

“My UC Story”: A Qualitative Descriptive Study Describing the Patient Journey for Ulcerative Colitis

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Abstract

Background: Personal perspectives of patients are seldomly reported in the literature, most notably their journey to diagnosis. Literature is heavily focused on the patient journey from a healthcare professional's point of view during the treatment process. The objective of this study is to conduct a qualitative study on a video-sharing site, YouTube, to determine if the patient journey from a subjective perspective is truly linear for those who suffer from ulcerative colitis.

Methods: Phrases searched on YouTube included “ulcerative colitis story” and “ulcerative colitis diagnosis story”. Video monologues chronicling the patient journey before diagnoses were transcribed using the YouTube transcription function to identify patterns amongst users' experiences. Thematic analysis was used to identify whether certain themes were present in the monologues. Analysis was performed using NVivo 12 QRS International and used line-by-line coding to create an initial codebook that represented the concepts covered in the monologues.

Results: We viewed a total of 48 videos and included 29 videos from 2010 to 2020 for qualitative analysis. Overall, three major themes were identified in the patient journey prior to ulcerative colitis diagnosis: 1) initial symptoms, 2) initial encounter with the healthcare system, and 3) gastroenterologist referral.

Conclusions: The literature depicts the patient journey as a linear path. This qualitative study discovers that the reality of the patient journey is, in fact, non-linear. Many creators did not identify pharmacists in their patient journey; however, we know from the literature that pharmacists are the most accessible healthcare professional. With the appropriate tools, pharmacists can help guide patients in prioritizing signs and symptoms to streamline the non-linear path that patients experience.

Keywords: patient journey, ulcerative colitis, subjective experiences

Introduction

The patient journey highlights the personal path a patient experiences on the way to better health outcomes. The growing importance of the patient journey in health care decision-making and treatment planning is asserted by Doyle and colleagues,¹ who concluded that the patient experience is positively associated with clinical effectiveness and patient safety and should be regarded as one of the central pillars of quality healthcare, especially for chronic diseases. In the literature, patient journey maps have been used to communicate normalized patient experiences from initial symptoms to maintenance treatment, often in the form of easy-to-understand visual representations.^{2,3,4} Girerd and Seronde,² for example, illustrate the assessment of congestive heart failure in a figure detailing stages of patient care from pre-admission to home monitoring, while Arthritis Canada provides an overview of what patients can expect pre-diagnosis through possible treatment plans.³ The British Columbia Cancer Agency provides visual outlines of patient and provider experiences and perspectives in receiving and delivering cancer care using a stepwise process from pre-diagnosis to end-of-life care.⁴ While

informative, close examination of these patient maps and the associated literature presents the patient journey as a linear, step-by-step process and heavily biased through the lens of the practitioner. Typically, the patient's subjective experiences or agency in the process are side-lined in favour of the clinical work of measuring and delivering patient safety and clinical effectiveness.¹

Ulcerative colitis (UC) is a chronic, lifelong condition that significantly impacts a patient's physical and mental health.⁵ It is the most common form of inflammatory bowel disease (IBD) worldwide, with an estimated 120,000 Canadians living with UC as of 2018, a number that is expected to climb over the next decade.⁶ To date, we have found no patient journey maps for UC, neither from the practitioner nor patient perspective, and in particular, from symptoms to diagnosis for patients. For the purposes of this study, we created Figure 1 using available literature on typical practitioner-focused UC treatment plans.^{7, 8} As shown, the pre-diagnosis stages of the patient journey for UC begins when patients first present with symptoms and eventually transitions to specialist referral ensuring appropriate testing, accurate diagnosis, treatment planning, and on-going monitoring. Importantly, many patients at the pre-diagnosis stages will not receive an accurate diagnosis for months, even years after their initial visit to a general practitioner.^{5,7} In a 2005 European survey of UC patients, for example, 53% of patients experienced symptoms for one year before diagnosis with 20% waiting over 5 years.⁵ Fifteen years later, a UK study found that 10.4% of patients continued to experience

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symptoms for 5 years before UC diagnosis. This prolonged waiting period can be particularly difficult for UC patients, greatly impacting their physical and psychological health. As Calvino-Suarez and colleagues emphasize, improving the quality of daily life for patients living with UC and other IBDs should be a central focus of clinical management.⁹ Since IBD is heterogeneous with a wide variation of presentation,⁷ the bottleneck during the pre-diagnosis period for UC sufferers appears to be a gastroenterologist referral, which is often delayed unless a patient presents with strongly suggestive symptoms or there is high suspicion of the disease.^{5,7}

Aligned with the heart failure, arthritis, and cancer care examples described earlier and our understanding from Figure 1, the healthcare practitioner's objective, linear and algorithm-based perspective on UC treatment neglects the patient's subjective experiences and quality of life. We ask, where is the patient's perspective in this process? For UC patients, why is the patient's comprehensive understanding of their own symptomology not taken more seriously or used more strategically in UC treatment, most notably during their journey to diagnosis. In our view, this lack of insight is a serious gap in the provision of health care for UC patients as a clear understanding of the true nature of the patients' journey and experiences appears critical for early diagnosis, ongoing treatment and monitoring, and quality of life.¹⁰ A better understanding of the subjective patient journey with UC might help fill this gap.

