Interprofessional Development of Learning Resources for IBD Patient Portal

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ABSTRACT

Background: This paper summaries our experiences from a six-month pilot study of a web portal that provided secure communications, education, and support for self-management by Inflammatory Bowel Disease (IBD) patients. An analysis of “don't know” responses revealed room for improvement in site organization and content analysis.

Objectives: To address a gap in knowledge, information, access, and peer support for IBD patients and to improve the quality of the website as a knowledge resource.

Methods: As part of this pilot study of a web portal for IBD patients, patients’ learning outcomes were studied. The portal contents were analyzed for coverage and completeness. Content on the website was written by an interprofessional team of nurses, physicians, pharmacists, dietitians, IBD patients, and health informaticians. It included frequently asked questions, curricula, glossary, Cochrane plain language summaries, and discussion forums. Patients were recruited from the IBD Clinic in Nova Scotia. The study evaluated the impact of this intervention on quality of life using the the SF-36 and the Inflammatory Bowel Disease Questionnaire (IBDQ) pre and post. Patients' learning outcomes were evaluated using the Crohn’s and Colitis Knowledge Score (CCKNOW) test instrument pre and post. A survey of primary physicians was done. Portal content was analyzed by concepts using manual indexing and the MetaMap Transfer software for automatically mapping text to Unified Medical Language System.

Results: 76 patients (26 male, 50 female) were enrolled from the IBD Clinic in Nova Scotia; 2 withdrew; 57 accessed the site; 49 completed the SF-36 and IBDQ; and 47 completed the CCKNOW pre and post. Patients logged into the portal 893 times. Usage ranged from 96% for FAQs to 28% for private messaging; and 64% reported improved IBD knowledge. The mean scores on the SF-36 were virtually unchanged and on the IBDQ were 151.62 pre and 156.04 post. The mean scores on the 24-item CCKNOW were 12.61 (CI 11.32-13.90) pre and 13.17 (CI 11.85-14.49) post with median of 13 at both times. The CCKNOW items were categorized as strong improvement (N=6), improvement/nochange (N=10), and worsened (N=8). Nevertheless, there was moderate improvement in CCKNOW scores approaching statistical significance (P<.07). There were insufficient responses to the primary physicians' survey (N=5) to support a meaningful analysis. The completeness analysis
determined that while all items were answerable through inference, there was a coverage mismatch. Text analysis revealed 3,142 unique concepts in 29,373 occurrences.

**Conclusions:** Patients perceived the portal’s dual purpose as a communications and learning platform as its strength. Clinicians participating in this study value the importance of patient education and enablement. The pragmatic enrichment method showed promise for improving information retrieval.

**Keywords**

Inflammatory bowel disease; patient education; information science; Internet; communication/therapy

**Introduction**

Canadian healthcare struggles with a shortage of physicians and long wait times for patients with chronic health care needs. Traditionally, health care has reacted to acute episodes of illness rather than taking a proactive stance in helping patients to manage their illness [1]. Many of these patients live in remote locations necessitating long trips to visit their specialty health clinics.

The IBD patient portal is an Internet-based resource for patients, collaboratively developed by Medical Informatics, Faculty of Medicine, Dalhousie University and the Inflammatory Bowel Disease (IBD) Clinic, Queen Elizabeth II Health Science Centre, Capital Health District. It uses the HealthInfoRx™ development platform and was funded from a combination of the Canadian Office of Learning Technologies and in-kind support.

Having healthcare professionals guide patients in their learning ensures that patients will have the support needed to interpret information and apply it to their unique situations [2]. Sifting though information on the Internet to find credible source of health information can be very time consuming [3]. Patients require information from trusted sources. With this in mind, a patient portal was developed aimed at increasing the knowledge of patients with IBD. The patient portal had content developed by healthcare providers (nurses, dieticians, physicians/surgeons) and their patients.

This patient portal was designed to help patients with IBD cope with their condition. It supports an asynchronous as well as real time messaging patient/clinician encounter as opposed to face-to-face clinic visits. It facilitates a proactive self-management approach to health and the opportunity to connect with other patients in a virtual community of support. Lifelong learning is especially important for chronic disease patients and their caregivers.

Reducing the sense of isolation patients feel, creating a sense of community, and reducing wait times at the hospital-based clinic by enabling patients to better manage their condition are important benefits of Internet-based clinics. Such clinics can reduce travel time and expenses for patients and give them timely access to professional advice when they need it.

**Methods**

The research questions were:

1. Is there an improvement in the quality of life and an increase in knowledge of IBD in IBD patients with inactive or mildly active disease enrolled in the study over the study duration?

