

Current Landscape of Telemedicine Practice in Inflammatory Bowel Disease

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Inflammatory bowel disease (IBD), comprised of Crohn's disease and ulcerative colitis, affects 1.6 million people in the United States. Although effective medical treatments exist to treat the disease, outcomes are still suboptimal. The reasons for poor outcomes vary but include nonadherence to therapy, inadequate monitoring of patients, limited access to IBD specialty care, concurrent psychiatric disease, limited patient knowledge of the disease and treatments, and patient provider discordance. Telemedicine is a candidate intervention that can be used to improve patient outcomes through more frequent monitoring, patient self-management, delivery of education (patient and provider), and to increase access to multidisciplinary IBD care. Telemedicine includes remote monitoring, telehealth, teleconsultation, and teleconferencing.

Telemedicine systems have been used in patients with IBD with widespread patient acceptance of the technology. However, early clinical trials demonstrated high attrition rates among intervention patients. In general, use of telemedicine systems have been associated with improved quality of life, improved patient knowledge, and decreased utilization of health care resources. Early studies evaluating telehealth visits report high patient satisfaction, decreased indirect costs to patients, and no decrease in quality of care delivered.

Due to widespread access to computers and smart phones among patients, telemedicine will continue to expand in the care of patients with IBD. To optimize use and effectiveness of telemedicine, barriers for use including concerns over increased liability, need for informed consent, licensure restrictions to providing interstate telehealth visits, and cybersecurity need to be addressed.

Key Words: Crohn's disease, inflammatory bowel disease, telehealth, telemedicine, ulcerative colitis

Inflammatory bowel disease (IBD) is a chronic relapsing and remitting disease with potential to progress to complications that require surgery. Optimal management to prevent complications requires frequent routine monitoring for symptom recurrence, medication adherence and tolerance, and health maintenance. Patients also benefit from empowerment through education about the disease process and shared decision-making. Although acute problems or significant symptoms may require physical examination, telemedicine offers an alternative method to monitor, manage, and educate patients with IBD. The ideal telemedicine system would have the potential to increase access to specialty IBD care, facilitate early intervention for symptoms and signs of active inflammation, reduce outpatient clinic

burdens, improve adherence to medication, augment patient education, and decrease cost of care. Whereas great strides have been made towards these goals, much work remains to overcome significant barriers to realizing the true potential of telemedicine.

Current roles of telemedicine include the following: teleconsultation/telecare, the remote delivery of care; telemonitoring, use of wearables and mobile devices in tracking patient symptoms and signs; and tele-education, the use of technology platforms to augment patient and provider education¹ (as shown in [Figure 1](#)) and ([Table 1.](#))

TELEMONITORING

Multiple methods have been investigated for remote monitoring of patients with IBD. These methods involve hardware, web-based programs, or mobile device applications that facilitate the entry and transmission of data regarding patient symptoms and signs of disease. These data can be used as purely an assessment of patient status or as the first step in implementation of a change in management. Methodological concerns exist for many of the published studies in the area of telemedicine for patients with IBD. Early studies were uncontrolled and most studies were of 1 year duration or less. A number of the early studies also suffered from high attrition rates in users of telemedicine.

A home telemonitoring system, IBD Home Automated Telemanagement (IBD HAT), was developed by our group

Received for publications December 5, 2017; Editorial Decision February 2, 2018.
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Conflicts of Interest: The authors have no conflicts to report.

