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High Patient Activation Is Associated With Remission in Patients With Inflammatory Bowel Disease

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Background: High levels of patient activation (having the knowledge, skills, and confidence to effectively manage one's care), have been associated with improved outcomes in many chronic conditions. There have been few studies of the effects of activation in patients with inflammatory bowel disease (IBD). We performed a large, prospective Internet-based study to assess the relationship between patient activation level and clinical remission in patients with Crohn's disease or ulcerative colitis.

Methods: We administered the Patient Activation Measure (Insignia Health) to 1486 cohort participants. Patients completed a follow-up survey within 13 months (median, 189 days). We collected demographic and clinical data; anxiety and depression were assessed using Patient-Reported Outcomes Measurement Information System instruments. We used bivariate analyses and multivariable logistic regression to identify characteristics associated with low or high patient activation and to evaluate the association between levels of patient activation and subsequent disease activity.

Results: Higher anxiety (adjusted odds ratio [aOR], 0.32; 95% confidence interval [CI], 0.29–0.36) and depression (aOR, 0.33; 95% CI, 0.29–0.37) scores were associated with a decreased odds of high patient activation. After we adjusted for education status, smoking, medication use, and other confounders, we found that patients with high activation at baseline were more likely to be in clinical remission during the follow-up period (aOR, 1.71; 95% CI, 1.20–2.45).

Conclusions: In a large, prospective Internet-based cohort of patients with IBD, we found a strong association between patient activation and clinical remission. These findings suggest that patient activation affects disease outcomes.

Key Words: PAM, disease activity, clinical outcomes, psychologic factor

INTRODUCTION

As the care of patients with inflammatory bowel disease (IBD) has become more complex, it is even more important that providers engage patients in the decision-making process. Patient involvement in the management of IBD is particularly critical to improving treatment adherence,[1–3] especially in the setting of an expanding array of medical and surgical treatments for Crohn's disease (CD) and ulcerative colitis (UC).

There is an increased interest in the concept of patient activation,[4] which is defined by a patient's demonstration of the skills, knowledge, and motivation needed to effectively manage one's health and participate in health care decisions.[5, 6] In many chronic conditions, higher levels of patient activation have been linked to improvements in health outcomes,[6, 7] better patient experiences related to their health care,[8] and lower overall health care costs.[9, 10] In comparison, less activated patients demonstrate higher unmet medical needs and are significantly more likely to delay medical care.[11] In prospective evaluations, increases in patient activation over time have been linked to significant improvements in health management behaviors such as regular exercise, stress management, and dietary modifications.[12] In other populations, increasing patient activation through tailored interventions has been associated with improved adherence and decreased resource utilization such as hospitalizations.[13, 14]

Although patient activation has not been extensively investigated among patients with IBD, it is highly relevant given the strong desire of patients to be involved in their care[15, 16] and an increased emphasis on shared decision-making.[16] Given the association between better health outcomes and higher levels of patient activation in other chronic conditions, we hypothesized that patients with IBD demonstrating high patient activation at baseline would be more likely to demonstrate clinical remission in follow-up evaluations when

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compared with patients with low patient activation. We performed a prospective cohort study utilizing the Crohn's and Colitis Foundation's IBD Partners Internet-based cohort to identify patient-specific and disease-related factors associated with high levels of patient activation and to assess the relationship between patient activation level at baseline and clinical remission in follow-up.

METHODS

Study Population

We identified patients with a self-reported history of UC or CD within IBD Partners, an Internet-based cohort of patients with IBD. The study cohort has previously been described in detail.[17–19] Since its initiation in 2011, >15,000 patients with self-reported IBD have enrolled in the cohort. Members complete baseline and follow-up surveys (given at 6-month intervals). Surveys include core questions with information on disease phenotype, activity, medication use, and patient-reported outcomes (PROs), along with optional "modules" to assess specific areas of interest among patients with IBD. For this study, we invited consecutive patients who completed an IBD Partners survey between June 2, 2016, and January 5, 2017, to complete the 13-item survey of patient activation known as the Patient Activation Measure (PAM; Insignia Health)[20] as an optional module.