As depicted in the literature, pharmacists are seldom involved in the management of UC, yet pharmacist intervention has been shown to have significant positive impacts on patient care. For example, in the case of blood pressure management, for example, the Canadian Pharmacists Association (CPHA) estimates that for every five people receiving pharmacist intervention, one cardiovascular event is avoided, and four years of life are saved.¹¹ The trusting relationship patients build with their pharmacist appears to be a major contributor to positive outcomes. Given that pharmacists interact with patients five to eight times more frequently than primary care doctors,¹² there is potential for pharmacists to play a role in the patients' journey living with UC in the early stages such as triaging and screening.

To address these issues, the aims of this study were to: 1) examine the patient journey for UC patients using YouTube video analysis of their personal experiences with the disease; 2) create a patient journey map representative of the patient's subjective experiences with the disease, and 3) propose how pharmacist intervention could support the patient journey for those living with UC.

Methods

Study Design

To address the study aims, a qualitative descriptive study design incorporating social media was used to examine the subjective experiences of UC patients emphasizing, where possible, the patient journey pre-diagnosis. Various forms of social media including personal online blogs (Staite) and platforms such as Reddit (Chew) have created a unique window into the lives of those living with chronic illnesses by providing insightful, ready-made personal narratives that are accessible to those sharing similar experiences.^{13,14} For this study, YouTube (www.youtube.com), the popular public video sharing site, was used to examine the patient journey of UC patients. YouTube is the second largest internet search engine (behind Google) with over two billion users worldwide and one billion hours of YouTube videos watched daily.¹⁵ YouTube creators may upload videos of up to fifteen minutes in length (for non-verified accounts) which are freely viewable by anyone, without a password. Videos may be enabled with a comments section intended to connect and engage viewers with the creator, as well as the ability to "like" or "dislike" content. These features permit YouTube users to share personal stories, connect emotionally, and engage with a larger audience.¹⁶ As a result, YouTube videos describing the patient journey for chronic illnesses such as UC, can provide a rich source of data for qualitative research purposes. Given that YouTube videos are considered publicly available information, this study was deemed exempt from formal ethics review.

Data Collection

We aimed to identify YouTube videos describing the patient journey prior to UC diagnosis. The search process involved two phases: an initial broad search followed by a closer evaluation step to identify the subset of videos to be used for primary analysis. Searches were conducted using the YouTube search engine. To control for a potential search history effect, the search history was deleted on the study computer, and the search conducted using a newly loaded web browser (Google Chrome). For the initial broad search, search phrases included 'ulcerative colitis story', 'ulcerative colitis diagnosis story', and 'my IBD story'. Videos targeted during this search phase were those created and uploaded by authentic patients, defined as creators who recorded themselves sharing their personal thoughts and experiences without anyone else present. Selected videos were added to an initial playlist. Videos uploaded by foundations and institutions were immediately excluded to avoid potential interview and media biases arising from third party editing or outside influence.

The initial search phase yielded 48 videos with titles including, among others, "ulcerative colitis story", "ulcerative colitis diagnosis", "my IBD story", and "IBD diagnosis." These videos, saved to the 'playlist', were subjected to a second review specific for experiences pre-diagnosis, a process involving repeated video views and close listening to the accompanying narratives. Following this process, videos that neglected to mention the journey prior to diagnosis and those about Crohn's

disease were excluded. Videos with poor sound quality were also excluded. The final data set, including 29 videos, was saved to a separate playlist for transcription and analysis. The search process was completed by the primary author alone.

Analysis

Thematic analysis was used to interpret the subjective experiences of the YouTube creators included in the final video data set. Guided by the study aims, the approach combined the theoretical perspectives of Sandelowski and the practicalities of Lincoln and Guba's constant comparative method. 17,18 Transcripts, including the title, date uploaded, video URL, description box information, and the creator's monologue, were generated using the YouTube transcription function, exported as Microsoft Word files, and carefully reviewed alongside the videos to address inconsistencies in the YouTube transcription function, ensure transcription accuracy, and facilitate data familiarisation. As part of the review process, monologue and/or description box information detailing UC pathophysiology, symptoms during flares, management and/or life issues after diagnosis, and information unrelated to UC was removed along with time stamps. The final transcripts were uploaded to NVivo 12 (QRS International) for analysis. The transcript-generating process was completed by the primary author.

To generate meaning from the raw transcripts, a deductive and researcher-driven process was used. An initial code book, including a set of codes and themes derived from the literature review, framed the analysis (Figure 1. The patient journey for ulcerative colitis: a literature perspective). Although the code book was based on an expectation of what might be found in the data by the authors, reflexivity and open-mindedness were maintained throughout the analysis to attempt to ensure the findings remained rooted in the data.

In NVIVO, each transcript was read carefully and coded inductively line-by-line to generate a parallel set of codes for comparison purposes. No limit on the number of codes was established at this stage, with the final set developed iteratively through reading and reviewing the transcripts individually and collectively as needed. Key text and critical quotes defining each code were identified as part of this process. Codes were then grouped into patterns, identifying emergent themes and related sub-themes. Comparison with the initial codebook produced the final set of themes matched with related sub-themes and representative text and quotes. The analysis was completed independently by the first and second authors, with variations and disagreements handled by discussion until a consensus was reached.

Results

As mentioned previously, the data collection phase of this study yielded 29 YouTube videos, each with a unique creator. The videos spanned a 10-year period (December 2010 to April

2020), had an average length of 13.5 minutes, and 93% involved female patients. While the systematic transcription process provided high-quality raw data and the deductive approach to analysis provided high-level themes for guiding the process, the final thematic analysis resulted in the construction of three themes with associated sub-themes highlighting steps in the patient journey prior to diagnosis and illustrative of the challenges and gaps in the health care system UC patients face: 1) initial symptoms 2) initial encounter with the health care system and, 3) gastroenterologist or colonoscopy referral.

