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Abstract

There is strong evidence indicating that Inflammatory Bowel Disease (IBD) is increasing among Black and Minority Ethnic (BME) communities. Despite this rise in prevalence there is a paucity of research relating to ethnicity and IBD outside of the USA. Furthermore, the symptoms of IBD are reported to start during childhood or adolescence in 20-25% of people with the condition. It is therefore important that young people's experiences of diagnosis, treatment and living with IBD are fully understood to ensure effective services and information provision.

The study reported on in this paper was commissioned by a UK charity (Crohn's and Colitis UK) with the aim of increasing understanding of the specific issues and service needs of young people with IBD from BME communities.

Empirical research entailed in-depth semi-structured interviews with 20 young people from BME groups accessed through Gastroenterology Departments at three collaborating NHS Hospitals in England serving ethnically diverse populations. Interviews were carried out from June to December 2010 and sought to capture young people's views with IBD. A thematic analysis of their experiences identified many commonalities with other young people with IBD, such as the problematic route to formal diagnosis and the impact of IBD on education. The young people also experienced tensions between effective self-management strategies and cultural norms and practices relating to food. Moreover the ability of parents to provide support was hampered for some young people by absences of culturally competent services that were responsive to the families communication needs.

Findings highlight the need for more culturally-appropriate information concerning IBD, and improved responsiveness to young people with IBD within primary care and the education system, as well as culturally competent messaging relating to the specific nature of the condition among the wider South Asian and Black communities.

Key words: young people, inflammatory bowel disease, ethnicity, minority background

What is known about this topic:

- Prevalence data indicate recent increases of IBD among BME groups.
- 20-25 percent of IBD patients are diagnosed in childhood and adolescence.
- There is a paucity of research literature on ethnicity and IBD and an absence of UK-based research focusing on long term conditions among young people from BME backgrounds.

What this paper adds:

- The limited ability of some young BME people to partake in the food sharing practices of their cultural communities emerged as a source of tension with the young people's extended families.
- There was variability in parents' ability to navigate the primary care and education systems as advocates for their children due to a matrix of individual, cultural and structural influences, most notably an absence of culturally appropriate information provision.
- Interviewees demonstrated varied capacity for effective self-advocacy and disease-specific self-management coping adaptations.

Introduction

Inflammatory bowel disease (IBD) is an umbrella term that encompasses a group of chronic relapsing and remitting inflammatory conditions of the intestine, the commonest of which are ulcerative colitis (UC) and Crohn's disease (CD). In the UK, 180,000 patients are affected by this debilitating condition (NACC 2010).

Inflammatory bowel disease is traditionally thought of as a condition that affects Caucasian patients. More recently, epidemiological data (from both the US and UK) have indicated that these conditions are increasing in prevalence in patients from Black and Minority Ethnic groups (BME), and often present differently than in the Caucasian population (Sawczenko et al. 2001, Nguyen et al. 2006, Goodhand et al, 2012). In some areas in the UK, the rates of IBD in certain BME groups are equivalent or even more prevalent than the local Caucasian population (Probert et al. 1993, Tsironi et al. 2004).

The incidence of IBD in young people is likely to be rising (Henderson et al. 2012) with symptom onset starting in childhood or adolescence in 20-25% of patients. Inflammatory bowel disease research with adults has identified how the problems associated with disease fit into an established, adult lifestyle (Dudley-Brown 1996, Sainsbury and Heatley 2005). However, young people need to learn to cope with IBD during adolescent development (Daniel 2002, Nicholas et al. 2007, Lynch and Spence 2008).

The effects of IBD can have a profound, and typically negative, impact on a young person's life. Along with physical consequences, IBD during adolescence can have long-term emotional and psychological consequences (Helms 2007) as young people face potential exclusion from social, sporting and educational opportunities and can face difficulties in maintaining peer relationships (Brydolf and Segesten 1996, Daniel 2002, Nicholas et al. 2007, Lynch and Spence 2008). In one large UK study, 17% of respondents reported missing significant periods at school or college (Alexakis et al. 2013). Moreover, the symptoms of IBD, and their discussion, could be perceived as contravening social norms and etiquette, making life even more difficult socially than for adolescents with other long-term illnesses (Brydolf and Segesten 1996, Calsbeek et al 2002).

