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# Survivors of an Acute Coronary Syndrome with Lower Patient Activation Are More Likely to Experience Declines in Health-Related Quality of Life

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# Abstract

**Background**—Patient activation comprises the knowledge, skills, and confidence for self-care, and may lead to better health outcomes.

**Objectives**—We examined the relationship between patient activation and changes in health-related quality of life (HRQOL) following hospitalization for an acute coronary syndrome (ACS).

**Methods**—We studied patients from 6 medical centers in central Massachusetts and Georgia who had been hospitalized for an ACS between 2011 and 2013. At 1 month after hospital discharge, patients completed the 6-item Patient Activation Measure and were categorized into 4 levels of activation. Multinomial logistic regression analyses compared activation level with clinically meaningful changes ( 3.0 points generic, 10.0 points disease-specific) in generic physical (SF-36 PCS), generic mental (SF-36 MCS), and disease-specific (Seattle Angina Questionnaire, SAQ) HRQOL from 1 to 3 and 1 to 6 months after hospitalization, adjusting for potential sociodemographic and clinical confounders.

**Results**—Patients (n=1,042) were on average 62 years old, 34% female, and 87% non-Hispanic white. Ten percent were in the lowest level of activation. Patients with the lowest activation had 1.95 (95% CI: 1.05, 3.62) and 2.18 (95% CI: 1.17, 4.05) times the odds of experiencing clinically significant declines in MCS and SAQ QOL scores, respectively, between 1 and 6 months than the most activated patients. Patient activation level was not associated with meaningful changes in PCS scores.

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**Conclusions**—Hospital survivors of an ACS with lower activation may be more likely to experience declines in mental and disease-specific HRQOL than more activated patients, identifying a group at risk of poor outcomes.

#### Keywords

self care; heart disease; health status

#### Introduction

The estimated 1.1 million US adults who annually survive a hospitalization for an acute coronary syndrome (ACS)<sup>1</sup> may often experience poor health-related quality of life (HRQOL).<sup>2</sup> Patient self-care behaviors, such as medication adherence and lifestyle modification, may improve health outcomes following an ACS.<sup>3–5</sup> Self-care can require substantial knowledge, skills, and confidence, terms collectively described as "patient activation."<sup>6</sup> Since more activated patients are more likely to engage in self-care activities, <sup>7–9</sup> patient activation may be required to maintain, if not improve, HRQOL following an ACS.

The role of patient activation in prognosis among survivors of an ACS remains unclear as prior studies have pooled patients with and without heart disease.<sup>6,10,11</sup> While cross sectional studies in general populations suggest a positive association between patient activation and HRQOL,<sup>11,12</sup> we are unaware of previous studies on how patient activation may predict subsequent changes in HRQOL. Since clinical interventions may improve patient activation,<sup>13</sup> knowledge about the relationship between patient activation and changes in HRQOL may be valuable for treating patients with an ACS. We hypothesized that patients with low activation were more likely to experience declines in general and disease-specific HRQOL than more activated patients in the 6 months following hospitalization for an ACS.

# Methods

#### **Study Setting and Sample**

We used data from the Transitions, Risks, and Actions in Coronary Events: Center for Outcomes Research and Education (TRACE-CORE).<sup>14,15</sup> Adults hospitalized with an ACS were recruited at 3 hospitals in Worcester, Massachusetts, 1 in Macon, Georgia, and 2 in Atlanta, Georgia in 2011–2013. These sites were selected to facilitate recruitment of a cohort with racial and socioeconomic diversity.<sup>15</sup> Eligibility criteria included a confirmed diagnosis of an ACS,<sup>16,17</sup> 21 years of age, and being discharged alive. Exclusion criteria included having an ACS secondary to another acute medical event, delirium, pregnancy, and receiving hospice or palliative care. Data were collected by chart abstraction, an in-person interview during the index hospitalization or by telephone within 72 hours of discharge, and telephone interviews at 1, 3, 6, and 12 months after hospital discharge. Institutional review boards at each study site approved this study. The present study sample consisted of patients with complete data on patient activation at 1 month, HRQOL at 1, 3, and 6 months, and socio-demographic and clinical covariates.

#### **Patient Activation**

We examined patient activation at 1-month after hospital discharge as this measurement reflects changes in activation resulting from discharge education and outpatient follow-up. <sup>9,18</sup> Patient activation was measured using the 6-Item Patient Activation Measure<sup>®</sup> (PAM-6), a shortened version of the validated 13-item Patient Activation Measure.<sup>6,19</sup> On a 4-point Likert scale ranging from "strongly disagree" to "strongly agree," patients rated six statements representing their knowledge, skills, and confidence in self-care. Following the PAM developer's guidelines,<sup>20</sup> we summed PAM-6 item responses and transposed the resulting score to a scale ranging from 0 to 100, with higher scores indicating greater activation. In the current sample, internal consistency (Cronbach's alpha) of the PAM-6 was 0.79. Prior analyses of the original 22-item PAM<sup>6</sup> and PAM-13<sup>19</sup> scales found that patient activation develops through four stages of: (1) not recognizing one's role in self-care (Disengaged; least activated), (2) being aware but lacking necessary skills and confidence (Aware), (3) taking action for self-care (Taking Action), and (4) maintaining self-care in spite of challenges (Maintaining Behaviors; most activated). Using standard PAM-6 cutpoints provided by the developer, we categorized patients into these four stages of activation. Patients with higher levels of activation, as defined by the PAM-6, are more likely to perceive success in achieving health goals, supporting the validity of these categorizations.<sup>21</sup>