Theme 1: Initial Symptoms

The first theme encompasses the YouTube creator's experiences of and reactions to their initial symptoms. While most were experiencing typical early onset UC symptomology such as persistent stomach cramps, diarrhea, blood or mucus in the stool, and bowel urgency, they either did not take their symptoms seriously or ignored them, thinking they were related to other more familiar conditions. Despite significant impacts on their quality of life and daily routines, the often-persistent nature of the symptoms rarely triggered a personal 'red flag' to seek medical advice. Said one creator, "I thought nothing of it. I took some Imodium [loperamide, an anti-diarrheal]¹⁹ to subside whatever was going on, and it worked. I ended up going to school the next day...in the library, I got really sick...I ended up going to the bathroom like 20 times...chalked it up to be food poisoning..." Regarding the all-too-common tendency to endure and ignore, another stated, "I had really bad stomach cramps; my stomach would hurt every single day...I kind of thought it was period cramps because [it] felt exactly like period cramps, but my period came and went...and the pain continued for weeks...I never went to the doctor."

An important subtheme related to initial symptoms included the reasons for not visiting a healthcare professional. Many creators indicated that they kept their experiences to themselves due to embarrassment and a reluctance to talk about it or tell anyone. They were particularly worried that people, including health practitioners, might think they were overreacting. Even though their quality of life was being negatively affected, they were hesitant to seek care, preferring to suffer alone. Additionally, many creators were unaware of the symptoms that should be considered abnormal or alarming and prompted a visit to the doctor. Summarizing the prominent feelings of embarrassment and reluctance shared by many creators, one stated, "I had been dealing with something for a long time, but because it was you, it's something you don't want to just tell people, go up and say you know my stomach is hurting so bad or I'm constantly using the bathroom or I'm bleeding out of my butt...I didn't want to tell anybody...it's embarrassing." Another emphasized commonly-held concerns about perceptions of overreaction (both personal and by others) and the resolve to live with the situation, "I have this kind of innate worry that [my friends or a doctor] aren't gonna

believe me, that my pain isn't really that bad, I'm over exaggerating...I just had this worry in the back of my head that it's really not that bad, other people have it worse than me. I will be fine, and it will go away."

Exacerbating early reactions to their condition, many creators appeared to have limited and, in some cases, no knowledge of UC and associated symptomology and what could be considered normal or abnormal, "When I went to have a bowel movement, I saw white stuff. At the time, my pre-ulcerative colitis terrifically, naïve self did not know that was mucous."

For those who did choose to reach out, a second subtheme emerged around the sources of advice. After experiencing initial symptoms, most of this group sought guidance from friends or social media before seeking professional care. As highlighted by one creator, "My best friend's mom was a nurse, so I kind of told her about the whole experience, everything that happened. She was like you know you might have celiac disease." Another creator using social media for help and support, "I'm just like why am I having diarrhea with the fever that doesn't go together, so I posted it on Facebook to let the world know I just wanted some help. I was in so much pain I just wanted help."

To summarize, the early experiences of patients suffering with initial UC symptoms could be characterized as a mostly solitary one in which creators often dealt with prolonged, unfamiliar, and disruptive symptoms on their own. Embarrassment, reluctance to share, worries about what others might think about their situation, and a lack of awareness of UC etiology and/or typical and/or abnormal symptomology were key drivers in the creator experiences. Rather than seeking professional care or visiting a doctor, many chose to reach out to friends or social media for help and support.

Theme 2: Initial encounter with the health care system

The second theme emerging from the creator's experiences with UC pre-diagnosis involved their initial encounters with the healthcare system, that is, an emergency room visit or doctor's examination motivated by symptom severity. While creators were clearly aware of their pain and suffering, they voiced frustration with lack of support and empathy within the healthcare system to help them navigate the process. As stated by one creator, "[they] gave me some medication for the constipation and said it should help, nothing happened, I was still sick...I just wanted my doctor to help."

Once contact was initiated, improper diagnosis appeared common, adding confusion, stress, and, in some cases, fear to a growing apprehension and uncertainty about their health and prognosis. "I was having so much pain and blood and everything, and I didn't know what was going on...I was really scared." Failure to resolve symptoms often required multiple visits to emergency and/or with their doctor: "the pain carried

on, it got a lot worse, we went back to the doctor's six or seven times." Interestingly, some first encounters were triggered by non-UC-specific signs and symptoms, such as joint pain and stress-induced flares. "I was having a lot of problems with pain in my body, I had joint pain, I had pain in my hands, I had pain in my arms, in my back, a lot of pain...I actually went to the doctor about this...they ran a bunch of tests that came back without showing anything at all. I was perfectly healthy and fine, so time went by, and these pains came and went."

For most, however, it was not until their symptoms became almost unbearable, such as blood in the stool, paralyzing gastrointestinal pain, and/or nonstop diarrhea, that decisions to go to the emergency or visit a doctor were made. Regarding misdiagnosis, after examination and/or undergoing various blood and stool tests, many creators were diagnosed with conditions other than UC, such as irritable bowel syndrome (IBS), gastritis, constipation, a stomach virus, or hemorrhoids. Expressing frustration, one creator said, "I went to the doctor's eight times in a month, and everyone told me it was IBS. I was eventually diagnosed with indeterminate colitis." She was prescribed Buscopan, an antispasmodic (hyoscine butylbromide)²⁰ for cramps, and told to go home. Another shared that her doctor was adamant, "You are only 14, so it's not going to be Crohn's or Colitis or IBD or anything like that because you are too young; those diseases are old people diseases."

