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**BRIDGING THE INFORMATION GAP
FOR ULCERATIVE COLITIS PATIENTS**

A Masters Thesis

Presented to

The Graduate College of
Missouri State University

In Partial Fulfillment

Of the Requirements for the Degree

Master of Arts, Writing

By

Amanda Mae Morgan

May 2015

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BRIDGING THE INFORMATION GAP FOR ULCERATIVE COLITIS

PATIENTS

English

Missouri State University, May 2015

Master of Arts, Writing

Amanda Mae Morgan

ABSTRACT

Nearly all humans, throughout the course of their life, have been diagnosed with everything from a mild cold, to a viral infection, or perhaps a diagnosis of a chronic condition. Upon experiencing symptoms, patients are exposed to a plethora of information. The Internet holds home remedies, for those wary of the doctor's office, or there are advice boards where people share their experiences, trials, and tribulations. In some cases, the doctor is the purveyor of the information and written materials are sent home with the patient dictating the regimen to follow to achieve wellness. However, some patients, particularly ulcerative colitis patients, find themselves without these written materials and without access to health information specifically tailored to their needs. Patients must forage for information while trying to maintain their health after diagnosis. This study explores the holes in the information-sharing process through interviews and surveys, focusing specifically on patients, technical medical writers, and gastroenterologists. The study finds most ulcerative colitis patients do not receive the information they need.

KEYWORDS: patient education, patient materials, ulcerative colitis, technical medical writer, gastroenterologist, information foraging theory

This abstract is approved as to form and content

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ACKNOWLEDGEMENTS

I'd like to start by thanking my thesis committee: Dr. Lyn Gattis, Dr. Marianthe Karanikas, and Mr. John Turner. Throughout my academic career at Missouri State University they have supported me with guidance, especially during my thesis work. Without their insights, this thesis would not be possible. I'd also like to thank all of the participants who gave their time and input into my study. I'd like to thank my parents for their unfailing support throughout my life and my academic endeavors; this thesis is a testament to the work ethic they've instilled in me. Thank you all so very much.

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INTRODUCTION

Ulcerative colitis (UC) patients rely on good communication from the healthcare industry not only to maintain their condition, but to help alleviate some of the panic and stress associated with an ulcerative colitis diagnosis. Ulcerative colitis is a chronic disease resulting from an abnormal response to the patient's immune system where the immune system mistakes food, bacteria, and other materials in the intestine for foreign or invading substances (Crohn's and Colitis Foundation of America). Patients often feel overwhelmed by the amount of information they receive from healthcare providers (Curtis, Hahn, & Stevermer-Bakken, 2008, p. 119). If patients are left without sufficient information on how to manage this condition and keep themselves healthy, they can become increasingly ill to the point where their entire intestine may need to be removed.

Currently, UC patients do not have the best resources to discover more about their disease. According to Kennedy and Rogers (2002) Physical patient education materials are what is specifically lacking (p. 258). The lack of information and insufficient communication between gastroenterologists and patients leave patients to begin foraging for accurate information to better understand their disease or find ways to manage it. Information foraging theory provides the explanation for the ulcerative colitis patient's quest for information. Pirolli & Card (1999) state the patients begin with a scent, follow the scent to a patch and then ultimately add the good information to their diet.

These patches of information are created by the gastroenterologist providing expertise from the healthcare industry. Expert information is provided, then it becomes up to healthcare companies and writers to access the aggregate of information and

provide it to the patients. However, there is no guarantee a trained technical medical writer is brought in to create the patient education materials.

While studies have shown UC patients do not feel satisfied with the information they receive upon diagnosis, no steps have been taken to create patient education materials that are fully comprehensive for the UC patients. Current studies based in medical writing advocate for the use of principles of plain language and recognizing the need for improved health literacy; however, the medical writing publications have focused on the same topics with similar information since the first issue of the medical writing publication in the early 1980s.

This study is beneficial because results affirm the lack of literature for ulcerative colitis patients while incorporating the understanding of the search for information from the patient's perspective. The study also incorporates the perspectives of a medical writer and gastroenterologist to further define the areas of information communication that are lacking. This study also serves to incorporate the need for technical medical writers when it comes to creating and designing future patient education materials.

LITERATURE REVIEW

According to the Crohn's & Colitis Foundation of America, over 700,000 Americans currently suffer with UC. Current literature indicates that UC patients receive very little educational information regarding their disease after diagnosis. Furthermore, hardly any literature exists on how UC patient materials are created and adapted for distribution. Few studies investigate how patients access information, how writers design patient information, and how the information is still lacking in substance for patients. The same writing trends have dictated the medical writing profession since the early 1980s. These trends are still the main focus of the medical writing profession today; implying the trends have been insufficiently adopted. In Malone's (2007) historical review of areas of study within technical writing, patient education materials and ulcerative colitis are completely absent from the discussion. Malone states researchers should look into patient education materials to enhance the field of technical writing.

Current literature relevant to my study is discussed in topical sections throughout the literature review, with an overview of ulcerative colitis literature and patient education materials; a discussion on the development of patient education materials; different informational outlets for patients; and a brief link between technical communication and UC-specific patient education.

Current Ulcerative Colitis Literature

A plethora of patient education materials currently exist within the healthcare field. However, patient education materials for such things as the common cold, asthma,

or after-hospital care, do not cover the spectrum of information patients with ulcerative colitis need. Ulcerative colitis is a chronic disease, impacting patients from diagnosis throughout the rest of their lives (Rosenthal, date unknown); without having some kind of education material covering this spectrum, many patients could feel as though their concerns about the disease are not addressed or discussed. Most cases of ulcerative colitis are diagnosed in the United States; therefore, patient education materials developed in other countries for patients with this disease are not crafted for U.S. patients with different cultural customs when it comes to health care. This is the underlying issue in the lack of UC education materials.

Several factors explain reasons as to why this information gap exists and why UC patients are left without quality materials to educate them throughout the course of their disease. Some of the faults of the American health system, which focuses solely on ulcerative colitis patients and preexisting studies offer dated information as researched by Kappelman, Moore, Allen & Cooke. (2012). In the following excerpt Kappelman discusses Irritable Bowel Disease (IBD) which encompasses both Crohn's disease and UC, as well as other digestive diseases.

Because IBD is not a reportable condition in the USA and comprehensive, nationwide registries for IBD surveillance have not been established, published studies on the epidemiology of IBD in the USA are limited and primarily include studies which have sampled small, geographically restricted populations. Furthermore, no studies of IBD prevalence have been published using data from the last 5 years and, therefore, current time trends remain unknown (p. 519).

With this lack of information, it is extremely difficult to gauge the trends in UC and what information has been the most successful in helping patients return to their original quality of life, geared with information specifically tailored and explained based on solely their case of UC.

Because of this gap in information, James Gregor (2012), a Canadian researcher, pointed out UC patients can remain relatively ill-informed regarding the nature of UC, its management, and its ultimate prognosis (p. 6). “One reason for remaining ill-informed about UC is the lack of time and staffing of healthcare facilities,” as revealed by Diane Monsivais and Audree Reynolds (p. 172). Since doctors and nurses are already pressed for time, and creating healthcare materials takes a significant amount of focus and dedication, it stands to reason that healthcare materials lose attention and doctors and nurses rely on their interactions with the patient post-diagnosis to serve as the best educational outlet.

Furthermore, no studies indicate a systematic effort within the healthcare system to study this disease and write the information to go along with it. Most agencies rely on preexisting materials that they can quickly update and produce in large volumes. This process is accompanied with substantial revisions. The solutions offered in the literature are less than pleasing. Only one researcher offers a fix to enhance the information: “It is possible for various tasks to be assigned to others, such as student nurses, community health aides, and high school students in health professions classes” (Horner, Surratt, & Juliusson, 2000, p. 21). While this suggestion may offer a temporary fix, it does not offer a group of trained writers who understand fundamentals of audience analysis, document design, and consistent and concise messages. None of the studies mentioned even consider a technical writer as being a part of the solution, which is why technical writers focusing on the medical industry are necessary to help assist in bridging the information gap.

In a case study of ulcerative colitis, Hannah Bellwoar (2012), in *Technical Communication Quarterly*, follows a patient called “Meagan” and her experience with ulcerative colitis while being pregnant. Meagan started experiencing pain and was diagnosed with ulcerative colitis. She was met with aloofness from her doctor and began seeking nutritional cures and alterations to her diet due to this response. She repeats her quest for information throughout the study, and describes how personal research was conducted. Bellwoar focuses her study mainly on research methods and processes, rather than focusing on the information gap from “Meagan’s” gastroenterologist. “Although health-related literate activity research such as the research project I offer here could include practical applications to help us better understand patient practices that contribute to product design, the implications I want to highlight for this argument are for technical communication research” (p. 343).

Bellwoar overlooks the absence of information and instead focuses on how technical communicators research and how this research could facilitate better understanding of a condition. There should be some explanation of why there is a disconnect of information and why Meagan was experiencing “aloofness” from her doctors after her diagnosis. Even without the existence of quality materials, the question of whether technical writers should develop information comes into play when addressing missing information. Technical writers become highly specialized in their field, from health writing to program coding, and without a capable writer understanding both the concept and audience, it cannot be said with confidence that accurate materials will be created. There is a second part that goes hand-in-hand when addressing the lack of patient information; that is, if the

information is to be designed and distributed, what are the proper processes to implement to ensure the education materials are clear, concise, and accurate?

General Overview of Patient Education Materials

According to Harris, Smith, and Veale (2005), “[P]rinted materials for patient self-education are a comparatively low cost, flexible and potentially useful aid for dealing with the growing burden of chronic disease. Ulcerative colitis is a chronic disease and the management of the disease lasts throughout a patient’s lifetime. Patient education materials are necessary so UC patients can maintain their health and quality of life” (p. 712). Harris et al. also argue while education materials do require funding, they are the lowest cost component of [patient education forms] and should be evaluated independently (p. 711). While these claims could be true, Harris et al. reviewed statistics from 1985 to 1992 and their study was published in 2005; therefore, the study cannot accurately reflect the current trends in patient education.

It is important to consider why the funding and creation components affect the UC realm of patient education materials. According to a Canadian-based study (Green, Elliot, Beaudoin, & Bernstein 2006), “[S]ince the mid-1990s, the incidence of IBD (which includes Crohn’s disease along with Ulcerative colitis), has been observed to be rapidly increasing in Northern European and North American populations” (p. 615). Green et al.’s study also recognizes that a majority of those being diagnosed are in younger populations, particularly young adults. While these numbers steadily increase, the need for accessible patient information becomes necessary, in printed forms and online forms as well. Patients should have easy access to this information so they can

maintain their quality of life. As Harris et al. ascertain, creating these materials, especially printed ones, are a low-cost means to widely distribute education materials, indicating that a solution to the information gap does exist.

Plain Language

As the prevalence of ulcerative colitis began to steadily increase in the early 1990's many publications tackled the "art" of writing patient education materials. As part of the American Medical Writers' Association, Cox (1989) published one of the first articles dictating how the art should be conducted. Cox identified the creation process as having three phases: patient determination, actual writing, and production (p. 75). The process seems simple to execute, but Cox recognizes the complications that may accompany the procedure and the implications it provides. Cox advocates for the use of plain language throughout her article, stating the following, "The problem of implementing research and best practices across a broad enough spectrum of organizations to create observable and measurable change is variously described using the terms of translation or diffusion. Resistance is often based on misunderstanding what plain language is" (p. 78).

Cox describes a simple three-phase process for developing patient education materials and recognizes the resistance health institutions have in implementing this process; the research is outdated, and a process implementing plain language is not necessarily the best means for creating a solution to the lack-of-information problem.

