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# Health Literacy and Education As Mediators of Racial Disparities in Patient Activation Within an Elderly Patient Cohort

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# Abstract

The Patient Activation Measure (PAM) assesses facets of patient engagement to identify proactive health behaviors and is an important predictor of health outcomes. Health literacy and education are also important for patient participation and successful navigation of the health care system. Because health literacy, education and patient activation are associated with racial disparities, we sought to investigate whether health literacy and education would mediate racial differences in patient activation. Participants were 265 older adults who participated in a computer-based exercise interventional study. Health literacy was assessed using the Test of Functional Health Literacy in Adults (TOFHLA). Of 210 eligible participants, 72% self-identified as Black and 28% as White. In adjusted analyses, education and health literacy each significantly reduced racial differences in patient activation. These findings are especially important when considering emerging data on the significance of patient activation and new strategies to increase patient engagement.

# Keywords

Health literacy; education; patient activation; racial disparities

Empowering patients to participate actively in their health care is paramount for improved health care quality and clinical outcomes.<sup>1–4</sup> Hibbard et al. developed the Patient Activation Measure (PAM) to assess patient empowerment and distinguish between passive and

#### Conflict of interest

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proactive health behaviors.<sup>2</sup> Patients with lower PAM scores have been shown to have more symptoms and disabilities within a given illness, have less satisfaction with clinical care, and have less disease-specific knowledge compared with those with higher scores.<sup>5–7</sup> Furthermore, increases in patient activation scores over time have been correlated with improvements in medication adherence, self-management knowledge, health behaviors, and functional health.<sup>8</sup> Accordingly, it is important to foster environments where patients can successfully take an active role in their care to improve their health.<sup>9</sup>

Racial and ethnic disparities in patient activation may be an important determinant of racial and ethnic disparities in health outcomes. Hibbard et al. demonstrated that White subjects scored significantly higher on the PAM than Black subjects in both national and Medicaid samples.<sup>10</sup> Similarly, in a national survey, Cunningham et al. found racial and ethnic differences with patient activation among Blacks, Hispanics, and Whites.<sup>11</sup> Hispanic and Black subjects had significantly lower average scores than White subjects; only 24.8% of Hispanics were at the highest level of activation, compared with 39.5% of Blacks and 45.3% of Whites. Controlling for demographic and socioeconomic factors as well as health insurance status did not completely explain racial differences in patient activation.

Health literacy, defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions",<sup>12</sup> has been associated with numerous patient outcomes<sup>13–16</sup> and has been shown to be an important mediator of racial disparities in a variety of contexts.<sup>17–19</sup> An estimated 90 million U.S adults are thought to have limited health literacy which has large social and political implications given the association with poor health outcomes.<sup>16</sup> Both education and health literacy are strongly linked to racial disparities and health promotion;<sup>20</sup> however, the association of either of these two factors with patient activation are less well-described.<sup>21–23</sup>

Prior studies have not examined the role of health literacy or education in the relationship between race and patient activation. Thus, the objective of this study was to investigate whether differences in health literacy and education would mediate racial differences in patient activation.

# Methods

To study the association of health literacy and patient activation, we analyzed data collected at the baseline and 12-month visits of a randomized controlled trial to improve walking in older adults.<sup>24</sup> The institutional review board at Boston University Medical Campus approved the study.

### **Participants**

Participants were 265 older adults recruited from internal medicine and geriatric ambulatory care clinics at Boston Medical Center between April 2009 and September 2011. Community-dwelling adults who attended the clinics were aged 65 years and older, English speaking, inactive (not engaged in regular moderate-intensity or greater physical activity three or more days/week for at least 20 minutes/day over the previous six months),<sup>25</sup> free of

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any medical condition or disorder that would limit participation in moderate intensity physical activity (e.g., decompensated congestive heart failure, unstable angina, and vertigo) and stable on all medications for at least three months. Exclusion criteria included individuals who had cognitive impairment (Mini-Cog score < 2),<sup>26</sup> significant depressive symptoms (Patient Health Questionnaire [PHQ-9] score 16),<sup>27</sup> were at high risk of falls based on screener, had a timed maximal walking velocity of less than 0.5 m/s (< 0.2 m/s consistent with frailty),<sup>28,29</sup> or did not self-report Black or White race.

