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Validation of the Patient Activation Measure in a Multiple Sclerosis Clinic Sample and Implications for Care

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Abstract

Purpose. Patient engagement in multiple sclerosis (MS) care can be challenging at times given the unpredictable disease course, wide range of symptoms, variable therapeutic response to treatment and high rates of patient depression. Patient activation, a model for conceptualising patients' involvement in their health care, has been found useful for discerning patient differences in chronic illness management. The purpose of this study was to validate the patient activation measure (PAM-13) in an MS clinic sample.
Methods. This was a survey study of 199 MS clinic patients. Participants completed the PAM-13 along with measures of MS medication adherence, self-efficacy, depression and quality of life.
Results. Results from Rasch and correlation analyses indicate that the PAM-13 is reliable and valid for the MS population. Activation was associated with MS self-efficacy, depression and quality of life but not with self-reported medication adherence. Also, participants with relapse-remitting MS, current employment, or high levels of education were more activated than other subgroups.
Conclusions. The PAM-13 is a useful tool for understanding health behaviours in MS. The findings of this study support further clinical consideration and investigation into developing interventions to increase patient activation and improve health outcomes in MS.

Keywords: *Multiple sclerosis, patient activation, illness behaviour, self-efficacy, patient compliance*

Introduction

Engaging patients in health behaviours related to the management of chronic illness is a challenging endeavour for healthcare professionals. Although treatment adherence is difficult in many chronic conditions, the need for regular self-injections or hospital based infusions and the side effects of these disease modifying therapies (DMT), such as fever, chills, sweating, muscle aches and fatigue, can be especially trying in multiple sclerosis (MS) [1]. Although these treatments have been found to decrease the frequency of exacerbation, disability progression, and demylination, outcomes vary widely. Treatment failure is not uncommon, which further complicates care [2]. Given that DMT are frequently not the only therapeutic intervention employed, patients also must contend with the complexities associated with managing secondary symptoms, such as fatigue, pain, depression and urinary and bowel incontinence [3,4].

In addition to the difficulties pertaining directly to the treatment itself, certain psychosocial factors have been shown to predict how well a patient will comply with DMT. Patients' perceptions of how a treatment is working [5], their sense of MS-related self-efficacy (i.e., confidence that one can administer self-injections), anxiety about self-injections [6] and whether

or not a patient believes that the injections are actually beneficial [7] also have been strongly related to whether or not they continue the treatment.

Patient activation

One construct that has proven useful when considering patient commitment and follow-through with treatment is patient activation, which has been used to describe patients' degree of engagement in their health care. Components of patient activation include one's knowledge about his/her health condition, perceived ability to follow through with treatment, and comfort collaborating with and being able to express concerns to health care providers [8].

Hibbard et al. [8] conceptualise patient activation as a developmental patient process of four progressive levels. At the lowest level, patients tend to be overwhelmed with the task of managing their health and may not feel ready to take an active role. At level two, patients realise that they have a role to play in their health care, but may lack the knowledge and confidence to manage their health. At level three, patients are beginning to take action, but may still lack some confidence to manage all aspects of their health. At level four, patients struggle with being able to maintain the behaviours they have already adopted.

Because highly activated patients assess their role in the management of their conditions as very important, they will pursue and strive to access the best health care available. Alternatively, patients with lower activation are less likely to carry out self-management behaviours and adhere to medications [8,9]. Higher levels of patient activation have been associated with better health overall [10] and have also been shown to predict a number of specific health-related outcomes among people with chronic disease, such as hypertension control in diabetics [11] and pain management in patients with chronic kidney disease [12]. It appears that patients who actively participate in their care may be better able to provide doctors with valuable information needed for diagnosis and treatment [13], which in turn can result in more informed and supportive providers and improved health outcomes [14,15].

Researchers have also begun to examine to what extent patient activation can be modified. One intervention designed to raise patient activation levels in individuals with diabetes was found to increase the number of questions that patients asked of their clinicians. Moreover, these patients reported fewer physical limitations at a 4-month follow-up [16]. Hibbard et al. [10] conducted an intervention with patients with chronic disease to determine whether changes in activation were accompanied by changes in health behaviour, concluding that a variety of health behaviours improved when activation increased, such as engaging regularly in exercise, managing stress, paying attention to amount of fat in diet, and taking diabetes medication as recommended. In another study of patients with chronic conditions, those with higher patient activation were more likely to perform self-management tasks, use self-management services, and report high levels of medication adherence [9].

