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# Factors Associated with Patient Activation in an Older Adult **Population with Functional Difficulties**

Kelly T. Gleason<sup>a</sup>, Elizabeth K. Tanner<sup>a,b</sup>, Cynthia M. Boyd<sup>b,c</sup>, Jane S. Saczvnski<sup>d</sup>. and Sarah L. Szanton<sup>a,c</sup>

<sup>a</sup>School of Nursing, Johns Hopkins University, Baltimore, MD USA

bSchool of Medicine, Johns Hopkins University, Baltimore, MD USA

<sup>c</sup>School of Public Health, Johns Hopkins University, Baltimore, MD USA

dSchool of Medicine, University of Massachusetts, Worcester, MA 01655

#### Abstract

Objective—Patient activation, the patient's knowledge, skill, and confidence to manage his or her health, is an important indicator of future health and use of health care resources. Understanding factors associated with patient activation in an older population with functional difficulties may inform care in this population. This study aimed to determine whether patient activation is associated with depression, chronic conditions, family support, difficulties with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), hospitalizations, education, and financial strain.

**Methods**—(N=277), We administered surveys measuring patient activation, financial strain, depressive symptoms, family support, and chronic conditions to an older adult population. We tested association through multivariate linear regressions controlling for race, sex, and age.

**Results**—Patient activation is significantly (p<0.05), positively associated with family support and self-rated overall health, and significantly (p<0.05), negatively associated with depressive symptoms and difficulties with ADLs and IADLs. We found no association between patient activation and financial stress, hospitalizations, and education.

Conclusions—Older age, depressive symptoms, and difficulties with ADLs and IADLs were associated with decreased patient activation.

Corresponding author at: Kelly T. Gleason, 525 N Wolfe Street, Baltimore, MD 21205; Telephone: (708)334-4876; kgleaso2@jhmi.edu.

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**Practice Implications**—Developing interventions tailored to older adults' level of patient activation has the potential to improve outcomes for this population.

## 1. Introduction

It is increasingly recognized that patients' choices play an essential role in health outcomes. Multiple studies have confirmed that patients who are engaged in their healthcare better manage their health and achieve improved health outcomes. This crucial patient role in improving health outcomes has recently been acknowledged in the Affordable Care Act. As patients are expected to engage in their care and take ownership of complex selfmanagement tasks, assessing a patient's capacity and willingness to be involved in managing their health is essential. "Patient activation" is defined as the patient's knowledge, skill, and confidence to manage his or her health. Understanding patient activation and its interplay with the largely unchangeable social determinants of health, is crucial to decreasing healthcare utilization and costs. 3–5

Hibbard and colleagues developed the Patient Activation Measure (PAM) to assess patients' abilities to manage their own health.<sup>6</sup> The goal of the PAM is to identify an individual's stage of activation in order to provide support that is congruent with his or her level of activation while maintaining autonomy, focusing on adherence, and ultimately increasing activation. While PAM is similar to other related constructs, it is a global construct and therefore different from other related assessments that focus on a single behavior at a time.<sup>7</sup> PAM includes self-efficacy, behavior, and knowledge, and is thus predictive of a diverse range of health behaviors.<sup>8</sup>

Patient activation is a significant predictor of healthcare utilization, patient outcomes and health behaviors. <sup>9,10</sup> Patient activation has been associated with positive health outcomes among adults with chronic illnesses. <sup>4,5</sup> Findings from recent studies suggest that patients with a higher activation are more likely to adhere to medical regimens and effectively manage chronic medical conditions, and less likely to be hospitalized. <sup>11–13</sup> Limited prior studies of patient activation in older adults (individuals age 65 and older) indicate that higher PAM activation scores are associated with higher functional status, health care quality, and adherence in older adults. <sup>14</sup> The few studies that examined PAM in older adults have focused on individuals with specific chronic diseases but not necessarily functional difficulties. <sup>14–16</sup>

Older adults with functional difficulties use notably more healthcare resources than those without functional difficulties.<sup>17</sup> People with chronic conditions and functional difficulties incur three times as much cost on overall average annual health expenditures than people with only chronic conditions.<sup>17</sup> Functional difficulties are associated with diminished self-efficacy and high healthcare costs. Estimates suggest that approximately 30% of older adults are living with functional difficulties and the prevalence will increase with the aging of the baby boomers.<sup>18</sup> Also, functional difficulties are higher in those of lower socioeconomic status.<sup>19</sup> Low socioeconomic status is associated with poor health.<sup>20,21</sup> It thus crucial to investigate patient activation in a low-income older adult population with functional difficulties, which uses substantially more healthcare resources than the general population.

