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Living with inflammatory bowel disease: The experiences of adults of South Asian origin

Short Title: The **LISA Project**

FINAL REPORT

February 2015

NACC Grant reference SP2012-1

**Suzanne Mukherjee, Bryony Beresford, Shaji Sebastian
and Karl Atkin**

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Contributions from the research team

Dr Suzanne Mukherjee, SPRU, University of York – Principal Researcher.

Recruitment of project advisory group (PAG) members and running of PAG meetings; recruitment, training and supervision of LISA Project interviewers; coordination of research participant recruitment; development of recruitment and interview materials; pilot interviews; data analysis, including review of all interview transcripts, development of thematic framework, and charting, summarising and interpretation of data; write up of final report.

Professor Bryony Beresford, SPRU, University of York – Co-applicant for research funding.

Attendance of PAG meetings; recruitment and training of LISA project interviewers; development of recruitment and interview materials; contribution to data analysis, including review of a selection of interview transcripts, development of thematic framework, and summarising a selection of charts; review of final report.

Professor Karl Atkin, The Department of Health Sciences, University of York - Co-applicant for research funding.

Advice on ethnicity related issues throughout the project; attendance of PAG meetings; input to LISA Project interviewer training days; contribution to data analysis, including development of 'thematic framework' and review of chart summaries; review of final report.

Dr Shaji Sebastian, Hull and East Yorkshire Hospitals NHS Trust - Co-applicant for research funding.

Advice on clinical issues throughout the project; recruitment of research sites; attendance of PAG meetings; input to LISA Project interviewer training day.

Executive Summary

Living with inflammatory bowel disease: The experiences of adults of South Asian origin

Background

IBD is chronic inflammatory disorder 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. 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 in people of South Asian origin living in these countries. However, little is known about their experience of the condition. This is of concern because it has been known for some time that minority ethnic groups with a range of health conditions encounter barriers to accessing acceptable health and other support services.

The LISA Project

The aim of the LISA Project was to describe what living with IBD is like for South Asian adults, and to understand whether ethnicity impacts on this experience and, if so, how. Thirty-three people with IBD (20 women, 13 men), recruited from five gastroenterology clinics in England, took part in an in depth face-to-face or telephone interview. The 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. Participants also represented the three most prominent faith groups (Hindus, Muslims and Sikhs). Participants had been diagnosed with IBD for between three months and 21 years (median six years). Eighteen had been diagnosed with Crohn's disease, 14 with ulcerative colitis; and one person with indeterminate colitis.

Key findings

Living with IBD – the shared experience

Findings suggest there is a generic experience of IBD, irrespective of ethnic background. In common with others who have IBD, 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.

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 influences on living with IBD

Although there was a 'generic' IBD experience, the research revealed that aspects of South Asian identity, cultures and/or faith did impact on the experience of living with 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 include: many people have never heard of the condition; there is no word for Crohn's in some South Asian languages; and the word 'disease' has different connotations in South Asian communities.

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 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 unfounded concerns for the health of future offspring. Furthermore, 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 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 knowing it would make them unwell.

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.

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 would not be forgiven by others in their community if they failed to take on the duties expected of a wife and mother.

Visits to family living overseas

Making trips overseas to visit family was common and many worried about this due to concerns about travelling whilst experiencing bowel related symptoms and limited access to toilets. Many 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 difficulties praying because it involved a physical act which they were sometimes not 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

Experiences of gastroenterology services were overwhelmingly positive, with just a few exceptions. Participants appreciated the ease of access to the team outside of scheduled appointments; how comfortable they felt talking to staff about sensitive issues, such as bowel related symptoms; and the information provided about IBD. Nevertheless, there was disappointment that the focus of consultations was purely on medical treatment, 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 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. Very few people consulted their GP for advice or treatment for IBD.

When asked about their needs as South Asian patients, some interviewees offered experiences of culturally sensitive practice (i.e. consultants taking time to help prepare people for trips overseas, advising patients about the increased risk of vitamin D deficiency). Where shortcomings did exist, 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

Knowledge and understanding of Crohn's and Colitis UK was typically very low. Key reasons why people did not engage with the organisation 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;
- many felt they already had all the information and support they needed, largely through gastroenterology clinics, family and friends;

- the organisation does not provide the ‘uncensored’ information about dietary regimes and CAMs which, although untested, were of interest.

A number of South Asian specific barriers to engagement with Crohn’s and Colitis UK were also identified. It was suggested that the older generation of South Asian patients are unlikely to be ‘on line’ and/or necessarily able to read English, making it hard for them to access Crohn’s and Colitis UK’s website. Barriers to attending meetings of local Crohn’s and Colitis UK groups included:

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

Finally, 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.

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 should include:**
 - opportunities for people to discuss how they are managing their everyday life, and any strategies that might be helpful;
 - access to psychological therapies for those experiencing 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.**

Chapter 1 Introduction

Background to the project

Although Inflammatory Bowel Disease (IBD) has traditionally been considered a condition prevalent in white European populations and those of Jewish origin, in recent years an increased incidence has been reported in people of South Asian (South Asian) origin who live in Western countries (Molodecky et al., 2012). The rise in incidence of IBD in this group is of particular concern in the UK, where efforts are being made to understand why this pattern may be emerging (Ravikumara and Sandhu, 2006; Wilson, 2011). However, little attention has been given to the experiences of South Asian patients living with IBD, despite guidelines for health professionals on the management of IBD acknowledging that the patient's perspective and expectations should be taken into account (Mowat et al., 2011); and concern that the South Asian population is not making use of self-help groups provided by Crohn's and Colitis UK (Moody et al., 1993).

In the UK it has been recognised for some time that minority ethnic groups with a range of health conditions experience barriers to accessing acceptable health and other services. Recent research into conditions such as diabetes, coronary heart disease and various forms of cancer suggest that difficulty accessing appropriate services continues to be an issue for South Asian patients. In addition to social disadvantage and social exclusion, difficulty is often explained by misperceptions among service providers about the needs of this group (Kalrsen et al., 2012, Postenote, 2007; Szczepura, 2005). Such findings emphasise that the importance of understanding when ethnicity and cultural differences make a difference to a person's experience and when they do not.

Most research on the illness experience of IBD among South Asian people in the UK is based on studies carried out some years ago, predominantly with people of Indian origin, which focused on specific issues such as diet, use of complementary medicine, and information needs (Moody et al., 1998; Probert et al., 1996; Conroy and Mayberry, 2001). In recent years a study has been carried out which took a more comprehensive approach, investigating the lived experiences of people from South Asian communities (Nash et al., 2011). However, this research focused specifically on young people aged 16-24 years, and was based on a small sample (n=20), most of whom were Muslim. It is essential that research on the experiences of the South Asian patients is up to date since the experiences of this population are changing rapidly (Jayaweera, 2011), and reflects and explores the diversity of the South Asian population, in terms of country of origin (and/or association), faith and religion, socio-economic circumstances, history of migration and whether individuals are UK born (Craig et al., 2012). Therefore, there is still a significant gap in the

research literature, with the experiences and views of young people from other faith backgrounds, as well as older South Asian IBD patients, left unexplored. It was against this background that Crohn's and Colitis UK funded the LISA Project - a research project investigating the experiences of South Asian adults in the UK living with IBD.

Aims of the research

The primary aim of this study was to describe what living with IBD is like for South Asian adults and to understand whether ethnicity impacts on this experience and, if so, how. In addition, this study aimed to identify met and unmet needs for support. The specific research objectives were to:

- understand the impact of IBD on everyday life for people from a diverse range of South Asian communities;
- explore perceptions and understanding of the condition and how this influences lifestyle/treatment decisions;
- describe the support (both formal and informal) that members of the South Asian community have available to them and their feelings about utilising this support;
- to understand and explain the extent to which ethnicity and broader cultural and religious difference moderates the experience of IBD, while also exploring the extent to which there is a generic experience of IBD, irrespective of ethnicity;
- to offer Crohn's and Colitis UK evidence to inform and support the way it seeks to better respond to the needs of the South Asian population living with IBD.

Overview of research design and methods

As this was the first research to be carried out on this topic, the study adopted an exploratory approach aimed at understanding the potentially diverse experiences of the South Asian population, without presupposing what those experiences might be. In-depth qualitative interviews were used to gain an insight into participants' perceptions, experiences and support needs. Qualitative interviews are particularly effective in exploring complex and sensitive issues, and in understanding people's belief systems and how they interpret what is happening to them.

Given that many people with IBD are reluctant to talk about their condition to anyone other than close friends and family (Kelly, 1992), and that the response rate of IBD patients from the South Asian community to other studies has been found to be substantially lower than that of European patients (Moody et al., 1993, 1998; Conroy and Mayberry, 2001), careful thought was given to how to overcome these potential barriers to recruitment. A key element was providing participants with a choice of interviewer. Specifically, participants were aware, when recruited to the study, that they could state a preference regarding the gender of their interviewer, whether or not he/she has IBD, their ethnicity (that is, South Asian or white British) and which

language they were interviewed in. The research team would endeavour to match them with an interviewer who met their requirements. In addition, participants were able to choose between a face-to-face interview (at home or in hospital) or a telephone interview. Such an approach has been used in other fields of research where the subject matter for discussion is sensitive and/or being interviewed by someone with a 'shared experience' is likely to support both recruitment to the study and openness in the interview (Warr et al., 2011; Beresford et al., 2008). In order to be able to offer this choice of interviewer, qualitative researchers already working in the department undertaking the research were supplemented by a small number of freelance qualitative researchers specifically recruited and trained for this project.

Research participants were recruited through gastroenterology clinics located in different areas of England. A purposive sampling strategy was adopted to ensure that men and women, ulcerative colitis and Crohn's disease patients, and a range of ages were represented. Special efforts were made to ensure the sample reflected the complex heterogeneity and inter-relation of regional, religious, linguistic, and national identities within the South Asian population (Karlsen and Nazroo, 2006).

Structure of the report

In Chapter 2 of this report, we put the research into context, outlining what is already known about the experience of living with IBD, the specific experiences of South Asian patients, why it is important to look at the experiences of ethnic minority groups and how best to approach such research. Chapter 3 provides details on the research design and methods, including the characteristics of the final sample of patients who took part in the study. The research findings are reported in Chapters 4-8. Chapter 4 reports on the generic experience of IBD – that is experiences that South Asian patients share with the wider IBD patient population. In Chapter 5 we go on to describe findings on how South Asian culture and faith influence the experience of living with IBD. Chapter 6 describes patients' experiences with health services, including both GP and gastroenterology services, while Chapter 7 deals with participants' views on Crohn's and Colitis UK and the support it provides. Finally, in Chapter 9 we reflect on the research, discussing what the study adds to the existing literature on the experiences and support needs of adults with IBD, and the implications of the findings for Crohn's and Colitis UK and health service providers.

Chapter 2 Background Literature

Introduction

In this chapter, for readers who are unfamiliar with IBD, we begin by providing an overview of the condition and its treatment. Then, in order to help contextualise the findings from the LISA project, the generic evidence on what it is like to live with IBD, and the experiences of the South Asian patient population, are reported.

Understanding IBD and its treatment

IBD is chronic inflammatory disorder with no known cure. There are two main forms: ulcerative colitis (UC) and Crohn's disease (CD). A recent review of epidemiological data across the world indicate that that IBD is most prevalent in Europe and North America (Molodecky et al., 2012). Based on estimates from this review it is suggested that up to 620, 000 people in the UK may currently be living with IBD (IBD standards update, 2013).

In both conditions the clinical course is variable with individuals experiencing periods of remission and recurrent attacks. This may result in frequent hospital visits and spells as an inpatient. Symptoms include diarrhoea, with blood and mucus, abdominal pain, weight loss, and sometimes vomiting. Fatigue is often prominent and can be disabling. Faecal incontinence is also common. Possible complications include anaemia, malnutrition, intestinal obstructions, abscess formation and fistulas. The exact nature of symptoms experienced depends on which part of the bowel is affected, resulting in considerable variability between patients (Ford et al., 2013; Kalla et al., 2014; Norton et al., 2013; Czuber-Dochan et al., 2013; Thompson, 1990). In woman with CD fertility is reduced, but evidence suggests this is linked to voluntary childlessness, rather than there being any physiological causes. In men with CD there is also a reduction in fertility, but not in reproductive capacity (Tavernier et al., 2013). While some people may appear ill because of the bloating effects of medication or, alternatively, because they are thin, pale, and emaciated, others may not appear in any way different and can choose to keep their health difficulties private if they wish. It has been suggested that many people opt to conceal the nature of their illness to all but a few intimate friends and or relatives because of the embarrassing nature of some of their symptoms (Kelly, 1992).

Current medical treatment aims to bring about a remission in the condition and, when this has been achieved, prevent relapse thereby minimising the impact of IBD on quality of life. Treatments for both UC and CD include: drug therapy, to reduce symptoms, inflammation and suppress the immune response; nutrition, including an individualised diet and, in some, enteral nutrition; and surgery. For patients with UC surgery can be curative but may mean having an ileostomy or ileoanal 'pouch'.

Surgery may also be offered to patients with CD, but here it largely alleviates symptoms for a period of time, and the condition is likely to recur in other sections of the digestive tract (Ford et al., 2013; Kalla et al., 2014). While drug therapies are increasingly effective, resulting in a reduction in the use of surgery (Ford et al., 2013), the side effects of such therapies can be unpleasant and of concern to patients (Hall et al., 2007). Long-term use of corticosteroids can also lead to the development of osteoporosis and therefore requires careful management. Both UC and CD patients are now considered at increased risk of colorectal cancer and, in the case of Crohn's, there is also a small increased risk of bowel cancer. In the UK, coloscopic surveillance is recommended for patients starting 10 years after the onset of symptoms, with the exception of those with ulcerative proctitis (Cairns et al., 2010). Investigations carried out in order to make an accurate diagnosis, decisions about management of the condition, and for cancer surveillance can be uncomfortable, involving various forms of endoscopy, barium x-rays and scans. In summary, while progress in the diagnosis and treatment of IBD has resulted in marked improvements in prognosis for people who have the condition, it remains the case that IBD can have a considerable impact on those who have the condition.

What do we know about the experience of living with IBD?

Evidence as to the impact IBD has on the everyday lives of people living with the condition is provided by research using a number of different methodologies, and studies have explored a range of issues, including education and employment, mental health difficulties, quality of life, and the lived experience.

Research on the education and employment status of people with IBD does tend to suggest that there is an economic burden for patients as, despite attaining a similar level of education as the general population, there is a higher rate of non-participation in the labour force (Marri and Buchmann, 2005). When employed, people with IBD are said to have a high work ethic, with a recent UK survey finding that 80 per cent continue working despite feeling unwell (Gay et al., 2011). Nevertheless, or perhaps because of the effort involved in working while unwell, people often take early retirement and cite IBD as playing a major part in this decision (Crohn's and Colitis UK, 2014).

For many years there has been interest in whether people with IBD are at increased risk of mental health difficulties, initially driven by the belief amongst both patients and clinicians that IBD is exacerbated by stress (Theis and Boyko, 1994; Drossman, 1988). In recent years, a number of studies have been published indicating that rates of anxiety and depression are higher in people with IBD than in those without the condition (Goodhand et al., 2012; Loftus et al., 2011; Graff et al., 2009; Fuller-Thomson and Sulma, 2006; Kurina et al., 2001). It is, however, hard to come to any firm conclusions about prevalence rates since there is considerable variability

between studies in the rates reported. Importantly, it has now been established that factors such as active/severe disease and socio-economic status increase the risk of experiencing such difficulties (Hauser et al., 2011; Graff et al., 2009; Nahon et al., 2012). In other words, mental health difficulties are not inevitable but depend on individual circumstances.

Looking at the lives of people with IBD more generally, early research using generic quality of life measures suggested that overall people with IBD were doing well relative to other groups of patients (those with rheumatoid arthritis, chronic back pain, or receiving haemodialysis). However, this research also found that the impact of IBD is quite distinctive in that, unlike other chronic conditions, it is the social and emotional aspects of everyday life that are affected rather than physical functioning (Drossman et al., 1989; Patrick and Deyo, 1989; Hjortswang et al., 1999; Drossman, et al, 1991). As a result, researchers shifted to examining quality of life using IBD specific measures, one of the most popular being the Inflammatory Bowel Disease Questionnaire which assesses bowel, systemic, social and emotional functioning. Research using this measure has revealed variability in the impact of IBD on quality of life, with IBD symptomatology, higher perceived stress, lower socio-economic status, and low perceived social support all associated with lower scores. However, the direction of the relationship between these variables is often unclear (Sainsbury and Heatley, 2005; Moradkhani et al., 2013; Borgaonkar and Irvine, 2000).

Evidence that physical symptoms alone cannot explain patients' subjective sense of wellbeing, as well as a desire to understand patients' support needs, has led many to investigate the worries and concerns of IBD patients. An initial review of the research on the topic suggested eight major issues for patients: lack of energy; the sense of lack of control; body image (which can be altered by medication and surgery); isolation and fear (due to the embarrassing and unpredictable nature of the condition, and the possibility of developing colon or bowel cancer); feeling a burden to others; feeling dirty; and lack of information from the medical community, in part due to the cause of IBD being unknown (Casati et al., 2000). After taking perceived health status into account, women are reported to be more concerned than men about attractiveness, feeling alone and having children (Maunder and Esplen, 1999). Research comparing studies carried out in different countries has found cross-cultural variation, both in the issues that concern patients and the level of concern reported (Hjortswang et al., 1999; Levenstein et al., 2002). However, the reasons for these differences are unclear, with some speculating that they may reflect differences in the socio-economic background or disease type of participants, rather than cultural differences *per se* (Sainsbury and Heatley, 2005).

There are concerns that the growing body of research on the psychological wellbeing and quality of life of patients with IBD does not fully represent the subjective experience of living with IBD and is too negatively focussed (Wolfe and Sirois, 2008). A recent review of research articles published up until August 2010 identified just six

studies on the lived experience (Kemp et al., 2012). After carrying out a metasynthesis of the findings, the authors conclude that fear of incontinence, and behaviours related to this fear is the most significant issue to emerge from the data, resulting in people curtailing their daily activities and impacting on work, social and leisure functioning, even when well. They also note that trying to control the illness or symptoms was a theme in all studies and suggest that attempting to cope with the condition is all encompassing, so that that people often 'live in the world of the disease' even when in remission.

Qualitative research looking specifically at how people manage IBD indicates that many people show a determination to live as normal a life as possible and use a combination of different strategies to control or fight their disease (Hall et al., 2005). These include psychological (e.g. positive attitude, denial, acceptance etc.); behavioural (e.g. diet, situational avoidance, meditation, exercise, information seeking etc.); social (e.g. seeking support from others, being secretive, keeping up appearances); and biomedical (e.g. seeking medication, health care or surgery) strategies. Some strategies seem to be specific to IBD, or at least to bowel related conditions. For example, active management of one's diet, 'bathroom mapping' (where people make themselves familiar with toilet facilities available at places they frequent regularly or on a journey they make routinely); and avoiding locations and social functions without toilet facilities (McCormick et al., 2012). It has also been noted that some of the strategies people adopt overlap with the impact of the condition on their everyday life. For example, planning outings around toilet facilities can result in social avoidance and isolation (Hall, 2005).

