Measuring participation in people living with multiple sclerosis: A comparison of self-reported frequency, importance and self-efficacy

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Abstract

Purpose—To compare three dimensions related to participation in everyday situations in community-dwelling adults with multiple sclerosis (MS).

Methods—Mail survey was obtained from 112 respondents. Data were analyzed using Kendall's tau-b correlation coefficients between responses to participation items relative to three question dimensions (importance, frequency, and self-efficacy) and criterion variables (mobility, depression, general health, fatigue and pain).

Results—No significant associations were found between item responses in the importance dimension and the criterion variables. Weak associations were found for items in the frequency dimension, and stronger associations were found for items in the self-efficacy dimension.

Conclusions—Different dimensions of participation in specific life situations yielded different responses and associations of those responses with key criterion measures. Subjective importance of participating in everyday situations is relatively independent of measures of mobility, general health, depression, fatigue and pain. Subjective judgments of self-efficacy for participation are more closely linked to these criterion measures. Caution is warranted when interpreting scales of participation because participation is a complex construct, potentially composed of several dimensions.

Keywords

Multiple sclerosis; participation; treatment outcomes; healthcare survey

Introduction

In 2001, the World Health Organization (WHO) proposed a model that integrates the many dimensions of disability and health called the *International Classification of Function, Disability and Health* (ICF) [1]. This model not only provides a conceptual framework for measuring outcomes but also provides common language for describing and discussing human functioning and disability. The ICF defines *activity* as the execution of specific actions and *participation* as involvement in life situations. Although activity and participation have been merged into a single component (activities – participation) for classification and measurement purposes, distinction between the two constructs can be made. Tasks that reflect the Participation level are relatively more complex than those that reflect Activity because they

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are more likely to be performed with others, influenced by environmental factors, and assessed in the community by self-report [2].

The construct of participation has been studied extensively in traumatic brain injury [3–9], spinal cord injury [10–13], stroke [14], and other disabling conditions such as leprosy [15]. Examination of populations such as multiple sclerosis (MS) is an important next step in better understanding participation. Exploring characteristics of participation in this population would extend our understanding of participation among individuals with a progressive condition. Because MS occurs among individuals ranging from early adulthood to senior years, measuring participation in this population allows us to sample individuals who are engaged in a variety of social roles – student, employee, parent, household manager, retiree and so on.

Participation is of great importance to individuals with disabling conditions and is becoming increasingly recognized as an important outcome domain in rehabilitation research [2,16–20]. A number of new tools have recently been proposed to assess participation [16,21–24]. When comparing these tools, it is apparent that there is a lack of consensus on the range of domains to be measured [2]. Tools vary in terms of the life situations and social roles assessed. Tools also vary in terms of the dimensions being measured. Some scales measure several dimensions, for example, the Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children [25], asks participants to rate six dimensions of participation: Diversity, intensity, location, involvement of others, enjoyment, and preferences. In an effort to be 'relatively free of subjective judgment,' (page 1045) the PAR-PRO rates only frequency of occurrence on a 3 point scale; 0 – activity did not occur, 1 – occurred monthly, and 2 – occurred at least weekly [24]. In other scales, the dimensions and response sets change depending on the activity or situation. For example, the Community Integration Questionnaire [8] asks for responses about frequency (e.g., 'Approximately how many times a month do you usually visit your friends or relatives?'), assistance (e.g., 'Who usually prepares meals in your household?'), and companions (e.g., 'Do you have a best friend with whom you confide?').

Considerable discussion has emerged in the literature about which aspect(s) or dimensions of participation to measure. On one hand, participation clearly has a number of dimensions that would be important when developing a full understanding of the construct. On the other hand, it is also important to choose only key dimensions to reduce assessment burden while still allowing for the collection of critical information [17,18]. Salter and colleagues [2] suggest that a variety of issues should be consider when evaluating measurement tools, including appropriateness (the match of the instrument to the purpose of the study), responsiveness (sensitivity to changes within patients over time), precision (number of gradations or distinctions with the measurement), interpretability (How meaningful are the scores? Are there norms available for comparisons?). All of these issues are pertinent when considering what dimensions of the complex construct of participation to measure.

