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Living with Inflammatory Bowel Disease: The experiences of adults of South Asian origin

Inflammatory bowel disease (IBD) is a chronic health condition with no known cure, of which there are two main forms: ulcerative colitis (UC) and Crohn's disease (CD). Globally IBD is most prevalent in Europe and North America. In recent years there has been an increase in incidence of IBD in people of South Asian origin living in these countries. The aim of this research was to describe what living with IBD is like for South Asian adults living in the UK, and to understand whether ethnicity impacts on this experience and, if so, how. The research was commissioned by Crohn's and Colitis UK as part of their 'Living with IBD' research programme.

Key findings

- In line with previous research on other IBD patient groups, participants reported that flare ups were painful, exhausting and involved frequent trips to the toilet. Feeling low, depressed or anxious added further to the difficulties people experienced so that, even when symptom-free, some curtailed their activities, particularly outside the home.

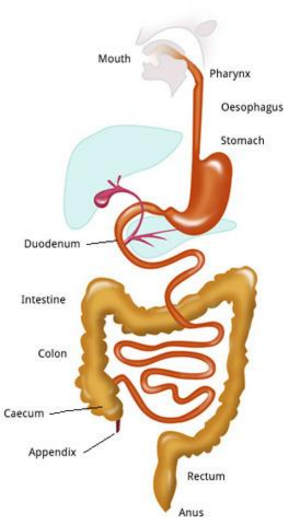
- A number of aspects of South Asian cultures and/or faiths were reported to make a difference to the experience of living with IBD, including:
  - culturally specific barriers to understanding IBD
  - a culture of silence around ill health and bowel symptoms
  - 'spicy' food is the norm
  - religious and cultural beliefs about links between food and health
  - cultural expectations regarding roles within the family
  - living with extended family
  - practising faith and making overseas trips to visit family

- Experiences of gastroenterology services were overwhelmingly positive, with participants appreciating:
  - ease of access to the team
  - being able to talk to staff about sensitive issues
  - information provided on IBD
  - being offered advice and support in making trips overseas.

- Where participants experienced shortcomings with gastroenterology services these were:
  - disappointment that the focus of consultations was purely on medical treatment
  - lack of adequate translation services
  - staff not appreciating the importance of being able to fulfil cultural expectations around what constitutes a 'good' wife or mother.

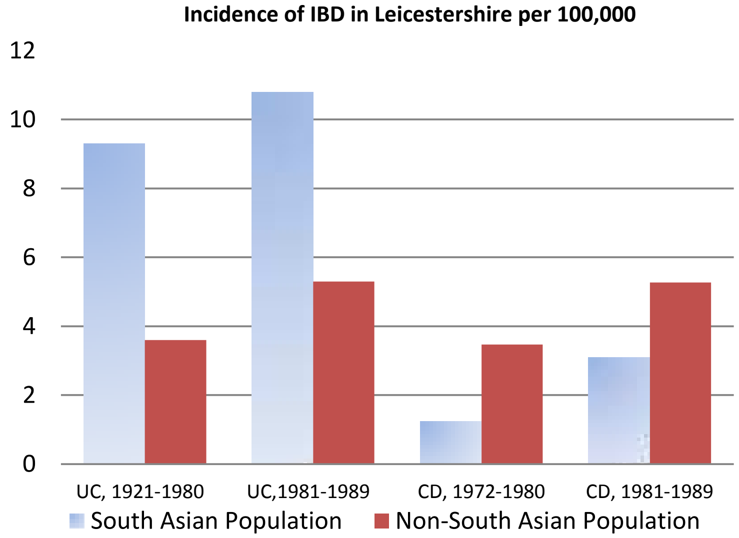
- Knowledge and understanding of Crohn's and Colitis UK was typically very low, with a number of ethnicity-specific barriers to engagement identified.

Background



Inflammatory bowel disease (IBD) is chronic health condition with no known cure. There are two main forms: ulcerative colitis (UC) and Crohn's disease (CD). In both conditions, individuals experience periods of remission and recurrent attacks, during which part of the digestive system become inflamed and ulcerated. Symptoms are highly variable depending on which part of the bowel is affected, but can include: diarrhoea, with blood and mucus; faecal incontinence; abdominal pain; weight loss; vomiting and fatigue. Current treatments aim to bring about remission, but can have unpleasant side effects. Even when well, fear of bowel related symptoms can result in people curtailing their daily activities, impacting on work, leisure and social life.

Globally IBD is most prevalent in Europe and North America, and in recent years there has been an increase in incidence of IBD in people of South Asian origin living in these countries. However, little is known about their experience of living with the condition. This is of concern because it has been known for some time that minority ethnic groups encounter barriers to accessing acceptable health and other support services.



Source: Probert *et al*., 1992; Jayanthi *et al*., 1992.

