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Recall of Care Objectives by Patients with Inflammatory Bowel Diseases

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Abstract: The management of IBD is highly complex, given the heterogeneity of treatment plans for an equally diverse patient population. Given the intricacy of treatment, improved health literacy may be associated with better outcomes. Methods: Patients were assessed before and after their endoscopy and for their knowledge of their disease status, their correct recall of the endoscopy results, their provider–patient communication, and communication preferences. Results: A total of 37 patients completed both surveys and were included in the final analysis. The median age was 45 years. The median number of years diagnosed with IBD was 13. Most patients correctly recalled the results of their surveillance endoscopy after their procedure (84%). Many patients (65%) felt they were equally involved in the decision making process in regard to their surveillance endoscopies. Most patients (92%) reported having results clearly explained to them. Most patients (76%) preferred receiving an email or patient message with results, and 69% of patients reported receiving results in the way they preferred. Conclusions: Most of the patients with IBD who were surveyed had adequate knowledge of their disease process and could accurately recall the results of their endoscopy. However, the delivery of health information can be optimized, as nearly one-third of our patients did not receive their endoscopy results in their preferred method.

Keywords: inflammatory bowel diseases; patient education; endoscopy

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1. Introduction

Inflammatory bowel disease (IBD) is a chronic condition that requires patients to often undergo extensive and complicated medical management, routine endoscopies to monitor disease activity, and occasional surgical intervention. Even 8 years after post-diagnosis, those with IBD are recommended to undergo colorectal cancer screening every 1 to 5 years depending on the severity of the disease [1]. A study in Manitoba, between 1988 and 2008, showed cumulative incidence of surgery for newly diagnosed patients with Crohn's Disease (CD): 13%, 24%, 32% and 39% at 1, 5, 10, and 20 years, respectively [2]. Patients with CD often have complications such as fistulas and frequent refractory disease, which leads to a complex treatment regimen with multiple medications [3–5]. Patients with difficulty understanding health information have been found to be 3.4 times more likely to be physically inactive and three times more likely to have unhealthy dietary habits [6]. Difficulty in understanding health information suggests a fragmented understanding of a patient's disease process, and may unfortunately lead to practices contraindicated to optimal disease control. The course of a patient's disease can be significantly affected with an incomplete understanding of medical management. Thus, the intricacies of IBD treatment require providers to work closely with patients to develop a safe and effective treatment plan in order to better understand one's disease.

Patient health literacy and changes in outcome among adult patients with IBD have not been adequately studied. One study that examined the assessment of transitioning pediatric patients with IBD to adult care found a disparity between formal assessment of patients, 11%, using regimented guidelines and informal assessment of patients, 47%, determined by their clinicians [7]. Misconception of IBD health literacy may not be limited to pediatrics and adolescents, but it may very well apply to adults patients with IBD. One of the primary factors in patient health literacy and shared decision making as the model for optimal patient care is the ability to recall information after a discussion with a health care provider. One study demonstrated that patients with better recall of information after a GI consultation clinic visit also had better IBD medication compliance [8]. Other chronic health recall studies found that 83% of lung cancer patients knew the treatment procedure proposed, 49% recalled the goal of treatment, and only 39% were satisfied with communication of their treatment goal [9]. Two small studies have shown that a printed endoscopy report given immediately after the procedure leads to better patient understanding of their results and recollection compared to a simple verbal report [10,11]. Studies on IBD-related patient recall as well as in general IBD information recall are lacking. Based on the studies from other chronic diseases, patient recall of health information is contingent on both the health report per se and the means of how that report is relayed to the patient.

Although IBD treatment management can be highly complex and challenging to learn for patients, an IBD patient who is well versed in IBD literature may likely be associated with better health outcomes and patient empowerment. Thus, it is important for health care providers to assess and address gaps in a patient's knowledge of his or her health information as part of the treatment plan. The goal of this study is to investigate patients with IBD' accuracy to specifically recall the results of their IBD surveillance endoscopies and to examine effective means of relaying health reports to patients with IBD.

2. Methods

2.1. Objectives

The study will assess if there is a correlation of more informed patients utilizing shared decision making with their providers more frequently. The education and level of care of the cohort seems to be contingent on the complexity of their chronic disease and the level of demand for frequent procedures, thus the primary objective of the study compared the patient's ability to correctly recall information about their upcoming endoscopy. Furthermore, the study examined the patient's ability to accurately recall their endoscopy results when their preferred method of health information delivery was met. The secondary objective was to educate patients with the physician's rationale for the endoscopy and to tailor the physician's delivery of health information based on the patient's preference.

2.2. Design

The study was approved by UCLA IRB protocol number 16-000183-AM-00001.

Patients were contacted by email at least 2 days prior to their endoscopy appointment. Typically, the physician performing the endoscopy was also the one providing explanations and answering questions. The participants were selected from the city of Westwood and Santa Monica, California, IBD clinics between March 2017 and January 2018. Patients were asked to participate by using de-identified web-based questionnaires before and after their endoscopy through a 128-bit secure sockets layer (SSL) encrypted link. The link led to a data capture tool called REDCap (Research Electronic Data Capture), a web-based application used in research studies for secure data capture, hosted at UCLA. REDCap provides a user-friendly interface for data entry, tracking of data manipulation and data export, data export procedures for use in common statistics programs, and data import procedures for use of external data. No patient health information identifiers were collected.