Abbreviations: HAT, Home Automated Telemanagement; IBD, Inflammatory bowel disease; IBD LIVE, Inflammatory Bowel Disease Live Interinstitutional Interdisciplinary Videoconference Education; UC, ulcerative colitis; 5-ASA, 5-aminosalicylic acid

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doi: 10.1093/ibd/izy113
Published online 28 April 2018

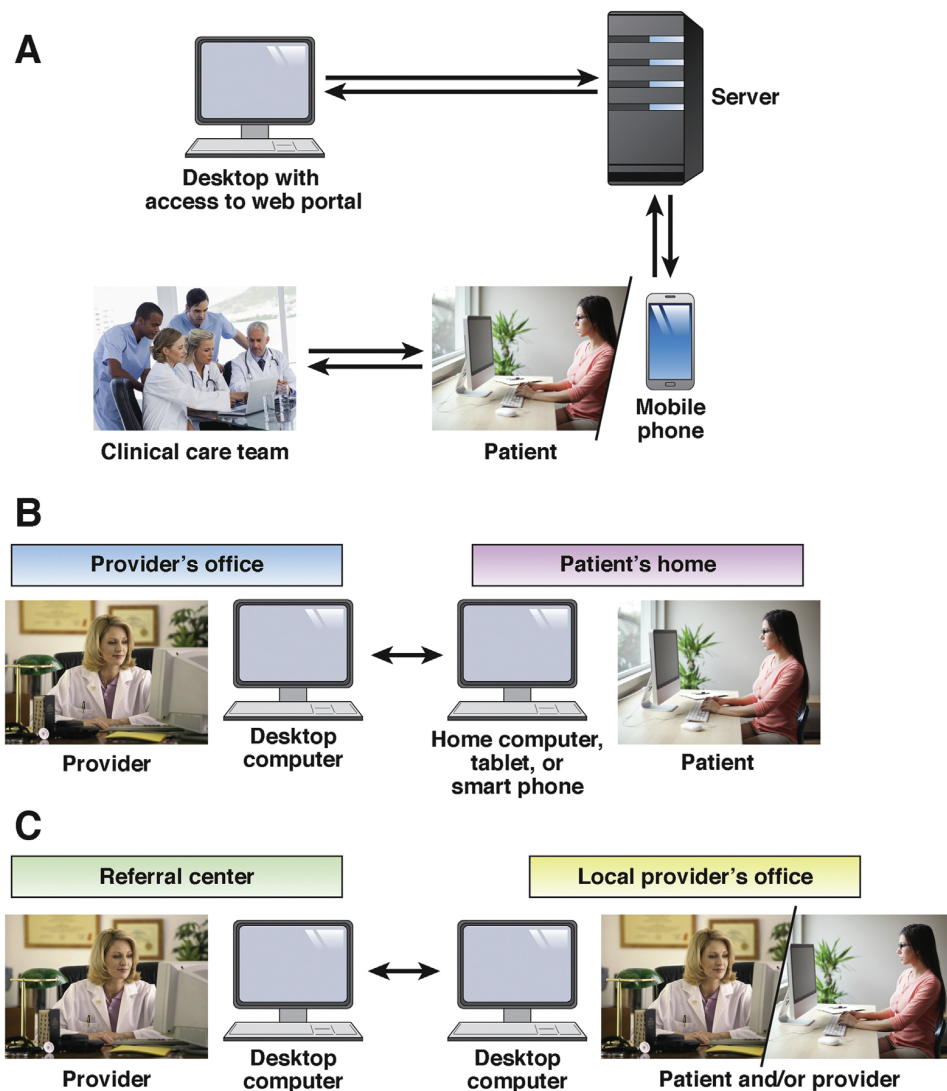


FIGURE 1. (requested) Reprinted from *Clin Gastroenterol Hepatol*, 2017;15(2), Cross RK, Kane S. Integration of Telemedicine Into Clinical Gastroenterology and Hepatology Practice, 175–81, with permission from Elsevier

at the University of Maryland to monitor multiple important aspects of patient care, including symptoms, medication adherence, adverse effects of therapy, and weight. In addition, it provided a platform for delivery of educational materials to the patient. The system was comprised of a laptop computer connected to an electronic scale and a server, which recorded and relayed information to a remote server. The information was used to construct a patient profile on a web portal that could be accessed by the provider and research team. Alerts were generated if questionnaire values completed by the patient fell outside designated thresholds.² In a pilot study, the IBD HAT system was shown to be successfully utilized by patients with 88% of patients' adherent to weekly testing over 6 months, and subsequent improved satisfaction with care. Patients also were noted to have trends towards decreased disease activity, improved quality of life, and had significant improvements in disease knowledge.³