However, the three aforementioned studies reveal statistics and ideas of how to tackle the lack of information problem. The research has found its way throughout a

majority of works published about patient education and the few works published about patient education materials for ulcerative colitis patients.

Cox is not the only writer to advocate for the use of plain language. Stableford and Mettger (2007) focused on the so-called health literacy challenge in their study and found plain language to be a solution for effective patient education materials. According to the study, “plain language embodies clear communication and “uses evidence-based standards in structuring, writing, and designing to create reading ease” (p. 75). Additionally, Willamers (2006) also advocates for the use of plain language in health writing. Willamers states, “plain language is another way to achieve clarity...meaning straightforward language” (p. 108).

Although, using plain language in patient education would be an effective method to employ in creating usable content, none of the studies directly speak to plain language or give comprehensive examples on how to implement plain language in the materials, nor do these studies discuss the use of plain language in long-term management materials.

Guidebooks for Ulcerative Colitis Patients

Guidebooks have been at the forefront of patient education documents. A UK-based study conducted at the School of Primary Care Research and Development Center focused on developing a comprehensive guidebook for patients with ulcerative colitis. The study acknowledges that “many [patients] felt their need for information had been greatest following diagnosis and this is when the guidebook would be of most use” (Kennedy & Rogers 2002). This guidebook was created in order to compensate for a

prior lack of access to useful information and contained more comprehensive and user-friendly information than other available sources (Kennedy & Rogers 2002). Nineteen of the patients assessed did not receive information about the disease from their diagnosing hospital; instead they had to wait on information from their gastroenterologist (Kennedy & Rogers 2002). Kennedy and Rogers expand by saying, “[D]octors were generally open to the idea of providing patients with information that allowed them to take more control of managing their condition and the patients were generally willing to take on a greater role in self-management” (p. 262). Kennedy and Rogers’ study is quite relevant to the overall patient disconnect issue at hand; however, there are a few areas where their research falls short. The study is conducted in the United Kingdom and does not address patients diagnosed with the disease in the United States. In addition, the guidebook developed for the patients was not intended for other countries. A small control group received the guidebook, but the group did not accurately represent the entire sample of patients with ulcerative colitis. Without working with a larger percentage of patients and not developing this guidebook for the needs of patients in other countries, this study cannot be viewed as complete despite the fact the study makes accurate claims, such as improved quality of life, that are true of most patients post diagnosis.

Kennedy, Robinson, Hann, and Thompson (2003) also piloted another study in the United Kingdom, focusing again on a guidebook for patients with ulcerative colitis; however, this research was concerned with how a guidebook would affect patient knowledge, anxiety, and quality of life, rather than the development of a guidebook overall. Kennedy et al. points to other studies recognizing deficiencies in the provision of information to patients with inflammatory bowel disease, stating information is produced

mainly by pharmaceutical companies or charitable organizations. However, it stands to reason medical offices, which are most commonly the scene for diagnosis, are not equipped with the staff or materials to produce printed education materials.

Kennedy et al.'s study shifts focus away from the organization creating the materials and begins to focus on the relationship between patient and document crafter. According to Kennedy et al.'s findings, the Centre for Health Information Quality, for information to be satisfactory, patients should be involved at the design, writing, and piloting phases of production, and that the content should be evidence based. Kennedy et al. brings up a valid point, because documentation, no matter the topic of information, cannot succeed if the audience is not taken into consideration during the planning and creating of said materials. The information designed is created by the organizations as aforementioned by Kennedy & Rogers. Again, the study solely focusing on the United Kingdom does not accurately address the issues in health documentation in the United States, nor does the study offer any kind of pattern to follow to improve existing documentation; it serves to illustrate the necessity of patient involvement in creating materials to help them cope and manage with a chronic illness.

Guidebooks have not been completely disregarded by the United States for ulcerative colitis patients. Both the Crohn's and Colitis Foundation of America and Walgreens have put together a comprehensive guidebook, *A Patient Guide to Crohn's Disease and Ulcerative Colitis*, for patients struggling with ulcerative colitis. However, both of these guidebooks follow a similar organization of comparing ulcerative colitis and Crohn's disease side-by-side, leaving neither population with a guidebook targeted specifically for them. While the guidebooks are comprehensive in nature, they are both

riddled with complex jargon and confusing explanations of further complications that may ensue after diagnosis. For example, in the guidebook provided by Walgreens, further complications with ulcerative colitis are explained as:

Total proctectomy with ileostomy – removing the colon and rectum and creating an ileostomy (an opening through the stomach wall that allows waste to empty into an attached pouch).

Restorative proctocolectomy/ileal pouch anal anastomosis – a two-stage operation that does not require a long-term ileostomy (p. 9).

Both of the above examples offer minimal explanation of the procedures and complications from the disease. The use of complex vocabulary would cause further fear and panic within a recently diagnosed patient.

The Crohn's and Colitis Foundation of America guidebook, *The Facts About Inflammatory Bowel Diseases*, follows a similar pattern to that of Walgreens, incorporating both Crohn's disease and ulcerative colitis into one guide. The guide, similar to Walgreens, contains jargon and complex terminology including perforated bowel, fistulas, and strictures with limited definitions. Additionally, the guide digs deeply into complications of both diseases, including cancers and bowel obstructions, which “may or may not be experienced by all IBD sufferers” (p. 7).

Ardizzone and Porro (1998) offer a practical guide as a result of their research on the management of ulcerative colitis. The first definition of the disease to greet patients is as follows, “Ulcerative colitis is an inflammatory disease primarily affecting the colonic mucosa; the extent and severity of colon involvement are variable. In its most limited form it may be restricted to the distal rectum, while in its most extended form the entire colon is involved” (p. 520).

In order for this guide to be considered practical, it should include definitions that adopt the plain language method Cox started arguing for in the early 1990s. However, this definition is very complex and patients may not understand what exactly the disease is or how it affects the body. The practical guide does not contain any kinds of images to help patients understand exactly where the disease can be located. Without a point of reference or further definition of complex terms, the guide can hardly be viewed as practical.

A chronic disease self-management program focused in China also advocates a guidebook for patients. Fu Dongbo and his team (2003) recognized the effectiveness of self-management programs from previous studies in the U.S., Canada, and U.K., agreeing the programs enhance overall self-efficacy for patients (p. 175). Furthermore, the study for heart disease, stroke, cancer, and lung disease patients revealed similar concerns and problems amongst the participants. Therefore, Dongbo and his team insisted upon a detailed manual given to these patients addressing their concerns and assisting in furthering the patient's education (p. 175). Unfortunately, the study did not reveal precisely what the detailed manual would contain, nor did it reveal any kind of results of success after these manuals were distributed to patients. Again the trend is also seen here to not focus on ulcerative colitis patients in the United States specifically, so using the study as a complete example to follow becomes irrelevant.

Audience Analysis

The aforementioned organizations and studies put people at the front of their documentation. However, no guidebook states who specifically developed the content or

the criteria used to create the guidebooks. Due to the high concentration of jargon within the text, it is clear the processes used to develop these books ignored a complete audience analysis. The process ensured to make “people” the subject of the books, but ignored how their target audience might translate the vocabulary and content contained within the book. Audience analysis is a pillar of technical writing and is stressed greatly by the American Medical Writers’ Association (AMWA). Birkby (1987) wrote one of the first articles for AMWA’s publication focusing on a sense of audience when writing materials. Birkby argued:

A medical writer must therefore find out: if the potential readers are, for example, medically trained or laypersons, colleagues, or strangers, specialists or generalists and if these readers are already knowledgeable about the subject, are not at all familiar with the subject or know something about the subject indirectly as perhaps former patients. (p. 17)

Cox (1989) also discusses the development of patient education materials in her article discussing plain language. Cox discusses evaluating the learning needs of the targeted readership in order to determine both the content and tone of the piece that needs writing (1989). It appears Cox and Birkby are in agreement when it comes to fully understanding the reader of the patient education material.

The importance of audience analysis is evident throughout studies focusing on writing patient education materials outside of AMWA. Vahabi (2007) sets the following standard for patient education materials: “An assessment of people’s ability to read, process and understand health materials should be conducted prior to any health communication to identify people with deficient literacy and ensure that they receive assistance to overcome barriers to proper functioning in the health care environment” (p. 31). Enhancing patient literacy through the use of plain language and adapting to the

potential patient's literacy levels is the most substantive argument made by Vahabi. Health literacy became the main trend dictating the development of patient education materials.

Health literacy can be defined in a multitude of ways, and these definitions can dictate how health care information is written. Mitty and Flores (2008), two nurses, define health literacy as "the ability to access, understand, and use basic information about health conditions and services that is necessary to make informed decisions" (p. 230). Horner et al. (2000) agree literacy is of primary importance to physicians and nurses who strive to reach health needs of diverse groups (p. 15). The importance of health literacy cannot go unrecognized; without establishing adequate health literacy standards, writing patient education materials would not exist as it does today. However, the trend of health literacy seems to act as a "hot topic" throughout a multitude of studies.

An area where health literacy could improve is through discharge instructions, giving patients a clear outline of how to transition to life at home. Chugh, Williams, Grigsby, and Coleman (2003) focused on improving the comprehension of discharge instructions for patients and ensuring a smooth transition from hospital to home and the administration of self-care. However, Chugh et al. relied heavily on health literacy as the definitive solution for patients, ignoring the construction and distribution of patient education materials and other factors that may affect patient comprehension. Health literacy problems include difficulty reading and interpreting medical instructions, medication labels, and appointment slips, and poor understanding of chronic conditions and accompanying management (p. 13). While it is important to understand why there is

a disconnect between patient and written material, none of the aforementioned studies sought to look at how organization of the material or images could aid in health literacy.

Typically, nurses and residents are left to create patient education materials that are not otherwise funded by healthcare institutions. Mary Mumford (1997), a nurse, discussed the readability of patient information designed by nurses in her study.

Mumford states:

Written patient information materials can be valuable communication tools for teaching and reinforcing the verbal message, especially in the present climate of today's health service where patients are in hospitals for such short times. They are only useful if the patient is able to read and understand them, otherwise they become an expensive waste of resources. (p. 985)

Many researchers believe health literacy is the one factor to improve upon to ensure patients fully understand their course of action and treatment. Rudd, Rosenfeld, and Simonds (2012) focused solely on health literacy and how health literacy is the direct link to positive health outcomes (p. 16). Rudd et al. also looked to the U.S. Department of Health and Human Services to reinforce their findings. "The U.S. Department of Health and Human Services' (2010) report, the National Action Plan to improve health literacy, calls for efficacious action and highlights the importance of ensuring that health information is accessible, useable, and actionable" (p. 18). With accessible, useable, and actionable patient education materials, patients are more likely to understand the information they receive. With enhanced understanding from patient education materials, Rudd et al.'s link could prove true.

The health literacy issue comes down to one major point: clear, effective communication between doctor and patient. David Taylor and Peter Cameron (2000) recognize the direct link between effective self-care and patient education materials.

Taylor and Cameron state, “Effective communication between the physician and patient is required for optimum post-emergency department management. Written emergency department discharge instructions have been shown to improve communication and patient management” (p. 86). Echoing Cox’s article, Taylor and Cameron argue for three different types of patient education materials including instruction notes, pre-formatted instruction sheets, and oral instructions (2000). Other researchers recognize the variety of formats when it comes to dispersing instructions to post-emergency room patients. McCarthy, Engel, and Buckley recognize both handwritten and pre-formulated instruction types and understand the need for these materials to be consumable by the patient (McCarthy et al. 2012). Unlike Taylor and Cameron, McCarthy et al. recognize these types of instructions undergo no type of quality check process. “Regardless of the source of information, individual ER clinicians have no simple means of assessing if a patient will understand the content, if the content addresses the patient’s key questions, or even if the patient will read the piece of paper” (p. 1).

