22 (23.9%)
Town	31 (33.7%)
City	39 (42.4%)
Type of house	
Detached house	46 (50.0%)
Apartment	46 (50.0%)
Floor of apartment block	1 (0-9)
Presence of elevator	14 (15.2%)
Need for architectural changes	78 (84.8%)
Having difficulty in doing housework	85 (92.4%)
Car parking difficulties	7 (7.6%)
Having difficulty outside the house	63 (79.1%)
Having difficulty in social life	69 (75.0%)
Having difficulty in accessing healthcare	7 (7.6%)
Having difficulty in exercising political rights	53 (57.6%)
Having difficulty at home	84 (91.3%)

TABLE 3: Relationship between demographic characteristics and FIM, CHART-SF and BDI scores.

	FIM	BDI	CHART-SF
Age			
Correlation coefficient	-0.084	0.171	-0.076
p value†	0.424	0.104	0.474
Educational status			
Correlation coefficient	0.224	-0.177	0.131
p value†	**0.032**	0.091	0.214
Duration of wheelchair use			
Correlation coefficient	0.298	-0.236	0.424
p value†	**0.004**	**0.023**	**<0.001**

†Spearman's Rank correlation test; FIM: Functional Independence Measurement; CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form; BDI: Beck Depression Inventory.

The median FIM and CHART-SF scores were significantly lower and the median BDI scores were significantly higher for participants who had difficulty outside the home compared with those who had no difficulties outside the home (p=0.032, p<0.001, p=0.007, respectively). In respect of accessing health care, no significant differences were determined between the two groups in the comparisons of the FIM, CHART-SF and BDI median scores (p>0.05).

Patients who had difficulty in social life had lower median FIM and CHART-SF scores than those did not have any difficulty (p=0.040, p<0.001), but there was no significant difference between the two groups in the median BDI scores (p>0.05).

Of the patients who experienced and did not experience car parking difficulties, there were significant differences between the two groups in the median FIM and CHART-SF scores (p=0.019, p<0.001), and no significant difference in the median BDI scores (p>0.05).

The participants who reported that they were able to exercise political rights had significantly lower median FIM scores than those who experienced difficulty in exercising political rights (p=0.004).

DISCUSSION

In this study, evaluation was made of the factors that WC users experienced with regards to sociodemographic conditions, social and enviromental factors, activity limitation and psychological condition. The sociodemographic and enviromental factors were introduced descriptively. The second part of the research included face-to-face interviews with participants and the difficulties experienced were recorded and the participants were compared in re-

TABLE 4: Relationship between clinical characteristics and FIM, BDI and CHART-SF scores.

	FIM	BDI	CHART-SF
Gender			
Female	71 (29-130)	21 (6-48)	207 (133-363)
Male	66 (19-130)	20 (4-50)	208 (120-386)
p value†	0.368	0.754	0.585
Marital status			
Married	65 (24-130)	21 (6-48)	200 (120-363)
Widow	79 (39-98)	24.5 (10-42)	227 (159-324)
Single	68 (19-130)	20 (4-50)	208 (154-386)
p value‡	0.595	0.956	0.444
Presence of social support			
Yes	68.5 (19-130)	22 (6-50)	239 (154-386)
No	66.5 (24-130)	21 (4-48)	204 (120-363)
p value†	0.861	0.819	0.315
Type of wheelchair			
Powered	69 (19-128)	18 (6-33)	275 (154-360)
Manual	67.5 (21-130)	21 (4-50)	201 (120-386)
p value†	0.617	0.236	**0.008**

†Mann-Whitney U test; ‡Kruskal-Wallis test; FIM: Functional Independence Measurement; CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form; BDI: Beck Depression Inventory.

TABLE 5: Relationship between the groups according to difficulties experienced and FIM, BDI and CHART-SF scores.

	FIM	BDI	CHART-SF
Experiencing difficulty at home			
No	96.5 (56-130)	20.5 (6-28)	249 (174-330)
Yes	66 (19-130)	21 (4-50)	206.5 (120-386)
p value†	**0.006**	0.321	0.129
Experiencing difficulty in doing housework			
No	86 (45-125)	15 (4-24)	268 (206-386)
Yes	66 (19-130)	22 (6-50)	202 (120-363)
p value†	0.057	**0.044**	**0.016**
Experiencing difficulty in car parking			
No	108 (43-125)	23 (4-29)	322 (206-386)
Yes	66 (19-130)	21 (6-50)	202 (120-363)
p value†	**0.019**	0.606	**<0.001**
Experiencing difficulty outside the home			
No	91 (21-130)	15 (4-42)	306 (156-386)
Yes	65 (19-130)	23 (6-50)	200 (120-360)
p value†	**0.032**	**0.007**	**<0.001**
Experiencing difficulty in social life			
No	80 (29-130)	19 (4-46)	246 (174-363)
Yes	66 (19-130)	21 (6-50)	197 (120-386)
p value†	0.040	0.095	<0.001
Experiencing difficulty in accessing health care			
No	68 (19-130)	21 (4-50)	206 (120-386)
Yes	69 (45-95)	20 (6-46)	244 (194-319)
p value†	0.718	0.802	0.129
Having difficulty in exercising political rights			
No	76 (24-130)	18 (4-48)	224 (120-386)
Yes	63 (19-130)	24 (6-50)	200 (129-330)
p value†	**0.004**	0.053	0.062

†Mann-Whitney U test, ‡Kruskal-Wallis test; FIM: Functional Independence Measurement; CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form; BDI: Beck Depression Inventory.

spect of difficulty for each of the conditions (at home, outside the home etc.).