Current approaches to research on the experiences of ethnic minority groups and their support needs

As mentioned in Chapter 1, there is now a considerable body of literature highlighting the need for research on the illness experience of people from ethnic minority groups due to evidence that these groups experience health disadvantage as assessed by indicators of morbidity and mortality (Kalrsen et al., 2012; Postenote, 2007; Szczepura, 2005). In recent years the UK Department of Health has commissioned a number of initiatives in an attempt to ensure greater equality in health and social care provision (Postnote, 2007). Such initiatives are based on an understanding that provision of services alone does not ensure equitable access for all and that, in addition to making services accessible to patients by addressing their language needs, organisations and their staff require 'cultural competence' (Szczepura, 2005). However, unlike the United States where a number of states have introduced mandatory cultural competence training for health professionals, there is no such legislation in the UK. It therefore seems likely that some providers and practitioners will unfamiliar with the concept.

Cultural competence entails: understanding the importance of social and cultural influences in patients' health beliefs and behaviours, including their attitudes to care providers, and ensuring these influences do not become the basis of discrimination and inequality; considering any organisational, structural or clinical barriers to accessing care; and devising interventions that take such issues into account (Szczepura, 2005; Betancourt et al., 2003). Examples of organisational barriers include the extent to which the leadership of an organisation and its workforce reflect the ethnic composition of the patient group. Structural barriers include shortcomings such as lack of interpreter services or culturally/linguistically appropriate information, and slow speed of referral to services. Clinical barriers refer to socio-cultural differences between the patient and provider in relation to health beliefs, attitudes towards medical or other care, and levels of trust in health and other professionals. Even when service providers and patients are from the same ethnic background there may be differences in beliefs and attitudes.

There is, however, a danger that providing general information on the attitudes, values, beliefs, and behaviours of specific groups, in an attempt to increase the provision of culturally competent care, can in itself lead to further stereotyping. Therefore it is currently advised that, when discussing ethnic differences, it is important to stress that these are only *potential* differences. Service providers caring for people from an ethnic background should be encouraged to explore individual patients' perceptions of their condition, as well as the role that family, gender, and socio-economic issues play in their lives and service provision preferences (Betancroft, 2003). Recent research on the illness experiences of ethnic minority groups suggests that while some differences between groups are due to cultural influences, it is important not to overemphasise these as age, gender, social class and disadvantage can be equally important in understanding an individual's experiences. Individual's experiences also occur within a social context so that the meaning of the illness is negotiated through interactions with family members, people within their wider community, and health professionals. In effect, an individual's perception of who they are influences how they manage their illness, but others perceptions are equally important and will also influence their experience (Karlsen et al., 2012). It follows that anyone carrying out 'ethnicity research' needs to attend to this multitude of factors, and the potentially complex relationship between them, rather than simply viewing all experiences in relation to ethnic identity.

What do we know about the experiences of those who are South Asian?

In general, research evidence on the experiences of people with IBD who are from an ethnic minority group is extremely limited. Ethnic minority groups are often poorly represented in studies of the wider IBD population. For example, in their recent

metasynthesis of studies on the lived experience of people with IBD, Kemp et al., (2012) pointed out that, of the six studies included, only one had included anybody from an ethnic minority background (Kemp et al., 2012). In some cases researchers report excluding people whose first language is not English from studies due to the lack of resources to facilitate involvement (for example, Rochelle and Fidler, 2013; Borgaonkar et al., 2002).

Very few researchers have carried out research specifically investigating the experiences of people from an ethnic minority background. However, in the UK there is a small body of evidence on the experiences of South Asian patients in the Leicester area, based on studies carried out by the same group of researchers over a number of years. They began with a study investigating the characteristics of people who joined a newly formed Crohn's and Colitis UK support group, finding that those from ethnic minority groups were unrepresented. They warned that, not only might attending be beneficial for patients, but that their underrepresentation means that the needs of ethnic minority patients are frequently excluded from the plans made by the organisation (Moody et al., 1993). Next, in a postal survey examining the diet of South Asian patients with IBD they found that Hindu UC patients had significantly altered their traditional diet, reducing their intake of spices, flour and milk (Probert, 1996). In 1998 the group went on to research the use of complementary medicine in both European and Asian patients (Moody et al., 1998). They acknowledged that some UK hospitals offer complementary services (e.g. acupuncture, hypnotherapy, reflexology, osteopathy and herbal medicine etc.), but speculated that in communities with a substantial ethnic population other options such as Ayurvedic and Unani medicine, as well as traditional healers, may be more popular. A survey asking about advice sought from alternative practitioners was mailed out to 192 European and 190 Asian patients with IBD. Unfortunately, while a response rate of 83 per cent was achieved for European patients, only 42 per cent of South Asian patients returned the questionnaire. Results indicated that there was no significant difference in the use of complementary medicine between the two groups. However, there did seem to be a slight difference in the type of practitioner consulted. While the most commonly reported practitioners (herbalists and homeopaths) were consulted by both groups, only Asian patients had sought the help of a Hakim.¹ Both groups reported consulting a spiritualist, but there did seem to be a greater tendency for South Asian patients to do so. South Asian patients were also significantly more likely to have found the alternative treatment beneficial. The authors note that they were surprised that South Asian respondents did not report the use of Ayurvedic practitioners, acknowledging that this may indicate that the study suffered from sampling bias.

In 2001 the group carried out a survey of South Asian UC patients to obtain feedback on information leaflets on UC (Conroy and Mayberry, 2001). Forty people

¹ A Hakim is a physician using traditional remedies from a predominantly Muslim culture.

responded (representing a 53% response rate). Although 14 requested a leaflet in English, a further 21 requested it in Gujarati and 5 in Punjabi, indicating a clear need for information in South Asian languages. Almost all respondents felt that doctors should do more to help with language problems. This study was carried out some years ago and it is possible that the support health service offer to IBD patients whose first language is not English has changed in this time. The authors caution that although a third of respondents said the leaflet had alleviated anxiety, a third also reported it increased anxiety, so care must be taken to distribute such leaflets to those most likely to benefit from them and to be prepared for the fact that people may still need one to one discussions with health staff.

Aside from research undertaken by this group, there is one further qualitative study on the experiences of South Asian people with IBD in the UK. This investigated the experiences of 20 young people aged 16-24 years from an ethnic minority group, 18 of whom were South Asian and the majority Muslim (Nash et al., 2011). This found that young people of South Asian background faced three main challenges. First, where parents had limited English, the lack of translated information impacted on their ability to understand IBD and reduced parents' abilities to support their child either directly, or to act as an advocate for them both in health and education settings. Second, two-thirds of the sample had problems tolerating spicy food. This resulted in people sometimes feeling excluded from family life or, where separate food was cooked for them, guilty that they had created extra work for family members. It also made it difficult for them to participate in community life since this involved sharing food. In some cases the young people had chosen not to travel abroad to visit family because of lack of choice over the food they would be expected to eat. Third, young Muslim men reported some difficulty attending the mosque for prayers when experiencing symptoms due to the need for cleanliness. However, they derived strength from their faith as it helped them to stay calm and positive, and also provided an explanation as to why they were ill. Finally, participants also spoke of their experiences with health services, with two-thirds of the sample reporting significant delays in having their IBD diagnosed as a result of lack of referral by their GP. None attributed these delays to their ethnic background. However the authors note that in a few cases people were misdiagnosed with tuberculosis and a tropical disease, which they suggest indicates 'culturally diagnostic stereotyping'.

Chapter 3 Research Design and Methods

Preliminary work

There were two main elements to preliminary work undertaken at the start of the project. First, a Project Advisory Group (PAG) was established. The group had 13 members, including patient representatives, gastroenterologists, IBD Specialist Nurses, representatives from Crohn's and Colitis UK, and an academic specialising in ethnicity research. The group met at two points during the project: prior to and on completion of field work. Issues discussed included: the strategy for recruiting research participants; the interview topic guide; preliminary research findings; and the potential implication of the findings for Crohn's and Colitis UK.

Second, visits were made to five gastroenterology clinics who had expressed an interest in being a research site for the study. During these visits the lead researcher meet with staff to: explain the study further; hear about staffs' experiences in caring for South Asian patients and issues they would like explored during the research; find out about the potential pool of research participants available from the site; and discuss the best approach to recruiting patients.

Recruitment and training of interviewers

As outlined in Chapter One, in order to offer participants a choice of interviewer with respect to a number of key characteristics, it was decided that a team of 'in-house' (University of York) and freelance researchers would be used to carry out interviews. The posts for freelance interviewers were advertised through the national press and University websites, and applications went through a formal interview process. A team of six LISA project interviewers were recruited to the project (four freelance and two 'in-house'). All had an applied health or social science background and experience of conducting qualitative research on sensitive topics. Five were female and one was male. Two people had personal experience of living with IBD and two were of South Asian background. One of the South Asian interviewers was fluent in a range of South Asian languages (Hindi, Mipuri, Punjabi and Urdu); the other could speak a limited amount of Gujarati.

All the interviewers (freelance and 'in-house') attended a two day residential training course run by the research team. Input was also provided by a gastroenterologist and a member of the PAG who had a South Asian background and personal experience of living with IBD. During the course, interviewers were given an overview of IBD (including etiology, symptoms, investigations, treatment options) and

doing research with ethnic minority groups. In addition, specific training and preparation for the project was delivered including: arrangements for setting up and carrying out interviews; informed consent and data protection; the research topic guide; specific interviewing techniques, including differences between telephone versus face-to-face interviews; establishing personal boundaries; ethical issues likely to arise during fieldwork; and arrangements for the monitoring and supervision of work.

Recruitment of research participants

Patients who took part in the study were recruited through five gastroenterology clinics in England. These clinics were purposively selected so as to include clinics with small and large proportions of South Asian patients and therefore different levels of experiences in supporting the needs of this patient group. Within these clinics the research team worked with nurses to identify all patients eligible for the study.

In order to be eligible for the study, patients were required to have:

- A confirmed diagnosis of IBD²;
- Be 18 years or older;
- Identify themselves as being of South Asian origin (come from or descend from a South Asian country, i.e. Bangladesh, India, Pakistan or Sri Lanka).

To protect patient confidentiality, the project was introduced to patients by clinic staff, who also passed on a project information pack (containing a project information leaflet, letter of invitation, response form and reply paid envelope). This project information pack was passed on either face to face (in clinic), or by post, depending on what staff at the gastroenterology felt was appropriate for their clinic and the circumstances of individual patients. Where possible, clinic staff went through the information pack with a patient, explaining its contents. Clinic staff were asked to make it clear to patients that they were under no obligation to participate in the project and that their decision would not affect the services they receive in any way. Project information packs were translated into appropriate languages (Bengali, Gujarati, Hindi, Punjabi, and Urdu) and made available to patients as required. In addition, arrangements were made for gastroenterology staff to make use of interpreters to explain the contents of the project information pack as and when necessary. If a patient was interested in taking part in the project, they were asked to return a response form to the research team, providing details on the type of person they would prefer to be interviewed by. Options included someone: male;

² Please note, our initial intention was only to include people who had been diagnosed for at least a year. However, during the early stages of fieldwork, interviews were carried out with people who had only recently been diagnosed. As they had a great deal to say about living with IBD, it was decided their views should be included in the study.

female; South Asian; around my age; with personal experience of IBD. Alternatively participants could indicate that they had 'no preference'. Participants were also asked which languages they were happy to be interviewed in. Language options were: English; Urdu; Gujarati; Hindi; Mirpuri; Bengali; and Punjabi. On receipt of a response form, the lead researcher allocated the interview to the interviewer who best matched the participant's preferences and this interviewer made contact with the potential participant to discuss the project and, if agreeable, make arrangements for an interview. Consent to take part in the project was obtained at the time of the interview.

A total of 101 people received an information pack about the project through their gastroenterology clinic, with 41 responding expressing an interest in the research (response rate 40.6 per cent). A further three members of PAG were invited to take part and two people approached the research team directly, having heard about the project through family or friends. In order to reflect the diversity of the South Asian population, out of the potential pool of 46 participants, a purposive sample of 37 people were selected to take part in the research and arrangements were made for the interview. Where a potential participant was not selected for interview, they were sent a letter thanking them for their interest in the project and letting them know that a short report on the project findings would be sent to them in completion of the project.

Out of the 37 selected for interview, three later decided not to take part in the project. In one case this was because of family concerns that the interview would be demanding for the person, who they perceived to be too elderly and unwell to take part in the process. In the remaining two cases, the decision was made by the patient themselves. In one case the reason given for delaying was that the person was experiencing a flare up; in the other the person was well and felt they would have little to contribute. One person had to be excluded from the study because further discussion revealed that his heritage was not South Asian as first thought. This resulted in a final sample of 33 patients. A description of the sample is provided at the end of this chapter.

Development of the interview topic guide

The development of the interview topic guide involved a number of stages. First, an initial topic guide was drafted after: (a) reviewing the existing research literature on the lived experiences of patients with IBD and previous studies describing the experiences of South Asian patients with other health conditions; (b) consulting with gastroenterology staff as to their experiences in caring for South Asian patients; (c) presentation of potential interview topics to the PAG for review and comment.

Next the draft topic guide was presented to the LISA Project interviewers at their two day training course. Together the research team and interviewers reviewed the topic guide, discussing how best to approach potentially sensitive topics and whether the draft topic guide was missing any important issues. During this process the research team paid particular attention to the views of interviewers who had a South Asian background (n=2) or who had personal experience of IBD (n=2).

Following this discussion, the interview topic guide was amended and tested out by the lead researcher through pilot interviews (n=3). Feedback from these pilot interviews was positive, so only very minor changes were required, before sending a final version of the topic guide to the interview team for use.

Data collection

Each participant was interviewed once, with interviews lasting between 30 minutes and three hours. After discussions with the interviewer, 15 participants opted to be interviewed by telephone, 11 at home and seven in hospital (in a private room within or near to the gastroenterology department the patient attended). In terms of interviewer characteristics, 15 people were interviewed by a female interviewer with a South Asian background and 10 people by a female interviewer with personal experience of IBD. The remainder of the participants did not express a preference for a particular type of interviewer and were interviewed by a female white British interviewer. To thank people for their contribution to the project, all interviewees were offered a £20 shopping voucher, or could make a £20 donation to a charity of their choice.

Interviews began with the interviewer introducing themselves, explaining the project and taking informed consent. The interview explored: biographical details and initial diagnosis experience as a way of building rapport and contextualising subsequent discussions; diagnosis, management and the reactions of others to IBD; the impact of IBD on everyday life; experiences with health services; support from Crohn's and Colitis UK; ideas and recommendations for improving support to people of South Asian origin and their families. A copy of the interview topic guide is provided in Appendix 1.

In order to facilitate discussions two visual aids were used: (1) a 'life map' for use when discussing 'Living with IBD', particularly in cases where people found it difficult to spontaneously identify/talk about the impact of IBD on their lives; (2) a 'map' of the services/support provided by Crohn's and Colitis UK for use when discussing support from Crohn's and Colitis UK (please see Appendix 2 for the visual aids). The consent form and visual aids used during the interview process were available to participants in five South Asian languages.

In order to allow issues concerned with ethnicity to emerge from the interview, rather than presuppose what they might be, a staged approach was taken to the interviews, with initial questions encouraging participants to describe experiences in a general way. Only after this data was gathered were participants asked to reflect on the extent to which the factors such as faith, culture, age and gender impacted on their experiences.

In order to ensure data quality, the lead researcher reviewed all interviews shortly after completion. Reviewing interview material at this point allowed for an iterative data collection process, enabling the lead researcher to identify issues which required further exploration in later interviews, and who should be interviewed next (i.e. more males/females; more people from a particular faith) in order to reach 'data saturation'. Any issues that required further exploration were communicated to the whole of the interview team via email.

Ethical considerations

The fact that the focus of this research was on living with IBD, and that many people with this condition prefer not to talk about it with anyone other than close friends and family, meant that the topics discussed during interview were sensitive. In addition, it was possible, that in providing a space to reflect on their situation, a participant might become upset during an interview. The research team put a number of measures in place to deal with this possibility. (1) All interviewers were given training on how best to deal with such situations if they occurred, including guidance on the importance of a neutral, but compassionate, reaction, ensuring that the participant continues to feel in control of the interview and whether it continues, is paused or terminated; (2) in each gastroenterology clinics a named contact was identified who would act as a first point of contact should a participant express to the interviewer a need for support. Where a need for support was expressed, the participant or, at the participant's request, the interviewer got in touch with the named contact; (3) the LISA project research team put together a 'Useful Contacts' leaflet which provided information on national organisations and local groups (including Crohn's and Colitis UK) that offer support to people with IBD. Everyone who took part in the project was sent a copy of this leaflet on completion of their interview. (4) The lead researcher held regular debrief meetings with the project interviewers throughout the fieldwork period to address any concerns interviewers had about research participants, and decide whether any further action was required.

NHS Research Ethics and Research Governance Approval from each of the Research and Development (R&D) departments attached to the five NHS Trusts involved in the study was applied for and granted before the fieldwork began.

Data analysis

All but one interview was audio-recorded (with permission) and fully transcribed. In the instance where it was not possible to record the interview, notes were made during the interview and written up in full once the interview was completed. In two cases, the interview was conducted in a South Asian language (one in Mirpuri and one in a mixture of Punjabi and English) and a back translation, focusing on conceptual rather than literal equivalence (Atkin and Chattoo, 2006), was carried out. The transcripts or summaries were then subject to a thematic analysis using 'Framework' (Lewis and Ritchie, 2003), a well-established method which supports the robust management of the data analysis process, including systems and processes which allow external scrutiny of the analytical process. This is a key requirement of rigorous, high quality qualitative data analysis (Pope et al., 2000). Key processes of thematic analysis are: data immersion; identification of themes; data reduction; data display; and analytical writing, including conclusion drawing and verifying (Miles and Huberman, 1994).

To assist with data immersion, the lead researcher (R1) carried out an initial read through of all transcripts and the field notes written by the interviewer, and then wrote a 'pen portrait' for each interview. A pen portrait is a 1-2 page summary which 'which makes the person come alive to the reader' (Holloway and Jefferson, 2000). It includes any inconsistencies, contradictions and puzzles noticed within the data. In addition, a list of all themes observed in each interview was drawn up.

The process of moving from this initial list of themes to final thematic framework was lengthy and a full description of the steps taken is given in Appendix 3. In order to ensure rigour in the process, a number of systems were put in place. First, a team-based approach was taken, with three members of the team involved in developing the thematic framework. Second, a 'Review and Reflection' meeting was held for LISA Project interviewers, where they were presented with an overview on the themes emerging from the data and asked whether these themes fitted with their understanding and interpretation of the interview data. Third, the research team reported on the draft thematic framework at the second meeting with the PAG, and asked for their feedback on themes emerging, as well as the team's initial interpretation of the data.

