

Application of Telemedicine for Patients with Inflammatory Bowel Disease: Review of the Literature and Future Implications

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Inflammatory bowel disease (IBD), comprised of Crohn's disease (CD) and ulcerative colitis (UC), is a chronic inflammatory condition of the intestines that results in diarrhea, abdominal pain, fistulas, and extraintestinal manifestations of disease. IBD is common, affecting over 1 million people in the United States [1]. The symptoms and disease course have a profound, detrimental impact on quality of life in patients with IBD [2]. In the United States, the economic impact of IBD is substantial, estimated at an annual cost of 6.3 billion dollars [3]. Effective treatments for induction and maintenance of remission exist for IBD; however only 40-60% of patients with quiescent UC are adherent to aminosalicylate therapy (5-ASA) [4-7]. Nonadherence to therapy is not trivial as nonadherent patients are five times more likely to have disease exacerbations [8] and direct health care costs are increased in nonadherent patients [9]. Sewitch and colleagues found that many instances of nonadherence in IBD were unintentional with 31% of patients simply forgetting to take medicines [7]. Patient miscomprehension is another important factor leading to nonadherence since 62% of patients feel misinformed about their illness [10]. Miscomprehension can be linked to nonadherence when patients do not understand why they are taking medications or when they are surprised by unexpected side effects [11,12].

Improved monitoring of IBD symptoms is another potential mechanism to improve outcomes. Currently, patients with IBD are seen at scheduled intervals. Because exacerbations of bowel symptoms are sporadic, scheduled office visits are often discordant with disease flares. In addition, when patients develop recurrent symptoms, delays may ensue before office visits are scheduled. Patient self-management in UC has been shown to be effective adjunct in patient care. Robinson *et al.* successfully implemented a patient-focused self-care plan in patients with moderate to severe UC. Participants that responded to treatment with intravenous steroids during hospitalization were randomized to usual care or to self-management. Participants in the usual care group underwent scheduled clinical visits after hospital discharge. Those in the self-management group received individualized, written action plans without clinical follow up. During the one-year study, relapses in the self-management group were treated earlier, were shorter in duration, and utilization of health care resources was decreased [13]. Similarly, self-care plans implemented in UC patients in the United Kingdom decreased hospitalization rates and sustained quality of life without increasing the number of outpatient visits or increasing patient anxiety. In fact, patient education and self-management improved coping with UC [14].

Telemedicine is a candidate intervention that can help practitioners follow current clinical guidelines, help providers educate patients, assist providers in monitoring patients, and help patients adhere to self-care plans. Several studies have evaluated the use of telemedicine to improve outcomes in the IBD population. One pilot study assessed the acceptance of a home telemanagement system (IBD HAT) in ten patients with IBD. IBD HAT was comprised of three components: a patient home unit, a decision support server, and a web-based clinician portal. The patient home unit includes an electronic weight scale connected to a laptop computer via a serial port. The laptop computer contains a symptom diary, side effect inventory, adherence check, and

assessment of body weight. Clinicians used the secure web portal to customize medication and side effect profiles for patients. A clinical alert based on responses to the symptom diary, medication side effect questions, self-reported adherence, and body weight was developed. Once self-testing was completed, patients received an IBD-related educational prompt in the format of a "tip of the day"; the following testing session, patients were asked a question about the tip. The results of self-testing were submitted telephonically and were available for review immediately on the secure web server. Five participants had CD and five had UC. Thirty percent of participants reported limited knowledge of IBD, two participants had never used a home computer, and one had never used the Internet. All participants found the self-test procedures to be uncomplicated and reported no difficulty using the computer or answering the symptom diary and side effect questions. All patients felt the self-testing procedures took very little time and would result in very little to no interference with their daily activities. All participants felt that weekly testing was realistic [15].

A follow-up study was performed to assess acceptance and feasibility of IBD HAT among 34 participants with IBD. After an initial 40 minute training period, participants were asked to complete weekly self-testing for six months. Disease activity, quality of life and IBD knowledge were assessed at baseline and at six months. Overall, weekly adherence to self-testing over the 6 month study was 91%. Participants reported that IBD HAT was easy to use and did not interfere with their daily activities. Patient knowledge also improved significantly after using the IBD HAT educational curriculum. Trends towards decreased disease activity and higher quality of life scores were noted compared to baseline [16].

