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The clinical correlates of participation levels in people with multiple sclerosis

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Abstract.
BACKGROUND: Multiple sclerosis (MS) has a huge impact on patients and affects their ability to participate in meaningful activities.
OBJECTIVE: To identify motor and non-motor factors that are associated with the participation level in instrumental activities of daily living (IADL), leisure, social and religious activities in people with MS.
METHOD: This is a cross-sectional study conducted on 110 individuals with MS. The used outcome measures are: Arabic version of the Activity Card Sort, Berg Balance Scale, Modified Fatigue Impact Scale, Nine Hole Peg Test, 6-Minute Walk Test, Brief International Cognitive Assessment for Multiple Sclerosis, Stroop test and Hospital Anxiety and Depression Scale.
RESULTS: Hand function, balance, gender and cognitive status can predict the participation in IADL ($R^2 = 0.425$, $P < 0.0001$); depression, age, and cognitive status can predict the participation in leisure activities ($R^2 = 0.372$, $P < 0.0001$), and fatigue, balance and cognitive status can predict social activities participation ($R^2 = 0.492$, $P < 0.000$).
CONCLUSION: Balance, cognition and fatigue affect the level of participation in instrumental activities of daily living, leisure, and religious and social activities.

Keywords: Participation, multiple sclerosis, instrumental activities of daily living, leisure, quality of life

1. Introduction

Multiple sclerosis (MS) is a neurodegenerative disease of the central nervous system that is characterized by repetitive inflammation occurrences, which causes demyelinating and consequent axonal damage (Bishop & Rumrill, 2015). It is estimated that there are around 2.5 million people with MS worldwide (Mesa et al., 2012). The disease imposes a huge impact on patients and societies and also affects patients' ability to participate in meaningful activities (Jennum et al., 2012).

Overall, participation is defined as "involvement in a life situation" which includes daily activities, leisure, social activities and work ("Occupational Therapy Practice Framework: Domain and Process (3rd Edition)," 2017, p4). Naturally, participation occurs when people are involved in performing daily life activities which they find purposeful and meaningful ("Occupational Therapy Practice Framework: Domain and Process (3rd Edition)," 2017). Participation is associated with quality of life, self-efficacy and self-esteem and has been proposed as a determinant of the health status (Cahn et al., 1998). Thus, currently, the rehabilitation process tends to focus on improving

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the participation level among patients (Cahn et al., 1998; Foster & Hershey, 2011).

Growing evidence, though very limited, suggests that MS affects the participation level in all daily activities but specifically in instrumental activities of daily living (IADL), leisure and social activities (Ben Ari et al., 2014; Cattaneo et al., 2017; Taheri et al., 2016). Data from other neurological populations including stroke (Kwok et al., 2011), traumatic brain injury (Cicerone et al., 2004), and spinal cord injuries (Ripat & Woodgate, 2012) indicate that the participation level may deteriorate dramatically in these populations.

The participation level in people with MS is most likely to be multifactorial. Several motor and non-motor factors may contribute to the participation level in this population. Among those are deficits in balance and mobility (Kanekar & Aruin, 2013; Ripat & Woodgate, 2012), fatigue (Sumowski et al., 2014), cognitive impairments (Chiaravalloti & DeLuca, 2008), and anxiety and depression (Siegert et al., 2005). Very little research has been conducted in this area. For example, the interrelationship between participation in IADL and mobility deficits were examined only in one study among people with MS (Salter et al., 2010). Additionally, the relationship between participation in IADL, social activities and cognitive function was investigated in a few studies (Ben Ari et al., 2014; Kalron, 2014; Kwiatkowski et al., 2014; Plow et al., 2015). The interrelationships between participation in general activities and other motor and non-motor symptoms that are frequent in MS have not been reported. We hypothesize that the participation level in people with MS is the result of the interaction among motor and non-motor disease-related factors such as balance, fatigue, anxiety, depression and cognitive status. Therefore, our main aim was to evaluate the motor and non-motor factors associated with the participation level including participation in IADL, leisure, religious and social activities in people with MS. Understanding the impact of these factors on participation and how they relate to each other will shed light on new therapeutic targets that may improve the quality of life in people with MS.