The purpose of this study was to compare three dimensions of participation (frequency, importance and self-efficacy) and key adjustment or outcome constructs in individuals with MS (mobility, general health, depressive symptoms, fatigue and pain). To help determine the relative contribution of each dimension (for predicting important criterion measures), we examined the strength of the associations between that dimension and criterion variables. Specifically, we were interested in determining if the strengths of associations were similar or different across the dimensions of importance, frequency and self-efficacy. Addressing this issue is important because it can help determine whether or not one participation dimension can be used as a proxy for others, and, if not, to better understand the explanatory power and relevance of the three dimensions. The findings from this study will provide future participation scale developers with empirical evidence to guide the selection of dimensions and response sets.

Methods

Sample population

Participants were selected from a sample of community-dwelling persons with MS who had previously been contacted through the Multiple Sclerosis Association (MSA) of King County, Washington, USA, as part of a survey that assessed a variety of symptoms and other aspects of living with MS [26–28] and who indicated that they were interested in being contacted in the future regarding additional research studies. A consent form and a cover letter inviting the potential study participants to participate in the study accompanied each survey. Respondents were paid $25 for completing and returning the consent forms and survey. In order to minimize missing data, research assistants contacted respondents via telephone in order to complete items that were left blank or to clarify responses were unclear. The study procedures were approved by the University of Washington Human Subjects Review Committee.

MS-related measures

Demographics and MS type—Participants responded to questions regarding demographic, psychosocial, and functional or disease specific characteristics. In order to determine the type of MS, participants were asked to indicate disease subtype by selecting a pictorial graph most closely corresponding to their disease course over time [29]. Graphs were accompanied by written descriptions of the various clinical courses of the disease. Participant responses were then used to place each individual into one of the following categories: relapsing-remitting; secondary progressive; or primary progressive MS [30].

Five additional variables of interest were selected for analysis because scores on these measures vary as a function of the severity of MS.

Mobility—For the current mailed survey, the Self-Administered version of the EDSS (EDSS-S) was used and scored for mobility [29]. In our analyses, mobility scores were categorized as minimal, intermediate, and advanced to reflect milestones in progressive loss of functioning in MS. Those in the minimal category are able to walk without aid or rest for more than 500 m and are independent; those in the intermediate category have disability severe enough to limit daily activities; and those in advanced category are essentially restricted to wheelchairs.

Depressive symptoms—The PHQ-9 depression scale was used to assess depressive symptoms [31]. The PHQ-9 was chosen because it has excellent internal and test-retest reliability as well as criterion and construct validity in medical samples [31–33]. The PHQ-9, based upon DSM-IV diagnostic criteria for a depressive episode, asks if the participants had been bothered by the following problems in the past 2 weeks: (*a*) little pleasure or interest in doing things, (*b*) feeling down, depressed, or hopeless, (*c*) sleeping too little or too much, (*d*) feeling tired or having little energy, (*e*) poor appetite or overeating, (*f*) feelings of worthlessness or guilt, (*g*) concentration problems, (*h*) psychomotor retardation or agitation, and (*i*) thoughts of suicide. Participants were asked to rate how often each symptom occurred: 0 (not at all), 1 (several days), 2 (more than half the days), or 3 (nearly every day). Several methods exist for scoring the PHQ-9. For the purposes of this study, we summed the nine items for a total depressive symptom severity score that has a range of $0 - 27$. The total score was then grouped into 5 categories ranging from minimal $(1 - 4)$ to severe depressive symptoms $(20 - 27)$ [32].

General health—Overall health was assessed using the general health question from the SF-36 [34]. Subjects are asked to respond to the question: 'In general would you say your health is: Excellent, Very good, Good, Fair or Poor?'

Fatigue—Fatigue was measured using the abbreviated Modified Fatigue Impact Scale (MFIS) [35], which asks participants to rate how their fatigue has affected their ability to be alert, do things, maintain physical effort, complete tasks and concentrate on a 5-point Likert scale ranging from never (0) to almost always (5). These responses were combined into a summary score ranging from 0 – 20 with 0 indicating no fatigue (all responses 'never') and 20 indicating severe fatigue (all responses 'almost always').

Pain—Participants were asked to indicate the presence or absence of any recent pain problem using the following question: 'Are you currently experiencing, or have you in the past three months experienced, any pain (other than occasional headaches or menstrual cramps)?' Participants who answered 'Yes' to this question were considered to have pain for the purposes of analysis. Participants with pain were also asked to rate the average intensity of their pain during the past week on a 0 – 10 Numerical Rating Scale (NRS), with 0 = 'No pain' and 10 = 'Pain as bad as could be'. Such numerical rating scales have demonstrated their validity as measures of pain by their strong association with other measures of pain intensity, as well as by their responsivity to treatments known to impact pain [36,37].

