



ULCERATIVE COLITIS – HEALTH INEQUITIES AND BARRIERS TO CARE ACROSS THE PATIENT JOURNEY

WHITE PAPER

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Introduction

Approximately 600,000 to 900,000 people in the United States have ulcerative colitis (UC),^{1,2} a chronic inflammatory bowel disease (IBD) that develops when the immune system reacts abnormally, causing inflammation and ulcers in the lining of the large intestine. It is not clear what causes UC, but genes, abnormal immune reactions, the microbiome, and environmental influences may be factors. People may develop UC at any age, although it most often occurs between the ages of 15 and 30.³ The disease may lead to complications that develop over time, may become serious or life-threatening, and may require hospitalization or surgery.² Diagnosis is based on symptoms, medical and family history, physical exam, and medical tests, including blood tests, stool tests, and endoscopy of the large intestine.³

Along with developing new treatments, current research on UC and other types of IBD focuses on genes associated with IBD in African Americans, the effect of diet on bacteria in the large intestine, and how the immune system controls inflammation in the digestive tract in people with IBD.⁴

There are not much data on UC in patients of racial/ethnic minorities, including variations in disease severity at presentation, compared to data on White patients. A cross-sectional study of adult patients with UC at a large, ethnically diverse safety-net hospital compared race/ethnicity-specific disparities in disease severity at presentation⁵ and found that simple clinical colitis activity index scores were significantly higher in non-White patients. Mayo scores showed similar trends. The researchers concluded that the differences may be a reflection of

disparities in timely access to specialty care and treatment.

Additionally, the Ulcerative Colitis Narrative Global Survey⁶⁻⁸ assessed aspects of living with UC and identified healthcare disparities, social determinants of health, and emotional impacts related to UC disease management, patient experience, and quality of life. Survey findings noted that there were substantial differences in disease management and healthcare experience among various patient demographics and psychological comorbidities. Specifically, low-income patients were less likely to have participated in a peer mentoring or UC education program, patients who were unemployed were less likely to report “good” or “excellent” health, patients with lower education levels were less likely to contact patient associations or organizations, and patients younger than 50 years were less likely to have an office visit at an IBD center or clinic in the past 12 months.⁸ Patient-reported survey results corroborated these findings.⁶

Premier partnered with Henry Ford Health, Henry Ford Innovations, and Lilly to obtain learnings and insights from providers to better understand the socioeconomic drivers of health disparities for patients with UC. These findings will help us better understand the social, physical, economic, and political contexts that influence poor health outcomes. Results from this study will be used to develop a broader stakeholder analysis and stakeholder engagement model. From there, culturally sensitive public health interventions centered on improving health in minority and marginalized populations can be created.



Project Objectives

Interviews were conducted with six clinical staff members, comprising two gastroenterologists, one internal medicine specialist, two nurse coordinators, and one infusion nurse who care for patients with UC at Henry Ford Health, a large, ethnically diverse safety-net hospital. Interview questions addressed the following areas:

- Patient access to care and treatment
- Resources and programs available to patients
- Health literacy and communication
- Healthcare providers’ role in addressing socioeconomic barriers

Method

Henry Ford Health and Premier developed a structure, approach, and discussion guide for 1-hour individual in-depth interviews (IDIs) with providers who care for patients with UC. The interviews were recorded and transcribed, and project team members also took notes. The medical writer scanned and synthesized text from the IDI transcripts and notes to develop a thematic analysis of concepts and topics. NVivo 12 Plus software (Lumivero, Denver, CO) was used to organize and manage data collection and analysis scans.

Findings

Patient Population Characteristics

Respondents described their patient populations as having a range of characteristics. Of those respondents who work in Detroit, 70-75% of their patients live in the ZIP codes near the hospital. Others stated that about 60% of their patients live near their respective hospitals and clinics. Respondents also noted they take care of patients who want a higher level of care for more complex issues or complications, as well as patients receiving tertiary or quaternary care.

The internal medicine specialist manages a small percentage of patients with IBD – a little over 1% of patients. Another respondent estimated that about 30% of their patients have UC. Respondents stated that some patients developed colon cancer or other complications from UC, such as liver disease. In addition, some patients are well managed whereas others

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have uncontrolled disease and poor health habits (smoking, drinking, substance abuse, obesity, poor diet, lack of exercise, etc.).

