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Variables Associated with Patient Activation in Persons with Multiple Sclerosis

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Variables associated with patient activation in persons with multiple sclerosis

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Abstract

Identifying variables associated with patient activation in the multiple sclerosis population could serve to facilitate better multiple sclerosis self-management behaviors. Using a cross-sectional survey design, 199 participants were recruited from a multiple sclerosis center in the Southeastern United States. Depression, multiple sclerosis quality of life, and multiple Sclerosis self-efficacy were all significantly correlated with patient activation. Results of a hierarchical regression indicated that patient activation was significantly related to educational attainment, depression, and self-efficacy but not to quality of life. The results suggest several possible targets for intervention to increase patient activation, including health literacy, depression symptoms, and self-efficacy for multiple sclerosis disease management.

Keywords

chronic illness, coping, depression, health psychology, self-efficacy

Introduction

Multiple sclerosis (MS) is a chronic disabling neurological illness with no known cure that typically necessitates disease-modifying therapies (DMTs) often having adverse side effects (Murray, 2006). DMTs, frequently administered via injection, are not curative and patient response is varied, impacting motivation for adherence in some cases (Holland et al., 2001). Moreover, managing MS also involves emotional, relational, occupational, and lifestyle adaptations secondary to disease progression (Lester et al., 2007) that can further complicate treatment. The self-management model developed from Bandura (2005) addresses people's self-efficacy beliefs, their self-management

capabilities, and how prepared and motivated they are to make changes. Utilizing this model, the following study aims to understand the extent to which self-efficacy and barriers to

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self-management capabilities, such as depression and quality of life (QoL), are related to individuals' perceived abilities to manage their care.

Patient activation

Patient engagement in health care, also termed patient activation, has been increasingly identified as a key component for managing chronic diseases like MS (Forbat et al., 2009; Holman and Lorig, 2000), demonstrating positive effects on both health outcomes and cost containment (Bodenheimer et al., 2002). Patient activation embodies a developmental process of patients' willingness and ability to manage health and health care; four progressive levels of competency have been described, ranging from patients being relatively passive and not seeing themselves as playing an active role in their health to patients having the knowledge and confidence to self-manage health behaviors and garner additional supports when needed (Hibbard et al., 2004).

Higher levels of patient activation have been associated with better adherence to treatment, improved medical outcomes, and greater satisfaction with care (Hibbard et al., 2004, 2007; Mosen et al., 2007). For example, patients with diabetes who had higher levels of activation have been found to utilize effective self-management behaviors, report less difficulty managing diabetes care, (Rask et al., 2009), and have improved glycemic (Williams et al., 2005) and hypertension control (Naik et al., 2008).

Given the chronic and unpredictable nature of MS and the need to engage in lifelong, multifaceted treatment regimens, it is critical that patients be highly engaged in their MS care. Although a survey instrument assessing patient activation has been validated within the MS population (Stempleman et al., 2010), specific factors that may facilitate or hamper optimal patient activation still need to be identified.

Patient factors

Several salient patient attributes have been associated with activation in other patient populations that may be relevant to MS, including

demographic characteristics and psychosocial variables. Pinpointing these factors would assist in (1) provider identification of patients most at risk of low activation and related suboptimal MS health outcomes and (2) development of treatment plans that include additional supports to increase engagement in care. Additionally, to the extent that some patient attributes impacting activation may be malleable (e.g. depression), it affords the opportunity for therapeutic intervention that consequently may also impact activation levels.

Demographic characteristics. Initial work on the assessment of patient activation identified that higher activation was associated with being female, younger, and having more education (Hibbard et al., 2004, 2005). However, the research subsequently has been less consistent regarding the relationship between background variables and activation (Skolasky et al., 2008). For example, significant differences in patient activation with regard to race have also been reported, with African Americans reporting lower activation in some instances than their White counterparts (Alegria et al., 2008; Williams and Heller, 2007). Conversely, others have offered that these findings may be better explained by socioeconomic status (SES) (Blustein et al., 2008; Rask et al., 2009) and health literacy factors (Alegria et al., 2008).

Psychosocial factors. Psychosocial factors need also be considered in relation to self-management behavior. Variables such as mood and distress (Fisher, 2006), self-efficacy (Glasgow et al., 2001), and QoL (Lahdensuo et al., 1996) among others have been found to contribute to patients' ability to initiate and maintain health behaviors.