Participation survey

Item stems—Participants responded to a 28-item survey designed to sample common activities in which community-dwelling adults are expected to participate. In order to ensure coverage of relevant areas, items were written and selected by the study authors to represent four areas of participation: Routines, recreation, responsibilities and relationships. See Appendix for a list of item stems.

Question domains—Participants were asked to respond to three questions about each item stem. Each response set involved a domain critical to participation.

1. *Importance*. Participants were asked how important the activity or situation was to them. It was noted that an activity may be important because you need to do it every day, e.g., grooming, or because you value it highly, e.g., staying in contact with family. Responses were rated on a 5-point scale (Not important, Slightly important, Somewhat important, Important, Very important).

2. *Frequency*. Participants were asked how often they took part in the activity or situation described in each item. Responses were rated on a 5-point scale (Never, Less than once a month, Once a month, Once a week, and Every day).

3. *Self-efficacy*. Participants were asked to rate their confidence about their ability to participate in the activity using the question, Can you do this as often as you would like? This item combines self-efficacy (confidence in ability to perform) and satisfaction with frequency (as often as you would like). Responses were rated on a 5-point scale (Not at all, A little, Somewhat, Very much, As much as I want).

For this study we conducted the analyses at the item level, no summary scores were used for the participation questions.

Analysis

Univariate descriptive statistics (response frequencies, means and standard deviations) were calculated for each variable of interest. Kendall's tau-b correlation coefficients were calculated for bivariate comparisons between each participation item within each domain (e.g., importance, frequency, and self-efficacy) and the ordinal variables: mobility (from EDSS-S), depression (PHQ-9), general health item (from SF-36), fatigue (0 – 20 scale) and pain (average pain intensity). Kendall's tau-b determines bivariate associations between ordinal variables by converting values to ranks before calculating the correlation [38,39]. To account for increased

risk of Type I error rates due to multiple comparisons, a Bonferroni correction was used to determine significance ($p < 0.0001$). All analyses were conducted using SAS 9.1.3 and Stata 9.0 [40,41].

Results

Response rate

Of the 176 surveys sent, seven were returned due to incorrect addresses. No addressees represented individuals who were deceased or ineligible for inclusion in the study because they did not have MS. Of the remaining 169 possible participants, 112 returned completed surveys, for a response rate of 66.3%.

Description of the sample

Demographic information and disease characteristics (see Table I) included age, time since diagnosis, gender, ethnicity, employment status, education, and marital status. Mean age of the participants was 52.7 years (SD: 10.6). The mean time since diagnosis ranged from was 14.6 years (SD: 9.6). Most of the participants were female (81%), Caucasian (97%), Married (72%), Unemployed (59%), and reported post high school education (93%). The most common subtype of MS was relapsing-remitting (46%), followed by secondary progressive (32%), and primary progressive (22%). Extent of the mobility disability (as measured by EDSS-S) was distributed across a range of severity – mild (33%), intermediate (39%) and advanced (28%).

Relationship of domains to criterion measures

Importance

Table II lists each item, the number of responses, and Kendall's tau-b correlation coefficients between responses in the importance domain and the variables of interest. There were no items with significant associations ($p < 0.0001$) between the criterion measures and the importance domain. When participants were asked to rate the importance of each item, the importance of 'getting around the community' was weakly associated with mobility and fatigue and 'going places on the spur of the moment' was weakly associated with general health and fatigue. The importance of 'well-being activities' was associated with depression (PHQ-9) while 'shopping' was weakly associated with pain. All associations were negative and no association exceeded −0.29. None were considered statistically significant.

Frequency

Table III lists each item, the number of responses to each item stem, and Kendall's tau-b correlation coefficients between responses in the frequency domain and the variables of interest (mobility, depression, general health, fatigue, and pain). The frequency with which participants reported participating in 'active leisure', was associated with all five variables, though these associations were only statistically significant ($p < 0.0001$) for mobility and general health. Responses to items, 'getting around the community', 'getting around to activities', and 'spur of the moment' were associated with all variables of interest except pain. Frequency of participation in 'managing the home' was associated with mobility, general health, and pain. 'Shopping', 'cleaning', and 'helping others' activities were associated with mobility and general health and 'well-being activities', and 'sex', were associated with depression (PHQ-9) and fatigue. 'Cooking' and 'civic duties' were associated only with general health and 'significant other relationships' was associated only with fatigue. All of the associations were negative, and none of these significant associations exceed −0.46. Though many associations between responses to item frequency and criterion variables were observed, only those with a p-value of < 0.0001 could be considered statistically significant. In summary, 20% of items

were statistically significantly associated at the $p < 0.0001$ with mobility, 16% of item with general health, and 4% with fatigue.