#### Data collection

Data were collected during face-to-face sessions in a private room using trained research personnel who administered structured research protocols. Participants who agreed to participate and passed the screening procedures were enrolled and completed the baseline assessment. This included sociodemographic information, co-morbidities, depressive symptoms (Patient Health Questionnaire-9 or PHQ-9),<sup>27</sup> cognitive status (Mini-Cog),<sup>26</sup> fitness and mobility (timed maximal walking velocity),<sup>28</sup> patient activation and health literacy. Participants completed additional assessments at two and 12 months with a different research assistant who was blinded to group assignment and findings from earlier data collection. Further details regarding the methods of this trial have been previously published.<sup>24</sup>

#### Variables of interest

**<u>Health literacy:</u>** Health literacy was assessed using the Test of Functional Health Literacy in Adults (TOFHLA).<sup>30</sup> A TOFHLA score cutoff of below 23 was used for low health literacy.<sup>31</sup>

**Patient activation:** Patient activation was assessed using the 13-item Patient Activation Measure (PAM) which has been validated for diverse patient populations in numerous healthcare settings.<sup>32–35</sup> Response categories for each item was strongly agree, agree, disagree, and strongly disagree. Responses were then transformed into a score between 0 and 100 with higher scores correlating with higher levels of patient activation.<sup>35</sup>

#### Statistical analysis

Given known discrepancies in health literacy and education correlations,<sup>20</sup> these two variables were examined separately. Four separate linear regression models were then fit, with continuous PAM score as the dependent variable and race as the independent variable, including the following sets of covariates: 1) core covariates only (clinic location, age, sex, co-morbidities, and PHQ-9 score); 2) core covariates plus education; 3) core covariates plus health literacy; and 4) core covariates, education, and health literacy. Model fit was summarized with the R<sup>2</sup> statistic; regression diagnostics including plots of residuals, residuals versus fitted values, and residuals versus quantiles were examined to assess appropriateness of the linear model. To assess possible mediation of race by education and health literacy, the Baron and Kenny approach was followed.<sup>36</sup> This approach involved examining three questions: 1) Is race correlated with PAM (from Model 1)? 2) Is race associated with education (Model 1a – not displayed) and health literacy (Model 1b – not displayed)? and 3) Are education and health literacy correlated with PAM, controlling for

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race (Models 2, 3, and 4)? To rule out moderation of the effect of race on PAM by education and health literacy, models including interaction terms between race and education and race and health literacy were also fit. Significant interaction terms would indicate possible moderation. As we were interested in examining models including two potential mediators (education and health literacy) together, Spearman correlations were examined to ensure that the two potential mediators were not highly correlated with each other. For each model, appropriateness of linear regression was examined graphically through plots of residuals, residuals versus fitted values, and residuals versus quantiles. A significance level of .05 was set for all analyses, and all analyses were conducted using SAS/STAT 9.3 of the SAS System for Windows 2002–2010 (SAS Institute Inc., Cary, North Carolina).

# Results

Of the two hundred and sixty-five participants who completed the Patient Activation Measure, fifteen who did not report having English as their primary language were excluded. An additional twenty-five participants were excluded due to answering "Strongly agree" to all PAM statements, which invalidates a participant's PAM score. Fifteen were excluded as they had reported a race other than Black or White, which left a final sample size of two hundred and ten. Of these participants (Table 1), the mean age at enrollment was  $71.3 \pm 5.5$ . 72% identified as Black, 28% as White and 59% were female. 23% of participants had not completed a high school education, and 42% had low health literacy. One third of participants were married at the time of enrollment, 56% had at least one co-morbidity, and 81% had no evidence of depression.

In the unadjusted results, there were significant racial differences across several variables. For instance, 54% of Blacks had low health literacy compared with 12% of Whites (p value < .01, Table 1). A lower proportion of Blacks were male and married compared with Whites. More Black participants also had a lower level of formal education and slower mean velocity walk times versus White participants. There were no racial differences with regards to age, number of co-morbidities, or depression severity. There was no racial variation in baseline PAM score.

The adjusted linear regression analyses are shown in Table 2. After controlling for age, sex, number of co-morbidities, PHQ-9 score, and clinic location, race was significantly different in patient activation with Blacks having lower PAM compared with Whites (Model 2;  $\beta$  (95% CI) for race = -4.57 (-8.57, -0.58)). With the introduction of either education (Model 3;  $\beta$  (95% CI) for race = -3.19 (-7.30, 0.92)) or health literacy (Model 4;  $\beta$  (95% CI) for race = -2.18 (-6.45, 2.09)), racial differences were no longer significant (p value = 0.13, 0.32 respectively). These findings were consistent (race p value = 0.41) with the addition of both education and health literacy. (Model 5,  $\beta$  (95% CI) for race = -1.79 (-6.11, 2.52)).