2. Methods

2.1. Participants

This is an observational cross-sectional designed study in which 110 participants with MS were recruited. MS patients attending routine neurology clinics between October 2018 and June 2019 at the King Abdulla University Hospital (KAUH) in Irbid, Jordan were screened for eligibility by a neurology consultant. Eligible participants were invited to participate in this study. Additionally, eligible participants who already participated in other Jordan University of Science and Technology funded research and provided consent to be contacted for future studies were also invited to participate. All participants provided written informed consent approved by the Institutional Research Committees of Jordan University of Science and Technology (HK-20190022) that informed them of the study's risks and benefits, that their participation was voluntary, and that their identity would not be disclosed. Inclusion criteria were: 1) diagnosed with MS by a neurologist according to the revised McDonald criteria (Polman et al., 2011); 2) a Patient Determined Disease Steps (PDDS) score less than 7.0 (Learmonth et al., 2013); 3) no exacerbation of symptoms 30 days prior to completing testing; 4) age $\geq$18 years; and 5) capacity to provide informed consent. Exclusion criteria were: 1) the presence of additional neurological disorders such as stroke; 2) patients diagnosed with aphasia; and 3) the presence of severe visual impairments due to the visual requirements of the main outcome measure (the Activity Card Sort; see sections below).

2.2. Outcome measures

The Activity Card Sort (ACS) is a widely used outcome measure to evaluate the level of participation among adult patients (Baum & Edwards, 2001). In this study, the Arabic version of the ACS was used. The ACS was translated and adapted to accommodate the Jordanian culture (Hamed et al., 2011). The Arabic version of the ACS proved to be valid and reliable among MS patients (Hamed et al., 2011). The Arabic version consists of 88 items, 19 unique to Arabs in five domains: 32 items related to the instrumental activity of daily living, 15 items related to low physical-demand leisure, 6 items related to high physical-demand leisure, 27 items related to social activities, and 8 items related to religious activities (Hamed et al., 2011). In this study, we combined the low physical-demand leisure score and high physical-demand leisure score in one composite category called leisure. We used the recovering version which detects the change in the activity pattern. By using the recovering version of the ACS, it is possible to determine what the patient did before the illness or

injury and if (s)he continues to do, do less, or gave up the activity (s)he did before. This version is valuable when the person lives at home and receives outpatient or in-home services. The sort categories include: Not Done Prior to Current Illness/Injury, Continued to Do During Illness/Injury, Do Less Since Illness/Injury, Given up Due to Illness/Injury, and New Activity Since Illness/Injury. A high retained score indicates a high level of participation (Baum & Edwards, 2001).

According to our aims, three main domains of factors (i.e. motor, cognitive, and affective) that may impact participation in IADL, leisure, social and religious activities were included. Motor factors included the Berg Balance Scale (BBS) (Cattaneo et al., 2007) to assess balance. BBS includes 14 items that assess dynamic and static balance while performing different tasks including ability to sit, stand, lean, turn and maintain the upright position on one leg (Berg et al., 1989). It is valid and reliable for balance assessment among MS individuals (Cattaneo et al., 2006). The 6-Minute Walk Test (6-MWT) (Goldman et al., 2007) was used to measure physical endurance. The participants were asked to walk in the 15-meter hallway back and forth for six minutes at their preferred speed. The 6-MWT is valid and reliable to use for people with MS (Toomey & Coote, 2013). The Nine Hole Peg Test (9-PHT) was used to evaluate the hand function (Mathiowetz et al., 1985a). 9-HPT consists of a square wooden board with nine pegs. At one end of the board there are holes for the pegs to fit into, and at the other end is a shallow round dish to store the pegs. It is a simple, quick and commonly used test in the clinic and for research (Mathiowetz et al., 1985). Additionally, the 9-HPT has good psychometric properties among MS patients (Drake et al., 2010; Hoogervorst et al., 2004).