Patient activation may be especially important in chronic illnesses like MS, because fluctuating physical circumstances require patients to stay involved and continually make new decisions regarding their care [17]. As DMT are often begun early in MS disease course, it is important that even newly diagnosed patients begin to appreciate their role in the management of symptoms [2]. Increasing patient knowledge about the condition and available treatments is key, as unrealistic expectations of MS treatments and insufficient or inaccurate knowledge about medications affect levels of compliance [1,18,19]. Likewise, improved health care communication could help patients more readily express their concerns about self-injection [18], treatment side effects, and frequently unaddressed issues like sexual dysfunction to improve education and early intervention efforts. Additionally, fatigue in MS impacts communication [20] and therefore communication is of primordial importance for patients with MS.

Another component of patient activation is self-efficacy, which is a person's belief that they can overcome particular challenges and carry out a course of action [21]. According to one study, self-efficacy was found to be a major predictor of adjustment to having MS [22] and also predicted self-worth after diagnosis [23]. Another study reported that low self-injection self-efficacy, was related to patient expectation of having major difficulties or a complete inability to self-inject [6]. Self-efficacy training has been shown to increase exercise adherence in MS patients [21]. Further, involving MS patients in counselling to identify treatment related problems, create goals, and develop intervention strategies increased MS self-efficacy ratings [24].

Because self-efficacy in MS patients has been shown to be lower in patients with depression and/or anxiety [25], these individuals may be especially at risk for having low activation levels. It is estimated that lifetime rates of major depression are as high as 50% after diagnosis [26] and that MS patients have higher rates of depression than in many other chronic illnesses, including other neurological illnesses [27,28]. Depression can negatively impact levels of patient activation, as depression leads to loss of incentive and increased participation in avoidance

behaviours that can directly affect a patient's level of functioning [29] and affect quality of life [30]. In the MS population, it has been shown that higher rates of depression are associated with avoidance strategies and that lower rates of depression are associated with patients acquiring new strategies for problem solving [31,32]. Thus, treatment of depression is vital, as decreasing depressive symptoms could assist in increasing activation.

The patient activation measure

One psychometrically sound instrument that has been used to assess patient activation is the patient activation measure (PAM), a unidimensional scale reflecting Hibbard et al.'s [8] developmental model of activation. The PAM is a self-report measure designed to assess a patients' knowledge, skill and confidence in managing their health or chronic condition [8]. The 22 item PAM was developed using Rasch modelling, a measurement method which has gained popularity, in part, because of its ability to assess constructs with fewer items and thus lessen patient questionnaire burden [33]. Rasch models are based on item-response theory as a method of describing latent traits (abilities or attitudes) [34] and can produce interval-level, unidimensional and probabilistic Guttman-type scales from ordinal data [10]. Participants are located on the measurement scale from least to most of the assessed ability (in this case activation) while items are located on the same scale from least difficult to most difficult. Although located on the same scale, item and person measures are statistically independent of each other, enabling the calibration of item difficulty to be independent of the ability level of the respondent. Information weighted fit (INFIT) and outlier-sensitive fit (OUTFIT) mean squares are calculated to determine the goodness of fit to the Rasch model, with most studies utilising a range of 0.70–1.30 as acceptable fit with 1.00 indicating perfect fit [33]. Finally, the standard error of measurement represents the precision with which an item's or individual's scale location has been estimated [8].

The PAM was initially validated on a randomly selected national probability sample of 1515 participants 45 years or older [8], but has since been utilised with other populations, including persons with chronic illness (e.g, diabetes, arthritis, hypertension, heart disease, chronic obstructive pulmonary disease and hyperlipidemia) and persons undergoing spinal surgery [9,35]. The initial PAM study demonstrated good psychometric properties including a high Rasch person reliability statistic with INFIT values ranging from 0.71 to 1.44 and all but one of the OUTFIT statistics ranging between 0.80 and 1.34 [8]. A short form of the PAM (PAM-13) was developed and validated from the original sample and yielded similar psychometric properties to the 22-item version, with lower, but acceptable, reliability and INFIT and OUTFIT statistics falling within a range of 0.50–1.50 [36].