In Model 2, a significant association between race and PAM was demonstrated. This met the first criteria of the Baron and Kenny approach. In both the adjusted ordinal logistic regression with education as the dependent variable (Model 1a) and the adjusted logistic regression with health literacy as the dependent variable (Model 1b), there were significant associations with race, with Blacks having higher odds of a lower educational level

compared with Whites (OR: 4.13 [95% CI 2.05 to 8.35]) and higher odds of low literacy compared with Whites (OR: 14.15 [95% CI 5.15 to 38.87]), meeting the second criteria of the Baron and Kenny approach (full models not shown). In Models 3, 4, and 5, with the addition of education, health literacy, and both variables to the model, racial differences were attenuated compared with Model 2 (the beta estimates for race decreased, from  $\beta = -4.57$  in Model 2 to  $\beta = -1.79$  in Model 5), and race was no longer significant. This met the third and final criteria of the Baron and Kenny approach, supporting mediation by education and health literacy in the association between race and PAM. Additional models were executed that included interaction terms between race and the potential mediators of education and health literacy (results not shown). None of these interaction terms reached statistical significance so there was no evidence of moderation by education or literacy. To check for potential multi-collinearity between education and health literacy, Spearman correlations between the two variables were examined and found to be <0.40, indicating low correlation and justification for including both of the potential mediators in Model 5.

# Discussion

In this study, the relationship between race and patient activation was significantly mediated by health literacy and level of education. Indeed, when controlling for either of these factors, the effect of race was no longer significant. This study's findings are especially important when considering emerging data on the significance of patient activation and new strategies to increase patient engagement.<sup>37–39</sup>

As modern health care systems evolve, individuals are expected to make more complex health decisions and assume new roles in acquiring information to effectively manage their health conditions.<sup>12</sup> As health literacy is a shared function of a patient's education, culture, and language, healthcare providers must be sensitive to these specific factors when expecting patients to engage in care plans. For example, Bohanny et al. investigated the impact of health literacy on self-efficacy among patients with Type 2 diabetes.<sup>40</sup> Self-efficacy, or the confidence in one's capabilities to organize and deliver the course of action required to manage personal tasks is believed to be an important motivational factor for completing daily activities.<sup>41</sup> Limited health literacy was apparent in 24% of study participants and was a powerful contributor to poor self-efficacy along with diabetes education and employment status. Similarly, Macabasco-O'Connell et al. found that patients with symptomatic heart failure and limited health literacy had lower general heart failure knowledge, lower selfefficacy, and lower prevalence of self-care behaviors compared with those with adequate health literacy.<sup>42</sup> These studies affirm that although the relationship between education and health literacy remain complex, they both are key determinants of health.<sup>20</sup> Our findings were consistent with these conclusions which suggest that the combination of education status and higher health literacy may be important precursors to improved preventative and therapeutic self-management behavior. Accordingly, designing health and public health services with fewer educational and health literacy barriers should be paramount aims.

Traditionally, clinicians have found promoting patient engagement challenging, especially when tailoring effective approaches to an individual.<sup>9</sup> Racial disparities in patient activation in part may result from the "one size fits all" strategy when delivering relevant education

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during health care encounters. Patients must feel proficient in their abilities to care for themselves however diverse backgrounds necessitate different needs. It is already a known phenomenon that limited health literacy disproportionately affects disadvantaged populations such as racial minorities and those with limited education and income.<sup>43</sup> Our data reinforce the notion that health literacy is an important pathway that may mediate the link between education and racially-influenced perceptions of the health care system;<sup>44</sup> this could subsequently affect patient empowerment. Acknowledging differences in health literacy among patients is critical to effectively supporting people in their self-management roles—a hallmark of excellent patient-centered quality care.<sup>45</sup>

Hibbard et al. delineated the major domains of patient activation including self-management, collaboration with health care providers, maintaining function/prevention of declines, and accessing appropriate and high-quality care.<sup>1</sup> A focus on programs and interventions that increase patient competency in health behaviors may indeed be a potential mechanism for reducing racial disparities in patient activation.<sup>4</sup> Effective methods of education may include individual and/or peer group instruction, interactive services using information technology, and distribution of educational materials with dedicated follow-up and personal feedback.<sup>46–52</sup> For instance, Greiner et al. recently sought to improve screening rates for colorectal cancer (CRC) among a racially diverse sample of older adults cared for in urban safety-net clinics.<sup>52</sup> Patients who were randomized to computerized education programs specific to CRC screening had higher odds of completing CRC screening at 26 weeks post-intervention. In addition to educational efforts, the creation of supportive environments within the community and workplace may serve as sources of peer support and skill building to encourage healthy habits, ultimately increase activation, and reduce racial disparities.<sup>10</sup>