### Health Related Quality of Life

We assessed generic HRQOL at 1, 3, and 6 months after hospital discharge with the SF-36v2<sup>®</sup> Health Survey<sup>22</sup> which has demonstrable reliability and validity in populations with CHD.<sup>23</sup> The physical (PCS) and mental (MCS) component summary scores measure overall physical and mental health, respectively. PCS and MCS use norm-based scoring such that the U.S. general population has a mean of 50 (SD 10), with higher scores indicating better HRQOL.<sup>24</sup> We selected the 1-month assessment of HRQOL as the baseline measure since this best captures a patient's health in the aftermath of their ACS and avoids endogeneity in measuring changes in HRQOL as related to PAM at 1 month. We used a cutoff of 3.0 points to define clinically meaningful decreases and increases, following published recommendations.<sup>25</sup>

We measured disease-specific HRQOL with the 3-item quality of life (QOL) subscale of the Seattle Angina Questionnaire (SAQ)<sup>26</sup>, a validated and reliable measure for patients with CHD.<sup>26</sup> This was scored from 0 to 100, with higher scores indicating better HRQOL. Following cutoffs validated in instrument development, we defined decreases and increases of 10.0 points in SAQ QOL as clinically meaningful.<sup>26</sup>

#### **Baseline Study Variables**

We controlled for potential confounding by sociodemographic and clinical characteristics including age, sex, race (non-Hispanic white versus other race/ethnicity), and education. Financial strain was measured by asking patients "in general, how do your finances usually work out at the end of the month?" (some money left over, just enough to make ends meet, not enough to make ends meet).<sup>27</sup> Trained staff abstracted data on documented comorbid conditions, health insurance, and referral to cardiac rehabilitation from in-hospital medical

records during the patient's index hospitalization for an ACS. Interviewers asked patients if they had seen an outpatient medical provider for their CHD during the 1-month interview.

#### **Data Analysis**

We compared the baseline sociodemographic and clinical characteristics across 1-month patient activation levels through linear tests and Cochran-Armitage tests for trends for continuous and categorical variables, respectively. We compared mean HRQOL scores between 1 month and 3 and 6 months after hospital discharge using paired t-tests. Linear tests for trend were used to compare SF-36 PCS, SF-36 MCS, and SAQ QOL scores at each time point across the 4 levels of patient activation.

To test whether patients with lower levels of activation were more likely to experience declines in HRQOL than more activated patients, we calculated odds ratios (ORs) and 95% confidence intervals (95% CIs) for experiencing a clinically meaningful increase or decrease in HRQOL between 1 month and 3 and 6 months after hospital discharge for an ACS using multinomial logistic regression analyses. In multinomial logistic regression, the outcome takes one of three or more categories and models are simultaneously fit using maximum likelihood to estimate odds ratios for each group compared with a common reference group (i.e., no change).<sup>28</sup> For all regression models, Maintaining Behaviors (the highest activation level) served as the referent group. We included clinical site and sociodemographic factors (age, sex, race) in multivariate-adjusted models; we included other covariates if their inclusion produced changes in the beta coefficients for the association between activation and HRQOL for at least one level of patient activation by 10%.

### Results

The analytic sample included 1,042 (68.1%) of the 1,529 TRACE-CORE patients who completed the 1-month telephone interview. We excluded patients without 1-month PAM scores (n=18), did not participate in the 3-and 6-month telephone interviews (n=422), or were missing HRQOL scores (n=5) or information on covariates included in multivariable-adjusted models (n=42). Excluded patients were younger, on average, and were more likely to be non-Hispanic Black, have not graduated from high school, report financial strain, and lack health insurance (p < 0.05 for all comparisons). The distribution of levels of patient activation was statistically similar between included and excluded patients. Included patients had higher mean 1-month MCS (51.0 vs. 48.2) and SAQ QOL scores (76.3 vs. 71.9) than excluded patients.

#### **Baseline Study Population Characteristics**

The mean age of the study population was 61.9 years (SD 11.2), 34.3% were women, 87.1% were non-Hispanic white, and 51.2% had a prior history of CHD. In terms of patient activation, 9.7% were Disengaged, 40.3% Aware, 21.1% Taking Action, and 28.9% Maintaining Behaviors. Level of patient activation was inversely associated with age and with non-completion of high school (Table 1). Patient activation was also inversely associated with being non-Hispanic white, and having a history of previously diagnosed

#### Physical Health Related Quality of Life

At months 1, 3, and 6, after patients' hospital discharge, generic physical HRQOL was significantly higher among patients with higher levels of patient activation (Table 2). On average, PCS scores increased by 1.8 points between 1 and 3 months, but remained statistically unchanged, on average, between 3 and 6 months. A similar pattern was observed among patients in each of the four different levels of activation. Overall, the proportion of patients experiencing a meaningful improvement in PCS scores between 1 and 3 months (40.5%), and between 1 and 6 months (39.7%), after hospital discharge was nearly double the proportion of patients experiencing a meaningful decrease in PCS scores (23.0% and 25.1%, respectively: Table 3). Contrary to our hypothesis, lower patient activation was not associated with clinically meaningful changes in generic physical HRQOL (Table 3).