Body image issues related to IBD symptoms and side effects have been found to be more important for adolescents than for either children or older people, with appearance perceived as a key factor for social acceptance and the establishment of long term relationships, including intimate relationships (Calsbeek et al. 2002, Nicholas et al. 2007). The experience of being a young person with IBD can lead to self-imposed restrictions on lifestyles including adopting strategies to maintain secrecy about their condition for fear of being stigmatised (Nicholas et al. 2007). This behaviour means that young people with IBD tend to withdraw socially and can feel isolated. For some patients, this can be

exacerbated by bullying related to IBD symptoms (Brydolf and Segesten 1996). Research does suggest however that how families, and how parents in particular, respond and react to the young person's IBD impacts significantly on the development of robust coping mechanisms (Brydolf&Segesten 1996, Daniel 2002, Nicholas et al. 2008). For most adolescents with IBD, family support is very positive, valued and appreciated, with young people benefiting from the 'safety' of being able to talk to someone about such a private disease, especially when they may be feeling socially isolated (MacPhee, Hoffenberg, &Feranchak, 1998, Daniel 2002, Nicholas et al. 2007).

In contrast to the body of clinical evidence concerning the aetiology of the disease, social studies addressing the patient experience of IBD in relation to ethnicity are more sparse (Straus et al. 2000, Finlay et al. 2006). Two key studies from USA focusing on Black African Americans with IBD, found negative impacts on career choices, awareness of support organisations, internet use for IBD-related information, absenteeism and healthcare, the latter frequently related to health insurance (Straus et al. 2000, Finlay et al. 2006). Differences were even greater in terms of social support in that African Americans with IBD were far less likely than their White counterparts to feel able to tell employers, colleagues or friends about their condition (Finlay et al. 2006).

It could be argued that many of the difficulties experienced by young patients with IBD in general are inevitably shared by young patients from BME communities. However, there is marked paucity in the literature looking specifically at the burden of disease in this important group of patients. Differences in language, culture and religion could arguably play an important role in how young BME people experience, react and respond to symptoms, treatments, and relations with both peers and members of the healthcare services.

It is therefore important to elicit the narratives of those from BME communities in order to gain an understanding of whether these groups experience IBD in the same way as young people from non-BME communities, or whether they may require differing forms of support as has been suggested in the broader disability and long term conditions literature (Watson et al. 1999, Jones 2003). Thus, the primary aim of this project was to identify and characterise the experiences (positive and negative) and difficulties faced by young IBD patients from BME communities. The information could provide a valuable resource to allow supporting groups and agencies to develop socially inclusive service provision and information for these patients and their families, as well as raising awareness amongst healthcare providers into the culturally-specific issues that interplay with their management.

Methodology

This pilot study was commissioned by Crohn's and Colitis UK (a large UK-based charity with over thirty thousand members) with the intention of addressing a variety of issues faced by patients from BME with IBD. The project was carried out by the Centre for Research in Primary and Community Care (CRIPACC) at the University of Hertfordshire.

The study comprised of one-to-one detailed semi-structured interviews lasting up to one hour with patients who met the study criteria. Entry criteria for eligibility included; i) being aged between 16 and 24 years inclusively, ii) having an established diagnosis of Crohn's disease (CD) or Ulcerative Colitis (UC), and iii) having a Black or South Asian background.

A research steering group (comprised of three university researchers, a member of the funding body, two consultant gastroenterologists with an interest in IBD and two young IBD patients from BME) facilitated the research methodology, and met every three months during the 15 month project to discuss recruitment strategies, review literature on the topic, address ethics applications, prospectively evaluate the study findings and feedback on any issues encountered. A further consultant gastroenterologist based in Bristol, and a dietician also provided input and assistance.

Prior to formal patient selection, recruitment and interview, a pilot consultation was conducted with a young female Black patient with CD to highlight potential themes, issues and concerns experienced by young IBD patients from BME. This information added to the broad experience of the steering committee on the general topic of cultural issues in IBD, and aided in the structuring of the subsequent interviews.

