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Human Information Behavior

December 2017

On the Information Acquisition Process of People Diagnosed with IBD and a Service Proposal to Streamline this Process

Abstract

By addressing patient concerns and various research studies on the discourse of information pertaining to IBD, I will develop a thorough and concise approach to the dissemination of vital medical information to patients newly-diagnosed with IBD. By acknowledging patients' fears, concerns, and questions, my process aims to deliver the most important information in the most empathetic manner possible. Often patients experience a sense of alienation or may otherwise be dissuaded from the information seeking process due to a lack of recognition for their feelings, as well as an inability to interpret or understand medical jargon. In order to promote and endorse patient-physician relationships, a new approach to the cultivation of knowledge must be developed.

There are numerous factors, both physical and psychosocial, which influence patients' behavior and actions near or during the process of diagnosis. In order to yield the most fruitful treatment, as well as promote greater quality of life, the diagnostic process should be carefully elaborated on. Patients are urged to work in tandem with their physicians, without fear of stigma or blame, in order to develop a greater individualized approach towards the medical process. A new information service will be developed, in which important information will be related in a cordial manner. Patients should also work towards being well-informed, in order to manage symptoms as well as develop healthy practices, so as to proceed unhindered by their diagnosis, and enjoy a balanced life.

Introduction

Getting diagnosed with a chronic illness is primarily anxiety-inducing, “with potentially debilitating physical symptoms, which in turn can have a substantial impact on patients' overall well-being and quality of life” (Norton, Thomas, Lomax, and Dudley-Brown, 2012). In addition to physical symptoms one is inclined to suffer, there is a wealth of psychosocial factors one must confront in overcoming his or her newfound diagnosis. A lack of research resources disallows patients from properly communicating with their physician, and describing their symptoms with acumen. Researchers have submitted that, “better information should be considered as a potentially important component in improving patients' outcomes in IBD” (Pittet et al., 2016.). Thus, patient experience and medicinal information should be blended together in an empathetic approach to addressing one's concerns about his or her diagnosis. Patients should be informed of

vital information through a comforting system that does not diminish quality of life, but transcends patients to a new level of understanding and appreciation for the body.

One is first tasked with defining the disease and seeking advice from an appropriate medical professional; for this a gastroenterologist will prove sufficient in determining the type and severity of Inflammatory Bowel Disease (or IBD). There are many subcategories of IBD, based on what part of the digestive tract is affected. Identifying the exact problem area is a primary concern of patient and doctor alike. Often, the physician is a patient's primary source of consultation. In a Swiss clinical study, "gastroenterologists were patients' favorite source of information, although patients were also opened to other sources such as books, internet or nurses". (Wong, et al., 2012). This reflects a generalized patient desire to rest their concerns in the capable hands of a dedicated medical professional, which may lead to some issues.

Pittet writes, "Having sufficient or adequate information was shown to potentially increase compliance to treatments" (Pittet et al., 2016), but "other studies showed that having access to health-related information on IBD negatively impacted on quality of life or anxiety levels" (Borgaonkar, Townson, Donnelly, and Irvine, 2002). In other words, some patients may be induced to worry unnecessarily, or may otherwise be prone to "information fatigue," in which the complexity or amount of information diminishes one's studying ability. The Crohn's & Colitis Foundation of America provides the public with a 28-page color pamphlet on IBD, which discusses the phases of chronic illness from diagnosis to treatment, and provides additional layers of support such as stress-related therapy and diet and nutrition, but ultimately only touches the surface of a few important questions on the mind of the patient.

Often before considering treatment, a patient's primary concern is with balancing his or her illness and his or her work or social life. The patient may be induced to make compromises moving forward. "Living with IBD can have a major impact on the patients' physical and emotional well-being, placing considerable demand on their management of daily activities such as social function/interaction, family life, and work or studies" (Lesnovska, Borjeson, Hjortswang, and Frisman, 2013). Patients must work with their healthcare professional in determining their needs and concerns. During this process, information must be adequately communicated to the patient, "which requires an understanding of how each individual acquires knowledge" (Lesnovska et al., 2013). There is demand on patient as well as physician, so that the individual and the healthcare system which surrounds them can work in tandem to promote the greatest quality of life.

A primary information service needs to be concise, simplistic, and accessible, which can provide valuable information to the patient in a language he or she can understand, and affords the patient and his or her loved ones a level of comfort and repose, and a foundation of knowledge on which to make informed decisions.. In their review of information available to patients," Raynor writes: "the heterogeneity of knowledge needs in a group of patients who all have the same diagnosis places considerable demands on healthcare professionals because the information must be individualised to support each patient in the best possible manner" (Raynor et al. 2007). Through diligent study of numerous materials and different media digitally or non-digitally, the modern patient is more informed than ever before, but the responsibility still lies on medical professionals and caregivers to disseminate important information to patients, while still maintaining a level of personalized instruction and care.