The system was subsequently modified for use in patients with ulcerative colitis (UC) with acceptable patient acceptance. One modification in the system was to include action plans that would provide instructions for patients to implement self-care if certain criteria were met⁴ (Fig. 2). A subsequent randomized controlled trial of the system in UC patients (UC HAT) demonstrated an improvement in disease activity as measured by the Seo index and in disease-specific quality of life in those who completed the 1-year study. Study participant dropout was significant in this study, with only 56% of the UC HAT group completing the study versus 72% of the control group. This may have been related to a somewhat onerous home installation of the system.⁵ In an effort to avoid this issue, a subsequent telemedicine system (TELE-IBD) using text messaging was developed by our group.⁶ We conducted a multicenter randomized controlled trial that included 348 participants with IBD. To be enrolled in

TABLE 1: Summary of Various Telemedicine Systems Evaluated in Patients with Inflammatory Bowel Disease

Name	Type of Telemedicine System	Trial Design Used to Assess System	Trial Length	Trial Results
IBD Home Automated Telemanagement (IBD HAT)	Telephonic connection to remote server	Quasiexperimental	6 months	<ul style="list-style-type: none"> • High rate of adherence to self-testing • Improved disease activity and quality of life • Increased knowledge of disease
UC HAT	Telephonic connection to remote server	Randomized controlled trial	1 year	<ul style="list-style-type: none"> • High attrition • Improved quality of life
TELEmedicine for Patients with IBD (TELE-IBD)	Text messages to remote server	Randomized controlled trial	1 year	<ul style="list-style-type: none"> • Low attrition • Decrease in IBD-related hospitalizations
Constant Care	Secure connection to website	Randomized controlled trial	1 year	<ul style="list-style-type: none"> • Improved adherence • Shorter duration of relapses • Improved quality of life • Decreased office and acute care visits • Increased phone calls and emails • Increased knowledge of disease • High attrition
eIBD	Secure connection to website	Retrospective cohort	1 year	<ul style="list-style-type: none"> • Decreased ER visits • Decreased hospitalizations • Decreased steroid use
myIBDcoach	Secure connection to website	Randomized controlled trial	1 year	<ul style="list-style-type: none"> • Decreased ER visits • Decreased hospitalizations
Young Constant-Care	Secure connection to website	Randomized controlled trial	2 year	<ul style="list-style-type: none"> • Decreased office visits • Decreased school absences
Stanford and San Francisco VA Telehealth Visit	Telehealth visit	Controlled trial	Single visit	<ul style="list-style-type: none"> • High patient satisfaction • No change in length of encounter or number of patients per clinic session
University of Maryland Telehealth	Telehealth visit	Retrospective	Single visit	<ul style="list-style-type: none"> • Decrease length of visit • Time saving of 1 hour or more in the majority of patients
Dartmouth- Hitchcock Telehealth	Telehealth visits	Retrospective cohort	2 years	<ul style="list-style-type: none"> • Strong patient preference for subsequent telehealth visits • No difference in steroid use or health care utilization compared standard encounter
Project Sonar	Care pathway implementation through electronic medical record	Retrospective	2 years	<ul style="list-style-type: none"> • Decreased health care utilization
HealthPromise	Integration of remote monitoring application with the electronic medical record	Randomized controlled trial	1 year	<ul style="list-style-type: none"> • Increase in quality of life • Increase in quality indicators

