The Effect of Socioeconomic Barriers on Health Outcomes in Patients with Inflammatory Bowel Disease

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I was diagnosed with Ulcerative Colitis (UC), a chronic condition characterized by inflammation of the large intestine and rectum, in 2019. Seven months after my initial diagnosis, I was approved for infusions of Entyvio, a medication commonly used to treat UC and Crohn's Disease. However, before I entered remission on this treatment, I was prescribed many different oral and rectal medicines, including a different biologic medication. As none of the therapeutics effectively mitigated my symptoms, I was hospitalized a few times, requiring multiple blood transfusions. Infusions of the drug cost the insurance company \$38,000 per dose. I am extremely fortunate to have my medical expenses covered by my insurance plan, which I have access to through my father's employer. Receiving infusions of Entyvio required me to be absent from high school frequently and took up a lot of time. I was lucky, however, that as a student, I could afford to take as many excused absences as necessary. My parents had to take off from work frequently to take me to and from appointments. I was especially fortunate to have retired grandparents nearby who could often drive me to and from my doctor's visits and infusion appointments to help share the responsibility with my parents.

Keywords

Inflammatory Bowel Disease • Ulcerative Colitis • Crohn's Disease • Social Determinants of Health • social barrier score • healthcare access • patient health outcomes

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Abstract- Patients who experience more severe symptoms of Ulcerative Colitis are associated with having greater socioeconomic challenges or higher social barrier scores (SBS).

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Inflammatory Bowel Disease describes two conditions, Ulcerative Colitis and Crohn's Disease, characterized by gastrointestinal (GI) tract inflammation. Ulcerative Colitis is a type of Inflammatory Bowel Disease (IBD) characterized by large intestine inflammation. Research has shown that multiple social determinants of health (SDOH) hinder achieving desirable health outcomes in the Inflammatory Bowel Disease community. These include financial strains, poor health literacy, and lack of access to education. Additionally, social barriers disproportionately affect non-Hispanic Black and Hispanic people.

- **Background** Social determinants of health are environmental conditions that influence health outcomes. Such factors include access to education, access to healthcare, neighborhood and housing, socioeconomic background, and one's social network. In data collected from IBD patients, 56.2% of Hispanic Patients experience financial strain, 40% of non-Hispanic Black patients, and 24.85% of non-Hispanic Whites. The cost of out-ofpocket care for IBD patients is three times greater than that of non-IBD patients. IBD patients also have higher costs due to the time required to receive treatment. These costs are estimated to be \$26,555. Social determinants of health (such as financial strains, poor health literacy, and lack of access to education) make it more difficult for IBD patients, especially non-white patients, to receive health care. Therefore, their symptoms are more severe because patients cannot receive treatment for their illnesses. IBD is costly, in both time and money, to have and treat. Socioeconomically challenged people are further disadvantaged because IBD treatment is expensive even with high-quality insurance. Additionally, having the disease can require patients to be absent from work, which serves as an extra financial barrier. Lack of medical literacy and education makes it more difficult to advocate for medical treatment. It makes it more difficult to contact doctors, advocate for one's needs, and fill out paperwork.
- **Assessment** Social determinants of health (such as financial strains, poor health literacy, and lack of access to education) make it more difficult for IBD patients, especially non-white patients, to receive health care. "The annual aggregate economic burden of CD in the United States was 6.3 billion (USD) in 2013"(Quiros et al., 2021, p.1).
- **Recommendation** To correct the problem, I propose that the government should grant additional sick leave to people with qualifying chronic illnesses and disabilities. This would effectively reduce the additional costs in time and money that patients with chronic illnesses including IBD incur in order to receive effective treatment and withstand the physical burden of illnesses. Additionally, the state of Michigan should create a universal financial assistance program (FAP) to cover healthcare costs for people who have remaining expenses that are not covered by their current insurance plans. This program would improve the quality of healthcare insurance to which patients with chronic illnesses, including IBD, have access to.

Navigating the healthcare system put my experience into perspective; my family relied on our privileges to absorb the burden of my Ulcerative Colitis. Because of this, I realized the role that socioeconomic factors play in mitigating the financial and temporal costs required to receive treatment for Ulcerative Colitis.