One respondent described a range of patient socioeconomic characteristics – some patients are very wealthy compared to others; some are on Medicare, whereas others have commercial insurance. About half face socioeconomic barriers. Another respondent noted that according to the Socioeconomic Depravity Index from the US Census Bureau, which measures the level of depravity that people experience, 42% of their patients were in the wealthiest quintile. The respondent said, “...we take fantastic care of people who can physically get to us, and we take fantastic care of patients who can afford the time to come to their doctor’s visits and their colonoscopies and their infusions. But we make it way too hard for people to get to us, and [we’re] making patients drive 2 1/2 hours to come see a doctor for 20 minutes. By making access easier, we [can] take care of a broader, [more] socioeconomically diverse population.” Indeed, after establishing virtual and specialty clinics to reach a broader and more socioeconomically diverse patient population, the quintile percentage dropped to 32%.

Patient Journey

Some patients get a diagnosis in the emergency department (ED) due to a symptom flare and are given oral steroids. Other patients receive their UC diagnosis incidentally as part of a colonoscopy and may have mild disease. Still others have chronic symptoms that lead to referral to a specialist who diagnoses them. There may be outside referrals for second or third opinions, or patients may have referrals from the ED. Patients may also have co-morbid conditions along with UC, which may make their cases more complex.

Patients may be managed in primary care if their disease is mild and well-controlled, whereas those who develop complications or more advanced disease will likely progress to specialist care. Management in primary care often involves managing some medications and encouraging patients to get routine and follow-up testing, such as colonoscopies. It was noted that primary care providers may not have established relationships with gastroenterology specialists and may not possess the same depth of knowledge a specialist has, which may make them less comfortable managing patients receiving certain medications or those with advanced disease.

Finally, respondents said that some populations of doctors may not be up to date on the newest research in IBD, or they may not have much experience with patients with IBD, which may lead to treatment recommendations that do not align with best practice or to hesitancy to treat.

Preventive Care

When asked about early detection and preventive measures, respondents stated that often, they see patients after a diagnosis or symptom flare or when patients

have severe disease; therefore, the focus may be more on cancer prevention, symptom monitoring, and catching flares early. Several respondents pointed out that

Preventive care is difficult given the long wait times to see doctors for screenings and patient reluctance or difficulty in seeking and accessing healthcare in general.

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Patient Awareness of Clinical Trials

Several respondents said that patients may find out about clinical trials from their healthcare providers. In addition, study principal investigators may contact other doctors, potentially in places that have few specialists, to alert them to trials, and they may also use community outreach. Patients may also be referred to trials if they cannot afford treatment or if their insurance will not approve the recommended treatment.

Although clinical trials may provide more treatment options for patients and may increase understanding of treatment

effectiveness in various populations (given the expanded awareness and need for more patient population diversity in studies), they require significant time commitments. Some patients may not be able to participate due to the inflexibility of their jobs, such as those who work at manual labor jobs, unlike those who work remotely. In addition, there are stigmas and myths associated with clinical trials. One respondent described patients' concern with being "experimented" on and with providers "making money off them," which demonstrates that patients need to be reassured that these are Phase III trials and that safety of therapy has been established.

Definitions of Inequity and Disparity

Respondents offered a range of descriptions of inequity (systematic differences in health outcomes of different population groups that have significant social and economic costs to individuals and societies⁹) and disparity (differences in health status that are linked to social determinants of health¹⁰). Several described them as differences in outcomes



in patients with lower socio-economic status, those in underserved populations, and those who may not be able to use or access technology. Others described inequity and disparity as receiving a lower quality of care and difficulty accessing care due to issues such as transportation, cost, and wait times to see doctors. One respondent defined health inequity and disparity as “anything that gets in the way of a patient being able to receive evidence-based standard care.” Another pointed out that inequity and disparity can stem from medical school training, which often teaches care based on northern European populations and may not include other races and ethnicities.

Influence of Socioeconomic Status on Outcomes

Because patients experiencing lower socioeconomic status may have difficulty accessing and affording care, managing their conditions, and trying new therapies, their health issues may worsen, and as one respondent stated, “Ongoing inflammation is harder to control the longer it has gone on.” This may be further influenced by therapy that is interrupted or inconsistent, resulting in flares and hospitalizations. Several respondents also described issues with insurance, stating that approvals may only be for ineffective therapies – “they make you trial and fail things that waste time.” Time commitment away from work and out-of-pocket costs for patients may also affect outcomes because without a flexible schedule and funds for co-pays, patients can’t get the infusion treatments they need, and they may be further stressed and inconvenienced with “jumping through hoops” to fill out paperwork or apply for financial assistance, which may also contribute to treatment delay.