Literature Review

Psychosocial Factors

Literature concerning information-seeking behavior of people diagnosed with IBD stresses a need for more informative and relatable literature on the topic. Different treatment options available should also be discussed, as well as how each treatment caters to the individual, and how these treatments affect an individual's quality of life thereon. In Valerie Pittet's article "Patients' information-seeking activity is associated with treatment compliance in inflammatory bowel disease patients," published by the University of Zurich, she writes: "at least 30% to 45% of the patients are noncompliant to treatment" (Pittet et al., 2014), and that there is a general disconnect between searching for available treatment options and other material relevant to IBD. "In Switzerland, IBD patients noncompliant to treatment were more often seeking disease-related information than compliant patients" (Pittet et al., 2014), and that patients were generally more concerned with daily management of symptoms and disease. The question is, why might individuals be focused on temporary relief of symptoms rather than long-term treatment techniques?

Part of the issue has to do with psychological issues and stress factors, an invisible but prevalent issue which lurks in the mind of the patient. M.S. Sajadinejad's stresses the importance of IBD as being a definitively psychosomatic disease in the article: "Psychological Issues in Inflammatory Bowel Disease: An Overview." In their article on the methodology of stress research, Keefer writes: "Historically, it was first in the 1930s that gastroenterologists and

psychiatrists suggested that emotional life events and experiences are likely related to exacerbation of intestinal symptoms” (Keefer, Keshavarzian, and Mutlu, 2008) and that “stressful experiences could adversely affect the course of IBD” (Sajadinejad, Asgari, Molavi, Kalantari, and Adibi, 2012). Although the genesis of IBD is relatively unknown, and there is disagreement over who may be affected, “environmental factors trigger immune dysfunction and bowel symptoms...in a person who is predisposed genetically” (Neuman 2007). Although each patient is likely to respond differently to the challenge of overcoming chronic illness, many patients may feel inclined to blame themselves or their genetics, and may believe that “complaining might be regarded as a weakness” (Sajadinejad et al., 2012).

Many patients may be dissuaded or refrain from seeking information. In a qualitative study by Andrew McCombie, Roger Mulder, and Richard Geary in 2013, all relevant articles on Ovid and Pubmed databases were analyzed according to subject and attendance over the course of 6 months. “The most common theme was that emotion-focused coping was associated with worse psychological outcomes, while the effect of problem-focused coping was less consistently associated with better psychological outcomes” (McCombie, Mulder, and Geary, 2013). With that being said, the line isn’t always clear, as newly-diagnosed patients are wholly unequipped to confront the monster of dealing with chronic illness, and may need or seek professional guidance outside of virtual circles.

While McCombie’s study presents emotion-focused coping as being associated with worse psychological outcomes, it was also found that some adolescent emotion-focused coping strategies were adaptive, which may be representative of the absence of decision-making in juvenile patients, being that most juvenile medical decisions are made by proxy. “Another study

found that adolescents with IBD are more dependent upon catastrophizing and helplessness for coping with pain, thus making them more susceptible to depression, anxiety, and QOL (quality of life)” (Raffle and Bush, 2009). There is a mismatch of coping techniques exhibited by patients, which may often result in psychological epidemics. Healthcare professionals require a standardized approach which reduces patient concern and promotes growth.

Seeking Information

The majority of patients express an interest in challenging their disease with firsthand and erudite knowledge, which is comprised of individual experience and medicinal know-how, and is often expressed by a need for more knowledge about anatomy (Lesnovska et al., 2013). For instance, patients were often concerned with the correlation between particular symptoms and their diagnosis, and whether or not they were eligible for surgery or likely to relapse. On the other hand, patients who opted to neglect studying their disease often “explained that such knowledge merely created a feeling of guilt or that more knowledge seemed pointless as there was no cure” (Lesnovska et al., 2013), but were concerned with times when their symptoms appropriately elicited contact with a medical professional. Such stigmatic feelings are not entirely uncommon in the patient, often alienating the patient or causing one to abandon their information search

In Lesnovska’s Swedish study, when it comes to the information-seeking habits of newly-diagnosed individuals, there were two schools of thought: “Those who did not want information [on risks and complications] argued that it only created anxiety about something that might never happen,” whereas “patients who wanted to know about possible complications

considered such knowledge valuable because it would help them to be vigilant” (Lesnovska et al., 2013). None of the patients had explicit medical training or expert knowledge on the subject, but were concerned with obtaining this information as a personal matter, which could potentially protect them down the line or alert them to symptoms when not in the presence of a healthcare professional. This proactive instruction allows patients to better understand their body in the context of IBD, and may also predict recovery from surgery, in addition to some other weakly positive benefits (McCombie et al., 2013).

