

Inflammatory Bowel Disease and Young People from Black and Minority Ethnic Communities in the UK

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May 2011



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Acknowledgements

Firstly, and most importantly, our thanks go to all the young people who took part in the study and shared their experiences with us. They made the research a pleasure and displayed great fortitude in the face of what were, sometimes, very difficult circumstances. Without their co-operation and openness the project would not have been as successful in identifying the challenges that need to be addressed.

Invaluable expertise, guidance and enthusiasm came from the steering group which comprised Ms Helen Terry from Crohn's and Colitis UK, Dr James Lindsay and Dr Andrew Poullis, the two London-based consultant gastroenterologists, and Miss Shade Amar and Mr Yogesh Parmar, two young people with IBD who provided an excellent service-user perspective. Contributions from all steering group members were greatly appreciated by the research team. Professor Bhupinder Sandhu, based in Bristol, also provided valued advice, and we would like to acknowledge the critical role played by all three consultants in helping to recruit participants for the study.

We would like to thank Dr Roger Green and acknowledge his pivotal role as the original Chief Investigator on the project. He provided the initial impetus for the research, secured the funding, established contact and relationships with the collaborating consultants, and was instrumental in the operation of the steering group.

We would also like to specifically acknowledge and thank the following people for their valued contribution and input to the project: Ms Champa Jetha, Dr Sally Mitton, Ms Angela Cole, Dr Angela Madden, Ms Sam Shakes, Mr Wilfred Carneiro, Ms Serena Nuttall-Smith Dicks, and Ms Barbara Scott.

Glossary

BME	Black and Minority Ethnic
CD	Crohn's Disease
CRIPACC	Centre for Research in Primary and Community Care
GP	General practitioner
IBD	Inflammatory Bowel Disease
LTC	Long-term condition
NACC	National Association for Crohn's & Colitis
TB	Tuberculosis
UC	Ulcerative Colitis

Executive Summary

Introduction

The research in this report was commissioned by Crohn's and Colitis UK with the aim of ensuring that, as a support organisation, its policies incorporate evidence-based findings to develop and increase social inclusivity. In this instance, the focus was on young people with Inflammatory Bowel Disease (IBD) from Black and Minority Ethnic (BME) groups.

Increased prevalence of IBD among young people from Black and South Asian backgrounds determined the target ethnic population for research and the age range of 16 to 24 was selected as around 20-25% of patients are diagnosed in adolescence. Young people face immense developmental changes during this period that affect them socially, psychologically, physically and emotionally. Learning to cope with IBD has to accompany, interact with, and at times, interfere with typical adolescent development. This research investigated whether, or to what extent, young IBD patients from BME backgrounds experience difficulties, arising from the interaction of their ethnicity and their condition, which exceed those of their non-BME peers with IBD.

Research

A literature review identified issues specific to young people with IBD, such as social isolation, delayed independence, restricted living space. However, it also revealed a paucity of research into the non-medical interaction of ethnicity and IBD generally, and an apparent absence of data for young people with IBD from BME backgrounds specifically. The review was followed by qualitative research which comprised interviews with 20 young people (18 British Asian and two British Black) diagnosed with either Crohn's Disease or Ulcerative Colitis. All participants were recruited through consultant gastroenterologists working in London and South-West England.

Key findings

A thematic analysis of the experiences of these young people from BME backgrounds identified many commonalities with other adolescents with IBD. However, ethnicity and cultural identity posed additional challenges for our cohort and two key issues emerged:

- Nearly half our sample had parents who had limited proficiency in English, and a paucity in the provision of culturally-appropriate information seriously impacted on their parents' understanding of IBD. Crucially, this diminished the ability of some parents to provide valuable support and advocacy. Furthermore, it increased stress for several of the young people.
- At least two-thirds of the sample experienced difficulties in tolerating the spicy nature of food which is typical of traditional Asian and Black cuisines. This impacted both on everyday life and on young people's ability to be part of their cultural communities which value the social importance of sharing food.