Self-efficacy. Self-efficacy, the belief that one can overcome particular challenges and carry out a course of action, has been linked with chronic illness management (Farrell et al., 2004). Having high levels of perceived self-efficacy appears to be more consistently correlated with self-management behaviors than

demographics or other health characteristics (Curtin et al., 2008; Joekeles et al., 2007). MS-specific self-efficacy has been found to predict adjustment to having MS and self-worth after diagnosis (Barnwell and Kavanagh, 1997), and has been linked to anticipation of DMT injection difficulties (Mohr et al., 2001). Because self-efficacy levels in patients with MS appear to be inversely correlated with severity of depression and/or anxiety symptoms (Thornton et al., 2006), individuals suffering from these conditions may be especially at risk of low levels of activation.

Depression. The role of depression in managing chronic illness has been extensively studied. Not only does depression impact QoL (Orenius et al., 2013) but depressed patients were three times more likely than nondepressed patients to be noncompliant with treatment recommendations (DiMatteo et al., 2000). The extant literature suggests a prevalence of mood disorders as high as 50–75 percent for individuals living with MS (Minden et al., 2006). Greater levels of depression have been related to lower levels of illness management self-efficacy (Lester et al., 2007) and use of avoidance coping (Mohr et al., 1997), while treatment of depression has been found to increase adherence to DMTs (Mohr et al., 1997). Persons with depressive symptoms have been found to be less likely to increase activation or improve their self-management behaviors than those without depressive symptoms (Hibbard et al., 2007). Conversely, higher levels of patient activation have been associated with lower severity of depressive symptoms in patients following spine surgery (Skolasky et al., 2008). Given the frequency of depression in MS and the profound impact it can have on initiation and maintenance of health behaviors (Wallbridge et al., 2008), further investigation of the relationship between activation and depression in MS is warranted.

Quality of life. Patients' perceptions of their QoL have also been linked to practice of self-management strategies. Hibbard et al. (2007)

found that better health-related QoL was associated with greater activation. Furthermore, patients scoring at the highest activation level were five times more likely to report better QoL than patients in the lowest activation level (Mosen et al., 2007). Persons with MS tend to have a significantly lower QoL than the general population (Montel and Bungener, 2007) related to a variety of factors including physical factors, psychological factors such as depression and cognitive complaints, and social factors such as economic disadvantage (De Judicibus and McCabe, 2007; McCabew and De Judicibus, 2005). One study identified depression as the single most important predictor of QoL in persons with MS (Amato et al., 2001). However, QoL in MS is not static and is higher in individuals who use positive coping skills (Goretti et al., 2009) and who are more physically active (Motl and Snook, 2008). QoL has been an important outcome in health research but may also in turn be a predictor of patient activation given that perceived high QoL may motivate individuals to stay activated in order to retain it.

Using a self-management model, the purpose of this study was to examine the contributions of patient demographic and psychosocial variables to activation levels in persons with MS. Better clarification of these relationships could serve to identify individuals at risk of low activation levels as well as possible therapeutic targets for activation intervention in MS.

Methods

Participants

Participants were recruited from a MS Center in an academic medical institution in the Southeastern United States. Of the 199 participants who consented to participate in the study, the majority were female ($n = 163$, 82%), Caucasian ($n = 137$, 68.8%), married ($n = 120$, 60%), had at least some college ($n = 144$, 71%), were unemployed ($n = 109$, 55%), and have been diagnosed with relapse-remitting MS ($n = 131$, 66%). The mean age was 46.24 years (standard deviation (SD) = 10.83 years) (see Table 1).

Table 1. MS clinic sample demographics.

	M (SD)	n	%
Sample		199	100.00
Female		163	81.90
Age	46.24 (10.83)		
Years since diagnosis	8.30 (6.84)		
Race			
Native American		1	.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/high school 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		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

MS: multiple sclerosis; SD: standard deviation; GED: General Equivalency Diploma.

Measures

Demographics. Participants were asked to answer questions regarding their ethnicity/race, gender, age, marital status, income, education, date of diagnosis, type of MS, and disability/employment status.

Beck Depression Inventory–II. The Beck Depression Inventory–II (BDI-II; Beck et al., 1996) is a 21-item, multiple-choice self-report instrument for assessment of somatic (13 items) and affective (8 items) depression symptoms. Individual item responses range from 0 to 3, with higher item scores indicating greater endorsement/frequency of that symptom. Item scores are totaled and higher scores indicate higher severity of symptoms. The BDI-II items have been utilized and validated in MS samples with good reliability (Mohr et al., 2001) and Cronbach's alpha was .92 in our sample.