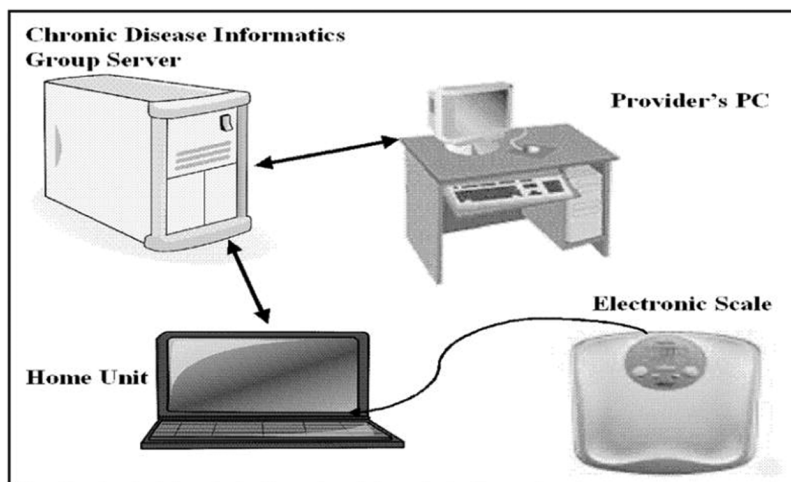


FIGURE 2. Reprint from *Inflamm Bowel Dis* 2012, 18(6), Cross RK, Cheevers N, Rustgi A, Langenberg P, Finkelstein J. Randomized, controlled trial of home telemanagement in patients with ulcerative colitis (UC HAT), 1018–25.

the study, patients were required to have a flare of disease within 2 years of randomization. Patients were randomized to monitoring with the TELE-IBD system weekly, every other week, or to standard care. With improvements in the system, the rate of attrition was much lower (~14% overall). Furthermore, nearly 75% of all participants completed the 1-year assessment. All

participants experienced improvements in disease activity and quality of life, irrespective of the group to which they were randomized. There were no differences in change in disease activity or quality of life between the groups over 1 year. Health care utilization increased significantly in all groups 1 year after randomization compared to 1 year before. Increased utilization was primarily driven by a higher number of office visits, infusions, and telephone calls. IBD-related hospitalizations were significantly decreased in TELE-IBD weekly participants compared to controls (27 vs 11 compared to 22 vs 26, $P < 0.05$).⁷ Studies are ongoing to determine predictors of adherence to testing in the TELE-IBD trial and to better understand patient preferences for testing (ie, the type of questions asked and the best platform for self-assessment).

Elkajer et al devised a web-based system to implement “Constant Care.” The system was initially validated in a study of 21 UC patients, resulting in increased patient knowledge of the disease and sense of empowerment.⁸ Subsequently, the authors tested the Constant Care system in a randomized controlled trial of mild to moderate UC patients from Denmark and Ireland who were being treated with 5-aminosalicylic acid (5-ASA) medications. Assessments were done monthly in patients in clinical remission, whereas patients experiencing a flare underwent testing daily until they entered the green zone at which point they were tested weekly for 1 additional month. Patients were randomized to receive care both with Constant Care and as needed visits or usual care. Participants in the Constant Care group experienced improved adherence to acute treatment, shorter duration of relapses, improved quality of life, decreased number of acute care and office visits, and **higher** electronic communications and telephone calls. Attrition was high in this study also, with only 41% of the participants completing the study.⁹

Another web-based program has been developed at the University of California, Los Angeles. The eIBD program



FIGURE 3. (requested) (myIBDcoach screenshot).

allows patients to input information regarding their disease activity, quality of life, and work productivity. Patients were organized into 9 care pathways based upon disease activity and treatment regimen, which included scheduled in person clinic visits, laboratory data, and home monitoring. An initial study validated a scoring system comprised of patient-reported outcomes, which correlated well with a modified Harvey-Bradshaw index in Crohn's disease (CD), a modified partial Mayo score in UC, and with endoscopic activity in UC.¹⁰ In a retrospective study of 60 patients with IBD who participated in the eIBD program, trends toward fewer emergency department visits, hospitalizations, and long-term corticosteroid courses were observed in comparison to controls who received standard care.¹¹

