The Effect of a Tailored Patient Activation Intervention in Inflammatory Bowel Disease Patients

Chisom Kanu, MS; Carolyn Brown, PhD; Jamie Barner, PhD; Casey Chapman, MD; Heather Walker, RN

Abstract

Purpose

A pre-test, post-test, control group design was employed to investigate the impact of a tailored patient activation intervention (PAI) among inflammatory bowel disease (IBD) patients.

Methods

Patients who met the inclusion criteria were selected from medical records via convenience sampling, were consented, and completed a baseline survey. Based on responses to the baseline 13-item patient activation measure (PAM-13), they were categorized into one of four patient activation stages. During office visits, intervention patients (N=23) were given a tailored PAI based on their baseline stage, which consisted of an information booklet and focused discussion with the gastroenterologist, while the control group (N=27) received usual care. Baseline and 1-month post-intervention scores were compared between the intervention (N=20) and control (N=21) groups for changes in patient activation score, medication adherence, and satisfaction with care.

Results

Most participants were Caucasian (88%), female (64%), college graduates (56%), and had Crohn's disease (59.2%). Overall, females had a significantly higher (p=0.04) mean activation score (mean=70.9±15.4) than males (mean=60.9±10.7) at baseline. This trend was the same post-intervention (75.6 females vs 64.4 males; p=0.03). The difference in mean activation scores pre- vs post-intervention was not statistically significant between the intervention and control groups (mean=4.9±12.3, p=0.21). However, this difference could be considered to be clinically significant based on results from previous studies. There were no significant differences in medication adherence or satisfaction scores pre- vs post-intervention for either group.

Conclusion

Tailored PAIs have the potential to increase activation level of patients with inflammatory bowel disease. This customized medical interaction increased patient involvement in disease management and could potentially lead to improved health outcomes.

Keywords

Patient activation; patient activation intervention (PAI); tailored intervention; inflammatory bowel disease

Introduction

Inflammatory bowel disease (IBD) is characterized by relapsing and remitting inflammation of the intestinal tissue, giving rise to a myriad of physical, psychological, and social disabilities in patients with this condition. Crohn's disease and ulcerative colitis are the two major manifestations of IBD. Crohn's disease can affect the entire gastrointestinal tract while ulcerative colitis is confined to the large intestine. These life-altering disease manifestations are not associated with increased mortality; however, individuals that suffer from them have increased morbidity and decreased quality of life. Although the exact etiology of this immunologic disease is unknown, a combination of genetic, environmental, and immunoregulatory factors have been implicated in its occurrence.\(^1\)\(^2\)

IBD is more prevalent in developed countries like the United States and United Kingdom, with a higher occurrence in urban than rural areas. This trend can be attributed to changes in lifestyle, diet, and frequency of exposure to pollutants resulting from westernization.\(^3\) Even though IBD is a relatively rare disease, accounting for a small proportion of annual healthcare budgets, the lifetime treatment costs of individual patients are comparable to those of patients with major diseases like diabetes.\(^4\) Overall, costs vary widely depending on disease severity with the costs of severely ill patients being three to nine times higher than that of patients in remission. Hospitalization account for 55 to 63 percent of direct medical costs with an average cost per hospitalization of $37,459.\(^5\) Ulcerative colitis cost-of-illness profile is similar to that of Crohn's disease.\(^4\)

Even though adherence to treatment regimens is a major determinant of disease outcome, a large percentage of patients with IBD do not respond positively to pharmacologic therapy due to poor adherence, and consequently suffer from disease flares. In general, rates of non-adherence in patients with IBD is 20 percent for short-term therapy and escalates to 50 percent during long-term therapy.\(^1\) This trend is especially common in patients whose inflammation is in remission. Such patients are least likely to adhere to IBD treatment regimen when they feel well.\(^6\)\(^8\)

