Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later?

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Abstract

Patient activation is an important predictor of health outcomes and health care usage, yet we do not know how enduring the benefits of greater patient activation are. This study uses a large panel survey of people with chronic conditions (n = 4,865) to examine whether a baseline patient activation measure predicts outcomes 4 years later, and whether changes in patient activation measure scores are associated with changes in outcomes. The findings indicate that the benefits of health activation are enduring, yielding benefits in the form of better self-management, improved functioning, and lower use of costly health care services over time. Furthermore, the findings indicate that when activation levels change, many outcomes change in the same direction. Patient activation seems to be an important and modifiable factor for influencing chronic disease outcomes; health care delivery systems can use this information to personalize and improve care.

Keywords

patient activation, patient engagement, population health

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Patient engagement and patient activation have been referred to as "the blockbuster drug of the century" (Dentzer, 2013). The degree to which this turns out to be true is yet to be determined. However, the statement emerges from the realization that patients themselves, through their own actions and choices, determine to a large extent their need for care and health care outcomes. While the importance of the patient role has largely been ignored in earlier health reform efforts, it is now a major focus of health policy efforts, and is included in many elements of the Affordable Care Act, which aim to improve care, improve outcomes, and reduce costs (U.S. Department of Health and Human Services, n.d.).

To appropriately inform policy in this area we need to know how changeable activation is, and what an investment in patient engagement yields. In this study, we build on previous research to begin laying a foundation for answering these questions.

Background

Patient activation is defined as having the knowledge, skill, and confidence to manage one's health and health care. It is most commonly measured using the patient activation measure (PAM), a 13-item scale that has strong psychometric properties (Hibbard, Mahoney, Stockard, & Tusler, 2005). Patient engagement, on the other hand, is less well defined, but is often understood to be the activities and interventions that are used to support increased activation in patients and consumers (Hibbard & Greene, 2013).

A growing body of research that quantifies patient activation indicates that it is a significant predictor of most health behaviors, many clinical indicators, and some costly service utilization such as emergency department use and hospitalizations (Hibbard & Greene, 2013; Hibbard, Greene, & Overton, 2013). The PAM scale measures a latent construct—likely reflecting an individual's overall self-concept as a manager of his or her own health. This self-concept, reflected by the totality of one's responses to the individual items, may not be consciously recognized on the part of the patient. However, altogether, the PAM scale reveals one's understanding of his or her role in the care process and how competent one feels in taking on this role.

This notion that the PAM is tapping into an underlying concept of being a self-manager of one's health helps explain why the measure is predictive of a wide range of health behaviors. For example, higher activated patients are more likely to adhere to medical regimens, to engage in regular exercise, and maintain a healthy diet (Fowles et al., 2009; Hibbard et al., 2005; Mosen et al., 2007). Higher activated patients are also more likely to seek out health information on their own, to more effectively self-manage chronic conditions, and to maintain a healthy weight, than are less activated patients (Fowles et al., 2009; Hibbard, Mahoney, Stock, & Tusler, 2007; Hibbard & Tusler, 2007; Mosen et al., 2007; Remmers et al., 2009). The more proactive role that higher activated patients assume with regard to their health, translates into better health outcomes and better use of health care resources. For example, higher activated patients are more likely to have blood pressure, cholesterol, and hemoglobin A1c in a normal range than are less activated patients (Greene & Hibbard, 2012; Marshall et al., 2013; Remmers et al., 2009). They are more likely to get preventive health screenings, and to

follow through on their physical therapy regimens after surgery (Greene & Hibbard, 2012; Skolasky, Mackenzie, Wegener, & Riley, 2008). At the same time less activated patients are more likely to be hospitalized, to use the emergency department, and almost twice as likely to be readmitted to the hospital within 30 days of discharge as are higher activated patients (Begum, Donald, Ozolins, & Dower, 2011; Greene, Hibbard, Sacks, & Overton, 2013; Remmers et al., 2009). These findings hold true even after controlling for the effects of an individual's socioeconomic status, insurance status, and health status. The studies have been conducted in a variety of settings, among different patient populations, including disadvantaged or low-income, racially diverse populations.