Survey Instruments

Patient activation measure

Each of the 13 items in the PAM is followed by a 4-point Likert scale (Supplementary Table 1). The PAM assesses 4 levels of activation: (1) the patient is disengaged and overwhelmed, (2) the patient is becoming aware but still struggling, (3) the patient takes action, and (4) the patient maintains behaviors. In the creation of the original PAM, Rasch analysis was used to select an initial set of items for inclusion,[5] which allows for the creation of unidimensional scales from ordinal data, in addition to calibrating the difficulty of an item as related to response probabilities. Once a measure has been created, individuals can then be assessed in relation to a particular scale. When evaluating the PAM, a respondent's location on the scale indicates how activated the patient is.[5] The psychometric properties of the PAM have been assessed in multiple health care settings.[21–23] Based on varying levels of agreement or disagreement to the 13 statements included in the PAM, scores were transformed from the initial patient response scale to a continuous (0–100) scale, where higher scores represent higher levels of patient activation.[5, 20] Using prespecified threshold values,[10, 20] patients were grouped into the 4 levels of activation. For our analyses, high patient activation was defined as level 3 or level 4 activation.[10, 24] We also performed sensitivity analyses comparing those patients with level 4 activation (the highest activation) with all other patients surveyed.

Clinical remission

Clinical remission was defined as a short Crohn's Disease Activity Index (sCDAI)[25] score ≤150 for subjects with CD or a Simple Clinical Colitis Activity Index (SCCAI)[26] score ≤2 for subjects with UC.

Study Variables

In addition to the PAM and disease activity measures, other demographic and clinical factors were collected, including age, sex, years since IBD diagnosis, history of IBD-related surgery, maximum education level attained, and tobacco use. Anxiety and depression were assessed using Patient-Reported Outcomes Measurement Information System (PROMIS) instruments. Developed by the National Institutes of Health, PROMIS instruments are general measures, not specific to IBD, that have been previously described in the IBD Partners population.[27] These measures are calibrated using a T-score metric, with the mean of the general population equal to 50 and the standard deviation equal to 10.

Statistical Analysis

Cross-sectional analysis

Continuous variables were summarized using means and SDs and compared using the Student *t* test and Wilcoxon rank-sum test as appropriate. Categorical variables were expressed as proportions and compared using Fisher exact and chi-square testing. Bivariate and multivariable logistic regression models were utilized to evaluate the clinical and demographic characteristics that were associated with high (level 3 or level 4) patient activation. In creating the odds ratios (ORs) for anxiety and depression, ORs were transformed to indicate the odds of an increase in anxiety or depression 1 SD from the mean T score. The decision to include covariates in the final multivariable models was made a priori, based on prior associations with patient activation or the clinical course of patients with IBD.

Prospective analysis

We used similar bivariate techniques as those described above to evaluate the relationship between patient activation and clinical remission during the follow-up period. Additionally, we used multivariable logistic regression to control for potential confounders when evaluating the relationship between patient activation and clinical remission. All covariates included in the multivariable analysis were identified a priori based on prior association with patient activation or clinical disease activity in IBD. We intentionally did not include anxiety or depression

in the analyses of patient activation and disease activity in the follow-up period. This decision was based on prior evaluations that have demonstrated an association between anxiety and depression and disease activity in the IBD Partners population[28, 29] and prior demonstrations of a significant relationship between patient activation and depression.[30] We believe that the relationship between anxiety and depression and clinical remission may be in part mediated by patient activation (and thus patient activation may be on the causal pathway between anxiety/depression and disease activity). In addition, we made the intentional decision not to adjust for baseline disease activity based on prior literature suggesting the potential bias in adjusting for baseline disease status when performing evaluations such as disease activity over time.[31]

All statistical analyses were performed using SAS (version 9.4) statistical software (SAS Institute, Cary, NC, USA). The study protocol was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

RESULTS

Study Population

The study population included 1486 total participants (976 with CD [66%] and 510 with UC [34%]) from all 50 states and Puerto Rico, along with 84 patients from other countries. Overall, the response rate to the PAM module was 84%. There were no demographic or clinical differences among those who declined to participate when compared with the responders. The full demographic and clinical characteristics of patients completing the PAM module are presented in Table 1. The mean age of participants (SD) was 43.8 (15.2) years; 74% were female. Of the 1486 total participants, 77% reported their highest level of education as college or graduate school. The mean disease duration (SD) was 14.4 (12.6) years, with 43% of patients with CD reporting a history of CD-related surgery.

