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Spanish and English Language Symposia to Enhance Activation in Pediatric Inflammatory Bowel Disease

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Abstract

Background—Patient activation is an important consideration for improved health outcomes in the management of chronic diseases. Limited English proficiency (LEP) among patients and primary care providers has been shown to be a predictor for worse health across disease states. We aimed to determine the baseline patient activation measure (PAM) among Spanish-speaking (SP) and English-speaking (ES) pediatric IBD patients and parents, and to describe the feasibility and efficacy of a novel peer-group education symposium designed to enhance patient activation as measured with the PAM.

Methods—Two separate half-day educational symposia in either Spanish or English were presented and moderated by 2 native Spanish-speaking physicians. Content for each of the presentations were highly standardized and interactive, designed to address each of the activation domains (self-management, collaboration with a health care provider, maintenance of function and prevention of disease exacerbation, and appropriate access to high-quality care). Descriptive statistics were used to describe changes between pre- and post-symposium PAM trends.

Results—11 primarily SP and 21 ES families participated in their respective symposium. Paired pre- and post-PAM scores were available from 24 pediatric IBD patients (8 SP; 16 ES) and 41 parents (15 SP; 26 ES). The mean age for SP and ES patients was 11.6 and 12.0 years, and female gender in 80% and 62%, respectively. Paired pre- and post-PAM scores for all participants (n=65) were analyzed. PAM scores uniformly increased in all 4 groups after the symposia (SP-patients 59.1 to 70.3, $P=0.05$; SP-parents 69.8 to 75.2, $P=0.2$; ES-patients 59.9 to 64.0, $P=0.08$; ES-parents 61.9 to 69.1, $P=0.002$), although only the ES-parents group had sufficient sample size (n=26) to achieve statistical significance. The overall cohort had an aggregate increase from pre-PAM of 62.9 (SD 14.5) to post-PAM of 69.4 (SD 13.9) (<0.001).

Conclusion—We describe a novel peer-group educational symposium presented in Spanish and English languages to increase patient and parent activation in pediatric IBD patients and their care-giving parents. The use of PAM to assess levels of activation appears to be feasible and effective in these groups.

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Conflict of Interests

Authors have no conflict of interest to report.

Keywords

Patient activation; patient engagement; limited English proficiency; pediatric inflammatory bowel disease; PAM

INTRODUCTION

High-value care in pediatric inflammatory bowel disease (IBD) requires patients and their families to actively participate in health maintenance and disease management.¹ Adherence to therapy plans and engagement in health care are particularly important given the natural relapsing and remitting course of IBD. Research evidence has highlighted the importance of patient “activation” – the possession of motivation, knowledge, skills and confidence to effectively co-manage chronic disease within the health care system.^{2,3,4,5,6} For pediatric populations, since parents adopt a major role in the co-management of their child’s care, the construct of parent activation has also been described.⁷

The patient activation measure (PAM) is a validated tool to assess activation levels in English and Spanish speaking patients based on adult studies.⁸ The PAM consists of a short survey that results in a score of 0–100 (higher scores reflect higher patient activation levels) assessing 4 specific consensus domains: 1) self-management, 2) collaboration with a health care provider, 3) maintenance of function and prevention of disease exacerbation, and 4) appropriate access to high-quality care. The parent-PAM is a parallel measure developed to assess parental activation for management of their child’s health.⁷ As higher levels of patient activation have been linked to improved health outcomes and lower health care costs,^{9,10} the PAM is increasingly used to assess the impact of interventions designed to optimize patients’ ability to manage their chronic disease.

Although pediatric IBD represents a high-risk and vulnerable patient group with high rates of non-adherence¹¹ to treatment regimens, limited pediatric IBD literature exists on measuring patient or parent activation or on interventions to increase it. In addition, many of the existing studies assessing adherence or engagement with healthcare in pediatric IBD have excluded non-English speaking individuals. There is robust literature describing limited English proficiency (LEP) as a known predictor for worse health outcomes.^{12,13,14,15,16,17} LEP patients and families are particularly vulnerable to known barriers of receiving high-value care within the health care system, especially in patients living with chronic disease.^{18,19,20,21,22} One study found that LEP parents had 3-fold increased odds of having a child with worse overall health and 2-fold increased odds of increased acute care services.¹³

Based on our knowledge of patient activation and the increasing need to provide IBD-specific education to affected families whose primary language is not English in our IBD Center, we hypothesized that: 1) LEP is a contributor for lower patient and parent activation in Spanish-speaking (SP) compared English-speaking (ES) IBD families; and 2) a peer-group educational symposium for pediatric IBD patients and their parents would be effective in increasing activation in both groups. The objective of our pilot intervention study was to 1) determine the baseline PAM among SS and ES IBD patients and parents and 2) describe

the feasibility and efficacy of a novel peer-group education symposium designed to enhance patient activation as measured with the PAM.