Finally, there are a growing number of studies that evaluate the impact of interventions designed to increase patient activation. Generally, these studies show that targeted interventions can increase activation levels in patients and often result in improved behaviors and clinical outcomes (Deen et al., 2012; Deen, Lu, Rothstein, Santana, & Gold, 2011; Frosch, Rincon, Ochoa, & Mangione, 2010). These studies include web-based interventions, coaching interventions, clinic-based and community-based interventions (Deen et al., 2012; Kangovi et al., 2014; Lawson et al., 2013; Lorig et al., 2010; Lorig, Ritter, Villa, & Armas, 2009; Nagykaldi, Aspy, Chou, & Mold, 2012; Shively et al., 2013; Solomon, Wagner, & Goes, 2012; Terry, Fowles, Xi, & Harvey, 2011).

Conceptual Framework

The research to date indicates that patient activation is an important determinant of health and health care usage. Because it is changeable, we can design interventions to increase it. However, in our attempt to answer the policy question, "Is this something worth investing in," we need to first answer the question how enduring are the benefits of patient activation over time? One hypothesis is that once people gain knowledge, skill, and confidence they will retain those assets and use them to meet the different challenges that emerge over time: just like learning to ride a bike or learning to swim, the skills are enduring. A 4-year follow-up is longer than any other study to date, and it is a sufficiently long time interval to explore whether the level of activation changes over time and whether the benefits of being more activated persist over time. The benefits of greater activation likely operate through behaviors. When one is consistently proactive about one's health, the advantages may accumulate over time. For example, being persistent in engaging in effective self-management may avert acute crises, and ultimately reduce the need for emergency department visits and/or hospitalizations. The 4-year time interval used in this study was part of the design for the Aligning Forces for Quality (AF4Q) evaluation study. We take advantage of this long follow-up to assess how long the benefits of greater activation persist.

New Contribution

In this study, we build on this earlier research, which has largely been cross-sectional, observational studies. We assess how well a PAM score, measured at baseline, predicts

outcomes approximately 4 years later using a large panel of community-dwelling individuals who have at least one chronic illness. We also examine how much individuals' PAM scores change in that period of time, and the degree to which changes in PAM scores predict changes in outcomes. This study represents the longest time period a panel of patients has been followed to observe whether baseline PAM scores are predictive of subsequent outcomes. The findings from this study help determine the durability of the benefits of greater patient activation.

Method

Data

This study used a large panel survey of people with chronic conditions to examine whether baseline PAM predicts outcomes 4 years later, and whether a change in PAM was associated with a change in outcomes. The survey was conducted as a part of the evaluation for the AF4Q program (Scanlon et al., 2012), which is the Robert Wood Johnson Foundation's signature initiative to improve health care quality in 16 communities around the country.

The first wave of the survey, completed in August 2008, was a random-digit-dial survey of chronically ill adults (18 years or older) from the 14 initial AF4Q communities, as well a comparison group sampled from the rest of the country (herein, the first wave). All survey respondents had visited health care professionals during the previous 2 years for the care of one or more of the following chronic conditions: diabetes, hypertension, asthma, chronic heart disease, or depression. The response rate for the baseline survey was 27.6% based on the American Association of Public Opinion Research standard and 45.8% based on the Council of American Survey Research Organizations standard. First-wave respondents were resurveyed in a second wave, which was completed in November 2012. The panel response rate was 63.3%. A total of 4,865 people completed both waves of the survey.

Variables

The key independent variable in the study is the patient activation measure or PAM. The PAM measures one's knowledge, confidence, and skill for managing health and health care. It is made up of 13 statements about managing one's health, such as "I am confident that I can tell a doctor my concerns, even when he or she does not ask," which respondents answer on a 4-point Likert-type scale (Hibbard et al., 2005). The items are summed and normalized to a 100-point scale, with higher scores reflecting higher levels of activation. The activation spectrum has often been divided into four levels: from passive recipient of care (Level 1) to highly proactive about one's health (Level 4).