Predictors of High Patient Activation

Overall, 1259 (85%) respondents demonstrated high levels of patient activation, defined as level 3 or 4 activation. In the unadjusted analysis, patients with a history of IBD-related surgery demonstrated an increased odds of high patient activation (OR, 1.48; 95% confidence interval [CI], 1.07–2.05), whereas nonwhite patients (OR, 0.57; 95% CI, 0.33–0.97), and those reporting current smoking (OR, 0.40; 95% CI, 0.21–0.78) had a decreased odds of high patient activation; however, these results were not significant in multivariable analysis (Table 2). In both unadjusted and multivariable analysis adjusting for confounders, patients with higher anxiety (adjusted OR [aOR], 0.40; 95% CI, 0.34–0.46) and higher depression scores (aOR, 0.40; 95% CI, 0.34–0.46) demonstrated a decreased odds of high patient activation. Patients with longer disease duration demonstrated an increased odds of high patient activation (aOR, 1.42; 95% CI, 1.02–1.97).

Patient Activation and Remission

Of the 1486 participants who completed the PAM module, 1082 (73%) completed a follow-up survey within 13 months of their baseline survey (median interval [interquartile range], 189 [183–209] days). Those patients who did not complete a follow-up survey were less likely to demonstrate high patient activation at baseline (81% vs 86%; $P = 0.008$). The other demographic and clinical comparisons of these groups are depicted in Supplementary Table 2.

In the evaluation of the relationship between patient activation level and remission, patients with high activation at baseline were significantly more likely to demonstrate clinical remission at the follow-up assessment (65% vs 51%; $P = 0.002$, Figure 1). When analyzed with multivariable analysis, high patient activation at baseline was associated with clinical remission at follow-up after adjusting for potential confounders (aOR, 1.71; 95% CI, 1.20–2.45, Table 3). In a sensitivity analysis comparing patients with level 4 activation with all others, the relationship between high patient activation at baseline and clinical remission at follow-up was also demonstrated after adjusting for potential confounders (aOR, 1.74; 95% CI, 1.34–2.25) (Supplementary Table 3).

DISCUSSION

In a prospective analysis using a large, geographically diverse cohort of patients with IBD, we prospectively demonstrated that patients scoring in the highest levels of patient activation were more likely to be in clinical remission during subsequent surveys. This demonstrates a potential role for patient activation in the disease course of patients with IBD and suggests the need for efforts to design and test interventions to improve patient activation in this population. Additionally, in a cross-sectional analysis, we identified a positive association between patient activation and time since diagnosis and inverse relationships between patient activation and anxiety and depression.

In a prior cross-sectional study that utilized the PAM to evaluate patient activation among IBD patients in the Veterans Affairs system, Munson et al.[32] demonstrated strong correlations between patient activation and health-related quality of life. Our results expand upon this earlier study in a number of ways. First, the demographics of our cohort were quite different than in this VA population, which was 90% male with a median age of 63 years.[32] Additionally, our study utilized a prospective design and evaluated outcomes of patient-reported disease activity/remission.

In a cross-sectional study of more than 25,000 patients presenting for primary care visits, Greene and Hibbard demonstrated an association between higher patient activation and a variety of health-related outcomes including improved blood pressure control and follow-up with recommended preventive screening.[7] Although the rates of smoking were higher than those reported in our population, Greene and Hibbard[7] also demonstrated a stark decrease in rates of smoking moving

TABLE 1. Comparison of Demographics and Clinical Characteristics Among Patients From IBD Partners Comparing Patients With Low (1 and 2) vs High (3 and 4) Levels of Patient Activation