Patients' motivation and the degree of behavioral change required are two important factors that affect the level of patients' adherence to their treatment regimen. The knowledge, skills, and confidence that a patient possesses about his/her disease condition and management are directly proportional to his/her adherence rate. These qualities have been termed “patient activation.” Highly activated patients partner with their healthcare providers...
to manage their disease condition, which results in better health outcomes.9

In 2004, Hibbard et al. described the development of the patient activation measure (PAM), which enables the assessment of an individual’s knowledge, skills, and confidence for managing his or her health and healthcare. The PAM is an interval-level, unidimensional, 13-item instrument that measures a patient’s willingness and ability to manage his/her health and healthcare. It is a highly reliable and valid instrument. Rasch analysis shows that the 22-item PAM scale has infit (0.71 to 1.44) and outfit (0.80 to 1.34) values within the normal range of 0.5 to 1.5. Also, the 22-item Rasch person reliability ranges from 0.85 (real) to 0.88 (model) and the Cronbach’s alpha is 0.91. The psychometric scores of the 13-item scale are similar to that of the 22-item version. The PAM-13 items have a calibrated scale range of 38.6 to 53.0, which is comparable with the PAM-22 item range of 38.3 to 54.5. The infit and outfit statistics for the PAM-13 items also fall within the acceptable scale range of 0.5 to 1.5. The statistically significant relationships (p < 0.001) between the PAM scores and conceptual variables (such as preventive behaviors, disease-specific self-management behaviors, and consumeristic behaviors) are evidence of the scale’s construct validity.9,10 Patient activation, as outlined in the PAM, involves four progressive stages, with higher stages indicating a higher level of activation and willingness/ability to participate in disease management. Patients in activation stage 1 usually do not feel in charge of their own health. These patients tend to lack basic knowledge about their condition as well as confidence in their ability to manage their health while patients in stages 4 have typically made the necessary behavior changes with regard to managing their health. However, they may have difficulty with being consistent over time, or during times of stress.10,11

A number of studies have examined the impact of activating patients with different chronic diseases such as diabetes, depression, HIV, and hypertension with results showing the financial, clinical, and psychological benefits of such interventions.12-14 The few studies that have investigated the relationship between patient activation and IBD provide evidence that there is a positive relationship between activation and quality of life. In particular, a study by Munson et al. showed a 26 percent correlation between patient activation scores and quality of life measures in patients with IBD.15 However, the impact of a tailored patient activation intervention (PAI) among patients with IBD has not been investigated to date.

The purpose of this study was to evaluate the effectiveness of a PAI tailored to the needs of individual patients with IBD in improving their activation scores as well as their medication adherence and satisfaction with medical care.

Methods

Using continuous enrollment, convenience sampling was utilized by the clinic staff at the gastroenterology clinic to select patients from the clinic medical records who had office visits scheduled for the months of April to August 2016. Patients who were eligible for study inclusion were adult patients with IBD who received care at the study site. Eligible patients were contacted by clinic staff via emails and phone calls to offer participation in the study. Patients who expressed willingness to participate were assigned a unique number by clinic staff in order to track baseline and post-intervention measures. Patients of the physician administering the PAI were assigned to the intervention group while patients of a different physician were assigned to the control group. All patients then received the baseline survey in the mail or electronically via a link to the University of Texas at Austin Qualtrics portal.