The cognitive status was determined by the Brief International Cognitive Assessment for Multiple Sclerosis (BICAMS) and the interference score of the Stroop test. Both tests were culturally adapted to the Arabic language. An international expert consensus committee recommends using the BICAMS to evaluate cognitive status in people with MS (Walker et al., 2016) because it targets the needs of clinical practice. The BICAMS includes tests of the mental domains that commonly affect people with MS; i.e. learning, memory and mental processing speed. It consists of three tests: the Symbol Digit Modalities Test (SDMT), the second edition of the California Verbal Learning Test (CVLT2), and the Brief Visuospatial Memory Test (BVMTR) (Benedict et al., 2017). The BICAMS website (www.bicams.net) was used to calculate regression-based norms, z -scores for the three tests. A composite score was created by averaging the z-scores of the three test (Goverover et al., 2015). This method of score calculation is commonly used in research and it proved to be valid in the MS population (Goverover et al., 2015; Walker et al., 2016).

Selective attention can also be affected in people with MS (Benedict et al., 2006). Selective attention refers to the ability to focus only on what is important, thus ignoring irrelevant information that was not included in the BICAMS battery (Morrow, 2013). The interference score of the Stroop test is considered as the gold standard for selective attention evaluation. It assesses the ability to inhibit cognitive interference that occurs when the processing of a specific stimulus impedes the simultaneous processing of a second stimulus attribute, known as the Stroop effect (Scarpina & Tagini, 2017).

Affective factors in this study include depression, anxiety, and fatigue. The Arabic version of the Hospital Anxiety and Depression Scale was used to evaluate the level of anxiety and depression. It is a 3-point Likert type scale consisting of 14 items, seven items for anxiety and seven items for depression. It is a valid and reliable scale in people with MS (Giordano et al., 2011; Patten et al., 2015). The Arabic version of the Modified Fatigue Impact Scale (MFIS) was used to evaluate fatigue and consists of 21 items (Kos et al., 2005; Tellez et al., 2005).

The demographic data and disease severity were recorded. Disease severity was evaluated using the Arabic version of the Patient Determined Disease Steps (PDDS) (Learmonth et al., 2013), a self-reported outcome adapted from the Disease Steps (DS). The rating system that ranges between 0 (normal) and 8 (bedridden) is valid and reliable among people with MS (Learmonth et al., 2013).

2.3. Data analysis

The data were analysed using SPSS 23.0 (Green & Salkind, 2016). The demographic data of age, gender, duration since diagnosis and MS type are presented as frequencies and percentages or in the mean and standard deviation. Data were visually assessed for normality using histograms and Q-Q plots. Additionally, data were checked for the presence of skewness, kurtosis and outliers before proceeding with the inferential analysis.

A stepwise method of multiple linear regressions was used to identify significant predictors for IADL,

Table 1
Patient characteristics

Variables	
Age, mean year ± SD	36.41 ± (10.09)
Gender, n (%)	
Male	31 (28.2)
Female	79 (71.8)
Type of MS, n (%)	
Relapsing-remitting	100 (90.9)
Secondary progressive	8 (7.3)
Clinically isolated syndrome	1 (0.9)
Primary progressive	1 (0.9)
Duration of disease, mean year ± SD	7.63 ± (6.26)
Patient Determined Disease Steps (PDDS), mean year ± SD	2.03 ± (1.61)

leisure, and religious and social activities. Variables that entered the stepwise multiple regression model included: PDDS, BBS total score, 9-HPT, 6-MWT, BICAMS z-score, SCWT-interference score, HADS-anxiety score, HADS-depression score, MFIS total score, age and gender. Age and gender were placed in the model to adjust for their effects.

Assumption of normality of distribution of the regression model was assessed. Additionally, collinearity of variables was assessed using the Variance Inflation Factor (VIF) to determine if the correlated variables are a concern in our regression model. The VIF for all variables was less than five which is considered a low VIF value (Cohen, 1977). The goodness of fit index of each estimated parameter was calculated after the construction of the regression model.

3. Results

The characteristics of the 110 participants who were enrolled in the study are shown in Table 1. Most of the participants were females (71.8%). 90.9% of the participants were diagnosed with a relapsing-remitting MS (see Table 1).

The stepwise regression analysis showed that 9HPT, BBS total score, gender and interference score of the Stroop test were significantly predictive of IADL participation ($R^2 = 0.425$, $P < 0.0001$), accounting for 42.5% of the variability of the current IADL around its mean (see Table 2).