It is important to note that there are several limitations of this study. The study population consisted of elderly native English-speaking patients in the metro Boston area. Future research would be needed to evaluate the generalizability of our findings. Additionally, the exclusion of people with severe depression and cognitive impairment may have influenced the distribution of health literacy and patient activation in this cohort. Another limitation is related to the fact that health literacy and patient activation assessments occurred at an arbitrary point in participant's lives. As a result, we were unable to evaluate variation of these traits over time or to test the proper conceptual ordering of these variables. While discerning temporal relationships and interactions between health literacy, education, and patient activation across the lifespan was beyond the scope of the current project, such data could be quite informative. Lastly, although the TOFHLA is a widely used and validated health literacy measurement tool, it is not a comprehensive measure. The TOFHLA does not measure multiple domains of health literacy such as verbal communication, navigation, and self-care.

Despite these limitations, to our knowledge, this study is one of the first to examine the impact of health literacy and education on racial disparities in patient activation. Integrating patient activation in standard processes of health care is important to assure that all patients have the skills and tools to function adequately as decision makers.<sup>45</sup> Historically, patient providers have incorrectly assumed that limited health literacy is a function of patient deficit with an emphasis on individual acquisition of skills to better navigate the health care

system.<sup>53</sup> Research that has traditionally focused on describing observed differences in health outcomes should shift towards creating practical interventions that are suitable for patients at all levels of health literacy to effectively reduce health inequalities.<sup>54</sup>

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Table 1

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Baseline Characteristics by Race<sup>1</sup>

Variable	All (N=210)	Black (N=151)	White (N=59)	P-value
Gender				<0.01
Male	86 (41.0)	48 (31.8)	38 (64.4)	
Female	124 (59.0)	103 (68.2)	21 (35.6)	
Age, mean $\pm$ SD (years)	$71.3 \pm 5.5$	$71.0 \pm 5.5$	$71.9 \pm 5.5$	0.22
Age (years)				0.74
65-69	96 (45.7)	72 (47.7)	24 (40.7)	
70-74	59 (28.1)	42 (27.8)	17 (28.8)	
75–79	38 (18.1)	25 (16.6)	13 (22.0)	
80+	17 (8.1)	12 (7.9)	5 (8.5)	
Education				<0.01
< High School	48 (22.9)	42 (27.8)	6 (10.2)	
High School/GED	69 (32.9)	57 (37.7)	12 (20.3)	
> High School	93 (44.3)	52 (34.4)	41 (69.5)	
Marital status				<0.01
Married	72 (34.3)	40 (26.5)	32 (54.2)	
Widowed	47 (22.4)	42 (27.8)	5 (8.5)	
Separated	20 (9.5)	19 (12.6)	1 (1.7)	
Divorced	42 (20.0)	30 (19.9)	12 (20.3)	
Never Married	29 (13.8)	20 (13.2)	9 (15.3)	
Total # co-morbidities				0.10
0	92 (43.8)	60 (39.7)	32 (54.2)	
1	59 (28.1)	43 (28.5)	16 (27.1)	
2+	59 (28.1)	48 (31.8)	11 (18.6)	
PHQ-9 Depression Severity				0.07
None	170 (81.0)	118 (78.1)	52 (88.1)	
Mild	29 (13.8)	22 (14.6)	7 (11.9)	

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Variable	All (N=210)	Black (N=151)	White (N=59)	P-value
Moderate	11 (5.2)	11 (7.3)	0	
Mean velocity walk time $(m/s)^2$	$1.1 \pm 0.2$	$1.0 \pm 0.2$	$1.2 \pm 0.2$	<0.01
Test of Functional Health Literacy in Adults (TOFHLA score)				<0.01

Proportions listed as (percentages) and means listed ( $\pm$  SD)

High literacy (23–36) Low literacy (1–22)

Mean PAM score

 $2Mean \pm standard deviation$ 

0.07

 $64.8\pm11.6$ 52 (88.1)

 $61.5\pm11.8$ 

 $62.5 \pm 11.8$ 121 (57.6) 89 (42.4)

7 (11.9)

82 (54.3) 69 (45.7)