Self-efficacy

Table IV lists each item, the number of responses, and Kendall's tau-b correlation coefficients between responses in the self-efficacy domain and the variables of interest. The proportion of items with significant associations with the criterion measures was higher for the self-efficacy domain than for the domains of importance or frequency. Measures of fatigue and general health were associated with all but a few of the participation items (tau-b coefficients ranging from −0.33 to −0.46). Of these associations, 56% reached the $p < 0.0001$ level of significance. Mobility and depression were associated with fewer items (tau-b ranging from −0.32 to −0.51) with 44% and 40% respectively reaching the established level of significance. Pain was associated with the fewest items. Some of the strongest associations were noted between mobility and activities conducted in the home such as 'cleaning' (tau-b = −0.51), 'cooking' (tau-b = −0.48), and 'managing the home' (tau-b = −0.48). 'Getting around the community' and 'helping others' were also significantly associated with mobility (tau-b = −0.48 and −0.49 respectively). Depression was notably significantly associated with social activities such as 'staying connected with friends' (tau-b = −0.44), 'maintaining a relationship' with a significant other (tau-b = −0.43) and 'interacting or maintaining a relationship with children' (tau-b = −0.41). As noted with the frequency domain, the inverse relationship between the participation items and the criterion measure in the self-efficacy domain indicates that as the severity of the criterion measure increases, confidence in the ability to participate in the activity decreases.

Discussion

Participants with MS were asked about three domains related to participation in a series of everyday activities or situations. Responses in each domain showed different patterns of associations with variables related to MS. When asked to rate the importance of the activities, participants' responses to most items were not associated significantly with variables known to vary as a function of severity of MS. This suggests that importance attributed to taking part in specific activities or life situations is relatively independent of the severity of symptoms of MS and associated characteristics. In other words, an activity may be judged to be important or unimportant by persons with MS regardless of the severity of the disabling condition and associated secondary conditions.

Although stronger relationships between responses to the participation item stems and the criterion variables were observed when participants were asked to rate frequency of participation, these relationships tended to be weak, and not many were statistically significant. In contrast, when participants were asked to rate self-efficacy concerning participation, their responses to most items were associated significantly with many of the criterion variables. Thus, the domain of self-efficacy assessed with the question, 'Can you do this as often as you would like?' appears to be the domain most strongly associated with variables that rate the severity of MS disease and associated conditions.

These findings are consistent with other reports. For example, when investigating the frequency or intensity of community activities reported by people with spinal cord injury, results revealed only slight, inconsistent relationships with respondents' expressed satisfaction with these activities, suggesting that the domains of frequency and satisfaction are different constructs [6]. Johnston and colleagues concluded by stating: "The significance of community activities to persons served cannot be presumed or reliably inferred from scales of objective function. The person must be asked". (p 741). Thus, objective measures such as frequency of participation must be supplemented by measures that reflect the perspective of the disability

insider [6]. In other words, it appears that one cannot use the frequency with which an individual participates in an activity as a proxy for the importance they attach to that activity. Although domains related to participation are sometimes categorized as either 'objective' or 'subjective', [16,17] our results suggest that even within the category of subjective measures, distinct domains may exist. While the domains of importance and self-efficacy are both subjective, they appear to differ in their pattern of association with other measures of MS.

It is important to note that in this study, the domain of self-efficacy included two components that need to be taken into account when considering the present findings. The first component ('can you do this') targeted participants' beliefs about their abilities to perform the specific activities or tasks listed, which is the usual definition of self-efficacy [42]. The second component of this domain's question ('as often as you would like') adds the dimension of the respondent's satisfaction with the frequency in which they engage in the activity or behavior. Although an individual's self-efficacy may influence his or her rating of satisfaction with the frequency, other factors, including external factors, may also contribute to this aspect. For example, an individual may feel capable of participating in a specific social activity such as church but limited by environmental barriers such as accessibility, transportation, or money. Given the strength of the relationships seen between the domain we labeled 'self-efficacy' and the variables in this study, further research is needed to improve our understanding of the roles self-efficacy and environmental barriers play in participation.