Taylor and Cameron offer no further discussion on the best methods to construct these different types of instruction sheets similar to McCarthy et al.; additionally, both studies solely focus on emergency room discharge instructions, which would be constructed differently from post-diagnosis instructions for an ulcerative colitis patient. While it is imperative the emergency room patient understands how to maintain their treatment and care, the instructions provided would differ greatly from a long-term management plan for a chronic disease. In addition, the emergency room instructions are given after discharge and a specific treatment has been performed; whereas most

ulcerative colitis patients are receiving a colonoscopy and have yet to experience a complicated procedure that directly relates to their disease.

Neither of these studies are incorrect in their claims; however, patient education materials have to be fully understood by their readers if the materials are to be successful and aid patients in their care. However, neither of the studies focus on patient education created for patients with a chronic disease, and the studies do not offer any guidelines for how to improve readability and enhance health literacy. Without providing any kind of actionable plan and by solely focusing on hospital discharge instructions for quick care, the studies do not add to the conceptual knowledge of patient education materials created for ulcerative colitis patients.

A similar study was conducted with German and Turkish patients, not diagnosed with UC, and their understanding of written patient instruction (Pette, Pachaly, and David, 2004). While the study was directed merely at comprehension of patient diagnosis and therapy instructions, the study harbors significance when considering implications for patient education materials for ulcerative colitis patients. According to Pette et al., “adequate patient knowledge is essential for good compliance, effective doctor-patient communications, and is the basis for informed consent” (p. 215). This study is not wrong in its claim; patients of any kind, especially ones diagnosed with a chronic disease, must have, at minimum, adequate patient knowledge in order to successfully manage their personal care. Furthermore, while patients in this study were able to identify their diagnosis and therapy correctly, the study cannot be directly applied to ulcerative colitis patients, nor give a clear picture of how United States citizens carry post-diagnosis information.

U.S. Patient Education

It is important to delve into what current trends dictate the writing of these materials. A majority of the patient education materials studies conducted in the United States focus on the readability of patient education materials (Arthur; Horner, Surratt, Juliusson; Taylor & Cameron). Arthur (1995) recognizes the studies that have taken place in the United States and their focus on written patient information (p. 1081). Arthur also recognizes “communication is highlighted as a major problem, especially as written information tends to be incomprehensible and patients remain non-compliant with therapies” (p. 1083). Arthur focuses on readability and legibility of health documents and how those aspects affect patient behavior change, compliance, and satisfaction. However, Arthur’s study is based in the United Kingdom and how their written documents work. Arthur also agrees with Kennedy and Rogers in the principal bodies responsible for creating the written patient education materials. Based upon Arthur’s insights into readability and legibility of documents, she dictates patient’s behavior, compliance, and satisfaction are solely based on good communication. While Arthur makes sound conclusions, there is no intended focus on ulcerative colitis education materials, and the study is not relevant to the US population. Without a clear explanation of how Arthur came to these conclusions and without seeing how these conclusions translate into information given regarding IBD , there is no sound answer that readability and legibility are the two pieces of the missing information puzzle.

The United States healthcare system employs more than just printed education materials for their patients. Helplines, group education sessions, tailored information,

medical staff, and other resources are used to try and assist patients in coping with new diagnoses.

Helplines. Other outlets of information exist for patients to access; for example, helplines have been established as an access point for patients to attain information and education about ulcerative colitis. According to Pearson Mariarty, and Lipscomb (2002), a helpline facilitated a major improvement in the quality of patient care. However, there is no statistical information supporting the claim or any patient input on the information they were calling the helpline for. There are not any details involving patient satisfaction with the helpline. Without knowing this information, it cannot be stated with confidence helplines facilitate a major improvement in the quality of patient care.

Group Education. Group education has increased in popularity among patients and many researchers look to group education as the best means of educating patients about their disease. According to Nossum, Rise, and Steinsbekk (2013) who conducted a study about patient education in Scandinavia, group education can help improve coping skills and educational programs should be established for enhancing education in patients. This statement falls into the qualitative model because the effectiveness of these programs focuses more on interpersonal relationships and establishing classes to teach about the specific disease, rather than presenting patients with quantitative data.

Following suit, Farrell, Wicks, and Martin (2004) conducted a study to see if participation in a chronic disease self-management program improved self-efficacy health and self-management behaviors in a rural population. The study recognized chronic illness as a social burden and success in the management of chronic disease can be limited (p. 291). Farrell et al. implemented a six-week course consisting of a two-hour

class where trained leaders would discuss a variety of topics related to chronic disease management (p. 292). Overall, the study found the program to better educate and enhance self-efficacy amongst patients. However, this study solely focused on rural populations where access to healthcare was limited, and there was no one particular chronic disease targeted with this program. A more detailed and centralized program, along with a centralized focus (i.e. ulcerative colitis), would enhance insight into the success rate of patient education programs and whether or not they serve as a better educational outlet compared to written materials.

Tailored patient education. It can be argued patient education materials for ulcerative colitis should be tailored with good design concepts in mind but also tailored to the individual needs of the ulcerative colitis patient. A study geared towards patients with breast cancer recognizes the need for specific patient document tailoring. Hirst, DiMarco, Hovy, and Parsons stated, “[M]uch health education must be initiated by the clinician in response to the patient’s medical situation, and the information must generally be presented on paper for the patient to refer to later” (p. 108). Hirst’s study presents a flow chart specifying how health documents are tailored in their creation as well as specific coding on how to accurately tailor documents. There is no recognition of how ulcerative colitis documents are tailored or if those documents even follow the same processes described in the study; however, employing a similar flow chart with needs of UC patients explicitly stated could be used in developing new materials.

A Finnish researcher, Helvi Kyngas (2013), agrees with the tailoring principle Hirst put forward. Kyngas stated, “The most effective patient educational programme is the one tailored to meet the patient’s individual needs” (p. 745). Both Hirst and Helvi are

correct in their recognition of the need for specific tailoring, but there is no insight provided on how to precisely follow these tailoring principles when creating documents.

Medical Staff. Doctors and nurses are the first point of contact for many patients and sometimes serve as the sole source of information. It is not as if doctors and care physicians have completely disregarded the need to educate their patients. “If asked, many nurses will say that they educate their patients, but education involves far more than handing out discharge instructions. Nurses expose patients to information, but education is more than exposure. Education must be planned, thought out, and intentional” (Griffin and Murdock 2013, p. 43). It stands to reason, however, that doctors and nurses simply do not have the time to relay this kind of information in a hospital or office setting when the intake of patients is high. With large volumes of patients coming in and out of the office, and a doctor seeing multiple patients a day with multiple, differing conditions, it removes the ability to successfully plan and think out the way the educational information is delivered to the patient. Additionally, these medical professionals may not have been trained in best writing practices and would not be adequate to offer written information to their patients upon diagnosis.

Despite the variety of existing outlets for patients to access information, Elizabeth Winslow (2001) recognizes the importance of the health care facility being the primary provider of patient education. “Despite the abundance of information available—from pharmaceutical companies, magazine, and newspaper articles, and the Internet—written patient education materials provided by health care facilities continue to be a primary source of information for many patients” (p. 33). Winslow goes a step further in revealing why patient education materials offered in the health care facilities may be subpar:

Compiling and creating patient education materials are difficult and time-consuming tasks that often fall to nurses, although other health care providers and outside agencies sometimes assume these responsibilities” (p. 33).

While it can be argued that nurses and doctors understand the needs of their patients, it still cannot be argued that they are the best equipped to write the patient education materials. For example, nurses in an assisted living institution clearly recognize the importance of doctors and nurses communicating effectively with their patients. “For the health care professional it requires sensitivity to cultural norms that can influence willingness and the ability to communicate personal information, assume responsibility for self-care, or make treatment decisions” (Mitty & Flores 2008). While doctors and nurses may be able to convey these messages at the time of diagnosis, it is difficult to gauge how much of this information a patient will retain without some kind of written document.

Monsivais and Reynolds offer guidelines for nurses and patients to develop materials for patients by using what is already available, reviewing that information, assessing what else is out there, and then putting all the pieces together in an updated version of the patient education material (Monsivais and Reynolds 2003). While this process involves systematically reviewing existing content and evaluating new content, it does not completely eradicate the possibility a doctor or nurse might include inaccurate information in the updated material. Monsivais and Reynolds also disregard any alternative writers in their study that could take the time to research and refine the information and edit existing content accordingly.

Additional Informational Outlets. Patients have the option to gain information through countless appointments with their gastroenterologist, the Internet, or from patient education materials, which focus on one facet of ulcerative colitis, rather than the disease as a whole. Angelucci, Ambrogio, Sandro, Guidi, and Sorrentino (2009) recognize the lack of information outlets in a foreign setting, focusing on patients in Italy. After completing a comprehensive survey of patients with irritable bowel disease, they concluded almost all the patients' usual source of education on their diagnosis was their gastroenterologist, followed by health-dedicated websites or the websites of Italian IBD-specific noncommercial organizations (Angelucci et al. 2009). Many patients focus on commercial organizations like the Crohn's and Colitis Foundation of America to obtain information about the disease. Based on the different societies, it cannot be directly determined that most patients would seek out information from noncommercial organizations when trying to gather information. In the United States, credibility of sources is stressed so sites such as WebMd or PubMed are used for their health information. Both of these are commercial centers offering a plethora of information about health conditions. While Angelucci's study might have resonance within the Italian culture, the findings become irrelevant when looking at American culture.

Websites. A majority of patients are discovering information about ulcerative colitis via the Internet (Moradkhani & Dudley-Brown, 2011) rather than from their gastroenterologists. According to Patrick Stephens (2009) an estimated 160 million web-users research health topics (p. 150).

Disease-specific websites have also started to expand to patients with ulcerative colitis. Internet sites help bridge the information gap, but a patient can be misinformed

without guidance from digital sources. Some patients may not even have access to the Internet to find out further information. An inclusive website was created in Iran to assist patients with ulcerative colitis, focusing mainly on “anatomy of gastrointestinal system”, overview of IBD, IBD in children, IBD in women, nutrition in IBD, how to cope with IBD, diagnostic procedures, ostomy, glossary, and list of Iranian gastroenterologists” (Mohammadreza, Delnaz, Shahin, and Reza 2006). This list is more inclusive; however, no mention is made of who is developing the content on the webpages, and the entire population cannot access it. The success rate of the website cannot be compared to that of the United States since no site like this has been specifically tested for patients with UC who may be dealing with low-levels of comprehension ability.

Spreading healthcare messages and publishing patient education content on the web continues to grow in popularity amongst healthcare institutions and patients looking for quick answers. Therefore, patient education content must be constructed in a way that is easily consumable for those accessing it. Stephens recognizes this need in his study focusing on writing health care newsletters for a “Google and go” generation. Stephens recognizes readers want access to information quickly and easily. In order to assist readers in this process, the newsletter should be written in a casual conversational style with a complete and interactive layout and should also employ search engine optimization (Stephens 150). Expanding upon this model, the American Medical Writers’ Association also advocates for the use of headings and subheadings to help readers decide what information is important to them (AMWA 14). Furthermore, AMWA recommends the use of plain language in online content as well to achieve clarity (AMWA 14).

Dr. Monique Giroux, an avid medical writer and member of AMWA, emphasized the importance of the participation of physicians and health care professionals in Internet sites to avoid the unchallenged propagation of faulty information (McCarty 2001).