Moreover, the experiences of the young people in our study were compounded by culturally-specific societal norms, such as the need for respect for elders, and by a lack of familiarity with IBD, particularly among the Asian community.

For some of the findings it was hard to disentangle how far negative experiences were a result of discrimination, being young, having a complex long-term condition, or a combination of any of these factors.

- While some schools displayed understanding and adopted supportive practices, the response from other schools to students with IBD in this study was found to be problematic in terms of the in-school management of their condition and their continued education.
- Young people's cumulative narratives indicated that a significant number experienced delays in diagnosis or mis-diagnosis. At primary care level there appeared to be a particular issue with some GPs' familiarity with the condition and with their skill in communicating with young people.

Conclusions and recommendations

As evidenced by the findings in this report, it is crucial that ethnicity and cultural identity is taken into consideration both at diagnosis and when providing healthcare and support for young people with IBD from BME backgrounds. Recommendations arising from the research focus on addressing parental understanding, referral pathways within primary care, educational and social support, and social inclusivity. They include:

- greater provision of more culturally-appropriate information and extra support where necessary;
- raising awareness and better understanding of IBD within primary care, education, and among South Asian and Black communities;
- helping this group of young people to cope and feel socially included within culturally-sensitive contexts.

The outcomes of the research are intended for Crohn's and Colitis UK. However, the findings also have implications for healthcare professionals both within gastroenterology and in other areas of specialism.

Chapter 1

INTRODUCTION

The Centre for Research in Primary and Community Care (CRIPACC) at the University of Hertfordshire was commissioned by Crohn's and Colitis UK (formerly the National Association for Crohn's and Colitis, or NACC) to carry out a study into social inclusion and the experiences of young people from Black and Minority Ethnic (BME) groups who have been diagnosed with Inflammatory Bowel Disease (IBD). The research combined a literature review with a qualitative study which directly sought the opinions and views of young people aged 16-24 from BME communities who had been diagnosed with either Crohn's Disease (CD) or Ulcerative Colitis (UC).

One of the prime aims of the research was to support Crohn's and Colitis UK's objective of developing inclusiveness, in this instance in relation to ethnicity. Evidence suggests that it is crucial to consider cultural and religious factors in relation to long-term illness and how these influence day to day living, health behaviours, healthcare choices and accessibility to services. The research findings seek to inform the charity's evidence base, with the aim of helping them to "reach out in a more planned and comprehensive way to ... groups who have been under-represented within NACC in the past", (NACC, 2010).

Background

Why focus on young people with IBD from BME backgrounds? Although in recent decades there has been a strong emphasis in the UK on addressing the health needs of an ageing population, children and young people still constitute a major proportion of the population: in 2007, there were 7.8 million young people aged 10-19 and 7 million children under 10 years of age in the UK - an increase of more than 11 % from a decade earlier (Coleman & Brooks, 2009). While it is true that young people tend to be healthier than older adults, high numbers of young people are affected by poor health, especially as a result of long-term conditions and disability.

Secondly, the symptoms of Inflammatory Bowel Disease are reported to start during childhood or adolescence in 20-25% of patients. It is therefore particularly important that young people's experiences of diagnosis, treatment and living with IBD are fully understood to ensure that effective services, advice and information are put in place. Research suggests that the effects of IBD can have a profound, and typically negative, impact on a young person's life and this is explored in greater detail in Chapter 2.

Finally, recent indications suggest that IBD is increasingly affecting people of Black, Asian and Hispanic origin, despite traditionally being regarded as a disease associated with Caucasians (Nguyen et al., 2006; Sung, Kamm, & Marteau, 2010; Tsironi, Feakins, Roberts, & Rampton, 2004). Indeed, in some instances, it appears to be more prevalent (Santana et al., 2007) and, in the UK, a number of studies

point to a high and growing incidence of diagnosis of both Crohn's Disease and Ulcerative Colitis among BME communities. For example, Probert, Jayanthi, Rampton & Mayberry (1993) found a higher incidence of UC among the South Asian population in Leicester than among local Caucasians. A prospective study in the UK of children returned similar findings, with Asian children being more likely to present with ulcerative colitis than other children (Sawczenko et al., 2001). In one London Borough IBD is now as common in the Bangladeshi community as in the local Caucasian community (Tsironi et al., 2004) and similar findings have been reported for CD in both Black and White populations in Derby (Sawczenko et al., 2001). It is therefore important to give a voice to 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 literature (Jones, 2003; Watson, Shakespeare, Cunningham-Burley, & Barnes, 1999).