2. Is there increased comfort among physicians around the use of technology for care and learning?

3. Is the portal content pragmatically complete for the task of answering the questions posed in the Crohn’s and Colitis Knowledge Score (CCKNOW) test instrument?
The study was done in four phases. Phase 1 consisted of a focus group of six patients who were asked what information and education pertaining to IBD was needed on the IBD patient portal. Phase 2 was the Beta trial of the portal to test the technology and human interface with the technology. Phase 3 was full pilot testing of the portal; its educational and virtual clinic functions; and a meeting place for IBD patients and clinicians. Phase 4 was analysis of feedback and results.

Potential participants were identified by IBD hospital clinic staff though face-to-face interviews. Of the 1200 patients in the Halifax IBD specialty clinic, 76 (26 males, 50 females) were enrolled in this pilot study. Of these, two patients withdrew from the study (one due to relocation and one due to change in disease status); 57 accessed the site; 49 completed the Inflammatory Bowel Disease Questionnaire (IBDQ) pre and post portal usage; and 47 completed the CCKNOW[4,5] pre and post portal usage.

The SF-36 was designed as a generic indicator of health status [6]. The IBDQ [7] addresses patients' bowel function, emotional function, systemic symptoms, and social function. The CCKNOW addresses learning outcomes in five areas: general, medication, anatomy, complications, and diet [4].

In the statistical analysis the proportion of patients who answered correctly for each CCKNOW question is calculated. This facilitates comparison with other studies.

Family physicians were approached to complete a short survey focusing on using the Internet to facilitate communication between IBD patients, IBD specialists and themselves. The purpose was to develop protocols for the direct consultation of patient, their primary care-givers and the IBD clinic.

**Design of the IBD Patient Portal and Data Collection**

The IBD patient portal incorporated a number of the strategies endorsed by the Institute of Medicine [8] including the facilitation of secure web messaging between patients and clinicians, discussion forums, online learning, anonymized frequently asked questions (FAQ), group discussions, a chat room, and a file library.

Technical and management concerns about privacy and security were addressed through housing the servers in a secure facility, routine offsite encrypted backups of data, administration of personnel confidentiality strategies, and technical development of patient controlled masking of individual profile data to other users of the system, development of governance policies, terms of usage and privacy statements and maintaining audit as well as access control. A 128-bit Secure Sockets Layer (SSL) is used to encrypt all data transmitted to and from the secured site to ensure that it is not intercepted as it is transmitted across the Internet. Discussions with the Canadian Medical Protective Agency and local health authorities were also conducted to ensure appropriate standards of care were followed. Patient consents were captured electronically via click-through technology, wherever appropriate, upon interaction via the secure 128 bit SSL. An audit log was maintained. Portal utilization was captured by user, resource used, IP address, search queries, and time.

Questions were posed by patients and answered by an inter-professional team of nurses, dieticians, physicians, and surgeons. FAQs were manually categorized using a topic indexing scheme so a user could browse the content in a guided fashion. A search facility was available to find matching results from pamphlet titles, learning modules, FAQs, the glossary, and discussion forums.

The portal development was dynamic and ultimately composed of 93 FAQs, 5 pamphlets, 13 learning modules, a discussion group with 32 discussion threads, 10 Cochrane plain language summaries, a glossary with 398 items, the IBDQ, the CCKNOW, and a continuing medical education module.
Design of the Completeness Analysis

Human indexers, familiar with the medical terminology, assigned appropriate UMLS concepts to the FAQs and glossary items in the collection. During Phase 3 of the study, the indexing was available as eXtended Markup Language (XML) metadata linked to the search function. During Phase 4, the remainder of the site was indexed using UMLS so the completeness analysis could be performed.

A text corpus was formed from IBD Patient Portal content from all sources. The MetaMap Transfer (MMTx) software takes an input sentence, separates it into phrases, identifies the medical concepts and assigns proper semantic categories to them according to the knowledge embedded in UMLS [9]. MMTx software version 2.4.B was used for the automatic indexing of the text corpus. The knowledge embedded in UMLS can be restricted to specific source vocabularies, such as International Classification of Diseases Version 9 Clinical Modifications (ICD-9-CM) and SNOMED CT. Since movement to personal health records is part of the chronic disease management strategy [10], term usage by patients and clinicians should reflect the standards proposed for such records. SNOMED CT is such a standard. Hence, we restricted our UMLS mapping to terms coming from SNOMED CT.

The concordance between the indexing terms from manual and automated methods was analyzed for each FAQ and glossary item.