Giroux also stated information and comfort can be derived from the Web by people with chronic illness, particularly if the illness tends to isolate them in their homes (McCarty 9).

In this case, while Giroux's advice does not specifically point out ulcerative colitis, it relates directly to the disease. Many people struggling with ulcerative colitis feel isolated, due to the embarrassing symptoms of UC, and turn to resources that can accompany them in their homes. With doctors being involved in these medical sites, patients could easily receive the right information, and start to manage their disease with more success.

Unfortunately, Giroux offered no means as to how to successfully implement her ideas to ensure patients receive the best materials and information available. Mitty and Flores (2008) recognize this missing link, stating, "Internet-based health information is widespread and better written...but there is no rating system regarding the quality and veracity of this information" (p. 231).

Perhaps pointing UC patients to resources like The Internet Chronic Disease Self-Management Program could prove viable for accurate and accessible information.

According to Lorig, Ritter, Laurent, and Plant (2006), "this program consists of password-protected, interactive, web-based, English-language instruction and a web-based bulletin board discussion group" (p. 965). However, this resource does not cover all chronic diseases, nor does it consistently offer the same resources at all times. This resource, while thorough and up-to-date, is not sufficient for UC patients who are trying to easily access online information about their disease and management.

Goals of Patient Education and Best Practices

The overall goal of patient education is to help patients facilitate change in their lives for disease management and/or prevention. This is especially true in patients dealing with a chronic disease like ulcerative colitis. Many patients upon diagnosis face misconceptions about their condition and feel insufficiently informed (Halpert, Dalton, Palsson, Morris, Hu, Bangdiwala, Hankins, & Norton, 2007). Patients are primarily interested in learning about what foods to avoid, causes of IBD, and coping strategies (2007). While it is critical to focus on these topics with ulcerative colitis, a patient education document should be much more encompassing than three main topics. The need is evident for in-depth information about chronic conditions and their development over time. The overarching goal of patient education for any disease or illness is accurately summed up by Vahabi:

Health education is the process of influencing people's behavior, producing changes in knowledge, attitudes, and skills required to maintain and improve health. Thus, health education is not just the process of giving information, but rather an active process that facilitates the use of the information to improve decision making, change behavior and ultimately lead to positive health outcomes. (p. 28)

Chronic diseases typically have a negative effect on the quality of life of the patient (Moradkhani & Dudley-Brown, 2011). If one facet of the disease is left out of a patient education document, it can continually add to a decrease in the quality of life for the patient. According to EJ Irvine (2004), "[M]ost individuals experience an impact of inflammatory bowel disease on their daily lives as well as on their attitudes, fears, and beliefs" (p. 54). The most important term to recognize here is fear. While inflammatory bowel disease has a daily impact on patients, a majority of newly diagnosed patients

experience fear which can inhibit them from properly following a self-care routine. Irvine continues:

Many patients with inflammatory bowel disease have fears, concerns, and unmet needs. They perceive and experience problems in all domains of their health-related quality of life... Impairment relates to disease severity, pattern and treatment, but also to age, other demographic factors, and comorbid medical conditions, including depression and anxiety. (p. 59)

Casellas, Lopez-Vivancos, Casado, & Malagelada (2002) recognize people with IBD experience a variety of levels of impairment, with the only difference being higher risk levels of cancer in ulcerative colitis patients (p. 775). Knowing this information can lead to a significant impact on the quality of life for an ulcerative colitis patient.

With a significant decrease in the quality of life after diagnosis and reaching stages of depression and anxiety, it is critical that the organization creating the patient education documents adequately understands how the patients feel and crafts material in a way the patients will find comprehensible in an altered state-of-mind.

Part of enhancing comprehensibility of patient education materials for ulcerative colitis patients with an altered state-of-mind and decreased quality of life, is a particular attention paid to the way the healthcare messages are written and overall word choice.

Mary Knatterud (2008), a medical writer, strives to excise terms that “dehumanize patients or derail readers” particularly avoiding “terms that are insensitive or obfuscating, or both” (p. 113). In a second article by Knatterud (1991), she advocates for treating patients as individuals, rather than symptoms, diseases, or outcomes (p. 10). By following this advice, patient education materials include the “right” words and phrase choices that convey a healthcare message or disease management tactic without further confusing or dehumanizing the patient.

THEORETICAL FRAMEWORK

The theoretical framework used for my study involves information foraging theory developed by Peter Pirolli and Stuart Card. Information foraging theory consists of three pillars: scent, patch, and diet. Humans start with a scent, follow the scent that leads them to particular patch of food, and then, decide if the food fits into the diet, the “food” being the information (Pirolli & Card 1999).

Scent, as it applies to my study, is the patients’ first awareness that information about ulcerative colitis exists, and the direction or path the patient takes to find it using information clues, such as references, links on web sites, and help lines. Patch, as it applies to my study, is what patients find at the end of the scent. Once they’ve reached the patch, patients must evaluate whether the path contains what they need, either making further research unnecessary or deciding if it is worth additional time and energy to keep searching for a better patch of information. Diet, as it applies to my study, is how the patient decides if the food fits within his/her individual needs, wants, and personal constraints.

My study investigates how information foraging theory applies to three main groups of people: patients, medical writers, and doctors. While doctors may start a patient with a scent, by mentioning an online resource or giving out a pamphlet, patients can find themselves on a frustrating search for a patch leading to a successful diet, despite the fact quality information exists. The medical writers also follow suit, beginning to forage to find the best, most accurate information to include in the materials they write and design.

By understanding the foraging patterns of the three groups, a conclusion may be drawn about how each group could do better when communicating across group boundaries.

Currently, our society is information-dense and fast-paced, and locating quality information is extremely difficult. Information exists in a plethora of outlets (i.e. Internet sites, different medical institutions, help lines), so patients, along with writers and doctors, must forage through the information. If the medical writer understands what patients need and how they are foraging, the writer can assemble information answering their questions, ultimately, pointing them to nutrient-rich patches. If the writer starts by harnessing the information early in their writing process, he/she may write the necessary information and offer a strong scent for the patients to follow to a patch of information they can incorporate into their diet.

Then, the doctors and medical personnel may have access to the most accurate and nutrient-rich information that they, too, can provide to patients upon diagnosis. The writer alleviates what patients go through: trying to pick up the scent, making false starts, reaching dead ends, and finding low quality patches.

Other researchers further apply the theory in terms of technological advancement, loosely relating to this study. Giuseppe Mantovani (2001) explains:

Information foraging has recently been proposed to explain how technologies for information seeking, gathering, and consumption can respond to the amount of information present in the environment. The model adopts an evolutionary ecological perspective that considers people's adaptation to the ongoing flux of information present in the environment in much the same way in which biologists study the adaptation of life forms to their physical environment. (p. 49)

Mantovani explains the major benefit to the theory is that it “acknowledges the active side of knowledge. Knowing becomes a strategic activity in which the critical point is that of discriminating what is relevant from what is not” (p. 49). This explanation is especially important to understand in terms of consuming medical information, because the chance of misinformation grows with the amount of informational outlets available to patients outside of the medical facility. Spink and Cole also point out that information foraging theory allows humans to use information to “resolve problems related to survival, work and everyday life” (p. 25). In most cases, UC patients seek information to enhance their survival with the disease and to minimize the disease’s impact on everyday life. Both Mantovani and Spink and Cole bring the theory into the tech-world and day-to-day life.

My study asks the different groups questions regarding the three pillars. By this means, the foraging process can be analyzed and deficiencies in the processes can be brought to light, as well as a better diet for the patient. Once the technical writer incorporates plain language and successful document design, they can satisfy the patient and help reduce or eliminate hours spent foraging. Furthermore, once the patient is satisfied with the deliverable, then the healthcare industry is encouraged to bring the successful material in-house, thereby shortening the scent trails to patches of high quality.

METHODOLOGY

The study uses a triangulated approach to collect qualitative data in an effort to answer the following research question: How do UC patients, medical writers, and gastroenterologists forage for and compile quality diets? To answer the question, the study consists of qualitative data collected from three sources as described below:

- The UC patient survey: This survey was administered via Typeform, an online survey creator, to collect responses from ulcerative colitis patients. Since the disease causes embarrassing side-effects, some patients do not feel comfortable disclosing their condition or sharing their experiences in person. The anonymous, online survey allows for patients to be as open and candid as they feel comfortable.
- The medical writer interview: This interview was administered via phone call to collect responses from a medical technical writer. The interview asked the technical writer to discuss his/her job responsibilities and the education she received to become qualified to create patient education materials.
- The gastroenterologist interview: This interview was conducted in-person to collect responses from a practicing gastroenterologist. The interview asked the gastroenterologist to elaborate on sources of good information and how Rush University gathers and distributes patient education materials to patients.

A research approach of this nature allows UC participants to exactly specify what kind of information each received, what kind of information each would have liked to receive, and how each became educated about their disease. A qualitative approach also allows for the writer and the gastroenterologist to freely speak about their expertise and the ways in which they were trained for the positions they currently hold. By examining responses from all three groups, the researcher will gain insight as to how the pillars of information foraging theory apply similarly and dissimilarly to each group. The methodology for the study is explained in-depth in the following sections.

IRB Requirements

To comply with human subject protection regulations, the Principal Investigator and I both completed the Collaborative Institutional Training Initiative modules for working with human subjects and health information, and achieved certification in the aforementioned areas. The Institutional Review Board of MSU granted permission for the study to take place (September 23, 2014; approval #14-0160).

Surveys and Interviews

While it is important to keep the UC participant surveys anonymous, the medical writer survey and gastroenterologist interviews were carried out face-to-face. These interviews asked more about the writer's and the doctor's day-to-day activities and experiences they have on-the-job. In terms of information foraging theory, the writer and doctor interviews focused more on patch and diet, compared to the UC participant surveys focusing mainly on scent.

By surveying and interviewing three unique parties, the assessment of UC patient education materials may be evaluated from three different angles: the perspective of the UC patient, the perspective of the medical technical writer, and the perspective of a practicing gastroenterologist.

The main purpose of the study is to understand the quality of information UC patients receive after diagnosis and how patients begin to forage for information. I developed the survey questions based on a pilot study I previously conducted. To avoid redundancy, I have placed the survey questions in the Findings section, as well as Appendix A, B, and C.

UC Patient Survey

It was imperative the survey collected responses from the UC patients that covered the pillars of information foraging theory. By writing questions dealing with scent, patch, and diet, and analyzing current trends in responses regarding these pillars amongst the UC population, a better understanding of the way a newly diagnosed patient retrieves information can be understood. The survey consisted of three questions focusing on scent, two questions focusing on patch, and three questions focusing on diet.

The participants who took part in this study are affiliated with the Crohn's & Colitis Foundation of America (CCFA) support group, Carol Fischer chapter, in Chicago, Illinois. The patients were informed of the study through the support group's online social media sources, as well as in-person, during a monthly meeting. It was made clear that participation in the study was completely voluntary and anonymous. The patients were provided with the link to the online Typeform survey.

The support group was selected for the study because all of the participants have experience being diagnosed with UC and each participant has known about their diagnosis for five or more years. A diagnosis of five or more years allows for all participants to have experience foraging for information about UC. The pilot study (Morgan) found UC patients have dealt with issues concerning the validity of the information they've foraged for throughout the length of their diagnosis. The group was also selected because of their willingness to participate in the support group; the members of CCFA support groups are typically more comfortable than a newly diagnosed patient divulging information about their disease and experiences, due to the comfort in the group, as found in my previous pilot study.