Chapter 2

IBD, YOUNG PEOPLE AND ETHNICITY - a review of the literature

A search of the literature in this field indicates a dearth of research in relation to the social aspects of being a young person with IBD from a BME background (see Chapter 3 for literature review methodology). The majority of published research relating to ethnicity and IBD is concerned with prevalence, and the medical aspects of genotypes and phenotypes (e.g. Basu, Lopez, Kulkarni, & Sellin, 2005; Probert et al., 1993). A more general search identified only two IBD studies that addressed social and economic issues that were specifically related to ethnicity (Finlay, Basu, & Sellin, 2006; Straus, Eisen, Sandler, Murray, & Sessions, 2000). However, both studies were USA based and focused on adults, rather than young people, from ethnic minority backgrounds. The poverty of information in this specific area means that the following summary has necessarily focussed on previous research into the experience of IBD for young people in general, rather than for young people from minority ethnic backgrounds. Nevertheless, such information establishes a valuable baseline of knowledge against which factors specifically related to ethnicity in young people with IBD can be identified and extracted.

IBD in adolescence

For young people, many of the negative aspects of coping with IBD are shared with adults, such as the pain, fatigue, overcoming social stigma, misdiagnosis and delays in diagnosis. However, their experience of IBD differs from that of adults in a number of ways. Whilst adults are coping with IBD within an established way of life (see, for example, Dudley-Brown, 1996; Sainsbury & Heatley, 2005), for young people, learning to cope with IBD accompanies, interacts with, and at times, interferes with typical adolescent development (Daniel, 2002; Lynch & Spence, 2008; Nicholas et al., 2007). Moreover, research suggests that IBD can have a greater functional impact on young, single people (Maunder, Greenberg, Lancee, Steinhart, & Silverberg, 2007).

When in remission, young people report few problems (Nicholas et al., 2007) although maintaining remission may involve some changes to lifestyle, such as dietary restriction. However, flare-ups or exacerbations can mean intense and disabling pain, bowel urgency and incontinence, flatulence, and extreme tiredness to the point of exhaustion and weakness, (Daniel, 2002) and result in major disruption to all areas of life (Lynch & Spence, 2008). In addition, medication and treatment side-effects can bring further challenges (Lynch & Spence, 2008; Nicholas et al., 2007; Savard & Woodgate, 2009). The following summary considers how IBD impacts on a young person's life and what factors can moderate the negative impact of the condition.

Social development and social acceptance

Young people with IBD frequently miss out on social, sporting and educational events and activities with their peers. Not only is this disappointing for them, but it comes at a critical time in their lives for development and can have

long-term emotional and psychological consequences (Helms, 2007). Indeed difficulties in maintaining peer relationships, coupled with a restricted social life arising from the constant need to be near a toilet and dietary restrictions to avoid flare-ups have profound effects on adolescent social development. Moreover the symptoms of IBD, and their discussion, contravene social norms and etiquette, making life even more difficult socially than for adolescents with other long-term illnesses (Brydolf & Segesten, 1996; Calsbeek et al., 2002).