Barriers

Respondents described a range of barriers that patients face in accessing care. All respondents said that financial issues,



including insurance coverage and out-of-pocket costs for expensive medications, testing, and

hospitalization, were the biggest barriers. One respondent said they were “constantly fighting” with the appeals after insurance denials and that it was a daily struggle. Even for patients who have insurance, the treatments they can receive depend on their insurance, and they may not have funds for co-pays, which means, as mentioned above, they can’t follow through on treatment plans. Further, some patients can’t hold a job due to These scenarios occur whether the patient has commercial insurance or Medicare, as there are high co-pays with Medicare, and even if Medicare approves a therapy, that doesn’t mean the patient can afford the co-pay. One respondent pointed out that providers may not be considering affordability of therapy when they recommend a treatment, as they may not be aware of the costs.

All respondents also mentioned

All respondents also mentioned health literacy and a lack of understanding of the chronic nature of the disease as major barriers.



health literacy and a lack of understanding of the chronic nature of the disease as major barriers. Several respondents noted that it can be difficult to explain complex medical information and the negative consequences of not receiving timely or consistent treatment to their patients due to patients’

varying levels of health literacy. None of the respondents had any formal means of assessing the health literacy of their patients. Some did state that more experienced providers can “read” a patient to determine their understanding of content and adjust the conversation accordingly.

Other barriers that respondents described include:

Behavioral-mental health issues	Patients with UC often have depression, anxiety, chronic stress, or post-traumatic stress disorder. One respondent said that although there is a large behavioral health department, it cannot meet the needs of all patients, especially long term.
Food insecurity	One respondent said that patients often have trouble accessing and affording good quality, healthy food.
Lack of resources that providers can offer	One respondent said that not every clinic has embedded resources like psychologists and case managers or coordinators, and that there may be few, if any, outside resources in local areas.
Patients lost to follow-up or no-shows	Patients with active disease may not be consistent with therapy or follow-up, and they may develop complications. Respondents described situations in which patients may go to the ED with a flare, are hospitalized, put on steroids and discharged, but have no follow-up after that. Several respondents mentioned having an increased number of no-shows in this population. None of the respondents had a clear or formal process at their sites to follow up with patients to determine why they did not come in. One respondent surmised that no-shows may be due to financial issues or transportation or to weariness dealing with treatments. Regardless of the reason for no-show, respondents said there is only so much time that can be given to trying to contact these patients if they don’t respond to messages or show up for appointments or infusion sessions.
Patient anxiety	Patients may be hesitant to start a new treatment and may be more comfortable with what they are used to, like prednisone, even though it has risks when used long term. Several respondents described patients’ concerns about having a chronic illness, the side effects of biologic therapies, and their previous negative experience at the hospital.
Patient hesitancy, refusal, or non-compliance	Respondents stated that many patients don’t trust doctors, nurses, and the health system in general, and they have personal beliefs about the effectiveness of therapies. Patients may also avoid dealing with paperwork that may be needed for prior authorization or financial or other resource assistance.



Patient lifestyle	One respondent noted that some patients have a poor diet, do not exercise, or may have substance abuse issues, which may affect their health outcomes and their ability to manage their condition.
Rural access limitations	Several respondents noted that patients in rural areas have less access to specialists and must drive longer distances to access healthcare.
Short-term vs long-term needs	Respondents said that while sites may have resources for patients in the short-term, they may not be available for long-term needs that chronic illness often entails. Using counseling or financial support as examples, sites may only be able to provide a limited number of sessions or a limited amount of financial aid for patients.
Social support	Many patients are caregivers themselves, and the added stress of managing their own health and coordinating their own care alongside their care giving duties may present issues in care access.
Technology	One respondent stated that technology can be a barrier for 20-30% of the population. Indeed, 28% of people in urban areas do not have access to broadband, while 38% may not have access in rural areas. In addition, patients be hesitant or uncomfortable using health portals, and may not have access to a printer to print forms or information at home.
Transportation	Patients may not be able to take off work for an entire day for an infusion session or testing, and not every clinic has a program to address access or costs of transport.
Wait time causing diagnosis or treatment delay	Wait time for procedures may be weeks to months due to the difficulty in getting appointments with IBD specialists.