Sufferers of IBD are genetically predisposed to the disease, and are not capable of avoiding it through heuristic or other therapies. Thus, actively searching for information on one’s diagnosis is the veritable first step on the pathway to recovery, in which a patient realizes he or she is incapable of going back to pre-diagnosis or wholly overcoming their disease. Research is a healthy and natural approach towards alleviating patient concern. As previously noted, many patients delay or even abstain from obtaining information on treatments, thinking wishfully that treatment won’t be necessary for them, or that regular diet and symptom-management will prove a sufficient substitute. This is due to the long-term and permanent nature of serious medical treatment. Only once one is familiar with his or her diagnosis, as well as the body’s needs and nature, can the patient proceed to the formal selection of treatment

Influence On Treatment

Patients are often asked to observe a strict, individualized regimen in order to promote healing and treatment of symptoms. Patients may seek additional medical guidance outside of their gastroenterologist or primary physicians, such as the mentorship of a dietitian, therapist, or

holistic healer, to name a few. In a Spanish study by Sophia Garcia-Sanjuan, it was found that “the professional treatment of patients with CD should include monitoring the difficulties and situations they must overcome in their daily lives” (Soares, Ribeiro, and Arena, 2008), which may often be manifested in the regulation and quantification of bowel movements, time and schedule of eating, and awareness of one’s own person including but not limited to stomach aches and cramps; all of which must be calculated and confessed to a physician with acumen.

Thus, the patient assumes the role of researcher, and their body of work with their physical well-being. The patient must work alongside medical professionals in determining which treatment is best, in order to “take into account patient subjectivity and their perceptions about the problem” (Rehnsfeldt and Arman, 2016). “Several studies have shown the interest of this kind of proposals [*sic*] toward care improvement from a holistic perspective, focusing on implementing specialized units for those affected by CD” (Casellas-Jorda, Borrueel-Sainz, Torrejon-Herrera, and Castells, 2012). Physicians are tasked with transposing patient experience and physical symptoms in order to produce the best treatment available, and may use qualitative data such as meanings, reasons, beliefs, values, and attitudes in making their decisions. (Garcia-Sanjuan, Lillo-Crespo, Richart-Martinez, and Quiles, 2017) The patient’s duty, on the other hand, is to be well-informed about the variety of treatments available.

There is no cure for IBD, and treatments are only capable of lessening symptoms or conceiving of remission. According to MayoClinic’s website, blood tests and endoscopic or imaging procedures may be used in the diagnosis phase, whereas treatment may be composed of anti-inflammatory drugs, immune system suppressors, antibiotics, and/or over-the-counter subscriptions for topical relief. Surgery, however, may prove necessary depending upon the

severity of patient symptoms, and additional measures may be taken such as a change in diet, reducing stress or smoking, and the use of alternative medicines. All of the above must be strictly regulated by a physician, and any changes must be made known to a physician or caregiver. Patients are not encouraged to experiment with additional modes of treatment, but some studies suggest symptom relief through the therapeutic use of cannabis (Ahmed and Katz, 2016). Due to the chronic nature of IBD, it is considered a permanent disability within the United States.

Service Proposal

Due to the complex and often disorganized nature of IBD information available on the web, I propose to develop a comprehensive brochure freely available to newly-diagnosed patients, which guides them on the pathway from acceptance of their disease to treatment selection and further, better living. It should be noted that the Crohn's & Colitis Foundation of America (CCFA) produces a 28-page digitally available brochure, which I believe can be improved upon through more humanitarian language and briefer discourse on relevant information. Patients often expressed linguistic annoyance with physicians and medical journals, or otherwise felt that the available material was in a language they couldn't understand.

My approach is to deliver the most important information to the patient in the simplest manner possible, promoting patient research. Through the use of simple language and quantifiable data, the goal serves to inform the patient. I want to create a pamphlet by patients for patients, which more elementally details the true patient experience, and expresses to him or her a nature of welcoming, inclusion, and understanding. I want patients to realize that, not only is it okay to express one's concerns and hidden symptoms, but it is crucial to the process of growth

and recovery. Doctors exist to assist patients in their troubles, and the IBD community at large exists to offer a lending hand, without fear of stigma or blame.