METHODS

Patient Identification and Enrollment

This was a pilot intervention study focused on IBD patient and parents' activation at Stanford Children's IBD Center. We performed a within-center patient registry (~500 pediatric IBD patients) query to find eligible patients. We obtained institutional IRB approval prior to beginning the study. Inclusion criteria included age 8–21 years with biopsy-confirmed Crohn's disease (CD) or ulcerative colitis (UC), primarily followed at Stanford Children's IBD Center, attending at least 75% of their scheduled outpatient appointments, absence of other medical conditions, and having either English or Spanish the preferred parental language. Participants were recruited via patient encounters, letters, telephone calls, and emails. A total of 11 primarily SP and 21 ES families agreed to participate.

Spanish and English peer-group educational symposia took place at Lucile Packard Children's Hospital at Stanford on two different Saturdays, one week apart. The SP symposium occurred on the first Saturday, and the ES symposium occurred on the following Saturday. Informed written consent from parents and assent from pediatric patients were obtained on the day of the symposium as part of the registration process. Two native Spanish-speaking physicians were the designated lecturer and moderator (MM and MG) for both SP and ES cohorts. The content in the presentations for both symposia were highly standardized and interactive.

Development of a Peer-Group Education Symposium

Designed to address all 4 major consensus domains in PAM with respect to IBD co-management, the symposium contents were finalized over a 4-month period through multiple course-development sessions by all co-investigators on this study (KP, AY, MG, RB, MC, and MM). Final descriptive titles for 3 presentations within the symposium are the following: 1) "*Patient activation and IBD 101*," 2) "*Quality of Life, Nutrition and Exercise*," and 3) "*Medication Adherence and Family Dynamics*." Each Power Point presentation was designed to last approximately 40 minutes in content with a flexible 15 to 30 minutes of interactive question-and-answer period and breaks between sessions. The entire symposium (Supplemental Digital Content Table 1) was designed to take place between 8:45 AM to 12:30 PM on the assigned Saturday morning.

Collection of Pre- and Post-PAM & Exit Survey

The PAM-SF (Insignia Health) was completed by each patient, and the parent-PAM was completed by representative parent(s) in the language of choice (English or Spanish) before and after the symposium. A separate 4-question exit survey regarding overall satisfaction and general recommendations with the content and delivery of the symposia was collected (Supplemental Table 1).

Statistical Analysis

Descriptive statistics were used to describe changes between pre- and post-PAMs. The Student T-Test assessed for differences in PAM scores between groups. The Chi-square test compared categorical data between the groups.

RESULTS

Paired pre- and post-PAM scores were available from 24 patients (8 SP; 16 ES) and 41 parents (15 SP; 26 ES). Table 1 summarizes the patient characteristics in both SP and ES cohorts. The mean age for SP and ES patients was 11.6 and 12.0 years, and female gender in 80% and 62%, respectively. The SP cohort had more participants with UC (80%) than CD compared to the ES cohort (p value <0.05). In addition, the SP cohort was also more likely to have government-subsidized insurance (p value <0.05). Pre- and post-PAM scores were similar across cohorts.

We assessed the variance of pre- and post-PAM scores within patient- and parent-participants. Figure 1 shows a box plot with median, 25th to 75th percentiles, and 95% confidence interval bars.

Paired pre- and post-PAM scores for all participants (n=65) were analyzed. The mean pre-PAM score was 62.9 (SD 12.5). The mean post-PAM score was 69.4 (15.1). Table 2 shows that this aggregate increase represented a statistically significant change (<0.001).

Each of the 4 groups within the 2 cohorts was assessed separately, as shown in Table 2. PAM scores uniformly increased in all 4 groups after the symposia (SP-patients 59.1 to 70.3, P=0.05; SP-parents 69.8 to 75.2, P=0.2; ES-patients 59.9 to 64.0, P=0.08; ES-parents 61.9 to 69.1, P=0.002) with the SP-patients showing the largest incremental change among the groups, although only the ES-parents group had sufficient sample size (n=26) to achieve statistical significance. Trends reflecting this data are shown in Figure 2.

DISCUSSION

High levels of patient activation have been associated with improved health outcomes in patients managing chronic disease.^{2,5} Although limited data are available around effective interventions to improve activation in children and adolescents and their care-providers, we performed a pilot education symposium in pediatric IBD patients and parents designed to enhance all 4 domains of patient activation levels.

A single prior study describes an intervention aiming to improve activation within pediatric IBD.²³ Our study is the first of its kind with a focus on parental activation within pediatric IBD and inclusion of individuals with a preferred language other than English. From our initiative, we showed that PAM scores uniformly increased for all four groups after the SP- or ES-specific symposium. Although only one of the four groups (ES-parents) demonstrated statistical significance when comparing pre- versus post-PAM scores, the pooled cohort data achieved significance. This may indicate that a family-centered, peer-group education symposium in either English or Spanish may be effective in enhancing patient and parent activation in families affected by pediatric IBD.