Through learning about the social determinants of health, I have learned that many factors influence health outcomes. In particular, financial strain, poor health literacy, and lack of access to education serve as barriers to minimizing the severity of disease symptoms and achieving remission for people with Inflammatory Bowel Disease (Damas et al., 2022).

Patients who experience more serious symptoms of Ulcerative Colitis are more likely to have higher social barrier scores or values that indicate socioeconomic disadvantages (Damas et al., 2022). These challenges include financial strains, poor health literacy, and lack of access to education. Social barriers disproportionately affect non-Hispanic Black and Hispanic people (Damas et al., 2022). A 2018 study found that socioeconomic status (SES) is associated with poor outcomes for patients with IBD, defined as any Crohn's Disease (CD)-related hospitalization (Anyane-Yeboa et al, 2022). SES is a greater predictor of poor health outcomes than race. "IBD literature also illustrates that those with worse outcomes across the IBD care continuum are more frequently Black/African-American patients" (Nguyen et al., 2020).

Background

Inflammatory Bowel Disease (IBD) describes two conditions, Ulcerative Colitis and Crohn's Disease (CD), characterized by inflammation of the GI tract. In both illnesses, one's immune system attacks the body, resulting in inflammation (Centers for Disease Control and Prevention, n.d.). "A flare is a period of time when symptoms and inflammation from ulcerative colitis or Crohn's disease become active" (*Causes of Flares*, n.d.). In Ulcerative Colitis, inflammation is concentrated in the large intestine and rectum. In Crohn's Disease, inflammation occurs in the gastrointestinal (GI) lining. Common GI-related symptoms include diarrhea, blood in the stool, rectal bleeding, feeling of urgency when moving bowels, abdominal pain, and constipation (*Signs and Symptoms of Crohn's Disease, n.d.*). This can result in weight loss, loss of appetite, fatigue, malnutrition, and anemia (*Signs and Symptoms of Crohn's Disease, n.d.*). Other symptoms of IBD include changes or loss in vision, swollen joints or joint pain, nocturnal sweating, osteoporosis, loss of a normal menstrual cycle, kidney stones, fever, rashes, and skin complications (*Signs and Symptoms of Crohn's Disease*, n.d.).

Common treatments for IBD include 5-aminosalicylic acids, an anti-inflammatory medication often administered rectally, immunomodulators or medications that act over a long time to calm the immune system, or corticosteroids– faster, acting anti-inflammatory drugs. Biologic medications are frequently used, sometimes in combination with other medications, to treat the condition. These drugs are often given by infusion and turn off the inflammatory immune system response to certain proteins (*Understanding Biologics and Inflammatory Bowel Disease*, n.d.). The most common type of biologic medication prescribed to treat IBD is called Tumor Necrosis factor-alpha (TNF-alpha blockers), which block a protein that causes inflammation in the GI tract (*Understanding Biologics and Inflammatory Bowel Disease*, n.d.). "Even with proper medication and diet, as many as two-thirds to three-quarters of people with Crohn's disease will require surgery at some point during their lives" (*Crohn's Disease Treatment Options*, n.d.). After 30 years of having the disease, up to 30% of people with Ulcerative Colitis will require surgery (*What Is Ulcerative Colitis?*, n.d.).

Social determinants of health are environmental conditions that influence health outcomes, including where individuals live, work, and play. These factors include access to education, access to healthcare, neighborhood and housing, socioeconomic background, and one's social network. Social barriers influence Inflammatory Bowel Disease (IBD) outcomes and disproportionately affect Hispanics and non-Hispanic Blacks with IBD. Data collected from IBD patients in the United States demonstrate that 56.2% of Hispanic patients experience financial strain, 40% of non-Hispanic Black patients do so, and 24.85% of non-Hispanic Whites do so (Damas et al., 2022). Low socio-economic status (SES) is associated with worse healthcare outcomes, specifically greater morbidity and increased healthcare resource utilization in patients with IBD (Gu et al., 2022).