In 2009, our group tested the feasibility and acceptance of a modified telemedicine system for UC (UC HAT). UC HAT contained a symptom diary specific for patients with UC and an electronic messaging system for patients to communicate to the medical provider and nurse coordinator. In addition, action plans were added to the system. Based on scores generated from the UC symptom diary, participants received action plans in one of three categories: 1) Green zone, for patients with no to mild symptoms, 2) Yellow zone, for patients with moderate symptoms, or 3) Red zone, for patients with severe symptoms. Each severity zone listed several actions that providers could choose for participants to initiate as part of their self-management plan. Ten patients with UC completed attitudinal surveys. All participants felt that using the computer and self-testing

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system was not complicated. Seven participants reported that they would feel safer using UC HAT. Participants also expressed a sense of improved communication, knowing that the provider would be informed of their flares immediately. This improved communication, along with an increased sense of self-awareness, resulted in participants feeling empowered [17,18].

The UC HAT system was subsequently evaluated in a randomized controlled trial to test the hypothesis that the UC HAT system would decrease disease activity, increase quality of life, and improve medical adherence compared with best available care. Forty-seven participants with UC were randomized to receive either UC HAT (25 participants) or best available care (22 participants). Participants in the UC HAT group underwent weekly self-testing. Participants in the best available care group underwent routine and as needed clinic and telephone follow up, received educational fact sheets about IBD and received self-action plans without reinforcement. During the trial, 8 participants withdrew in the UC HAT arm (compared to 1 in the best available care arm. There was no difference in disease activity scores or remission rates between the treatment groups at 4, 8 or 12 months. After adjustment for baseline quality of life, disease activity scores decreased 12 points from baseline in the UC HAT arm ($p=0.08$) compared to 1 point in the best available care arm ($p=0.84$). Disease-specific quality of life scores increased in the UC HAT arm and remained stable in the best available care arm, though these differences were not significant at any time point post baseline. However, after adjustment for baseline disease knowledge, UC HAT participants were noted to have a 16-point improvement in quality of life scores from baseline compared to the best available care group ($p=0.04$). Adherence was low in both groups at baseline, but improved in both groups over 12 months. No significant differences in adherence were noted between groups [19].

Elkjaer and colleagues evaluated the feasibility and patient acceptance of a web-based telemedicine program for UC. Construction of the "Constant-Care" website began in 2001, and was created to be available in Danish and English. Using this system, doctors were able to prescribe 5-ASA and topical steroids electronically. Ten participants with UC and five of their relatives participated in a validation study of the "Constant-Care" website. Prior to using the website, all participants in the web-group, and their relatives, were given educational training with a 1.5-hour slide presentation on IBD etiology, pathology, anatomy, medical and surgical treatments, disease course, adherence, nutrition, mortality risk, colorectal cancer chemoprevention, pregnancy, and breastfeeding. Participants and family members also underwent a 1.5-hour training session in using the Constant Care website. All participants in the validation group felt capable of self-initiating treatment after the educational training. Eight participants expected to see an improvement in quality of life, quality of the treatment, and knowledge of their disease after the educational training session [20].

A randomized controlled trial in Denmark and Ireland was subsequently conducted to assess the Constant-Care website. Patients with mild-to-moderate UC were randomly assigned to either the web group or a control group that received standard care for 12 months. Outcomes of interest included feasibility of the telemedicine approach and its influence on participants' medication adherence, UC knowledge, quality of life, safety, and health care costs. Symptoms were categorized similarly to the UC studies conducted by our group; quiescent-to-mild symptoms appeared as a green traffic light, moderate symptoms appeared as a yellow traffic light, and highly active symptoms appeared as a red traffic light. During symptom flares, participants were instructed to log onto the system daily to complete an assessment of disease activity until their symptoms entered the green

zone. Entry frequency was then reduced to once weekly until 4 weeks after the initial relapse. Disease-specific quality of life was completed at the beginning and end of each relapse. Once in remission, participants logged on to Constant Care once monthly until the next relapse occurred. If symptoms were entered such as rectal bleeding, 3 or more bowel movements daily or nighttime bowel movements, Constant Care recommended initiation of 4 gram daily or more of 5-ASA treatment for a total of 28 days. Participants were given the option to extend this treatment period by an additional 28 days if remission into the green zone was not achieved. Participants could also chose additional topical 5-ASA treatment and prednisolone, based on previous maximal extent of disease and participants' prior treatment experience. Guidelines for indications on when to call the provider included having greater than six stools per day, daily rectal bleeding, rectal bleeding occurring between relapses, fever >37.5 degrees Celsius, heart rate >90 beats per minute, severe abdominal pain, symptoms persisting more than eleven days despite escalation of therapy, unexplained weight loss, and/or for any doubts or questions regarding the study [21].