	Low Patient Activation (Levels 1–2) (n = 227)		High Patient Activation (Levels 3–4) (n = 1259)	
Ulcerative colitis, No. %	75	33	435	35
Age, mean (SD), y	43.4	(15.5)	43.9	(15.2)
Female sex, No. %	169	74	928	74
Race, No. %				
White	208	91	1197	95
African American	4	2	14	1
Asian	4	2	11	1
More than 1 race	5	2	26	2
Other	6	3	11	1
US Census Bureau Region, No. %				
Northeast	19	18	86	82
Midwest	43	14	268	86
South	57	15	328	85
West	56	12	394	88
Age at IBD diagnosis, mean (SD), y	30.9	(13.7)	29.2	(13.4)
Time since IBD diagnosis, mean (SD), y	12.5	(12.2)	14.7	(12.6)
Education, No. %				
<12th grade	5	2	7	1
12th grade	14	6	68	5
Attended college, did not graduate	48	21	200	16
Graduated from college	88	39	546	44
Graduate school	72	32	438	35
Current smoker, No. %	15	7	38	3
Saw a gastroenterologist in the past year, No. %				
Never	16	8	75	6
1–2 times	106	50	654	55
3–4 times	61	29	318	27
≥5 times	28	13	134	11
Saw a primary care provider in the past year, No. %				
Never	14	7	88	8
1–2 times	97	49	675	60
3–4 times	57	29	274	24
≥5 times	30	15	94	8
History of Crohn's disease–related surgery,[a] No. %	73	13	492	60
Hospitalized for IBD in the past year, No. %	23	11	107	9
Medication use at initial assessment, No. %				
No medications	51	22	289	23
Combination therapy with a biologic and an immunomodulator	31	14	204	16
Biologic therapy	74	33	370	29
Immunomodulator	32	14	154	12
Aminosalicylate	39	17	242	19
Clinical remission at initial assessment, No. %	88	43	725	65
High anxiety at baseline,[b] No. %	67	30	133	11
High depression at baseline,[b] No. %	80	35	174	14

[a]History of surgery only assessed among patients with Crohn's disease.
[b]Anxiety and depression were assessed by PROMIS measures; high anxiety or depression were defined as 1 SD from the mean.

TABLE 2. Odds of High Patient Activation Among Participants in IBD Partners, Unadjusted and Adjusted Analyses

	Unadjusted OR (95% CI)	Adjusted OR[a] (95% CI)
Female sex	0.93 (0.66–1.32)	1.28 (0.89–1.83)
Race		
White	Reference	Reference
Nonwhite	0.57 (0.33–0.97)	0.82 (0.44–1.55)
Education		
12th grade or less	0.94 (0.50–1.76)	1.22 (0.61–2.45)
Attended college, did not graduate	Reference	Reference
Graduated from college	1.46 (0.97–2.19)	1.13 (0.73–1.76)
Graduate school	1.38 (0.91–2.09)	0.99 (0.63–1.56)
Time since diagnosis, y		
≤10	Reference	Reference
>10	1.66 (1.21–2.26)	1.42 (1.02–1.97)
Current smoker	0.40 (0.21–0.78)	0.68 (0.33–1.42)
History of IBD-related surgery	1.48 (1.07–2.05)	1.42 (0.98–2.04)
Medication use at initial assessment		
No medications	1.20 (0.72–1.99)	1.45 (0.84–2.49)
Combination therapy	1.41 (0.81–2.44)	1.71 (0.95–3.08)
Biologic	1.06 (0.67–1.69)	1.08 (0.66–1.77)
Immunomodulator	Reference	Reference
Aminosalicylate	1.28 (0.76–2.14)	1.29 (0.75–2.24)
Anxiety[b]	0.32 (0.29–0.36)	0.32 (0.29–0.36)
Depression[b]	0.32 (0.29–0.36)	0.33 (0.29–0.37)
Ulcerative colitis	1.05 (0.77–1.44)	1.25 (0.87–1.80)

[a]All variables listed above were included in the final multivariable analysis.
[b]Anxiety and depression were assessed by PROMIS measures; odds ratios depicted above indicate odds associated with an increase in anxiety or depression 1 SD from the mean T score.