#### Mental Health Related Quality of Life

On average, patients' MCS scores were also significantly higher among patients with higher activation at 1, 3, and 6 months after hospital discharge (Table 2). In the overall study sample, the average MCS score increased by 1.5 points between 1 and 3 months after hospital discharge, with no significant change observed, on average, between 3 and 6 months. Within each level of patient activation, there were small increases in mean MCS scores between 1 and 3 months. However, patients in the lowest level of activation experienced a non-significant 1.1-point decline in the mean MCS score between 3 and 6 months.

A greater proportion of patients experienced a clinically meaningful increase in MCS scores between 1 and 3 months (36.8%), and 1 and 6 months (41.7%), than experienced a clinically meaningful decline (24.1% and 24.7%, respectively) (Table 4). As hypothesized, patients with the lowest level of activation had 1.95 (95% CI: 1.05, 3.62) times the odds of experiencing a clinically meaningful decrease in general mental HRQOL than the most activated patients between 1 and 6 months, after adjusting for confounding.

#### **Disease-Specific Quality of Life**

Disease-specific quality of life scores were, on average, significantly greater across patients with higher levels of patient activation at 1, 3, and 6 months after hospital discharge (Table 2). The average SAQ QOL scores for patients in the entire sample increased by 4.3 points between 1 and 3 months after hospital discharge and non-significantly increased by 0.6 points between and 3 and 6 months. Mean SAQ QOL scores increased significantly (p<0.05) or non-significantly for patients within each level of patient activation between 1 and 3 months after hospital discharge. Between 3 and 6 months, patients in the lowest and highest levels of activation experienced non-significant decreases (-1.9 and -1.0 points, respectively) in mean SAQ QOL scores (Table 2).

Higher proportions of patients in the entire sample reported a clinically meaningful increase in SAQ QOL scores between 1 and 3 months (24.4%), and between 1 and 6 months (26.9%),

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than reported a meaningful decline (12.8% and 13.5%, respectively) (Table 5). After multivariable adjustment, patients at the lowest level of activation had 2.69 (95% CI: 1.36, 5.31) and 2.18 (95% CI: 1.17, 4.05) times the odds of the most activated patients of experiencing a clinically meaningful decline in SAQ QOL scores between 1 and 3 months and 1 and 6 months after hospital discharge, respectively; these findings support our hypotheses.

# Discussion

We found that hospital survivors of an ACS with the lowest level of patient activation were more likely to experience clinically meaningful declines in generic mental and diseasespecific HRQOL compared with the most highly activated patients in the 6 months following hospital discharge. Patients with low activation were older, less educated, and more likely to have previously diagnosed coronary or cerebrovascular disease compared to more activated patients. Patients with lower activation also had lower generic and diseasespecific HRQOL at 1, 3, and 6 months after hospitalization.

Approximately half of patients in this study were in the lowest or second lowest level of patient activation at one month after hospital discharge for an ACS. Qualitative research suggests that while hospitalization for an ACS may motivate better self-care<sup>29</sup>, and perhaps lead to better activation, others can find the experience emotionally overwhelming,<sup>30</sup> and this could lead to declines in activation. Our findings of a high prevalence of low patient activation are consistent with studies of other inpatient and outpatient populations with chronic diseases. For example, a national survey in 2004 of 4,108 Kaiser Permanente enrollees with chronic diseases, including one third with coronary artery disease, found similar distributions of patient activation.<sup>11</sup> Other studies have found that between 10–20% of patients with chronic conditions would be in the lowest level of activation.<sup>10,31,32</sup>

Our results are notable given the importance of patient self-care in the outpatient setting, particularly after a diagnosis of CHD.<sup>33,34</sup> Multiple studies have reported that patients from general and chronic disease populations with lower levels of activation tend to have suboptimal self-care behaviors including dieting, exercise, and adherence to prescribed medications.<sup>6,7,11</sup> However, patient activation may be modifiable in populations with chronic diseases through interventions such as group workshops,<sup>9</sup> individual coaching,<sup>35,36</sup> and internet modules.<sup>37</sup> A trial of 479 patients with at least one chronic disease suggested that improvements in patient activation may lead to better self-care behaviors such as improved dietary practices.<sup>9</sup> Further exploration of the long-term consequences of low patient activation after hospital discharge for an ACS is warranted, particularly with regards to the potential benefits of intervening in patients with low levels of activation, and the high prevalence of low levels of patient activation observed in this study. The least activated patients may be the most responsive to interventions for improving activation,<sup>13</sup> and such improvements in activation may be associated with the need for less health care services.<sup>38</sup>