The patient portal is checked for its ability to deliver the correct answers to the CCKNOW items. This is done by determining whether the website supports navigation from a question in a knowledge quiz to content that answers the question. The completeness method uses semantic connections between concepts to focus its search for useful information. The semantics accurately reflect the potential reasoning ability if the correct conclusion can be found based on the right series of questions. This is known as the Socratic Completeness method [11]. The pragmatic enrichment method used in this study is based on that method and its implementation using topic maps [12]. All concepts are being entered into a topic map with their semantic structural knowledge drawn from UMLS sources. The topic map captures the subjects included in the IBD patient portal and the relationships between those subjects. Each concept is associated with occurrences of use in the context of the IBD patient portal. The pragmatic enrichment method can develop inference rules using first order logic to allow the patient portal to be evaluated for completeness with respect to the task of answering CCKNOW questions.

Results

Change in Health Status

Forty-nine patients completed the SF-36 and IBDQ pre and post. The results of the SF-36 were virtually unchanged. The results of the IBDQ are given in Table 1. There was a small improvement overall.

<table>
<thead>
<tr>
<th></th>
<th>Bowel Symptoms</th>
<th>Systemic Symptoms</th>
<th>Emotional Function</th>
<th>Social Impairment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>49.18</td>
<td>21.14</td>
<td>57.53</td>
<td>26.53</td>
<td>154.39</td>
</tr>
<tr>
<td>Post</td>
<td>48.10</td>
<td>21.47</td>
<td>58.63</td>
<td>26.84</td>
<td>156.04</td>
</tr>
</tbody>
</table>
Change in Knowledge of IBD as Measured by CCKNOW

There were forty-seven patients who completed the CCKNOW pre and post. There was moderate improvement in overall scores, 12.61 (CI 11.32-13.90) pre and 13.17 (CI 11.85- 14.49) post, approaching statistical significance ($P<0.07$).

The change in CCKNOW scores were categorized into three groups: most improved (N=6), improved or no change (N=10), and worsened (N=8). The item results are given in Table 2 using question numbering from Eaden [4].

Table 2. Learning outcomes measured by CCKNOW

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre (%)</th>
<th>Post (%)</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>q2</td>
<td>100.0</td>
<td>100.0</td>
<td>0.0</td>
</tr>
<tr>
<td>q3</td>
<td>56.3</td>
<td>60.4</td>
<td>4.2</td>
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<tr>
<td>q4</td>
<td>37.5</td>
<td>47.9</td>
<td>10.4</td>
</tr>
<tr>
<td>q6</td>
<td>100.0</td>
<td>95.8</td>
<td>-4.2</td>
</tr>
<tr>
<td>q7</td>
<td>68.8</td>
<td>64.6</td>
<td>-4.2</td>
</tr>
<tr>
<td>q9</td>
<td>68.8</td>
<td>64.6</td>
<td>-4.2</td>
</tr>
<tr>
<td>q10</td>
<td>70.8</td>
<td>75.0</td>
<td>4.2</td>
</tr>
<tr>
<td>q11</td>
<td>58.3</td>
<td>56.3</td>
<td>-2.1</td>
</tr>
<tr>
<td>q12</td>
<td>10.4</td>
<td>6.3</td>
<td>-4.2</td>
</tr>
<tr>
<td>q13</td>
<td>39.6</td>
<td>33.3</td>
<td>-6.3</td>
</tr>
<tr>
<td>q15</td>
<td>72.9</td>
<td>89.6</td>
<td>16.7</td>
</tr>
<tr>
<td>q16</td>
<td>52.1</td>
<td>70.8</td>
<td>18.8</td>
</tr>
<tr>
<td>q17</td>
<td>39.6</td>
<td>45.8</td>
<td>6.3</td>
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<td>22.9</td>
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<td>q20</td>
<td>47.9</td>
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<td>2.1</td>
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<td>6.3</td>
<td>18.8</td>
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<td>70.8</td>
<td>58.3</td>
<td>-12.5</td>
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<td>50.0</td>
<td>52.1</td>
<td>2.1</td>
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<tr>
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<td>43.8</td>
<td>16.7</td>
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<td>60.4</td>
<td>68.8</td>
<td>8.3</td>
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<td>16.7</td>
<td>16.7</td>
<td>0.0</td>
</tr>
<tr>
<td>q28</td>
<td>47.9</td>
<td>50.0</td>
<td>2.1</td>
</tr>
<tr>
<td>q29</td>
<td>83.3</td>
<td>62.5</td>
<td>-20.8</td>
</tr>
<tr>
<td>q30</td>
<td>50.0</td>
<td>52.1</td>
<td>2.1</td>
</tr>
</tbody>
</table>
**Change in Physicians’ Comfort Around the Use of Technology**

The survey of primary physicians was conducted but a low response rate (N=5) yielded very little data. An example question is “In your opinion, what are the most important issues regarding group communications with your patients and the IBD specialists?” The responses were: “Comfort level discussing patients’ condition” (N=1); “Confidentiality regarding overall health issues” (N=2); “Providing continuity of care” (N=1); “Other (please specify)” (N=1). To the statement, “Electronic records are a good idea,” three responded “agree somewhat” and two responded “strongly agree”.