The study examines outcomes related to self-management of chronic illness (medication adherence, self-management knowledge, and getting recommended diabetes care), general health behaviors, functional health, and costly utilization (Hibbard et al., 2007). The measures are described below.

Medication Adherence Index. A series of questions asked the respondents how often they were able to take the recommended medications for their chronic conditions in the past month (e.g., How often were you able to take your heart medication(s) as your doctor has recommended? This means you took the recommended doses at the right time). Respondents answered on a 5-point scale from 1 (*never*) to 5 (*always*). For respondents who had multiple chronic conditions, we computed the average score across all medication adherence questions for that individual (range = 1-5).

Self-Management Knowledge Index. Respondents with diabetes and heart disease were asked if they knew their recommended cholesterol level (*yes* = 1 or *no* = 0), and those with hypertension were also asked if they knew the blood pressure level recommended by their doctors. A respondent's knowledge score was the average across all relevant responses (range = 0-1).

Recommended Diabetes Care Index. We examined whether the respondents had received recommended diabetes care during the past 12 months, including four important components: cholesterol level test, hemoglobin A1c test, eye exam, and foot exam. For each respondent with diabetes, we calculate the average of the four yes/no indicators (range = 0-1).

Health Behaviors Index. Health behaviors were captured by four items: the maintenance of low-fat diet, participating in regular exercise, reading food labels in grocery stores, and eating 5 servings of fruits/vegetables every day. Each of these items used a 4-point Likert-type scale, and for each respondent, we calculated the average score, with a higher score indicating healthier behaviors (range = 1-4).

Functional Health Index. Three items captured how the respondents' health problems limit physical activities, doing daily work, and social activities. All 3 items were measured on a 5-point Likert-type scale (1 = *not at all limiting* to 5 = *could not do activity*) and an average score across the three items was calculated for each respondent (range = 1-5).

Costly Health Care Utilization. The survey asked respondents whether they had visited an emergency department and whether they had been hospitalized during the past 12 months. We created a dichotomous measure of use for each setting (where 1 = *any use*) and a separate count variable for each setting (e.g., 3 = *three hospitalizations in the past 12 months*).

Analytic Approach

We initially examined the demographic (gender, age, race/ethnicity, education, poverty status, insurance type) and health (chronic conditions and patient activation) characteristics of the sample. We then examined the extent to which these characteristics were related to baseline PAM score and change in PAM from baseline to follow-up 4 years later.

Next, we conducted bivariate analyses examining the relationship between PAM level and the nine outcomes. We estimated cross-sectional relationships between PAM and the nine outcomes using the first wave of the survey, and then estimated the relationships between the first-wave PAM scores with the second-wave outcomes. We then estimated separate multivariate regression models for each of the outcomes on PAM, controlling for the demographic and health characteristics listed above. The first seven regressions used the cross-sectional data (first wave) and the second set of seven regressions used the longitudinal data.

Finally, we examined the how changes in PAM levels were related to changes in the health outcomes. We examined the bivariate correlations for change in PAM and change in outcomes. Then, we developed individual-level, fixed-effects regression models for each outcome variable that controlled for individual factors that can change over time (e.g., insurance type, chronic conditions) and confounding factors that do not change over time for an individual (e.g., gender).

It is important to note that a change in PAM over the 4-year period could have been influenced by the Robert Wood Johnson's AF4Q programs, which aimed in part to improve patient engagement. However, we did not observe significantly greater increases in activation in the AF4Q communities compared with the national comparison. Therefore, the study is conceptualized and analyzed as an observational study.

Results

Table 1 presents the characteristics of the panel. Respondents were mostly women (68%), older than 50 years old (81%), White (65%) or African American (24%), and without a college degree (68%). The most common chronic illnesses were hypertension (66%) followed by diabetes (29%), depression (27%), asthma (17%), and heart disease (16%). The average activation score at baseline was 64.3, which is Activation Level 3 on a scale from 1 (*lowest level*) to 4 (*highest level*). At baseline, patient activation levels were higher for Whites, college graduates, those above the poverty threshold, and those with private insurance coverage, which is consistent with prior research (Hibbard & Cunningham, 2008; Hibbard et al., 2008).