In total, 333 adult participants from both Danish and Irish sites were randomized. Of these, 135 participants (41%) completed the 12-month study. In the Danish arm of the study, there were no differences in 5-ASA adherence, as measured by medication refills, between the web and control participants (68% vs. 69% respectively refilled at least 80% of their medication, $p=NS$). However, the web group demonstrated significantly higher adherence to four weeks of acute treatment compared to controls (73% vs. 42%, $p = 0.003$). There were significantly greater improvements in web group participants in IBD knowledge, disease-specific quality of life ($p = 0.04$), general health ($p = 0.009$), vitality ($p = 0.03$), and emotional ($p < 0.0001$) and social functioning ($p = 0.002$) compared to the control group. Half of all participants experienced at least one flare of symptoms during the study; relapses were significantly shorter in the web group compared to the control group (18 days vs. 77 days, $p < 0.0001$) [21].

In the Irish arm of the study, medication adherence to four weeks of treatment was significantly greater in the web group compared to controls (73% vs. 29%, $p = 0.03$). There were no differences between study groups in terms of IBD knowledge or disease-specific quality of life; however the web group demonstrated improved mental health ($p = 0.01$), physical functioning ($p = 0.03$), and social functioning ($p = 0.02$) compared to controls. The web group experienced a higher frequency of relapses compared to controls; however, these were shorter than the relapses experienced by controls (30 days vs. 70 days, $p < 0.03$). A cost analysis revealed that UC-related acute visits were higher in the control group compared to the web group (21 vs. 107 visits, $p < 0.0001$). There were also fewer routine visits in the web group. Conversely, there were a significantly higher number of emails (86) and phone calls (21) from web participants than from controls (7 emails and 17 phone calls). Eighty eight percent of participants in the web group preferred telemedicine to conventional care. Participants felt empowered by the ability to initiate treatment using the web-guided solution and safe with the option of a web-based follow-up with their provider [21].

Telemedicine has also been studied to provide remote office visits for patients with IBD. Krier and colleagues randomized newly established patients with IBD into one of two groups: 1) a remote clinical encounter via telemedicine with an IBD provider or 2) a conventional in-person encounter with an IBD provider. The telemedicine system consisted of two standard Apple computers running a secure protocol between the subspecialist and the participant. Fifteen participants were enrolled (8 with UC, 7 with CD). Participant experience was rated using the Ware Specific Visit Standard Questionnaire (1 = excellent,

5 = poor). Participants in both groups rated their clinic experience highly (1.2 ± 0.4 in the telemedicine group versus 1.1 ± 0.4 in the conventional group). Both remote and in-person clinic visits were of similar duration (58 minutes in the telemedicine group versus 53 minutes in the conventional group). High ratings on the technical and informational quality of the telemedicine sessions were reported from the providers involved [22].

In summary, telemedicine is well accepted by patients with IBD, including patients with UC. Longitudinal use of these systems seems feasible; however the high attrition rates reported in both one year randomized, controlled trials raises concerns about long term adherence to telemonitoring systems. In addition to showing high rates of patient acceptance and feasibility, available studies have demonstrated improvements in clinical outcomes. The quasiexperimental study by my group showed decreased disease activity, improved quality of life, and increased knowledge after use of IBD HAT for 6 months. Similarly, telemedicine for UC has been associated with decreased disease activity as measured by disease activity indices and improvements in quality of life. However, flare rates were increased among the Irish cohort in the study by Elkjaer and colleagues. Despite the higher rate of flares in the telemedicine arm, the length of flares was decreased in the telemedicine group. Despite improvements in disease activity, adherence was not consistently better in the telemedicine arms in either study, except in the acute treatment phase of the study by Elkjaer and colleagues. Utilization of health care resources was less in the telemedicine group in the European study (although email and phone calls increased in the telemedicine group). Therefore, the evidence thus far in IBD and UC, demonstrates a positive effect of telemedicine on clinical outcomes. Further studies are needed to confirm these results and to study the CD population. Further, larger studies are needed to explore subgroups that might particularly benefit from telemedicine, specifically patients with decreased access to care, a history of nonadherence, poor social support, more severe disease (moderate to severe IBD), patients with active disease versus disease in remission, and patients initiating new drug therapy. Lastly, the financial impact of telemedicine on IBD care, positive or negative, needs to be explored.

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