Understanding patient activation in this population has the potential to assist healthcare care providers effectively tailor self-management support according to the patient's needs. However, patient activation remains understudied in the older adult population.

The PAM can be used as a tool to customize the delivery of care for individuals with complex health needs. Assessing patient activation and tailoring care according to level of activation may have the potential to improve immediate health problems and reduce utilization of resources in older adults with functional difficulties. 10,12 An understanding of contextual factors associated with patient activation is required to inform providers' treatment strategies. 22,23 In this way, we conceptualized patient activation as a matter of patient resilience. We were guided by the Society to Cells Resilience framework<sup>24</sup> which emphasizes that individual resilience is interdependent with socioecologic resilience factors such as financial security, family support, education level, person (age, sex, race, and quality of life), and health factors (difficulties with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), depression, self-rated health, number of chronic conditions, and number of past hospitalizations). We hypothesized that higher quality of life, education level, financial security, and family support would be associated with higher PAM. We further hypothesized that difficulties with ADLs and IADLs, depression, lower self-rated health, number of chronic conditions, and number of past hospitalizations would be associated with lower PAM.

Therefore, the aim of this study is to determine whether patient activation is associated with depression, number of chronic conditions, family support, difficulties with ADLs and IADLs, number of hospitalizations, educational level, and financial strain in a low-income, older adult population with functional difficulties.

## 2. Methods

To test these aims, we used a study population of older adults enrolled in the study Community Aging in Place, Advancing Better Living for Elders (CAPABLE).

We conducted a cross-sectional, descriptive study of baseline data collected from the CAPABLE study. The CAPABLE study is a longitudinal randomized controlled trial that aims to reduce disability among older adults. Johns Hopkins Institutional Review board approved the study and all participants provided consent according to the approved protocol. An in-depth description of the CAPABLE study protocol has been previously published.<sup>25</sup>

Participants were recruited through a community effort with partners including collaboration with the Baltimore Meals on Wheels, the Baltimore City Health Department, the Baltimore Housing Department Green and Healthy Homes Initiative, Area Senior Centers, and the National Civilian Conservation Corps. Targeted direct mailing recruitment was also conducted by sending study brochures to specific Baltimore City zip codes of high poverty with a high proportion of older adults. When potential participants followed up, research staff members telephone screened for eligibility. If the participant was eligible, an in-home baseline interview was scheduled within 10 days

of the call. During the in-home interview, the research staff obtained written consent and conducted baseline data collection.

#### 2.1 CAPABLE enrollment process and criteria

Eligibility to be enrolled in the CAPABLE study included 65 years of age and older, reported income of 200% or less of the Federal Poverty Level (\$22,980 or less for a household of one), ability to stand with or without assistance, reported difficulties with at least one ADL (bathing, grooming, transferring, toileting, eating, walking across a small room), living in a house (not apartment), and normal cognition (Mini-Mental State Examination score greater than or equal to 24). Participants were excluded if they were receiving skilled nursing or occupational therapy home care, had a terminal diagnosis (<1 year expected diagnosis), were receiving active cancer treatment, or hospitalized more than three times in the prior 12 months.

#### 2.2 Measurement of variables

PAM was used to assess knowledge, confidence, and skill for managing health conditions in study participants. It is typically used with people who are managing chronic diseases while living in community settings and is both reliable and valid. <sup>7,26</sup> It is a unidimensional measure that consists of 13 statements measuring belief that taking an active role is important, confidence and knowledge to take action, taking action, and staying the course under stress, It includes statements such as: "When all is said and done, I am the person who is responsible for managing my health condition," "I know what each of my prescribed medications do," "I know how to prevent further programs with my health condition," and "I have been able to maintain lifestyle changes, like eating right or exercising." Participants are asked to rate their level of agreement with the statements using a 4-point Likert-type scale. The PAM is scored by summing the items and normalizing the raw score to the activation score on a 100-point scale.<sup>6</sup> PAM scores a patient's activation on a scale of 0 to 100. A higher score is indicative of a higher level of activation. There are four stages of PAM: 1) May not believe that the patient role is important, 2) Lacks confidence and knowledge to take action, 3) Beginning to take action, and 4) Has taken action but has difficulties maintaining behaviors over time.

Information on basic characteristics including race, age, gender, whether the participant lived alone, and education level was collected through the Sociodemographic Questionnaire, which relies on self-report. Data regarding prior hospitalizations was also collected through self-report.