The study's participants consisted of 11 currently diagnosed ulcerative colitis patients varying in age from early twenties to late forties. A majority of the patients were Caucasian, mostly in their early to late twenties or mid to late thirties, with a diagnosis of five or more years; one participant was Asian. The group of participants represented a fair sample of the ulcerative colitis population because according to CCFA, ulcerative colitis affects men and women equally, and most are diagnosed in their late teens to early thirties.

While the support group as a whole consists of thirty-plus members, a majority of the members are diagnosed with Crohn's disease, and their feedback would not be relevant to the study. Crohn's disease is characterized by different symptoms than UC, and affects a different population than that of UC as well. Additionally, not every member attends every support group meeting, nor does every member review the social media outlets. Without having access to all members of the support group, it was somewhat difficult to gather a broad sample. Many people diagnosed with the disease are embarrassed by their diagnosis, which leaves the support group with fewer members. However, members of a support group with ulcerative colitis feel more eager to share their experiences to increase understanding about the disease in the general population.

Medical Writer Interview

A key component of the study at hand is the medical writer who took part in the survey process. Similar to the questions asked to the ulcerative colitis patients, the medical writer survey focuses primarily on dissecting patch and diet. The questions relate

to the writer's experience creating patient education materials and focused on the most common requests from healthcare facilities when asking for those materials to be created.

While the medical writer was asked one question dealing with scent, it was important for the questions to focus on patch and diet. By analyzing the writer's patch and diet of patient education material writing and best practices, it can be revealed where the disconnect between patient and writer exists. Asking the medical writer questions focused on patch and diet, also may illustrate any misinterpretations of client wants and needs from the writer.

The medical writer who took part in this study was a medical health communications consultant, in Portland, Oregon. The consultant is a member of the American Medical Writers Association and has written patient education materials for over five years as part of a ten-year career as a medical writer.

Before beginning the study, I joined the American Medical Writers' Association group via LinkedIn. I contacted the head of the LinkedIn group and sought membership. Once accepted, I posted a call for volunteers to participate in the survey via the group message board. For writers to participate in the study, they needed to have at least five years of industry experience and have designed patient education materials. The requirements were stipulated as such in order to find a candidate who had produced patient education materials and could identify industry trends and practices.

The interviewed consultant was the only member of the group that reached out meeting the specified requirements. While other members were interested, not many had experience working solely with patient education materials for an extended period of time in their careers. Additionally, interviewing a single technical medical writer allowed for a

more in-depth interview to establish a baseline on how medical writers retrieve information for the materials they are asked to create.

The consultant contacted me directly and volunteered to take part in an interview discussing the consultant's career in patient education material creation. Contact information was exchanged and a phone call interview was scheduled. To avoid redundancy, the consultant's responses are discussed in the Findings section.

Gastroenterologist Interview

The last informational angle of the triangulated study involves the gastroenterologist. Similar to the questions asked of the medical writer, the gastroenterologist interview focused primarily on scent and diet. The interview for the gastroenterologist needed to bring forward an understanding of gastroenterologists' access to patient education resources and the acquisition of in-house materials to distribute to patients.

Scent and diet were the most important pillars to discuss because a full understanding of these pillars from the gastroenterologist's perspective can reveal misinformation between the doctor and the medical writer, as well as between doctor and patient. While the gastroenterologist may perceive scent easily, due to experience and exposure in the field, following the scent may not come easily for some patients. Furthermore, understanding the critical gap between the writers and doctors assists in targeting specifically what information should be disclosed and shared between the two groups.

The gastroenterologist who took part in this study is a gastroenterologist at Rush University in Chicago, Illinois. The gastroenterologist serves as the head of research and director of the gastroenterology department. The gastroenterologist also publishes over sixty scientific articles discussing a wide variety of health issues and their impact on patients with ulcerative colitis.

Only one gastroenterologist participated in the study in order for a more involved interview to take place. By speaking to a single gastroenterologist with extensive experience in the field, a better understanding of the role of patient education materials from a medical perspective can be found. It was imperative the interview with the gastroenterologist established a baseline to reveal disconnects between patient and doctor and writer and doctor.

Based on the gastroenterologist's work within the field and over thirty-eight years' experience, and as a patient of the gastroenterologist, I discussed the study over an office visit. After explaining information foraging theory and the purpose of the study, the gastroenterologist agreed to participate. After my office visit, I set up another appointment to conduct an interview for the study. To avoid redundancy, the gastroenterologist's responses can be found in the Findings section.

Data Analysis

The responses from the UC patients were grouped by ethnicity, age group, and years diagnosed. The survey questions focusing on information foraging theory were assigned a positive or negative category depending on whether or not the patient answered positively or negatively toward scent, patch, or diet.

The responses from the medical writer and the gastroenterologist were analyzed and aligned with the pillars of questions asked of the other two groups. The medical writer and gastroenterologist responses gave more of a foundational explanation of scent, patch, and diet, rather than a reaction to the different pillars. The data collection methods for the writer and gastroenterologist were quite different from the patients. Since the interviews with the writer and gastroenterologist were more involved and in-depth about their experiences, the responses could not be coded based on the positive and negative reactions to a pillar of information foraging theory similar to the UC patients. The results are analyzed in the following section.

FINDINGS

The results of the study are discussed in the order in which responses were collected. First, responses from the patient survey are reported according to the pillar of information foraging theory they coincide with along with the positive and negative coding. Overall positive and negative coding is displayed visually at the end of the Findings section. The medical writer's interview responses are discussed in their own section, followed by the gastroenterologist's interview responses. The responses from the survey and interviews are discussed at length with an overall discussion of common themes and trends found in the next section, Discussion.

Survey Results

The UC patient survey consisted of eleven questions. The first three questions of the survey captured demographic information; ethnicity, age, and years diagnosed with ulcerative colitis. It was not necessary to ask about the gender of the participants since ulcerative colitis affects men and women equally (CCFA). The following eight questions focused on information foraging theory, beginning with three questions focused on scent, followed by two questions focusing on patch, and concluding with three questions focusing on diet. The positive and negative coding for the responses is represented visually in a chart at the end of the Findings section. The survey questions in their totality can be found in Appendix A.

Question 1: Describe your ethnicity. Ten out of 11 participants classified themselves as Caucasian and one participant classified as Asian.

Question 2: Please select an age range. Participants selected from the following available age ranges: 21 -30; 31 – 40; 41 – 50. Four participants classified themselves in the 21 – 30 year old range (36%); four participants classified themselves in the 31 -40 year old range (36%); three participants classified themselves in the 41 – 50 year old range (28%).

Question 3: How many years have you been diagnosed with ulcerative colitis? Participants varied in their responses to this question. Five participants stated their diagnosis to be at least five years (45%). One participant stated their diagnosis to be at least six years. One participant stated their diagnosis to be at least seven years. One participant stated their diagnosis to be at least nine years. One participant stated their diagnosis to be at least 11 years. One participant stated their diagnosis to be at least 12 years. One participant stated their diagnosis to be at least 18 years.

Question 4: How did you learn about your UC condition after being diagnosed? (This question elicits information about scent.) All 11 participants stated they learned about their condition from their gastroenterologist and additional information came from the Internet. This question was given a positive rating. A typical response was:

The doctor told me about the condition and then I mostly researched the Internet and health sites like WebMD for more information.

Question 5: Were you given any supplemental materials upon diagnosis? (This question elicits information about scent.) Three out of the 11 (27%) participants received some kind of supplemental information upon diagnosis. Eight out of the 11 (73%) participants did not receive any supplemental materials upon diagnosis. This question

was given an overall negative rating. For the participants who received supplemental information, two of the responses are as follows:

- A binder of information was given to me at the hospital, but I wound up researching the Internet instead.
- I was given a pamphlet and some handouts on low-residue diet. Not much information about ulcerative colitis.

For the participants who did not receive supplemental information, two of the responses are as follows:

- I never received any written patient materials and I wasn't directed to any online resources.
- No. No materials were ever given.

Question 6: How did you keep yourself educated about your UC? What is your main resource of information? (This question elicits information about scent.) Two out of the 11 (18%) participants stated their doctors kept them educated about their UC and that their doctor is their main resource of information. Nine out of the 11 (82%) participants stated CCFA support groups and the Internet, including social media, kept them educated about their UC and these resources are their main source of information. This question was given an overall negative rating due to the fact that most participants use more than one Internet site for information about their condition. For participants who rely on their doctor for information, a response is as follows, "I've always relied on my doctor and the information he provided during office visits."

For participants who rely on a combination of support groups and social media, a response is as follows, "Started with the CCFA web site at first. Later on, I got involved in the (UC social) community and looked for word-of-mouth from others with this disease. Facebook has some support groups as well."

Question 7: If you were given a pamphlet or brochure upon diagnosis what did you like about it? If you weren't, would you like to have received one? If so, what kinds of information would you want a pamphlet or brochure to include? (This question elicits information about patch.) One out of the 11 participants stated the informational handout they received was great and they felt there was plenty of information in the pamphlet. One out of the 11 participants wanted a printed brochure, but offered no further information about what the brochure should have included. Nine out of the 11 (82%) participants stated they would have liked to receive a pamphlet with more information about diet and what to expect. This question was given an overall negative rating since a vast majority of patients did not receive the information they wanted. For participants who wished to have received a brochure, two responses are as follows:

- I would want one that gave me a general overview of my disease. It would be really great to have one with a more detailed look into my medical options and food suggestions.
- I really would have liked one. Something with quick facts and links that I could research for more information.

Question 8: Do you trust Internet sites to give you accurate, up-to-date information? If not, would you rather have printed up-to-date materials? (This question elicits information about patch.) Five out of the 11 (45%) participants stated they trust Internet sites, but the site must be credible. Five out of the 11 (45%) participants stated no, they do not trust Internet sites. One participant stated they would rather have printed materials authorized by a doctor. This question was given an overall negative rating since a majority of the participants either don't trust Internet sites or only trust Internet sites deemed as credible. For participants who said they trust Internet sites, two responses are as follows:

- I trust only websites that are doctor monitored. The CCFA is always providing up-to-date info regarding the latest disease management and research.
- Yes. I prefer electronic information so I always have access to it on-the-go, but it needs to be from a credible website.

For participants who said they do not trust the Internet, a response is as follows, “The Internet is ok, but you have to be very careful and fully research things. Not all websites give accurate info.”

Question 9: If you used a website to find out more information, how clear was that site? Did it include all the information you wanted/needed to know about UC? (This question elicits information about diet.) Eight out of the 11(73%) participants said the Internet sites they’ve used to access information are clear. Two out of the 11 (18%) stated Internet sites are pretty clear. One participant chose to not answer this question. This question was given an overall positive rating since the sites a majority of the participants use are clear. For the participants who stated the sites they used were clear, two responses are as follows:

- The sites today are much more specific. The problem is our disease, it’s not a one-size-fits all approach for information. Many sites acknowledge this and it does get frustrating.
- I typically like medical sites and online medical journals. These are the most clear.

For participants who stated Internet sites are pretty clear, an answer is as follows, “There are so many different variations that I think it's challenging for a site to provide information that might be relevant to people, yet still short enough and easy to understand enough that the majority will sit down and read it.”

Question 10: How well did your GI doctor communicate with you about your UC? (This question elicits information about diet.) Three out of the 11 (27%) participants stated their GI is great at communicating with them. Three out of the 11 (27%)

participants stated they had to switch GI doctors to receive better communication. Five out of the 11 (46%) stated their GI doctors did not communicate well with them. This question was given an overall negative rating since a majority of the participants did not feel their gastroenterologist communicated well with them about their disease. For participants who stated their gastroenterologist communicated well with them, a response is as follows, “My doctor answers all of my questions in detail, he’s amazing!” For participants who stated their gastroenterologist did not communicate well with them, two responses are as follows:

- He only answered questions, but I didn’t know what to ask.
- He doesn’t communicate well. He made it seem like a brief illness I had, not a lifelong disease.