Communicating With Patients

Several respondents stated that assessing health literacy can be complicated and can backfire because clinicians need to be able to “read” patients. The wide variety of patients seen inhibits any sort of generalization, although respondents acknowledged the need to address health literacy because it is a significant barrier for patients’ ability to adhere to care plans. Because there is no standard method used

to assess health literacy, at best, providers will ask if patients have heard of the disease or treatments for it, will ask if patients have questions (the questions themselves give a sense of what has been understood), and will key in on the need for further conversation and education if patients do not have questions after they’ve been given a lot of information. Several respondents specifically described patients’ lack of understanding about their disease and its treatment. Examples they gave included not



knowing that prednisone has long-term risks, not understanding the need for ongoing treatment management, or that UC is not temporary or curable.

Several respondents also acknowledged the issue of information overwhelm for patients, especially at diagnosis, and that there is variation in what, if any, information or education patients receive at various clinics. One respondent said that patients may need multiple appointments or phone calls to go over information to fully understand it. Compounding overwhelm is the lack of sufficient time during a patient visit, which makes it difficult to ensure information is thoroughly explained. One respondent said that health systems and hospitals may require physicians to see patients in a shorter time interval than is appropriate to cover all the needed elements and verify patient understanding of them.

Respondents also described several ways in which communication can be enhanced. One was the use of patient advocates. While not all patients may have access to someone they know and trust, advocates can help convey information, and even document information for the patient, especially if the patient is overwhelmed, upset, or scared about their diagnosis or the treatments they may initiate. Communication between providers may also enhance communication with patients. Discussion among nurses and physicians at monthly meetings can address recurring issues in how best to convey information to patients. Nurses can also follow up with patients and answer questions that may occur after a visit. Indeed, patients may feel more comfortable talking to a nurse or medical assistant than to a doctor, and the nurse may be able to explain things in a way the patient may better understand than they did during their doctor’s visit.

Current Resources and Programs

In addition to the barriers and challenges respondents described in the interviews, they also described current resources and programs available in various clinic settings in an effort to address them:

<p>Embedded staff</p>	<p>Several clinics have embedded roles to help with various tasks and encourage staff to practice to the top of their licenses.</p> <ul style="list-style-type: none"> • Case managers often help with transitions from inpatient to outpatient care. • Community health workers primarily work with patients with diabetes, but there can be overlap with other co-morbid conditions like IBD. • Health psychologists with a GI focus are funded by a donor grant and help patients address anxiety, depression, and stigma they may feel about their mental health issues or about dealing with digestive diseases. • Nurse coordinators or navigators “wear a lot of hats” and provide social work, care coordination, and prior authorization support, and they help get patients where they need to be, follow up with patients, answer questions, provide education, and provide co-pay assistance. • Nurses and medical assistants are trained to do the rooming process and medication reconciliation.
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Financial help	Respondents described ways in which their sites try to address financial issues with healthcare that patients may face. These include providing free drugs, helping patients sign up for co-pay assistance programs, and using an emergency patient needs fund.
Pharmacy	Some sites have a specialty pharmacy and embedded pharmacists. Patients may also be able to use the pharmacy advantage financial program.
Specialty clinics	One respondent described a project to develop specialty centers in rural communities and in areas that do not have providers with experience in IBD/UC. The goal is to fill in gaps at clinics that refer a lot of patients for UC. Space is rented at these clinics, medical assistants are cross trained, and they can conduct hybrid video visits in person with a patient and with an off-site specialist. The respondent noted that this helped lower the rate of hospital visits for flares or other complications as well as expand access to more patients at these sites.
Patient education	Several respondents said they often provided patient education materials from the Crohn’s and Colitis Foundation, and that a patient education committee reviewed materials for reading level appropriateness. They also said that these materials can be given to the patient at a visit or can be emailed or mailed to the patient.
Transportation	One respondent noted that they had researched transportation options and found services that were covered by insurance.
Technology availability	Although not all patients have the technology or comfort to participate in video visits, for those who want it, telehealth continues to be an option.

Opportunities

Respondents described various areas of opportunity to improve care in diverse populations. One area to address is additional training for providers to help improve their skills in managing patients struggling with inequities and disparities. Several stated that social determinants of health (SDoH) and conscious bias affect patient care, and that clinicians may need more training in these areas if it was not addressed in medical school. It was also suggested that improving primary care provider knowledge of IBD may help them better manage and coordinate ongoing care with specialists. Several said that communication skills need improvement – specifically, learning to listen so patients feel heard and engaging patients in shared decision-making. Others suggested a need for better understanding of insurance issues and timing of therapies for optimal effectiveness.