Though the PAM has been utilised in other chronic illness populations, it has not been validated on the MS population. Although MS shares similarities to other chronic illness groups, it is also unique in that a majority of individuals experience an unpredictable relapse-remitting disease course and receive DMT with widely varied outcomes. This could alter how 'in control' individuals living with MS feel with regard to their illness and hence how activated they might be. If the PAM were demonstrated to be a valuable tool for MS patients, it could help identify those who may benefit from increased patient activation through therapeutic, educational, and supportive interventions targeting factors affecting MS patients' ability to engage more fully in care. Thus, the purpose of this study is to evaluate the validity of the PAM in an MS clinic sample.

Method

Participants

A sample of 199 respondents was recruited from a regional Multiple Sclerosis Centre affiliated with an academic medical centre in the southeastern United States. Most participants were female ($n = 163$, 82%), married ($n = 120$, 60%) and Caucasian ($n = 137$, 68.8%), with a mean age at the time of the study of 46.24 (SD = 10.83), and their average years since diagnosis was 8.30 (SD = 6.84). Educational level varied, with 45 (22%) having earned a GED/High School diploma, 49 (24%) having some college education, 32 (16%) earning an associate's degree, and 16% a bachelor's degree (see Table I). Half were unemployed ($n = 109$), 29.6% were employed full time ($n = 59$), and 42% received disability benefits for MS ($n = 83$). Sixty-six percent of participants had relapse-remitting MS ($n = 131$).

Measures

A demographic survey collected information on age, gender, ethnicity, years of education, employment/disability status, and marital status. A second part of this survey collected specifics about MS disease, including MS subtype, years and months since MS diagnosis, and self-reported medication adherence.

Table I. Demographics of the MS clinic sample.

	M (SD)	n	%
Sample		199	100.00
Female		163	81.90
Current age	46.24 (10.83)		
Years since diagnosis	8.30 (6.84)		
Race			
Native American		1	0.50
African-American		54	27.10
Hispanic/Latino		2	1.00
Caucasian		137	68.80
Biracial		4	2.00
Marital status			
Single/never married		30	15.10
Married		120	60.30
Living with partner		3	1.50
Separated		7	3.50
Divorced		34	17.10
Widowed		5	2.50
Education			
Some high school		9	4.50
GED/HS diploma		45	22.70
Some college		49	24.70
2-year college/ Associate's degree		32	16.20
4-year college/ Bachelor's degree		32	16.10
Master's		23	11.60
Doctoral/PhD		2	1.00
Professional degree (MD, JD)		6	3.00
Employment status			
Full time		59	30.30
Part time		14	7.20
Unemployed		109	55.90
Retired		10	5.10
Disability		3	1.50
Type of MS			
Relapse-remitting		131	68.60
Progressive		8	4.20
Secondary progressive		15	7.90
Unsure		37	19.40

Adherence was measured using a single item in which patients responded to the frequency at which they missed doses of their DMT. Respondents also completed the PAM-13, along with measures of depression, MS self-efficacy, and quality of life to establish convergent and discriminant validity.

The PAM-13 [36] is the short form of the 22-item PAM developed by Hibbard et al. [8] and measures patient knowledge, skill, and confidence for medical self-management. Individuals respond to items such as 'I know how to prevent further problems with my health condition', using a scale ranging from 'strongly disagree' to 'strongly agree'. The PAM-13 is scored on a scale from 0 to 100 indicating strength of agreement, with larger numbers indicating greater agreement with the item. An average score of the 13 item responses is obtained with higher total scores equalling higher activation. The PAM-13 has similar psychometric properties to the original 22 item measure [36], with INFIT and OUTFIT statistics for each item ranging from 0.50 to 1.50. Cronbach's α was .88 for this sample.

The Beck depression inventory (BDI-II) [37] is a 21 item, multiple-choice, self-report measure of depression with affective (8 items) and somatic (13 items) subscales. Responses to each item range from 0 to 3, with higher scores reflecting more severe symptomatology. Total scale scores of 0–13 are considered in the minimal range, 14–19 are mild, 20–28 are moderate, and 29–63 are indicative of severe depression. The BDI-II has strong reliability in the current sample ($\alpha = 0.92$) and has been used in treatment studies with MS samples [6].