Changes in Patient Activation

Over 4 years, the average change in activation score was 2.8 points (Table 1), which is notable since a gain of 3 points in activation scores has been linked with improvements in multiple health behaviors (Fowles et al., 2009). The greatest changes in activation over the 4-year period occurred for those with low activation at baseline. The average patient activation score for chronically ill adults who started at Level 1 increased 11.4 points (26%) over the 4 years. Respondents in Level 2 and Level 3 at baseline gained an average of 9.6 points (19%) and 6.3 points (11%), respectively, over the same 4 years. In contrast, the most highly activated at baseline (Level 4) lost an average of 5.8 points (−7%) over the 4 years. Those changes seem to indicate that patients with low level of activation are more likely to improve, whereas maintaining a high level of

Table 1. Panel Demographics and Relationships Between Activation and Demographics.

Demographic characteristics	Percent of panel (n = 4,865)	Mean PAM score at baseline	Mean PAM change from baseline to follow-up
Total sample	100.0	64.3	2.8
Gender			
Female	67.5	64.8	2.9
Male	32.5	64.1	2.6
Age (in years)			
<40	6.5	63.1	5.3**
41-50	12.4	64.1	4.5
51-65	40.3	64.7	3.1
65+	40.8	64.9	1.7
Race/ethnicity			
White non-Hispanic	65.2	65.1*	2.9
African American	24.2	63.6	2.6
Hispanic/Latino	6.4	63.6	3.9
Other	4.3	64.0	1.2
Education			
Less than college graduate	68.3	63.8**	2.4*
College graduate or more	31.7	66.2	3.6
Poverty status			
Below poverty threshold	22.4	62.7**	2.3
Above poverty threshold	77.7	65.1	3.0
Insurance type			
Private insurance	44.2	65.3**	3.7
Medicaid	13.3	63.8	2.0
Medicare	32.7	64.4	1.8
Other	2.7	62.3	3.2
Uninsured	7.2	63.2	3.4
Chronic conditions			
Hypertension	66.4	64.8	2.4**
Diabetes	28.9	65.4*	1.4**
Asthma	17.0	64.5	4.2**
Heart disease	16.2	65.0	2.2
Depression	27.2	62.6**	3.3
Patient activation level			
1 (*Lowest*)	6.8	44.1**	11.4**
2	19.0	51.7	9.6
3	37.2	58.7	6.3
4 (*Highest*)	37.0	80.9	−5.8

Note. PAM = patient activation measure. Statistical tests indicate a difference in mean PAM score (Column 2) or mean change in PAM score (column 3) across the subgroups (e.g., across the four age groups). For the chronic conditions, the statistical test is testing the difference from mean of respondents without the disease (e.g., who do not have diabetes).
*$p < .05$. **$p < .01$.

activation can be a challenge. In addition, gains in activation from baseline were greater for younger adults, college graduates, and those with hypertension, diabetes, or asthma.

Patient Activation Levels and Health Outcomes

In bivariate analysis, patient activation at baseline was significantly associated with seven of nine health-related outcomes at follow-up in the hypothesized direction (Table 2). Compared with the most activated (Level 4), less activated individuals had significantly worse levels of medication adherence, self-management knowledge, getting recommended diabetes care, health behaviors, functional health, emergency department use, and hospitalizations 4 years later. For example, the average functional health value for Level 4 activation was 1.8, compared with 1.9 for Level 3, 2.0 for Level 2, and 2.4 for Level 1, on a 1 (*high*) to 5 (*low*) scale. The difference in functional health between the Level 1 and Level 4 respondents was 0.6, which is more than a half standard deviation ($SD = 1.00$) on the index. For the emergency department, the likelihood of having a visit at follow-up was 28% for PAM Level 4 respondents, while it was 29%, 32%, and 38%, respectively for PAM Level 3, Level 2, and Level 1 respondents.