The PAM scores from the first survey served as a baseline and were used to group each unique patient in the intervention group into the different PAM stages. The charts of patients in the intervention group were then flagged by clinic staff with their patient activation stage prior to their appointment. The physician administering the PAI helped to develop the intervention but did not receive any extra training to administer it. During scheduled office visits, which lasted for about 12 to 15 minutes, the physician of intervention group patients implemented the PAI by tailoring patient-physician discussion to each patient’s baseline PA stage (PAM score). Patients in the control group received usual medical care from their physician during their scheduled office visit. The 27-item baseline survey instrument (Table 2) consisted of the PAM (13 items; score range of 0-100, with higher scores indicating greater activation), the Morisky Medication Adherence Scale (MMAS-4) (4 items; score range of 0-4, with higher scores indicating greater adherence), demographic/clinical questions (8 items), and 2 items measuring overall satisfaction with care in terms of care received and information provided (score range 0-5, with higher scores indicating greater satisfaction). The 13-item PAM16 and MMAS-416-18 are validated instruments that have been in used in numerous peer-reviewed studies. Therefore, additional validation of the survey used in this study was not deemed necessary. The PAM and MMAS-4 can both be licensed for a fee from Insignia Health (www.insigniahealth.com) and MMAS Research LLC (www.morisky.org), respectively. The 1-month post intervention survey was similar to the baseline survey except that it did not measure demographics. Similar to the baseline assessment, patients received the follow-up survey in the mail or electronically via a link to the University of Texas at Austin Qualtrics portal.

The PAI was a stage-based intervention designed to move patients to a higher activation stage or at least increase activation scores within a stage. To facilitate meaningful patient-physician interaction, an educational booklet containing disease, lifestyle, and treatment information about IBD was adopted by the intervention group physician using information from the Crohn’s and Colitis Foundation of America (CCFA), Crohn’s and Colitis Advocate Program, and the Centers for Disease Control websites. The booklet was divided into three sections:

• The first section contained general information about IBD; the two main manifestations, common symptoms, and questions to facilitate meaningful discussion with a healthcare provider.

• The second section contained information about how to maintain a healthy lifestyle with IBD and included information on triggers of disease flares, symptoms that indicate a disease flare, dietary recommendations to stay in remission, and tips to remain healthy when traveling.

• The third section contained information on available IBD treatment options, the goals of treatment, complementary therapies that have shown some benefit in IBD management, disease monitoring parameters as well as questions to guide meaningful discussion with healthcare providers.
Patients in the control group were all patients of a second physician in the same practice and only received routine medical care from their physician during their scheduled office visit. Patients in the intervention and control groups were contacted by clinic staff to complete the second survey one month after their office visit. Those who completed the second survey received a $10 gift card.

Analysis of pre- and post-intervention data was conducted after the one-month post-intervention surveys were completed using SAS 9.4. The a priori alpha level for all inferential analyses was set at 0.05. Independent groups t-tests, paired t-tests, and chi-square tests were used to test score differences between and within the two study groups based on patients’ responses to survey items on patient activation, medication adherence, and satisfaction with care. The normality of interval level variables was assessed by measuring the symmetry and kurtosis of each variable’s distribution. None of the interval level variables were problematic as their values fell within the threshold for skewness (≤ 1) and kurtosis (≤ 7). Fisher’s exact test was used instead in cases where the chi-square test assumptions of independence and percentage of expected cell counts were not met.

Finally, the key points in the booklet were provided as a summary on the last page in addition to a feedback section designed to encourage patient feedback on pressing IBD-related concerns.

The study team ensured that the information in the three sections of the booklet mapped on to the first three PAM stages in terms of relevant stage-specific knowledge. For patients in stage 4, PAI emphasis was on encouragement and provision of information to reinforce and/or update already existing knowledge. All the subsections were combined into a single booklet instead of separate-section booklets.

During scheduled office visits, the physician of the intervention group patients implemented the PAI according to each patient’s baseline patient activation stage. The PAI consisted of an educational session with the physician during which relevant disease and treatment information were provided to the patient with particular emphasis on information relevant to their activation stage. For patients with IBD in stage 1, the PAI emphasized IBD prognosis, treatment options, and the importance of participating in disease management. For stage 2 patients, the PAI emphasized the benefits of being actively involved in disease management and how to cue aspects of disease management with daily activities. Signs and symptoms that signify worsening of the disease condition were also emphasized for stage 3 patients. In addition, they were informed of the resources at their disposal to seek help during a disease flare-up in order to prevent ED visits. Patients in stage 4 were encouraged to remain partners in managing their IBD despite changes in disease severity or the occurrence of life events. Table 1 contains a summary of the PAI emphasis for patients at different activation stages.