Patient Activation Measure–13. The Patient Activation Measure–13 (PAM-13; Hibbard et al., 2005) is the short form of the 22-item PAM developed by Hibbard et al. (2004) to assess patient knowledge, skill, and confidence in disease self-management. The PAM-13 contains items such as “I know how to prevent further problems with my health condition” that participants rate from “strongly agree” to “strongly disagree.” The PAM-13 yields a total scale score from 0 to 100, with higher scores indicating higher activation. The PAM-13 items have been utilized in many patient populations with good reliability (Hibbard et al., 2005) including in MS (Stepleman et al., 2010). Cronbach's alpha was .88 in this study.

The MS Self-Efficacy Scale. The MS Self-Efficacy Scale (MSSE) (Schwartz et al., 1996) is an 18-item scale designed to assess patient certainty of being able to achieve a specific *function* (9-item subscale) or to *control* aspects of their MS (9-item subscale). An example *function* item is “As of now, how certain are you that you can walk 100 feet on flat ground?” whereas a *control* subscale item is “As of now, how certain are you that you can deal with the

frustration of MS.” Each item is scored from 10 to 100 in 10-point increments, with higher indicating a greater degree of certainty. Subtotals are calculated for the *function* and *control* subscales and a total MSSE score is obtained. The MSSE items have been shown to have high internal consistency and test–retest reliability (Schwartz et al., 1996). In this study, Cronbach’s alpha was .96, .94, and .96, for the full scale, function subscale, and control subscale, respectively.

Leeds Multiple Sclerosis Quality of Life. The Leeds Multiple Sclerosis Quality of Life (LMSQOL) (Ford et al., 2001) is an 8-item self-report measure that assesses well-being in patients with MS. It was designed to measure aspects of well-being that may be less related to physical health status. It includes statements such as “I have felt happy about the future” that are rated from 0 (Not at all) to 3 (Very Much). Total scores range from 0 to 24, with higher scores indicating higher levels of well-being. The LMSQOL items have been shown to have acceptable reliability ($\alpha = 0.79$) in the literature (Ford et al., 2001) and was near identical ($\alpha = 0.80$) to this study.

Procedure

The survey data were collected as patients attended their routine MS Center visits. Institutional Review Board approval was received prior to study initiation. Adult patients who were assessed by their neurologist as having definitive MS and limited cognitive impairment were eligible for participation. Participation was voluntary; verbal and written informed consent was obtained. Survey completion averaged 25 minutes and there was no participation remuneration. When requested, assistance with reading or marking items was provided.

Results

Preliminary analyses

Cronbach’s alpha coefficients were calculated for all survey instruments with the current

sample and found to range from .80 to .96, indicating good to excellent reliability.

Analyses of variance (ANOVAs) and *t*-tests were conducted to assess demographic differences in patient activation. Findings were not significant for age, gender, ethnicity, and marital status and were therefore not included in subsequent analyses. The *t*-test was significant for type of MS and patient activation, $t(186) = 2.95, p < .01$. Patients with relapse-remitting MS ($M = 64.31, SD = 11.93$) scored significantly higher on the PAM than patients with a progressive MS ($M = 57.39, SD = 10.54$).

Level of education was collapsed into (1) high school education and below, (2) patients with some college or a 2-year degree, and (3) patients with a 4-year degree and above. The one-way ANOVA evaluating the relationship between education level and patient activation was significant, $F(2, 192) = 15.68, p < .001$. The Gabriel post hoc testing (selected for group size differences) identified that those with an education level of high school and below ($n = 52, M = 59.08, SD = 10.25$) had significantly lower patient activation scores than individuals with some college or a 2-year degree ($n = 80, M = 60.72, SD = 11.85$) or than those with a 4-year degree.

Employment was collapsed into participants employed (full or part-time) and participants not employed (retirement, unemployment, and disabled). The independent *t*-test was significant, $t(190) = 2.65, p < .05$. Non-employed participants ($M = 61.48, SD = 12.27$) had significantly lower activation than those who were employed ($M = 66.12, SD = 10.90$).

Correlational analysis

Correlational analyses of the psychosocial and patient activation variables (with Bonferroni correction) are presented in Table 2. Depression was significantly inversely correlated with patient activation ($r = -.43, p < .01$), self-efficacy ($r = -.55, p < .01$), and QoL ($r = -.72, p < .01$). Self-efficacy and QoL were significantly positively associated with patient activation ($r = .50, p < .01$; $r = .42, p < .01$) and with each other ($r = .62, p < .01$).