Problems with ADLs were ascertained by questioning patients on whether they had difficulties in performing one or more of eight essential ADLs: bathing, dressing their upper or lower bodies, getting in and out of bed, eating, toileting, walking, and grooming. <sup>27</sup> Problems with IADLs were determined by asking patients whether they had difficulties in performing one or more of eight essential IADLs: making meals, doing housework, shopping, using the telephone, laundry, traveling independently, taking medications, and managing money. <sup>28</sup> For the measurement of both ADLs and IADLs, functioning on each task is classified from 0 to 2 depending on whether the person did not have difficulties in the

prior month and did not need help (0), had not needed help but did have difficulties (2), or did need help regardless od difficulties (2). A summary disability score ranges from 0 to 16 for both ADLs and IADLs. Higher scores were indicative of a higher level of difficulties or different domains of difficulties.

The Patient Health Questionnaire 9 (PHQ 9) was used to measure depression. The PHQ-9 has been validated for diagnosing depression and determining the level of severity of depression in the older adult population.<sup>29</sup> It asks participants to state on a 4-point Likert-type scales how often they have been displaying certain signs and symptoms of depression over the past 2 weeks.<sup>30</sup> Participants were also asked whether they have been told that they have the diagnosis of depression, which served as an additional measure of depression.

Quality of life was measured using the EuroQOL EQ-5D. The EQ-5D measures patients on five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has three levels: no problems, some problems, and extreme problems. For example, to assess mobility the participant chooses between the following responses: 'I have no problems with walking', 'I have some problems with walking', or 'I am confined to bed' to the question "Which one applies to your health today?" A higher score is associated with a lower quality of life. It also asks participants to indicate on a scale of 0 to 100 how their health state is today; a score of 100 indicates that the participant is in the best state of health imaginable.

Financial strain was measured using the Financial Strain Instrument<sup>32</sup> which provides a score for participants using a 4-point Likert-type scale and includes the following 3 questions: 1) How often does it happen that you (and your spouse) do not have enough money to afford meeting monthly payments on your bills? 2) How often does it happen that you (and your spouse) do not have enough money to afford the kind of medical care you (and your spouse) should have? 3) How often does it happen that you (and your spouse) do not have enough money to afford the kind of food you (and your spouse) should have? Participants were asked to select one of the following responses: never, once in a while, fairly often, or very often, and a higher score is indicative of increased financial strain. The Financial Strain Instrument includes a fourth question: In general, how do your finances usually work at the end of the month? Do you find that you usually end up with some money left over, just enough to make ends meet, or not enough money to make ends meet? This fourth question is scored separately.

Participants were asked if they had been diagnosed with the following chronic conditions: hypertension, arthritis, cholesterol, diabetes, cancer, heart disease, and depression.

The Family Support Scale, a validated instrument ( $\alpha$ >0.7), measured satisfaction with family support.<sup>33,34</sup> It consists of 13 statements in which participants are asked to respond with agree, disagree, or not applicable to statements about family support provided in managing chronic conditions, such as "When I do not feel well, I have family members who are able to offer me encouragement."

## 2.3 Statistical Analyses

The statistical software STATA, version 14.0 (StataCorp, College Station, TX), was used for all analyses. Model assumptions were checked before statistical analyses. Descriptive statistics were calculated for all variables included in the analysis to examine means, standard deviations, shapes of distributions for continuous variables, and frequencies for categorical variables. No imputation of missing data was performed, given the low overall number of missing values. The distribution of the study population's PAM scores among the four stages was calculated. The PAM score on the 100-point scale was treated as a continuous variable and used in the bivariate and multivariate analyses. PAM was treated as the dependent variable in all analyses. All other variables were treated as independent variables. Bivariate linear regressions were used to assess the relationship between PAM and PHQ 9, financial strain, education level, family support, comorbidities, difficulties with ADLs and IADLs, hospitalization in the past year, number of hospitalizations in the past year, gender, age, race, living alone, and the EQ-5D health scale. We then estimated separate multivariate linear regression models for each of the characteristics adjusting for race, sex, and age. P<0.05 was considered significant in all analyses.

## 3. Results

The study population, described in Table I, included 277 participants. The participants were on average 76(±8) years old, and predominantly female and African American. Participants enrolled in the study reported an average of four diagnosed chronic conditions out of seven specific listed conditions. Half of the participants lived alone. 85% of participants did not receive above a high school or general educational development (GED) level of education. A third were hospitalized in the last year. The participants' PAM scores had an overall normal distribution with the majority of the participants (41%) categorized in stage III of PAM, "Beginning to take action" (Table II).