| Baseline stage of patient activation | Stage 1 (≤ 41) | Stage 2 (42 < 50) | Stage 3 (50 – 51) | Stage 4 (≥ 52) |
|-------------------------------------|---------------|------------------|------------------|--------------|
| **Baseline Clinical Knowledge**     | No specific knowledge about disease | Knowledge about disease but low confidence to participate in management | Doesn’t know how to monitor disease progression or appropriate action to take during flares | Active participant in disease management |
| **PAI emphasis**                    | • Disease prognosis  
• Treatment options  
• Importance of being active in disease management | • Benefits of being involved in disease management  
• How to cue aspects of disease management with daily activities | • Signs and symptoms that signify worsening of IBD  
• Available resources during a disease flare | • Encourage patients to remain partners in managing their health despite changes in their disease severity or occurrence of life events |
### Table 2: Baseline survey

**Section 1:** This set of questions asks about your involvement in managing your inflammatory bowel disease (referred to as IBD from this point on). Please check the option that best corresponds to your response for each question!

|   | Disagree Strongly | Disagree | Agree | Agree Strongly | N/A |
|---|------------------|---------|------|----------------|-----|
| 1. When all is said and done, I am the person who is responsible for managing my health. |         |       |     |                |     |
| 2. Taking an active role in my own health care is the most important factor in determining my health and ability to function. |         |       |     |                |     |
| 3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health. |         |       |     |                |     |
| 4. I know what each of my prescribed medications does. |         |       |     |                |     |
| 5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself. |         |       |     |                |     |
| 6. I am confident I can tell a doctor concerns I have even when he or she does not ask. |         |       |     |                |     |
| 7. I am confident that I can follow through on medical treatments I need to do at home. |         |       |     |                |     |
| 8. I understand the nature and causes of my health problems. |         |       |     |                |     |
| 9. I know the different medical treatment options available for my health condition. |         |       |     |                |     |
| 10. I have been able to maintain the lifestyle changes for my health that I have made. |         |       |     |                |     |
| 11. I know how to prevent further problems with my health. |         |       |     |                |     |
| 12. I am confident I can figure out solutions when new situations or problems arise with my health. |         |       |     |                |     |
| 13. I am confident I can maintain lifestyle changes, like diet and exercise, even during times of stress. |         |       |     |                |     |
Section 2: Next, we are interested in how you take your IBD medications. Please check the option that best corresponds to your answer for each question.

14. Do you ever forget to take your medicine?
   - Yes
   - No

15. Do you ever have problems remembering to take your medication?
   - Yes
   - No

16. When you feel better, do you sometimes stop taking your medicine?
   - Yes
   - No

17. Sometimes if you feel worse when you take your medicine, do you stop taking it?
   - Yes
   - No

Section 3: The following questions are about your level of satisfaction with the medical care you receive for your IBD as well as how often severe symptoms have resulted in you visiting the emergency department. Please select the option that corresponds to your response for each question.

18. Overall, how satisfied are you with the medical care experience for your IBD?
   - □ Very Dissatisfied
   - □ Dissatisfied
   - □ Neutral
   - □ Satisfied
   - □ Very Satisfied

19. Did the medical education provided by your doctor increase your satisfaction with the care he/she provided?
   - □ Definitely No
   - □ Probably No
   - □ Probably Yes
   - □ Definitely Yes
Section 4: Finally, we would like to learn a little about you and the present state of your IBD. Please fill in your response or select the option that best corresponds to your answer for each question.

