

# An embarrassing subject

## Dr John Mayberry discusses the incidence of IBD in people of Asian origin living in England

Ten years ago, it was believed that people of Asian origin were less likely to be diagnosed with Inflammatory Bowel Disease. Today, the picture is rather different. Research shows that Ulcerative Colitis is in fact more common among many Asians in England than in the population as a whole.

These findings come from research by Dr David Rampton in Tower Hamlets, East London, which has one of the largest, if not the largest, populations of Bangladeshi people, and research by Dr John Mayberry in Leicester, where one in three of the population is of Asian origin.

Dr Mayberry is a consultant gastroenterologist at Leicester General Hospital. Leicester's Asian population is made up of around 80% people of Gujarati origin, and around 20% of people of Punjabi origin. The dominant groups are Hindus, Sikhs and Muslims.

At the time that he carried out his research, Dr Mayberry believed that his task was to identify why there was a lower incidence of IBD in people of Asian origin living in England. His starting point was to find out the number of cases of IBD in the Asian community. However, the findings surprised him. He says: "The research showed that far from being uncommon, Ulcerative Colitis (UC) was actually more common in people of all the Asian groups in Leicester. Crohn's Disease was less common than it was in the English communities, but since then we have gone on to look at the occurrence of the disease in that ten year period and the incidence of Crohn's has moved up towards that of the indigenous population."

Many second generation Asian people have a more western lifestyle than their parents. IBD does appear to be more common in the second generation, so this goes some way towards explaining the growth in incidence of IBD. But it is not the only explanation. Abdominal tuberculosis (TB) mimics the symptoms of Crohn's and is very common in the South Asian subcontinent. There is now a drive to establish whether some people of Asian origin might have been diagnosed with abdominal TB when they really have Crohn's.

However, this doesn't explain why it took so long to find out the real extent of UC. Dr Mayberry says: "We are beginning to see more diagnosis of UC in India. Whether that is because people have become more aware of it or because it really is beginning to grow in frequency, is hard to clarify. Some of our patients were diagnosed in East Africa. This means that the disease was present in East Africa and the facilities were there to make the diagnosis; it just wasn't very common. I think it is likely that there has been a significant increase in frequency of the disease, and this has been paralleled in other countries like Japan and parts of Scandinavia."

### fear of a stoma

Facing up to symptoms of diarrhoea and rectal bleeding is difficult for anyone, whatever their race or culture. Dr Mayberry says: "People are very reluctant to talk about bowels and bleeding from the bowels, and the fear of having a stoma is a major worry for many patients of Asian origin. I think a lot of that depends on how much you have adapted to the culture you are living in and I think it is probably less true of the second generation of Asian people living in Leicester, who are very westernised."

Dr Mayberry speaks just enough Gujarati to enable him to introduce himself to patients, but he is dependent on members of staff who speak Gujarati, such as doctors on rotation or other people within the hospital. Patients are asked to bring someone who can act as an interpreter when visiting the hospital.


One of the challenges he faces as a doctor is persuading his patients that they must take medication even when they are well, to stop the disease recurring. In many cultures, the concept of taking pills when you are well is one which is not readily accepted. His other challenge is to combat the stigma attached to stoma. "Some patients tell me: 'I would rather die than have surgery which involves a stoma'. Although a pouch can avoid that, there is still often the anxiety, 'well if that goes wrong, I must have a stoma', or the fear that they might have to have a stoma during



a series of operations for a pouch." This is a particular concern among some Asian communities because it can affect marriage prospects, particularly in arranged marriages. This applies to women as well as to men. Dr Mayberry explains: "A family might feel, 'how can a man who's got a bag provide properly for our daughter?'" Some of the problem is based on received wisdom. "For Islamic people, for example, the concept of a stoma is associated with uncleanness, although many leading religious thinkers in the world of Islam say that this is not true." Ironically, in India a number of people have readily accepted stoma surgery. Dr Mayberry believes that it would help to have some input from Indian surgeons and stoma advisers to the British scene to explain that there are ways of coping.

### reactions of the family

The reactions of families to IBD can also be a problem. Dr Mayberry says: "I talked to one patient and asked if he was worrying about his rectal bleeding and he said, yes, he was, and I said, 'have you talked to your wife about it,' and he said, 'good gosh, I've never even told her I've got this, let alone talked to her about rectal bleeding'."

Dr Mayberry thinks that there is much scope for support for Asian patients in Britain and improved awareness of IBD through links with community groups,  gurdwaras, mosques, Hindu temples, and articles in Asian newspapers and magazines.

He concludes by saying: "There's a great concern about fingerpointing and feelings of 'I've done something to cause this'. I tell my patients: 'No, you haven't done anything to cause it. It's one of the unfortunate consequences of living in Western Europe'."