A telemonitoring system developed in the Netherlands (myIBDcoach) involves both a web-based format and HTML application <Fig. 3>. The system includes monitoring and education modules. Patients complete questionnaires regarding disease activity, medication adherence, quality of life, anxiety, and depression, among others at regular intervals. The frequency of monitoring is modified based on disease activity, and alerts are generated when questionnaire scores exceed defined thresholds. In person visits were scheduled annually in the intervention group. Feasibility was demonstrated in an initial study of 30 patients.¹² A randomized controlled trial of 909 patients showed a significantly lower number of outpatient visits and hospital visits in the myIBDcoach group as compared to controls. No significant differences were seen in quality of life of life, mean numbers of flares, corticosteroid courses, emergency department visits, and surgeries.¹³ A smaller pilot study in adolescents confirmed that remote monitoring could be used to replace some aspects of standard care without worsening of disease activity and quality of life. In addition, participants in this study experienced fewer school absences.¹⁴

TELE-EDUCATION

Technology can be an invaluable tool for the education of patients. Over two-thirds of Americans have smartphones.¹⁵ Mobile devices offer easy and immediate access to information regarding a patient's illness and can be a mechanism to provide reliable and evidence-based resources for disease state awareness and treatment. Telemedicine offers an excellent platform to provide high quality and relevant information about IBD. The aforementioned IBD HAT and Constant Care systems both demonstrated improvement in patient knowledge after their educational interventions.^{3,9}

Gastroenterologists and IBD specialists also can benefit from the educational potential of telemedicine, specifically as it provides a forum in which to discuss patient cases with complex diagnostic or management dilemmas. The Inflammatory Bowel Disease Live Interinstitutional Interdisciplinary Videoconference Education (IBD LIVE) initiative is an example of a successful multisite and multidisciplinary virtual conference. Participating members include adult and pediatric gastroenterologists, surgeons, pathologists, radiologists, and other medical subspecialists. The goals of each session include a review of evidence-based data and exchange of input on management of patients with IBD. Additional benefits have included referrals between institutions for specialty services and collaborative research initiatives. The Continuing Medical Education evaluations completed after sessions included a high median overall score and indicated the conference significantly changed practice¹⁶ (Fig. 4).

TELECONSULTATION AND TELEHEALTH

The remote delivery of care via telemedicine technology can successfully address issues of geographic access to specialty care and cost of care to patients. Visits can occur between the

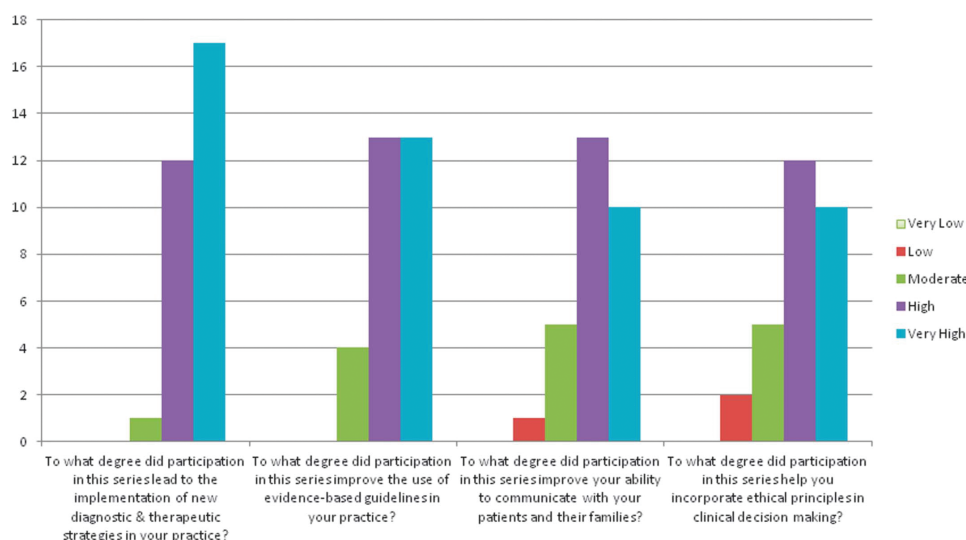


FIGURE 4. Reprint from *Inflamm Bowel Dis* 2014; 20(10), Regueiro MD, Greer JB, Binion DG, et al. The inflammatory bowel disease live interinstitutional and interdisciplinary videoconference education (IBD LIVE) series, 1687–95.