**IBD Patient Portal Usage**

Fifty-seven patients accessed the portal. They logged into the portal 893 times. Usage ranged from 96% for FAQs to 28% for private messaging. Of those who posted a question not found on the FAQs, most (91%) were comfortable or fairly comfortable doing this.

**Pragmatic Completeness of the IBD Patient Portal**

For the concordance analysis, manual indexers sought UMLS codes for 1361 indexing terms in 93 FAQs and were successful 782 times (57%). They sought UMLS codes for 398 glossary terms and were successful 348 times (87%). The automatic indexing of the FAQs using MMTx found 5302 UMLS codes, of which 1170 were unique. The automatic indexing of the 398 glossary terms generated 418 UMLS codes.

The automatic indexing of the entire IBD patient portal using MMTx found 29,373 UMLS codes, of which 3,035 were unique.

A comparison of manual and automatic indexing identified 107 UMLS codes in the manual indexing set that were not in the MMTx-generated set. This leads us to a bounded set of 3,142 concepts for the topic map used for our completeness evaluation.

The poorest performance by patients on the CCKNOW pre-test was q22 where only three patients answered correctly. This asks about the possible reduction of fertility in male patients who take sulphasalazine. The patients need to be able to infer that reduced fertility levels and low sperm count have an equivalent meaning. In the post test, five patients changed their incorrect response of “don’t know” to the correct response. This led to an improvement in the performance of that test item. However, it still showed that 65% of patients responded “don't know” to this question post test.

The CCKNOW had three questions (q16, q17, q22) on sulphasalazine, a medication with a British spelling as used in CCKNOW and an American spelling, sulfasalazine, as used in the IBD patient portal. A search for the term on the patient portal returns one result from the glossary, showing an association between 5-ASA, sulfasalazine, and mesalamine. A search for “5-ASA” returns 5 FAQs. There were two entries in Cochrane summaries for sulfasalazine that say male infertility occurs but there is no discussion of reversibility and three entries in pamphlets which state a side effect is a reduced sperm count in men that returns to normal when the drug is stopped. There was an entry in the discussion forum that was misspelled (sulfasaline) saying patient was on medication but no discussion of male infertility.

The patients expressed what they wanted to know about through FAQs, and the comparison of that breakdown with that of CCKNOW differs. This difference may have had an impact on how patients responded to the CCKNOW.

For the completeness analysis, inference rules were generated through question analysis. The information to answer all CCKNOW questions can be inferred from content on the IBD patient portal.
Discussion

The IBD patient portal addressed the information needs identified by patients and clinicians. This is in keeping with suggestions made by Quan et al [13] to place more emphasis on IBD complications and treatment, which are aspects of IBD that have a direct impact on patients' quality of life.

Patients found the portal useful. In keeping with Winkleman et al [14], the study aimed to promote a sense of illness ownership, of patient-driven communication, of personalized support, and of mutual trust. The relationship between patient-reported quality of life (SF-36, IBDQ) is not expected to improve significantly in patients with chronic illness.

The interplay between information technology solutions and healthcare required a sociotechnical [15] approach to implementing solutions. The study found that addressing concerns individually was the most effective way to create a synergistic relationship between all IBD patient portal users. This required ongoing alterations of the active site and reconsideration of project planning.

Previous research studies indicate that physicians are concerned that allowing participants to contact them via web messaging would inundate them with overwhelming numbers of messages to respond to. This study concurred with other studies in this area in that participants were reasonable and selective in contacting physicians in this electronic manner [15].

For the learning outcomes, the mean scores achieved by patients in this study were as high or higher than scores reported in other studies [4,5,13,16]. Clinicians participating in this study value the importance of patient education and enablement. Perhaps this is the reason that this patient group started with high CCKNOW scores and consequently were less able to show large improvement.

The content analysis revealed lexical variations that caused a mismatch between knowledge tested and knowledge presented. The study accounted for textual variations using a combination of automated and manual methods to address issues of ambiguity and precision. Through accounting for these the information retrieval can be improved [17] for future users.

Acknowledgments

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Conflicts of Interest

None declared.

References


Abbreviations

CCKNOW: Crohn’s and Colitis Knowledge Score test
FAQs: frequently asked questions
IBD: inflammatory bowel disease
IBDQ: Inflammatory Bowel Disease Questionnaire
MMTx: MetaMap Transfer
SF-36: Short-Form-36 Health Survey
SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms
SSL: Secure sockets layer
UMLS: Unified Medical Language System
XML: eXtended Markup Language