The multiple sclerosis self-efficacy scale (MSSE) [38], is an 18-item scale divided into two subscales: function and control. The items aim at assessing how confident individuals feel that they can achieve specific functions (e.g., 'As of now, how certain are you that you can walk 100 feet on flat ground'?) or *control* various aspects of their MS (e.g., 'As of now, how certain are you that you can control your fatigue'?). Responses are rated on a 100-point continuum, from 10 to 100 in 10-point increments, with higher scores associated with higher degrees of certainty. Scores are totalled on each subscale (function and control) and a total MMSE score is obtained as well. The MSSE has been found to have high internal consistency and test–retest reliability [38]. The Cronbach's α in this sample was high ($\alpha = 0.96$) for the total scale.

Leeds multiple sclerosis quality of life (MSQOL) [39] is an 8-item self-report scale assessing well-being in patients with MS in the last month. Items like, 'My health has affected my relationships with my family' are rated on a 0–3 point scale (0 = 'not at all' to 3 = 'very much'). The total scale score ranges from 0 to 24, with higher scores indicating higher well-being. The scale demonstrated acceptable reliability ($\alpha = 0.79$) [39]. The reliability coefficient in this sample was 0.80.

Procedures

The data was collected in conjunction with patients' routine MS Centre visits. Adult patients with definitive MS and limited cognitive impairment, per neurologist assessment, were deemed eligible for participation. Patients were queried during their visit regarding voluntary study participation and those interested were provided with verbal and written informed consent. Survey packets took approximately 25 min to complete and patients received no remuneration for participation. Assistance with completion due to MS symptoms (reading or

marking items) was provided at MS patient request. Institutional Review Board approval was received prior to study initiation.

Results

Data was reviewed for completeness prior to statistical computation. For patients with less than 10% of their data missing on any given questionnaire, a respondent-specific mean score was computed from the completed items and imputed. Individual questionnaires with more than 10% of the data missing were eliminated prior to the specific analysis utilising that data. Missing data appeared to be randomly distributed across the survey instruments.

Patient activation measure scores for this sample ranged from 36.07 to 99.97 with a mean of 63.18 (SD = 11.87). We used Hibbard's scoring [9] to determine individuals' level of patient activation. The PAM scores of 14 participants (7.1%) were under 47, indicating level 1 of patient activation (not understanding an active role is important). Thirty-seven participants (18.9%) scored between 47.1 and 55.2 on the PAM, indicating level 2 of patient activation (lacks knowledge and confidence to take action). The majority ($n = 78$, 39.8%) scored between 55.2 and 67.0 on the PAM, indicating level 3 of patient activation (beginning to take action). Finally, 67 participants (34.2%) scored above 67.1 on the PAM indicating a level 4 level of patient activation (maintaining behaviours over time). These results are on par with Hibbard and Cummingham's [40] findings of activation levels for patients with chronic conditions. One exception was that our sample seemed to have a higher percentage of patients in level three and a lower percentage in level four as compared to the mean percentages among those with chronic conditions in Hibbard and Cunningham's work [40] as seen in Table II.

PAM-13 fit in MS

The PAM-13 was assessed for unidimensionality and item fit using the Winsteps Rasch modelling software application [41]. The PAM-13 showed good reliability (Rasch person reliability = 0.83 and Rasch item reliability = 0.98) and unidimensionality ($\alpha = 0.88$). The high reliability coefficients indicate that the measure is appropriate for individual-level use.

The fit of the individual items was evaluated using the Rasch analysis model. The fit of each item to the Rasch model is assessed by the information weighted mean-square residual goodness of fit statistics INFIT and OUTFIT] [42]. An INFIT/OUTFIT valued of < 0.7 indicates that the item does not provide any more information than the rest of the items on the scale, possibly because items are similar or highly correlated. An INFIT/OUTFIT value > 1.3 indicates that the item is either poorly constructed, ambiguously defined, or does not define the same construct as the rest of the items. An acceptable range for an INFIT/OUTFIT value is usually between 0.7 and 1.3 [43]. For our sample, The PAM-13 INFIT/OUTFIT values range 0.76 and 1.15, for 12 out of the 13 items, well within the range required for a unidimensional measure. Only one item (Item 1 – 'When all is said and done, I am the person who is responsible for taking care of my health problems') had an INFIT value of 1.57, indicating a possible lack of fit with the model. The INFIT/OUTFIT statistics are presented in Table III.