The final framework consisted of five main themes: Living with IBD; access to support; perceptions and beliefs about the causes of IBD; visits to South Asian countries; feedback and recommendations to Crohn's and Colitis UK (see Appendix 4 for full list of themes and codes). Having finalised the thematic framework, R1 charted all transcripts, using Excel 2010 software to support the process. The 'chunks' of coded data were summarised, participant by participant, into the relevant chart. Each participant's data was entered into a different row. Small portions of verbatim text (or quotes) were also transferred onto the charts. Each chart entry was

referenced back to the transcript by noting the transcript page number alongside each summary or quote. Each chart thus displayed each individual's views/experiences relating to a particular theme/issue, as well as allowing the accounts of different participants, or groups of participants, to be compared.

The charts were then explored and interrogated, with analytical notes being made of this process. Given the aims of our research, we were especially interested in exploring the nuanced influences of ethnicity and culture, rather than assuming one or the other 'essentialises' and dominates a person's experience of IBD (Atkin, 2009). In effect, we were concerned with understanding when 'ethnicity' and culture make a difference and when they do not; and to what extent there is a generic experience of IBD, irrespective of ethnicity. For every theme, the data was explored to see if the experiences were essentially the same *for all* participants, or whether there were differences according to gender, faith, country of birth, age. We were especially keen to avoid using ethnicity as an essentialising variable, which explained all aspects of a person's experience. We wanted to understand ethnicity within the broader context of a person's life. Gender, for example, might be more important in understanding a person's experience than ethnicity. In addition, interview transcripts were searched for any explicit references made by participants to South Asian identity, culture, faith, traditions or community. Where evidence was found, the data was highlighted. Summaries of charts were then written up and the final structure of the report decided, with different members of the research team responsible for interrogating and writing up different themes. Finally, towards the final stages of writing, all members of the research team reviewed the findings.

The research participants

The final sample of research participants included 20 women and 13 men aged between 18 and 65 years of age. Twenty people identified themselves as being Indian/British Indian; nine as Pakistani/British Pakistani and four as Bangladeshi/British Bangladeshi. A large proportion (n=19) were born in the UK. Table 1 and 2 provide further details on the ethnic background, faith, gender and age of participants.

Table 1: Country of birth and ethnic background of research participants

	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

Response forms completed by the 33 research participants prior to taking part in the project indicated that 16 were Muslim, nine Hindu, seven Sikh and one person had 'no faith'. While interview data revealed that most participants practised this faith, six people (three Hindu, two Sikh and one Muslim) said that this faith was *not* an important part of their everyday life, describing themselves as not religious, only attending to religious events to pay respects to others, breaking religious observances (i.e. drinking alcohol) and/or being drawn to faiths other than the one they had ticked on the form.

Table 2: Breakdown of study sample by gender, age and religious affiliation

	Age	Muslim	Hindu	Sikh	Other	Sub-total
Male	18-24 yrs	2	0	0	0	2
	25-44 yrs	3	1	2	0	6
	45-65 yrs	2	1	2	0	5
Sub-total		7	2	4	0	13
	Age	Muslim	Hindu	Sikh	Other	Sub-total
Female	18-24 yrs	2	3	0	0	5
	25-44 yrs	5	3	2	0	10
	45-65 yrs	2	1	1	1	6
Sub-total		9	7	3	1	20
Grand total		16	9	7	1	33

Participants had been diagnosed with IBD for between three months and 21 years (median six years). Eighteen had CD and 14 had UC. Almost all had been prescribed steroids and over two-thirds had been prescribed immunosuppressants for their IBD at some point in time. Many had been also been prescribed biologics (n= 13) and/or been through surgery (n=8).

Table 3: Health background of research participants

	Number
Diagnosis	
CD	18
UC	14
Participant unclear	1
Surgery for IBD	
Yes	8
No	25
Ever prescribed steroids	
Yes	31
No	2
Ever prescribed immunosuppressants	
Yes	24
No	9
Ever prescribed biologics	
Yes	13
No	20

At the time of the interview, 17 participants were in paid employment (either full or part-time). Another six people described themselves as having caring responsibilities for either children or ill parents, five were students, and one was involved in voluntary work on a daily basis. Just one person described themselves as unemployed and another said they were on long term sick leave.

Table 4: Socio-demographic background of research participants

	Number
Marital status	
Married	19
Single	12
Divorced	1
Separated	1
Employment status	
Working (full or part-time)	17
Caring responsibilities	6
Studying	5
Voluntary work	1
Unemployed	1
Retired	2
Long term sick leave	1

Chapter 4 Living with IBD: The Shared Experience

Introduction

Interviewees typically struggled, at least initially, to identify ways in which their experiences might be different from the rest of the UK IBD population. For some this was because they were born and brought up in the UK and as a result had a reduced sense of South Asian identity and/or limited contact with the South Asian community, seeing themselves as 'British' or 'Westernised'. For others, it was because their experience of living with IBD was driven symptoms such as pain, tiredness, diarrhoea, and faecal incontinence and, as these having no ethnic or culture boundaries, it was hard to see how their experiences or needs might be different to others living with the condition:

'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, Indian/British Indian, Sikh]

And

'I never really thought of it like that, like the South Asian woman type thing, I just think as a patient'.

[Female, Pakistani/British Pakistani, Muslim]

This view that there is a generic IBD experience is important because it reminds us that South Asian patients have a great deal in common with the rest of the IBD patient population and much of the support they need and want will be the same. In order that this is not forgotten, and so that later data is contextualised, in this chapter we report on experiences for which we could find no evidence of influence by South Asian culture or faith. As we shall see, there does seem to be a generic experience of IBD irrespective of ethnic or cultural origins.

Dealing with physical symptoms

In this study participants varied considerably in the extent to which they experienced symptoms of IBD, from those who reported that their condition was well controlled and had little impact on their everyday life, to others who experienced frequent flare ups, spending periods of time completely debilitated by the condition, often housebound. However, 'flare ups' were not the only issue for participants. In between flare ups, many patients spoke of ongoing, milder but nonetheless troublesome symptoms (usually pain and fatigue), and worry that their health might worsen.

All participants spoke of the efforts they made to control or minimise the physical symptoms they experienced, and improve their sense of well-being. The most common approach was to seek medical advice and take up recommended treatments. In a number of cases people struggled with the side effects of medication, but for most people the benefits (e.g. avoiding pain, avoiding surgery, being able to work etc.) outweighed the disadvantages. Some spoke of how they had become more compliant over time, either through nurses explaining how the medication worked and would help them, or through experiencing how their health fluctuated according to the medication they were taking. Where patients did *not* take the medication prescribed, the main reason given was side effects. All concealed their non-compliance from clinic staff, though sometimes this was not successful. In addition to medical treatment, often driven by beliefs that IBD symptoms were exacerbated by particular foods and/or stress, people also spoke of: adjusting their diet; limiting the amount they ate and/or fasting; complementary and alternative treatments; lifestyle changes (e.g. slowing down, exercise); seeking the help of faith healers; adopting cognitive strategies (being positive or stoical), or turned to their faith and religious practice to help them cope.

Support from others

Participants did not manage their IBD in isolation but were offered and accepted support from others. Just as might be expected for any group of IBD patients, there was variability in the support available, and who people turned to for help, depending on their life stage and personal circumstances.

Most young people living at home seemed to receive a great deal of practical support from parents (e.g. having meals prepared for them; being taken to hospital appointments; help with self-care when very unwell; and, in some cases, help with the administration of enemas), as well as emotional support, such as parents ensuring they 'kept their mind healthy' by continuing to go out during periods of illness. While many said that extended family (aunties, uncles, cousins and grandparents) knew of their health difficulties, few seemed to get a great deal of support from these people. Instead they spoke of these family members finding it difficult to accept that they had a long term illness, repeatedly asking when they would get better, and/or questioning the treatment they were receiving. Young people also spoke of talking to friends about having IBD, but were selective about who they talked to and what they told them, keeping it a small group of close friends and not divulging a great deal about symptoms. Very occasionally friends visited the young person in hospital, or offered practical help, such as collecting notes from lectures.

For most married participants their main source of support was their spouse and overall spouses were reported to be very supportive. Support was practical (i.e.

taking over cooking, cleaning and childcare tasks etc.), health related (i.e. administering enemas, managing medication regimes, gathering information on IBD and treatment options etc.) and emotional (i.e. encouraging and helping the person to go out, encouraging the person to put their health before other priorities, calming the person down when stressed/upset etc.). However, there were also arguments and moments of tension and, in a few cases, support was said to be limited because the partner was tired from working or the couple did not have a close relationship.

Married people varied in whether they told extended family and friends about having IBD. Often they told people about their illness when it became obvious they were unwell due to fluctuations in their weight or a hospital stay. Conversely the illness, or at least the extent of the illness, could be kept hidden from people who did not live nearby and with whom participants only had telephone contact. The amount of practical support offered to participants by extended family was limited. While a couple of participants spoke of siblings and parents living nearby and being around to help (e.g. accompanying the person to hospital appointments, cooking meals during periods of illness etc.), it was more common for participants to report they did *not* have family members who were in a position to offer support, making comments such as the following:

'Everybody has their own life. Everybody has children. My sister has five children. Nobody can really help. The best they do, is if they come to visit me, they make their own tea. You know in this country everybody is busy with their own children and work. The most support comes from my husband. When I'm ill he helps and does everything'.

[Female, Pakistani/British Pakistani, Muslim]

A very small proportion of participants were living alone. Those who were younger tended to be in regular contact with family and friends, and could turn to them for support when necessary. In contrast to this, older single participants had few family or friends who they saw on a regular basis. Out of the all research participants, this group seemed most alone in dealing with their illness.

The emotional toll of IBD

Despite the efforts people were making to manage their condition, and the support received from others, the negative impact of having IBD on emotional well-being was a significant and frequently occurring theme in interviewees' accounts of their lives. It was apparent that many people were struggling to cope not only with the physical symptoms of IBD, but with the toll these symptoms had taken on their emotional well-being. Most commonly people spoke of experiencing periods when they felt 'low' or 'hopeless'. For example:

'You get depressed, you're trying to think of what I've done wrong, you know, in a sense, you know, why, cos your pain is such a severe pain, you can't even think of anything else'.

[Male, Pakistani/British Pakistani]

And

'It's just a battle everyday like. Sometimes I feel all right, but most of time like, I don't know, I feel quite down'.

[Female, Pakistani/British Pakistani, Muslim]

A very small minority spoke of times of intense despair and of wanting to 'give up'. One interviewee had attempted suicide on a number of occasions. Comments such as the following were made:

'You get to that stage you will say, what's the point of living, when, you know, sometimes it's so bad that you, you just don't want to be in that situation'.

[Female, Indian/British Indian, Sikh]

And

'I feel like I'm not living life, I'm existing. When I count the years, I'm going, "Okay, now you're probably going to live 'til you're 65" and I think, "You're 46 next year, how many years have I got?" That is it; that is my life. So I'm thinking how much longer have I got? It's almost like waiting for it to end, for life to end. I want to believe in reincarnation and maybe the second time round will be better'.

[Female, Indian/British Indian, No religion]

A number also spoke of feelings of anxiety and/or panic. Most often people described these feelings being brought on by worries about needing the toilet urgently, as described by the following participants:

'We've just left the house ten minutes ago, why couldn't you have gone then? I didn't need to go then, now I need to go .. and then I'm in a panic even more because I think oh I'm not going to get to the toilet on the journey there .. so that makes me want to go even more. It might not be a flare up, I think it's sort of probably psychological half the time'.

[Female, Indian/ British Indian, Hindu]

And

'I'm a bit wary now, of sort of going on a long trip, because with the problem I have got is I can't really hold my bowels too long, you know, just literally minutes, just a few minutes and I've got to get to a bathroom. It may not, you know, may not ever happen, I may not ever have an accident. But it's just this fear that, you know, if I'm say, you know, travelling on the motorway, it's always going to be nagging in my head, oh no, no, if something happens there's

nothing – you know, I'm not going to get to a bathroom for another 30 miles. So, it's just things like that really that...

[Male, Indian/British Indian, Sikh]

Other worries, such as minor symptoms which might indicate the onset of a flare up; worries about eating the wrong foods and triggering symptoms, and thoughts about developing cancer were also mentioned.

Some people spoke of how their low moods, including feelings of irritability and anger, affected not just themselves but also the rest of the family, including both spouses and children:

'I try my family .. telling them "Do not say anything which I do not .. I dislike, or I don't like it, try to avoid it. And when I'm in a position where I, I'm not well, I don't like certain things, do not argue with me" because I get very angry and I shout at them'.

[Male, Pakistani/British Pakistani, Muslim]

And

'Sometimes I'll get agitated, you know, it'll affect my mood when I'm not well, because I'm so tired cos of the pain .. I find it affects my mood, and I, I get upset with that because then it's a knock-on effect on everyone else isn't it? And if you're kind of the backbone of the family, so if it affects you, it's gonna affect, it's a ripple effect, it's gonna affect everyone else isn't it?'

[Female, Indian/ British Indian, Hindu]

Impact of IBD on everyday life

Although participants were making considerable efforts to manage their IBD, nevertheless it remained the case that IBD impacted on many aspects of participant's lives, with some variation according to life stage.

Social and leisure activities

An issue for participants of all ages and life-stages was the impact of IBD on social and leisure activities. People spoke of difficulties taking part in family activities or outings (e.g. going to the park, cinema, shopping, or to visit friends and family etc.), avoiding meeting up with friends and family, or attending social events, as well as giving up taking part in or going to watch previously enjoyed sport. In some cases, people's social life was only affected when they were having a flare up. For others the impact was more pervasive, with them explaining that even when they were *not* having a flare up they avoided going out socially because of milder ongoing symptoms such as pain and/or tiredness, fears that they *might* experience

symptoms, worries about whether it would be possible to get access to a toilet when out, embarrassment about using toilets in public places or other people's homes, and generally feeling unhappy or 'low':

'I don't actually socialise, I don't go out, I don't feel comfortable going out with the condition I've got .. because I feel too tired.....I just don't make plans because I don't know what the severity of the pain is going to be like. I just don't make plans...because the severity of the pain varies day to day'.

[Female, Indian/British Indian, Sikh]

And

'I think with the social gathering bit I would just, even if it wasn't a day that I was feeling particularly unwell I'd probably avoid, or maybe avoid it .. because I don't know, it, it feels like you've got so much going on and then everyone's just going to be talking about their hairstyle or their nails or something and, and you're not really bothered, so I'd just avoid going'.

[Female, Indian/British Indian, Hindu]

Some young people also spoke of not even having the energy to telephone or text friends. In a few cases people spoke of gradually losing touch with friends after seeing less of them, making it difficult to re-establish a social life when they were feeling well enough to do so:

'I used to go out drinking with friends, but I can't do that so much now because of the colitis. It's spoiled my life in some ways, you know, my interactions with other people, playing golf at the weekend; I don't go out so much now. I used to play golf at the weekends, and I really enjoyed that. I had lots of friends there, my golfing friends, and we would have a drink and a chat afterwards; that was very nice. But you know, there are no toilets on the golf course of course [laughs] and so it became too difficult, and eventually I stopped going there. So it's very sad, and I don't see those friends now, not really'.

[Male, Pakistani/British Pakistani, Muslim]

Education, employment and finances

Younger people spoke of struggling to complete further education (HNDs and degrees), particularly when the course involved placements. Many managed to complete their course, though it took more time than it should have, but a few did not. A couple of young people who were ill in the period immediately after completing a degree or training course said that, even though they had now recovered, they were struggling to find their first job.

Amongst participants who had experience of employment, some spoke of IBD causing some to give up work completely, a few to work part-time, one to take early retirement, and another to be on long term sick leave. Others spoke of how they managed to work by: changing to a less stressful job or one that involved less travel; trying not to work excessive hours; using annual leave to rest at home during a flare up; and not eating or drinking prior to work so as to avoid an upset stomach/bowel.

Most participants chose to tell colleagues or employers they had IBD, explaining that people would find out anyway due to the need to take medication at work or have time off for treatments and investigations. Responses had been mixed. There were examples of extremely supportive work colleagues and employers, with people speaking appreciatively of colleagues who visited them when they were ill, and employers who had offered flexi-time contracts and offered to pay for private medical treatment. A small number of people spoke of having a very difficult time, with employers placing increasing demands on people despite knowing about ill health, or threatening to take disciplinary action due to lateness for work when unwell. A few people who were unable to secure flexi-time or short working hours spoke of struggling with work and worrying whether they would be able to continue in their current job.

A number of people spoke of financial difficulties, explaining that they had run into problems for a number of reasons, including: the need to work part-time; the need to change to a less demanding but lower paid job; spouses reducing their working hours because the interviewee being too ill to look after children; being refused disability living allowance; and/or no longer being eligible for sick pay.

Relationships with partners and spouses

Although most people who were married had very supportive partners, a number spoke of how having IBD had at times put a strain on their relationship. This included both major and everyday sources of stress or strain. For example, financial worries caused by having IBD, the strain caused by a partner having to take over the running of the household, being too ill to be interested in sex, and the inconvenience of the frequent need to find a toilet when out. Two people who were single spoke of how having IBD had contributed to the breakdown of their relationship with previous partners, both attributing this to not being well enough to go out and socialise. The period prior to or shortly after diagnosis, when partners had limited understanding of the interviewee's illness was reported to be particularly difficult. For example:

'At the beginning when it was .. it was all really bad .. I, it was really hard in the bedroom just to be sexually active, it was so hard. .. I couldn't make him understand that, you know, I was having stomach pain, stomach pain, we were arguing constantly because he'd think I've had something bad to eat or, when

he's at work, or having too many chips or too much curry or what not. So it was really hard to make him understand, and things were really emotional for me back then because I, I didn't know what was wrong with me to make him understand, so it was hard for him cos he, he's had to basically cut down his hours at work .. just so he can be at home to look after our daughter, cos she was only one year old then. So it was very hard at that time for me. I mean there was a point was where things were stretching so hard that I just felt like I wanted to run away from this relationship. It was really bad'.

[Participant's characteristics withheld to ensure anonymity]

Parenting and caring responsibilities

Parents, mostly but not exclusively mothers, spoke of what a struggle it was to care for young children. Pain, tiredness and frequent trips to the toilet made tasks such as taking children to and from school, cooking, washing and dressing children, keeping up with physically active children, and helping with homework difficult:

'They all need their hair done. Bathing them and getting them dressed. They are all young and need their mother, I'm their mother. They are not mature enough to take care of themselves. When it comes to children, you have to take care of everything for them. You need to make sure they eat. A mother will make dinner for her children. But when the mother is ill who will take care of them?

Interviewer: *How does the mother cope?*

Participant: *With great difficulty'.*

[Female, Pakistani/British Pakistani, Muslim]

And

'I don't want to go out, I want to rest quietly on my own and sometimes it's difficult because I don't want to play with the kids, you know, staying upstairs in bed; I don't go out, I don't go to the park with kids, don't go out, do the shopping, so it's very hard'.