| Question                                                                 | Answer |
|--------------------------------------------------------------------------|--------|
| 20. What year were you born in?                                          | 19____ |
| 21. What is your gender?                                                 | ☐ Male  ☐ Female |
| 22. Which of the following best describes your race/ethnicity?           | ☐ African-American or non-Hispanic black  ☐ American Indian or Alaska Native  ☐ Asian-American or Pacific Islander  ☐ Caucasian or non-Hispanic white  ☐ Mexican-American or Hispanic  ☐ Other (please specify) |
| 23. What is your highest level of education?                             | ☐ Less than High School  ☐ High School Graduate or GED  ☐ College graduate  ☐ Other (please specify) |
| 24. What type of IBD were you diagnosed with?                            | ☐ Ulcerative colitis  ☐ Crohn’s disease  ☐ Other (please specify) |
| 25. How would you describe the current state of your IBD?                | ☐ Active  ☐ In remission |
| 26. How long ago were you diagnosed with IBD?                            | ☐ 6 months or less  ☐ greater than 6 months to 1 year  ☐ greater than 1 year to 18 months  ☐ greater than 18 months to 2 years  ☐ greater than 2 years to 3 years  ☐ greater than 3 years to 4 years  ☐ greater than 4 years to 5 years  ☐ greater than 5 years |
| 27. What is/are the name of the IBD medication(s) you are currently taking? |                                  |

Adapted from the 13-item Patient Activation Measure\(^1\) and Morisky Medication Adherence Scale (MMAS-4 © 2007\(^2\))

\(^1\)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(6 Pt 1):1918-1930.

\(^2\)The MMAS (4-item) content, name, and trademarks are protected by US copyright and trademark laws. Permission for use of the scale and its coding is required. A license agreement is available from Donald E. Morisky, ScD, ScM, MSPH, MMAS Research LLC., 294 Lindura Ct. Las Vegas NV 89138-4632, USA; dmorisky@gmail.com.
Ethical Considerations
The study was conducted in accordance with the guidelines set forth by The University of Texas Institutional Review Board (IRB). The application sent to the IRB for review was approved.

Results
Fifty patients from the gastroenterology clinic completed the baseline survey (N=23, intervention group and N=27, control group). The demographic characteristics of the study participants are described in Table 3. The mean age of patients was 48 years. The majority were Caucasian (88%), female (64%), college graduates (56%), and had Crohn's disease (59.2%). Half had been diagnosed with IBD for over five years. The distribution of participants between the two states of IBD was approximately equal, with 51 percent having an active disease inflammation. The distribution of patients in the two study groups was similar across the different drug classes. Most patients on monotherapy were either on aminosalicylates (16.7%) or biologics (22.9%), and a quarter (25%) were on a treatment regimen with IBD drugs from more than one class. There was high retainment of study participants as 82 percent (41 participants) of the original 50 respondents completed the post-intervention survey (N=20, intervention group and N=21 control group). Only the responses of these 41 patients were used for inferential data analysis.

After converting the PAM-13 responses to a patient activation score (ranging from 0 to 100) using the PAM-13 scoring spreadsheet, the patient activation scores were used to categorize patients into one of four patient activation stages (Table 4). Most patients were in the higher stages of activation (stages 3 and 4) at baseline. Patients in the PAI group and control group had a similar distribution across the 4 stages. However, the average difference in pre- vs post-patient activation scores of the PAI group (mean=6.8) was almost five points higher than that of the control group (mean=1.9) (Table 5).

Overall, the pre-post difference in medication adherence (p=0.25) and patient satisfaction scores (p=0.97) were not statistically significant for both groups. The mean adherence scores were fairly high (range of 2.85-3.68) in both intervention and control groups in the pre- and post-intervention periods. Similarly, satisfaction scores (range of 4.15-4.62) were high at baseline and post-intervention.

Discussion
Most patients in the intervention and control groups were already in the higher stages of activation at baseline. However, the difference in pre- vs post-patient activation scores of the intervention group patients was almost five points higher than that of control group patients. This indicates that the intervention was successful in increasing the activation level of intervention group patients and consequently improving their confidence, skill, and knowledge in actively managing their health. Sub-analysis to compare the activation score changes by patient activation stage were not conducted due to the small sample size.