IBD specialist and the patient or between the IBD specialist and a primary gastrointestinal (GI) provider, in the presence or absence of the patient.

A 2011 pilot study by Krier et al investigated the feasibility of teleconsultation to provide specialty IBD care at a Veterans Affairs hospital. The experience of patients who underwent a combination in person and teleconsult encounter with a remotely located IBD specialist was compared with those who underwent a standard in person encounter. Both experiences were rated by patients as excellent, with no difference in patient satisfaction, mean duration of visits, or mean patients seen per session.¹⁷

We began telehealth visits at the University of Maryland in 2015. To be eligible for this service, patients had to be insured by Blue Cross Blue Shield and reside in the state of Maryland. Informed consent was obtained before the telehealth visit and all encounters were conducted between the provider and the patient in his or her home using Vidyo Desktop. An analysis of postvisit surveys over 1 year after implementation revealed that 83% of patients reported the telehealth visits were not complicated or only slightly complicated to use. Seventy-one percent reported the telehealth visit took significantly less time than a standard encounter, and all patients felt the telehealth visits were more convenient. Ninety-four percent reported they would definitely like to have a telehealth visit in the future. Importantly, most patients reported that the telehealth visits saved them at least 1 hour.¹⁸

Li et al recently explored the ability of telemedicine to provide high value care to outpatients with IBD in the Dartmouth-Hitchcock IBD program. Fifty-three patients interacted with an IBD specialist, with or without an IBD nurse, through video software. Over 90% of patients felt the visits were of adequate duration and their physician understood their disease state during the visit. Over 75% reported they clearly understood the follow-up plan after the visit. Finally, 77% of patients preferred to continue to use telemedicine for follow-up. There were no detectable differences in clinical outcomes before and after telemedicine visits, including current steroid use or biologic exposure, and no difference in health care utilization.¹⁹

CHALLENGES

Access to health care in general, and specialty care in particular, is a key driving force behind the expansion of telemedicine. Reimbursement is provided for some form of telemedicine in all 50 states in the US and the District of Columbia, whether by Medicaid or by commercial payers. However, significant differences in level of coverage and type of service covered exist between states. In addition, providers are currently required to be licensed in the state of the patient who is receiving care by telemedicine. The lack of portability of licensure results in inability to provide interstate care. Interstate compacts are being proposed to address this issue.²⁰

Concerns have been raised about the safety of providing remote care to patients. Both the American Telemedicine Association (<http://www.americantelemed.org/home>) and the Federation of State Medical Boards have developed best practice guidelines for the use of telemedicine. Some states require a prior provider-patient relationship in an effort to ensure an existing knowledge of the patient history and physical exam. Some states are also developing an informed consent policy specific to telehealth. Patient data security and privacy are also important considerations (Model Policy for the Appropriate Use of Telemedicine Technologies in the Practice of Medicine).²¹

In our clinical practice, we offer telehealth services as an alternative to an office visit for follow-up after initial consultation. Telehealth users must reside in Maryland and have health insurance coverage with a payer that reimburses telehealth at an equal rate to in person visits. Telehealth visits are ideally suited for routine “well visits” or as needed visits to counsel patients on treatment options. Telehealth visits are discouraged for patients with specific physical complaints that would benefit from a physical exam (ie, evaluation of perianal fistula). Further, telehealth visits are generally avoided in patients reticent to use the technology. We acknowledge also that there is still trepidation among providers in conducting telehealth visits. As discussed above, there have been methodological issues with studies of telemedicine in patients with IBD. More recent studies, particularly of remote monitoring, have improved trial designs. Furthermore, more recent studies have experienced lower attrition rates that may be related to increased ease of use of remote monitoring systems and/or greater patient acceptance and comfort with the technology. Few long-term studies of remote monitoring have been completed. Additionally, little work has been done in identifying patients who would be best served with remote monitoring and which system is preferred by patients.