Overall, this theme, much like Theme 1, was characterized by an intense reluctance on the part of creators to seek professional care; only after symptoms had deteriorated badly were they compelled to seek help through emergency room visits or a family physician. Due to non-specific UC symptomology, creators commonly experienced misdiagnosis and/or prescribed inappropriate medication and therapy. Failure of symptom resolution led to extended cycles (sometimes months, even years) of recurring symptomology, emergency room and/or doctors' visits, and worry about whether they would ever get better. During this stage of their UC journey, many creators' quality of life suffered significantly.

Theme 3: Gastroenterologist Referral

The third theme associated with the creator's experiences with UC prior to diagnosis focused on the challenges with specialist referral, specifically to a gastroenterologist. Of the 29 YouTube videos analyzed in this study, only a small number of creators were referred to a gastroenterologist early on during their visits with their doctor. Although it was unclear whether these doctors were more familiar with UC, the creator's symptomology (bloody diarrhea, multiple bowel movements a day, or severe gastrointestinal pain was unclear) was taken seriously. Describing her reaction to seeing blood in her stool, one creator shared, "I panicked and [made] an appointment with the GP for the following day. I go in and tell him what

happened, and he said oh that's definitely not normal I'm going to refer you to a gastroenterologist."

For most creators, however, this was not the case. Often, gastroenterologist referral came only after worsening symptoms, multiple doctor visits, and failed alternate treatments. Some creators lamented that gastroenterologist referral seemed to be a strategy of last resort for their doctor as many creators were relying on their physician's expertise and not proactively asking for a specialist referral. Shared one, "the hemorrhoids did eventually disappear, but the chronic diarrhea [and] blood in my stool...was still there...it got to the point where finally the doctor was like, you know what, I'm gonna send you to a gastroenterologist." Confounding the referral process seemed to focus on the results from a colonoscopy test, an invasive internal examination procedure ordered by some doctors. The often negative or inconclusive findings appeared to lock creators in a prolonged cycle of doctors' visits, worsening symptoms, and deteriorating quality of life. "I had my first colonoscopy at age I was 18, and that was quite scary; unfortunately, the doctor didn't find anything. She's just like, "You're fine, don't worry about it", so I just kept on trying to live my life normally".

Importantly, once the referral was made and creators were under the care of a gastroenterologist, careful endoscopic and lab testing resulted in a correct UC diagnosis for most. The importance of receiving a proper diagnosis cannot be underestimated for creators. Most talked about "the end of a long, painful road" and a "resurgence of hope"; "there's an answer, it wasn't in my mind". Summarized succinctly by one creator, "eventually they worked out it was ulcerative colitis, and I just felt this sense of relief."

Overall, this theme could be described as more of the same, except that the experiences of creators were specifically related to the challenges with receiving a specialist referral. Whether it was due to the complexity of diagnosing UC, an unwillingness on the doctor's part to make a referral, or long wait times to see a gastroenterologist, creators were caught in a further cycle of doctor's visits and testing that impacted their mental health and quality of life. For most, the referral, along with the specialist care, resulted in a proper UC diagnosis and life-changing treatment plans.

Discussion

The patient journey highlights the subjective experiences of patients on their way to better health outcomes. What is lacking in the literature is the personal experiences of patients to help guide the process, particularly for chronic diseases.¹ Patient journey maps, where they exist, typically represent the practitioner's perspective, casting the patient journey as a linear series of steps from prehospitalization and emergency room care through hospitalization to discharge and monitoring. In the case of heart failure, arthritis, and cancer care,²⁻⁴ for

example, the primary aim appears to illustrate how the best research-informed tests reduce disease-related morbidity and mortality along with improved quality of life. While the importance of practitioner involvement and appropriate testing in quality health care cannot be understated, the reality of the patient experience is often quite different. Our study of the patient journey for patients with UC, to our knowledge, the first of its kind, demonstrates that the patient journey is complex and cannot be reduced to a systematic and predictable series of steps.

The social media site YouTube, where individuals can publicly engage with each other, share experiences, and exchange information, provided a rich data source for addressing the first aim of the study: examining the patient journey of people living with UC. Focused on experiences prior to diagnosis, often the most challenging stage of the disease, this qualitative descriptive study used deductive thematic analysis to attempt to make meaning of their personal postings. While each creator's journey was considered unique, our analysis identified three separate-yet-overlapping themes characterizing stages of the patient journey pre-diagnosis: initial symptoms, initial encounters with the health care system, and gastroenterologist referral. The findings from our study emphasize just how messy the journey can be for UC sufferers and why, with greater attention from both patients and practitioners, clearer guidance and understanding is necessary to help UC patients navigate their journey more effectively and efficiently.

Supporting the second aim of this study, we created Figure 2, a thematic map illustrating the patient journey based on the YouTube creator's experiences. Placing the patient at the center, the reality for UC sufferers stands in stark contrast to Figure 1, the literature-generated patient journey map. For UC patients, particularly during the pre-diagnosis stages, their journey cannot be accurately described as a series of linear sequential steps. Instead, the subjective experiences of UC patients are better characterized as an almost random movement through a series of interconnected themes and subthemes on the way to diagnosis. Due to embarrassment and a reluctance to share their experiences with others, initial symptoms were often ignored or assumed to be caused by other, more familiar conditions. Initial contact with the health care system, in the form of emergency room or doctor's visits, was only prompted by increasingly severe symptoms that seriously impacted daily living. Preferring to suffer alone, help and support was sought through friends and social media before health professionals. A lack of personal knowledge of UC and related symptomology seemed to exacerbate the experiences.