We found that patients with lower levels of activation at a month after hospitalization had lower generic and disease-specific HRQOL on average than more activated patients. Other cross-sectional studies suggest that HRQOL tends to be higher among patients with higher

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levels of patient activation.<sup>11,12</sup> In the Kaiser Permanente study of enrollees with a range of chronic diseases, patients in the three highest levels of activation had mean SF-8 PCS and MCS scores that were 0.2 to 0.3 points higher than the least activated patients.<sup>11</sup> Another study of 278 adults (mean age: 53 years) recruited from two Israeli primary care clinics found small positive correlations between PAM-13 scores and SF-12 PCS and MCS scores.<sup>12</sup> These prior studies and ours do not shed light on whether lower patient activation may lead to a worse initial HRQOL, if suboptimal HRQOL was driving patients to feel less activated, or if a third factor negatively impacts both patient activation and HRQOL in the aftermath of a hospitalization for an ACS. Future research is needed to better understand the association between patient activation and HRQOL.

The least activated patients were more likely to experience clinically meaningful declines in generic mental and disease-specific QOL than the most activated patients. Survivors of an ACS with better adherence to clinical recommendations are likely to be healthier than their non-adherent peers.<sup>3,4</sup> Patients with lower activation may be at greater risk for declines in disease-specific HRQOL due to worse self-care; studies in chronic disease populations have identified a strong association between lesser degrees of patient activation and engagement in self-care behaviors.<sup>6,11</sup> Conceivably, the weaker associations between levels of patient activation with changes in generic physical HRQOL (compared to the stronger associations found for generic mental and for disease-specific HRQOL) may be due to the PCS capturing the impact of other health issues in addition to the ACS.

The association between low patient activation and subsequent declines in generic mental HRQOL could result from a relationship between low patient activation and a negative emotional state. A national survey of 843 adults aged 25 to 75 years old found that those with low activation levels tended to feel overwhelmed and worried about managing their health than those with higher activation.<sup>39</sup> After finding that patients with the least activation were less likely to have specific health goals, the authors postulated the negative affect of the least activated patients may inhibit their ability to manage their own health. Patients with low activation may, therefore, have psychological barriers to addressing stressors after hospitalization for an ACS. This could explain why patients with lower activation are at higher risk for declines in emotional health over time, while those with higher activation could have more capacity to engage in self-care behaviors that also maintain their emotional health. Further research is needed to elucidate the complex, but potentially modifiable, relationships between stressors, mental health, and patient activation among adults following hospitalization for an ACS.

#### Study Strengths and Limitations

To the best of our knowledge, this is the first prospective study to examine the relationship between patient activation and changes in HRQOL following hospitalization for an ACS. The strengths of this study include a large, contemporary sample of survivors of an ACS and longitudinal assessments of HRQOL using well-validated measures.<sup>23,26</sup> Limitations include the potential for selection bias due to loss to follow-up, which may have biased findings towards the null as excluded patients were more likely to have markers of socioeconomic deprivation, a potential risk factor for poor outcomes after an ACS.<sup>40</sup> Although the PAM-13

has been validated<sup>19</sup> and used extensively,<sup>7</sup> there are more limited data on the PAM-6, particularly for patients with an ACS. Unmeasured confounders, such as completion of a

# Conclusion

Hospital survivors of an ACS at the lowest level of patient activation had lower HRQOL in the months following hospital discharge and were more likely to experience clinically meaningful declines in mental and disease-specific HRQOL over 6 months, suggesting that patients with low activation may be at particularly high risk of unfavorable outcomes following hospital discharge for an ACS. Further studies are needed to elucidate ways to enhance patient activation and improve their long-term prognosis, including completion of cardiac rehabilitation programs, adherence to effective lifestyle changes, and adherence to medication regimens.

cardiac rehabilitation program, may have also introduced bias.

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## References

- Mozaffarian D, Benjamin EJ, Go AS, et al. Heart Disease and Stroke Statistics-2016 Update: A Report From the American Heart Association. Circulation. 2016; 133:e38–e360. [PubMed: 26673558]
- Xie J, Wu EQ, Zheng ZJ, Sullivan PW, Zhan L, Labarthe DR. Patient-reported health status in coronary heart disease in the United States: age, sex, racial, and ethnic differences. Circulation. 2008; 118:491–7. [PubMed: 18625894]
- Kumbhani DJ, Steg PG, Cannon CP, et al. Adherence to secondary prevention medications and fouryear outcomes in outpatients with atherosclerosis. The American journal of medicine. 2013; 126:693–700. e1. [PubMed: 23800583]
- Chow CK, Jolly S, Rao-Melacini P, Fox KA, Anand SS, Yusuf S. Association of diet, exercise, and smoking modification with risk of early cardiovascular events after acute coronary syndromes. Circulation. 2010; 121:750–8. [PubMed: 20124123]
- Hall SL, Lorenc T. Secondary prevention of coronary artery disease. Am Fam Physician. 2010; 81:289–96. [PubMed: 20112887]
- Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004; 39:1005–26. [PubMed: 15230939]
- Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: a systematic review. Patient education and counseling. 2015; 98:545–52. [PubMed: 25744281]
- Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. Journal of general internal medicine. 2012; 27:520–6. [PubMed: 22127797]
- 9. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? Health services research. 2007; 42:1443–63. [PubMed: 17610432]