   In the multivariate regression models that controlled for demographics and health conditions, activation remained associated with seven out of nine outcomes at follow-up (Table 3). For example, individuals at Activation Levels 1, 2, and 3 at baseline scored, on average, 0.4, 0.3, and 0.2 points lower on the health behaviors index (0-4) at follow-up than individuals at Level 4. As a point of comparison, the standard deviation for the health behaviors index was 0.5, so the difference between the Level 1 and Level 4 PAM respondents was close to a standard deviation. The magnitude of differences between Level 1 and Level 4 PAM were approximately a half standard deviation for medication adherence index and functional health index. The coefficients were smaller for the self-management knowledge index, getting recommended diabetes care index, any emergency department use, and any hospitalizations.

Changes in Patient Activation and Outcomes

Increases in patient activation scores over 4 years were correlated with improvement in five of the nine health-related outcomes measured (medication adherence, self-management knowledge, health behaviors, functional health, and number of emergency department visits as shown in Table 4). The correlation coefficient was moderate for the healthy behaviors index (0.26), but lower for the other outcomes (Hemphill, 2003). The fixed-effects models, which controlled for changes in health and demographics as well as time-invariant characteristics, show that increases in patient activation were associated with slight improvements in the same five outcomes. The magnitude of the relationships was quite small. For example, a 10-point increase in activation was related to a less than 0.1 point (or 2.5%) improvement on the health behaviors index.

Table 2. Bivariate Analysis of Baseline Patient Activation Level and Follow-up Health-Related Outcomes.

related outcomes (follow-up)	Sample size	Mean health outcomes by baseline patient activation level			
		Level 1	Level 2	Level 3	Level 4
Medication adherence index	3,246	4.1	4.4	4.4	4.5**
Self-management knowledge index	3,886	0.6	0.7	0.7	0.8**
Getting recommended diabetes care index	1,634	0.7	0.8	0.8	0.8**
Health behaviors index	4,865	2.6	2.7	2.8	3.0**
Functional health index	4,865	2.4	2.0	1.9	1.8**
Costly utilization					
Any ED use	4,861	0.4	0.3	0.3	0.3**
Number of ED visits	4,861	0.8	0.7	0.6	0.6
Any hospitalizations	4,861	0.3	0.2	0.2	0.2**
No. of hospitalizations	4,861	0.4	0.4	0.3	0.3

Note. ED = emergency department. The scale for the medication adherence ranges from 1 (*low*) to 5 (*high*), for healthy behaviors it ranges from 1 (*low*) to 4 (*high*), and functional health from 1 (*high*) to 5 (*low*). Scales for self-management knowledge and getting recommended diabetes indices range from 0 (*low*) to 1 (*high*).
**Indicates a statistically significant difference in mean score across patient activation levels overall at $p < .01$.

Discussion

Previous research indicates that patients who are more activated are significantly advantaged in terms of health-related outcomes. However, most of this research was cross-sectional in design, only observing activation and the outcomes at one point in time. The findings from this study indicate that the benefits of being more highly activated are enduring for several years, yielding durable benefits in the form of better self-management, improved functioning, and lower use of costly health care services over time. Furthermore, the findings indicate that when activation levels change, many health-related outcomes change in the same direction. However, the impacts of changes in activation on outcomes, while statistically significant, appear to be limited, likely too limited to have any meaningful impact on health. It may be that when activation changes, there is a time lapse between that change and when changes in outcomes can be observed. It may take time for the benefits of increased activation to accumulate and be manifest. Moreover, it may be that increases in activation may have to reach a

Table 3. Multivariate Analysis of Baseline Patient Activation Level and Follow-up Health-Related Outcomes.