[Male, Indian/British Indian, Hindu]

Mornings were particularly problematic because of frequent and urgent need for the toilet at this time.

Chapter 5 How Does South Asian Identity, Culture and Faith Influence the Experience of Living with IBD?

Introduction

This chapter reports on how South Asian culture and faith influence people's experience of living with IBD. As we have seen many of participants' experiences were generic and might be experienced by anybody with IBD, irrespective of their ethnic background. However, as interviews unfolded many described how aspects of their South Asian identity (i.e. faith, language, ethnic background, country of birth) and relationship with others in the South Asian community affected their experience. Analysis revealed that many of the issues were concerned about the social context in which people lived with and managed their condition, with a number of cultural factors influencing both how family, friends and members of their wider community responded to them having IBD and, in turn, how participants felt about having IBD and how best to manage it. These cultural influences were numerous and wide-ranging, including:

- culturally specific difficulties understanding IBD;
- the stigma of ill health within South Asian communities;
- the perception that bowel movements are a taboo subject;
- beliefs about the links between food and health;
- alternatives to conventional medical treatment;
- cultural expectations about a woman and a man's role with the family;
- 'Spicy' food is the norm;
- living with extended family.

In addition, participants described challenges which we would argue are more likely to be encountered by, but are not exclusive to, people who are South Asian. These were:

- making visits to extended family living overseas;
- practising faith.

These cultural influences and additional challenges are described further below.

Culturally specific difficulties understanding IBD

A number of people spoke of it being difficult for family to understand IBD because it was not a condition they had heard of before. Many also spoke of not knowing

anyone from their own community who had IBD and/or that it was rare in the country their family originated from:

'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, Indian/British Indian, Hindu]

Language barriers could make it difficult to explain the condition to family, with some people mentioning that the situation was made worse for them due to there being no word for Crohn's in Punjabi:

'Of course they have no understanding about the Crohn's, even abroad as well, they, all they know is about TB or... they have infection, or ulcers, but Crohn's is something unfamiliar abroad. What is Crohn's? But this is not a name abroad, in the UK or any foreign country, they have given it Crohn's or colitis, but abroad is, this, this thing is totally unfamiliar, they have not given this name'.

[Male, Pakistani/British, Muslim].

The term 'inflammatory bowel disease' also caused some confusion for some participants' families since 'disease' had different connotations in South Asian countries, the implication being from a number of participants that a disease was generally considered infectious and/or life-threatening:

'The first day I told my husband he was gobsmacked because he's never heard of having a disease where you don't end up dying'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

A perception that others, even close family members, would not understand the condition prevented individuals telling people about their condition. This seemed to apply particularly to older family members and those not living in the UK:

'I haven't told my brothers and sisters or anyone, I just feel like it's embarrassing for me and I just feel like, you know, to tell someone that you, you've got a disease .. just like the reaction I had at the beginning, oh it's something that's catchy, it's something that you may end up dying, I don't want no-one to feel like that, I don't want people to start treating me differently... Nobody else apart from husband and father knows - to be honest, not even my in-laws abroad..., they're not all that highly educated, they're just going to take things the wrong way round'.

[Female, Bangladeshi/ British Bangladeshi, Muslim]

And

'I just feel embarrassed to tell anyone really, especially my mum. If I tell her then, I don't know, just talking about it out of context, she's more on the traditional side, she'll think something's come over me like, I don't know, like, you know, black magic and all that stuff. She's more into that, she'll say, oh something's come over you, or like, let's make you see a Moulana or all that and everything. I just don't want to go through that with my mum'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

In a small number of interviewees (all Muslim men), and their families there seemed to be a culture of self-blame for illness, sometimes connected with some form of religious transgression. Muslim men who had moved to the UK from Pakistan prior to diagnosis, as well as their family, blamed their ill health on drinking alcohol and/or eating 'junk food' when they moved to the UK. For example:

'People say it's cos I've been eating most of the time outside [of the home] like. That's what I was thinking that's why it happened and maybe also that I've been eating outside food, takeaway food'.

[Male, Pakistani, Muslim]

Another spoke of his parents believing that him having IBD was a punishment for behaviour which had led to him spending some time in prison. In one case, a participant spoke of how perhaps if he had been a better Muslim, and not been so greedy, he would not have developed the condition. Here beliefs about what it was to be a good Muslim were combined with beliefs about the impact of lifestyle on IBD, with him explaining that because he had been greedy, he had worked too hard, and that this lifestyle had brought about ill health. One participant expressed the view that IBD might be sexually transmitted and that the increase in prevalence in South Asian patients was due to people having relationships with someone who is White British.

The stigma of ill health within South Asian communities

Some participants said that they did not tell others about having IBD because within their community being ill reflected badly upon people, impacting on prospects for an arranged marriage and raising concerns about the health of their children or any children they might have. For example:

'So I think, yeah, people tend not to talk about, you know not only IBD but like if they have any illness in general.... the Asian community like arranged marriage

is still prevalent, so if you were, wanted to do that and you said that, that you've got this then .. people, like an opposite party is less likely .. going to want to marry you...I think they also look for like .. they don't want it to seem like you've got bad genes or anything cos then you could like pass it down to your children or whatever'.

[Male, Indian/British Indian, Hindu]

And

'If you want an arranged marriage, if you are gonna have an arranged marriage, it probably is hard to find somebody because everybody will always think you're just ill, and nobody, I think in, in Asian culture everybody wants this perfect partner who's, you know, got everything and, you know, illness plays a big role, nobody really wants to be with somebody; it sounds really awful but there is, you know, this cultural expectation that you're fit and healthy and they don't, especially for a girl I think, because they expect you to have this like housework, take on this housework role, and if you're not well then you're not gonna be able to look after the family and your husband and what not'.

[Female, Pakistani/British Pakistani, Muslim]

This view that having IBD could impact on an individual's marriage prospects was also shared by an older male participant, who felt sympathy for younger patients with IBD:

'It's .. you get marked, don't you? When, when you live in a close knit community .. say for example .. if you're a young girl or, unmarried young girl or a man and .. people find out you're suffering from this condition .. I know for a fact that .. you know, people will look at, twice at them, you know, for relationships and stuff like that.....and .. other issues .. as well. So .. some people might even think it's contagious or something like that'.

[Male, Indian/British Indian, Muslim]

In addition, there was a perception that rumours about your health will spread quickly throughout the South Asian community, resulting in a loss of privacy and unwelcome visitors when you are in hospital. The following extract illustrates this issue:

'I think being, Asian people aren't, everything's taboo, everything's hidden, don't tell anyone and that's just the way things are. I think that's changing now as time's going on, people are talking and discussing. if you had a certain condition you'd end up, you know, through Chinese whispers, as having a different condition or being worse than it actually is, or somebody will say other things. So people tend to not say things as much. Initially that was the reasons, you know, we don't want to tell everyone cos people will start changing things and making things worse than they actually are, or people will come hounding in at, at the hospital, we don't like anybody at the hospital, we just want to be left alone .. that was the reasons why I didn't tell anyone .. and it's just sort of

carried on that you don't want to be labelled as different or weird or got a condition or a, .. something wrong with you'.

[Female, Hindu, Indian/British Indian]

The perception that bowel movements are a taboo subject

A number of people expressed the view that IBD is a taboo subject within South Asian communities, particularly within the older generation. This meant it could be difficult to discuss health problems with family members and/or members of the wider community. In discussing this, participants acknowledged that talking about bowel related issues can be difficult for anyone, whatever their background, but maintained that these difficulties were greater for people from a South Asian background, comparing their experiences talking to people from different backgrounds as evidence of this. For example:

'I had a colonoscopy there [Pakistan] and it was, it was awful, like they just, it's just not something they speak about. Or even when I went to see the doctor I just did not feel comfortable telling him about my bowel movements, whereas when I go to the doctors here [UK] it's fine. But I really did not feel comfortable at all discussing my bowel movements there, with him or actually the other, any other Asians really, whereas over here it's, it's more acceptable I think to discuss'.

[Female, Pakistani/British Pakistani, Muslim]

Beliefs about the links between food and health

Interviewee's reported difficulty getting others to accept their IBD related dietary restrictions because of beliefs about food. First, some spoke of there being a perception that if you change your diet you will no longer be ill because of beliefs that health problems are the result of an imbalance in the foods that you eat. Second, when a food is considered blessed within a particular faith, it can be difficult to get others to understand or accept an inability to tolerate it. As one man explained:

'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, Indian/British Indian, Sikh]

Alternatives to conventional medical treatment

Many participants spoke of using some form of complementary or alternative medicines or treatment (CAMs) to help them manage their condition, including: Aloe Vera gel; wheat grass; fennel seeds; Isabgol³; ayurvedic medicine⁴; herbal oils and tablets; homeopathic medicine; Reiki healing; hypnotherapy; yoga; and reflexology. Reasons given for using such treatments were: that people would rather do something that helps alleviate symptoms a little than do nothing at all; that it helps give you a more positive mental attitude to your condition; wanting to feel that something healthy was going back into their body (to counteract the effects of medications); wanting to do something that might reenergise their body; and feeling that giving themselves some 'TLC' (tender loving care) helped to make them feel better. In most instances, people said they did not know what was in the homeopathic or herbal remedies taken. It was notable that a number of people felt such treatments would not do any harm as they were 'natural' or herbal'. However, a few had suffered side effects and were surprised to learn from their IBD specialist nurse that some herbal remedies do not mix well with IBD medications.

Although anybody with IBD might choose to use such treatments, the data suggested that South Asian patients may be more likely to encounter such treatments during the course of their everyday life. It was notable that some of the CAMs mentioned were traditional Indian medicines or remedies (e.g. ayurvedic medicine, Isabgol) or participants mentioned buying them from 'Indian shops'. One person spoke of how in certain cities in the UK with a high South Asian population there are many shops selling herbal remedies. A few people spoke of seeking out homeopathic treatment when they had visited family in South Asian countries and one man spoke of how he planned to look into herbal treatments the next time he made a trip to Bangladesh as they were widely available and used to treat a number of illnesses. A number of patients also spoke of family members, encouraging them to seek out/or use CAMs, including 'Asian remedies', either within the UK or abroad.

³ **Isabgol** (also known as Psyllium seed husks) are portions of the seeds of the plant *Plantago ovata*, a native of India and Pakistan. Psyllium seed husk are indigestible and are a source of soluble dietary fibre. They are used to relieve constipation, irritable bowel syndrome, and diarrhoea. They are also used as a regular dietary supplement to improve and maintain regular GI transit. The husks are used whole in their natural state, or dried and chopped or powdered for easier consumption. In either of these forms, one takes them by mixing them with water or another fluid.

⁴ **Ayurvedic medicine** is a system of Indian traditional medicine which originates from the Indian sub-continent and is based on the belief that health and wellness depend on a delicate balance between the mind, body, and spirit. The primary focus of Ayurvedic medicine is to promote good health, rather than fight disease, but treatments may be recommended for specific health problems. Ayurveda is at present well integrated into the Indian National health care system, with state hospitals for Ayurveda established across the country (WHO, 2014). However, concerns have been raised about Ayurvedic products; with some U.S. studies have shown that up to 20% of Ayurvedic U.S. and Indian-manufactured patent medicines sold through internet contained toxic levels of heavy metals such as lead, mercury and arsenic (Saper et al, 2008).

However, it should not be assumed that all South Asian patients will be encouraged to use, or will automatically take up, such treatments. Some participants had family members who were health professionals and who had warned them against the use of CAMs which were not tried and tested. A number of participants spoke of their concern about taking any form of alternative remedy, sometimes because they had witnessed a family member use CAMs unsuccessfully, and expressed a preference for medical treatments. For example:

'I just feel like the doctors are in their places for a reason, the consultants are there in their places for a reason, we should just leave these things up to the professionals'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

Furthermore, although a couple of interviewees referred to pressure from one or more family members to seek help from a faith healer, this was resisted on both occasions due to feeling that it would not help, believing that the faith healer might be a 'Charlatan', and/ or feeling that seeking help from such people was not part of the Islamic faith. Just a small number of people said they had been to see some form of faith healer, and in two instances these had been '*English healers*' and not someone from their own faith. One Muslim had sought help from an Imam and had received prayers and holy water. In all of these cases, the help of a faith healer was being used in addition to, not instead of, medical treatment.

Cultural expectations regarding a woman's role within the family

A number of female participants spoke of how having IBD impacted, or could in the future, impact their ability to be a homemaker and/or mother. This concern was not just about the practical difficulties of managing these roles and responsibilities when ill, but also about the social consequences if they failed to do so, with interviewee's talking about how people within their community would think badly of them, with one person going as far as to say that people might think she has been affected by black magic if she is seen to be unable to look after her home:

'I do understand once I do have a family of my own it'll be much more difficult. If I don't have the energy to do things like that now I can't imagine how it will be then. So it does, that is a bit worrying.....I think that can be quite difficult for Asians to understand, South Asians. I think the fatigue thing as well cos people just think you're really lazy and there's like these expectations that you should be doing all the housework and things, because it's just like Asian culture, you know, you're expected to be like, like a housewife and if you don't do all that they just think you're useless and lazy'.

[Female, Pakistani/British Pakistani, Muslim]

And

'I mean if people, my family or anyone find out that my husband's helping with cooking and cleaning, not everyone's going to be happy about it, everyone's going to say well what's the wife there for? The husband has to go to work, has to cook, has to clean, get the children from school and everything, what's all that about, you know, what's the wife doing? It's really hard to explain to people that when you're unwell you're unwell, you know, you call it a day you can't do anything, people just expect, you know, wives get, probably get just the old sniff or flu or cold and, but they still get on with it, they still make the chapattis, they still make the rice and stuff, but with Crohn's it's totally different, it's totally the opposite, you can't do anything'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

A couple of recently married women spoke of how their new role as wife obliged them to attend family gathering and celebrations in a way that had not been expected prior to marriage:

'Before when I was living at home I was able to say to my mum that I don't think I can go to this wedding or I don't think I can go, you know, to someone's party or whatever. Now it's not like that. It's almost like when you're a daughter-in-law you're expected to go to everything'.

[Female, Indian/British Indian, Hindu]

Negotiating non-attendance of such events when unwell was made more difficult for these participants when they had not told others outside the family that they had IBD.

Sometimes concerns were specifically about difficulty becoming pregnant due to having IBD:

'If I'm honest, there's just that big burden in your head that, you know, I get the pressure in our culture just to say why aren't I getting pregnant again, that's, that's one of the big pressures that I get. My sister, she's got two kids, and then my younger sister, she's expecting, you know, people just question the fact "oh why aren't you getting pregnant, what's wrong with you?" etc. etc. but you can't go around telling everybody I've got Crohn's disease, I'm unwell, do you know, that's why I'm not getting pregnant maybe as quick as a normal person will'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

And

'Really I was supposed to be married and have ten kids by now, the Asian way. But yeah, life has just taken its own turn and I'm just taking it day-by-day and just kind of going with what I've got now. .. I'm gonna have IVF and have a baby, so I'm, and that's my hope, to have a baby, even if I just have one'.

[Female, British Punjabi, Hindu]

Cultural expectations regarding a man's role

It is important to acknowledge that men also felt pressure to meet culturally prescribed obligations, with one man describing how his ill health meant it was a struggle for him to be the father figure he was expected to be to his brothers, providing financial help and guidance, since his father passed away. He also spoke of his difficulty accepting that his wife needed to go out to work because of his ill health:

'Sometime I don't feel it's right thing to do it, you know, for a woman, even though it's, Asian family it's just a tradition, you know like men should be working, women stay .. but it's just a modern environment, so of course, she used to work, she used to work before she was born [their child]. But now she saying "OK, if you take a rest and let me just take over and, you know .. carry on .. work, you know, and you just take a rest" because the situation's deteriorating a little bit'.

[Male, Pakistani/British Pakistani, Muslim]

'Spicy' food is the norm

Most participants lived in households where eating traditional South Asian food was the norm. This was a significant issue for participants since the majority of participants believed that 'spicy' food, specifically food that contained chilli, was something they needed to avoid. Problems were also reported with vegetarian food, which often featured in family meals. Almost all participants who felt there was a link between South Asian diet and IBD felt that it exacerbated, rather than caused, their condition, though there were exceptions. For example:

'We have a lot of salt and chilli and dairy milk in our diets and that could again maybe contribute towards the Crohn's ...and maybe also the chilli. If you put chilli on your skin, if you ever put it on the skin and you're keeping it on the skin, eventually you're going to get – you're probably going to get – it's going to go all red, isn't it? Start stinging, etc. So if you're ingesting it...every day it's in the curries and it's got chilli, always got chilli every day constantly, week in week out, a couple of times a week, that chilli is going to start burning your insides, yeah, no? I don't know and this is just a thought maybe'.

[Female, Indian/British/Indian, no religion]

Where the person had responsibility for cooking, the need to avoid such foods was manageable, with participants describing how they modified meals and how, in general, their family had learnt to accept these adaptations. However, where the person was not in charge of cooking (usually a young person still living at home with their parents or a married woman living with her in laws) this could be difficult as

sometimes family members did not understand or accept the person's inability to tolerate spicy and/or vegetarian food. As a result some people spoke of eating food they knew would make them ill. For example:

'It was a struggle trying to get somebody to understand what non-spicy was, cos it was just wasn't, cos they used to think it was not spicy. Our definitions are totally different. .. But yeah, I think you just got on with it .. you just eat what's there, I'm lucky to have food on my plate, so yeah, it's fine, just eat it .. so yeah'.

[Female, Indian/British/Indian, Hindu]

And

'Or even at home if my mum's made something and I find it, if I tell her I, I find it quite spicy, she just thinks that, you know, it's just me being funny because everybody else is fine with it, and then because of that sometimes you just, you know, you try not to mention anything and you just carry on eating or whatever, which can affect you quite a bit, cos like I said I do think diet plays quite an important role in my IBD so it can flare up my Crohn's'.

[Pakistani/British Pakistani, Muslim]

South Asian diet also caused people difficulty outside the home. For anyone suffering from IBD, going to social events such as weddings or parties is difficult when unwell and experiencing fatigue, pain and or toilet urgency. For South Asian patients there is the added complication that attending such an event involves accepting food which is spicy and which they would rather avoid. Participants dealt with this in different ways. Some simply avoided going to family events, unless it involved close relatives. Others attended events but stayed a short time in order to avoid eating. Some attended social events and ate despite knowing they would be ill the next day. Visiting family members who were aware the person had IBD was less problematic, as under these circumstances people felt able to take their own food with them.

Living with extended family

A number of participants lived with extended family and most described these family members as broadly supportive. However, women who had moved in with in-laws on getting married described how they initially felt embarrassed about symptoms and their frequent need to use the toilet. This caused one woman to spend much of her time when unwell in her bedroom in order to maintain some privacy. Most people said that over time, as family members became more aware of their health difficulties, embarrassment gradually disappeared. In a few cases participants also spoke of having, or feeling they had to, cook and clean for the whole family despite being in very poor health. Participants also pointed out that living with larger extended families could mean speedy access to a toilet was more difficult.