Patients were recruited from gastroenterology clinics via one of the gastroenterology consultants or the IBD nurse specialist at one of St George's Hospital London, The Royal London Hospital or University Hospital Bristol. Patients were purposively selected to include the following disease parameters:

- Varying disease types including both UC and CD
- Varying length of time since diagnosis
- Varying ethnic backgrounds
- Varying genders
- Varying ages between the criteria limits

Patients were offered information about the study in clinic and if agreeable, were referred to the university researchers for interview. Informed consent was taken prior to commencing interview. The patients were offered a £15 gift voucher as a thank you for their participation.

The interviews were conducted between June and December 2010. The recruitment period was limited to seven months due to financial constraints. Participants were all fluent in English. Interviews were carried out by two researchers with backgrounds in psychology and sociology, experienced in interviewing techniques and sensitive to the nature of the discussion taking place, the age of the participants and to the interviewees' ethnic backgrounds. Both were of white British background. To limit interviewer bias, interviews were conducted in a semi-structured fashion, were open-ended and flexible in terms of questioning strategy to allow the key issues from the participants' perspective to emerge. The interviewer opened the discourse with the question 'How does IBD affect your daily life'. Interviewees were encouraged to talk freely and openly about all issues, and were guided by the interviewer to cover particular areas of interest including the impact of disease on their social lives, culture, religion and education, as well as enquiring into their experiences with the healthcare services at both primary and secondary level.

Interviews were conducted at a location convenient to the participant, be that their home, the hospital or a coffee shop. Those unable to attend in person (four of the final twenty) due to time, travel or illness constraints had interviews conducted via telephone (ensuring full privacy by using patient's mobile as opposed to the landline).

All interviews were recorded and transcribed. No formal second interviews were held, but patients were followed up with a telephone conversation or email exchange to clarify outstanding or missing information, including covering new themes that had developed since their original interview.

Transcripts were coded according to themes generated predominantly inductively during the process of analysing empirical data, and also deductively through being theoretically informed by existing research literature. Data was cross coded by the researchers and analysed thematically.

Ethical approval was granted (prior to study initiation) from the Outer North London Research Ethics Committee (REC no. 10/H0724/2, 12th February 2010). Research governance approval was sought and given at each of the three NHS sites.

Findings

A total of 20 young patients participated in an interview. Table 1 shows the demographics of the population sample. The breakdown of the ethnic groups interviewed revealed seven participants of Pakistani origin, five from Bangladesh, three from India, one from Sri Lanka, one from Nepal, one mixed white/Asian, and two Black/Black British.

The majority (13 from twenty) had been diagnosed with IBD in their early teenage years (11-15yrs), whereas two were diagnosed with IBD at less than ten years of age, and three had their condition confirmed after the age of twenty. The remainder were diagnosed when aged between 15 and 20 years.

Culture and religion

As well as a variety of nationalities there was also a broad range of religious backgrounds in our sample, as demonstrated in Table 2. Religious and cultural heritage had a bearing on many aspects of the patients' daily lives and interactions with other members of similar ethnic backgrounds.

Of particular note, was the impact of food and its cultural associations. Fourteen of the 20 participants experienced difficulties with certain food types, predominantly the spicy foods associated with their cultures. This was summarised by one interviewee:

'...spicy foods and stuff have never done me any good so I don't have anything with any significant spice in, or hot food in any shape way or form.' (male, aged 24, CD)

The fact that such foods are staple to these cultures compounds these difficulties as one young Asian participant highlighted:

'... In terms of diet it's very harsh, because with us, we have rice and curry all the time. You know, every meal is rice and curry' (female, aged 23, CD)

Restricting their diets to avoid the food that they felt exacerbated their symptoms, often resulted in a feeling of anxiety and social exclusion, as the participants had to have different meals to those of their siblings and parents (six of the 14 participants reported that their meals are prepared separately from the rest of their family). This was sometimes coupled with a sense of guilt, with young people feeling burdensome to their families for having to make a special effort to accommodate their dietary requirements. This sentiment was captured by a colitis sufferer:

'Well it means that I get meals made separately and the other members of my family get meals, well the other meals are made. ... sometimes I [feel excluded] because I'm obviously having to eat something different to them so, and it's extra work for my parents as well.' (male, aged 21, UC)

For most of the participants taking part in the study, food and food sharing have high cultural importance. One interviewee commented:

“it's just the way the ethnic community is and with food and obviously food is a big part of the culture ... everything is based around food, weddings are based around food, you go into people's houses, it's all about bringing as much food as you can and that's what entertaining is. That's the thing isn't it? It's like if you were back in the village and you were poor, you didn't want to show you were poor, so you'd bring out, you'd buy everything and your guests can't leave the house until they have tea and biscuits. If someone comes over to the house and I haven't sat them down and asked them for tea, my mum will like back-hand me and go 'Why haven't you offered them tea already?' sort of thing, so it's just the way... it is a different culture and just, you know, you will stand out ... because you're not eating.” (male, aged 20, CD)

Seven of participants reported difficulties with food extending outside the family setting. In some instances, patients reported having avoided large social functions, such as weddings, because of their difficulties with the food provided at such events. Patients displayed adaptive techniques for these situations:

‘...you take a packed lunch if you go, or you make some food with you and you just go and eat it in the car, get out the way, whatever.’ (male, aged 24, CD)

One interviewee reported using more radical methods (that he learned from a friend with anorexia) in a bid to conceal how little he was eating.

In addition, for certain subgroups of our cohort, religion had important associations with food and eating, and this was particularly the case for the Islamic participants during the period of Ramadan. In this religious festival, Muslim followers are expected to fast during daylight hours. This is more of a challenge when the event occurs during the summer months. Eight of the 13 Islamic patients reported that they did not fast because of their illness, with two undertaking a compromised ‘mini-fast’, and only three able to fast as normal.

Difficulties when attending places of public worship were also expressed by the Islamic cohort, particularly in periods of disease exacerbation. Anxieties were reported about feeling clean in a place of worship, having to interrupt a session of prayer to find a lavatory, or fears about public faecal incontinence.

Encouragingly, religious leaders were very accommodating to the needs of the patients, showing empathy, understanding and being non-judgemental. Patients reported access to leaflets explaining the

situations in which they could 'break' their fast (such as illness), and were offered alternative religious deeds (e.g. donation to charities) to compensate for the inability to fast. In turn, several young people spoke about the positive impact of their faith on their disease, indicating the calming effect of worship on their understanding and experience of illness.

Parents, families and the wider community

A key finding was that at least seven of the young people with IBD in this study appeared *not* to receive the same level of social support from their parents as the literature suggests their non-BME peers with IBD would be receiving, and this was primarily attributable to their parents having a poor understanding of the condition. The parents of nearly half the participants in the study (nine out of twenty) were poorly proficient in English and there was little, or no culturally-appropriate information available about the condition. Rather than having access to professionally-informed healthcare communications, this group of parents relied on lay sources of information, often their sons or daughters:

"my parents can speak a bit of English, but not as fluently ... so what I've had to do is translate most of what's been going on and try and explain as much as I can about the illness and the sort of progression it might take and sort of treatments" (male, aged 21, UC)

However, some participants found IBD difficult to explain and there were also examples of them censoring information about the nature of IBD and its long-term status to avoid upsetting or burdening their parents:

'... but I'm not really open about it (IBD), because I don't want them (parents) to worry about it.' (male, aged 20, CD)

As a result, some parents had misconceptions about IBD. In some instances they believed the condition to be "ulcer problems" or related to a poor diet. For example, one father, attributing his daughter's condition to not eating properly, kept buying milk and bananas for her, even though she would find them difficult to digest. In another instance, it was clear that the chronic nature of the condition was not appreciated by another parent, who asked of his son: *'You have been going to that hospital for how long? Why haven't they fixed you?'*

Another young man described the isolation he felt at home, with parents who had very little understanding of the condition, as *'hard, ... when you've got no-one to talk to in an everyday situation.'* Instead of having the supportive home environment that an informed parent can provide, it was apparent that some of the participants in this study were in a quite different situation. Furthermore this extended to their parents not always being able to offer the same levels of advocacy experienced by peers with parents who were fluent in English; there were examples of this in the study in terms of

both education (e.g. not realising that they should inform schools) and health, (e.g. not knowing what questions to ask).