The brochure will initiate from the stages of pre-diagnosis, but is intended for those who who have made the decision to visit an IBD specialist such as a gastroenterologist. It should be printed by gastroenterologist offices nationally within the United States, at small cost to these offices, which will ultimately be afforded by patient insurance companies. The pamphlet should be visible, accessible, and at eye-level within the patient waiting room or similar area. Multiple issues ought to be printed at any given time. The pamphlet should also be available digitally in PDF format, and a legible, bold-faced link should be provided by websites that contain relevant information on IBD, including, but not limited to: discussion forums, medical journals, and broad-spectrum medical knowledge websites such as WebMD and MayoClinic.

Diagnosis

The earliest material within the information packet describes the diagnostic processes and what one is to expect. People already diagnosed with IBD may feel free to skip this section. It will note that, one of the hardest and most painful experiences of the disease is the diagnosis itself, and undergoing the laborious medical procedures whereby that diagnosis is achieved. Some anecdotal evidence is welcome provided it serves to inform or relieve. It will alert the patient to treat the body as a temple. During the diagnostic phase especially, one should abstain from alcohol and junk food, and should otherwise observe a regimen of steady diet, nutrition, and sleep. One should not overburden themselves with stress, even when obtaining information on IBD, in order to approach the issue with level-headedness and tranquility. I've found that

patients often exhibit displeasure and stress in the diagnostic stage, which often manifests itself in psychosocial side effects like depression and anxiety. I want to approach the information process with a proactive mindset, which recognizes patients' fears and worries, but works to alleviate anxiety, in order to understand and overcome.

Support

I will recommend a number of virtual discussion forums, which meditate on beneficial approaches and coping mechanisms. For instance, the non-profit organization CCFA provides users with a database of local physicians and in-person support groups. Crohnsforum.com, on the other hand, contains a more extensive collection of articles and user queries, and contains an entire subsection devoted to treatment options, but has little to no physical presence. Here, patients are encouraged to discuss their concerns or questions on treatment. Reddit - as one of the world's leading user-based virtual discussion forums, contains pages on IBD and individual manifestations thereof, such as CD, UC, and IBS. While Reddit is the most user-friendly website, the discussion material on each site typically differs in style, demographic, and subject. Most evidence on Reddit is anecdotal, and approaches CD with dark humor or acceptance, providing users with relief and a sense of humility, while the other forums are generally based on hard evidence or fact and provide users with medical information.

Thus, each forum may be said to serve a different purpose, and users are urged to browse many in making their decisions. They are also urged to make posts or otherwise participate in forum activity, in a transition that includes them as a member of the community. These forums may be consulted for more direct discourse on questions or browsing complete articles, since the

intention of the brochure is only to touch on these subjects. Ideally, the patient should be able to find harmony cycling between these websites and the advice of their physician, using this information for a plethora of purposes, such as home remedies, treatment progress, advice on symptom or dietary management, or to otherwise produce a sense of comfort and community not afforded by the individual researcher or lone patient.

Symptom Management

One of many goals is to provide patients with the knowledge they need to treat themselves. While patients are encouraged to contact their physician or similar medical professionals in the event of an emergency, there are many issues which may be treated by the individual at home. This is an area in which patients of IBD make particularly adept problem-solvers, but the variety of home remedies available ought to be kept to a minimum so as to exhibit concise, evidence-based solutions. Part of this section will allow the patient to identify what are relatively normal symptoms or side effects, or when a symptom may be cause for concern should the need to contact emergency services arise. Ordinarily, symptoms are displayed in an ordered list at the beginning of an article on disease, but I feel that the management of these symptoms should be given a place in or near the treatment section.

Due to the litany of symptoms associated with IBD and the lack of available space in the brochure, only the most common symptoms will be addressed: such as belly pain, diarrhea, loss of appetite, and fever (WebMD). One will need to employ a comprehensive and individualized approach towards the management of these symptoms which may be tailored or amended, but the general principles involved in treatment remain the same. Antacids may be used in cases of

indigestion, and diarrhea medications may be used for the curtailing of fever, while fever reducers like acetaminophen may provide patients with relief. However, treatments are subjective, and patients should be informed or trained on how to properly care for their own body.

Treatment Options

The penultimate section is dedicated to treatment due to the seriousness involved in the selection process and necessary commitment to treatment. By this stage, the patient must be well-informed, or may otherwise linger before making any major decisions. In addition to personal health, costs and availability factor into the treatment process, often requiring of the patient a commitment of time or effort. The affected area and severity of symptoms may factor into treatment selection as well. Additionally, the patient must consider his or her predisposition to the side effects of treatment, and may benefit from considering alternative or non-invasive treatments. All of this should be taken into consideration by the patient and his or her family, due to the responsibilities that often transfer unto family members or loved ones.