Tailoring PAIs could help ensure that patients get the maximum benefit of efforts to increase activation, irrespective of baseline activation stage. Given the movement of patients even at higher activation levels in this study, it seems reasonable to assume that lower-level activation groups would benefit greatly from customized PAI. Greater changes might be seen in patients at lower activation stages (stages 1 and 2) because they have much more room for improvement than patients at the higher levels of activation (stage 3 and 4). Interventions targeted at improving patient activation in different patient populations have demonstrated activation score improvements ranging from 2.5 to 6 points on the 100-point activation scale. A study by Deen et al. showed that patients at the lower activation stages (stages 1 and 2) generally have a more marked increase in activation after an intervention than highly activated patients (stages 3 and 4), who tend to have slight to moderate increases in activation. This finding might be a result of the one-size-fits-all nature of interventions typically employed to improve patient activation. Consequently, a 6.8-point increase in the mean patient activation score of intervention group patients who were in the higher activation stages at baseline was remarkable. In addition, the approximately 5-point mean difference in pre-post activation scores between the intervention and control group could be considered to be clinically significant, as other studies have shown that a 5-point increase in patient activation scores is associated with improved clinical outcomes and is sufficient to move a patient from one stage of activation to the next higher stage. The statistical non-significance might be due to the small sample size. Moreover, the short follow-up time in this study might not have effectively captured the full effects of the PAI including its potential impact on health outcomes. Future studies in patient activation and health outcomes are warranted.

A similar pre- vs post-intervention trend was observed in the medication adherence and satisfaction scores for patients in the intervention group and the control group. The scores at baseline were generally high, tending toward the highest level of adherence (scores of 3 and 4 on the MMAS-4) and satisfaction (satisfied and highly satisfied). There were no significant changes from pre- to post-intervention, likely because the patients had minimal room for improvement from baseline. These findings are consistent with literature findings which show that high activation scores are associated with higher self-reported medication adherence and patient satisfaction. The effects of the intervention employed in this study may have been underestimated given the already high activation scores of the study participants at baseline. However, the findings suggest that even for patients at high activation stages, activation scores can be successfully improved with tailored interventions.
Table 3: Demographic Characteristics of Study Participants

| Variable               | Frequency (%) | Mean (SD) |
|------------------------|---------------|-----------|
| Age (n = 50)           |               | 47.8 (18.2)|
| **Study group (n = 50)** |               |           |
| Control                | 27 (54.0)     |           |
| Intervention           | 23 (46.0)     |           |
| **Gender (n = 50)**    |               |           |
| Male                   | 18 (36.0)     | 9 (33.3)  |
| Female                 | 32 (64.0)     | 18 (66.7) |
| **Race (n = 50)**      |               |           |
| Caucasian              | 44 (88.0)     | 23 (85.2) |
| African American       | 5 (10.0)      | 4 (14.8)  |
| Hispanic               | 1 (2.0)       | 0 (0.0)   |
| **Education (n = 49)***|               |           |
| Less than high school graduate | 2 (4.0) | 0 (0.0) |
| High school graduate   | 19 (38.0)     | 8 (30.8)  |
| College graduate       | 28 (56.0)     | 18 (69.2) |
| **Type of IBD (n = 49)*** |           |           |
| Ulcerative colitis     | 18 (36.7)     | 11 (42.3) |
| Crohn’s disease        | 29 (59.2)     | 13 (50.0) |
| Other                  | 2 (4.1)       | 2 (7.7)   |
| **State of IBD (n = 47)*** |           |           |
| Active inflammation    | 24 (51.1)     | 13 (50.0) |
| In disease remission   | 23 (48.9)     | 13 (50.0) |

| Study group | P value |
|-------------|---------|
| Control (%) | 0.77    |
| Intervention (%) |        |