Further limitations should be considered when interpreting the results of the study. First, the survey was limited to a single geographic region and the response rate was not full. Therefore, generalization to other regions or to the non-responders cannot be assumed. In addition, the study is based on correlational analyses, and therefore causal conclusion cannot be made from the results. Despite these limitations, however, the findings have important implications for the assessment of participation, and suggest that caution needs to be exercised when interpreting the participation scales that only assess one dimension of participation. Participation is clearly a complex construct that consists of many dimensions. As existing tools are evaluated and new tools developed, careful attention should be given to the dimensions being sampled, because the results will be dependent, among other things, on the dimension of participation (e.g., frequency, satisfaction, self-efficacy) being assessed.

Acknowledgments

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Table I

Demographic and disease characteristics of sample ($n = 110$).

Variable	Mean	SD
Age (in years)	52.7	10.6
Years since MS diagnosis	14.6	9.6
	n	Percent
Gender		
Female	89	81%
Male	21	19%
Ethnicity		
Caucasian	107	97%
Hispanic/Chicano	1	1%
Native American	2	2%
Employment status[*]		
Employed full-time	23	21%
Employed part-time	16	15%
Student full-time	2	2%
Retired	25	23%
Homemaker	17	15%
Unemployed	55	59%
Education		
< 12 years	1	1%
High school graduate/GED	7	6%
Voc/tech/some college	37	34%
College graduate	39	35%
Graduate/professional school	26	24%
Marital status		
Married/significant other	79	72%
Separated/divorced/widowed	25	23%
Never married	6	5%
Disease subtype		
Relapsing-remitting	49	46%
Secondary-progressive	34	32%
Primary-progressive	23	22%
Disease severity (EDSS-mobility)		
Mild (0 – 4.0)	36	33%
Intermediate (4.5 – 6.0)	42	39%
Advanced	31	28%

[*] *Note*: Percentages add up to more than 100 as participants were allowed to select more than one response option.

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Table II

Kendall's tau-b correlation coefficients for importance dimension and variables of interest.

Item	$n^\dagger$	Mobility	PHQ9	Gen health	Fatigue	Pain
1. Grooming/hygiene	110	-0.13	-0.18	-0.09	-0.08	0.08
2. Medical routines	108	0.01	-0.04	0.07	0.05	0.11
3. Well being activities	110	-0.11	-0.22*	-0.14	-0.13	-0.08
4. Personal services	108	0.00	-0.09	-0.13	-0.13	-0.09
5. Around community	109	-0.29**	-0.17	-0.18	-0.218*	-0.12
6. To and from regular activities	98	-0.21	-0.10	-0.16	-0.05	-0.06
7. Spur of moment	105	-0.19	-0.15	-0.23*	-0.24*	-0.10
8. Civic/community activities	92	-0.03	-0.13	-0.15	-0.07	0.02
9. Home	105	-0.20	-0.02	-0.11	-0.09	-0.20
10. Finances	104	-0.12	0.04	-0.12	-0.10	-0.08
11. Shopping	107	-0.19	-0.06	-0.17	-0.08	-0.25*
12. Cleaning	105	0.07	-0.03	-0.05	-0.07	0.01
13. Cooking	106	-0.09	-0.12	-0.17	-0.12	0.01
14. Pets	73	-0.10	-0.12	-0.12	-0.12	-0.09
15. Help others	81	-0.26	-0.08	-0.17	-0.07	-0.06
19. Volunteer work	75	0.03	-0.07	-0.10	0.11	0.04
20. Quiet leisure	108	0.02	-0.15	-0.17	-0.15	0.06
21. Active leisure	100	-0.04	-0.04	-0.18	0.00	0.01
22. Social friends	107	-0.14	-0.10	-0.12	-0.01	-0.09
23. Friends – connect	107	-0.16	-0.07	-0.07	-0.07	-0.06
24. Social – family	104	-0.02	-0.14	-0.07	0.01	-0.02
25. Family – connect	106	-0.03	-0.13	-0.14	-0.12	0.06
26. Significant other relationships	90	-0.04	0.06	0.04	-0.07	-0.01
27. Child relationship	78	-0.26	-0.13	-0.11	-0.05	0.12
28. Sex	85	-0.08	-0.17	-0.14	-0.09	0.11
Number of items with significant ($p < 0.0001$) correlation		0	0	0	0	0
Proportion of items with significant correlation		0	0	0	0	0

†Frequency of responses; n used to calculate Kendall's tau-b may be smaller due to pairwise missing data.