Study Design and Methods

The aim of this study is to describe what living with IBD is like for South Asian adults living in the UK, and to understand whether ethnicity impacts on this experience and, if so, how. Thirty-three individuals with IBD aged between 18 and 65 years (20 women, 13 men), were recruited from five gastroenterology clinics in England, and took part in an in-depth telephone or face-to face interview.

The interviews were carried out by a team of researchers, including women and men, people who spoke a range of South Asian languages, and some also had personal experience of IBD. Participants could express preferences regarding the characteristics of their interviewer (i.e. gender, experience of IBD, ethnicity).

The final sample reflects the diversity of the South Asian population in the UK, including people who identified themselves as being Indian/British Indian; Pakistani/British Pakistani and Bangladeshi/ British Bangladeshi. The three most prominent faith groups (Hindus, Muslims and Sikhs) were all represented.

Participants had been diagnosed with IBD for between three months and 21 years (median six years). Eighteen had been diagnosed with Crohn's disease, fourteen with ulcerative colitis; and one person with indeterminate colitis.

	Number
Country of birth	
UK	19
India	4
Pakistan	4
Kenya	2
Uganda	2
Bangladesh	2
Ethnic group	
Indian/British Indian	19
Pakistani/British Pakistani	9
Bangladeshi/British Bangladeshi	4
British Punjabi	1

Findings

Living with IBD – the ‘shared experience’

Findings suggest there is a generic experience of IBD, irrespective of ethnic background. In common with previous research on largely white European, Canadian and US populations, participants reported that flare ups were painful, exhausting and involved frequent trips to the toilet. As a result many were housebound when experiencing them. In between flare ups, ongoing milder symptoms were reported.

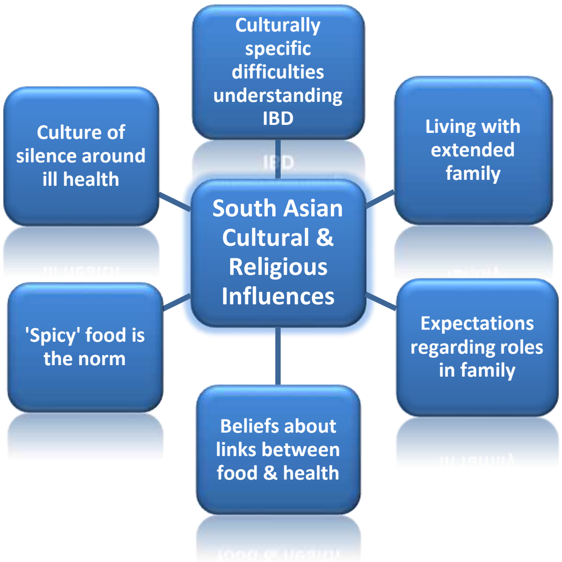
> *‘I don’t think it makes much difference whether you’re Sikh or Indian or English or anything. Pain is pain at the end of the day’* (Female participant)

The majority of participants adhered to prescribed medication, but also used a wide range of other strategies to control or cope with the symptoms of IBD. Practical and emotional support was typically provided by immediate family. Extended family were often not in a position to help due to living too far away or having caring, or other, responsibilities.

Many interviewees described the emotional toll of having IBD. Feeling low, depressed or anxious added further to the difficulties people experienced so that, even when symptom free, some curtailed their activities due to loss of interest or worries about the possibility of experiencing symptoms. This combination of physical symptoms and emotional difficulties meant individuals struggled at times with maintaining a social life and friendships, completing higher education/training courses, managing work, caring for children, and relationships with partners. A few also reported financial difficulties.

South Asian cultural and religious influences on living with IBD

Although there was a ‘generic’ IBD experience, the research revealed that a number of cultural and religious factors were perceived to influence how family, friends and members of the wider community responded to a person having IBD, and also how participants themselves felt about having IBD. These are described below.



Culturally specific difficulties understanding IBD

Participants said there were a number of culturally specific reasons why people within the South Asian community had difficulty understanding IBD. These included: many people have never heard of the condition; there is no term for Crohn’s in some South Asian languages; and the word ‘disease’ has different connotations in South Asian communities compared to white British communities.

> *‘If I say to someone who’s non-Asian ‘I’ve got Crohn’s’, they’ll say, ‘oh yeah, my brother’s got that’, or, ‘my boss at work’ or, you know, someone. If I say to someone who’s Asian like I’ve got Crohn’s, they wouldn’t have a clue what it is probably, or probably they do know someone that has it, but cos they don’t talk about it they don’t know about it.’* (Male participant)

A culture of silence around ill health and bowel symptoms

Most participants spoke of being reluctant to talk to others within the South Asian community about having IBD. This was for two reasons. First, ill health is particularly stigmatised in South Asian communities due to the perception that it impacts negatively on ‘marriageability’ and caused concerns for the health of future offspring. Second, while it was acknowledged that talking about IBD symptoms (particularly bowel-related) might be embarrassing for many people, there was a perception that this subject was particularly taboo within South Asian communities.