Social factors that determine health outcomes, such as financial strain, poor health literacy, and lack of access to education, make it more difficult for IBD patients, especially non-white patients, to receive health care. As a result, IBD patients in this racial group experience "higher hospitalization rates, longer stays, increased hospitalization costs, higher readmission rates, and more complications after IBD surgery" (Anyane-Yeboa et al, 2022, p.2429). Additionally, Black and Hispanic IBD patients had longer hospital stays than their white peers.

The direct annual cost of care for IBD patients (\$22,987) is three times greater than those without the condition (\$6956) (Park et al., 2019). Also, people with IBD face twice the annual out-of-pocket costs compared with a control group (Park et al., 2019). The costs are estimated to be \$26,555 on average in the first year (Park et al., 2019). IBD patients face additional financial challenges compared to non-IBD patients in the same socioeconomic class because the costs of treatment for the disease serve as an additional financial burden. Access to specialized care is also unequal—Black/African-American patients were found to be less likely to undergo annual visits to a gastroenterologist or IBD specialist" (Anyane-Yeboa et al, 2022). Lack of access to specialized care symptoms.

Patients with IBD pay significant costs in time to receive proper health care compared to patients without IBD (Park et al., 2019). Spending time to receive proper treatment can require patients to take time off from their jobs. "IBD patients are increasingly incurring higher costs associated with workplace productivity losses" (Park et al., 2019). Being absent from work means that IBD patients earn less money. "Patients with IBD also absorbed significantly higher wage-related opportunity loss" (Park et al., 2019). The amount of wages IBD patients lost due to missing work to receive treatment was an even more significant value than the average out-of-pocket monetary costs (Park et al., 2019). A lack of medical literacy makes navigating the healthcare system more difficult, specifically filling out paperwork (Damas et al., 2022). One study says that 22.22% of patients with IBD "did not feel comfortable completing medical forms" (Damas et al., 2022). This trend was the most prominent among Hispanics and non-Hispanic Blacks. 27.48% of Hispanics, 50% of non-Hispanic Blacks, and 15.57% of non-Hispanic Whites reported feeling uncomfortable completing medical forms (Damas et al., 2022). Also, "Higher patient education correlates with a reduction in health care costs" (Click et al., 2016). Access to education improves health outcomes in patients with IBD by improving their ability to receive proper treatment, lowering their costs overall.

Assessment

Social determinants of health, particularly financial strains in tandem with the cost of time and money required to receive treatment, make it difficult for IBD patients to attain proper health care, leading to poorer disease outcomes. This is especially true for Black and Hispanic patients, who are disproportionately socio-economically disadvantaged, and as a result, this group experiences worse health outcomes. IBD is a costly condition, in both time and money, to have and treat. Of adults with IBD, 23% face financial challenges due to medical bills (Nguyen et al., 2020). Socioeconomically challenged people are further disadvantaged because IBD treatment is expensive, even with high-quality insurance. "The annual aggregate economic burden of CD in the United States was 6.3 billion (USD) in 2013" (Quiros et al., 2021, p.1).

For economically disadvantaged people, it is even harder to receive IBD care because of the cost. Results from the National Health Interview Survey in 2015 talk about cost-related nonadherence (CRN) in patients with IBD, when patients delay medical treatment to reduce costs (Nguyen et al., 2020). According to this research, "16% of patients reported CRN, and 31% reported cost-reducing behaviors" (Nguyen et al., 2020). Due to its exorbitant cost, many IBD patients fail to maximize their treatment options because they cannot afford to do so. The inability to utilize proper medical interventions can lead to worse health outcomes characterized by more intense symptoms of IBD. Severe flares of IBD can cause patients to be hospitalized and increase their length of stay. Those who face financial challenges lack access to treatment, resulting in more prevalent symptoms and increased hospitalizations. Hispanic and non-Hispanic Black people experience disproportionately socio-economic challenges, which explains why these racial groups encounter worse health outcomes.