The challenges for patients seemed to be mirrored by the doctors. Since UC tends to initially present as nonspecific symptoms, accurate differential diagnosis was often difficult. Aligned with the work of Lix and colleagues,²¹ the result was

often misdiagnosis, significant delays, and inadequate treatment. For patients, these experiences manifested over weeks to years as repeated emergency room or doctor's visits, inappropriate drug therapy, failure of symptom resolution, disease progression, heightened stress and anxiety, an increased burden on daily life, and a growing sense of hopelessness.⁸ The quality of life for UC patients suffered noticeably, intensified by a general unfamiliarity with the health care system and what can be expected and a seeming lack of empathy for the patient experience.

As researchers such as Westwood and Travis⁷ have stressed, the bottleneck in the diagnosis of UC seems to be gastroenterologist referral. For many doctors, specialist referral seemed to come only after multiple patient visits, various inconclusive diagnostic testing, including colonoscopy, and failure of symptom resolution. For some, the referral seemed to be a strategy of last resort. Prolonging the referral process appeared to be the wait times for specialists (two to three months), which compounded the cycle of symptomology and doctors' visits for UC patients. What was very clear is the importance of gastroenterologist referral for patients. Not only did securing the referral provide a noticeable psychological boost for patients and an improvement in their quality of life, but once under the care of the specialist, proper diagnosis was common. Graff and colleagues²⁰ have studied this phenomenon amongst IBD patients, showing the negative psychological effects of active disease and the changes with proper diagnosis. Timely diagnosis with associated treatments is effective at normalizing quality of life and bringing patients peace of mind.²² It should also be noted that while the challenges with diagnosis and referral were clearly voiced by UC patients, confounding the process was a seeming lack of patient knowledge about UC, what questions to ask, and an unwillingness to advocate for themselves. Importantly, neither patient education nor the patients' experiences were included as part of the care provided to UC patients during the pre-diagnosis phases of the disease.

Interestingly, pharmacists were not mentioned or included as part of any of the creator's journeys with UC, this despite being considered the most accessible healthcare professional.²³ Pharmacists in Canada are evolving with an expanded scope of practice and are usually the first point of contact for many Canadians in the health care system; 51% of Canadians visit the same pharmacy monthly.²⁴ In addition, pharmacists can also access various point-of-care testing tools that help screen for diseases and manage patients' medications (e.g., INR). Regarding UC specifically, point-of-care testing of fecal calprotectin has proven to be a suitable alternative for the assessment of disease activity in IBD patients, which can provide insights for patients and physicians to achieve early detection in the case of UC.²⁵ We feel that pharmacists can be better involved in a UC patient's journey by supporting and educating the patient as well as recognizing key symptoms,

prioritizing symptoms, and guiding the patients when seeking medical advice and specialist referral, and decreasing the time to UC diagnosis.

Below, as depicted in Table 1, is a stepwise guide that pharmacists can use to assess patients who present with gastrointestinal symptoms to determine if patients would benefit from point-of-care testing and/or specialist referral:

Assessment of Patients with Gastrointestinal Symptoms and Patient Guidance

Step 1: Ask and Assess Specific questions, using the SCHOLAR approach, to ask patients looking for gastrointestinal over-the-counter medications to determine appropriateness and referral as necessary. ^{26, 27, 28, 29}

Step 2: Assess and Refer For any assessment questions marked with an '*' where the answer is 'yes', physician referral for fecal calprotectin, endoscopy, and/or specialist referral.

Step 3: Educate

3a: Encourage patients to document their symptoms daily: abdominal pain, nausea, frequency and characteristics of bowel movements, fatigue, and any other symptoms the patient is feeling. In addition to any medications they are taking, specifically over-the-counter medications they might be using to alleviate symptoms.

3b: Using Figure 2, inform patients that it takes time to receive a diagnosis as there are multiple steps involved in the diagnosis process.

Limitations of our study include use of the YouTube platform to gather patient stories. The accuracy of video transcription was dependent on our ability to understand the creator, who may mispronounce words, speak with a strong accent, or use jargon or slang. Poor audio quality may also play a role in transcription errors. Our goal was to focus on the patients' journey before diagnosis, so videos with titles other than "my ulcerative colitis diagnosis" or "my ulcerative colitis story" were excluded. There is a possibility that diagnosis stories with alternate video titles may have been overlooked, and there may be more patient journeys that we have not captured. The phrases generated to search the YouTube database were limited with the nature of the platform, potentially limiting the amount of videos captured, increasing the risk of data saturation in this study. Additionally, the included patient journeys may not be representative of all patients with UC. Finally, all aspects of the journey were conveyed by creators who may have intentionally or unintentionally excluded information and/or altered the timeline from when symptoms were first experienced to diagnosis.

Many patients choose to share stories about their journey using social media. This provides a rich source of data for researchers trying to gain a better understanding of a patient's experience and their needs. We were able to identify and analyze YouTube videos describing patient journeys, which conveyed that the journey is, in fact, not linear, and pharmacists can play an important role in identifying red flags that would warrant referring the patient for further examination and tests, overall shortening the patient journey to diagnosis. Within the scope of pharmacy practice, there is potential for further studies to be conducted to explore pharmacists' effectiveness in referral as part of the patient journey, strengthening interdisciplinary collaboration.