Visits to extended family living overseas

A large proportion of participants spoke of making trips to South Asian countries, usually to visit family or attend a family event, such as a wedding. For many it was the family related nature of the trip that encouraged people to go despite a number of worries and concerns. The most common worry was about making the journey itself, with people referring to fears about being able to get to a toilet whilst on an aeroplane or when travelling long distances within the country:

'And my worry would be what if I don't get a toilet from Bombay just to where I'm going which is five hours' car journey... what happens if I can't get to a toilet or there's not a decent toilet to go to, or I have to keep stopping. I've already started thinking about that'.

[Female, Indian/British/Indian, Hindu]

And

'I've not been on a plane since 2007 because on a plane, you have to queue for the toilets, and you feel embarrassed if something happens to you, that's the reason'.

[Male, British Pakistani, Muslim]

Other concerns about making visits to South Asian countries were: worries about having to seek out medical treatment from people who are not familiar with IBD; getting a 'tummy bug' as this could have a huge impact on the health of someone with IBD; and difficulty disposing of stoma pouches. As a result of such worries some people had chosen not to make trips to South Asian countries. Where participants had relatives they were close to living in these countries, this could be a source of considerable upset.

Where people had made trips, they spoke of preparing for and managing such trips by: eating nothing at all whilst travelling; carefully planning of toilet stops (including seeking out mosques for their toilet facilities); and carrying medication and/ or their own food with them wherever they went. One patient went as far as to take a mini fridge on her trip in order to store humira injections at the appropriate temperature. Unfortunately, the medication became inactive due to it not being stored correctly whilst travelling. This in turn brought about a flare up in her condition, resulting in her having to cut short her trip in order to return to the UK for treatment. The person in question spoke of not fully understanding how quickly the medication became inactive when stored incorrectly.

A few participants spoke of being encouraged by family and friends to seek a second opinion or treatment for their IBD from doctors in South Asian countries and in a few cases people had done so. Others had sought help due to a flare up will abroad.

One spoke of running into difficulties because the doctor had not heard of ulcerative colitis and of how taking along leaflets in Punjabi to overcome any language barriers did not help:

'I took the Crohn's and Colitis .. Punjabi leaflets with me .. they haven't really heard much about it.and just to kind of explain it to Asians is really hard. They're like "What is this? What do you mean? Ulcers, where? What happens to you?" They're, they're just like oblivious like that. So that was a bit odd. ..'

[Female, British Punjabi, Hindu]

Another said that, although he had consulted a doctor abroad, he did not trust the advice offered so he had not taken the medication recommended:

'I don't trust that much the foreign medication, even though I'm bred and born there, you know, spend half my life there'.

[Male, Pakistani/British Pakistani, Muslim]

Perhaps because of the difficulties they anticipated, seven participants were surprised to find that their health improved while they were abroad:

'That was remarkable because I had no flare up when I was in Pakistan. I mean I thought I might struggle there, because there's a bit of a culture shock as well, you know, different foods, different environment, and I was staying there for four weeks .. I came out completely unscathed, it was a bit of a miracle for me, you know. I thought to myself I've had four flare ups already, now I'm going to Pakistan, I was feeling a bit worried about it, should I go, shouldn't I go, you know, with the different climate there, but I came through perfectly fine'.

[Male, Pakistani/ British Pakistani, Muslim]

People speculated as to why their health improved, most commonly referring to the warmer climate. Other possible explanations given were that it was less stressful abroad as they were looked after and/or well fed by family. Unfortunately, a few people did become ill while making trips. In most cases, people were clear as to why this had happened, referring to how they 'relaxed' and had stopped taking prescribed medication and eaten food they cannot tolerate.

Practising faith

People of all religious denominations spoke of how their faith helped them to cope with having IBD, particularly at times when they were in pain. A number described: the calming, almost meditative, effect of prayer; the benefit of being active within their faith community since this provided a reason to overcome difficulties caused by

IBD. Muslim interviewees in particular expressed the view that having IBD was God or Allah's 'will'. They explained that this helped them to view IBD not as a problem, but as a challenge sent by God, which they needed to both accept and rise up to. One participant took comfort from the thought that if she suffered in this life she would suffer less in the afterlife. A few people commented on the fact that they had learnt about the benefits of fasting as means of reducing IBD symptoms after fasting for Ramadan. Much of what patients had to say about their use of faith to cope with IBD is encapsulated in the following quote:

'It would be easy to say 'why me?' but being Muslim everything is seen as a test. They question is "How are you going to deal with it?" Even if you prick your finger on a thorn. The prophet was closer to God when ill and so I may be too. This is my destiny. If I didn't have Crohn's I wouldn't be as understanding of people as I am. Also, this life is temporary, which helps. What doesn't kill me makes me stronger. Also prayer helps to calm me down. This hospital Imam was also very helpful. He would try to give me a pep talk. Help me to see things in a positive way. Despite what they say in the media, Islam can be a positive thing and it's very relaxed. During Ramadan you don't have to fast if you are unwell, even if it's just a headache'.

[Female, Pakistani/British Pakistani, Muslim]

However, a common theme among Muslim interviewees was the difficulties they encountered in practising their faith. There were three main reasons for this. First, the act of Salat⁵ is a physically demanding one, so was difficult for people to perform when in pain and fatigued. Secondly, participants explained that prior to praying they had to perform Wudu⁶ and, if they were going through a flare up, this could be physically demanding as they would be required to repeat it prior to each prayer. Finally, people also spoke of worries about passing wind if going to the Mosque for prayers. As prayer was an important part of daily life, some pushed themselves to pray as much as possible despite these difficulties since not doing so led to feelings of guilt. Others prayed more when they were well to make up for missed prayer.

In addition to the difficulties Muslim patients had practising their faith, they also explained that the cleaning rituals required as part of their faith made it difficult to go out of the home when having bowel related symptoms since it was hard to find bathrooms with the appropriate washing facilities:

⁵ **Salat** is the practice of ritualistic prayer in Islam. It is usually performed five times a day and preceded by ritual ablution. It consists of the repetition of a unit called *arak'ah* (pl. *raka'āt*) consisting of prescribed actions and words.

⁶ **Wudu** - Before conducting salat, a Muslim has to perform a ritual ablution. Wudu is performed using water (*wudu*) and involves washing the hands, mouth, nose, arms, face, hair (often washing the hair is merely drawing the already wet hands from the fringe to the nape of the neck), ears, and feet three times each in that order. It is not obligatory to wash the hair three times, once is sufficient, and men must also wash their beard and moustache when washing the face.

'When you [someone who is not South Asian] would have to go to the bathroom, you would just go to the bathroom. When I'm outside [the home] I have to go to the bathroom where there's like maybe water facilities or I'll take a bottle or something with me. We clean ourself in a different way, because of our religion, so that would be a big issue for me. When I first got Crohn', and I was suffering from diarrhoea, it put a lot of fear on me. .. So yeah, it would probably prevent me going out for long periods of time'.

[Female, Indian/British Indian, Muslim]

Chapter 6 Experiences with Health Services

Introduction

In this chapter we report on support from the two main providers of health services and support to IBD patients: General Practitioners (GPs) and gastroenterology services. Much of what people had to say was about their generic support needs, irrespective of their South Asian background. However, we report it here since we consider it important that this evidence is not lost, but is added to the existing literature on the support that IBD patients' value. Views on how well services attend to the needs of South Asian patients are reported later in the chapter. Finally, we end by reporting on the additional support participants would like to see provided by health services, including South Asian specific recommendations.

Support from GP services

Very few of the participants in this study consulted their GP for treatment or advice on IBD. A wide range of reasons were given, including: feeling that their GP did not have sufficient knowledge to treat the condition; the gastroenterology clinic is quicker to respond to requests; the GP is not up to date on their test results and health status; prior experience of their GP being unsympathetic; and lack of continuity of care within general practice, with people seeing a different doctor every time they made an appointment. The following quote encapsulates many of these feelings:

'The doctors [GPs] don't give you any time, you only have ten minutes with them, and they don't listen to you. You see a different doctor every time, and you have to explain it all again, so they don't know what's going on with you – they are not interested'.

[Male, Indian/British Indian/Hindu]

In some cases, a breakdown in the relationship with the GP seemed to stem from the initial diagnosis, with participants stating that they felt disappointed with or let down by their GP during this time. Sometimes this was because the GP had failed to refer them for investigations despite numerous requests for help and/ or obvious signs that investigation was required (bleeding or extreme weight loss). Participants also spoke of the consequences of GPs being slow to refer them for investigations and treatment, saying this had led to: traumatic emergency admissions to hospital; severe pain; the unnecessary development of infections; lengthy hospital stays; long term consequences for their health; and, in one instance, the near loss of a baby during pregnancy.

Given these experiences it is perhaps not surprising that most participants chose to turn to gastroenterology services for IBD treatment and advice, and the remainder of this chapter focuses on these experiences.

Support from gastroenterology services

When asked about support from gastroenterology services, it was clear that there was a great deal of good practice, with half the participants having only positive things to say about their experiences. Most of the remaining participants reported a mixture of things they liked and didn't like about the support received.

Positive aspects of support provided by gastroenterology services

By far the most common reason for being positive about support from gastroenterology services was ease of access, with the majority of respondents mentioning that if they had any questions or worries they could get in touch with their specialist nurse or a consultant either by telephone or email, and that they would usually receive a swift response:

'My nurse gave me her phone number and email so I can call her if I want to, which is helpful. I called her once and explained to her my problems and she was very helpful, very nice. It's an excellent service I think, the clinic is excellent'.

[Male, Pakistani/British Pakistani, Muslim]

And

'I've got to say she's probably one of the best .. you know, nurses I've come across in my life. .. From the minute I was introduced to her .. up until even today, she's still with us, she's only a phone call away, like she says, you know, she returns our calls on time, even on the days when I'm feeling really bad .. she'll tell me what I need to do'.

[Female, Bangladeshi/British Bangladeshi, Muslim]

In a few cases, people (usually those who have been very unwell recently) spoke of how they could get an outpatient appointment immediately, or within a few days of requesting it.

Participants also spoke of how easy it was to talk members of the gastroenterology team, (including both nurses and doctors), often alluding to the personal nature of the conversations:

'I can tell her [IBD Specialist nurse] anything, and she is not embarrassed because she knows all about colitis, and so I am not embarrassed to tell her about the toilet and my problem'.

[Male, Indian/ British Indian, Hindu]

And

'He's really kind of, he's a good, he's a good doctor in that way, and he does loads of clinical trials and this and that, so he's always letting you know about stuff. Easy to approach, easy to talk to. .. Yeah, he's good. I can't, I can't say anything bad about him'.

[Female, British Indian, Hindu]

In terms of information giving, nurses and doctors appeared to have different roles, with participants referring to how it was easier to talk to nurses since they had more time available to explain things, and that they were good at giving practical advice, but that it was reassuring to speak to doctors about treatment because they had more expertise on this subject. Overall participants spoke positively about the information they were given about the condition and their treatment options, including information provided in written form, by DVD and verbally, often referring to the efforts some staff made to ensure that they fully understood the information provided:

'The doctors they were very good, you know, these consultants up at [name of hospital], they asked me if I had any questions and if I didn't really understood or if I'm not sure, if I'm worried, they talk it through, and if they started treatment they told me, you know, we're going to start so-and-so treatment, and this is how it works and what happens'.

[Female, Pakistani/British Pakistani, Muslim]

Participants explained that one of the main benefits for them in developing a better understanding of their condition and how to manage it, was that it gave them an increased sense of control over the disease. In some cases, discussions between staff and patients moved beyond information giving to providing emotional support, with a few participants explaining that staff played an important role in boosting their morale or relieving anxiety:

'She [nurse] told me to just stay calm and she just told me about the A to Z of colitis and its occurrence, how it affects your daily life, and I just .. it, it was a bit of a shock to my system to me, at that time. He [consultant] told me to just keep going. He, I think he came to see me every other day on the ward. He just told me to be brave and strong and be courageous and his support was invaluable really'.

[Male, Pakistani/British Pakistani, Muslim]

In a few cases people spoke of the gastroenterology team taking on an advocacy role, writing to employers who patients were having difficulties with to explain their health condition and its implications for work, and to other health specialists in an attempt to secure speedy access to IVF treatment. These efforts were greatly appreciated by patients, even though they had not been effective in getting people the help needed.

The value of peer support which had been organised or facilitated by the IBD specialist nurse was described by a number of participants. This included an online discussion group set up for patients by nurses, a nurse putting someone in touch with another patient the same age, and meeting patients through attending infliximab infusion clinics. The person who had met others through an infliximab infusion clinic was particularly positive about the experience, explaining that it had become an important source of information and support for him, particularly as the IBD specialist nurse was at hand to provide advice. For further details on how this operates, and why it is a so beneficial, see Figure 1.

Figure 1: Example of infliximab infusion clinic acting as an informal support group for patients

'For me having these infusions done allows me to talk to other people in a similar situation. Okay, their Crohn's might be in a different area, but you've always got someone there who's ready to talk about it. Because you've got someone there who's medical [IBD Specialist Nurse], it's great because, you know, someone might say something like "Have you tried this?" And I'm like, "Oh yeah, that's a good idea, I'll try that." But my nurse might say, "Alright, be careful of those because your Crohn's is in a different place to that gentleman's Crohn's." She said, "You've got it in your colon, he's got it in his smaller intestine." So for example, we were talking peanuts and almonds and things like this. And I said, "I might try that" and she goes, "Oh, you could actually maybe try it," she said, "but because of where your Crohn's is crush them [nuts] down and try them," and, you know, you're not going to get that off the Crohn's and Colitis website. It's just not going to happen'.

[Male, Indian/British Indian, Sikh]

Although many people spoke of the excellent support provided by the IBD specialist nurse, it is worth noting that a few said it had taken them some time to realise what support was available, suggesting that in some cases more could be done to make this clear to patients:

'The IBD nurse gave me loads of information, access to .. NACC and .. information on lifestyle, drugs .. treatment .. issues with work and all that kind of stuff. I email her and say, you know, do you know what else I could take and, you know, and she'd get back to me and say, well try this, and so .. we have that sort of working dialogue. .. But not, it's not always been that way it's just been recently, and I think, I don't know whether that was me not understanding that she was there all the time or just feeling .. that that wasn't part of her role. It took me a while'.

[Female, Indian/British Indian, Hindu]

Difficulties with the support provided by gastroenterology services

Although most participants were happy overall with the support provided by their gastroenterology team, there were areas of difficulty. Many of the difficulties people reported were about communication failures. Other concerns were about the focus of consultations being purely medical, the infrequency of outpatient appointments, medical errors and the shock of transfer from child to adult services.

Communication failures

Problems with communication were wide ranging in nature. Some participants spoke of how they had been given no clear explanation as why they had IBD and of how difficult this was to come to terms with:

'Why is it happening? They don't have an answer and they can't give me an answer. They know how to treat it, they can use different things.... "Oh try this, oh no, this is better cos it's a different chemical. Oh okay, yeah, this works really well." So this is what basically these experts are doing. Yes, they're doing their best, I'm not saying they're not doing their best, you know, but it's something, you know, not in their hands, I would say the medical experts have their limitations in the sense they have not come to the conclusion or anything in terms of how they can treat this hundred percent. Yes, they have all these medications, and Infliximab, they have nothing else after that. But my question is "Why does this happen?" which they don't have an answer to. If they don't have answer they can't satisfy me, so I still have the question in my mind'.

[Male, Pakistani/British Pakistani, Muslim]

Sometimes it was that people felt they had not been given a full explanation of treatment decisions and it was notable that when people had not been given a clear

explanation, *and* they were unhappy with treatment decisions, this led to feelings of anger and frustration.

Just a few people complained about the way in which staff spoke to them, referring to them not being sympathetic or not listening to their health problems. Failure to feed back test results, usually to GPs, was mentioned by a small number of participants. In just once case, a person complained that the clinic had failed to inform her about test results. However, this was very distressing for the patient in question:

'I have given blood twice now and I haven't heard anything about the results. No letters or phone calls. A doctor should take care of their patients. Like I'm ill here, I keep thinking should I continue with these medications or not? The doctors should tell me. When a patient gives blood the doctor should tell them whether they should continue with the medication or not. I've heard nothing and it's been a month and a half now... Sometimes I tell my husband, if I could get someone to help me put a complaint in, I would do it. It just feels like we are crying because we are ill and they are trying to follow procedures and protocols'.

[Female, Pakistani/British Pakistani, Muslim]

The focus of consultations is purely on medical treatment

The short time allocated to outpatient appointments meant people felt there was limited time to talk about anything other than medical treatment. A number of participants spoke of the focus of consultation being solely on medical treatment, with gastroenterology staff not taking the time to ask how they were coping with everyday life, or to understand how their health was impacting on them emotionally:

'They ask the question of what symptoms am I getting with my Crohn's where I can just waffle on and just say "Oh I've got diarrhoea" etc., etc. But it's not, the question's not there as to saying like "what are you finding difficulty with, how are you living at home or have you got someone supporting you at home?"'

[Female, Bangladeshi/British Bangladeshi, Muslim]

One woman who had been dealing with depression due to ill health for many years, said she did not talk to her gastroenterology team about these issues, explaining:

'I mean, as brilliant as my Gastroenterologist is, they're there to prescribe the medicines, try and prescribe me something that will help, that will work'.

[Female, Indian/British Indian, no religion]

Another woman who was prescribed diazepam by her GP for panic attacks brought on by anxiety about travelling due to IBD symptoms, said her gastroenterology team were unaware she had these difficulties or was receiving this treatment. Others who

had less severe mental health issues felt this was any area where staff could do more to help:

'I think both with Crohn's & Colitis UK and with the clinic there's not much emphasis on like mental wellbeing with like IBD .. cos I've found like during periods of flare-up I've been really, really depressed .. but I've not really done anything about it in terms of approaching my doctor or .. not that I want to be on antidepressants but, you know, just anything that they might be able to suggest or they might be able to say, you know, this might help or that might help. .. I've not, like they've never asked me about it and therefore I've never mentioned it to them. .. Yeah, I think maybe more emphasis needs to be put on that, because personally I think the psychological effects are much worse than the physical ones'.

[Indian/British Indian, Hindu]

There were also a number of complaints about lack of dietary advice. One man spoke of how, despite experiencing 'morning sickness' for many years, he had only been referred to a dietician once in the past seven years and was left to work out what he should and should not eat for himself. Another spoke of asking his consultant twice for a referral to a dietician, but he had been refused without explanation. In a rare example of a person being referred to a nutritionist, the advice offered was considered unsatisfactory as the dietician told the patient she was doing everything she should, which left the participant wondering whether the dietician knew much about the relationship between diet and IBD. A number of people spoke of health professionals' uncertainty about the links between diet and IBD, and this was clearly a source of frustration for some:

'IBD and diet, I feel, this is one of the things I do feel quite, quite strongly about, because every time you go .. and speak to a professional they, they'll tell you that there's no clear links between IBD and diet, but there has to be because, you know, you can't have, I mean I have met so many people with IBD who have issues with food intolerances, and even if it, for me I just want to know is it because the IBD triggers some changes that, that causes you to be intolerant or is it that food intolerance is part of IBD .. and no-one seems to be able to give us an answer'.

