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Inflammatory Bowel Disease: The Bellevue Experience



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Bellevue Hospital Center (Bellevue) treats a large, diverse and indigent patient population and has recently expanded its scope to support a growing group of patients with inflammatory bowel disease (IBD). Here, we discuss some of the triumphs and challenges of the Bellevue IBD Clinic and review the tools we utilize to improve access to critical resources for this patient cohort.

INTRODUCTION

Bellevue Hospital Center (Bellevue), the oldest public hospital in the United States, was founded in 1736 as a six-bed infirmary utilized to quarantine ill patients. In 1811, the hospital moved to its current location on Manhattan's east side, when New York City (NYC) purchased the Kips Bay farm and began construction of an almshouse (the "Bellevue Establishment"), consisting of two pavilions for men and women, respectively.¹ Bellevue has been known as

an institution willing to serve the poor and underserved since its creation.² Currently, Bellevue is a level 1 trauma tertiary care teaching hospital in New York City's Manhattan borough, serving as a major referral center for complex medical cases citywide.^{1,2} It serves as the flagship for the NYC Health and Hospitals Corporation (HHC), which is the largest public healthcare delivery system in the United States, overseeing 11 acute care hospitals.³ Bellevue has been affiliated with NYU School of Medicine since 1847.

Bellevue's mission is to "provide the highest quality of care to New York's neediest populations and to deliver health care to every patient with dignity, cultural sensitivity and compassion, regardless of ability to pay".² There are 828 beds in operation with nearly 528,000 clinic visits, 125,000 emergency room

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visits, and approximately 32,000 inpatient discharges annually.¹ According to New York State healthcare center cost records from 2010, HHC hospitals provided the highest proportion of care to uninsured, self-paying patients.²

Bellevue's patient population resides mainly in the following communities: Southern Manhattan, Northern Brooklyn, and Western Queens. The Bellevue patient population differs from that of NYC as a whole. In NYC, 63.4% of individuals are younger than age 65, while 67.1% of Bellevue's patients are younger than age 65. The racial background of Bellevue's patients are as follows: 40% White, 38.1% Hispanic, 21.9% Black, 15.4% Asian, and 22.5% other.^{2,4} In addition, poverty rates of families cared for at Bellevue, especially those with children, are significantly higher than those of NYC overall. At Bellevue, 22% of families and 31% of families with children live below the federal poverty guideline. In NYC overall, these numbers are 16.7% and 24.4%, respectively.^{2,4,5}

Prior to implementation of the Affordable Care Act, 45% of Bellevue outpatient visits were covered through Medicaid and 31% of Bellevue outpatient visits were self-pay. This degree of poverty goes hand in hand with the difficult social circumstances facing this patient population and adds to the complexity of providing care to these individuals. In addition to facing high poverty rates, the population served by Bellevue consists of individuals with lower education levels than patients of surrounding city hospitals.

Bellevue has long offered a Gastroenterology Clinic for patients who are in need of screening, diagnostic, and/or treatment services in the area of digestive diseases. More recently, due to a growing number of patients presenting with suspected or diagnosed inflammatory bowel disease (IBD) along with the complex nature of IBD treatment, Bellevue implemented an Inflammatory Bowel Disease Clinic, specifically to serve patients with Crohn's disease and ulcerative colitis.

IBD Epidemiology

IBD is a chronic, relapsing and remitting intestinal condition with increasing incidence worldwide. Currently, ulcerative colitis has an incidence of 2.2-19.2 cases per 100,000 person-years and Crohn's disease has an incidence of 3.1-20.2 cases per 100,000 person-years.⁶ It is a disease of the developed world and typically affects those originating from Northern Europe and North America. The incidence and prevalence of

1. System Factors

- A. Complex to navigate
- B. Long wait times for appointments
- C. Limited dedicated support staff
- D. Difficulty with coordination of care

2. Patient Factors

- A. Language barriers
- B. Cultural barriers
- C. Poor health literacy
- D. Lack of compliance
- E. Lack of insurance

