Low Acceptance of Surgery Results in High Morbidity and Mortality Among Asian Patients With IBD

Ruveena B. Rajaram, M.R.C.P.1 • Ida N. Hilmi, M.R.C.P.1 • April C. Roslani, F.R.C.S.2

1 Department of Medicine, University of Malaya Medical Centre, Kuala Lumpur, Malaysia
2 Department of Surgery, University of Malaya Medical Centre, Kuala Lumpur, Malaysia

IBD in Malaysia
IBD is a common condition in the West, with incidence rates of ulcerative colitis (UC) and Crohn’s disease (CD) of 6.0 to 15.6 and 3.6 to 15.6 per 100,000 persons across Europe and in America and prevalence rates of 21.4 to 122.0 and 8.3 to 214.0 per 100,000 persons.1 In Asia, the incidence is much lower, with a mean incidence of \( \approx 1.37 \) per 100,000 persons,2 but it appears to be increasing.3 In Malaysia, the incidence and prevalence rates of IBD are relatively low, at 0.68 and 9.24 per 100,000.4 Malaysia is a multiethnic country made up of Malays, Chinese, and Indians. The main religions are Islam, Buddhism, Hinduism, and Christianity.

Refusal of Surgery in Patients With IBD
Although medical therapy remains the primary treatment, many patients with IBD may require surgical intervention for refractoriness to medical treatment and severe complications such as GI perforation, bleeding, fistulas, and cancer. Many of these patients may require an ileostomy or colostomy as part of their surgical treatment.5

However, even when surgery is strongly indicated, there are patients who refuse because of various reasons. To explore this, we retrospectively evaluated 385 patients with confirmed IBD aged \( \geq 18 \) years and under active follow-up from 2010 to 2017 at the University Malaya Medical Center, Kuala Lumpur, Malaysia (ethics approval number MECID: 20161-2038). Patients who were referred only for perianal fistula/abscess related procedures (eg, seton insertion, incision, and drainage) and who did not require bowel resection or an intestinal stoma were excluded. Patients who were referred for surgery were counselled regarding perioperative and postoperative risks and the possibility of a temporary or permanent stoma creation, as well as regarding stoma care and complications. Refusal at first referral for an indicated surgery was deemed patient refusal for surgery. Reasons for refusing surgery and the patient’s clinical status on data collection were documented.

We identified 206 UC (53.5%), 177 CD (46.5%), and 2 IBD unclassified (0.5%) patients, of whom 54 patients were referred for intestinal surgery with the intention of bowel resection. The mean patient age was 33 years (SD, \( \pm 11.7 \) y), the majority were males (n=37 (67%)). The ethnic group distribution was as follows: 22 Chinese (41%), 21 Indians (39%), and 11 Malays (20%). Among these patients, 29 (53.7%) had tertiary education, 23 (42.6%) had secondary-level education, and only 2 (3.7%) had basic education. The majority of patients had CD (39 patients, 72%), and the remaining patients had UC (15 patients, 28%). Mean duration of disease on referral for bowel surgery was 60 months (SD, \( \pm 61 \) mo). Half of the patients had been exposed to biologics before referral for surgery.

Over two thirds of patients (37 patients, 68.5%) were referred for elective surgery, whereas just under one third were referred for emergency surgery (17 patients, 31.5%). Almost half of patients refused surgery (n=24 (44.4%)). This was more common in the elective setting, where 23 (62%) of 37 patients refused surgery, in contrast to the emergency setting, where only 1 (6%) of 17 patients refused surgery.

Funding/Support: None reported.

Financial Disclosure: None reported.

Presented at the meeting of Asian Pacific Digestive Week, Seoul, Korea, November 15 to 18, 2018.

Correspondence: Ruveena B. Rajaram, M.R.C.P., Department of Medicine, University of Malaya Medical Centre, 59100 Kuala Lumpur, Malaysia. E-mail: ruveena@ummc.edu.my

DOI: 10.1097/DCR.0000000000001606
© The ASCRS 2020


415
FIGURE 1. Reasons for refusal of bowel surgery among patients with IBD.

Reasons for Refusing Surgery
The common reasons for refusal of surgery included stoma aversion, fear of surgery, patient misperception of disease severity, a desire to seek alternative treatment, religion, and financial reasons (Fig. 1). Among these, stoma aversion was by far the most common cause. In many cases, probably also as a result of wanting to avoid a stoma, many patients were quoted as wanting to try alternative therapies before resorting to surgery. Cost and loss of earnings were also cited as common reasons for refusing surgery.