'Spicy' food is the norm

Most participants believed that spicy South Asian food exacerbated IBD symptoms and avoided it. This could mean eating, or preferring to eat, different food from other members of the household. This was manageable when the person was in charge of family meals and cooking, but more difficult if they were not (i.e. young person living with parents, woman living with in-laws). A reluctance to eat/avoidance of spicy food was also an issue when out socially, particularly when participants had chosen not to tell others they had IBD. Some dealt with this by avoiding social events. Occasionally the difficulty of refusing food, or social pressure to eat, either in or outside the home, meant that people ate despite believing it would make them unwell.

> **'***It was a struggle trying to get somebody to understand what non-spicy was, cos they used to think it was not spicy. Our definitions are totally different.***'** (Female participant)

Beliefs about the links between food and health

Some participants spoke of difficulty getting others to accept the diet they had chosen to follow because of cultural and religious beliefs about food. They spoke of two types of beliefs. First, the belief that health problems are the result of an 'imbalance' in the foods a person eats, resulting in the perception that might be possible to be cured of IBD through changing your diet. Second, beliefs within a particular faith that certain foods are blessed and therefore must be good for you.

> **'***I think the biggest problem will be some people will not be able to differentiate from their religion to medicine. They just can't seem to see why this food is breathtakingly bad for me.***'** (Male participant)

Cultural expectations regarding roles within the family

Women, in particular, from any background might worry about their ability to manage childcare and housework when ill. The women participating in this study were furthered concerned about the social consequences of not being able to fulfil these roles, feeling that they may not be forgiven by others in their community if they failed to take on the duties expected of a wife and mother.

Living with extended family

A number of participants lived with extended family and most described them as supportive. However, some described being embarrassed about their IBD symptoms when they first moved into their in- laws home. They also pointed out that living with larger families could mean lack of easy access to toilet facilities**.**

Challenges more likely to be encountered by people who are South Asian

In addition to describing South Asian cultural and religious influences on the experience of living with IBD, participants described a number of challenges which are *more likely* to be encountered, but are *not* exclusive to, people who are South Asian. These included overseas trips to visit family and practising faith.

Visits to family living overseas

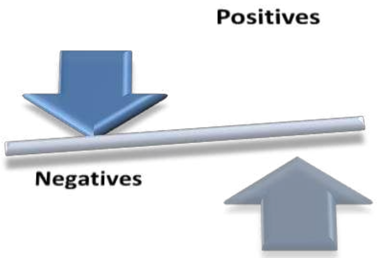
Trips overseas to visit family were a common experience. Many worried about travelling whilst experiencing bowel related symptoms, particularly when there was likely to be limited access to toilets (for example, on a flight or long car journey). Many of those who chose to make such trips were pleased to find their health improved while away. Where people did experience flare ups, there were often clear reasons for this, such as not adhering to medication or changes to diet.

Practising faith

A number of participants spoke of deriving a great deal of benefit from their faith, describing ways in which it helped them to cope with having IBD. However, Muslim participants reported sometimes experiencing difficulties praying because it involved a physical act which they might not be well enough to perform. Furthermore, when experiencing bowel related symptoms they often limited the amount of time spent away from home due to few public toilets having the amenities needed for them to clean themselves with water, as required by their faith.

Experiences of gastroenterology services

With just a few exceptions, experiences of gastroenterology services were overwhelmingly positive. Participants appreciated the ease of access to the team outside of scheduled appointments; felt comfortable talking to staff about sensitive issues, such as bowel related symptoms; and valued the information provided about IBD. Some interviewees offered experiences of culturally sensitive practice (For example, consultants taking time to help prepare people for trips overseas, advising patients about the increased risk of vitamin D deficiency).



Where shortcomings were identified, these included disappointment that the focus of consultations was purely on medical management of the condition, with staff not having or taking the time to discuss how they were coping with the condition, failing to provide dietary advice, or respond to requests to see a dietician. Many interviewees were using, or interested in using, Complementary and Alternative Medicines (CAMs). However, a number had not discussed these options with the gastroenterology clinic team feeling that they were not interested in, or 'negative' about, such treatments.

In relation to their needs as South Asian patients, a lack of adequate translation services was mentioned, as well as staff not appreciating the importance to (some) South Asian patients of being able to fulfil cultural expectations around what constitutes a 'good' wife or mother, and the need to find treatments and/or strategies which enabled them to take on these roles.