- Prey JE, Qian M, Restaino S, et al. Reliability and validity of the patient activation measure in hospitalized patients. Patient education and counseling. 2016; 99:2026–33. [PubMed: 27422339]
- Mosen DM, Schmittdiel J, Hibbard J, Sobel D, Remmers C, Bellows J. Is patient activation associated with outcomes of care for adults with chronic conditions? J Ambul Care Manage. 2007; 30:21–9. [PubMed: 17170635]
- Magnezi R, Glasser S, Shalev H, Sheiber A, Reuveni H. Patient activation, depression and quality of life. Patient education and counseling. 2014; 94:432–7. [PubMed: 24331277]
- Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013; 32:207–14. [PubMed: 23381511]
- Waring ME, McManus RH, Saczynski JS, et al. Transitions, Risks, and Actions in Coronary Events--Center for Outcomes Research and Education (TRACE-CORE): design and rationale. Circulation Cardiovascular quality and outcomes. 2012; 5:e44–50. [PubMed: 22991349]
- Goldberg RJ, Saczynski JS, McManus DD, et al. Characteristics of contemporary patients discharged from the hospital after an acute coronary syndrome. The American journal of medicine. 2015; 128:1087–93. [PubMed: 26007672]
- 16. Anderson JL, Adams CD, Antman EM, et al. 2012 ACCF/AHA focused update incorporated into the ACCF/AHA 2007 guidelines for the management of patients with unstable angina/non-STelevation myocardial infarction: a report of the American College of Cardiology Foundation/ American Heart Association Task Force on Practice Guidelines. Journal of the American College of Cardiology. 2013; 61:e179–347. [PubMed: 23639841]
- 17. Kushner FG, Hand M, Smith SC Jr, et al. 2009 focused updates: ACC/AHA guidelines for the management of patients with ST-elevation myocardial infarction (updating the 2004 guideline and 2007 focused update) and ACC/AHA/SCAI guidelines on percutaneous coronary intervention (updating the 2005 guideline and 2007 focused update) a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. Journal of the American College of Cardiology. 2009; 54:2205–41. [PubMed: 19942100]
- Ledford CJ, Ledford CC, Childress MA. Extending Physician ReACH: influencing patient activation and behavior through multichannel physician communication. Patient education and counseling. 2013; 91:72–8. [PubMed: 23219484]
- 19. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005; 40:1918–30. [PubMed: 16336556]
- 20. Insignia Health L. Patient Activation Measure (PAM) 6 (TM) License Materials. 2011.
- 21. Adams SR, Goler NC, Sanna RS, et al. Patient satisfaction and perceived success with a telephonic health coaching program: the Natural Experiments for Translation in Diabetes (NEXT-D) Study, Northern California, 2011. Prev Chronic Dis. 2013; 10:E179. [PubMed: 24176083]
- 22. Ware JE Jr. SF-36 health survey update. Spine (Phila Pa 1976). 2000; 25:3130–9. [PubMed: 11124729]
- Muller-Nordhorn J, Roll S, Willich SN. Comparison of the short form (SF)-12 health status instrument with the SF-36 in patients with coronary heart disease. Heart. 2004; 90:523–7. [PubMed: 15084550]
- Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care. 1996; 34:220–33. [PubMed: 8628042]
- Frendl DM, Ware JE Jr. Patient-reported functional health and well-being outcomes with drug therapy: a systematic review of randomized trials using the SF-36 health survey. Medical care. 2014; 52:439–45. [PubMed: 24714581]
- 26. Spertus JA, Winder JA, Dewhurst TA, et al. Development and evaluation of the Seattle Angina Questionnaire: a new functional status measure for coronary artery disease. Journal of the American College of Cardiology. 1995; 25:333–41. [PubMed: 7829785]
- Rahimi AR, Spertus JA, Reid KJ, Bernheim SM, Krumholz HM. Financial barriers to health care and outcomes after acute myocardial infarction. Jama. 2007; 297:1063–72. [PubMed: 17356027]
- 28. Kutner, MH. Applied linear statistical models. 5. Boston: McGraw-Hill Irwin; 2005.
- 29. Eshah NF, Bond AE. Acute myocardial infarction survivors experiences: A qualitative literature review. Jordan Medical Journal. 2009; 43:238–46.