Clinical Outcome
The only patient who refused surgery in the emergency setting was lost to follow-up. Among the 23 patients who initially refused elective surgery, the mortality rate was 13% (3/23); 2 patients died of colorectal cancer and 1 because of a pulmonary embolus as a consequence of uncontrolled disease. Nearly one third (39%, 9/23) of the patients continued to have active disease. These deaths could have been avoided if they had undergone surgery when they were initially referred. Nearly half of the patients who initially refused surgery for more than 2 years for biologic refractory disease but immediately underwent surgery on receiving the diagnosis of rectal cancer (he subsequently died from neutropenic sepsis after chemotherapy). The results of this misperception is clearly demonstrated in our cohort; 2 patients died from colorectal carcinoma from longstanding active disease, and another died because of presumed pulmonary embolism with severe extensive disease. These deaths could have been avoided if they had undergone surgery when they were initially referred. Nearly half of the patients who initially refused surgery eventually underwent surgery and in 2 cases with emergent surgery, which is associated with higher complications.

DISCUSSION
From our study, 22.0% of patients with CD were referred for surgery, and only 7.3% of UC patients were referred for intestinal surgery. In those who were referred for surgery, however, it is clear that almost half of these patients were extremely reluctant to undergo surgery, which would require a bowel resection, unless they were extremely ill, requiring emergent surgery. IBD is a chronic disease, and the common perception among Asian patients is that surgery is a last resort. This is in contrast to the perception of surgery for colorectal cancer, which is seen as a lifesaving procedure. The majority of our Asian patients with IBD cannot accept the need for surgery and would rather continue with alternative treatments, long-term steroid use, and ongoing symptoms with its associated poor quality of life.

The overwhelming reason for refusing surgery was stoma aversion (74%), with most of them expressing body image as a concern. This is despite the fact that, in most cases, the stoma is temporary. Body image is the perception of physical appearance and function that forms gradually after birth, which can be impaired easily, including in people with diseases treated by ostomy. These patients may end up with more depression and stress, and there have even been documented cases of suicide. Their family relationship may be affected, and they may be isolated from their family. Most of our patients are young, and it is not surprising that body image plays a very important role in their psychological well-being and leads to genuine concerns with regard to finding a partner, having a sexual relationship, being able to work, and the potential negative perception of others.

Religion is also a very important component in the majority of the population, and 15% mentioned religion as an important reason for refusing a stoma, because they felt that it was inappropriate to enter places of worship with a stoma. This perception is inaccurate, because it is well established that a stoma is not prohibited at places of worship and also does not prevent them from performing religious activities, as long as the outer part of the bag is kept clean without staining.

Although not fully explored at length, it is also understandable that many patients have an inherent fear of surgery. Because most of these patients are young, with limited resources, the cost of surgery and loss of income were also cited as important reasons for refusal of surgery.

Patient misperception with regard to disease severity plays an important role for refusal of surgery. Patients often understand cancer as a life-threatening disease and are often willing to undergo surgery for this, but not for IBD. A case in point is a 44-year-old man with UC who refused surgery for more than 2 years for biologic refractory disease but immediately underwent surgery on receiving the diagnosis of rectal cancer (he subsequently died from neutropenic sepsis after chemotherapy). The results of this misperception is clearly demonstrated in our cohort; 2 patients died from colorectal carcinoma from longstanding active disease, and another died because of presumed pulmonary embolism with severe extensive disease. These deaths could have been avoided if they had undergone surgery when they were initially referred. Nearly half of the patients who initially refused surgery eventually underwent surgery and in 2 cases with emergent surgery, which is associated with higher complications.
The social and cultural differences between the Asian and Western populations are huge. One can postulate that this low acceptance of surgery is predominantly seen in Asians for several reasons. First of all, the general education level is lower, and knowledge of any disease is limited in the general population, let alone a rare condition such as IBD. In addition to this, cultural acceptance of stomas is much lower in Asian populations, and, as mentioned earlier, religious rituals such as Muslim prayers, which are very important to many Asians, are thought to be impeded by having a stoma. In addition to this, arranged marriages are still the norm in some ethnic groups. Having an intestinal stoma would have major impact in the perceived marriageability of the individual. Family members play an active role in the lives of these mainly young patients with IBD. Husbands often make decisions of behalf of their wives (the other patient who eventually died of colon cancer was a 33-year-old Malay woman whose husband had refused surgery on her behalf). Many of the older generation (well-meaning parents and relatives) believe very strongly in complementary alternative therapy. We need qualitative, exploratory studies to fully understand and subsequently address the current situation accordingly, or the lives of many of our patients with IBD will be needlessly lost or impaired.

CONCLUSION

We found that, among our Asian IBD population, there is low acceptance for elective surgery, even when clearly indicated. Delaying surgery from the initial referral results in significant morbidity and death.

ACKNOWLEDGMENT

The authors thank Dr Suman Rao Samudram and Dr June Lee Pui Yin for their contribution to this study.

KEY WORDS: Colorectal cancer; Inflammatory bowel disease; Mortality; Surgery; Surgery refusal.

REFERENCES