Social support at a wider level, in the extended family and local community was often reported as missing too, with poor awareness of IBD, and a general unfamiliarity with the disease process, its causes and impact. This too impacted on participants' ability to cope with the condition. As one interviewee reflected:

'some awareness would be nice just so I don't have to sort of ... explain myself all the time.'
(male, aged 20, CD)

Education

Fifteen of the respondents experienced a significant level of disruption to their education. Eight of these 15 missed considerable amounts of the primary and secondary schooling, and two had to drop out of college because of their illness. Five reported that they missed a year at university requiring them to re-sit the year. These difficulties were conveyed by a female Crohn's sufferer:

"...for like the last two years literally, I was literally home unless I had to go to the hospital and I became isolated, so education wise I kind of, I don't see myself doing it anymore, I've lost that."
(female, aged 20, CD)

Three of the participants undertook home tutoring due to their poor school attendance. However, this brought with it a sense of heightened social isolation, a perceived sense of underachievement, and rarely improved educational outcome. However, of the quarter of patients who experienced no interference to their education, three completed full secondary school and two achieved university degrees.

Bullying at school was reported by a fifth of the participants. Although also targeted for their race, there were reports of disease specific harassment (mainly on toileting habits among others):

'I spent eight months of one year with a tube up my nose. Being brown you get bullied enough but being in a school like that with a tube up your nose you're going to get some stick and some flack, it teaches you to be a stronger person and get over stuff like that.' (male, aged 24, CD)

Where IBD-specific issues were raised with the schools, however, there was encouraging reports of appropriate support for the patients (e.g. allowing use of the staff toilets, special dispensation during exams, leniency with time off etc.). Also, interviewees reported that providers of higher and further education (sixth form colleges, universities) showed greater understanding to the needs of young people with IBD.

Healthcare services and support

The time to diagnosis from symptom onset ranged from one month to three years. Twelve of the interviewees felt they experienced delays or difficulties in the time prior to diagnosis. Of particular note was the issue of misdiagnosis. Tuberculosis (TB) was diagnosed initially in two of the patients. Other conditions the patients had been labelled with included Irritable Bowel Syndrome, stress related diarrhoea, and in one case a rare tropical disease. There were a number of reports of perceived scepticism of the patients' ailments (prior to diagnosis) particularly from primary care practitioners, who were invariably their first point of contact with the health services. One patient, whose experience mirrored that of a number of the other interviewees commented:

"I went back there (GP practice) quite a few times and the doctor was, my GP was trying to convince me that it was in my head and I was just imagining it." (male, aged 24, CD)

In one instance, a patient was referred by his GP for psychiatric evaluation for a psychosomatic disorder, with the blessing of patient's own relative (who was a medical doctor too). Given the experiences faced during diagnosis, it is unsurprising that patients reported feelings of isolation, frustration and confusion in this period of their illness, prior to firm diagnosis. The general impression by the participants who experienced delays in diagnosis was that there was a widespread lack of awareness of IBD in BME in primary care. This would have clearly had a deleterious effect on the relationship between the undiagnosed sufferer and the primary care provider, a point that was underlined by one young IBD patient:

'... when I have a problem I call her (consultant gastroenterologist), I don't even think about calling the GP.' (female, aged 17, CD)

The patient experience in secondary care was markedly improved. The predominance of white healthcare professionals in the field of IBD was not seen as a problem to the respondents. In particular, the IBD nurse specialists (IBD-NS) were highlighted as valuable team members particularly during acute flares. Continuity of care was also deemed very important, particularly in the transition from paediatric to young adult IBD clinics. Those who had been offered specialist counselling were complementary about the service.