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- Jensen BO, Petersson K. The illness experiences of patients after a first time myocardial infarction. Patient education and counseling. 2003; 51:123–31. [PubMed: 14572941]
- Skolasky RL, Green AF, Scharfstein D, Boult C, Reider L, Wegener ST. Psychometric properties of the patient activation measure among multimorbid older adults. Health Serv Res. 2011; 46:457–78. [PubMed: 21091470]
- Dunlay SM, Griffin JM, Redfield MM, Roger VL. Patient Activation in Acute Decompensated Heart Failure. J Cardiovasc Nurs. 2016
- 33. Smith SC Jr, Benjamin EJ, Bonow RO, et al. AHA/ACCF Secondary Prevention and Risk Reduction Therapy for Patients with Coronary and other Atherosclerotic Vascular Disease: 2011 update: a guideline from the American Heart Association and American College of Cardiology Foundation. Circulation. 2011; 124:2458–73. [PubMed: 22052934]
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. Jama. 2002; 288:1775–9. [PubMed: 12365965]
- Deen D, Lu WH, Rothstein D, Santana L, Gold MR. Asking questions: the effect of a brief intervention in community health centers on patient activation. Patient education and counseling. 2011; 84:257–60. [PubMed: 20800414]
- 36. Shively MJ, Gardetto NJ, Kodiath MF, et al. Effect of patient activation on self-management in patients with heart failure. J Cardiovasc Nurs. 2013; 28:20–34. [PubMed: 22343209]
- Thiboutot J, Sciamanna CN, Falkner B, et al. Effects of a web-based patient activation intervention to overcome clinical inertia on blood pressure control: cluster randomized controlled trial. J Med Internet Res. 2013; 15:e158. [PubMed: 24004475]
- Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015; 34:431–7. [PubMed: 25732493]
- Hibbard JH, Mahoney E. Toward a theory of patient and consumer activation. Patient education and counseling. 2010; 78:377–81. [PubMed: 20188505]
- 40. Bernheim SM, Spertus JA, Reid KJ, et al. Socioeconomic disparities in outcomes after acute myocardial infarction. American heart journal. 2007; 153:313–9. [PubMed: 17239695]

## What's New and Important

- This is one of the first studies to examine the relationship between patient activation and changes in health-related quality life in the 6 months following hospitalization for an acute coronary syndrome
- Patients in lower levels of activation had lower physical, mental, and diseasespecific health-related quality of life at 1, 3, and 6 months after hospital discharge
- Patients in the lowest level of activation were more likely to experience clinically meaningful declines in mental and disease-specific health-related quality of life between 1 and 6 months after hospital discharge

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# Table 1

Baseline characteristics of patients hospitalized with an acute coronary syndrome according to level of patient activation at 1 month after hospital discharge: TRACE-CORE, 2011-2013

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	Disengaged (least activated) (n = 100)	Aware (n = 420)	Taking Action (n = 220)	Maintaining Behaviors (most activated) (n = 302)	p for trend
Sociodemographic /Lifestyle					
Mean Age $\pm$ SD (years)	62.7 (11.9)	63.3 (11.2)	61.1 (10.8)	60.4 (11.1)	< 0.001
Women (%)	40.0	34.8	32.7	32.8	0.24
Non-Hispanic White (%)	80.0	86.4	0.09	88.4	0.05
Education (%)					
Less than High School	14.0	12.6	7.7	7.3	< 0.01
High School Graduate	26.0	31.0	28.6	28.8	0.91
Junior College/Technical Degree	30.0	32.6	30.5	30.1	0.65
College Graduate	17.0	13.1	20.9	18.9	0.07
Graduate School	13.0	10.7	12.3	14.9	0.20
Low Monthly Financial Reserves (%)	23.0	13.6	15.0	13.9	0.23
Avoided Care Due to Cost (%)	28.0	15.0	18.2	16.6	0.26
No Health Insurance (%)	11.0	5.0	4.6	8.3	0.76
Site (%)					
Worcester MA	60.0	60.7	70.5	72.5	
Macon GA	34.0	33.1	26.4	21.5	
Atlanta GA	6.0	6.2	3.1	6.0	
Clinical					
Medical History (%)					
Atrial Fibrillation	10.0	9.3	8.6	5.3	0.05
Arthritis	22.0	23.3	18.2	17.9	0.08
Cerebrovascular Disease	13.0	10.5	6.8	7.3	0.04

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	Disengaged (least activated) (n = 100)	Aware (n = 420)	Taking Action (n = 220)	Maintaining Behaviors (most activated) (n = 302)	p for trend
Chronic Kidney Disease	8.0	10.7	13.2	8.6	0.83
Chronic Lung Disease	20.0	17.4	19.6	16.6	0.61
Congestive Heart Failure	14.0	13.6	10.9	9.3	0.06
Coronary Heart Disease	62.0	52.6	51.4	45.4	<0.01
Diabetes	38.0	37.4	35.0	31.5	0.09
Hyperlipidemia	78.0	67.6	73.2	63.6	<0.05
Hypertension	84.0	76.7	72.3	74.2	0.07
Cardiac Rehabilitation Referral (%)	42.0	39.8	44.1	45.4	0.18
Outpatient visit between discharge and 1-month interview (%)	76.0	80.0	78.2	80.8	0.50