Figure 1. Barriers to Care: IBD at Bellevue

IBD appears to be lower in Asia, the Middle East, and Central and South America, likely reflecting both genetic and environmental differences between these patient populations. While the incidence of IBD has plateaued in the Western world, areas previously unaffected by IBD are exhibiting an increase in this disease.^{7,8} Due to the makeup of the Bellevue patient population we are now seeing more individuals presenting with Crohn's disease and ulcerative colitis at our hospital. Few studies have evaluated the IBD phenotype of the more recently affected patient populations; however, there is no clear pattern of age at time of diagnosis, pattern of disease distribution, or severity.^{9,10}

Areas of Disparity in IBD Care

Patients with IBD typically require close surveillance by their care providers for management of symptoms, adjustment of medication regimens, and endoscopic interventions. Moreover, individuals with this disease face unique barriers to accessing medical care that greatly impact their clinical outcomes and prognosis. Studies have shown that race and socioeconomic status weigh heavily in the type of care patients who are suffering from chronic disease states receive.¹¹ Sewell and colleagues performed a systematic review, studying

Patient Assistance Programs (PAPs)	Reduced fee medications provided direct from the pharmaceutical company Available at: www.needymeds.org
Drug Discount Cards	Reduced fees for medications; not to be used in conjunction with drug coverage plan Available at: www.needymeds.org
Osto Group	Ostomy supplies at reduced cost Available at: www.ostogroup.org
Oley Foundation	Providing support for those on parenteral nutrition www.oley.org
Health Well Foundation	Financial assistance with insurance premiums and co-pays, etc. www.healthwellfoundation.org

Table 1. Financial Resources for the Uninsured or Underinsured

the role of socioeconomic status and race and the quality of care delivered to patients with IBD. They specifically focused on differences in utilization of medical and surgical therapies, rates of adherence to therapy, clinical outcomes, access to healthcare, utilization of healthcare, patient’s individual perception and knowledge about IBD, employment rates, and medical insurance status. The authors hypothesized that patients who were non-white and of lower socioeconomic status would receive less effective and lower quality care for their IBD. The majority of studies in this review found that white patients were more likely to be treated with immunomodulators and infliximab when compared with non-white patients, despite the severity of illness being reported as similar.¹¹ The majority of studies also displayed disparities in surgical care among different racial and socioeconomic groups, with minorities and impoverished patients less likely to undergo colectomy

when compared with white, affluent patients.^{11, 12} Medication compliance is a particularly important issue in the management of IBD. This review found that black patients were less likely to adhere to prescribed medications and more likely to discontinue medications if they perceived subjective improvement of symptoms. They also noted that black patients understood less about the nature of their disease.¹¹⁻¹⁵

With the increased incidence of IBD being seen among minority patients, this information is highly relevant to the Bellevue patient population.^{3, 4, 10, 11} Although studies evaluating outpatient utilization of IBD healthcare resources among different races have yielded different results, follow-up rates have been universally and unequivocally low at Bellevue. Patients have been lost to follow-up due to barriers such as difficulty paying for medications, perceived difficulty

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paying for visits, employment and familial obligations, and substance abuse.

Thus, the need for an IBD Clinic at Bellevue was identified not only because of the growing numbers of Bellevue patients presenting with IBD, but also due to potential barriers to care and the complexity of the diagnostic, treatment, and surveillance care required for these individuals.

IBD at Bellevue: The IBD Clinic

In late 2011, Bellevue opened the first clinic within the NYC HHC system dedicated solely to the comprehensive evaluation of patients with IBD. The IBD Clinic includes two physicians who specialize in IBD and engenders a collaborative multidisciplinary approach to the care of this patient population. The IBD Clinic works to coordinate care with all needed physicians and other healthcare professionals from other departments and divisions including: infectious diseases, general and colorectal surgery, rheumatology, endocrinology, radiology, pathology, nutrition, and psychiatry.

In terms of the IBD patient population being seen in the Bellevue system, during an 18-month span between 2012 and 2013, 218 patients were referred through the gastrointestinal clinic system with a diagnosis of Crohn's disease or ulcerative colitis based on the ICD 9 codes 555 and 556. Since its inception, the IBD Clinic patient volume has grown steadily and currently treats 110 patients in an ongoing fashion. Most patients are referred from within the medical clinic system at Bellevue, other HHC hospitals, and by providers outside the institution after providing treatment in an acute care setting. Roughly half of the patients have ulcerative colitis and half have Crohn's disease. Due to economic barriers, delayed diagnosis, and low health literacy, a disproportionately high percentage of our Bellevue patient population is treatment-naïve. The IBD Clinic population consists of approximately 40% Hispanic, 25% Asian, 20% Caucasian, and 15% African/African-American patients. Since the majority of these patients are uninsured or underinsured, it became necessary for the Clinic to pioneer access to medical care that would otherwise be financially prohibitive.