[Female, Indian/British Indian, Hindu]

As discussed in Chapter 5, some patients were using, or were interested in using some form of alternative or complementary medicine or therapy. In a number of instances, the gastroenterology team were aware of the treatments being used and had advised that it was safe to do so, but that it might not help a great deal. One woman said she had attempted to discuss such options with her team but had received such a negative response that she no longer initiated such discussions.

Others had not discussed the treatment with gastroenterology staff, feeling they were not interested in discussing anything but ‘conventional treatment’.

The infrequency of outpatient appointments

A number of people made complaints about the scheduling of appointments. A few said that infrequent appointments meant that, even when they had something important to discuss with the team, by the time their appointment came around they had often forgot about it. While some were aware they could contact a nurse in between appointments, others spoke of wanting to speak directly to the doctor:

‘You don’t always want to see the nurse specialist, you want to see the doctor, you want to see the doctor who’s actually dealing with your case rather than just being passed down messages through your nurses’.

[Female, Bangladeshi/British Bangladeshi, Muslim]

Difficulty getting an emergency appointment was particularly upsetting when it was requested because of a flare up:

‘I feel like I have no peace, when I am ill. In these circumstances you want them to see you really quickly and give you treatment to make you feel better. If you have to wait two weeks, you feel worse. We shouldn’t have to wait 2 weeks. Not even a week. Doctors should feel caring towards patients and get appointments for them in one or two days. They have your medical records and they should see you quickly’.

[Female, Pakistani/British Pakistani, Muslim]

Complaints about medical treatment

Complaints about medical treatment were rare but sometimes serious. They included: medication errors, usually by junior members of staff (in one case resulting in miscarriage); poor care both during and after a colonoscopy (attempts to persuade the patient not to have anaesthesia and lack of time to recover before being asked to leave the clinic); and being refused requested medication without a full explanation.

The shock of transfer from child to adult services

Given the background of the patients who took part in this study very few were in a position to speak about the transfer from children’s to adult services. The one person who did speak about the issue, spoke of what a shock it had been to be an environment that was more nurse-led and where she was expected to make her own decisions about treatment options, leaving her feeling that her care was not being taken seriously.

Views on how well services attend to the needs of South Asian patients

Study participants were asked if gastroenterology staff were aware of and responded to their needs as a South Asian woman/man. Many could not see how their needs were any different from the wider IBD patient population. Some seemed to interpret the question as being about whether they had experienced any form of discrimination, and most of these people reported that they had not:

'Many, many people waiting, some are Indian, people from different countries, also like other people, like white people, and the clinic is treating everyone just the same; if you come late, they say stay there, we're going to see you later. It doesn't matter your colour, or anything like that, they will help you, so it doesn't make any difference'.

[Male, India/British Indian, Hindu]

Only one participant felt there might be some small element of racial discrimination from doctors but said he did not want to say much more about this because he felt it might be held against him.

A number of South Asian patients not born in the UK spoke of their gratitude for the service they received, which they were aware was not always available in other countries. For example:

'I think we're very fortunate and lucky here in this country, that we have consultants and treatments available to us and are looked after quite well. Back home they can't afford to go to a hospital, because you have to pay a fee, even for your medication and stuff like that and then they, I'm sure, suffer big time and for that I feel really, really sorry for them .. and I'm really grateful that I'm here'.

[Male, Indian/British Indian, Sikh]

There were also examples of culturally sensitive practice, with a few participants speaking of being pleased with the guidance and support they received from their gastroenterologist prior to going abroad. One explained that she had been in constant contact with her consultant in the lead up to her trip as she was taking immunosuppressants at the time and needed help with arranging to have the appropriate vaccinations. Another spoke of her consultant helping her overcome her fear of going on holiday by giving her additional medication in case of a flare up, clear instructions on how to take the medication and an email address so that she could get in touch with the clinic should she run into any difficulties whilst abroad. One person spoke positively about consultant warning her that, as she is South Asian, she is more likely than other patients to be deficient in Vitamin D.

A few people did highlight shortcomings in service provision to South Asian patients and these fell into two main areas: (1) not appreciating the importance of being able to fulfil cultural expectations of what constitutes a good wife, mother or husband; (2) not providing adequate translation services to patients whose first language is not English.

With regard to not appreciating the importance of being able to fulfil cultural expectations of what constitutes a good wife, mother or husband, as discussed in Chapter 5, some participants felt that having IBD impinged on their ability to fulfil these roles. This was a topic that two people returned to when discussing support from gastroenterology staff, feeling that staff did not fully appreciate the importance of providing them with support that enabled them to fulfil these roles:

'For an Asian woman there are a lot of responsibilities. Taking care of the children and her husband and her home. According to my responsibilities I don't feel like I am receiving the best treatment. What should I focus on, my children, husband or the disease?'

[Female, Pakistani/British Pakistani, Muslim]

And

'I'm just now with the issue with the pregnancy and stuff, cos obviously I've been pushing it towards them saying, like it's important that I need to get pregnant and they don't understand. ... it's a big stress thing for me in the fact that I'm not getting pregnant and I want to get pregnant.'

[Female, Bangladeshi/ British Bangladeshi, Muslim]

With regard to the provision of adequate translation services, we have limited evidence from this study on the experiences of South Asian patients who do not speak English since only two participants were in this position. However, interview data from one of these participants clearly illustrated how difficult it can be to access support when you do not speak English, particularly when the clinic fails to provide an interpreter:

'I can't speak English with the white doctors. Sometimes an interpreter is at the appointment but for the past 3 or 4 appointments no one was booked..... Sometimes the hospital tells me to wait for the interpreter. I have waited a couple of times but if I wait then where do I leave the kids? My husband normally goes with me. We need appointments at times that suit us. My husband works from 7am to 3pm. Then it's time to pick up the kids. If I wait for the interpreter and find someone to take care of the kids, they will not look after the younger children for the whole day. The hospital should be aware of these issues and make allowances in how they allocate appointments. Yes, I am ill and so I should wait, but I can't do this all the time'.

[Female, Pakistani/British Pakistani, Muslim]

She goes on to explain that she relies on her 12 year old daughter to look up information about IBD and the treatment she is receiving on the internet, and then translate it into Mirpuri for her. Her daughter tries to reassure her that she will be okay.

A participant who spoke English herself, but who had a cousin with IBD who does not, spoke of how she has recently begun accompanying this cousin to clinic appointments because he did not have an adequate interpreter. She thought her involvement had helped her cousin to understand the importance of adhering to medication.

Other participants who spoke fluent English said they had noticed South Asian patients attending clinic who the nurses did not appear to be able to communicate with. Some commented that although there is written information on IBD available within clinics, they had never noticed any in South Asian languages. Lack of translated materials was considered a particular problem for people who speak Punjabi as there are no words for IBD in this language and knowledge of the condition was considered to be particularly limited in this community. One person warned that, given that she speaks English and it had still taken her some time to understand the support provided by the IBD specialist nurse, patients who do not speak English are likely to be particularly vulnerable to missing out on the support that is available.

Additional support wanted from health services

Participants made a number of suggestions regarding the additional support they would like to see provided by health services, most of which fit with the difficulties with services outlined above. These are listed below.

Gastroenterology services:

- Advice on alternative therapies.
- Access to a dietician.
- Access to a counsellor who specialises in supporting people with medical conditions.
- Help making a successful application for disability benefits.
- A private room when first diagnosed so there is easy access to a toilet and privacy.
- To be given a choice over which member of the team you see.
- Clinics for teenagers.

GPs:

- GPs need to have a better understanding of IBD in order to: (1) prevent delays in diagnosis; (2) ensure a more empathetic GP service.
- Access to faecal calprotectin and blood tests via GP surgeries rather than having to travel to hospital.

South Asian specific recommendations

While the small number of shortcomings in service provision for South Asian patients point to ways in which services could be improved for people with this background, very few participants made clear recommendations as to how to develop services. One participant felt that setting up a peer support group specifically for South Asian patients might be useful as people would be able to talk to someone who understands their lifestyle. Another person felt that South Asian patients need dietary advice which takes into account the kind of food that people from a South Asian background eat.

Chapter 7 Views on Crohn's and Colitis UK and the Support it Provides

Introduction

This chapter begins by reporting on participants' awareness of, and engagement with, Crohn's and Colitis UK, before describing views on the support offered by the organisation. We then go on to outline perceived cultural barriers to South Asian patients' engaging with the organisation, and recommendations as to how Crohn's and Colitis UK can better support South Asian patients.

Awareness of Crohn's and Colitis UK

Knowledge and understanding of the support offered by Crohn's and Colitis UK was, typically, very low. Only a small minority identified themselves as members and even fewer actively used the organisation in an on-going way. Indeed, for many, the research interview (particularly the use of the visual aid depicting Crohn's and Colitis UK's services and support, see Appendix 2) proved to be educational in terms of demonstrating to participants the different ways Crohn's and Colitis UK seeks to support patients and families.

However, it is important to stress at the outset that there were some very positive accounts of the support Crohn's and Colitis UK provides from some of those who had actively sought information and advice:

'...they're very good. They give you information, they sent me the IBD book....and the lady I spoke to...they are helpful'.

[Female, Indian/British Indian, Sikh]

And

'I think the website is full of good information. And, you know, if you're going through a bad, bad stage, you can speak confidentially to someone who will give support and help'.

[Male, Pakistani/British Pakistani, Muslim]

One interviewee particularly applauded Crohn's and Colitis UK's presence on social media and the way this generated 'open' conversations about IBD:

'They're starting to get on social media now which I think it's really good...like they're on Facebook, Twitter and everything. And I think on Twitter especially I've found loads of people just talk about IBD really openly'.

[Female, Indian/British Indian, Hindu]

Overall, the form of support most consistently identified as Crohn's and Colitis UK's core function was as an information source. Many recalled Crohn's and Colitis UK leaflets being given to them around the time of diagnosis or seeing them in clinic subsequently. It is important to note here that despite the popularity of social media, not everyone wanted on-line resources. For example, some had stopped reading the Crohn's and Colitis UK newsletter when it was delivered as an email attachment rather than through the post:

'...I'm not very good with email, like computer, I prefer paper'.

[Female, Indian/British Indian, Hindu]

Reasons why individuals did not engage with Crohn's and Colitis UK

A key reason for not engaging with Crohn's and Colitis UK which emerged from the interview data was the episodic nature of the condition. During periods of good health interviewees spoke about not perceiving there to be a need to draw on the support Crohn's and Colitis UK might have to offer them. At the same time, the often debilitating symptoms during a flare up meant interviewees did not have the energy or motivation to explore Crohn's and Colitis UK as a source of a support or use its services.

In addition, even after being shown the Visual Aid depicting Crohn's and Colitis UK's services and support, some interviewees did not perceive Crohn's and Colitis UK as being able to offer any new or additional information to that which they received from clinic staff and/or family and friends who had a medical background and/or experiences of IBD themselves. It is important to remember here that interviewees were consistently very positive in their accounts of the specialist IBD team caring for them. It is worth noting, however, that Crohn's and Colitis UK was viewed as having a potential role in terms of providing emotional support – something which clinics were typically viewed as not having the resources to offer. Indeed a minority had used the Crohn's and Colitis UK helpline in this way.

A further reason for not using the Crohn's and Colitis UK as an information source was that it did not address, in the way that was wanted, one of the dominant information needs identified by our interviewees; namely, a range of 'uncensored' suggestions and advice on new dietary regimes and CAMs that they might try. A number of participants said they favoured using unofficial forums instead:

'On the non-official forum you get the voice of real people. People who are actually suffering with it, and their view might not be the same as NICE. On Crohn's and Colitis UK website they have to be careful what they say and that's

not useful. ...Unofficial websites are more honest – people tell you the truth’.

[Male, Indian/British Indian, Sikh]

A handful of interviewees had attended, or were a regular member of, a support group. Typically they described this as a positive experience:

‘I went to the meeting. I found it really good just to talk to people. I didn’t really talk to many people, but just listening to people and hearing the medical advisor. Listening and thinking, “Oh, I’m not alone”. There’s other people who have got this’.

[Male, Indian/British Indian, Hindu]

And

‘I know I am with like-minded people. That I don’t have to explain everything to. And it has helped a bit knowing that everyone has had the same kind of issues as I have had’.

[Female, Indian/British Indian, Hindu]

Among those who had *not* linked up with a local Crohn’s and Colitis UK, there were mixed feelings about the benefits of attending something like this. Some expressed a disinterest in other people’s experiences and stories and saw it having no benefit to themselves. Indeed, some spoke of wanting to avoid speaking with others with the same condition in case they heard about experiences that were worse than their own. Interestingly, those participants who had had the opportunity to talk to other patients with IBD in a clinic setting, or through pre-existing friendships with people who had happened to have IBD, had found this a helpful experience. Furthermore, a number of participants who opted to be interviewed by a LISA project interviewer who had personal experience of IBD spoke of how enjoyable an experience this had been, with many taking the opportunity before or after the interview to ask the interviewer how they managed their IBD.

Do cultural issues impact on South Asian patients’ engagement with Crohn’s and Colitis UK?

We examined the interview data to see if participants located their reasons for a lack of use, or engagement with Crohn’s and Colitis UK on cultural or religious factors. Participants offered views on this with respect to their own situation and in terms of their ethnic group more generally. At the outset, however, it is important to note that some interviewees seemed to expect that Crohn’s and Colitis UK would know they had IBD and contact them directly to offer support perhaps, in part, flagging up a lack of understanding that voluntary sector organisations operate separately to the NHS:

'I thought they would have made themselves known... written to me...when I became a Crohn's disease patient'.

[Female, Indian/British Indian, Hindu]

Barriers to use of on-line resources

Overall, access and use of the internet and social media varied enormously within our sample. Many had not viewed Crohn's and Colitis UK's website and, as noted above, there are a range of reasons why individuals may not regard Crohn's and Colitis UK as a necessary or desired source of support.

In addition, however, some of the older people interviewed reported they were unfamiliar with using the internet and social media and would not use these media to access information and support regarding their IBD. Other interviewees also noted that the 'older generation' were not 'on-line' and that this, combined sometimes with literacy difficulties, were barriers to older people using Crohn's and Colitis UK's on-line resources.

The representation of South Asian individuals in publicity and information resources

Whilst not a personal barrier to using Crohn's and Colitis UK as a source of support, the observation was made that Crohn's and Colitis UK should review the presentation of minority groups per se in its printed materials and its website:

'I really don't think there's anything like specifically for South Asians that I saw on the website or in newsletters or anything. There really does obviously need to be more work done with South Asians'.

[Female, Pakistani/British Pakistani, Muslim]

Support groups

A small minority of participants had attended or were regular members of a local Crohn's and Colitis UK support group. We noted earlier the reluctance of some to hear other people's stories and an ambivalence to engage with support related to IBD during periods of good health. These in themselves were, for some, barriers to joining a support group. In addition, those who struggled with on-going 'low level' symptoms such as tiredness, or issues such as low mood, identified these as barriers to joining a support group. Others said family/caring responsibilities meant they were unable to get along to a group. However, among the individuals we interviewed, none of these barriers were explicitly linked to South Asian identity.

Over and above these, however, certain (perceived) features of support groups were identified as barriers to patients of South Asian origin attending a support group. As with other issues, sometimes interviewees, whilst not viewing something as a barrier themselves, believed they could be for some individuals with the same racial/ethnic background. First, support groups could be perceived as for 'white, middle class' people. It was noted that, for some, going to a meeting where there were no other South Asian people in attendance would be an alien and uncomfortable experience:

'...in this country a lot of Asian people tend to socialise with other Asian people and they talk to other Asian people, go to Asian shops and everything...so it might seem strange to them to go somewhere where there's no Asians at all. They need to know they aren't gonna be the only brown face in the room'.

[Female, Indian/British Indian, Hindu]

Second, using pubs as venues for meetings was a barrier for some. A familiar venue, such as the hospital where the clinic was held, was preferred. Meeting in a pub also, implicitly, suggested a lack of racial/cultural awareness among the organisers of a group. It was noted that greater representation of South Asians among those organising local groups, and where South Asians were involved, making this explicit in publicity, were two strategies which could address these issues.

A few participants expressed the view that South Asian people are more 'private' than other ethnic groups. The notion of sharing experiences in a group, particularly perhaps regarding a culturally sensitive aspect of body function, and with people outside of their own community, was an alien concept. It is essential to note here that some individuals who had held such views in the past, through conversations with other patients at 'infusion clinics', now saw the value of peer support.

Support in languages other than English

Not unexpectedly, the importance of making Crohn's and Colitis UK publications available in South Asian languages was noted. However, a couple of participants noted that literacy in any language would be an issue for a minority of South Asian patients. Here older patients were identified as being most likely to have issues around language and literacy. Importantly, a number of interviewees expressed the view that patients who did not speak English, or had English as a second language, were particularly vulnerable to unmet support needs as their ability to draw on support and advice during clinic appointments was likely to be limited to some degree. The suggestion was made the information resources should be specifically written for this group.

In addition, one participant predicted that the Crohn's and Colitis UK helpline would be unlikely to be able to assist if someone whose first language was not English got in touch:

'Being realistic, would Crohn's and Colitis UK really be able to help someone who can't speak English with applying for benefits? Seems unlikely. Imagine they would be put off at first phone call to the organisation when it becomes apparent that they don't have people to respond to enquirers who speak South Asian languages'.

[Female, Pakistani/British Pakistani, Muslim]

Views on how Crohn's and Colitis UK can better support South Asian patients

In addition to addressing the barriers to using Crohn's and Colitis UK outlined above, three further areas of work or activity were identified by interviewees:

- Awareness raising about IBD in South Asian communities.
- Supporting the wider family.
- Addressing specific information needs.

Awareness raising about IBD in South Asian communities

When asked about how Crohn's and Colitis UK could improve its support to South Asian patients, one of the dominant themes to emerge was the role of awareness-raising about IBD within South Asian communities. Interviewees sometimes gave the example of the awareness-raising activities regarding diabetes, high cholesterol, and alcohol, which they believed had led to people talking more openly about these health problems and needed to be replicated for IBD. They called for publicity and information about IBD to be widely distributed in a range of different settings such as GP surgeries, places where South Asian people go to socialise, and temples and mosques. One participant suggested using South Asian 'personalities/celebrities' to promote this work. Another mooted the idea of workshops or information events as well as printed information and publicity. A number noted the need for this information to be provided in a range of languages.