The HADS-depression score, age, and BICAMS were significantly predictive of leisure participation ($R^2 = 0.372$, $P < 0.0001$), accounting for 37.2% of the variability of the current leisure activities around its mean (see Table 3).

Table 2
Regression analysis of explanatory variables of IADL

Variables	Parameter estimates	Standard error	Beta value	*P* value
Constant	3.32	5.12		0.52
BBS	0.15	0.07	0.23	0.02*
Interference score of the Stroop test	0.08	0.04	0.23	0.03*
9HPT	–0.08	0.04	–0.24	0.04*
Gender	2.50	1.15	0.19	0.03*

BBS: Berg Balance Scale, BICAMS: Brief International Cognitive Assessment for Multiple Sclerosis, 9HPT: Nine Hole Peg Test. *$P < 0.05$.

Table 3
Regression analysis of explanatory variables of leisure activities

Variables	Parameter estimates	Standard error	Beta value	*P* value
Constant	13.52	1.40		0.000*
BICAMS	1.92	0.46	0.38	0.000*
Age	–0.11	0.03	–0.26	0.00*
HADS-depression	–0.15	0.07	–0.19	0.04*

MFIS: Modified Fatigue Impact Scale, BICAMS: Brief International Cognitive Assessment for Multiple Sclerosis. *$P < 0.05$.

Table 4
Regression analysis of explanatory variables of social activities

Variables	Parameter estimates	Standard error	Beta value	*P* value
Constant	3.32	5.12		0.03*
BICAMS	2.05	0.65	0.33	0.00*
MFIS total score	–0.07	0.02	–0.25	0.00*
Stroop test	0.07	0.03	0.23	0.03*
BBS	0.10	0.05	0.18	0.04*

BBS: Berg Balance Scale, BICAMS: Brief International Cognitive Assessment for Multiple Sclerosis, MFIS: Modified Fatigue Impact Scale. *$P < 0.05$.

The MFIS total score, BICAMS, and BBS total score test were significantly predictive of social activities participation ($R^2 = 0.492$, $P < 0.000$), accounting for 49.2% of the variability of the current social activities around its mean (see Table 4).

The BICAMS, BBS, MFIS, age and gender were significantly predictive of religious activities ($R^2 = 0.452$, $P < 0.0001$), accounting for 45.2% of the variability of the current religious activities around its mean (see Table 5).

4. Discussion

This study aimed to investigate the contributing factors to the participation in IADL, leisure, social

Table 5
Regression analysis of explanatory variables of religious activities

Variables	Parameter estimates	Standard error	Beta value	*P* value
Constant	0.38	1.12		0.01*
BICAMS	0.60	0.17	0.32	0.00*
Gender	0.94	0.30	0.26	0.00*
BBS	0.05	0.01	0.29	0.00*
Age	–0.01	0.007	–0.19	0.02*
MFIS total score	0.60	0.17	0.32	0.00*

MFIS: Modified Fatigue Impact Scale, BICAMS: Brief International Cognitive Assessment for Multiple Sclerosis. *$P < 0.05$.

and religious activities among people with MS. The overall results showed that hand function, gender, balance and cognitive status can significantly predict the participation in IADL, whereas depression, age, and cognitive status can significantly predict the participation in leisure activities. Regarding social activities, fatigue, balance and cognitive status were the significant predictors of the participation in these activities. Gender, age, fatigue, cognitive status and balance activities were the significant predictors of the participation in religious activities.

Other studies collaborated with these findings that cognitive status is a predictor for participation in four domains of activities (IADL, leisure, social and religious) (Ben Ari et al., 2014; Cattaneo et al., 2017; Plow et al., 2015). Generally, it is known that all daily activities require adequate cognitive abilities, such as driving, which requires cognitive abilities to follow directions and calculation of distances, and doing laundry, which requires cognitive abilities for cloth sorting and planning. Finally, participation in leisure and social activities requires adequate cognitive abilities since they are more complex and several steps are required for a changing environment (Téllez et al., 2005).