Question 11: Were you ever misinformed about any part of your UC? If so, where did you receive this misinformation? (This question elicits information about diet.) Five out of the 11 (45%) participants stated they were not misinformed about their disease. Six out of the 11 (55%) stated they were misinformed about their disease from their gastroenterologist and other health professionals like dietitians. This question was given an overall negative rating since a majority of the participants stated they were misinformed about their disease. For participants who stated they were not misinformed, their answers were simply “No.” For participants who were misinformed, two responses are as follows:

- My gastroenterologist told me that UC had nothing to do with my tooth decay. However, upon visiting other doctors and speaking with other people with UC told me the disease affects skin, nails, hair, and teeth, including tooth decay.
- Medication I was prescribed didn’t include information about a rare side-effect that put me in the ICU (Intensive Care Unit).

Medical Writer Interview Responses

The medical writer's interview consisted of seven predetermined questions, with two follow-up questions asked based on the response to the original question. All of the interview questions focused on information foraging theory, but the questions were not asked in any particular order so as to not disrupt the flow of the interview and to ensure the writer remained candid throughout. The predetermined interview questions can be found in Appendix B.

Question 1: What kinds of patient education materials do you design? What has been your experience working with patient education materials? (This question elicits information about diet.) Response: It really depends on what the client wants from me. I talk to my client and always ask what's the purpose of the piece, and what's the most important message. With patient education materials, you have to convey just one message. I try to think of it like an email, you don't need to put more than one subject on an email and the same is true for patient ed. I then look to my audience and think about what they might need from me and what I need to convey.

Sometimes, clients have a predetermined format – if you write for a company that has already set their format and used a health literacy expert, say for a hospital website, they have probably already worked out what will be on the page. So my job is to make sure what is on the page is delivered clearly.

Question 2: Is design more important than content when it comes to patient education materials or vice-versa? Or do design and content have equal importance? (This question elicits information about diet.) Response: To start, health literacy is a big part of this process. I got interested in health literacy about five or six years ago. Health

literacy is a very important field and it's growing. One of its main principles is the need-to-know versus the right-to-know. Doctors don't tend to prioritize materials; I have to write comments on the documents a doctor gives me stating, "This is a nice-to-know, but not a need-to-know." Content for patient education needs to be short and actionable.

For instance, I visited a web page about thyroid disease that referred to a certain bone by its Latin name only. People who have thyroid disease don't care about the name of the bone; that's not where their concerns lie. As a medical writer you have a very important role as a mediator saying what does the patient need. Content is really at the heart of patient education.

But design is important as well. If I decide to put together a booklet or something like that, I'm thinking about how is the patient going to navigate it? I suggest things like color tabs so the patient can return to a spot in the information or keep something in mind to refer back to. Navigation and page layout are the two more critical design elements after the appropriate content is created.

Question 3: How do you select the kinds of content to include in patient education materials (need-to-know vs. right-to-know)? (This question elicits information about scent.) Response: I'm always thinking about the patient and I'm always thinking that the patient education material is situational. I really focus on the immediate needs the patient has and then I think about design. I'm always thinking about what a patient needs at the point they are in their experience. I'm pretty lucky the people I work with directly are usually direct patient contacts; you can't be a successful medical writer without going hand-in-hand with the patients.

Question 4: Have you had much experience designing materials for patients with ulcerative colitis? (This question elicits information about patch.) Response: I did write one material for children diagnosed with ulcerative colitis. This particular client had a template and I was writing the patient information for a database that aggregates the latest literature that assists doctors in looking through current information at-a-glance. This project was one of the more rigorous ones that I've worked on, mainly because of the volume of the content.

The format for the database, as suggested by the client, was that the patients and patient parents would want to know how the disease is treated, if there is a need for surgery, and the risks for developing colon cancer. So I went in writing about these questions and I realized I needed more input on these topics, since I found colon cancer isn't a huge concern for children diagnosed with UC.

I turned to my editor, and the editor for the project encouraged, as I read more professional topics, to suggest any questions outside of their normal template that the parents might be asking. What I realized after reading through some professional journals on the topic of ulcerative colitis in children was that parents wanted to know how it was treated and what the road ahead looked like. Most people, when they're diagnosed with a disease or caring for a loved one who has been diagnosed, *know* they have the disease. So going into the physiology of the disease isn't really as important. It's less important in patient ed to give up a discussion of the disease than to lightly discuss the actions parents and patients can take to combat it.

Question 5: So what are the "best practices" for developing patient education materials? Response: Well, I'm trained in patient education through AMWA and I take

their available courses throughout the year. I read literature about patient education and I keep those resources on my shelf. So by keeping up-to-date on the current literature and resources, I've come to see some best practices.

In sentences I avoid the use of abbreviations, limiting myself to only two to three abbreviations per line based on AMWA guidelines. I also refer to the Health Literacy A to Z guidelines and federal plain language guidelines. I can't stress how much reading articles and being a part of organizations that are committed to this effort are. There's plenty of evidence out there about how people read and how they come to understand things the way that they do.

The best practices are out there, with plain language and health literacy. You can refer to any of AMWA's classes or publications to see the best practices at work. Medical writers get hired because we understand these practices, but that's to be taken with a grain of salt. There are plenty out there who don't practice it.

Question 6: What diseases do you typically write the most content for? Why are these diseases the main focus of your content? (This question elicits information about patch.) Response: I really don't write about one disease in particular. Medical writers can cover everything from a common cold to cancer to side-effects of medications. It truly depends on what the client is looking for.

Question 7: How do you feel patient education materials could be improved? (This question elicits information about patch.) Response: As a writer, I pick things up and save things, examples that are out there. When you're a writer you can't not do that. I notice who has good patient education materials and who doesn't. The thing I usually see

the most is that the information is too text heavy. There's way too much text and big blocks of it.

Poor design is another issue – not enough subheadings, no lists, and not enough graphics to give the emotional pull for the patient to want to go through the materials. For example, I was at a talk and there was a woman there from New Zealand who designed a book for native women with breast cancer, because the native women didn't see any materials with pictures of women who looked like them. This is a crucial factor to consider when designing and including graphics – who is your audience?

Graphics are very important, but again, too much text is the number one problem and the use of rich words and materials full of jargon. Doctors typically like to demonstrate how much they know and put out booklets that show how much they know. The patient isn't happy about having a disease and then to pack on a convoluted booklet on top of it – well, it's no fun for them.

I wish more writers would think about the use of their graphics and would put themselves in the shoes of the patient – instead of designing and writing to show off their knowledge.

Follow-up question 1: Why do you think more technical medical writers aren't employed in the healthcare field? Do you think there's a way to standardize patient education? (This question elicits information about patch.) Response: Well, in the United States, healthcare is totally decentralized. Sure, the US government passed the Plain Writing Act of 2010 and there's been a government shift in this country to sign things about plain language into law. There's a ton of things like this, but we have private healthcare. When the healthcare is private, a hospital or doctor's office, it's up to them to

either hire their own writer, use someone in-house, or to buy content from a company like Staywell that produces generic health content. Everybody does it, and there's plenty of foundations and associations that do it, too.

Anyone could hire me from an association from a clinic, hospital, or hospital system that produces patient materials. If the associations don't recognize the specialization for written patient education, they're likely to go with somebody in-house.

Follow up question 2: You said earlier that you have to do research when you write patient education materials. Can you elaborate on that? (This question elicits information about scent and patch.) Response: Sure. I use reputable secondary sources and then I usually go to PubMed. The average patient is scared and mad and the feelings they have can be overwhelming. It's difficult to find authoritative information sources and apply them correctly. It would be nice for there to be a unified source, like the National Institute of Health that already writes in plain language. Right now, you really have to dig for information and think about the information you do find and how to convey it.

Gastroenterologist Interview Responses

The gastroenterologist's interview consisted of five predetermined questions, one follow-up question based on the original questions asked. All of the interview questions focused on information foraging theory, but the questions were not asked in any particular order so as to not disrupt the flow of the interview and to ensure the writer remained candid throughout. The predetermined interview questions can be found in Appendix C.

Question 1: What kinds of information do you give to your patients after they've been diagnosed? Pamphlets, oral instructions, etc.? (This question elicits information about scent.) Response: I don't distribute any pamphlets that aren't created by us. I spend a great deal of time explaining the disease, the cause, and the impact. The first explanation is overwhelming so I'll ask patients to email me and then in a subsequent meeting I would refer them to other sources of information.

Follow up question 1: Can you elaborate on "materials produced by us"? Response: We are currently working to revamp our website. We are limited to do what we want in terms of being a corporation. We plan to have an online newsletter with a different topic focus each quarter – starting with what UC patients need to know after diagnosis. We do use some pamphlets and handouts in-house.

Follow up question 2: Who currently maintains your in-house patient education materials? Response: At the moment we ask trainees and faculty to write the newsletters. I have one fellow and one attending, but they aren't trained writers and have other responsibilities to attend to before we can start putting together new sources of information or updating the ones we already have.

Question 2: Do you recommend your patients to attend any support groups? (This question elicits information about patch.) Response: Yes, both CCFA and a clinical psychologist I've hired. There are support groups through our institution as well as clinical trials and placebo studies patients can participate in.

Question 3: How do you keep patients educated about their disease after diagnosis? (This question elicits information about diet.) Response: Depends. Many patients are out-of-state, so I meet with them between one and four times a year. We

discuss different topics they might be concerned about and I make sure to stress CCFA and continue their education. We have limited funding, however, so it is difficult to keep patients involved in our programs. They are left to do a lot on their own.

Question 4: Is there one particular source of information for your patients you prefer? What makes the source the preferred means of information? (This question elicits information about diet.) Response: None. I tend to not give out pharma pamphlets. CCFA is a grass roots patient organization so that is the safest means for me. The Internet is like a fire hydrant that patients should use appropriately. They need to be aware of the sensational aspect and share with me the information they find so I can verify it.

Question 5: What kinds of information (pamphlets, books) would you like to see in your office to supply to your patients? Why would this particular kind of information be beneficial to your patients? (This question elicits information about scent.) Response: I think a pamphlet would be good. Most pamphlets come from companies with bias entries. Usually for a specific drug or new means of treatment. We hope to create one in time, but again we have limited funding – but we would be able to provide a non-biased opinion on the disease.

DISCUSSION

Based on the results of the survey, ulcerative colitis patients have a poor scent and a poor patch when it comes to discovering information about their disease. Overall, the survey questions focusing on scent and patch received a negative coding (Figure 2). A few questions were answered positively, for example, the ratio of positive to negative responses regarding scent and patch was two to one (Figure 1). In terms of scent, patients felt the quality of information they receive from their gastroenterologist is inadequate. All of the participants stated their scent begins between gastroenterologist and themselves after initial diagnosis. Three of the 11 received an additional scent but were unsure how to follow this scent to a patch of good information and research. This led the majority of patients to rely on their gastroenterologist to provide them with more information, but the patients were unaware of what kinds of questions they needed to be asking about their diagnosis.

The gastroenterologist recognized patients are often left to fend for themselves after diagnosis. The gastroenterologist interviewed for this study advocates thoroughness in explaining the disease with patients; however, based on patient responses to the survey, not all gastroenterologists take this time with their patients. While it is beyond the scope of the study at hand to discuss communication methods between doctor and patient, the lack of significant communication is evident in the patient and gastroenterologist responses. The lack of significant communication is imperative to highlight because the initial contact between the patient and gastroenterologist sets the foundation for the patients' quest for information. Additionally, the explanation of the disease is described

as overwhelming, which results in a poor scent for patients, especially if the gastroenterologist does not craft the overwhelming explanation in digestible chunks of information for the patients. Furthermore, the gastroenterologist recognizes the difficulty in creating in-house materials due to lack of funding and untrained writers creating the material. A lack of funding may to be to blame for inadequately informing patients, but it does not explain why the communication between the patient and gastroenterologist fails at starting the patients with a strong enough scent to find adequate information.