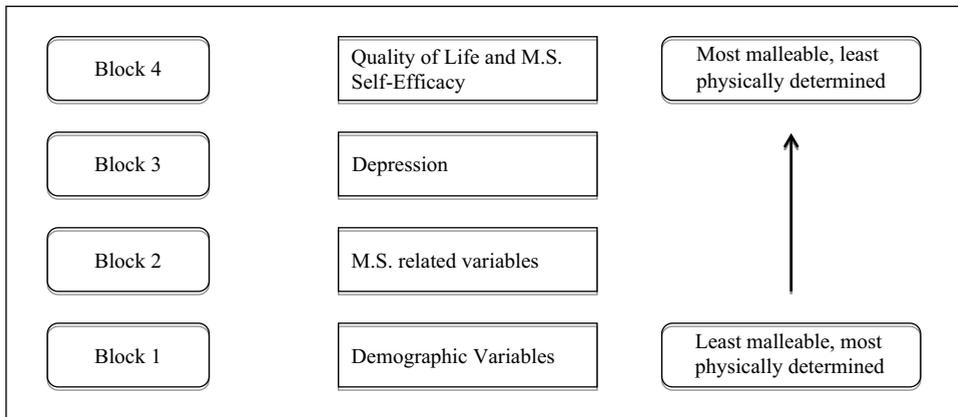


Figure 1. Hierarchical regression framework.

Hierarchical regression analyses

A hierarchical regression was conducted in order to examine the unique and combined contribution of depression, QoL, and MS self-efficacy to patient activation (Figure 1). Variable blocks were entered in order from those deemed least malleable and most physically determined to those most amenable to behavioral intervention and influenced by perception and attitude. Demographic variables associated with patient activation (education and employment) were entered first. MS physical health-related variables (type of MS and the function subscale of the MSSE) were entered second. BDI-II scores were entered third, and the fourth block consisted of the LMSQOL and the control subscale of the MSSE. The MSSE subscales were entered into different blocks because the function subscale involves items about performing physical tasks (walking 100 feet on flat ground) whereas the control subscale involves controlling certain aspects of MS (dealing with the frustration or uncertainty of MS).

All regression blocks were significant, accounting for 35 percent of the total variance in patient activation (Table 2). Demographics accounted for 10 percent of the variance, with education related to patient activation but not employment. The second block accounted for an additional 11 percent of the variance; MSSE

function was significant but MS type was not. Depression accounted for another 5 percent of the variance. The fourth block accounted for an additional 8 percent of the variance; MSSE control was related to patient activation, whereas LMSQOL was not.

Discussion

Results of this study provide some insight into factors that may contribute to patient activation in patients with MS and generally concur with past findings about patient activation in relation to self-efficacy, depression, and QoL.

In the hierarchical regression, education level was associated with patient activation. This is consistent with Hibbard et al.'s (2004) initial patient activation research and other studies (Williams and Heller, 2007). Lower levels of education also have been associated with lower health literacy (Williams et al., 1998). Since MS treatment regimens can be complex, patients with low levels of health literacy may have more difficulty understanding and complying with treatment, presenting a real challenge to MS care.

In terms of physical variables, MS type was not related to patient activation in the model though the progressive MS sample was quite small. Although preliminary, this finding cautiously supports other findings indicating that although patient activation may fluctuate over

Table 2. Hierarchical regression analyses of depression, QoL, SE to the PAM.

Variable	R ²	R ² _{change}	F	df	β
Demographic variables	.10	.10	7.64*	2	
Employment					-.13
Education					.27*
MS variables	.21	.11	9.43*	2	
Type of MS					-.06
MSSE function					.34*
Biopsychosocial	.27	.05	9.95*	1	
BDI-II					-.26*
Psychological variables	.35	.08	7.92*	2	
LMSQOL					.13
MSSE control					.38*

QoL: quality of life; SE: self-efficacy; PAM: Patient Activation Measure; df: degrees of freedom; MS: multiple sclerosis; MSSE: MS Self-Efficacy Scale; BDI-II: Beck Depression Inventory-II; LMSQOL: Leeds Multiple Sclerosis Quality of Life.

* $p > .05$.

time, it is not necessarily related to changes in health status or serious adverse health events, and instead may be associated with other factors such as age or self-reported health at baseline (Chubak et al., 2012). In contrast, the function subscale of the MSSE, assessing self-perception of being able to handle many physically related functions, was related to patient activation. Persons with higher certainty that they could perform these functional activities of daily living had higher levels of patient activation. This is consistent with the findings by Chiu et al. (2011) where persons with MS who had better perception of their ability to perform physical activity perceived fewer barriers to activity, resulting in higher physical activity levels. Overall, it seems a plausible hypothesis that health status or changes in health status are less related to changes in patient activation than perception of health and function.