Supporting the information needs of the wider family

Another sphere of information and awareness-raising, requiring more specific and detailed information, was to close and wider family members of patients, and including family members living overseas. The need for materials to be tailored to the particular audience, which took account of cultural and/or religious influences on beliefs about health, illness and diet, was noted.

Addressing specific information needs

Lastly, the following areas of information need – all perceived to be specific to South Asian patients or requiring the provision of information which was culturally appropriate – were identified:

- travelling to South Asian countries, including:
 - managing long journeys;
 - dealing with flare-ups, including use of local health care;
 - transporting and storing medication.
- South Asian food/diet and IBD.
- complementary and alternative medicines (CAMs) commonly used within South Asian communities, including advice on effectiveness and warnings if likely to cause complications, or be unsafe when combined with IBD medications.

It was clear that as well as being useful resources which Crohn's and Colitis UK could produce (in written and audio-visual formats), these were also information needs which clinics should be aware of.

Finally, and on the face of it counter to the resistance to hearing other patients views and experiences noted earlier, a number of interviewees noted they would value hearing about how others coped with living with IBD on a day to day basis. Audio-visual resources or the opportunity to speak with someone else with the condition (but not requiring attendance of a support group) were both suggested as effective ways of addressing these sorts of information needs.

Chapter 8 Discussion

Introduction

In this final chapter of the report, we summarise the research findings and reflect on what they add to the existing literature on the experiences and support needs of adults with IBD, before outlining the implications for both Crohn's and Colitis UK and gastroenterology services. Finally, we discuss the strengths and limitations of the study.

Summary of the findings and what they add to the literature

This is the first study to give South Asian adults in England an opportunity to talk about their experience of living with IBD. The research confirms there is a generic experience of IBD, irrespective of ethnic background. As participants explained, much of their experience was driven by IBD symptoms, and these symptoms are common to IBD patients of all backgrounds. IBD flare ups were painful, exhausting and involved frequent trips to the toilet, so many people remained housebound when experiencing them. In addition to this, in between flare ups, many people experienced ongoing milder symptoms, as well as anxieties that such symptoms might indicate the onset of a flare up.

As in the wider IBD literature (McCormick et al., 2012; Hall, 2005), this study found that people were making considerable efforts to control or cope with physical symptoms of IBD. The majority of participants saw medication as necessary for preventing flare ups and controlling symptoms, despite having concerns about side effects, but they also used a wide range of other strategies, some of which were driven by beliefs that IBD is exacerbated by diet and stress. Practical and emotional support was provided by immediate family. While members of the extended family were often aware of the person's health difficulties, they were often unable to help due to living too far away or having their own caring, or other, responsibilities. Despite the efforts people were making, and the support received, having IBD often took its toll on people emotionally. Feeling low, depressed or anxious added further to the difficulties people experienced so that, even when symptom free, some people curtailed their activities due to loss of interest or worry about the possibility of experiencing symptoms. As a result of this combination of physical symptoms and emotional difficulties, people reported struggling at times with maintaining a social life and friendships, completing higher education/training courses, managing work, caring for children and in relationships with partners. A few people also reported financial difficulties as a consequence of giving up work/reducing their working

hours and/or their partner having to stop work/reduce working hours in order to care for children.

In relation to health services, once diagnosed, very few consulted their GP for advice or treatment. Most often this was because they felt their GP did not have sufficient knowledge about IBD and/or they did not have up to date information about the person's health status. Sometimes trust in a GP had been broken by the GP being slow to make referrals to gastroenterology services when the person first became unwell, resulting in delays to diagnosis, an issue familiar within the IBD literature and which efforts are being made to address (IBD Standards 2013 Update)

On the other hand, experiences of gastroenterology services, and relationships with staff, were overwhelmingly positive, with just a few exceptions. Participants appreciated the ease of access to the team outside of scheduled appointments, and some spoke of how comfortable they felt talking to staff about sensitive issues, such as bowel related symptoms. The information provided by IBD services was generally considered good, giving people an increased sense of control over their condition. In a few cases, the team had taken on an advocacy role and/or facilitated peer support, which was much appreciated. Nevertheless there were areas for improvement. These were largely around the feeling that the focus of consultations was purely on medical treatment, 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 patients were using or interested in using Complementary and Alternative Medicines (CAMs) but a number had not discussed these options with the team, feeling that they were not interested or were 'negative' about anything aside from conventional medical treatments. This is of concern given that a number had suffered side effects from CAMs and it was only at this point that they learnt that some CAMS were best avoided when taking IBD medication.

All these findings fit with concerns expressed recently by a number of clinicians and academics writing about IBD services. For example, Andrews et al. (2010) has suggested that the medical management is increasingly being directed at acute flare ups of the disease at the expense of other aspects of care. Further, there is a danger with the development of new biological therapies that management will become even more narrowly focussed, failing to address the psychological burden of living with IBD, quality of life, and specific psychological comorbidities, along with others issues. Others have also called for psychological care to be incorporated into the management of IBD (Mikocka-Walus et al., 2012; Moser, 2006). Unfortunately, within the UK providing such support may be a challenge. The fourth round of the UK IBD Audit (Royal College of Physicians, 2014) found that around a third of services routinely gave patients information on how to access counselling from a primary care or a third sector organisation, and only one in ten had access to a psychologist via a defined referral pathway. This report concluded that psychological support needs to be given greater priority at a local level and this could be helped by

the sharing of good practice by the small number sites that have managed to establish a dedicated service.

Knowledge and understanding of Crohn's and Colitis UK was typically very low. Key reasons why people did not engage with the organisation which could apply to people with IBD from any ethnic background 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; they believed they already had all the information and support they needed, largely through gastroenterology clinics, but also sometimes through family members who were health professionals and friends who had IBD; and the organisation did not provide the 'uncensored' information about dietary regimes and CAMs which, although untested, they might like to try.

Although there was a generic experience of IBD, the research also revealed that aspects of South Asian identity and relationships with others in the South Asian community, did affect experiences. A number of factors were identified which influenced both how family, friends and the wider community responded to the person having IBD, and how participants themselves felt about having the condition. Participants reported that there were a number of culturally specific difficulties understanding IBD (e.g. people have never heard of the condition, there is no word for Crohn's in some South Asian languages, the word 'disease' has different connotations in South Asian communities etc.). Some said they withheld details of their diagnosis from all but their immediate family. This was primarily because ill health was particularly stigmatised in South Asian communities due to the perception that it impacted negatively on 'marriageability' and caused concerns for the health of future offspring. Furthermore, 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, further adding to the culture of silence around IBD. While researchers investigating the experiences of the wider IBD have found that people tend to see their illness as embarrassing, taboo and often misunderstood by others populations (Hall, 2005), taken together these findings from the LISA Project suggest that such feelings may be amplified in South Asian patients.

In their study of younger South Asian adults, Nash et al.'s (2011) identified that being part of a culture in which eating spicy food is the norm can cause difficulties for people with IBD. Similarly in the LISA Project most participants believed that such food exacerbated IBD symptoms and avoided it, which could mean eating 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, a 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 knowing it would make them unwell. An additional food related issue, not identified in Nash's study, were beliefs within the South Asian community about the links between food and health. In some religions, some foods are blessed and there are beliefs that ill health is brought about by an imbalance in foods. Such beliefs made it difficult for some individuals to get others to accept their preferred diet.

Moody et al. (1998) has suggested that South Asian patients may live in areas of the country where CAMs, particularly South Asian CAMs, are widely available and may therefore be more likely to use them. As this was a qualitative study we did not attempt to examine the extent of CAMs use amongst participants. However, the research did find that people had mixed views on CAMs. While some had used them and found them beneficial, others were more sceptical, particularly when they had family members who were health professionals and had warned them not to use 'untested' treatments.

Participants also spoke of expectations within their community as to the role of women and men and its impact on their experiences of living with IBD. For women, this mostly concerned being a mother and homemaker. For men, it was about financial responsibilities. While men and woman from any background might worry about their ability to undertake gender orientated roles when ill, in this study some of the women were also concerned about the social consequences of not being able to do so, feeling that they would not be forgiven by others in their community if they failed to take on the duties expected of a wife and mother. These are not issues found in other research investigating the experiences of white British IBD patients in their parenting role (Mukherjee et al., 2002).

Making visits to extended family overseas was something that a substantial proportion of participants did on a regular or occasional basis. While people often worried about making these trips due to concerns about travelling whilst experiencing bowel related symptoms and limited access to toilets, for many they were worthwhile as it allowed them to attend important family events. These trips often involved stays of a few months, during which time there was potential for fluctuations in people's condition. Many were pleased to find their health improved while away, which they accounted for as being a consequence of a warmer climate and being cared for by family members. Where people did experience flare ups, there were often clear reasons for this, such as not adhering to medication or changes to diet.

Many people reported deriving a great deal of benefit from their faith, describing ways in which it helped them to cope with having IBD. However, Muslim participants spoke of difficulties praying because it involved a physical act which they were sometimes not well enough to perform. Despite knowing that praying when unwell

was not a requirement of their faith, not being able to do so was a source of great upset to some. Furthermore, Muslim patients explained that 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.

Finally, a small number of participants felt living with extended family was difficult due to the need to share (limited) toilet facilities. Embarrassment about bowel related symptoms was also an issue when people first moved in with extended family.

In 2012, a UK gastroenterologist published a paper commenting on the provision of gastroenterology services to South Asian patients in the UK (specifically Panjabi patients), stating that the availability of appropriate services is woeful and yet seldom leads to formal complaints. He expressed particular concern about the lack of adequate translators, and failure to provide translated versions of information literature (Mayberry et al., 2012). Our research found that, although important, translation is just one of many issues that gastroenterology services need to be aware of when supporting South Asian patients. Typically when asked about their needs as a South Asian patient, people were simply appreciative of the care they received and could not identify ways in which their needs might be any different from other IBD patients. It is important to note that there were also examples of culturally sensitive practice. For example, consultants taking time to help prepare people for trips overseas, and advising patients about the increased risk of vitamin D deficiency. Where shortcomings did exist, not providing adequate translation services to patients whose first language is not English were mentioned, but concerns were also expressed about gastroenterology staff not appreciating the importance to (some) South Asian patients of being able to fulfil cultural expectations of what constitutes a good wife, mother or husband, and the need to find treatments and/or strategies which enabled them to take on these roles.

A number of South Asian-specific barriers to engagement with Crohn's and Colitis UK were also identified. It was suggested that the older generation of South Asian patients are unlikely to be 'on line' and/or necessarily able to read English, making it hard for them to access the Crohn's and Colitis UK website. Concerns were expressed some years ago that South Asian do not attend local Crohn's and Colitis UK meetings (Moody et al., 1993). Participants in the LISA project identified a number of barriers to attendance. These included: the perception that such meetings would mostly be attended by white middle class people and that being the only South Asian person present would be uncomfortable; the use of culturally inappropriate venues such (i.e. pubs); and that South Asian people are relatively private so would be uncomfortable sharing experiences in a group. Finally, the fact that most of Crohn's and Colitis UK's 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.

Implications for practice

Participants who took part in this study were a diverse group and differed considerably in the extent to which they saw themselves as South Asian or engaged with the wider South Asian community. Many of the experiences and views outlined in this report were experienced by some, but not all participants. It follows that when reading this report it should not be assumed that the experiences reported here will apply to *all* South Asian patients, and/or across all South Asian ethnic groups. Instead, an individualised approach to care is needed, in which practitioners take the time to explore the particular social and cultural context in which individual patients live their lives and the support that fits with these circumstances. Nonetheless, taken together, the findings from this study do suggest ways in which organisations might be able to improve support to South Asian people in general. Some of the issues identified are generic, that it is developing support would benefit both the South Asian and the wider IBD population. Others are specifically about the South Asian population. As will be seen, most of these issues need to be taken on by *both* Crohn's and Colitis UK and gastroenterology services, though their roles in developing or providing support may differ.

Psychological Support

Given that disease remission alone is insufficient to improve patients' quality of life and alleviate their worries and concerns, many researchers have called for health professionals to take a more holistic or integrated approach to care, attending to the psychological burdens of the disease and patients' quality of life when developing treatment strategies (Mikocka-Walus et al., 2012; Moser, 2006; Hall et al., 2005; Casati et al., 2000). It is clear from the findings from this study that South Asian patients would also benefit from more psychological support. This needs to include:

- Access to psychological therapies for those experiencing feelings of depression and/or anxiety brought on or exacerbated by having IBD.
- Opportunities for people to discuss how they are managing their everyday life, and any strategies that might be helpful.

Given time and resource limitations, and that psychological support falls outside of gastroenterology staff's areas of expertise, it seems unlikely that such issues can or will be addressed within gastroenterology clinic appointments. However, it might be possible for teams to develop links with other services who can offer such support. Furthermore, patients may benefit from having the opportunity to talk to others who IBD about how they manage their condition. While difficulties getting people to attend 'support groups' are well known, the example given in this study of people

swapping experiences and ideas whilst attending an infliximab infusion clinic, with facilitation by an IBD specialist nurse, is one that other clinics might want to consider pursuing.

Information on the usefulness and safety of CAMs for IBD

Many people were either using CAMs, interested in using CAMs or had been advised to use CAMs by family or friends. Given that some CAMs can cause complications for patients, particularly when combined with IBD medications, and that many seemed unaware of this, it is important that Crohn's and Colitis UK and/or gastroenterology services offer advice in this area. Without such advice, people will continue to look to unofficial online forums for new treatments and remedies and conceal this from their consultant and other clinic staff.

Dietary advice which is culturally appropriate

The possible link between South Asian diet and IBD was clearly an issue for people, with many avoiding all spicy food in an attempt to control symptoms. Others spoke of fasting on a regular basis after fasting for religious reasons and finding that it helped. While limited availability to dieticians is likely to make provision of individualised dietary advice difficult, it should be possible to produce information leaflets on diet which are tailored to the needs of South Asian patients, covering foods typically included in their diet, but also advice on issues such as fasting which may be of particular interest to Muslim patients.

Awareness raising about IBD within the South Asian communities and families

Taken together, the findings on how cultural factors influence both how South Asian people who have IBD, and those around them, respond to the condition suggest that awareness raising about IBD should be a priority. Any awareness raising needs to:

- Dispel myths that may exist about IBD (i.e. suggestions that it might be infectious, and/or life-threatening).
- Clarify the relationship between IBD and diet. In particular, it should be made clear that it cannot be 'cured' by eating particular foods, but that people may benefit from following a particular dietary regime, including the avoidance of spicy food.
- IBD symptoms and the possibility that during flare ups people may need rest and time out from usual roles and responsibilities.

Given the reported stigma around having an illness which children might inherit, any information provided about the causes of IBD, and a possible genetic component, needs to be dealt with sensitively.

Awareness raising needs to happen both at a community and family level. It would seem appropriate for Crohn's and Colitis UK to take on awareness raising at a community level, and indeed research participants recommended the approach taken on by other health charities who were reported to have visited temples and mosques to distribute information leaflets and give talks on the condition they represented.

In addition, there is a need for awareness raising at a family level, ensuring that those who live with the person with IBD, and other close family members, really do understand the condition, treatment regimes, and the help and support the person with IBD may need. Given that this requires an individualised approach, input from the gastroenterology team is likely to be needed. It is hard to prescribe how clinics should take this on as much will depend on the resources they have available to them. However, a good starting point might be welcoming family members to clinic appointments so that they have an opportunity to hear the information and advice being passed on to patients and ask questions. Crohn's and Colitis UK could support awareness raising at a family level by providing generic information resources which cover culturally relevant topics and are available in South Asian language, as well as occasionally running local meetings to which family members are invited.

The need for advice and support on making trips to visit family overseas

The trips people made to see extended family overseas often involved stays of a few months, during which time there was potential for fluctuations in people's condition. These trips have implications for both Crohn's and Colitis UK and gastroenterology services since the data suggest that people need support with: being adequately prepared for making the journey, including advice on how best to store medication when travelling; advice on 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; and, in case people needed medical attention while overseas, a brief written summary of the person's diagnosis and the treatment they are receiving in the UK which can be given to medical staff.

Increasing the visibility of South Asian members of Crohn's and Colitis UK

While people welcomed the LISA project, signifying an interest in South Asian people, there was a clear sense that Crohn's and Colitis UK is an organisation run by and for white British people. For many this was reflected in the lack of South Asian presence on publicity materials, publications or the website, and at local meetings.

This lack of visibility needs to be addressed so that South Asian individuals feel comfortable engaging with the organisation at either a local or national level.

Strengths and limitations of the study

Given that the study involves patients known to be hard to involve in research, we are extremely pleased with recruitment to the study. Indeed, we exceeded our recruitment target and could have interviewed more individuals had time and resources allowed. The sample included 19 people who described themselves as Indian/British Indian, nine as Pakistani/British Pakistani, four as Bangladeshi/British Bangladeshi and one as British Punjabi. In terms of faith, there were 17 Muslims, nine Hindus and seven Sikh participants. Such a sample reflects both the ethnic background and the spread of faith groups within the UK population (Office for National Statistics, 2013; Office of National Statistics, 2012). Furthermore, both men and women were represented, as were all age groups, with the exception of people over 65 years of age. It did appear that giving patients the option of being interviewed by someone with personal experience of IBD was beneficial, with some participants reporting that it was one of the reasons they had decided to take part. It also resulted in some very frank discussions about experiences. As most of the participants in this study spoke English, we have limited information on the experiences of South Asian people for whom language barriers are an issue. However, discussions with gastroenterology staff in the clinics we recruited from indicated that the English language abilities of our sample reflected their experience of South Asian patients attending clinic, with them reporting only a very small proportion (5-10 per cent) required an interpreter present during appointments.

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Appendix 1 Interview Topic Guide

1. Introduction (10 mins MAX)

Briefing note: This section covers the preliminaries to the interview itself. Use this time to get a 'feel' for the interviewee (and them for you!), establish rapport, ascertain any language issues. The section concludes with working through the consent form. Whilst necessary, it is important not to make completing the form too 'formal' or intimidating. By the end of this section you should have either switched on the recorder or be ready to

- Thank for interest in project and time given to take part.
- Introduce self
 - interviewer working for University of York, carrying out a research project funded by Crohn's and Colitis UK.
 - Explain that not medically trained
 - Project is working with 5 gastroenterology clinics in different parts of the country. By the end of the project will have interviewed ~35 IBD patients
- Remind about the project and purpose of interview:
 - to find out about people's experiences of living with IBD and the types of support they would like from Crohn's and Colitis UK and from health services. These are the topics the interview will cover.
 - Purpose is to pass on recommendations to Crohn's and Colitis UK & Gastroenterology clinics as to how they can improve the services they provide
 - **REMIND/EMPHASISE:** they can ask to skip any questions they don't want to answer and/or end the interview anytime they like.
- Check re timings
 - Explain that interview will take around an hour (maybe a little longer).
 - Check how much time they have available, any interruptions anticipated.
 - Explain that they can take a break whenever they wish.
- Recording the interview.
 - Explain: it's easier for us to audio-record but, if not happy can make notes instead. It's their choice.
 - Reassure:
 - all data and information collected is treated as confidential.
 - it is only seen by members of the research team.
 - it is very stored securely.