Bivariate and multivariate analysis results are described in Table III. Older age was significantly associated (P<0.05) with to lower patient activation. No relationship was found between PAM and sex or race. Lower health-related quality of life was associated with a lower level of patient activation (B=-2.4, p<0.05). Education level, the total financial strain score and finances at the end of the month not significantly associated with patient activation. Higher family support was significantly associated with a higher level of patient activation in multivariate analyses (B=0.84, p<0.05).

Lower patient activation was associated with difficulties in performing ADLs (B=1.14, p<0.05) and IADLs (B=-1.3, p<0.05). Symptoms of depression were negatively associated with patient activation in both males and females (B=-0.9, p<0.05); however, the strength of the relationship differed for males and females. Females reported more symptoms of depression than males, but symptoms of depression had a stronger association with PAM scores in males compared to females. Gender was a significant (p<0.05) effect modifier of symptoms of depression's association with PAM. Depression diagnosed by a health care provider (self-report) was not significantly related to PAM. Participants who rated themselves closer to their "best imaginable health state" on the EQ-5D health scale had high

levels of patient activation (B=0.14, p<0.05). Number of chronic conditions, and number of hospitalizations in the past year were not significantly related to PAM.

## 4. Discussion and Conclusion

#### 4.1 Discussion

In this study of 277 older adults with functional difficulties, our hypotheses that a higher quality of life and family support are associated with higher patient activation were supported. This finding shows that patient activation and family support are intertwined, which emphasizes the importance of family-centered care. Less than 50% of the participants reported a high level of family support, and half of the study population lived alone. Family support may be an unmet need in this population. Living alone had a significant, positive association with patient activation; this finding indicates that older adults who live alone may be more likely to be activated. Our hypotheses that financial security and education level were associated with patient activation were not supported. This unexpected finding reinforces the importance of providers approaching patients without assumptions about their motivation to manage care based on their race or socioeconomic status.

Difficulties with ADLs and IADLs, symptoms of depression, and lower self-rated health were associated with decreased patient activation, which are expected findings that support our hypotheses. The inverse association between functional difficulties and patient activation has been documented in previous studies. <sup>26</sup> The lack of association between the diagnosis of depression and patient activation is interesting in consideration of the significant association between symptoms of depression and patient activation. This difference may indicate that older adults with diagnosed depression sought medical care and are receiving treatment for depression, while those with the symptoms of depression may have undiagnosed depression and thus experience a negative impact on their patient activation. The association between depressive symptoms and patient activation corroborates findings from previous research. <sup>7,36</sup> Number of chronic conditions was not found to be predictive of patient activation, which agrees with previous studies' findings. <sup>14,26</sup> The inverse, though nonsignificant, association between past hospitalizations and patient activation is in line with previous findings of an association between low PAM scores and a higher number of hospitalizations. <sup>11</sup>

Age was inversely associated with patient activation. Considering older adults use substantially more healthcare resources than other age groups, this association is essential for healthcare providers to take into account. Race was not associated with level of patient activation. These findings conflict with previous studies' findings that whites were more likely to have high levels of patient activation. 8,37

The strength of the findings must be considered in relation to its limitations. The findings of this study are limited by the cross-sectional nature of the data. A causal relationship between the variables examined and patient activation cannot be inferred since the data was only collected at one time point. The sample also consists of participants who were willing to participate in a longitudinal study, therefore, they may be more activated than the general

population. It is also a predominantly female and African American sample. However, since females and African Americans are commonly underrepresented in study samples, we believe it is a strength that these populations are adequately represented. The strengths of this study are that it examines older adults with functional difficulties, a particularly important and heretofore frequently ignored population in which to understand activation.

#### 4.2 Conclusion

In our examination of 277 older adults with functional difficulties, there was a higher level of patient activation among older adults who had higher self-rated health and quality of life, increased family support, lived alone, were relatively younger, and had fewer depressive symptoms and functional difficulties. Understanding that older adults may have lower activation than middle aged adults is important for clinicians to consider, since this population may require additional coaching to improve outcomes. The inverse relationship of difficulties with ADLs and IADLs highlights the importance of both assessing and addressing difficulties with ADLs and IADLs. Longitudinal studies are needed to determine if interventions that decrease functional difficulties result in increased patient activation. Further research is needed to determine how patient activation can be used as a clinical tool to guide care in older adults.