*Chi-square test
**Study Limitations**

There were some limitations in this study. First, 18 percent of the 50 patients (n=9) that completed the baseline survey did not fill out the post-survey. Second, all the data used in the study were self-reported. There was no objective validation of participants’ responses which could have been subject to recall bias or social desirability. Third, it is possible that more engaged patients chose to participate in this research leading to higher initial scores and non-significant changes from pre- to post-intervention. Fourth, study participants were followed for only one month. Consequently, the long-term effects and durability of the intervention, could not be assessed. Fifth, the intervention was not administered by a pharmacist. However, a majority of pharmacists are typically involved in patient education/counseling and the intervention in this study could be equally done by a pharmacist in a community or clinical pharmacy setting. Sixth, clinical significance of study results was based on findings from other studies and was not defined a priori. Finally, the study sample was from only one clinic and the patients at this site might not be representative of the national IBD population. Consequently, the study results can only be generalizable to IBD populations similar to participants at the study site.

**Suggestions for Future Research**

Although our study findings are encouraging, further research is needed to replicate this study in a larger and more diverse population of patients with IBD (and other chronic disease patients) and with different healthcare providers administering the intervention. Even though the intervention in this study was administered by a physician, pharmacists are ideal healthcare providers to consistently administer such interventions to improve patient activation in IBD as well as other chronic disease patients. With current advancements in provider status for pharmacists, this could be another avenue for pharmacists to provide value-based care to patients that is customized to “meeting patients where they are.” A study published by Milani et al. in 2017 examined the effects of a digital hypertension program to improve blood pressure control, which consisted of patient education, drug management, and lifestyle recommendations by pharmacists and health coaches. Study results showed significant 90-day improvement in blood pressure control rates and patient activation scores as well as a decrease in sodium consumption of the 156 study participants with uncontrolled hypertension.

Although tailored PAIs have been shown to increase activation irrespective of baseline activation stage, greater changes might be seen in patients at lower activation stages (stages 1 and 2). Thus, targeting stage 1 and 2 patients could provide a greater return on investment and should be the subject of future studies. In addition, the follow-up time of future studies should employ periods longer than one month post-intervention in order to assess the long-term effects of the intervention. If higher patient activation results in improved outcomes (e.g., lower use of healthcare resources, improved quality of life), then incorporating tailored PAIs in routine care could represent a quality of care improvement opportunity.

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**Number of years since diagnosis with IBD (n = 50)**

| Time Since Diagnosis  | Less than 1 year | 1 - 5 years | More than 5 years |
|-----------------------|------------------|-------------|-------------------|
|                       | 8 (16.0)         | 17 (34.0)   | 25 (50.0)         |
|                       | 3 (11.5)         | 6 (23.1)    | 17 (65.4)         |
|                       | 5 (21.7)         | 10 (43.5)   | 8 (34.8)          |

**IBD drug (n = 48)**

| Type of Drug               | Less than 1 year | 1 - 5 years | More than 5 years |
|----------------------------|------------------|-------------|-------------------|
| Aminosalicylates           | 8 (16.7)         | 5 (20.0)    | 3 (13.0)          |
| Corticosteroids            | 1 (2.1)          | 0 (0.0)     | 1 (4.3)           |
| Immunosuppressants         | 4 (8.3)          | 1 (4.0)     | 3 (13.0)          |
| Biologics                  | 11 (22.9)        | 5 (20.0)    | 6 (26.1)          |
| More than 1 IBD drug class| 12 (25.0)        | 7 (28.0)    | 5 (21.7)          |
| Adjunct therapy alone      | 2 (4.2)          | 1 (4.0)     | 1 (4.3)           |
| No IBD drug                | 10 (20.8)        | 6 (24.0)    | 4 (17.4)          |