- Check if have any questions
- Check if happy to proceed
- **If given permission, turn recorder on**
- **Complete consent form**
- **If you don't have any background information on the person**, explain that at present all you know about them is what they have written on the response, form, so before you begin the interview it would be helpful to know a little more about their circumstances. Then check:
 - Whether working, studying or caring for others
 - Who they currently live with

2. Diagnosis, management and other's reactions (~ 15 mins)

Briefing note: There is no need to obtain a detailed history/description of symptoms and treatments. Early on you will identify what words the interviewee uses to refer to/describe their condition. Use these words during the remainder of the interview. Here we are also trying to find out about their understanding of the condition/ treatments. We also explore

- **Explain that at present all you know about their health is what they have written on the response, form, so would like to begin by finding out a little bit about their health.**
- **Brief history**
 - Check specific diagnosis, and when diagnosed
- **Current health/situation with condition**
 - How has your health been over the past year? (IBD; minor illnesses; tiredness/energy levels)
 - Frequency of flare-ups (eg. approx no times/year; % of year badly affected).
- **Management**
 - Past and present treatments:
 - medication, diet,...anything else
(NB Make a note of any medications as you will need this information at the end of the interview to complete 'Background Information Form 2'.)
 - understanding of how current treatments manage the condition
 - any issues / difficulties /concerns sticking to treatment regime
 - Any surgery

- very brief details; successful or not
- Have you declined any medical treatments or investigations?
 - explore reasons
- Any alternative/non NHS treatments/approaches to managing condition
 - brief details and reasons for pursuing
 - clinic awareness of & reaction to use of these treatments
- Any ways in which your faith influences how you manage your condition
 - We know some people use faith healers. Have you?
 - Brief details and reasons for pursuing
- **Understanding of condition**
 - Reflect back on how much they appear to know about IBD, THEN
 - Check where they gathered this knowledge from
 - check if there is anything unsure about and would like more information on
- **Family's reactions to the investigations and treatments**
 - If you don't already know, check family composition & who is in the household.
 - Who in close and wider family knows about diagnosis
 - justification for who have told/not told
 - How have they responded to diagnosis and, treatments and lifestyle recommendations
 - check for both positive & negative responses
 - Who have you decided not to tell and why
- **Other's knowledge/ reactions**
 - Who knows else have you talked to about having IBD
 - justification for who have told/not told
 - their reactions

3. Living with IBD (~15 minutes)

Briefing note: In this section we want to hear whether/how IBD affects people's lives. Because IBD is a fluctuating condition, it is important that you emphasise that we would like them to think about when things are bad (a flare up) and when things are more settled.

We have created a visual aid ('life map') to facilitate this section in case people find it difficult to spontaneously identify/talk about the impact of IBD on their lives.

This section ends with exploring who supports/looks after them when they are poorly with IBD in terms of family/informal support networks. The next part of the interview will explore support from the clinic.

- For each distinct issue mentioned, probe using questions such as:
 - Can you explain a little more how it affects
 - Can you give me an example of when that has happened?
- **Show the interviewee the 'life map'.** Some areas may have already been mentioned.
 - Ask interviewee to identify **any further life areas affected by having IBD**. Use same pattern of questioning as above.
 - Repeat until feel have explored as much as interviewee wants to discuss.
- **Support when unwell**
 - Who tends to know?
 - Who supports / helps out when unwell?
 - Ask if feel adequately supported.
 - Ask to describe any areas where need more help/support
- **Reflections on being South Asian**
 - This project is about the experiences of people are from South Asian communities. We'd really like to know whether living with IBD is different in any way for people from this background. What are your views on this? Does being [use ethnic group option ticked in response form] and/or [use faith ticked in response form] make any difference to the impact IBD has had on your life?
 - If not made a difference to them, check if they feel it makes a difference to other people who are South Asian makes a difference to the Impact IBD has on *other* people's lives

4. Contact with gastroenterology services (~15 mins)

Briefing note: *In this section we want to find out about their experiences of NHS clinics / other services. Patients may contact the clinic outside of routine appointments if they are concerned about their health, though not all do this. We also want to explore whether anyone accompanies them to appointments, the reason/role of that person (e.g. companion, chaperone, interpreter etc.) and feelings about the person's presence. Finally, we would like to find out about any inpatient experiences, specifically any difficult/negative or positive experiences of being on the ward. Across all these topics, we want to find out what would improve their experiences as NHS patients.*

- Explain that this section is about experiences with clinics. Remind participant that your independent from the clinic everything they say will be kept confidential.
- **Frequency of appointments** at the clinic and **who usually sees** (doctor, nurse, dietician....)
- **Ask if usually go to appointments on own or take someone with them**
 - If take someone, explore why.
- **Contact with clinic outside of appointments**
 - Frequency and reasons for contact
 - How make contact (eg phone)
 - Who speaks with?
- **Check if had any overnight stays in hospital for IBD.**
- **Satisfaction and concerns**
 - Anything particularly stand out about experiences with gastroenterology services: either a very positive or very difficult experience.

Check for

 - Clinic appointments
 - Contact between clinic appointments
 - Inpatient care
 - Perception of whether clinic staff are aware of and respond to needs as a South Asian woman/man [insert words as appropriate]

Make sure to check for **both** positive and negative experiences

5. Support from Crohn's and Colitis UK (~15 mins)

Briefing note: This section of the interview is concerned with interviewee's knowledge and use of Crohn's and Colitis UK; and views on accessing support from such an organisation. We use a 'map' of the services/support Crohn's and

- Signal that this is the last section of the interview (as interviewees may begin to tire at this stage)
- Explain that Crohn's and Colitis UK have funded the research because they are concerned that what they provide is not appealing to people from South Asian communities, so it would be very helpful to have their views on what they provide.
- **Awareness of/use of Crohn's and Colitis UK and the support / services they offer.**

- Show list of support and services offered by Crohn's and Colitis UK
- Check for any contact with / use of Crohn's and Colitis UK resource
 - Reasons for contact / use of resource
 - Views on quality of support / information.
- Is there anything on the list that you didn't know they provided, which would have been useful in the past if you had known about it or which you might be interested in using in the future?
- Identify which support/services they regard as not useful/ of interest to them
 - Why not
- What could Crohn's and Colitis UK do to:
 - increase the number of people who are members of their organisation?
 - cater for the needs of South Asian patients?

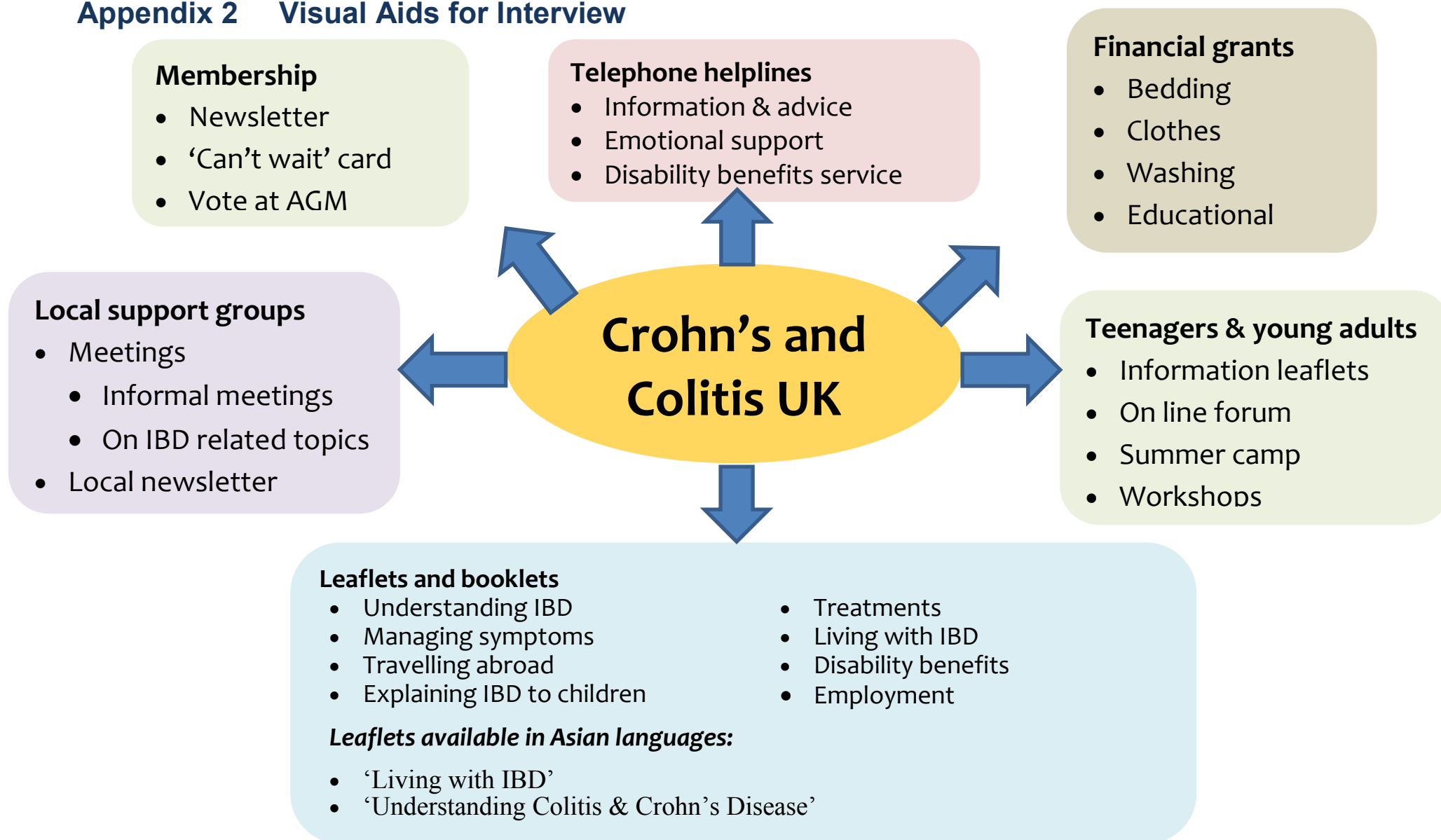
6. Close

Briefing note: *This is the final section of the interview. It provides interviewees with a final chance to raise issues/mention views. Thanks for participation is very important, as is reminding about confidentiality. We close with some practical aspects of participation.*

- Any further ideas and recommendations for improving support to people of South Asian origin and their families
 - NHS.
 - Crohn's and Colitis UK.
 - Other
- Thank participants for their time and thoughts
- Explain that before end the interview need to check some background information on participants. **Complete 'Background Information Form 2'.**
- Explain that will be interviewing people until end of October, and will then analyse all the data and write a report. This work needs to be completed by April 2014 as this is when the project ends. A summary of the findings will then be available through the SPRU website. Ask if they would also like to be sent a copy of the findings through the post. (Record this on the background info form)
- Check if they have any further questions.

- 'Useful Contacts' leaflets
 - For face to face interviews - hand out leaflet
 - For telephone interviews - mention that will be putting this leaflet in the post to them along with voucher.
- Find out about voucher preference and explain that it will be sent in the post, along with a receipt which would like them to sign so that we know they have received it.

Appendix 2 Visual Aids for Interview



Living with IBD

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graph TD; A((Living with IBD)) --- B[My relationship with my partner / wife / husband]; A --- C[Family life]; A --- D[Getting out & about, travelling]; A --- E[My feelings & emotions]; A --- F[Family or community gatherings/ events]; A --- G[Social activities with friends]; A --- H[Cooking, housework and/or jobs around the house]; A --- I[Practising my faith]; A --- J[My hopes & plans for the future]; A --- K[Work or studying]; A --- L[Being a parent]
```

My relationship
with my partner /
wife / husband

Family
life

Getting out
& about,
travelling

My feelings
& emotions

Family or
community
gatherings/
events

Social activities
with friends

Cooking, housework
and/or jobs around
the house

Practising my
faith

My hopes & plans
for the future

Work or
studying

Being a
parent

Appendix 3 The development of the thematic framework

Development of the thematic framework involved a number of steps as follows:

1. The lead researcher (R1) carried out an initial read through of all transcripts and field notes and then wrote a 'pen portrait' for each interview. A pen portrait is a 1-2 page summary which 'which makes the person come alive to the reader' (Holloway and Jefferson, 2000). It includes any inconsistencies, contradictions and puzzles noticed within the data. In addition, the researcher developed a list of all the themes observed in each interview.
2. Next the R1 passed on a sample of five transcripts, representing participants of different genders, faiths, ages, and years of experience of living with IBD to two members of the research team (R2 and R3). Having read these transcripts, the research team met to discuss: (1) the *A priori* and emergent themes identified within the data and (2) whether any of these themes appeared to be grounded in South Asian identity or culture. At these stage it was agreed that the data fell into 8 higher order themes (The impact of IBD on people's lives; strategies that help people live with IBD; understanding of IBD; disclosing illness to others and their response; going abroad; experiences with health services; unmet support needs; feedback and suggestions for Crohn's and colitis UK).
3. R1 reviewed all the themes identified from the initial read through of the data and the team meeting, and assigned them to one of 8 higher order themes. This constituted the first draft of the thematic framework.
4. This first draft of the thematic framework was then presented to the PAG for comment. Feedback was as follows:
 - a. The PAG validated a number of themes emerging from the data (pain, fatigue, being housebound), but noted that many of these were generic and asked that the final report makes clear which experiences are likely to be specific to South Asian patients.
 - b. They note that a number of beliefs about the cause of IBD seemed to be about self-blame.
 - c. Diet was not as prominent an issue as expected. Members of the PAG were interested in understanding which dietary restrictions were particularly difficult for South Asian patient and why, and asked that this is addressed in the final report.

- d. The PAG was interested in the importance of people's living circumstances in shaping their experiences and suggested that it might be worth exploring differences between those who do and do not live with extended family.
 - e. Patient representatives *not* of South Asian background urged caution in labelling experiences as South Asian, reporting that some of the themes which might appear to be linked to South Asian faith or culture were also familiar to them (e.g. IBD being a punishment for sins).
5. R1 and R2 met to revise thematic framework in light of feedback from PAG. The following decisions were made:
- a. R1 & R2 reflect on the fact that while the PAG were familiar with the idea that pain and fatigue are central to IBD patients experiences and quality of life, they seemed less familiar with the possibility that anxiety about loss of bowel control can be significant for some people's lives, causing them to be housebound even when their symptoms are well controlled. This is seen as important by the research team as it suggests that improvements to quality of life could be brought about by some form of psychological intervention. Efforts will be made to explore whether anxiety is as prominent within the data as it appeared to be during the first read through.
 - b. In order to remove duplication of data being charted into different themes, it was decided that the themes 'Support needs expressed by patients' and 'Strategies people use to live with IBD' should be subsumed within 'The impact of IBD on people's lives'. It was also agreed that this newly merged theme should be given a different title as it is now about more than just 'impact' and forms the core of the interview. It will therefore be renamed 'Living with IBD'. Following this decision, the framework includes 6 themes: Living with IBD; Disclosure of IBD diagnosis to others & their response; Perceptions and beliefs about cause of IBD; Visits to South Asian countries; Experiences with health services; Feedback and recommendation for Crohn's and Colitis UK.
6. Next R1 carried out data extraction on 10 interviews, then met with R2 to review progress. After jointly reviewing the charts it is agreed that:
- a. The themes 'Disclosure of IBD diagnosis to others and their response' and 'Experiences with health services' are both about support, so should be managed under one 'Social support' theme.

- b. Care needs to be taken with data on impact to be clear whether participant is referring to impact when having a flare up or on a more ongoing basis.
- 7. The final draft of the thematic framework (see Appendix X) is agreed. It includes 5 main themes: Living with IBD; Access to support; Perceptions and beliefs about the causes of IBD; Visits to South Asian countries; Feedback and recommendations to Crohn's and Colitis UK.

Appendix 4 Thematic framework

Theme 1 – Living with IBD

Codes

- **Getting diagnosed**
- **Symptoms**
 - Pain
 - Fatigue
 - Bowel control
- Anticipatory anxiety re bowel control
- **Strategies for dealing with symptoms & any barriers to using them**
 - Medication
 - Surgery
 - Altering diet
 - Alternative/complementary therapies
 - Spiritual healer
 - Lifestyle changes (i.e. rest, exercise, stress reduction etc.)
 - Turning to faith
 - Other
- **Impact on life (positive or negative)**
 - Being confined to bed
 - Work/study
 - Financial
 - Fulfilling cultural expectations of good wife/husband/mother/father (including worries for future ability to take on role)
 - Activities of daily living (i.e. cooking, cleaning, self-care)
 - Social events/activities
 - Caring responsibilities
 - Relationships with spouses/partners
 - Relationships with children
 - Relationships with other family members
 - Friendships
 - Religious practice
- **Emotional well-being**
- **Outlook on life**
- **Articulated support needs**

Theme 2 – Access to support

Notes:

This theme will include unsupportive responses, such as:

- lack of support in adhering to preferred diet/treatment
- unwanted advice i.e. suggestions to seek out alternative treatment
-

Barriers related to lack of knowledge will include any explanations as to why they have chosen/not to disclose.

Codes

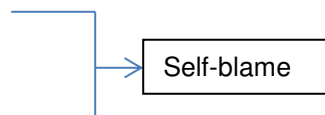
- **Support in household**
 - **Partner**
 - Perception of support from partner
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support

- **Parents**
 - Perception of support from parents
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
- **Children**
 - Perception of support from children
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
- **Other family members**
 - Perception of support from other family members in household
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
- **Contact with GP**
- **Articulated support needs**
- **Support from outside household**
 - **Employers/work colleagues/academic supervisors**
 - Perception of support
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
 - **Extended family and those in wider community**
 - Perception of support
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
 - **Friends**
 - Perception of support
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
 - **The web**
 - **Articulated support needs**
- **Support from health**
 - **Gastroenterology**
 - Perception of support from Gastroenterology
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
 - **Inpatient services**
 - Perception of support from inpatient services
 - Barriers to support (including lack of knowledge/understanding)
 - Facilitators/enablers to support
 - **Contact with GP**
 - **Articulated support needs**

Theme 3 – Perceptions and beliefs about cause of IBD

Codes

- Cause - unclear
- Cause - Anxiety/stress
- Cause - Lifestyle
- Cause - diet
- Cause - punishment
- Cause - God/Allah's will
- Cancer related
- Articulated support needs



Theme 4 - Visits to South Asian countries

Codes

- Purpose of visit
- Impact of visit on health
- Adjustments made to medical treatment when abroad
- Seeking further/alternative treatment when abroad
- Barriers to getting support/treatment when abroad
- Articulated support needs

Theme 5 - Feedback & recommendations to CCUK

Codes

- Awareness of CCUK
- Helpful support
- Unhelpful support
- Ways in which support could be developed – generic
- Ways in which support could be developed – for South Asian patients