Patient Scent, Patch, and Diet

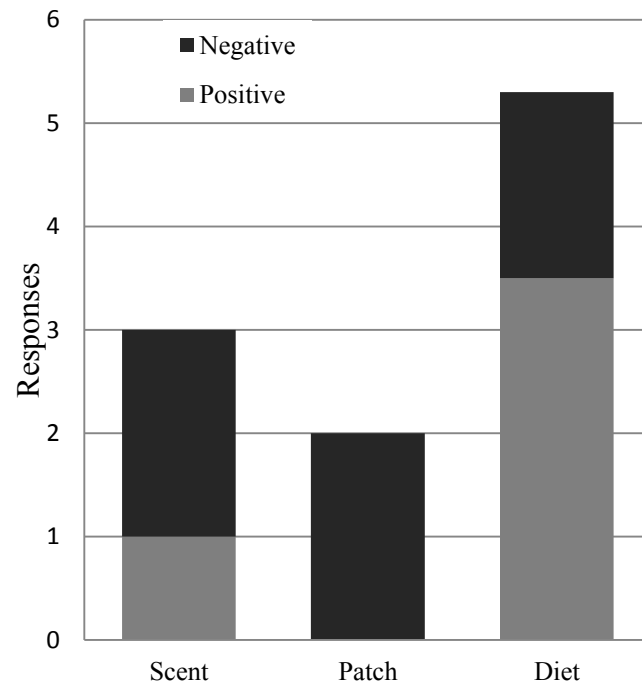


Figure .1 Data are divided by positive and negative responses.

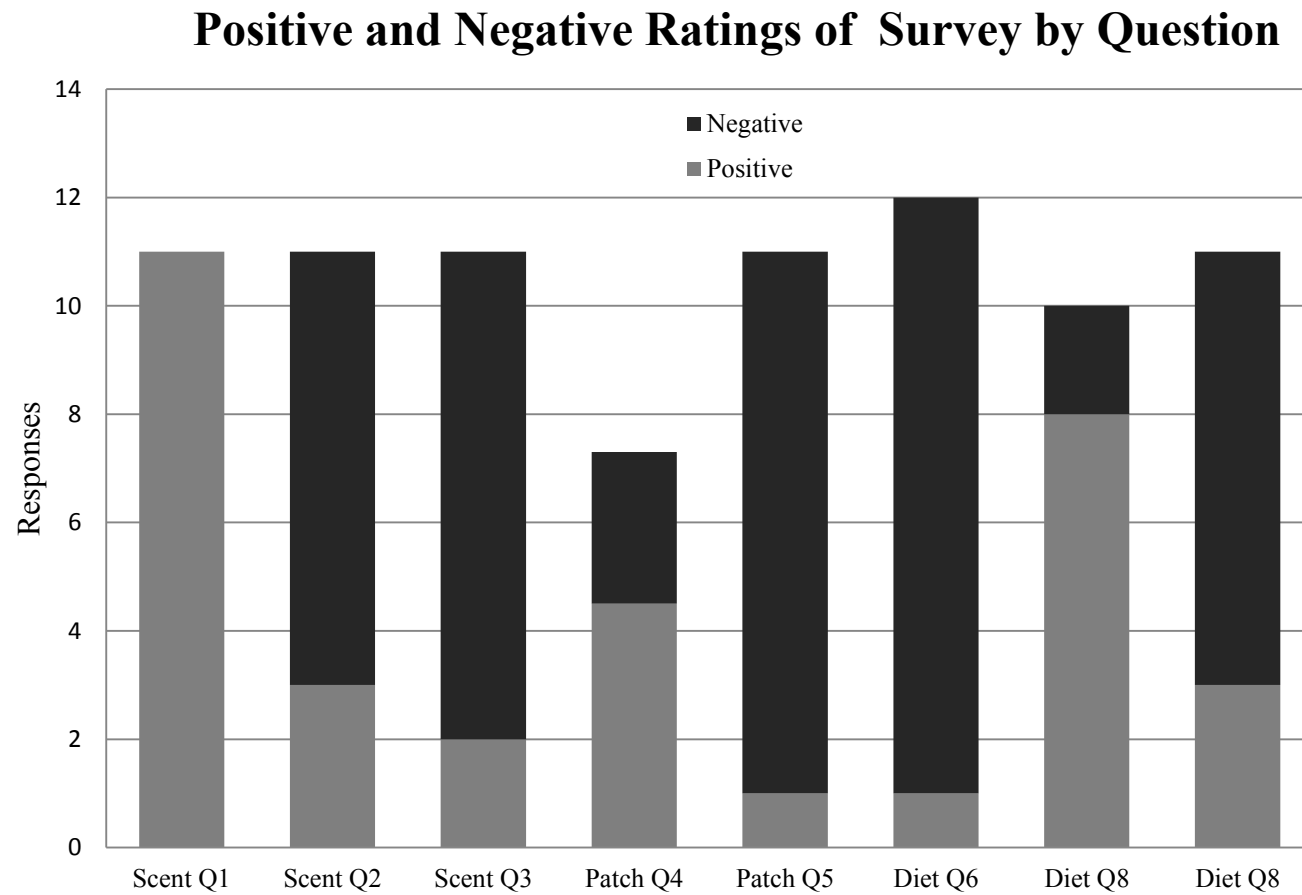


Figure 2. Data are divided by positive and negative responses per question.

In addition to initial communication between the gastroenterologist and patient, the poor scent also seems to develop from the lack of supplemental resources given to the patient upon diagnosis as mentioned previously. A majority of the patients (83%) stated they did not receive any supplemental material upon diagnosis, and the gastroenterologist brought up the fact of pointing patients to CCFA, rather than providing them with a brochure of information to take home and reference. If an informational foundation is not laid out for patients, their scent becomes weaker because there is no outlet disclosed to them where they can begin searching through a patch.

Although the interview responses were not coded as positive or negative, the medical writer pointed out an issue dealing with scent when writing patient education materials. The medical writer receives a scent from the hiring client, and the writer scours through databases like PubMed and Mayo Clinic to find additional information about the particular condition needing documentation. The medical writer, while given a scent from the client, still searches through the same patches patients may access. The medical writer and the patient shadow similar patterns when it comes to following a scent. This suggests the writer has enough experience and familiarity with the topic to make the most of the initial scent, even though the scent might be weak. Unfortunately, patients do not necessarily have that experience. The informational outlets are there, but as the medical writer stated, it is a matter of correctly applying authoritative information.

In terms of patch, the patients also negatively responded. For most patients, roughly 82%, finding a strong patch has been a difficult process throughout the length of their diagnosis. A majority of the participants heavily focus on what they deem as “credible” websites to give them information about their condition. However, sources

within their patches have provided incorrect information or have omitted critical information. Nearly 55% of patients found incorrect information and omission of critical information that weaken their patch. New scents must be discovered to lead to new patches in order to satisfy the patients' needs for information.

Another factor contributing to weak patches is discussed by the medical writer and the gastroenterologist pertaining to the accessibility of specialized ulcerative colitis information written with the patient in mind. The medical writer maintains membership in AMWA and takes required courses to retain membership and to keep on-trend with the medical writing industry. While these courses assist the medical writer in producing quality patient education materials, there is no guarantee that all medical writers are partaking in the same practice. Furthermore, the medical writer describes collecting pieces of documentation that are poorly constructed, whether it is in terms of poor language, too much text, or inappropriate use of graphics, to learn from and avoid making similar mistakes. If the medical agencies are bringing in writers who do not follow similar practices to the interviewed medical writer in this study, there is no guarantee the patient education produced will meet the standards as defined by AMWA.

The gastroenterologist's interview responses also shed light on the existence of weak patches. The gastroenterologist stated patients are directed to the CCFA's website, in addition to the clinical psychologist on staff as well as opportunities for patients to participate in research studies conducted at Rush University. However, patients explained in their survey responses after diagnosis they typically search for a particular kind of information regarding diet or long-term care of their disease. The clinical psychologist may be too expensive for most patients, and the clinical psychologist may not be able to

answer questions patients might have. Furthermore, if patients are pointed directly to CCFA, there is no guarantee the patient will find the information they are searching for, or if they do find the information they need, they may not be able to consume it with ease. Therefore, when patients begin searching for information outside of the intended patch, they run the risk of encountering misleading information and the possibility of misinterpreting documentation. Research studies may also not provide the information patients are initially searching for. Participating in research studies may allow patients to focus on one new drug or method of treatment for their disease, but there is no guarantee for the research study to produce significant results. Therefore, the patients are still experiencing a weak patch, since the information contained within the patch is insufficient.

Despite the weak scents and patches described by the parties involved in the study, surprisingly, diets received an overall positive rating; 73% of participants are satisfied with the diet information they currently use. This begs the question: If the scents and patches are weak, how can the patients' diet be strong? There are a few factors contributing to this finding. Firstly, patients spend the time following scents and researching patches until they find the information they need. Once a piece of successful information is located, the patient can then add it to his/her diet of information. Slowly, the diet begins to build and satisfies the needs patients have throughout the length of their diagnosis. Since the patients who participated in this study have been diagnosed with ulcerative colitis for five years or more, it makes sense that by this time their diets would be strong and meet their needs. Unfortunately, the strong diet had to be achieved through years of research and determining which patches were weak and which were strong. Not

one patient who participated in this study immediately started off with quality information to build up a suitable diet quickly.

It is difficult to compare the medical writer's and gastroenterologist's diets against those of the patients. The medical writer is responsible for a plethora of information covering a wide range of health topics; the medical writer is not solely devoted to writing about ulcerative colitis, so the diet the medical writer has is not stagnant. Depending upon requests from clients, the writer may need to start the information foraging process over to decide what information should be included in the documentation. While the medical writer may have a store of previously created work, the patient education materials may not directly reference what the next client is looking for or what the patient desires. In terms of the study at hand, the medical writer's diet was not as important to analyze since the main interaction with patients deals with scent and patch.

The gastroenterologist's diet comes strictly from the practice of gastroenterology and the multitude of experiences that allows the gastroenterologist to discern between quality and poor information. The doctor is able to draw conclusions based on studies witnessed, patient experiences, and conducting procedures with patients. The gastroenterologist has the strongest diet, since the gastroenterologist is the main source of information for patients, as well as the medical writer's clients. The gastroenterologist's diet must be analyzed accurately and carefully by patient and medical writer in order to gain insight into certain procedures and recommendations.

Above all, the comparison of the survey results and the insight of the medical writer and the gastroenterologist reveal some of the reasons disconnect occurs between

the three parties, and why patients are tasked with intense information foraging. The patients and the medical writer are exposed to the same information from the experts (gastroenterologists) themselves, grass roots organizations, and other medical repositories including information dense information with rich, jargon-filled language. The duty of the writer is to locate the proper authoritative information, analyze the information, and re-write the information based on the needs and wants of the patients. However, some medical institutions employ their own un-trained writers including fellows, attending physicians, and nurses due to limited funding. Medical institutions may not realize the need for technical medical writers to be involved in their documentation process or they may not have the funds to bring in a contract technical medical writer. Because of the disconnect between medical institution and technical medical writers, patients are forced to scour the Internet and other resources to discover information about their condition, ultimately spending years trying to find the most accurate, up-to-date, and sound information.