The prerequisite for this study included: identification as male or female, at least 18 years of age, diagnosed with IBD (Crohn's disease or ulcerative colitis) by endoscopy or radiologic evaluation, able to give informed consent, and had an upcoming scheduled endoscopy with participating physicians. Patients who completed questionnaires for both before and after the endoscopy were included in the study.

2.3. Questionnaire and Data Collection

In this study, questionnaires prior to the endoscopy and questionnaires post endoscopy were administered to participants. The questionnaire prior to the endoscopy asked the patient whether they understood the following: (1) the type of endoscopy to be performed, (2) the diagnosis of their disease, (3) pinpoint the location of their disease using an illustrated colon, (4) indication for their endoscopy, (5) level of involvement in the decision for an endoscopy. The questionnaire given after the endoscopy assessed the following: (1) the type of endoscopy performed, (2) the diagnosis of their disease, (3) current location of their disease, (4) the contents of the endoscopy findings, and (5) delivery preference for their endoscopy results (e.g., in-person, electronic delivery, mail).

2.4. Outcomes

We analyzed descriptive statistics of our patients with IBD in respect to two categories: Patient knowledge of disease and patient–provider communication. To characterize patient knowledge, we calculated the percentage of our cohort who could: (1) correctly recall the type of endoscopy they would be receiving, (2) correctly self-identify the diagnosis of their IBD, (3) recall the major result(s) of the endoscopy received, (4) remember the initial reason for the procedure, and (5) identify the location of the affected area post-endoscopy. To characterize patient–provider communication, we calculated the percentage of patients who: (1) chose from a four-point scale of the level of involvement in the decision-making for the initial endoscopy, (2) reported to receive a full explanation of their results, (3) had a preferred method for receiving their results, and (4) claimed to have received their results in their preferred method.

2.5. Definition and Scale Specifics

In order to determine the accuracy of the patient's response, the answers were compared to the physician's last progress note or endoscopy report of the patients.

(1) Disease location post-endoscopy was categorized as fully correct if the response matched all the locations listed in their endoscopy results, and the response was categorized as partially correct if the response matched some, but not all the affected section listed in the report. Finally, responses that did not match any of the locations listed in the progress note or endoscopy report were categorized as incorrect.

(2) The accuracy of the patient's knowledge of their upcoming endoscopy was graded as correct, incorrect, or "did not know".

(3) The patient's preferred method of medical information delivery was compared to the actual delivery of their results post-endoscopy as shown in the electronic medical record.

3. Results

3.1. Patient Characteristics

Emails were sent out to a total of 152 patients requesting completion of the pre-procedure survey. Out of requested cohort, 59 patients (38.8%) completed the pre-procedure survey. A total of 37 participants (62.7% of completed pre-procedure survey) completed the post-procedure survey after completing the pre-procedure survey (Table 1). All 37 patients who completed both surveys were included in the analysis. Out of a total of 37 patients, 15 (62.2%) were male, the median age was 45 years (range 22–81), the majority of the patients identified as not Hispanic/Latino (88.9%), 21 patients (56.8%) were diagnosed with Crohn's Disease, 15 (40.5%) were diagnosed with Ulcerative Colitis, and 1 (2.7%) was diagnosed with IBD Unclassified (IBDU). The median number of years diagnosed with IBD was 13 (range 1–49 years). In the population of patients who did not respond to the survey (n = 115), the median age was 39 years (range 20–81), 63 of the patients in this category were male, and 52 were female.

Table 1. Demographics of the included patients vs. the non-respondents.

Demographics of IBD Population	
N = 37	
Male sex, n (%)	23 (62%)
Age, median (range), years	45 (22–81)
Disease duration, median (range), years	13 (1–49)
Ethnicity, n (%)	
Hispanic or Latino	4 (11%)
Not Hispanic of Latino	32 (87%)
Unknown	1 (3%)
Demographics of non-respondents	
N = 115	
Male sex, n (%)	72 (63%)
Age, median (range), years	39 (20–81)

3.2. Patient Knowledge of Disease

In our study, 94% of the completed survey patients had correctly identified the type of procedure for their appointment, 84% had correctly specified their type of IBD, 84% of patients understood the findings from their results, and 92% of the participants also understood the indication for the procedure. However, among the Crohn's Disease cohort only 35% of the patients were able to correctly report the location of the active disease after the endoscopy, see Table 2.

Table 2. Characterizing patient knowledge of their disease and endoscopy findings.