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*
$p < 0.01;$

**
$p < 0.001;$

***
$p < 0.0001.$

Table III

Kendall's tau-b correlation coefficients for the frequency dimension and variables of interest.

Item	$n^{\dagger}$	Mobility	PHQ9	Gen health	Fatigue	Pain
1. Grooming/hygiene	110	−0.19	−0.03	−0.14	0.00	0.12
2. Medical routines	108	0.08	0.06	0.12	0.22	0.09
3. Well-being activities	110	−0.10	−0.30**	−0.21	−0.23*	−0.13
4. Personal services	108	−0.16	−0.19	−0.19	−0.12	−0.14
5. Around community	109	−0.46***	−0.24*	−0.33***	−0.31**	−0.14
6. To and from regular activities	98	−0.42***	−0.18	−0.34**	−0.24*	−0.17
7. Spur of moment	105	−0.23*	−0.29**	−0.42***	−0.38***	−0.19
8. Civic/community activities	92	−0.19	−0.11	−0.26*	−0.07	−0.07
9. Home	105	−0.31**	−0.16	−0.24*	−0.19	−0.21*
10. Finances	104	−0.01	−0.15	−0.20	−0.05	−0.14
11. Shopping	107	−0.34***	−0.12	−0.31***	−0.19	−0.14
12. Cleaning	105	−0.32***	−0.09	−0.31**	−0.17	−0.01
13. Cooking	106	−0.15	−0.13	−0.25*	−0.10	0.00
14. Pets	73	−0.06	0.00	−0.11	−0.07	−0.05
15. Help others	81	−0.28*	−0.01	−0.27*	−0.18	−0.06
19. Volunteer work	75	−0.14	−0.21	−0.12	0.03	−0.03
20. Quiet leisure	108	0.04	−0.13	0.01	−0.05	0.04
21. Active leisure	100	−0.35***	−0.23*	−0.37***	−0.27**	−0.24*
22. Social friends	107	−0.05	−0.25	−0.23	−0.18	−0.19
23. Friends – connect	107	0.02	0.24	−0.07	−0.11	−0.03
24. Social – family	104	0.01	−0.20	−0.07	−0.11	−0.06
25. Family – connect	106	−0.08	−0.10	−0.06	−0.05	0.12
26. Significant other relationships	90	−0.25	−0.18	−0.22	−0.27*	−0.14
27. Child relationship	78	−0.25	−0.18	−0.01	−0.06	−0.04
28. Sex	85	−0.18	−0.25*	−0.22	−0.28*	−0.13
Number of items with significant ($p < 0.0001$) correlation		5	0	4	1	0
Proportion of items with significant correlation		0.2	0	0.16	0.04	0

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[†]Frequency of responses; *n* used to calculate Kendall's tau–b may be smaller due to pairwise missing data.

*
$p < 0.01$;

**
$p < 0.001$;

***
$p < 0.0001$.

Table IV

Kendall's tau-b correlation coefficients for the self-efficacy dimension and variables of interest.