Although the majority of participants (52%) scored in the minimal depression range on the BDI, many (47.3%) had totals on the BDI-II that reflect higher symptomatology. Our severity distribution was similar to that of

other MS samples (Patten et al., 2003; Siegert and Abernethy, 2005) and supports the association of depression and patient activation found in the literature (Hibbard et al., 2007). Although the cross-sectional nature of our data hinders any directional interpretation of these data, identifying individuals with depression may also identify those at risk of, or who have, low activation; intervention in either could result in improvement in both.

The control subscale of the MSSE accounted for a significant amount of the variance in patient activation over and above depression. Low self-efficacy has been associated with low levels of patient activation, low hope, and low locus of control (Skolasky et al., 2008). The PAM measure does itself contain self-efficacy-type items: “I am confident I can figure out solutions when new problems arise with my health condition,” so this overlap may account, in part, for this finding relationship.

Even though QoL has been related to patient activation in prior studies (e.g. Hibbard et al., 2007), QoL was not significantly related to patient activation in our model. Although scores on the QoL and the PAM were positively correlated in our study, QoL does not appear to account for additional variance in this model. This could be due to the fact that the Multiple Sclerosis Quality of Life (MSQOL) instrument used in this study is a very broad and general measure of QoL. A more specific measure, such as the multidimensional MSQOL-54 (Vickey et al., 1995) should be considered for future studies.

Limitations

Limitations include the geographically restricted sample from a single site and under-representation of men, even when accounting for lower rates of MS in men. Although we had good representation of African Americans and Caucasians, other racial/ethnic minority groups were not as well represented. The findings also may not be reflective of the experience of persons with progressive MS given the small sample in our study. The cross-sectional design

limits directional interpretation of the relationships between the variables and patient activation. Other limitations include reliance on self-report measures and not controlling for treatment differences (whether patients were receiving DMTs, antidepressants, etc.).

Implications

Activated patients respond differently than non-activated patients to information from the medical provider, suggesting that assessment of patient activation can help target how to tailor physician messages (Ledford, 2012). Several studies have focused on increasing patient activation by tailoring coaching to patient activation level (Hibbard et al., 2009; Shively et al., 2013) or by intervening at the communication level, helping patients build question formulation skills prior to their visit with the physician (Deen et al., 2011). These results are very encouraging given the impact of patient activation on self-management behaviors. However, few studies have focused on determining what psychosocial variables and potential barriers are associated with patient activation in persons with MS.

Based on the strong education-related findings in this study, it is possible to surmise that targeting health literacy could be helpful in improving patient activation in MS. Becoming activated not only involves increasing skills and confidence, but also knowledge. Some basic literacy skills are important to attain this knowledge. Greene et al. (2005) found that those with adequate health literacy levels had patient activation levels higher than those with inadequate or marginal health literacy levels. Although some efforts to overcome health literacy barriers have been underwhelming (e.g. Williams et al., 1998), other findings do suggest that increased health literacy may be helpful in self-management behaviors (Kim et al., 2004) and worthy of additional study. Administering a brief health literacy questionnaire such as the Test of Functional Health Literacy in Adults (Baker

et al., 1999) as part of the initial patient assessment could help identify patients who may need more education regarding the MS process and treatment. Another target for patient activation intervention may be MS-self efficacy. One example in the literature is Luszczyńska and Tyrburcy's (2008) self-efficacy intervention on exercise for cardiovascular and diabetes patients, which demonstrated moderate effects.

Finally, according to our findings, depression was also a key factor in patient activation. Depression is common and often goes untreated, especially in minorities (Gonzalez et al., 2010). Furthermore, the patient activation literature suggests that depressed individuals may be at increased risk of low activation, particularly when they belong to low SES. Addressing depression may be a key element to improving patient activation, especially given the availability of high-quality, effective depression care.

Conclusion

The results of this study provide additional insight into the individual factors that affect patient activation in persons living with MS. Although several interventions have successfully increased patient activation, it is helpful to know what other variables associated with patient activation could be targeted, especially in the MS population where multiple factors influence patient outcomes. Further research should examine the relationship between patient activation in MS and specific health outcomes using longitudinal designs to assess change over time.

Declaration of conflicting interests

Judith Hibbard is a stakeholder in and consultant to Insignia Health.

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