Support from Crohn's and Colitis UK

Crohn's and Colitis UK is the leading charity in the UK representing people with IBD. It provides information and advice on IBD; emotional and financial support; a disability benefits service; and runs local groups for members. In addition, the charity carries out campaign work on behalf of people with IBD; funds research; and works with the UK health sector to improve diagnosis, treatment and management of IBD. Most participants had very little knowledge or understanding of what the organisation had to offer, and just a few had sought support from the charity. Those who had been in contact with the charity were very positive about information provided on IBD. They also welcomed the organisation's presence on social media since it encouraged people to talk openly about the condition.

Where people had not made use of the charity, key reasons were:

- the episodic nature of the condition, with people reporting not being motivated to use the organisation when well and being too ill to do so when having a flare up;
- feeling they already had all the information and support they needed, largely through gastroenterology clinics, family and friends;
- the organisation was perceived as not fulfilling their need for the 'uncensored' information about dietary regimes and CAMs which, although untested, were of interest.

A number of barriers to using Crohn's and Colitis UK specific to ethnicity were also identified. It was suggested that the older generation of South Asian patients are unlikely to be 'online' and/or necessarily able to read English, making it hard for them to access Crohn's and Colitis UK's website or information provided via social media. The fact that most of Crohn's and Colitis UK publications are only available in English, and telephone helplines are unlikely to be manned by people who speak South Asian languages, were highlighted as shortcomings that might need to be addressed. Participants also identified a number of reasons why South Asian people might be reluctant to attend local Crohn's and Colitis UK group meetings

- the belief that they would be the only South Asian person present and this would feel uncomfortable;
- the use of culturally inappropriate venues (i.e. pubs);
- a perception that South Asian people are relatively private so would be uncomfortable sharing experiences in a group.

Recommendations

South Asian patients are a diverse group, differing considerably in their faith and cultural backgrounds, as well as in their social and economic circumstances. An individualised approach to care is therefore needed. That said, the findings from the LISA Project suggest that there are a number of things that could be done to improve the life experience of South Asian people living in the UK who have IBD. Some of the recommendations made are generic. That is, developing support would benefit both the South Asian and the wider IBD population. Other recommendations only apply to those who are South Asian. Addressing these issues may require new, innovative partnerships between organisations and agencies concerned with the health and well-being of South Asian adults in the UK living with IBD.

Action that would benefit those who are South Asian and the wider IBD population

- **Increasing access to psychological support.** This is necessary to alleviate feelings of depression and/or anxiety brought on or exacerbated by having IBD.

- **Providing advice on the usefulness and safety of Complementary and Alternative Medicines (CAMs).** Our findings suggest that without this patients will use unofficial online forums for information and advice on treatments and remedies, and may conceal this from their consultant/other clinic staff.

- **Greater information and advice on diet**, including access to a dietician for individualised support.

- **Offering advice and support on making trips overseas,** including:
    - the storage of medication when travelling;
    - how best to deal with a flare up should this occur while overseas;
    - reminders as to the importance of adhering to prescribed medication and usual diet;
    - a brief written summary of the person's diagnosis and treatment in case there is a need for medical attention.

Action aimed specifically at supporting people with IBD who are South Asian

- **Increasing awareness and understanding of IBD within South Asian Communities.** Participants suggested that Crohn's and Colitis UK could assist with this by: developing culturally appropriate information resources; ensuring these are available in South Asian languages; and visiting temples and mosques to distribute such material.

  Gastroenterology clinics can also play a role, increasing understanding and awareness, particularly among close family members. For example, asking patients if they would welcome the opportunity for family members to 'sit in' on an appointment or meet with the gastroenterology team.

- **Dietary advice needs to be culturally appropriate**, including advice on foods typically eaten by South Asian families, as well as on the risks and benefits of fasting.

- **Increasing the visibility of people of South Asian origin on Crohn's and Colitis UK materials, and their representation within the organisation at both a local and national level.**

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The Research Team

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Acknowledgements

This project was funded by a 'Living with IBD' research grant from Crohn's and Colitis UK (NACC Grant reference: SP 2012-1). We are extremely grateful to the research participants who took part in the project for sharing their experience of living with IBD with us. Special thanks also go to the gastroenterology staff who made this project possible by assisting with the recruitment of research participants, and to members the Project Advisory Group, who provided invaluable advice and encouragement throughout the research process. Finally, we would like to thank the LISA project interview team for collaborating with us in the development of the interview topic guide, and for carrying out sensitive in-depth interviews. These interviewers were: Zahira Latif, Melanie Lovatt, Hina Patel, Penny Rivlin, Lucy Stuttard, and Jim Wade.

Further information

This is a summary of The LISA Project. A full report on the project and other outputs are available online at http://bit.ly/infSA. For further information on the project, please contact: Dr Suzanne Mukherjee, Email: suzanne.mukherjee@york.ac.uk

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