Conclusions

This study illustrated that the ulcerative colitis (UC) patient journey from the patients' perspective, unlike what the literature suggests, is non-linear, complex, confusing, and frustrating. From a patient's perspective, various points between themes identified in this study where community pharmacists, have potential to play a significant role in the patient journey and positively impact patients' quality of life. We hope that increasing awareness of the steps of the patient journey will better equip pharmacists and other healthcare providers to navigate the patient and implement these strategies into their practice to fill the gaps.

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References

1. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3(1):e001570. doi:10.1136/bmjopen-2012-001570
2. Girerd N, Seronde MF, Coiro S, et al. Integrative Assessment of Congestion in Heart Failure Throughout the Patient Journey. *JACC Heart Fail*. 2018;6(4):273-285. doi:10.1016/j.jchf.2017.09.023
3. Arthritis Society Canada. Rheumatoid Arthritis (RA): Patient Journey. Published 2021. Accessed May 10, 2021. https://arthritis.ca/getmedia/76998ca3-ae22-4cb9-802a-68f3c6345faa/RA_Flowchart_April8_small.pdf
4. BC Patient Safety & Quality Council. Journey Mapping in Cancer Care Maps. Published February 21, 2019. Accessed May 10, 2021. <https://bcpsqc.ca/improve-care/cancer-care/>
5. Ghosh S, Mitchell R. Impact of inflammatory bowel disease on quality of life: Results of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) patient survey. *J Crohns Colitis*. 2007;1(1):10-20. doi:10.1016/j.crohns.2007.06.005
6. Kaplan GG, Bernstein CN, Coward S, et al. The Impact of Inflammatory Bowel Disease in Canada 2018: Epidemiology. *J Can Assoc Gastroenterol*. 2019;2(Suppl 1):S6-S16. doi:10.1093/jcag/gwy054
7. Westwood N, Travis SP. Review article: what do patients with inflammatory bowel disease want for their clinical management?. *Aliment Pharmacol Ther*. 2008;27 Suppl 1:1-8. doi:10.1111/j.1365-2036.2008.03605.x
8. Bernklev T, Jahnsen J, Schulz T, et al. Course of disease, drug treatment and health-related quality of life in patients with inflammatory bowel disease 5 years after initial diagnosis. *Eur J Gastroenterol Hepatol*. 2005;17(10):1037-1045. doi:10.1097/00042737-200510000-00006
9. Calviño-Suárez C, Ferreiro-Iglesias R, Bastón-Rey I, Barreiro-de Acosta M. Role of Quality of Life as Endpoint for Inflammatory Bowel Disease Treatment. *Int J Environ Res Public Health*. 2021;18(13):7159. doi:10.3390/ijerph18137159
10. Siegel CA, Lofland JH, Naim A, et al. Novel Statistical Approach to Determine Inflammatory Bowel Disease: Patients' Perspectives on Shared Decision Making. *Patient*. 2016;9(1):79-89. doi:10.1007/s40271-015-0126-z
11. Marra C, Johnston K. Improving Care and Lowering Costs: Benefits of pharmacist care in hypertension in Canada. Canadian Pharmacists Association. Published 2017. Accessed November 24, 2021. https://www.pharmacists.ca/cpha-ca/assets/File/cpha-on-the-issues/Benefits_of_Pharmacist_Care_in_Hypertension_EN.pdf
12. Tsuyuki RT, Beahm NP, Okada H, Al Hamarneh YN. Pharmacists as accessible primary health care providers: Review of the evidence. *Can Pharm J (Ott)*. 2018;151(1):4-5. doi:10.1177/1715163517745517
13. Staite E, Zaremba N, Macdonald P, et al. 'Diabulima' through the lens of social media: a qualitative review and analysis of online blogs by people with Type 1 diabetes mellitus and eating disorders. *Diabet Med*. 2018;35(10):1329-1336. doi:10.1111/dme.13700