From a non-clinical perspective, patients were satisfied with the level of hospital services responding to young patients from BME communities, including the accessibility of appropriate foods to cater for specialist dietary requirements (Halal, vegetarian etc) and availability of praying facilities in the form of multi-faith prayer rooms.

Discussion

This qualitative study provides new insights on the experiences of young IBD patients from BME communities in the UK, a topic that is under-reported in academic literature.

Although many of the issues identified in this study shared common themes with all young IBD patients in general, there were some culturally specific topics that were highlighted. Of note was the apparent language barrier that existed in almost half the patients' parents. Family support, particularly parental support, plays a vital role in the development of coping strategies by young sufferers (Daniel, 2002). However, parental support and parental understanding of the disease process go hand in hand. Language barriers coupled with limited or no access to culturally appropriate information about IBD will undoubtedly affect parents' capacity to provide the appropriate support for their children. With this in mind, hospitals, GP practices and IBD websites should strive to provide information about the disease in multiple language formats, appropriate to the local demographic.

Understanding of the disease process within the patients' local communities was also very poor. This issue led to reported feelings of isolation, inadequacy and secrecy by the patients. This will invariably cause distress for the patient as they are torn between their requirement to respect the cultural norms of their community and their need to ensure that they act in the best interest of their own health. Outside the immediate family, peer groups within the local community have been highlighted as beneficial in the supporting process of young patients with IBD (Nicholas 2007, Nicholas 2008). To assist in this line, awareness of IBD and its implications need to be raised in such communities. Incorrect assumptions, such as the condition being related to 'stomach ulcers' or poor diet, need to be addressed through education within these groups. This could be via primary care in the form of information booklets, or via community health workers with group meetings set up between those with IBD and their peers. From our patient cohort, there were encouraging reports of support and empathy from religious leaders. Such people are often well respected ambassadors for their local communities and through their influential position could encourage and assist in improving IBD awareness in BME groups.

The difficulties experienced with food in this group of patients were emphasised in this study. Spicy food, which forms a staple part of the diets in BME societies, was particularly poorly tolerated by the IBD patients. This intolerance to spicy foods is not unique to BME patients (Cohen et al 2013), but because of the important social role of meals and food sharing within these communities, avoidance of aggravating foods (or social events where such foods would be served) propagated feelings of social isolation amongst our cohort of patients. Although the study does not focus on the nutritional aspects of diet in BME patients, we would encourage increased awareness by dieticians and

nutritionists (who will invariably come into contact with such patients), and to help them establish alternative diets which are both nutritionally valuable and appropriate for their ethnic origin.

The contrasting reports of experiences in primary and secondary care add further evidence for the need to raise community awareness of this condition in young BME patients. Whereas comments about all aspects of secondary care were generally favourable, reports of scepticism, delays and misdiagnosis were worryingly common in primary care. Again, this is almost certainly due to general misunderstanding and poor awareness by primary care providers about IBD in BME patients. Of note, primary care physicians should be wary of 'cultural diagnostic stereotyping', whereby symptoms are attributed to culturally associated conditions (TB in our patients), without considering other potentially significant conditions (Dein 2006).

The IBD nurse specialist (IBD-NS) has been highlighted in previous research as an extremely valuable member of the IBD Multi-Disciplinary Team (MDT), particularly in young patients (Alexakis et al. 2013). Similar sentiments were shared by BME patients. Although the majority of IBD-NS have predominant roles in secondary care, with improved resources, they could be deployed to the community and act in a bridging fashion between primary and secondary care, as well as between healthcare services and other faculties in the community (education/ employment/ community groups) to help raise awareness of IBD in BME populations.

Some limitations of this study are worthy of mention. The study number of twenty may be regarded as too small to make generalisations, but the narrow constraints of the selection criteria, and the depth of qualitative data captured, enhance the credibility of the findings. It was also apparent during data collection that for the majority of the themes generated, data saturation was reached. However, its role as a pilot study was to explore certain themes and topics, and subsequently act as a prompt for similar studies in larger samples.