There are three goals of treatment: to reduce inflammation, to relieve symptoms, and to eliminate nutritional deficiencies. Drugs, nutritional supplements, and/or surgery may be used in achieving remission (WebMD). One or multiple drugs in succession may be used to reduce inflammation, which may contain biologics, antibiotics, or immunomodulators. While this section is unable to formally advise patients on treatment selection, and serious considerations should be made in the presence of a physician, the “Treatment Options” section serves to inform the reader about the different types of treatments available, and will list a number of popular

drugs or treatment regimens, so as to service patrons with all of the options. It should be noted that the “Treatment Options” section will merely serve as a snapshot in time, since new drugs are continuously being developed, and pharmaceutical regulations may be subject to change.

Review and Survey

The fifth and final section of the brochure is dedicated to patient response and review, in which patrons are invited to provide feedback on the level of competence, relevance, and general value of the brochure in contributing to their information needs. This section will provide readers with a rating scale between 1 and 5, and an open-ended discussion box, which they may remove from the body of the brochure and submit for review via post. This will allow the author(s) of the brochure to alter its contents or appearance in a dynamic manner, so as to further reflect on the general patient mindset. This section is dedicated to assessment of the material itself and the information provided, and is a crucial component of the brochure due to its ability to interact with patients.

Altogether, this brochure should provide patients with general information about their diagnosis, steps towards achieving remission, and coping mechanisms for patients and families. The brochure is not intended to be used in lieu of proper medical care, but serves as an addendum which will elevate patient understanding and experience. As previously mentioned, the brochure is a device developed by patients for patients, which affords the average individual a sense of respite from the otherwise daunting process of dealing with chronic illness. Not only can patients obtain relevant information on their diagnosis, but they are also afforded the ability

to enter into discussion or obtain means of support. Thus, the brochure encompasses all relevant phases of diagnosis and treatment, and touches on material in an empathetic manner.

Conclusion

I've discussed the psychosocial ramifications of entering into the IBD research process without proper consultation or guidance, of which a division of all patients are normally subject to. So as to avoid unnecessary hindrances or worry, I've proposed an information service which caters to the individual, while still providing patients with broad-spectrum information which works to familiarize patients with their newfound diagnosis. Due to the necessity for understanding, the majority of IBD patients are regular information seekers. In Pittet's first study conducted in 2014, of the 512 patients surveyed, some two-thirds (353) were information seekers; however, general practitioners were the most often consulted (Pittet et al., 2014). Research shows a demand for credible information outside of physicians' offices.

Where this method falls short, however, is providing long-term advice and information for individual demographics. In McCombie's article, different instruments were used in the analysis of coping mechanisms, of which many were exclusive to either adults or children. Unfortunately, insufficient evidence exists for tailored information seeking behavior based on age, and while simple in language, the brochure I've described is intended for mature audiences capable of processing the complex and laborious task of dealing with illness. The partial aim is focusing on alleviating stress as being symptomatic of chronic illness. Once stress is dealt with in a healthy and capable manner, the patient can proceed to treating his or her diagnosis.

According to Andrew McCombie, the process which yields the most success in the treatment of patients is problem-focused coping, which “aims to alter or eliminate the source of stress” (McCombie et al., 2012), which may be exemplified by seeking information, withholding actions, and/or confronting the problem. While the brochure provides outlets for emotion-focused coping (“Support” section), which has traditionally shown less-satisfactory results in terms of clinical outcome, the majority of the material discussed deals in providing resources or solutions to the patient. During the course of longitudinal studies, it was found that “pain catastrophizing increased over the two-year study period” and that “adaptive (problem-focused) coping at baseline was positively associated with posttraumatic growth” (McCombie et al., 2012). In other words, patients can most benefit from a systematic and regulated problem-focused strategy, which prevents misfortunes before they occur.

Patient communication must be at all times sincere, and empathetic if possible. The information service’s aim is to convey to the patient a healthy and adaptive lifestyle, rather than to chastise the individual for misappropriated choices. As the old saying goes, “you catch more flies with honey than with vinegar.” Undergoing a new diagnosis is one of the most stressful experiences of one’s life, an experience that can be improved and reflected upon with ease, provided one has the right guidance and resources. While the brochure is composed with the patient in mind and from the patient perspective, it considers the process from a healthcare perspective as well. Just as one must periodically work with their physician over the course of their chronic illness, so this information service considers the demands of healthcare professionals and patients alike, and eases the exchange of information between the two. With

better communication between patient and physician, and with more informed individuals, better treatments may be developed over time.

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