Most of the participants were living in a city and half were living in an apartment, so it was considered optimal to evaluate the difficulties that WC users experienced in society or crowded places. However, only 15.2% of the participants had an elevator in their apartment block and 84.8% stated that there was a need for architectural changes.

As shown in Table 1, most of the participants (55.8%) were unschooled or only had an elementary school level of education. A total of 34.8% participants were unemployed or a housewife, 7.6% were retired and not working at the time of evaluation and 10.9% were in education. A previous study investigating the demographic characteristics of disabled patients reported that, as in the current study, most were unemployed with a low level of education.[10,11] A negative correlation was determined between FIM scores and educational level in the current study patients. Similarly to the current study findings, Akyürek et al., reported that low community participation and functional independence level were related to low employment and education rates in WC users. The same study suggested assessing enviromental factors associated with social participation in WC users because they indicated that lower community participation was more common in WC users than in patients using other mobility or assistive devices.[2]

The relationship between duration of use and FIM, CHART-SF and BDI scores was found to be statistically significant in the current study. As expected, this is related to adaptation over time since the event.[3]

Handicap, functional independence and BDI scores did not seem to be related to age, gender, marital status and social support. It has previously been reported that age is negatively correlated with social participation and life satisfaction in patients with multiple sclerosis and spinal cord injury.[12] However, no relationship between handicap scores and age was determined in the current study. This could have been due to the sample size and that there were patients with 4 different diseases in different age strata. Similarly, the reason for the lack of correlation between marital status and the handicap or depression scores may be due to the onset of some diseases at a very young age or even since birth, such as spastic paraparesia and cerebral palsy.

There was a significant difference between the types of WC in respect of the CHART-SF scores. Those using a powered WC had a low handicap according to the CHART-SF. Similar results were revealed in a previous qualitative study and upper extremity problems experienced by manual WC users were also reported.[13,14]

The participants in this study were compared according to the difficulties experienced. The FIM scores differed significantly between those who had difficulty at home or not. It was an expected result that those with high functional independence would not have difficulty at home. However, no correlation was determined between the two groups according to the handicap and depression scores. This might be because patients feel their disability in more social settings. In a previous study, it was reported that patients who had been using a WC for at least 14 years had the most problems in the community.[6] Therefore, patients who experienced difficulties outside the home had worse handicap, functional independence and depression scores in comparison with those did not have any difficulty.

In social life and car parking situations, significant differences were determined between the two groups according to the FIM and CHART-SF scores. D'Souza et al. stated that WC users reported that ramp use and boarding-disembarking activities were the most difficult situations.[5] The current study participants might have experienced some similar activities during car parking. Only 7.6% of the participants had difficulty in car parking, but the fact that few participants had car parking problems contradicts the complexity of mentioned condition. It might have been related to the interview question not being clear enough, and this should have been asked in more detail.

The vast majority of the current study participants (92.4%) had no difficulty accessing health care. In the comparison of two groups that had difficulty or not, there were no significant differences between the groups according to the functionality or handicap levels. The access to healthcare services without any difficulties for WC users may be the result of the widespread utilization of home care services in Turkey.

Nearly half of the participants could exercise their political rights without any difficulties. In the comparison of the two groups, the exercising of political rights was only related with functional independence, and there was no difference in respect of handicap scores. It may be thought that political rights only consists of voting, and as this occurs only every few years, it may not have been considered to cause any difficulty.

WC users experience many difficulties in society, at home or in other participatory activities in daily living and this affects life satisfaction.[15] Those who had difficulties at home and could not do housework were in the great majority (>90%), with a lower number reporting difficulties in outdoor activities and social life. This may indicate that patients are more likely to spend time at home or unfortunately, could not leave home. Most of the participants considered that there was a need for architectural changes. This study aimed to reveal sociodemographic characteristics and the difficulties experienced by WC users. Further more extensive studies will shed light on the steps that should be taken in national policies to overcome the difficulties experienced by WC users.

The current study has some limitations. Since the difficulties experienced by the patients were investigated only through the questions asked, the difficulties in other areas may be overshadowed. Similarly, the problems experienced by the patients could not be graded. Further more extensive studies will shed light on the steps that should be taken in national policies to overcome the difficulties experienced by WC users.

CONCLUSION

Most of the WC users reported difficulties in daily living activities indoor or outdoor. They also indicated there was a need for architectural changes. All these could serve as an initiation for future environmental changes for WC users.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Acknowledgements

Thanks to Jane Caroline Walker for the manuscript check.

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