Members of Black or Afro-Caribbean lineage were underrepresented (only 10% of study population), so it would be difficult to make generalisations on this ethnic group. In our study, this apparent bias is almost certainly a reflection of the ethnic mix of population served by the recruiting hospitals. This is clearly an area that needs further exploration, and could easily be achieved by recruiting from hospitals that serve a population with higher proportions of Black and Afro-Caribbean patients. For the non-black participants, one has to consider whether the patients selected were representative of their ethnic group served by other hospital catchment areas. Finally, the ethnic mismatch between interviewer (two Caucasians) and interviewees from BME communities may, in some opinions, be a barrier to the information gathering process (Elam 2003). Shared cultural references may, for example, enable ethnically matched interviewers to understand cultural norms and values. Conversely, ethnic mismatching at interview has also been reported to be superior as it protects against ethnic suppositions (Carter J 2004). Certainly within in our cohort of patients, the latter was

more apparent. Interviewees felt able to talk freely with our researchers, with one young Asian lady commenting that she would have felt less liberated to comment on the issues in front of an interviewer of the same ethnic background.

In summary, we have presented in depth qualitative data on the experience of IBD and its impact on various aspects of the lives of young people from BME backgrounds. The most prominent finding, and the probable cause of the majority of difficulties facing such patients, is rooted in the general lack of awareness and understanding about IBD which was found amongst their family, members of their immediate and extended community, and in primary care. We have also recommended a variety of proposals aimed at addressing these issues. We hope that this study would encourage further large scale studies in to the specific issues highlighted in this cohort.

References

- Alexakis C, Davies G, Stephens G, Clark S, Rogers S, Poullis A (2013) 'Perspectives and attitudes of young patients with inflammatory bowel disease: symptoms, burden of disease and communication with their healthcare professionals'. *Frontline Gastroenterol* doi:10.1136/flgastro-2013-100400
- Brydolf M, & Segesten K. (1996). Living with ulcerative colitis: Experiences of adolescents and young adults. *Journal of Advanced Nursing*, 23(1), 39-47.
- Calsbeek H, Rijken M, Bekkers M, Kerssens J.J, Dekker J, Henegouwen G.P.V. et al. (2002). Social position of adolescents with chronic digestive disorders. *European Journal of Gastroenterology & Hepatology*, 14(5), 543-549.
- Carter J. (2004). Research note: reflections on interviewing across the ethnic divide. *International Journal of Social Research Methodology*, 7(4), 345-353.
- Cohen A.B, Lee D, Log M.D, Kappelman M.D, Martin C.F, Sandler R.S, Lewis J.D. (2013) 'Dietary patterns and self-reported associations of diet with symptoms of inflammatory bowel disease.' *Dig Dis Sci*. 2013 May;58(5):1322-8. doi: 10.1007/s10620-012-2373-3.
- Daniel J.M. (2002). Young adults' perceptions of living with chronic inflammatory bowel disease. *Gastroenterol Nurs*, 25(3), 83-94.
- Dein S. (2006). *Culture and cancer care, anthropological insights in oncology*. Berkshire: Open University.
- Dudley-Brown, S. (1996). Living with ulcerative colitis. *Gastroenterol Nurs*, 19(2), 60-64.
- Elam G, Fenton K.A. (2003). Researching sensitive issues and ethnicity: lessons from sexual health. *Ethnicity & Health*, 8(1), 15-27.
- Finlay D.G, Basu D, Sellin J.H. (2006). Effect of race and ethnicity on perceptions of inflammatory bowel disease. *Inflammatory Bowel Diseases*, 12(6), 503-507.
- Goodhand JR, Kamperidis N, Joshi NM, Wahed M, Koodun Y, Cantor EJ, Croft NM, Langmead FL, Lindsay JO, Rampton DS. (2012) The phenotype and course of inflammatory bowel disease in UK patients of Bangladeshi descent. *Aliment Pharmacol Ther*. 2012 Apr;35(8):929-40. doi: 10.1111
- Helms P.J. (2007). Being Different: adolescents, chronic illness and disability. In J. C. Coleman, L. B. Hendry & M. Kloep (Eds.), *Adolescence and Health*. Chichester: John Wiley & Sons Ltd.
- Henderson P, Hansen R, Cameron FL et al. (2012) 'Rising incidence of paediatric inflammatory bowel disease in Scotland'. *Inflamm Bowel Dis*. 2012 Jun;18(6):999-1005. doi: 10.1002/ibd.21797.
- Jones B. (2003). *Childhood disability in a multicultural society*. Oxon: Radcliffe Medical Press Ltd.