CONCLUSION

Implications

After review of the aforementioned results and discussion, the study offers several implications. First and foremost, the study fills a gap in the current literature regarding ulcerative colitis patients and the ways in which they learn about their disease. Based on current literature, no study has analyzed ulcerative colitis patients' methods for gathering information, nor has any study looked specifically to a medical writer or gastroenterologist to try and determine the root cause of the communication gap. Results of this study show ulcerative colitis patients struggle significantly when it comes to developing their diet of information regarding their disease. Furthermore, results of this study reveal the disconnect between medical writers and gastroenterologists becoming more involved in relaying substantial information to patients. Despite the fact patients eventually find themselves with a strong diet of information, they spend a great deal of time searching for information that should be readily available to them.

However, if the gastroenterologist and medical writer had a better opportunity to communicate their findings and assess patient needs for tailored information, the time it takes the patients to form a formidable diet could potentially take no time at all. This ultimately would alleviate the amount of time spent foraging for information and put patients on a path to enhance their understanding of ulcerative colitis and foster better communication between the gastroenterologist and the patient. Identifying a different alternative to previous information foraging and communication techniques leads to the second and third implications of the study regarding the technical medical writer.

Second, the study investigates the way the technical medical writer is trained. However, since the study focused on one writer, it cannot be stated with confidence the writer's experience in the field is indicative of all medical writers in the healthcare industry. AMWA produces a publication covering the trends and hot topics within medical writing, and offers courses medical writers can take to enhance their writing skills; however, there is no guarantee all medical writers take these courses or read the publication, much less are active members of the organization.

The third implication of this study is that there is no determined benchmark for what constitutes a successful technical medical writer. Based on the interview, medical writers are typically contract workers taking on requests from clients and fulfilling a need the client stipulates. While AMWA does have a certification program for medical writers, it is purely voluntary, not required, so there is no guarantee all medical writers will take the certification. While contract medical writers may have a portfolio detailing their work, if the hiring client (in this case, medical institution) does not fully understand the need for tailored content employing a strong use of visuals and plain-language text, the possibility exists to employ a writer who may not have a full understanding of the best methods to employ when crafting patient education materials.

The fourth implication of the study also pertains to the technical medical writer, but particularly, to the field as a whole. A career in technical medical writing is another facet of the technical writing/technical communication field desperately in need of more writers. The medical writer in this study did not start out pursuing the creation of patient education materials; only after years of experience in the field did the writer begin to take on more projects focusing on patient education materials, and enjoyed these projects,

which allowed for specialization in this area of the medical writing industry. While education was not fully discussed during the interview, rather a focus on creating materials instead, it stands to reason that bringing this facet of writing to the table during academic careers, can bring more writers into the field to assist in giving patients the highly tailored information they need. Furthermore, by educating writers about the best practices in patient education material creation and setting a standard, more healthcare facilities and doctors would pick up on the effective information and recognize the best kinds of writing and writing style to bring to their supplemental materials. The gastroenterologist in this study discussed fellows and attending physicians in the hospital are the ones responsible for creating in-house materials, despite the fact they are not trained writers. The study suggests perhaps if medical technical writers were more readily available and accessible to gastroenterologists materials could be produced from the writer directly after the needs are understood from the fellows and attending physicians.

The fifth implication then points to the content of the patient education materials for UC patients. While the study reveals the holes in communication and awareness between patient, writer, and doctor, the study also recognizes the need for content to be created in a medium most preferred for the patient. A majority of the participants in the study stated they enjoy Internet sites and tend to view Internet sites as credible with the clearest information. The gastroenterologist also points patients directly to CCFA's web site, and the medical writer gains insight into the disease from web-based materials. Printed materials may be gradually giving way to web-based information. However, the current databases and repositories of information regarding ulcerative colitis are not fully tailored for patient and patient understanding. The writer's responsibility comes in to take

the authoritative information riddled with jargon and turn it into consumable pieces of information so the patient can take responsibility for their own health outside of the gastroenterologist's office.

The sixth and final implication of the study accompanies the desire of patients to have online education materials. In order to assess the accuracy and quality of online materials the patients need to be involved in some kind of user testing first-hand. The user testing can be implemented by the medical writer after the writer meets with the appropriate parties and creates a draft of the information. The writer would implement technical writing principles as dictated by AMWA and other scholars focusing on the use of plain language and document design. Then the participants, much like the ones in the study, could then assess the quality of information for understanding. If patients are satisfied overall with the quality of the information they would then be equipped with further knowledge of the disease and also be prepared to discuss certain aspects of the disease with their gastroenterologist during routine check-ups. Following this process would then give patients stronger scents, patches, and diets, more quickly, assuaging stress, fear, and other troublesome issues they experience after their diagnosis.

Limitations

Though the results of the study reveal the informational gap between the three parties involved, due to the broad scope of the study, there are several noteworthy limitations.

First, a significant limitation is the size of the population surveyed in terms of both the survey and the interviews. As stated previously throughout this study, over 700,000 cases of ulcerative colitis exist in the United States and this study captured 11 responses of the ulcerative colitis population. The number of participants in the study may be low, but the participants did represent the population of the majority of people diagnosed with UC including age, years of diagnosis, and ethnicity. It would be extremely difficult to conduct a study to gather responses from every single UC patient in the United States and it would be much more taxing to analyze the sheer quantity of responses in terms of information foraging theory. It is unrealistic to solicit a survey in which every member of the UC community would participate.

Furthermore, the second limitation of this study recognizes the somewhat colored results received from the survey. All of the participants in the survey live in the Midwest and their experiences with patient education materials may only be reflective of the region; this somewhat limits the scope of the survey since all regions in the United States were not represented. However, the study did expand on a pilot study (Morgan, 2013), and found similar patterns within the same region establishing a baseline for a typical ulcerative colitis patient experience in the Midwest region.

Additionally, only one medical writer and one gastroenterologist were interviewed for this study. While both interviewees have been in their respective fields

for ten years or more, they cannot serve as a fair and accurate representation of all medical writers or all gastroenterologists. However, the interviews did allow for more in-depth conversations about the writer and doctor's experience with patients and how they both go about providing patients with education about UC.

The third limitation of this study is there was no predetermined benchmark for the medical writer or the gastroenterologist to be assessed against. The medical writer was a willing participant to the study and no review of the writer's portfolio was conducted prior to the study; rather the medical writer fit predetermined criteria focusing solely on years spent creating patient education materials. Similarly, the gastroenterologist was also a willing participant to the study and no review of the doctor's work was conducted prior to the study. While no pre-established benchmark was implemented in the study to further determine the qualifications of the writer and the gastroenterologist, both participants showed a full range of knowledge in their field during the interviews. Plus, both participants spent a great deal of time in their fields with a variety of experiences and challenges, and undoubtedly, experiencing trends and changes within their fields and adapting to those trends and changes as necessary.

However, this does lead to the fourth limitation regarding the gastroenterologist in this study. The gastroenterologist works at a teaching hospital, which may make the input provided somewhat atypical of most gastroenterologists: the participant in this study works with attending physicians and fellows on a daily basis, constantly teaching them about the disease, and to prescribe the right kinds of behaviors for patients. Since the gastroenterologist is teaching day in and day out on the job and conducts the head of the research department at the teaching hospital, the viewpoints are coming from someone

who is an instructor. In other cases, it may be the gastroenterologist is the only specialist working at a clinic or other hospital office and may be the only expert in gastroenterology on staff. In this case the need to constantly teach and expand upon knowledge is removed. This means the situation for patients elsewhere could be worse, especially if their doctors are less concerned with patient education.

Finally, the fifth limitation of the study expands on the aforementioned benchmark. No standard of training in writing and health communication exists for either the medical writer or gastroenterologist. There is no prescribed method for the medical writer or gastroenterologist to follow to become experts or to receive accreditation as expert medical writers. The gastroenterologist may indeed receive a degree and pass certain state required exams to receive a license to practice there is no other measures absolutely required for the gastroenterologist to follow to achieve an expert level in medical writing or medical communication. Additionally, the medical writer can receive a formal education in technical writing, or the writer can simply choose writing as a career to pursue while educating his/herself in the field. Since there are no required checkpoints for either participant to reach at specific points throughout their careers, responses can, again, greatly differ from most other writers and gastroenterologists.

Future Research

Considering the implications and limitations of the study, future research should continue to address the information gap in terms of information foraging theory and also begin to address how to establish standards in the medical writing field to bridge the gap between patients and gastroenterologists. Since the study explored the pillars of

information foraging theory and established a baseline, future research could look to see what kinds of information could strengthen the scent and patch for patients. What kinds of information are best for patients to immediately receive? Are printed patient education materials the best form of education for patients? The current study only asserts the gaps between patients, writers, and doctors, not the best kinds of information for patients to receive. Future research may also consider analyzing the current healthcare industry and how they acquire information. Future research might also look at current health writing companies and see what their standards are and compare them against the standards of technical writing. The literature review demonstrates no study focused on ulcerative colitis information and the existence of any standards on how that information should be published for the general public. Finally, future research could look to collect information from larger samples of patients, writers, and gastroenterologists to attest the fact the findings of this study persist throughout the communities. Future research should continue to fill in these gaps in order to create a clear picture of how to solve the issue at hand.

This study sought to discover the weakest pillars of information foraging theory for ulcerative colitis patients and examine those against the ways a medical writer consumes and writes patient education materials, as well as how the gastroenterologist communicates with patients. Results show patients have weak scents and patches, but eventually find an information-rich diet; medical writers are privy to the same information as patients, yet are equipped with the skillset to make the information consumable; gastroenterologists do explain the disease to their patients but are reliant on information created by non-trained writers. By analyzing scent, patch, and diet of patients

and triangulating their results with a writer and gastroenterologist, this study extends the literature surround ulcerative colitis patient education materials and the necessity for technical writers to bridge the gap between the authoritative gastroenterologist and the newly diagnosed ulcerative colitis patient.

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APPENDICES

Appendix A. Patient survey questions.

1. How did you learn about your UC condition after being diagnosed?
2. How did you keep yourself educated about your UC? What is your main resource for information?
3. Were you provided with any supplemental materials (website address, pamphlet, brochure, journal)?
4. If you were given a pamphlet or brochure upon diagnosis, what did you like about it? If you weren't, would you liked to have received one? If so, what kinds of information would you want that pamphlet or brochure to include?
5. If you used a website to find out more information, how clear was that site? Did it include all the information you wanted/needed to know about UC? How could it have been improved?
6. How well did your GI doctor communicate with you about your UC?
7. Were you ever misinformed about any part of your UC? If so, where did you receive this misinformation?
8. Do you trust Internet websites to give you accurate, up to date information?

Appendix B. Medical writer interview questions.

1. What kinds of patient education materials do you design? What has been your experience working with patient education materials?
2. Is design more important than content when it comes to patient education materials or vice versa? Or do design and content have equal importance?
3. How do you select the kinds of content to include in patient education materials?
4. Have you had much experience designing materials for patients with ulcerative colitis?
5. What are the “best practices” for developing patient education materials?
6. What diseases do you typically write the most content for? Why are these diseases the main focus of your content?
7. How do you feel patient education materials could be improved?

Appendix C. Gastroenterologist interview questions.

1. What kinds of information do you give to your patient after they've been diagnosed? Pamphlet, oral instructions?
2. Do you recommend your patients to attend any support groups?
3. How do you keep patients educated about their disease after diagnosis?
4. Is there one particular source of information for your patients you prefer? What makes this source the preferred means of information?
5. What kinds of information (pamphlets, booklets) would you like to see in your office to supply to your patients? Why would this particular kind of information be beneficial to your patients?