FUTURE ENDEAVORS

Tight surveillance of blood glucose measurements at home using telemonitoring technology has been shown to improve outcomes in diabetes.^{22, 23} Regular use of objective markers of inflammation that can be obtained remotely would be a valuable addition to the patient reported outcomes gathered from current telemedicine systems in IBD.

Fecal calprotectin (FCP) is a well-validated surrogate marker for inflammation in IBD.^{24, 25} A home test of FCP has been developed that uses a smartphone camera and *IBDoc* software to analyze a collected specimen in real time. In a recent study, these results were compared to classic laboratory testing. Of the 170 specimens collected by 101 patients, 18 could not be appropriately analyzed by the *IBDoc* software due to operator and system errors. Eighty-seven percent of participants did not report difficulty performing the test, and 97% would use the home test in the future. When the FCP was ≤ 500 $\mu\text{g/g}$, 81% and 91% of *IBDoc* readings were within predefined limits of

agreement with the reference ELISA and Quantum Blue analyses, respectively. When the FCP was $>500 \mu\text{g/g}$, 64% and 71% were in agreement with the ELISA and Quantum Blue analyses, respectively.²⁶ Home monitoring of FCP can offer a more objective data point and can be linked to patient-reported outcomes to better guide management decisions in telemedicine. FCP was also used as an objective marker of disease activity in the Constant Care and myIBDcoach systems.

Patients can benefit from a multidisciplinary approach to IBD care, including the involvement of dietitians and mental health providers. Telemedicine could offer an opportunity to centralize access to multiple providers. Telepsychiatry has been implemented and plays a central role in the IBD specialty medical home at the University of Pittsburgh.²⁷ In addition, integration of these systems with electronic medical record systems also could improve the efficiency of patient communication and coordination of patient-reported data with objective data within their record. One example of use of the electronic medical record to improve IBD population health is Project Sonar that is a joint venture between the Illinois Gastroenterology Group and Blue Cross Blue Shield Illinois. Patients were screened at enrollment for depression and received monthly “Sonar Pings” to assess disease activity and quality of life. This data was integrated with other clinical data from the electronic health records and claims data from the payer. Existing care pathways for CD were implemented in at risk patients with a reduction in overall healthcare costs.^{28–30} Another example of integration of remote monitoring into the electronic medical records is the HealthPROMISE application that is being evaluated as part of a multicenter pragmatic clinical trial. HealthPROMISE integrates patient-reported outcomes into the electronic records so that providers can track symptoms in real time and intervene when appropriate.³¹

Additional research is needed in the field of telemedicine for patients with IBD. Qualitative studies are underway to better understand the types of questions important to patients to better engage them with telemedicine systems. Further work also is needed to identify specific subgroups of patients who engage best with telemedicine systems. For example, subanalyses of our TELE-IBD trial demonstrated that participants 18–40 years of age with depressive symptoms were MORE likely to adhere to remote monitoring (unpublished data). Researchers also need to better understand which systems (web, text message, apps) work best for patients and if improvements seen in short-term trials can be realized over the longterm.

CONCLUSIONS

The landscape of telemedicine in IBD is likely to change within the near future given the current pace of technological advances and policy development regarding reimbursement and licensure. Telemedicine is popular among patients as they seek increased access to high-quality, efficient healthcare. Unfortunately, multiple barriers still exist that prevent

widespread adoption of telemedicine including provider resistance in using the technology, requirements for multiple licenses to provide care across state lines, reimbursement issues, unique liability concerns, and requirements for informed consent in many locations. Nevertheless, telemedicine has the potential to improve access to IBD specialty care, particularly multidisciplinary care, decrease direct and indirect health care costs, improve the efficiency of care, and may improve health care outcomes.

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