- Lynch T, & Spence D. (2008). A qualitative study of youth living with Crohn disease. *Gastroenterology Nursing, 31*(3), 224-230.
- MacPhee, M., Hoffenberg, E. J., & Feranchak, A. (1998). Quality-of-life factors in adolescent inflammatory bowel disease. *Inflammatory Bowel Diseases, 4*(1), 6-11.
- NACC. (2010). *NACC Plan 2010-2012, Meeting the challenge of Colitis and Crohn's Disease*. St Albans: Crohn's and Colitis UK. Document Number)
- Nguyen G.C, Torres E.A, Regueiro M, Bromfield G, Bitton A, Stempak J et al. (2006). Inflammatory bowel disease characteristics among African Americans, hispanics, and non-Hispanic Whites: Characterization of a large north American cohort. *American Journal of Gastroenterology, 101*(5), 1012-1023.
- Nicholas D.B, Otley A, Smith C, Avolio J, Munk M, & Griffiths A.M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and Quality of Life Outcomes, 5*.
- Nicholas D.B, Swan S.R, Gerstle T.J, Allan T, & Griffiths A.M. (2008). Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy. *Health and Quality of Life Outcomes, 6*.
- Probert C.S.J, Jayanthi V, Hughes A.O, Thompson J.R, Wicks A.C.B, & Mayberry J.F. (1993). Prevalence and family risk of ulcerative colitis and Crohns Disease - an epidemiologic-study among Europeans and South Asians in Leicestershire. *Gut, 34*(11), 1547-1551.
- Sainsbury A, & Heatley R.V. (2005). Review article: psychosocial factors in the quality of life of patients with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics, 21*(5), 499-508.
- Sawczenko A, Sandhu B.K, Logan R.F.A, Jenkins H, Taylor C.J, Mian S et al. (2001). Prospective survey of childhood inflammatory bowel disease in the British Isles. *Lancet, 357*(9262), 1093-1094.
- Straus W.L, Eisen G.M, Sandler R.S, Murray S.C, & Sessions J.T. (2000). Crohn's disease: does race matter? *The American Journal of Gastroenterology, 95*(2), 479-483.
- Tsironi E, Feakins R.M, Roberts C.S.J, & Rampton D.S. (2004). Incidence of inflammatory bowel disease is rising and abdominal tuberculosis is falling in Bangladeshis in East London, United Kingdom. *American Journal of Gastroenterology, 99*(9), 1749-1755.
- Watson N, Shakespeare T, Cunningham-Burley S, & Barnes C. (1999). *Life as a disabled child: a qualitative study of young people's experiences and perspectives.*: ESRCo. Document Number)

Tables

	Male	Female	Total
No. Interviewed	13	7	20
Age yrs (mean/range)	20.2 (16-24)	19.7 (17-23)	20.1 (16-24)
Diagnosis			
CD	9 (69%)	4 (57%)	13 (65%)
UC	2 (23%)	3(43%)	6 (30%)
Other	1 (7%)	0	1 (5%)
Ethnicity			
Asian/Asian British	11 (85%)	6 (86%)	17 (85%)
Mixed Asian/White	1 (7%)	0	1 (5%)
Black/Black British	1 (7%)	1 (14%)	2 (10%)
Place of Birth			
UK	13 (100%)	5 (71%)	18 (90%)
Non-UK	0	2 (29%)	2 (10%)

Table 1: demographics of study population

Tables

Religion	Number (%)
Christian	2 (10%)
Hindu	1 (5%)
Hindu/Buddhist	1 (5%)
Islam	13 (65%)
Mormon	1 (5%)
Other/Agnostic	2 (10%)

Table 2: Religious background of study population