PAM-13 and relationships to other variables

As expected, the PAM was most strongly positively correlated to total MSSE ($r = 0.50$, $p < 0.01$), indicating patients with higher activation had higher MS self-efficacy. Because self-efficacy is part of the patient activation construct, it was expected that this

Table II. Comparison of MS patient activation levels with Hibbard & Cunningham chronic medical condition groups [37].

	Level of activation				
	Level 1 (least activated)	Level 2	Level 3	Level 4 (most activated)	Overall activation score (adjusted)
All persons with chronic conditions [40]	8.6%	17.3%	33.9%	40.1%	64.2
Selected conditions					
Diabetes	7.9	18.9	35.3	37.9	65.3
Arthritis	11.2	19.1	32.2	37.5	63.2
Asthma	8.1	16.8	32.5	42.7	64.8
Hypertension	9.6	18.5	34.2	37.7	63.5
Heart disease	11.6	18.9	34.0	35.5	64.0
Cancer	7.8	12.2	34.5	45.5	65.8
Depression	12.6	21.1	29.4	36.8	62.1
MS sample	7.1	18.9	39.8	34.2	63.2

Table III. PAM-13 with item calibration for MS population.

	Measure[*]	SEM[†]	INFIT[‡]	OUTFIT[§]
1. When all is said and done, I am the person who is responsible for taking care of my health problem	41.73	1.06	1.57	1.79
2. Taking an active role in my own health care is the most important thing that affects my health	39.47	1.10	0.93	0.86
3. I am confident I can help prevent or reduce the problems associated with my health condition	51.13	0.96	0.92	0.89
4. I know what each of my prescribed medications does	43.33	1.05	1.12	1.03
5. I am confident I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	46.64	1.00	1.10	1.07
6. I am confident that I can tell a doctor my concerns I have even when he or she does not ask	39.13	1.10	0.76	0.66
7. I am confident I can follow through on medical treatments I need to do at home	38.98	1.11	0.76	0.73
8. I understand my health problems and what causes them	45.00	1.02	1.06	0.97
9. I know what treatments are available for my health problems	46.48	0.99	0.98	1.15
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	58.65	0.90	1.1	1.14
11. I know how to prevent further problems with my health condition	58.13	0.91	0.79	0.79
12. I am confident I can figure out solutions when new problems arise with my health condition	58.55	0.90	0.92	0.92
13. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress	59.94	0.89	1.13	1.15

[*]The calibrated scale value of the item is how much activation is required to endorse this item.
[†]The standard error of measurement is precision of the item difficulty estimation.
[‡]INFIT is an information-weighted residual of the observed responses from the model expected responses. INFIT mean square error is a quality control fit statistics assessing item dimensionality.
[§]OUTFIT mean square error fit statistic is sensitive to unexpected observations made by respondents on items that would be either very easy or very hard for them. It is an outlier-sensitive statistic.

association would be strong due to the construct overlap, but still remain conceptually distinct. Significant correlation between the PAM-13 and the BDI-II ($r = -0.43$, $p < 0.01$) and MS QOL ($r = 0.42$, $p < 0.01$) were also in the anticipated direction, such that higher activation was associated with lower depression and higher well-being. With regard to adherence, self reported frequency of missing DMT injections (for those on treatment) unexpectedly was not correlated to patient activation ($r = -0.04$, $p = 0.57$).

Between-group differences in the PAM-13

Three of the demographic variables were significantly correlated with patient activation scores (employment status, education level, and type of MS) and thus were subjected to further analysis. To ensure adequate n within each group, the employment variable was collapsed into patients employed at any level (full or part time) and patient not currently employed (retirement, unemployment, disabled). Similarly, patients with any type of progressive MS (primary and secondary) were

grouped together as distinct from those with relapse-remitting MS. Three groups were created for education: patients with a high school education and below, patients with some college or a 2-year degree, and patients with a 4-year degree and above. Independent-samples t test were conducted with the PAM for MS type and employment. The test was significant for type of MS and the PAM, $t(149) = 2.95$, $p < 0.05$. Patients with relapse-remitting MS ($M = 42.29$, SD $= 5.11$) on average had higher levels of patient activation than did patients with a progressive MS ($M = 38.44$, SD $= 6.05$). The t test was also significant for employment status and patient activation, $t(190) = 2.65$, $p < 0.05$, such that those who were employed had higher activation levels than those not employed.