## 4.3 Practice Implications

These findings have important implications for providers. Previous research has shown that patients who receive coaching specific to their level of activation improve in their ability to manage disease and have improved health outcomes.<sup>3</sup> Patient activation is responsive to interventions and is modifiable. Understanding patient activation in older adults with functional difficulties and developing interventions tailored to older adults' level of patient activation has potential to improve outcomes and decrease costs in this patient population. As the proportion of older people in the US population grows, it is important to understand patient activation among this population at high risk for poor health outcomes. The lack of relationship of patient activation and race, education level and financial strain is encouraging, and should therefore not be taken into account when clinicians assess the role patients will take in managing their own health. Previous research suggests that patient activation is a modifiable and important factor for determining chronic disease outcomes.<sup>37</sup> The participants in this study are part of a well-defined cohort that is taking part in a policyrelevant study, which will evaluate healthcare utilization.<sup>25</sup> Our current study may help clinicians approach patient activation conversations with older adults with functional difficulties.

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Table 1
Basic characteristics and summarized variable scores (n=277).

Characteristics	X7-1
Characteristics	Value
Age [mean (SD), range]	76 (8), 65–100
Female [n (%)]	240 (87%)
Race [n (%)]	
Black	236 (85%)
White	40 (14%)
Asian	1 (0.4%)
Education [n (%)]	
<high school<="" td=""><td>89 (32%)</td></high>	89 (32%)
High school or GED	144 (52%)
Bachelor's degree	26 (9%)
>Bachelor's Degree	17 (6%)
Difficulties with ADLs [mean (SD)]	4 <sup>14</sup>
Difficulties with IADLs [mean (SD)]	6 (4)
PHQ 9 [mean (SD)]	7 (5)
Diagnosis of Depression [n(%)]	66 (24%)
EuroQOL [mean (SD)]	9(1)
EuroQOL Health Scale [mean (SD)]	64 (21)
Financial Strain [mean (SD)]	3 (2)
Increased financial security at end of month [mean (SD)]	0.8(0.7)
Chronic Conditions [mean (SD)]	4(1)
Number of hospitalizations past year [mean (SD)]	1.5 (0.6)
Hospitalization in prior year [n (%)]	89 (32%)
Family Support [mean (SD)]	10 (5)
Live alone [n (%)]	139 (50%)

Table 2

# Distribution of PAM Scores by Stage.

PAM Scores by stages (n=277)	
PAM Stage	Value [n(%)]
I: May not yet believe that the patient role is important (PAM score of 47 or lower)	33 (12%)
II: Lacks confidence and knowledge to take action (PAM score of 47.1 to 55.1)	36 (20%)
III: Beginning to take action (PAM score of 55.2 to 67)	112 (41%)
IV: Has difficulties maintaining behaviors over time (PAM score of 67.1 or above)	75 (27%)

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Table 3

Linear Regression Results: Correlates of Increased PAM score (n=277).

	Bivariate Analyses	ılyses		Multivariate Analyses adjusted for age, sex, and race	s adjusted for age	, sex, and race
	B (SE)	d	R2	B (SE)	P	R2
Age	-0.35 (0.11)	0.002	0.03	-0.35 (0.1)	0.002	0.04
Sex	0.3 (2.6)	6.0	0.00	0.93 (2.7)	0.73	0.04
Race	-1.19 (2.4)	0.62	600000	-1.3 (2.4)	0.58	0.04
School above high school/GED completed	1.7 (1)	60.0	0.01	1.1(1)	027	0.04
Difficulties with ADLs	-1.1 (0.3)	0.000	9.05	-1 (0.3)	0.000	80.0
Difficulties with IADLs	-1.3 (0.2)	0.000	0.12	-1.2 (0.2)	0.000	0.14
6 ОНА	-0.9 (0.16)	0.000	0.1	-1 (0.16)	0.000	0.16
Diagnosis of depression	-2.4 (2.1)	0.24	0.005	-3 (2)	0.14	0.04
EuroQOL	-2.4 (0.6)	0.000	90.0	-2.5 (0.6)	0.000	60.0
EuroQol health scale	0.12 (0.04)	9000	0.03	0.12 (0.04)	0.004	90.0
Financial Strain	-0.53 (0.4)	800.0	0.0033	-0.78 (0.4)	0.03	0.05
Increased financial security at end of month	1.3 (1.2)	0.3	0.004	1.6 (1.2)	0.2	0.04
Number of chronic conditions	56 (0.6)	0.36	0.003	-0.63 (0.6)	0.3	0.04
Number of hospitalizations past year	55 (2.5)	8.0	0.0006	-1.7 (2.5)	0.49	90.0
Hospitalization past year	-2.6 (1.9)	0.17	0.0069	-2.0 (1.9)	0.3	0.04
Increased family support	0.42 (0.2)	0.02	0.02	0.5 (0.2)	0.007	0.07
Live alone	4.9 (1.7)	90000	0.02	4.6 (1.8)	0.01	0.05