	Mean 1 Month Scores (SD)	Mean 3 Month Scores (SD)	Mean 6 Month Scores (SD)	Difference Between Mean 1 and 3 Month Scores (SD)	P value	Difference Between Mean 3 and 6 Month Scores (SD)	P value
Generic Physical HRQOL (SF-36 PCS)							
Overall Sample	42.2 (10.4)	44.0 (11.0)	43.9 (11.5)	+ 1.8 (7.4)	<0.001	- 0.1 (6.9)	0.59
Disengaged (Least Activated)	36.5 (9.6)	39.1 (10.1)	38.1 (11.3)	+ 2.7 (7.7)	<0.001	- 1.0 (6.1)	0.09
Aware	41.5 (10.3)	43.1 (10.9)	43.4 (11.0)	+1.7 (7.5)	<0.001	+0.3(6.8)	0.35
Taking Action	42.1 (10.7)	43.6 (12.1)	43.8 (12.3)	+ 1.6 (7.1)	<0.001	+0.2(7.0)	0.68
Maintaining Behaviors (Most Activated)	45.2 (9.7)	47.1 (9.8)	46.7 (10.8)	+ 1.9 (7.5)	<0.001	- 0.5 (7.3)	0.26
P for trend across levels of patient activation	<0.001	<0.001	<0.001				
Generic Mental HRQOL (SF-36 MCS)							
Overall Sample	51.0 (11.0)	52.5 (10.5)	52.7 (10.8)	+ 1.5 (8.5)	<0.001	+ 0.2 (7.2)	0.30
Disengaged (Least Activated)	45.6 (12.9)	46.6 (13.3)	45.5 (14.1)	+1.0(10.2)	0.32	- 1.1 (7.8)	0.16
Aware	50.6 (11.0)	51.9 (10.6)	52.7 (10.1)	+ 1.4 (8.6)	<0.001	+0.8(7.3)	0.03
Taking Action	50.8(10.8)	52.9 (9.4)	53.2 (10.5)	+ 2.1 (8.4)	<0.001	+ 0.3 (7.6)	0.55
Maintaining Behaviors (Most Activated)	53.5 (9.8)	54.9 (9.3)	54.7 (9.7)	+ 1.4 (7.8)	<0.005	– 0.1 (6.7)	0.73
P for trend across levels of patient activation	<0.001	<0.001	<0.001				
Disease-Specific HRQOL (SAQ)							
Overall Sample	76.3 (22.6)	80.6 (19.7)	81.3 (20.5)	+4.3(18.3)	<0.001	+0.6(15.9)	0.22
Disengaged (Least Activated)	64.9 (28.7)	68.6 (24.0)	66.9 (26.7)	+ 3.8 (22.5)	0.10	- 1.9 (18.8)	0.37
Aware	74.7 (22.8)	79.9 (20.6)	81.0 (19.9)	+5.2(19.4)	<0.001	+ 1.2 (16.6)	0.16
Taking Action	77.6 (21.1)	80.6 (17.6)	83.5 (16.6)	+3.0(18.0)	<0.05	+ 2.9 (14.4)	<0.005
Maintaining Behaviors (Most Activated)	81.5 (19.3)	85.7 (16.4)	84.7 (19.5)	+ 4.2 (14.9)	<0.001	- 1.0 (14.9)	0.24
P for trend across levels of patient activation	<0.001	<0.001	<0.001				

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# Table 3

Prevalence of and adjusted odds ratios (95% confidence intervals) for a clinically meaningful increase or decrease in physical health-related quality of life (HRQOL) between 1 month and 3 months and between 1 and 6 months after hospital discharge by level of patient activation at 1 month after hospital discharge for an acute coronary syndrome: TRACE-CORE, 2011-2013

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SF-36 PCS Scores			Clinically Meani	ıgful Decrease		Clinically Meani	ngful Increase
	% experiencing no clinically meaningful no HRQOL	% experiencing clinically meaningful decrease in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CI)*	% experiencing clinically meaningful increase in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CI)*
1 to 3 Months							
Overall Sample	36.5	23.0			40.5		
Disengaged (Least Activated)	31.0	24.0	1.14 (0.62 to 2.12)	0.96 (0.51 to 1.80)	45.0	1.13 (0.67 to 1.91)	1.17 (0.68 to 2.01)
Aware	37.3	22.9	0.90 (0.61 to 1.34)	0.80 (0.53 to 1.21)	39.8	0.83 (0.59 to 1.16)	0.82 (0.58 to 1.16)
Taking Action	40.9	23.2	0.84 (0.53 to 1.33)	0.83 (0.52 to 1.32)	35.9	0.68 (0.46 to 1.02)	0.67 (0.45 to 1.01)
Maintaining Behaviors (Most Activated)	33.7	22.9	Ref.	Ref.	43.4	Ref.	Ref.
1 to 6 Months							
Overall Sample	35.2	25.1	ı	I	39.7		
Disengaged (Least Activated)	34.7	29.7	1.39 (0.78 to 2.46)	1.15 (0.64 to 2.08)	35.6	1.09 (0.64 to 1.86)	1.17 (0.68 to 2.02)
Aware	32.0	25.4	1.34 (0.91 to 1.98)	1.21 (0.81 to 1.81)	42.6	1.39 (0.99 to 1.96)	1.45 (1.02 to 2.06)
Taking Action	35.0	24.2	1.14 (0.72 to 1.80)	1.10 (0.69 to 1.75)	40.8	1.21 (0.81 to 1.81)	1.20 (0.80 to 1.80)
Maintaining Behaviors (Most Activated)	39.3	22.8	Ref.	Ref.	37.9	Ref.	Ref.
* Adjusted for age, sex, race, site, educa	tion, avoidance of care	e due to costs, history	of coronary heart disease,	history of hypertension			