from level 1 of patient activation to level 4. In several other chronic disease states such as multiple sclerosis[33] and HIV,[34] higher patient activation scores have been associated with better health-related outcomes such as increased adherence and higher CD4 counts. Perhaps most concerning for patients with chronic, potentially debilitating diseases such as UC and CD, less activated patients are more likely to delay medical care.[11]

We have shown that IBD patients with high activation are more likely to achieve remission. Patients with IBD and high activation may be more adherent to therapies or may be more proactive in engaging in healthy behaviors such as exercise,[35] all of which could lead to increased rates of remission. Prospective interventional studies to evaluate the effectiveness of different strategies to improve patient activation are needed. Several prior studies in non-IBD populations have evaluated interventions for improving patient activation, including peer support groups[36, 37] and tailored coaching[13, 14] approaches aimed at increasing self-management techniques. In 1 randomized study of patients with heart failure, patients in the intervention group underwent a 6-month program aimed at increasing patient activation and self-management behaviors. These patients demonstrated significant increases in patient activation, along with improvements in medication adherence and lower rates of hospitalization when compared with the standard care group.[13]

Similar efforts to improve patient activation, where targeted goals are tailored to an individual's activation level,[14] have the potential to significantly impact the management of patients with IBD. Targeting interventions at an individual's activation level allows a patient to build a sense of confidence, increasing the ultimate likelihood of successful intervention. For example, at the lowest level of activation (level 1), interventions might focus on building self-awareness of how behaviors might impact the disease course of CD or UC. At the highest level of activation (level 4), interventions could be focused on handling new challenges or stresses in the management of CD and UC as they arise, in an effort to prevent disease relapse.[14] Finally, targeting specific populations for interventions may also prove beneficial. In addition to evaluating patient activation, larger-scale programs screening for anxiety and depression among patients with IBD could identify patients with psychiatric comorbidities. Targeting patients with both low activation and psychiatric comorbidities may allow for the use of concomitant interventions to improve activation and anxiety and depression, which may ultimately improve clinical outcomes.

Given the association of decreased health care utilization among patients with high patient activation,[6, 7, 9] efforts to identify patients with low patient activation who may be at increased risk of disease relapse may allow for such tailored interventions. Additionally, as treatment paradigms shift toward more shared decision-making processes,[16] increasing patient activation could represent 1 strategy to improve communication between patients and providers. Although there have been few published studies regarding patient activation among patients with IBD thus far, most patients with IBD express a desire to be involved in the decision-making process[15] and thus would likely welcome an opportunity for increased engagement with their provider.

When evaluating predictors of high patient activation, patients with a prior history of IBD-related surgery were more likely to demonstrate high patient activation in the unadjusted analysis. Prior surgery may be a marker of more severe disease, and thus the increase in activation may be a focused response to preceding events. We also demonstrated a decreased odds of having high patient activation among patients of nonwhite race in the unadjusted analysis. We are likely underpowered to fully evaluate this relationship given the small population of nonwhite patients in IBD Partners. Additionally, although we did not assess health literacy, in prior evaluations of internal

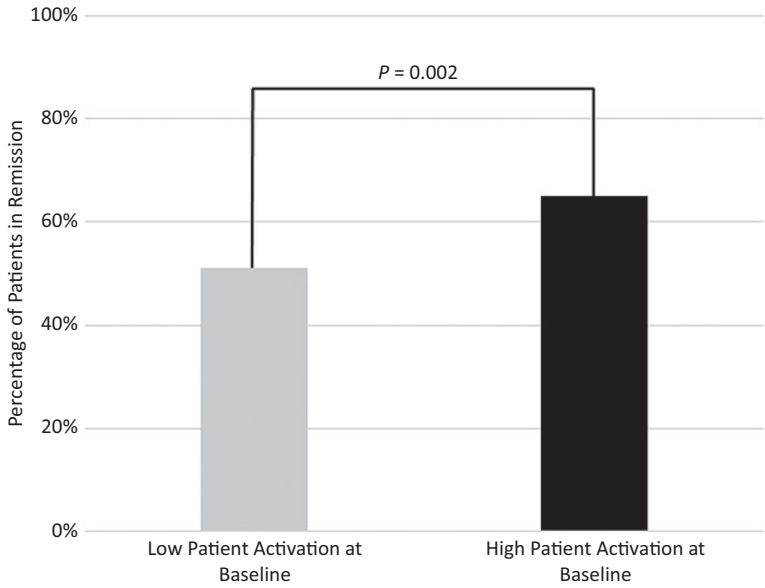

FIGURE 1. The percentage of patients in remission at follow-up, comparing patients with high activation with patients with low activation.