A one-way ANOVA was conducted to evaluate the relationship between education level and patient activation. The ANOVA was significant, $F(2, 192) = 15.68$, $p < 0.001$. Follow-up tests were conducted to evaluate pairwise differences among the means of the three groups. Because of sample sizes differences, a Gabriel's test was conducted. Individuals with 4-year degrees and above ($n = 63$) had significantly higher activation scores ($M = 69.47$,

Table IV. Correlations between PAM-13 and discriminant validity measures.

Total scores		PAM	MSQOL	BDI-II	MSSE-Full	MSSE-Fnct	MSSE-Control
PAM	r	(0.88)	0.42★	−0.43★	0.50★	0.41★	0.49★
	N		194	187	189	190	192
MSQOL	r		(0.80)	−0.72★	0.62★	0.41★	0.72★
	N			186	189	190	192
BDI-II	r			(0.92)	−0.55★	−0.38★	−0.63★
	N				184	185	187
MSSE-Full	r				(0.96)	0.91★	0.91★
	N					190	191
MSSE-Fnct	r					(0.94)	0.68★
	N						190
MSSE-Ctrl							(0.96)

Coefficient alpha estimates are listed on the main diagonal.
PAM, patient activation measure; MSQOL, multiple sclerosis quality of life; BDI-II, beck depression inventory-II; MSSE-full, multiple sclerosis self-efficacy scale full; MSSE-Fnct, Multiple sclerosis self-efficacy scale function subscale; MSSE-Ctrl, Multiple sclerosis self-efficacy scale control subscale.
★Pearson correlation is significant at the 0.01 level (2-tailed).

SD = 10.70) than individuals ($n = 80$) with some college or 2-year degrees ($M = 60.72$, SD = 11.85) or individuals ($n = 52$) with an educational level of high school or below ($M = 59.08$, SD = 10.25). A significance level of $p < 0.001$ in both comparisons was obtained. The difference between the some college or 2-year degrees group and the high school or below group was not significant.

Discussion

The results indicate that the PAM-13 is both reliable and valid for the MS population. The Rasch model supported the use of the PAM-13 in assessing patient activation in the MS population overall, and findings were similar to those from studies from the general population [36]. One item, 'When all is said and done, I am the person who is responsible for taking care of my health problems' fell outside the range of usually acceptable fit statistics. Of all of the items in the instrument, it is the one where responsibility for health problem management falls most decisively within the realm of the patient. Given unpredictability of MS relapse and the critical role that health providers play in the management of MS, especially within a multidisciplinary MS Centre, patients with MS may respond slightly differently than other populations to this item. This may also account for why a smaller percentage of MS patients were in the most activated category when compared to other disease groups. Yet, comparison of patient activation levels in this MS sample with other chronic conditions support that overall MS activation scores generally fall within the range of those with other chronic medical conditions.

PAM-13 scores did not correlate in this sample with gender, race, or age, as they did in the original PAM-13 study [36], but did correlate to employment status, education level, and MS subtype. Follow-up tests supported mean differences of activation using these demographic breakdowns, with those having relapse and remitting MS, employment of some kind, or in the highest educational group having higher activation scores than those having progressive MS, no employment, or in the lower educational groups. The current sample was much smaller than national studies of the PAM and may account for lack of significant findings within some of the demographic subgroups. Similarly, due to small sample size, the actual number of men and minorities in the study were small. On the other hand, 27.30% of the sample was African-American, which is well above the proportion of African-Americans in the US population in general. Additionally, when comparing our small and regionally restricted sample to Slifka longitudinal MS data (Minden, Frankel, Hadden, Perloff, Srinath, & Hoaglin, 2006), our sample was on the whole similar to the demographic characteristics of this national sample of persons with MS. For example, compared to the individuals in the Slifka study, participants in the current study had a similar mean age (46.24 years in our study compared to 50.70 years), were mostly female (81.90% *versus* 77.00%), were married (60.30% compared to 66.50%), and were in the workforce (37.50% compared to 43.50%). In terms of education, the samples did differ. Whereas 20.10% of participants in the current study were a college graduate or had completed postgraduate work, 40.10% were in the Slifka sample. The largest relative difference was in ethnicity, as the Slifka sample was 4.80% African-American *versus* 27.30% in the current study. We view this as a distinct

strength of this investigation, given how few MS studies have sizable African-American samples.