Health literacy can be addressed by providing more education for patients on their disease and treatment options, as well as on the ongoing need for treatment and management. Staff may

need more training in health literacy assessment as well as in the use of visual aids, tools, and apps to help convey clear, understandable information about disease management to ensure patients understand the chronic nature of UC as well as the importance of treatment adherence and regular follow-up with their healthcare providers. One respondent thought that education could be provided in the infusion clinic, given that patients will be there for an extended period of time during an infusion session, which makes it an opportune time to provide information and perhaps even answer questions.

Other opportunities for improving patient care include expanding patient diversity in clinical trials, improving insurance coverage for therapies, expanding transportation options, providing more convenient access to clinics, providing additional resources in clinics (such as social workers, mental health specialists, and insurance specialists), providing options for patient contact with providers and coordinators outside of patient visits, and encouraging the use of patient advocates when available.

A summary of barriers and challenges, current resources, and opportunities is in the table below.

Barrier or Challenge	Current Resources and Programs	Opportunities for Improvement
Costs	Co-pay assistance programs, emergency needs fund, care coordinators	Improving insurance coverage, easier prior authorization processes
Health literacy	Nurses, pharmacists; education materials from Crohn’s and Colitis Foundation	Additional training for providers, developing assessment tools and learning aids
Behavioral-mental health issues	Health psychologists with GI focus	Using assessment tools to determine if referral to health psychology is needed
Food insecurity		Investigating community resources and developing a list with links that providers can access
Lack of resources that providers can offer	Case managers, care coordinators	Investigating community resources and developing a list with links that providers can access
Patients lost to follow-up or no-shows	Care coordinators	Setting up follow-up appointments during the patient visit

Barrier or Challenge	Current Resources and Programs	Opportunities for Improvement
Patient anxiety	Health psychologists with GI focus	Additional training for providers, developing assessment tools and learning aids
Patient hesitancy, refusal, or non-compliance		Additional training for providers, developing assessment tools and learning aids
Patient lifestyle		Referrals to dietitians, links to exercise options (e.g., basic exercise routines on YouTube, walking recommendations)
Rural access limitations	Specialty clinics set up within clinics that often refer patients with UC; telehealth options for patients who want to use it	Technology training for patients who are not comfortable with it to enable remote visits
Short-term vs long-term needs		Additional training for primary care providers
Social support		Using assessment tools to determine if referrals are needed
Technology	Telehealth options for patients who want to use it	Technology training for patients who are not comfortable with it to enable remote visits
Transportation	Some local options covered by insurance	Investigating community resources and developing a list with links that providers can access
Wait time	Specialty clinics set up within clinics that often refer patients with UC	Alert primary care providers to specialty clinics for referral; reserve time slots in specialist schedules for new referral patients

Conclusions

Ulcerative colitis is a chronic condition that can lead to severe complications, so it is important for patients with UC to receive timely diagnosis and treatment. Yet many

patients face barriers to adequate care, including costs for testing and treatment, access and comfort with technology for online care and communication,

difficulty arranging time away from family, work, and other obligations to get to care appointments, difficulty obtaining transportation to get to care appointments, lack of access to specialty providers in rural areas, and health literacy issues that affect understanding of the disease and the care needed to manage it, which in turn may cause overwhelm, anxiety, and hesitancy or non-compliance with disease management recommendations.

Henry Ford Health has established resources to address some of these issues, such as embedding health psychologists and pharmacists in clinics, setting up specialty clinics in areas with high referral rates for UC, helping patients manage costs with co-pay assistance and other financial programs, and enabling nurses and care coordinators to provide patient education, assistance with financial applications, and follow-up communication. There are opportunities to continue to improve care for these patients, including additional training for providers regarding social determinants of health, health literacy assessment tools, community outreach and partnerships to expand and develop patient resources, expanded transportation options and more convenient

access to clinics, expanded insurance coverage for diagnosis and treatment, and improved diversity in clinical trials for new therapies that more effectively treat UC. In addition, we recognize that acting on the barriers presented in this study requires engaging more stakeholders, including patients with UC as well as community leaders and other patient advocates who shape UC care, to help cultivate a network that develops effective and sustainable interventions, programs, and resources. Working together to address these opportunities and to address inequity and disparity barriers will enable healthcare providers, policy makers, and other stakeholders to improve patients' access to care and their health outcomes and quality of life.

Abbreviations

UC – ulcerative colitis
 IBD – inflammatory bowel disease
 IDI – individual in-depth interviews
 ED – emergency department
 SDoH – social determinants of health

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