The time required to receive proper care for IBD is another reason IBD patients delay treatment, which inevitably leads to worse health outcomes. "We also found that 29.07% of patients reported delaying medical care in the last 12 months. The most common cause of medical care delay was waiting long hours to see the doctor (15.9%)" (Damas et al., 2022). Those with less flexible jobs are more unable to take time off work for being sick and to receive treatment, and therefore avoid or postpone treatment, leading to worse disease outcomes. Socioeconomically disadvantaged people are more likely to have blue-collar occupations, which prevents them from being able to take time off to receive care and therefore leads to more prevalent diseases in this population. Another economic barrier that many IBD patients from underprivileged backgrounds face is a lack of access to high-quality health care, if they have access to health care at all. Research on IBD patients suggests that "10% of patients deemed health care unaffordable" (Nguyen et al., 2020). One experiment sought to measure the effectiveness of increasing healthcare access by implementing a financial assistance program (FAP), to yield better disease outcomes in patients with IBD requiring treatment in the form of Biologic medications (Gu et al., 2022). The FAP increased patient access to biologics by discounting costs and eliminating steps like pre-authorization by insurance (Gu et al., 2022). The researchers concluded that the FAP positively impacted the healthcare of patients with IBD (Gu et al., 2022). Therefore, it is more evident that lack of quality insurance impedes patients' ability to obtain the proper treatment, which can cause worse disease outcomes. Financially disadvantaged people struggle to attain high-quality insurance. Therefore, they are more likely to experience more prevalent diseases resulting from a lack of access to treatment, like biological therapies.

Recommendations

A possible short-term solution is to create a universal state-wide financial assistance program (FAP) in Michigan to cover healthcare costs for people who have remaining expenses that are not covered by their current insurance plans. This would include but not be limited to patients with IBD expense of healthcare costs for IBD patients without health insurance or high-quality health insurance. The program would cover the costs of treatment and reduce out-of-pocket patient costs for patients with IBD and other chronic illnesses. The service would cover the finances of any healthcare-related costs for the enrollees. This coverage would include but not be limited to hospitalizations, medications, blood transfusions, surgeries, procedures, and medical imaging. Additionally, it would decrease the time required to receive treatment by eliminating steps required

to obtain traditional healthcare insurance like pre-authorization. The FAP would improve disease outcomes amongst socioeconomically disadvantaged patients, eliminating the typical time and money needed to receive treatment. This would allow patients to receive the proper treatment more quickly, decreasing the prevalence of their symptoms more rapidly. Increases on income taxes would be used to generate revenue tax credits, which would make up the revenue base for the program. The level of tax hike needed to fund this program would be relatively minimal.

There has been some emerging evidence to suggest that patients receiving virtual health care, compared to standard in-person care, have reported greater Quality of Life (QoL) and IBD-related knowledge (Kuzhiyanjal et al., 2023). However, study results show that health outcomes between the two groups are about the same (Kuzhiyanjal et al., 2023). Telemedicine is a more convenient method for patients to receive medical treatment (Kuzhiyanjal et al., 2023). It improves the efficiency of healthcare delivery and has decreased the cost of care (Kuzhiyanjal et al., 2023). Greater use of telehealth could increase access to care for IBD patients facing financial strain and improve the medical literacy of this population.

A long-term solution is to expand employment benefits for patients with disabilities and chronic illnesses including IBD to limit the expenses in both time and money that come with the disease. A proposed recommendation is automatically granting additional sick leave to patients with chronic illnesses every year, to compensate for the missed work needed to receive healthcare or the physical burden of IBD. The Department of Labor would establish criteria to qualify for benefits. Employees apply by submitting official medical documentation as proof of having a qualifying illness or disability. One method of accomplishing this goal is for Congress to pass a mandate financed by employers, requiring them to provide their employees extra time off every year without additional consequences. Employees would have to apply to be granted the extra time off by the federal government. In order to receive the additional benefit they would need to provide official medical documentation that demonstrate satisfaction of the criteria.

Conclusion

Social barriers, primarily financial strain, poor health literacy, and lack of access to education, prevent IBD patients from obtaining better health outcomes. Patients from low-income backgrounds, who are disproportionately non-Hispanic Black and Hispanic, experience more severe IBD disease symptoms. Lack of access to care among this patient population has led to worse outcomes and more severe disease. The exorbitant cost of medical treatments for IBD and the time required to receive proper treatment are the two most significant factors that limit IBD patients with low socio-economic status from accessing care.

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