Follow-up health outcomes	Regression coefficients for follow-up health outcomes based on baseline patient activation level			
	Level 1	Level 2	Level 3	Level 4
Medication adherence index	−0.35**	−0.10†	−0.07†	—
Self-management knowledge index	−0.15**	−0.08**	−0.04*	—
Getting recommended diabetes care index	−0.10**	−0.04*	−0.04**	—
Health behaviors index	−0.38**	−0.28**	−0.16**	—
Functional health index	0.48**	0.17**	0.05	—
Costly utilization				
Any ED use	0.06*	0.02	−0.00	—
Number of ED visits	0.04	0.00	−0.07	—
Any hospitalizations	0.07**	0.03*	0.01	—
No. of hospitalizations	0.11†	0.02	−0.02	—

Note. ED = emergency department. Regression models control for gender, age, race/ethnicity, education, poverty status, insurance type, and chronic conditions. The scale for the medication adherence ranges from 1 (*low*) to 5 (*high*), for healthy behaviors it ranges from 1 (*low*) to 4 (*high*), and functional health from 1 (*high*) to 5 (*low*). Scales for self-management knowledge and getting recommended diabetes indices range from 0 (*low*) to 1 (*high*).
†$p < .10$. *$p < .05$. **$p < .01$.

threshold before they start to meaningfully affect outcomes. In this study, we assessed activation and the outcomes at only two time points over 4 years, rather than repeated observations over the time period. The study did not include an intervention, instead we passively observed changes that occurred in the study cohort. If there were an intervention specifically designed to increase and/or maintain activation, the impacts may have been greater.

The study findings should be interpreted in light of its limitations, which include that all the outcome variables are all self-reported. Studies are needed that look at these relationships as they unfold over time, and that do not rely solely on self-reported variables for the outcome measures. Studies are also needed to determine if there is a threshold that must be reached for increases in activation to translate into meaningful changes in outcomes.

Our findings do suggest that higher patient activation levels are associated with improved outcomes for a long period of time. These findings are important as health care delivery systems and health care payers seek approaches that will both improve

Table 4. Relationships Between Change in Patient Activation and Change in Health-Related Outcomes.

	Bivariate correlation coefficients	Multivariate fixed-effects model coefficients
Medication adherence index	0.04*	0.003*
Self-management knowledge index	0.05**	0.001**
Getting recommended diabetes care index	−0.01	−0.000
Health behaviors index	0.26**	0.008**
Functional health index	−0.06**	−0.004**
Costly utilization		
Any ED use	−0.01	−0.000
Number of ED visits	−0.03†	−0.003†
Any hospitalizations	0.01	0.001
No. of hospitalizations	−0.02	−0.006

Note. ED = emergency department. The fixed-effects regression models control for changes in education, poverty status, insurance type, and chronic conditions, as well as all individual-level characteristics that do not change, such as gender and race/ethnicity. The scale for the medication adherence ranges from 1 (*low*) to 5 (*high*), for healthy behaviors it ranges from 1 (*low*) to 4 (*high*), and functional health from 1 (*high*) to 5 (*low*). Scales for self-management knowledge and getting recommended diabetes indices range from 0 (*low*) to 1 (*high*).
†$p < .10$. *$p < .05$. **$p < .01$.

health outcomes and reduce costs. The results, while not proving causality, suggest that increasing patient activation may help achieve these ends.

Policy Implications

Patient activation seems to be an important and modifiable factor for determining chronic disease outcomes. Once patients become more activated, the benefits endure for several years. Given these benefits, innovative delivery systems and health plans are using patient activation scores as a way to improve care for various patient segments. That is to say, some delivery systems are adding a behavioral lens to the current clinical lens for managing individual patients and whole patient populations. These organizations are providing more active outreach to patients who have limited self-management skills (low activation scores) and heavy disease burden, while providing less labor-intensive supports to highly activated patients with the same level of disease burden. This stratified approach means organizations can optimize their resources by matching the type of support to population needs. For example, providing lower cost, electronic resources to those who are more ready to use information on their own, and targeting more costly, person-intensive support to aid those who need it. In a rapidly changing health care sector, innovators who are able to create and implement new models of care that are effective in both improving outcomes and reducing costs, will

be substantially advantaged. Using information about patients' knowledge, skill, and confidence for self-management as the basis for these new care models, appears to be a promising direction.

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