TABLE 3. Odds of Remission at Follow-up Survey Among Participants in IBD Partners, Unadjusted and Adjusted Analyses for All Patients With IBD

	Unadjusted OR (95% CI)	Adjusted OR[a] (95% CI)
Patient activation		
Low patient activation	Reference	Reference
High patient activation	1.74 (1.23–2.46)	1.71 (1.20–2.45)
Female sex	0.84 (0.63–1.11)	0.83 (0.62–1.10)
Race		
White	Reference	Reference
Nonwhite	0.74 (0.42–1.31)	0.73 (0.41–1.30)
Education		
12th grade or less	0.86 (0.48–1.53)	0.84 (0.47–1.51)
Attended college, did not graduate	Reference	Reference
Graduated from college	1.19 (0.84–1.71)	1.17 (0.81–1.68)
Graduate school	1.42 (0.98–2.04)	1.38 (0.95–2.01)
Time since diagnosis, y		
≤10	Reference	Reference
>10	0.97 (0.76–1.24)	0.96 (0.69–1.34)
Current smoker	0.62 (0.31–1.23)	0.75 (0.31–1.79)
Medication use at initial assessment		
No medications	0.60 (0.39–0.94)	0.60 (0.38–0.95)
Combination therapy	0.66 (0.42–1.06)	0.64 (0.40–1.02)
Biologic	0.73 (0.48–1.12)	0.74 (0.48–1.13)
Immunomodulator	Reference	Reference
Aminosalicylate	0.74 (0.47–1.15)	0.71 (0.45–1.13)

[a]All variables listed above were included in the final multivariable analysis.

medicine and geriatric populations, the relationship between race and patient activation was significantly mediated by education and health literacy.[38, 39]

Our study was large, including a cohort of patients with self-reported UC or CD and careful methodology that has been utilized in numerous other studies within IBD Partners.[17–19, 28, 29] However, our study also has limitations. Given that the IBD Partners cohort is a voluntary Internet-based cohort, participants may exhibit higher levels of patient activation than the general IBD population, which may limit the generalizability of our findings. Despite the relatively selected population of the IBD Partners cohort, including a large number of college graduates, prior studies of IBD Partners participants have replicated the findings of these studies using other methods.[28, 29] Although the population represented all regions of the United States, we did not have access to other geographic or socioeconomic factors that may also influence patient activation such as urban or rural location, household income,[40] or employment status. To evaluate patient activation and clinical remission in this population, we used validated survey instruments that have been utilized previously in IBD Partners.[19, 25, 26, 28, 29] However, we did not have more objective evidence of clinical remission in this study, such as laboratory or endoscopic data. Although the majority of participants completed follow-up 6 months after the initial PAM assessment, there was some heterogeneity present in the interval between responses. We did have a loss of 27% of patients in the prospective evaluation, and these participants demonstrated lower patient activation at baseline compared with those participants who completed follow-up assessments. Given that high patient activation was associated with an increased odds of remission, the overall demonstration of significant findings despite the

lack of follow-up among this set of patients would seem to strengthen our findings.

In conclusion, using a large cohort of patients with IBD, we found that patients with high activation at baseline were more likely to be in remission during follow-up assessments. Patient activation is a relatively novel concept in IBD, and these findings suggest that patient activation may play an important role in disease outcomes. As this is a modifiable factor, screening for patient activation, coupled with appropriate interventions to improve patient activation among those patients with low activation levels, could improve care and ultimately improve outcomes among patients with IBD.

SUPPLEMENTARY DATA

Supplementary data are available at *Inflammatory Bowel Diseases* online.

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