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Table 2

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Unadjusted and Adjust	ed Analyses for B	aseline	e PAM Score by R	ace/Et	hnicity <sup>1,2,3</sup>					
	MODEL 1: unadj	usted	MODEL 2: multivar no HL, no education	iable,	MODEL 3: multivari no HL, education	able,	MODEL 4: multivariable, HL, no education		MODEL 5: multivariable, HL, education	
	B (95% CI)**	Ъ	B (95% CI)	ч.	B (95% CI)	Ч	B (95% CI)	Ч	B (95% CI)	4
Intercept	64.83 (61.81, 67.85)		69.59 (64.50, 74.67)		70.82 (65.72, 75.93)		70.04 (65.03, 75.04)		70.85 (65.78, 75.92)	
<b>Race:</b> Black vs. White	-3.30 (-6.86, 0.27)	0.07	-4.57 (-8.57, -0.58)	0.03	-3.19 (-7.30, 0.92)	0.13	-2.18 (-6.45, 2.09)	0.32	-1.79 (-6.11, 2.52)	0.41
<b>Clinic location:</b> DOB vs. GIM Geriatrics vs. GIM			-4.05 (-8.82, 0.72) 3.04 (-2.79, 8.88)	0.02	-4.49 (-9.20, 0.22) 2.53 (-3.26, 8.31)	0.01	–3.85 (–8.54, 0.85) 2.79 (–2.95, 8.53)	0.02	-4.25 (-8.94, 0.44) 2.45 (-3.30, 8.19)	0.02
<b>Age:</b> 70–74 vs. 65–69 75–79 vs. 65–69 80+ vs. 65–69			-1.78 (-6.96, 3.41) -1.03 (-7.11, 5.06) -1.61 (-10.19, 6.98)	0.84	-1.66 (-6.76, 3.43) -0.84 (-6.83, 5.14) -0.99 (-9.48, 7.49)	0.87	-1.59 (-6.68, 3.51) -1.42 (-7.41, 4.57) -1.92 (-10.36, 6.53)	0.83	-1.55 (-6.61, 3.51) -1.17 (-7.13, 4.79) -1.35 (-9.79, 7.09)	0.87
<b>Sex:</b> Female vs. Male			-0.60 (-4.12, 2.93)	0.74	-1.03 (-4.51, 2.45)	0.56	-1.45 (-4.97, 2.07)	0.42	-1.54 (-5.04, 1.95)	0.39
Number of co-morbidities 1 vs. 0 2+ vs. 0			-2.39 (-7.06, 2.29) -2.85 (-7.66, 1.96)	0.29	-2.06 (-6.67, 2.54) -2.29 (-7.04, 2.46)	0.42	-1.72 (-6.35, 2.90) -2.08 (-6.85, 2.69)	0.52	-1.65 (-6.25, 2.95) -1.86 (-6.61, 2.89)	0.57
<b>PHQ-9</b> Mild vs. None Moderate vs. None			-2.38 (-8.06, 3.30) 2.16 (-6.71, 11.04)	0.49	-1.88 (-7.51, 3.75) 2.69 (-6.04, 11.43)	0.52	-1.49 (-7.12, 4.14) 2.23 (-6.49, 10.95)	0.66	-1.36 (-6.99, 4.27) 2.61 (-6.06, 11.29)	0.63
Health Literacy										

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0.05

 $-5.16 (-8.76, -1.57) < 0.01 \quad -3.73 (-7.52, 0.06)$ 

Low vs. High

Education

	MODEL 1: unadju	sted	MODEL 2: multivaria no HL, no education	ble,	MODEL 3: multivarial no HL, education	ble,	MODEL 4: multivariable, HL, no education		MODEL 5: multivariable, HL, education	
	B (95% CI)**	Р	B (95% CI)	Р	B (95% CI)	P	B (95% CI)	P	B (95% CI)	Р
<hs vs.="">HS HS vs. &gt;HS</hs>					-6.53 (-11.64, -1.42) -2.10 (-6.64, 2.45)	0.01			-5.02 (-10.42, 0.37) -1.53 (-6.10, 3.03)	0.09
Model R <sup>2</sup>	0.02		0.07		0.12		0.11		0.13	

Excluding 15 subjects with non-English native language, 25 subjects who responded "Strongly agree" to all 13 PAM questions, and 15 "other race" subjects (n=210)

 $^2\!P$  -values are global (from Type III F statistic for variable)

 $\mathcal{J}_{\text{Confidence intervals are Tukey-adjusted}}$ 

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