Item	n[†]	Mobility	PHQ9	Gen health	Fatigue	Pain
1. Grooming/hygiene	110	−0.46***	−0.18	−0.37***	−0.26*	−0.18
2. Medical routines	108	−0.25*	−0.30**	−0.31**	−0.26*	−0.12
3. Well-being activities	110	−0.30**	−0.32***	−0.37***	−0.36***	−0.24*
4. Personal services	108	−0.23*	−0.42***	−0.37***	−0.29**	−0.25*
5. Around community	109	−0.48***	−0.29**	−0.40***	−0.41***	−0.33***
6. To and from regular activities	98	−0.45***	−0.20	−0.38***	−0.38***	−0.30**
7. Spur of moment	105	−0.37***	−0.32***	−0.40***	−0.41***	−0.27**
8. Civic/community activities	92	−0.39***	−0.30**	−0.42***	−0.39***	−0.31**
9. Home	105	−0.48***	−0.30**	−0.38***	−0.43***	−0.32***
10. Finances	104	−0.12	−0.26*	−0.26*	−0.28**	−0.25*
11. Shopping	107	−0.37***	−0.21*	−0.39***	−0.40***	−0.33***
12. Cleaning	105	−0.51***	−0.19	−0.42***	−0.41***	−0.35***
13. Cooking	106	−0.48***	−0.24*	−0.35***	−0.40***	−0.23*
14. Pets	73	−0.31*	−0.14	−0.15	−0.25	−0.23
15. Help others	81	−0.49***	−0.16	−0.40***	−0.41***	−0.32**
19. Volunteer work	75	−0.29*	−0.26*	−0.32**	−0.31*	−0.31**
20. Quiet leisure	108	−0.03	−0.34***	−0.23*	−0.28**	−0.17
21. Active leisure	100	−0.42***	−0.25*	−0.46***	−0.38***	−0.29**
22. Social friends	107	−0.33**	−0.34***	−0.29**	−0.34***	−0.18
23. Friends – connect	107	−0.18	−0.44***	−0.28**	−0.33***	−0.16
24. Social – family	104	−0.19	−0.38***	−0.26*	−0.37***	−0.23*
25. Family – connect	106	−0.28*	−0.38***	−0.25*	−0.29**	−0.22*
26. Significant other relationships	90	−0.30*	−0.43***	−0.34**	−0.35**	−0.36***
27. Child relationship	78	−0.34*	−0.41***	−0.15	−0.28*	−0.24
28. Sex	85	−0.28*	−0.30**	−0.35***	−0.33**	−0.25
Number of items with significant (p < 0.0001) correlation		11	10	14	14	5
Proportion of items with significant correlation		0.44	0.4	0.56	0.56	0.2

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Item	$n^{\dagger}$	Mobility	PHQ9	Gen health	Fatigue	Pain

†Frequency of responses; n used to calculate Kendall's tau–b may be smaller due to pairwise missing data.

*
$p < 0.01$;

**
$p < 0.001$;

***
$p < 0.0001$.

Appendix

Items in the participation survey

#	Title	Area or topic	Complete item
1.	Grooming/hygiene	Routines	Grooming/hygiene (for example, shaving, bathing)
2.	Medical routines	Routines	Tending to medical routines (e.g., taking meds, making doctor appointments)
3.	Well-being activities	Routines	Taking part in physical activities to improve your well being (e.g., exercise)
4.	Personal services	Routines	Arranging personal services (e.g., making an appointment for a haircut)
5.	Around community	Routines	Getting around the community
6.	To from regular activity	Routines	Getting to and from regular activities (work, doctor's appointments)
7.	Spur of moment	Recreation	Going places on the spur of the moment
8.	Civic community activity	Recreation	Engaging in community activities (e.g., neighborhood organizations, garden club)
9.	Home	Responsibility	Managing the home (e.g., arranging for a plumber, changing a light bulb)
10.	Finances	Responsibility	Managing finances (budgeting, paying bills, doing taxes)
11.	Shopping	Responsibility	Shopping (buying groceries, household necessities, clothing)
12.	Cleaning	Responsibility	Cleaning (vacuuming, dusting, laundry)
13.	Cooking	Responsibility	Cooking (planning meals, and preparing food, doing dishes)
14.	Pets	Responsibility	Caring for pets (feeding, grooming)
15.	Help others	Responsibility	Helping others in the household (driving others, doing their laundry)
16.[*]	Children	Responsibility	Caring for children (feeding, dressing, supervising)
17.[*]	Working	Responsibility	Working (paid employment)
18.[*]	Educational activities	Responsibility	Taking part in educational activities (e.g., taking adult education classes)
19.	Volunteer work	Recreation	Talking part in volunteer work.
20.	Quiet leisure	Recreation	Taking part in quiet leisure activities (reading a book, watching TV, browsing the web, computer games)
21.	Active leisure	Recreation	Taking part in active leisure activities (playing sports, going to a movie or play, visiting a museum)
22.	Social friends	Recreation	Interacting socially with friends (going to a party, dining out)
23.	Friends connect	Relationships	Staying connected with friends (e.g., phoning, writing, email).
24.	Social family	Relationships	Interacting socially with family (going to a party, dining out)
25.	Family connect	Relationships	Staying connected with family (e.g., phoning, writing, email)
26.	S/O relationships	Relationships	Maintaining relationship with significant other (e.g., spouse, romantic relationship)
27.	Child relationship	Relationships	Interacting with/maintaining relationship with your children
28.	Sex	Relationships	Engaging in sexual activity (physical intimacy with a partner)

[*] Deleted due to < 50% response rate.