14. Chew C, Rebić N, Baldwin C, Amiri N, Proulx L, De Vera MA. "r/Thritis", Pregnancy, and Parenting: A Qualitative Descriptive Study of Reddit Forums to Explore Information Needs and Concerns of Women With Rheumatoid Arthritis. *ACR Open Rheumatol.* 2019;1(8):485-492. doi:10.1002/acr2.11069
15. YouTube for Press. YouTube. Accessed June 26, 2020. <https://blog.youtube/press/>
16. YouTube About. YouTube. Accessed June 26, 2020. <https://www.youtube.com/about/>
17. Sandelowski M. Whatever happened to qualitative description?. *Res Nurs Health.* 2000;23(4):334-340. doi:10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
18. Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic Inquiry*. SAGE, Thousand Oaks, 289-331. [http://dx.doi.org/10.1016/0147-1767\(85\)90062-8](http://dx.doi.org/10.1016/0147-1767(85)90062-8)
19. Loperamide. In: Lexi-Drugs. Lexi-Comp, Inc. Updated August 5, 2023. Accessed August 12, 2023. http://online.lexi.com.eu1.proxy.openathens.net/lco/action/doc/retrieve/docid/patch_f/7192?cesid=2i2RfC2sN6B&searchUrl=%2Ffco%2Faction%2Fsearch%3Fq%3Dloperamide%26t%3Dname%26acs%3Dfalse%26acq%3Dloperamide
20. Buscopan. In: Lexi-Drugs. Lexi-Comp, Inc. Updated July 6, 2023. Accessed July 15, 2023. http://online.lexi.com.eu1.proxy.openathens.net/lco/action/doc/retrieve/docid/patch_f/1801741?cesid=6oxEmABaqdh&searchUrl=%2Ffco%2Faction%2Fsearch%3Fq%3Dbuscopan%26t%3Dname%26acs%3Dtrue%26acq%3Dbuscop
21. Lix LM, Graff LA, Walker JR, et al. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflamm Bowel Dis.* 2008;14(11):1575-1584. doi:10.1002/ibd.20511
22. Graff LA, Walker JR, Lix L, et al. The relationship of inflammatory bowel disease type and activity to psychological functioning and quality of life. *Clin Gastroenterol Hepatol.* 2006;4(12):1491-1501. doi:10.1016/j.cgh.2006.09.027
23. Manolakis PG, Skelton JB. Pharmacists' contributions to primary care in the United States collaborating to address unmet patient care needs: the emerging role for pharmacists to address the shortage of primary care providers. *Am J Pharm Educ.* 2010;74(10):S7. doi:10.5688/aj7410s7
24. Canadian Pharmacists Association. *Pharmacy in Canada*. Published February 2016. Accessed June 10, 2020. <http://www.pharmacists.ca/cpha-ca/assets/File/pharmacy-in-canada/Pharmacy%20in%20Canada.pdf>
25. Hejl J, Theede K, Møllgren B, et al. Point of care testing of fecal calprotectin as a substitute for routine laboratory analysis. *Pract Lab Med.* 2017;10:10-14. doi:10.1016/j.plabm.2017.11.002
26. Silverberg MS, Satsangi J, Ahmad T, et al. Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease: report of a Working Party of the 2005 Montreal World Congress of Gastroenterology. *Can J Gastroenterol.* 2005;19 Suppl A:5A-36A. doi:10.1155/2005/269076
27. Satsangi J, Silverberg MS, Vermeire S, Colombel JF. The Montreal classification of inflammatory bowel disease: controversies, consensus, and implications. *Gut.* 2006;55(6):749-753. doi:10.1136/gut.2005.082909
28. Sherman CB, McQuaid K. Approach to the Patient with Diarrhea. In: Podolsky DK, Yamada T, eds. *Yamada's Textbook of Gastroenterology*. Vol 4. Chichester, West Sussex: Wiley Blackwell; 2016:735-756.
29. Forrester A. Diarrhea. In: *Compendium of Therapeutic Choices*. Canadian Pharmacists Association. Updated February 25, 2022. Accessed May 10, 2022. <https://www.myrxtx-ca.eu1.proxy.openathens.net/search>