Activation levels were strongly correlated as anticipated to measures of MS self-efficacy, depression, and quality of life. Given that this study does not allow for examination of causal relationships, we do not know whether activation drives depression, MS self-efficacy, and quality of life, the other way around, or another, more complex relationship. Despite this, it is reasonable to consider addressing depression with MS patients as a way to increase activation, especially since as many as 25% of MS patients have untreated or undiagnosed depression [45]. Moreover, there is good evidence that both antidepressants [46] and psychotherapy [47] can improve and often alleviate depressive symptoms in MS.

Similarly, it may be worthwhile pursuing interventions focused on improving MS self-efficacy in order to increase activation. In one promising study, an 8-week multidisciplinary health promotion class was used as an intervention to increase MS patients' knowledge, skills, and confidence for health promotion activities [48]. At the end of treatment, the treatment group was found to have undertaken more health promotion activities and had more health promotion self-efficacy that did controls, and were higher on some quality of life indicators, even at 3 months post-treatment. In terms of other patient activation components, health literacy and patient-physician communication interventions should also be pursued further with the MS population. Interestingly, one recent study found that among several acute and chronic illness subgroups, there was no difference in desire for participation in health care, except for the MS group, which has significantly higher participation preferences than all other diagnostic groups [49].

Self-reported adherence to injection DMT was not related to patient activation in this study. As adherence was measured by a single item and the sample size was not large, measurement and power issues may have a role in these findings. Additionally, our sample was skewed such that few patients endorsed missing their medications in the upper frequency range, with 'somewhat often' or 'very often' representing <7% of the total sample, while over 73% of the sample being at levels 3 or 4 with regard to patient activation. It is also possible that many patients with chronic adherence issues were no longer on DMT and thus would have left that item blank altogether. Given that difficulty adhering to DMT is a well-documented issue for some individuals with MS [50] and patient activation has been related to medication adherence in other populations [9], it is prudent to consider additional, more sophisticated exploration of these variables in future studies.

The practical implication for this research is that the PAM enables the assessment of patient activation levels, which can be useful in informing clinical practice. Understanding patients' activation levels may help improve medical care by allowing health care providers to tailor their interactions and treatment according to the degree to which patients are ready to assume responsibility for their care. Patients' level of activation also may prove to be a useful gauge for likelihood of patients to follow though and comply with treatment, especially in the absence of family members and other caregivers to assist. Given the chronic nature of MS and the demanding treatment, understanding patients' level of activation may be crucial in identifying poor self-management groups and seeking to address their needs through supportive interventions. It is not yet clear what contributes to patient activation nor what type of intervention can increase it [8]. Future research should focus on interventions to increase activation in order to improve health care outcomes and utilise the PAM as a starting point.

Limitations

The study findings have some generalisability limitations, given the restricted geographic region and lack of men and minorities (other than African-Americans) in the sample. Given that women are disproportionately affected by MS, much larger samples are often needed to be able to draw conclusions about men when using a convenience sampling method. Additionally, the correlational nature of the study prevents us from making any causative conclusions about the directionality of the relationships between the PAM-13 and the other variables assessed. Another limitation is our use of self-report instruments and lack of corroboration with physician report and clinical findings. While future research should seek to incorporate this data, there is evidence that for some variables, like depression, a high degree of overlap exists between patient self-report and physician ratings [26]. Despite the limitations, this study provides many robust findings about patient activation in the MS population and can serve as a springboard to future work in this area.

Conclusion

In conclusion, the PAM-13 appears to be valid in the MS population and is related as anticipated to depression, MS self-efficacy, and quality of life. The PAM-13 can be used in the clinical setting as well as in research as a more general measure of patient engagement to augment MS specific

measures of care. Future studies can be directed towards developing interventions to increase activation and improve health outcomes in MS. Additional understanding of individuals at risk for low activation levels, especially among those with less education, would be especially beneficial in the development of targeted interventions for that MS sub-population.

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