IBD at Bellevue: Addressing Barriers to Care

As part of the specialized care provided by the IBD Clinic at Bellevue, several barriers to care have been

identified and continue to be addressed (Figure 1). Three major factors include significant language barriers, limited support staff for the IBD Clinic, and the patients' inability to pay for medications and other treatment needs.

First, English is not the primary language for a large proportion of the Bellevue population. For non-English speaking patients, coordinating care and gaining a true understanding of IBD and its treatment can be difficult. To help resolve potential language barriers, Bellevue offers a full phone interpretation service as well as in-person interpreters. Despite these services, gaps in communication can still occur and the IBD Clinic is exploring additional options to further address this issue.

Second, the IBD Clinic currently has limited support staff to assist with patient scheduling, phone calls, and paperwork. Moreover, patients may be scheduled for appointments without confirming their availability, resulting in a high no-show rate to the Bellevue clinics, which in turn can generate long wait times to be seen, in some cases greater than 90 days. This issue has been identified and plans are underway to address this need.

Finally, patients with IBD have significant treatment and care needs, both acute and ongoing, but many lack the financial resources to obtain their medications and other treatment services. To assist patients in this area, the IBD Clinic works with several organizations that address the needs of underserved patients.

Financial Resources for Our Patient Population

To assist patients who lack the funds to obtain the needed medications and supplies for the treatment of their IBD, the IBD Clinic has found great benefit in working with external organizations that help underserved patients. These organizations provide assistance ranging from free medications to reduced-cost ostomy supplies to assistance with insurance premiums and co-pays (Table 1).

For example, Needy Meds (www.needy meds.org) is an organization that has been helpful in assisting our underserved patient population with access to select prescription medications. The mission of the organization is stated as follows:

“to be the best source of accurate, comprehensive and up-to-date information on programs that help people facing problems paying for medications and healthcare; to assist those in need in applying to programs; and

to provide health-related education using innovative methods.”

Founded by a physician and social worker in 1997, Needy Meds assists patients who are unable to receive prescribed treatment through the hospital by providing prescriptions at a significantly reduced fee. The Needy Meds website notes a number of useful resources available to patients and providers, including a listing of reduced fee imaging centers and active governmental healthcare programs.

One such resource includes patient assistance programs (PAPs), which are typically sponsored by pharmaceutical companies and provide medications free of charge or at a significantly reduced fee for patients who earn a low to moderate income and are uninsured or underinsured. Eligibility and requirements for the programs differ by drug and all information can be viewed at www.needymeds.org.

Additionally, discount drug cards are available at [needymeds.org](http://www.needymeds.org) and can be printed for patients. These drug programs typically save patients up to 80% off the listed price and can be used at over 63,000 pharmacies nationwide. The card can be used in the following scenarios: in lieu of a patient's insurance when there is a costly co-pay and the reduced fee is more manageable; when the plan has a high deductible; when the drug is not covered by the patient's insurance plan; or for patients in the Medicare Part D “donut hole.” The card cannot be used in conjunction with insurance. There are no income insurance or residency requirements for use of the card. Pricing, coupons, and rebates can be found at: <http://www.drugdiscountcardinfo.com/disclaimer.htm>.

Other resources for the uninsured or underinsured with IBD include the Health Well Foundation, which provides financial assistance to eligible individuals to assist with co-insurance, co-pays, healthcare premiums, and deductibles for certain medications and therapies; the Osto Group, which provides ostomy supplies for the uninsured (patients pay for shipping only); and the Oley Foundation, which provides an equipment/supply exchange to patients that require total parenteral nutrition.

CONCLUSION

The Bellevue IBD Clinic serves a radically different IBD patient population than is treated in most US healthcare settings, represented in most clinical trials, or reflected in current management guidelines. To ensure

the standard of care in IBD diagnosis and treatment for this underserved patient population is met, barriers to care must continue to be identified and addressed. Great progress has been made since the Bellevue IBD Clinic's inception in 2011, and plans are underway for further expansion of this much needed clinical program for underserved patients with this complex disease. ■

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