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# Table 4

Prevalence of and adjusted odds ratios (95% confidence intervals) for a clinically meaningful increase or decrease in mental health-related quality of life (HRQOL) between 1 month and 3 months and between 1 and 6 months after hospital discharge by level of patient activation at 1 month after hospital discharge for an acute coronary syndrome: TRACE-CORE, 2011-13

SF-36 MCS Scores			Clinically Meani	ıgful Decrease		Clinically Mean	ingful Increase
	% experiencing no clinically meaningful no HRQOL	% experiencing clinically meaningful decrease in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CJ)*	% experiencing clinically meaningful increase in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CI)*
1 to 3 Months							
Overall Sample	39.1	24.1			36.8		
Disengaged (Least Activated)	32.0	30.0	1.75 (0.98 to 3.12)	1.65 (0.92 to 2.98)	38.0	1.47 (0.98 to 3.1)	1.36 (0.78 to 2.36)
Aware	38.1	24.5	1.20 (0.82 to 1.77)	1.18 (0.80 to 1.75)	37.4	1.20 (0.82 to 1.77)	1.19 (0.84 to 1.69)
Taking Action	39.5	22.3	1.05 (0.67 to 1.66)	1.05 (0.66 to 1.66)	38.2	1.05 (0.67 to 1.66)	1.20 (0.80 to 1.79)
Maintaining Behaviors (Most Activated)	42.7	22.9	Ref.	Ref.	34.4	Ref.	Ref.
1 to 6 Months							
Overall Sample	33.6	24.7			41.7		
Disengaged (Least Activated)	24.0	35.0	2.37 (1.30 to 4.3)	1.95 (1.05 to 3.62)	41.0	1.59 (0.90 to 2.78)	1.30 (0.73 to 2.34)
Aware	32.2	25.7	1.30 (0.88 to 1.92)	1.24 (0.82 to 1.86)	42.1	1.21 (0.86 to 1.71)	1.14 (0.80 to 1.63)
Taking Action	36.3	20.5	0.91 (0.57 to 1.46)	0.92 (0.57 to 1.50)	43.2	1.10 (0.74 to 1.63)	1.10 (0.73 to 1.65)
Maintaining Behaviors (Most Activated)	37.0	22.9	Ref.	Ref.	40.1	Ref.	Ref.
* Adjusted for age, sex, race, site, educat	tion, avoidance of care	e due to costs, history	of coronary heart disease, l	nistory of hypertension			

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(HRQOL) between 1 month and 3 months and between 1 and 6 months after hospital discharge by level of patient activation at 1 month after hospital Prevalence of and adjusted odds ratios (95% confidence intervals) for a clinically meaningful increase or decrease in disease-specific quality of life discharge for an acute coronary syndrome: TRACE-CORE, 2011-13

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SAQ QOL Scores			Clinically Meanir	ıgful Decrease		Clinically Meani	ngful Increase
	% experiencing no clinically meaningful no HRQOL	% experiencing clinically meaningful decrease in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CI)*	% experiencing clinically meaningful increase in HRQOL	Unadjusted OR (95% CI)	Adjusted OR (95% CI)*
1 to 3 Months							
Overall Sample	62.8	12.8		1	24.4		
Disengaged (Least Activated)	53.0	20.0	3.18 (1.65 to 6.17)	2.69 (1.36 to 5.31)	27.0	1.63 (0.95 to 2.79)	1.49 (0.86 to 2.61)
Aware	59.5	14.1	1.99 (1.21 to 3.29)	1.88 (1.12 to 3.15)	26.4	1.42 (0.99 to 2.03)	1.44 (1.00 to 2.09)
Taking Action	64.1	13.2	1.74 (0.98 to 3.09)	1.66 (0.93 to 2.98)	22.7	1.13 (0.74 to 1.73)	1.11 (0.72 to 1.71)
Maintaining Behaviors (Most Activated)	69.8	8.3	Ref.	Ref.	21.9	Ref.	Ref.
1 to 6 Months							
Overall Sample	59.6	13.5	ı	ı	26.9		
Disengaged (Least Activated)	49.0	24.0	2.51 (1.38 to 4.59)	2.18 (1.17 to 4.05)	27.0	1.40 (0.81 to 2.40)	1.24 (0.71 to 2.18)
Aware	58.3	12.4	1.09 (0.69 to 1.73)	1.06 (0.66 to 1.71)	29.3	1.27 (0.90 to 1.79)	1.33 (0.93 to 1.90)
Taking Action	62.3	12.7	1.05 (0.61 to 1.80)	1.07 (0.62 to 1.85)	25.0	1.02 (0.67 to 1.53)	1.00 (0.65 to 1.52)
Maintaining Behaviors (Most Activated)	62.9	12.3	Ref.	Ref.	24.8	Ref.	Ref.
* Adjusted for age, sex, race, site, educa	tion, avoidance of care	e due to costs, history	of coronary heart disease, l	nistory of hypertension			