In terms of fatigue, our results indicate that it is a contributing factor for participation in social activities. This result can be traced back to the fact that these activities need both physical and cognitive abilities because they are more complex (Scalfari et al., 2011). Regarding social activities, our finding is consistent with a previous study which suggests that fatigue adversely affects the ability to participate in social activities (Salter et al., 2010). These results suggest that targeting fatigue in interventions for people with MS could be vital in improving the participation in social activities, and thus improving the quality of life in this population (Braley & Chervin, 2010).

Our results showed that balance, measured by the Berg Balance Scale, has a good predictive ability for participation in IADL. This finding is in line with a previous study (Cattaneo et al., 2017) that considered balance as an important factor for participation in all activities. This result can be explained in part by the important role of balance in performing activities that involve outdoor interaction such as shopping and moving out in the community (Cattaneo et al., 2017). However, our result showed that balance did not emerge as a predictive factor for leisure activities which can be traced back to the absence of heavy motor skills required in most of the leisure activities included in the ACS.

Regarding the hand function, our results indicate that manual dexterity as measured using the 9-HPT can predict the participation of IADL activity. This finding is consistent with previous studies (Cattaneo et al., 2017; Kierkegaard et al., 2012). Kierkegaard et al. (2012) (Kierkegaard et al., 2012) suggested that the manual dexterity is one of the predictors that additionally discriminate participation in IADL between people with MS and healthy groups (Kierkegaard et al., 2012). Similarly, Cattaneo et al. (2017) suggested that manual dexterity can predict participation in IADL activities. The result can be explained by the fact that upper limb control, bilateral use for hand and manipulation are commonly used for performing IADL activities such as cooking and laundry (Cattaneo et al., 2017). Our results, as well as results from previous studies, highlight the importance of manual dexterity assessment in people with MS and the need to integrate this component in interventions aimed to improve participation in IADL in this population (Bertoni et al., 2015).

Our results highlight that signs of depression can predict participation in leisure. These results are consistent with a previous study in which it was indicated that depression predicted the participation restrictions in leisure (Ben Ari et al., 2014). This result might be explained by the fact that people who experience depression may find it difficult to enjoy activities. Unlike IADL that are routine activities in nature, leisure activities are performed based on internal motivation (Arnett et al., 2008). It is possible that depression decreases motivation and accordingly negatively affects participation in leisure activities (Siegert & Abernethy, 2005).

The result showed that gender can predict participation in IADL activities. This result is consistent with a previous study conducted on elderly people (Tomioka et al., 2017). Meanwhile, most of the par-

ticipants were female; these findings can be explained by the nature of the IADL activities. Most of these activities such as laundry and cooking are bounded to women more than men, particularly in Arabic cultures (Millán-Calenti et al., 2010).

To the best of our knowledge, this is the first study that examines the participation in religious activities among people with MS. The study found that fatigue, age, cognitive status and balance can predict the participation level in religious activities. Since the literature lacks studies in this area, further investigations are needed.

Overall, it should be noted that the predictors reported in our study have small effect sizes represented by the small observed beta coefficients (Tables 2, 3, 4). These findings are consistent with previous studies in which similar beta coefficients were reported regarding balance, cognitive status and hand function for predicting the ACS score (Ben Ari et al., 2014; Cattaneo et al., 2017). Additionally, this observation in our study can be explained by the characteristics of our sample; most of the participants in our study were in a mild or moderate stage of the disease. In this stage, the participants had a relatively low level of physical disability and minimal sign of cognitive dysfunction which suggests that the participation level in previous activities might be slightly affected in these stages of the disease. Additionally, most of the participants were young and living with the disease for a relatively short time knowing that MS can worsen with age progression, which negatively affects the participation level. Thus, all these characteristics may affect the size of the observed beta coefficients.

This work is not without limitations. Most of the participants were recruited from one geographical area. Additionally, the sample had a vast majority of participants with relapsing-remitting MS, who were relatively young (mean of age of 36.29 years) and had a low level of disability (mean PDDS score of 2.03 units). Future work with a larger cohort that includes patients across the continuum of the disease severity with different types of MS is needed to confirm our findings. Further longitudinal investigations of how participation in people with MS may change over time are also warranted.

5. Conclusion

The study sheds light on the role of motor and non-motor factors including balance, cognition and fatigue in determining the level of participation in IADL, leisure, and social and religious activities.

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Conflict of interest

The authors report no conflicts of interest.

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