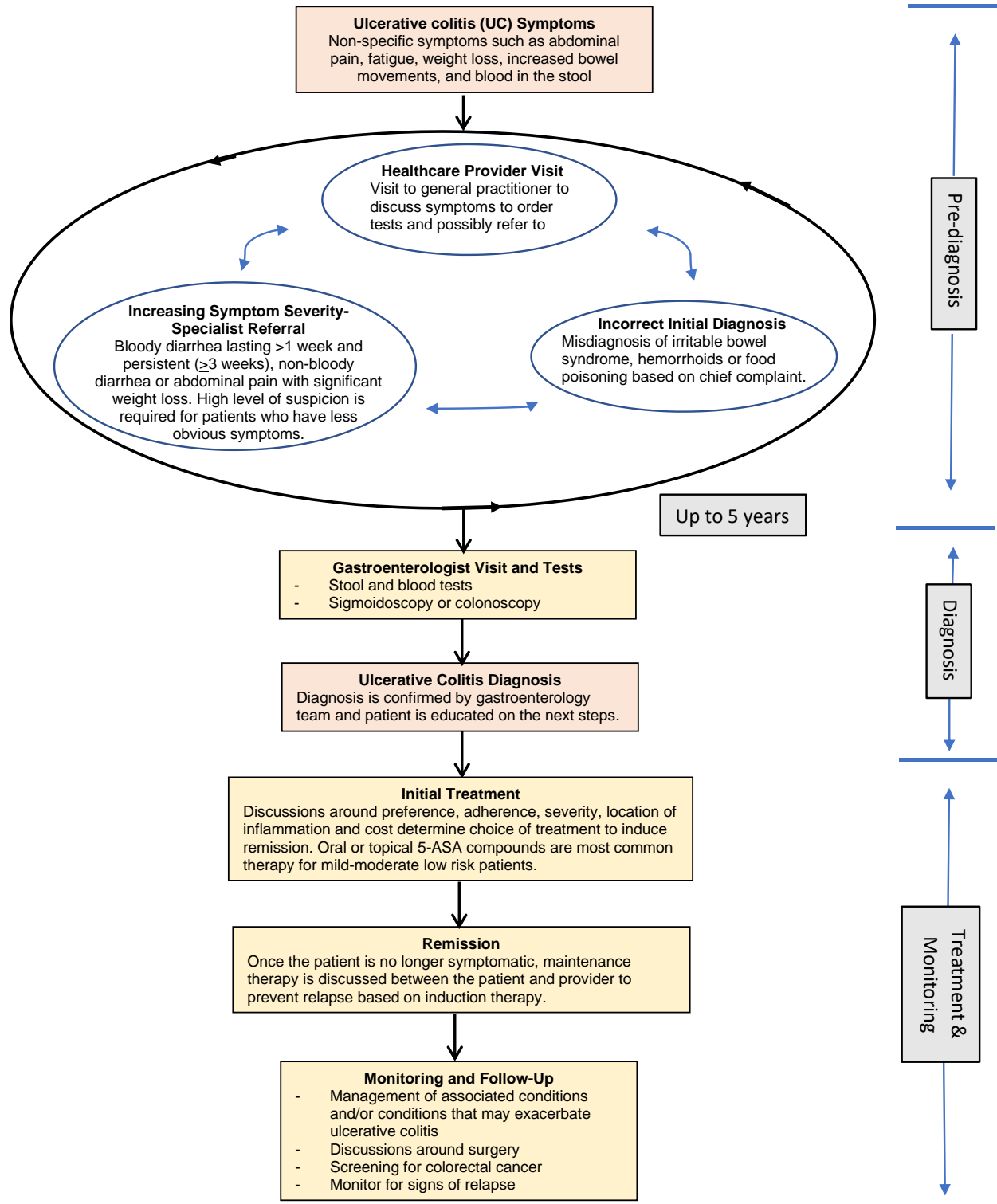
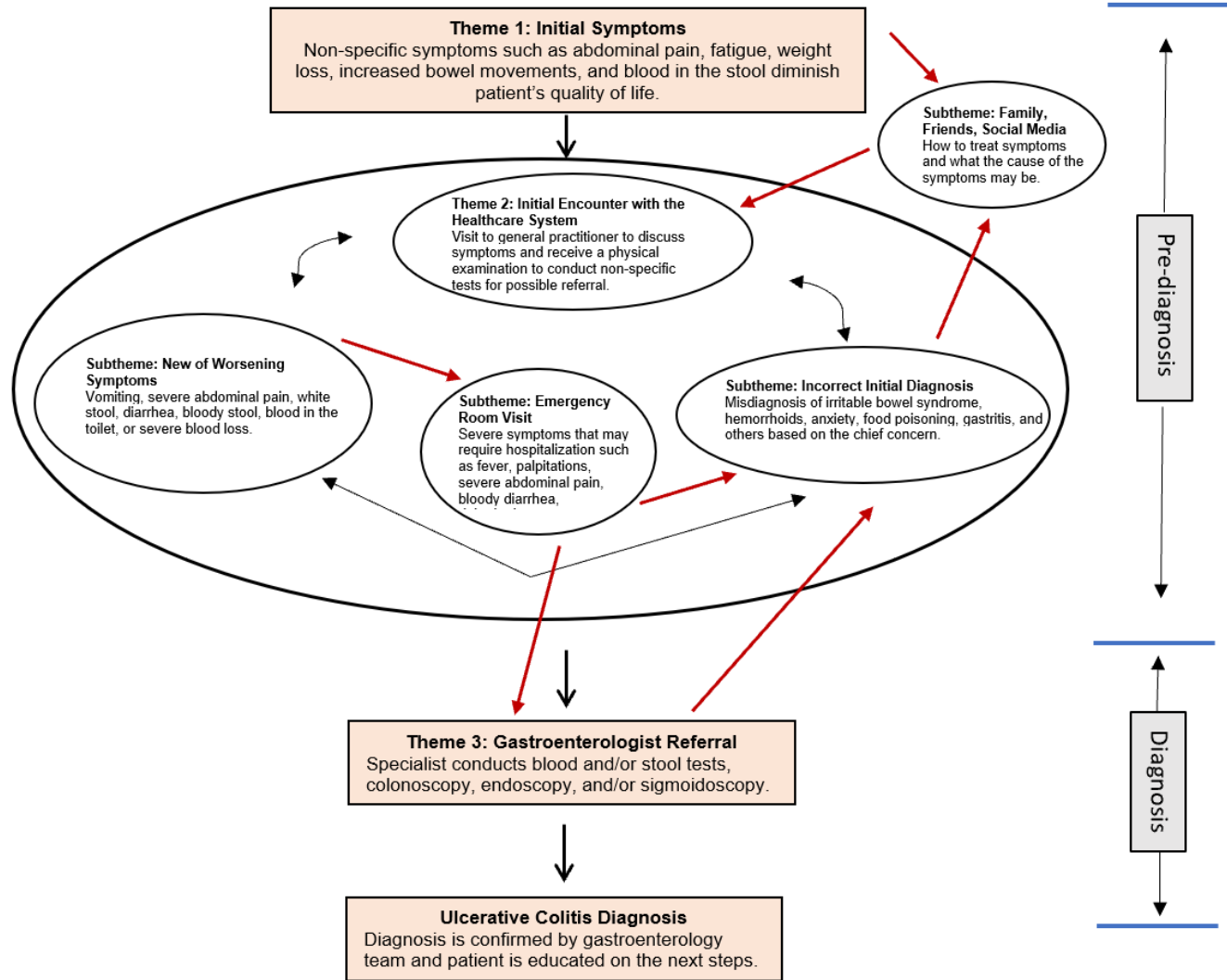
Figure 1: The patient journey for ulcerative colitis: a literature perspective.^{7,8}

Figure 2: The patient journey for ulcerative colitis: a subjective perspective.



Legend

= additional pathway identified from study

= patient journey steps from literature

Table 1. Structured questions to assess patient symptoms.

Symptoms	Do you have diarrhea or watery bowel movements? When you have diarrhea, do you also have nausea? When you have diarrhea, do you have stomach pain? Have you lost weight without trying in the last month? *
Characteristics	What color is the diarrhea? Is the diarrhea red? * Is the diarrhea jelly-like? * Are your bowel movements always watery? * Or are your bowel movements slightly formed? How many times a day is the diarrhea? Is there any blood in the toilet after you have a bowel movement? * Do you often feel the urge to have a bowel movement but only pass jelly or a very small amount of stool? *
History	Has this happened before?
Onset	When did the diarrhea/stomach pain/nausea start? Has it been longer than one month? *
Location	Is there a specific area of your stomach where you have pain?
Alleviating	Is there anything that makes it better?
Remitting	Is there anything that makes it worse?