While a prior study of the PAM demonstrated lower scores for foreign born Latino individuals, highlighting the potential disparity in healthcare engagement,²⁴ we did not find lower levels of baseline activation in the cohort of families with preferred Spanish language compared with preferred English speaking families as hypothesized. However, the small sample size for the SP cohort should be noted. Also, we observed a larger variation of pre-PAM scores (Table 2) for SP-parents. This would indicate baseline heterogeneity of activation in this group, which is observed in the clinical setting, including LEP parents of children affected by IBD who may be less enabled to actively engage in their child's IBD management within the health care infrastructure.

From clinician perspective, there is a growing need to actively engage LEP families affected by pediatric IBD. Epidemiologic evidence has described changing demographics of IBD worldwide, as it is no longer considered a disease limited to the Western Hemisphere.²⁵ Both the prevalence and incidence of IBD in minority groups, especially Hispanics, have increased with a rising annual incidence rate of approximately 8 per 100,000.²⁶

We acknowledge the several limitations of our study. First, our sample size was small. Even though we detected clear statistical significance in increased PAM before and after the symposium when all participants' scores were analyzed, we can only report increased PAM trends for individual groups. Secondly, activation was only measured at the time of the intervention and thus the durability of effect was not assessed. Third, we acknowledge that this was a pilot, clinician-driven initiative and may be subject to selection bias, although all IBD patients and families were welcome on a "first come, first served" basis. Future work needs dedicated guidance from experts in the field of child and family psychology along with input from patients and families. Lastly, since the PAM is not validated in children and our study is the first to report PAM scores in parents of pediatric IBD patients, established normative PAM values are not available for comparison.

There was overwhelming positive feedback about the usefulness of our peer-group education symposium. The majority of our participants noted the interactive nature of sharing patient and family experiences with IBD as an extremely helpful byproduct of the symposia. They described improved "connectedness" and empowering knowledge to better manage IBD.

In summary, this pilot intervention study highlights the importance of engaging families affected by pediatric IBD. We show the feasibility of a well-designed, clinician-initiated education symposium in pediatric IBD. Such an intervention, if standardized and reproduced, may be an effective and underutilized approach to improve patient and family activation levels, regardless of language and demographics. Although future work is needed to substantiate our preliminary findings and determine the durability of patient activation, it appears that proactively initiating a bidirectional dialogue between pediatric patients/families and providers within peer-group settings – focused around disease management education – is able to contribute to higher-value IBD care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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WHAT IS KNOWN

- Patient activation is an important predictor of health outcomes in patients affected by chronic disease.
- Previous studies in adults have validated the use of the Patient Activation Measure Short Form (PAM-SF) to assess quantifiable activation levels.
- Limited English proficiency (LEP) negatively affects patient activation, but data are lacking in pediatric inflammatory bowel disease (IBD).

WHAT IS NEW HERE

- The use of a novel, clinician-designed education symposium aimed to enhance patient activation in each of the four activation domains is feasible and effective, regardless of primary language (Spanish or English) in pediatric IBD patients and parents.
- Pre- vs post-symposium PAM trends increased for Spanish- and English-speaking patients and parents, and the aggregate change for all participants was statistically significant (< 0.001).
- A peer-group educational symposium can be an effective approach to increase patient and parent activation for children and adolescents affected by IBD and their care-giving parents.

Figure 1.
Pre- vs post-PAM Scores by Quartiles for all Parents and Patients

Figure 2.
Trends in Pre- vs Post-Symposium PAM Scores

Table 1

Participant Characteristics and PAM Scores

	Spanish Patients	English Patients	P-Value
Mean Age	11.6	11.95	0.812
Age at Diagnosis	9.2	9.95	0.633
%Female (n): %Male (n)	80% (8): 20% (2)	62% (13): 38% (8)	0.314
%UC (n): %CD (n)	80% (8): 20% (2)	38% (8): 62% (13)	0.029
%Gov't Subsidized Insurance (n)	90% (9)	4% (1)	<0.001
Pre-PAM Mean	59.1	59.9	0.888
Post-PAM Mean	70.3	64.0	0.213
	Spanish Parents	English Parents	P-Value
Pre-PAM Mean	69.8	61.9	0.183
Post-PAM Mean	75.2	69.1	0.207

Table 2

Within-Group Comparison of Pre- vs Post-Symposium PAM Scores

	Pre-PAM Score	Pre-PAM SD	Post-PAM Score	Post-PAM SD	P-values
SP-Patients (n=8)	59.1	12.742	70.3	10.975	0.055
SP-Parents (n=15)	69.8	20.110	75.2	14.180	0.218
ES-Patients (n=16)	59.9	10.727	64.0	11.398	0.078
ES-Parents (n=26)	61.9	12.491	69.1	15.120	<0.001
All Participants	62.9	14.488	69.4	13.859	<0.001