* N < 50 since some respondents did not answer demographic/clinical questions
### Table 4: Patient Activation Staging Distribution

|                  | Stage 1  | Stage 2  | Stage 3  | Stage 4  |
|------------------|----------|----------|----------|----------|
|                  | N (%)    | N (%)    | N (%)    | N (%)    |
| **Pre-intervention** |          |          |          |          |
| Control (n = 21)  | 2 (9.5)  | 2 (9.5)  | 9 (42.9) | 8 (38.1) |
| PAI (n = 20)      | 1 (5.0)  | 4 (20.0) | 7 (35.0) | 8 (40.0) |
| Total (n = 41)    | 3 (7.3)  | 6 (14.7) | 16 (39.0)| 16 (39.0)|
| **Post intervention** |          |          |          |          |
| Control (n = 21)  | 1 (4.8)  | 2 (9.5)  | 7 (33.3) | 11 (52.4)|
| PAI (n = 20)      | 0 (0.0)  | 3 (15.0) | 7 (35.0) | 10 (50.0)|
| Total (n = 41)    | 1 (2.4)  | 5 (12.2) | 14 (34.2)| 21 (51.2)|

### Table 5: Average Patient Activation Scores

| Study group                  | Control (n = 21) | Intervention (n = 20) | Mean score difference between groups | T-test | P value |
|------------------------------|------------------|-----------------------|--------------------------------------|--------|---------|
| Pre intervention score mean (SD) | 69.4 (17.3)     | 65.4 (11.4)          | 4.0 (14.7)                           | 0.86   | 0.39    |
| Post intervention score mean (SD) | 71.3 (14.3)     | 72.2 (16.9)          | - 0.9 (15.7)                        | -0.18  | 0.86    |
| Pre vs Post intervention score difference | 1.9 (12.5) | 6.8 (12.0) | - 4.9 (12.3) | -1.27 | 0.21    |
Conclusion

Studies have shown that patient activation is a modifiable factor that influences patients' participation in their health management and consequently impacts treatment outcomes. This study showed that a tailored PAI via education and focused patient-physician interaction had an impact on the patient activation scores of patients with IBD, which could be considered clinically significant based on results from previous studies. Tailoring PAIs might be an effective approach in providing relevant medical support to patients with IBD. Such interventions are likely to be more effective than a one-size-fits-all approach in consistently improving patient activation irrespective of baseline activation stage.

About the Authors

Chisom Kanu, MS is a doctoral candidate in the Health Outcomes & Pharmacy Practice division, College of Pharmacy, University of Texas at Austin. Her research interests center around patient activation which involves empowering patients with chronic conditions to be active participants in managing their health. She has no conflicts of interest to report.

Carolyn Brown, PhD is a Professor of Health Outcomes & Pharmacy Practice division at the College of Pharmacy, University of Texas at Austin. She holds a Tanabe Research Regents Endowed Faculty Fellowship and is a co-director of Texas Center for Health Outcomes Research and Education (TxCORE). Her research interests primarily involve understanding cultural and social elements that may impact both quality of care and therapeutic outcomes of patients with chronic illnesses. She has no conflicts of interest to report.

Jamie Barner, PhD is a Professor of Health Outcomes & Pharmacy Practice division at the College of Pharmacy, University of Texas at Austin. She holds an Abbott Centennial Fellowship in Pharmacy and is the current division head. Her research interests include examining the impact of pharmacy services on patient outcomes and understanding factors that affect health care utilization and outcomes. She has no conflicts of interest to report.

Casey Chapman, MD is Board Certified in Gastroenterology and practices at Gastroenterology Associates which is part of the Digestive Health Center of Louisiana in Baton Rouge, Louisiana. Dr. Chapman holds membership in the American College of Gastroenterology, Louisiana Gastroenterology Society, and the Crohn's and Colitis Foundation. He has no conflicts of interest to report.

Heather Walker, RN is a Board Certified Advanced Nurse Executive and the Director of Clinical Services at Gastroenterology Associates in Baton Rouge, Louisiana. She has no conflicts of interest to report.

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