N = 37	
Correct identification of type of procedure (upper endoscopy, colonoscopy, sigmoidoscopy, or a combination), N = 35, n (%)	33 (94)
Correct identification of type of IBD (UC or CD or Indeterminate), n (%)	31 (84)
Correct reporting of endoscopy findings after procedure, n (%)	31 (84)
Correct identification of indication for endoscopy procedure, N = 36, n (%)	33 (92)
Correct identification of location of active disease post-endoscopy, N = 23 (Crohn's Disease patients), n (%)	8 (35)

3.3. Patient-Provider Communication

We found that 65% of patients who completed both surveys reported they were equally involved in the decision-making when given a four-point scale option of four selections (primarily patient choice, equally involved, somewhat involved, and not involved at all). The remaining distribution of patient involvement included: 13.5 % who felt somewhat involved, 13.5% did not feel involved at all, and 8.1% felt it was primarily their choice. Our results showed that 92% of patients claimed they had results clearly and fully explained to them. Furthermore, 76% of completed participants preferred to be emailed for their results, and 69% of patients received results in their preferred means of delivery (Table 3).

Table 3. Effectiveness of the patient–provider Communication.

N = 37	
Patient-determined decision-making involvement	
Equally involved, n (%)	24 (65)
Somewhat involved, n (%)	5 (14)
Not involved at all, n (%)	5 (14)
Primarily patient choice, n (%)	3 (7)
Patient reported receiving fully explained results, n (%)	34 (92)
Proportion of patients who would prefer communicating results in the following ways N = 35 (Patients were able to select multiple answers)	
Online message or email, n (%)	29 (83)
Phone call, n (%)	7 (20)
Office visit, n (%)	11 (31)
Proportion of patients who received endoscopy results in their preferred method, N = 35, n (%)	24 (69)

4. Discussion

Our findings suggest that our patients have self-awareness of the condition of their disease and communication with their IBD health care provider. The data demonstrates that most patients from the completed cohort were knowledgeable about their disease. However, 16% of patients incorrectly answered their type of IBD and 16% of patients incorrectly reported their endoscopy findings, which suggest there is still room to improve effective means of relaying health information to patients. Only 69% of patients received their endoscopy results by their preferred method. The remaining 31% of patients may not have fully understood their results possibly due to a less desirable deliverance of their health information. Most patients felt equally involved in the decision-making process (65%), which suggests cooperative treatment and care. Additionally, 93% of patients felt they received a full explanation of their endoscopy reports from their health care provider, which may suggest a strong rapport between patient and health care provider. Finally, 83% of patients would prefer to receive their results digitally (e.g., online messaging, email), which seems to be indicative of the accessibility and the convenience of telecommunication.

However, it is difficult to interpret how the 28% of patients, who claimed lack of involvement, would have preferred their interaction. The same difficulty in interpretation is raised to the 7% of patients who reported it was primarily their choice in their disease management.

Most patients received their results via portal message or email, which is consistent and expected with the increased use of the UCLA patient portal and electronic health records in general as well as the increasing preference for quick electronic communication. In this study, 76% of patients preferred to receive their results via email or message, but only 75% of that group actually received their results electronically. Although electronic messages dominated the communication for results, 31% of patients had a mismatch in their endoscopy results delivery preference and actual method of delivery. To improve health literacy, a number of mediums may be used such as physician support, pamphlets, online modules, or decision aids [12,13]. A study found patients who did not subjectively feel to be a part of shared decision making were more at risk for primary non-adherence to medication [14]. These results show that there is potential for improvement of patient education by providing their endoscopy results are provided through their preferred medium (i.e., digital). Even though there are financial and practical aspects for delivering health care information electronically, one caveat of electronic messaging systems between patients and providers have led to a significant decrease in office visits [15]. Regularly determining whether or not a patient prefers to receive endoscopy results in person may similarly decrease unnecessary office visits.

This study was limited by the sample size, making it difficult to determine the significance of this study's findings. We hypothesize our low response rate (39%) and loss to follow up (20%) is due to 'survey fatigue' causing a potential nonresponse bias. Additionally, the health literacy of the patients from a tertiary care center may differ from the health literacy of the general population. Patients with internet access are more likely to be adequately health literate compared to those without internet access [16]. One study found responders to online surveys had a significantly greater proportion of people with higher education and a greater family income [17,18]. Thus, the online survey method may have been a factor in a selection bias for patients who were more health literate. The mean length of time since diagnosis in this population is 13 years, which may differ may also contribute to a difference in health literacy from the general population. The length between the time the survey was collected to the last provider visit varies considerably. This introduces a temporal factor for the patient's ability to recall their health information accurately. Given the nature of the study, patients who completed both the pre- and post-survey may have understood more about their recent endoscopy findings and might intrinsically be more motivated and have time to participate.

These preliminary results show that there is room for improvement to increase shared decision-making with patients with IBD. A future study to determine a relationship between shared decision making and a patient's care satisfaction, or between shared decision and health outcomes, would further this preliminary study.

5. Conclusions

Our findings suggest a change in health information delivery is needed, as nearly a third of our patients did not receive their endoscopy results through their preferred method. Although the reason for not receiving the patients' preferred method of health information delivery was not investigated, certain factors such as: availability to clarify survey questions, time constraints, and ability to process information through different mediums can be speculated. It may benefit a provider to establish a patient's preferred method of health information delivery to reduce unnecessary office visits and possibly improve the patient's knowledge about their own disease. Improvements in shared decision making and patient education are needed to continue to provide the best care possible to patients with IBD.

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