For young people this impacts on social acceptance by their peers. At a time when most adolescents are trying to fit in with their peers, develop independence and feel 'normal', young people with IBD often report feeling 'different' to their peers, are reliant on others and are vulnerable (Brydolf & Segesten, 1996; Daniel, 2002; Lynch & Spence, 2008; Nicholas et al., 2007). They have their privacy invaded (e.g. intimate medical examinations) (Brydolf & Segesten, 1996; Nicholas et al., 2007), are more likely to be absent from school, attend hospitals, etc., and may experience negative side effects of the condition and its treatment on their appearance (Savard & Woodgate, 2009). Research suggests that body image issues related to IBD symptoms and side effects are more important for adolescents than for either children or older people, with appearance perceived as an important factor for social acceptance (Nicholas, Swan, Gerstle, Allan, & Griffiths, 2008). It is not surprising then that many young people are distressed by the changes in their physical appearance such as wasting, weight gain or bloating, stunted growth, and skin eruptions (Daniel, 2002; Lynch & Spence, 2008; Nicholas et al., 2007; Sainsbury & Heatley, 2005). Moreover, alternative routes for social acceptance, such as sports activities, may not be accessible as exhaustion and the side effects of treatment mean that young people with IBD are less likely to participate (Lynch & Spence, 2008; Savard & Woodgate, 2009).

The experience of being a young person with IBD can lead to self-imposed restrictions on lifestyles and to maintaining secrecy about their condition for fear of being stigmatised (Nicholas et al., 2007). Many young people choose to hide their condition from peers and will only talk about it with their family, healthcare providers, employers or, for those attending university, with their professors. However, those that do confide in a friend indicate that it determines the value of the friendship (Nicholas et al., 2008). The stigma and associated secrecy mean that young people with IBD tend to withdraw socially and can feel isolated and, for some, this is exacerbated by bullying related to IBD symptoms (Brydolf & Segesten, 1996).

In terms of IBD's impact on romantic or intimate relationships there is comparatively little in the literature relating to adolescence. However, Calsbeek et al. (2002) found that young adults (<25y) with IBD were less likely than people with other chronic digestive disorders to have the self-confidence to initiate any form of intimate relationship.

Parents and families

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 (Daniel, 2002; MacPhee, Hoffenberg, & Feranchak, 1998; Nicholas et al., 2007). However, parents are likely to have concerns about the health of their child and his or her future and some become over-protective. Equally, negative responses (e.g. anxiety, teasing, poor communication) understandably make life far more difficult for the young person (Brydolf & Segesten, 1996). Many young people not only have to deal with the diagnosis for themselves, but also to 'cope' with their parents and their parents' reaction to the diagnosis (Brydolf & Segesten, 1996; Reichenberg, Lindfred, & Saalman, 2007). Frequently these young people are also aware of the demands that their illness places on their families, including reduced attention for their siblings (Brydolf & Segesten, 1996; Nicholas et al., 2008), and many indicate that they do not wish to be a burden or worry their parents.

Social support and support networks

Both adult and adolescent research emphasise the substantial benefits of social support in helping patients to adjust to their diagnosis and to cope effectively (see, for example, Nicholas et al., 2007; Sainsbury & Heatley, 2005). For young people this can come from family, healthcare professionals, or from peers once the issue of secrecy has been surmounted (Nicholas et al., 2007; Nicholas et al., 2008). For those reluctant to seek support or information elsewhere (2008) the internet provides a valuable resource with access to medical information, forums, and support organisations, such as Crohn's and Colitis UK (and similar worldwide), which provide practical and emotional support, and access to people in similar situations. Nonetheless, some young people feel that few truly understand their illness and what they are going through (Daniel, 2002; Reichenberg et al., 2007).

Education and employment

The sporadic nature of IBD means that it can have a profound impact on education and employment. Not only is frequent absenteeism from school or college a problem, but often diagnosis is comparatively recent and requires young people to gain skills and knowledge to manage their illness, adding to their educational burden (Daniel, 2002). Moreover, secrecy can lead to misunderstandings over absences. Surprisingly, however, research suggests that despite missed schooling young people with IBD are able to achieve comparable educational achievements to their peers (Mayberry, Probert, Srivastava, Rhodes, & Mayberry, 1992; Sainsbury & Heatley, 2005). Nonetheless when compared to other chronic digestive disorders, the consequences of having IBD can lead to being more dependent on benefits and being more likely to have long term financial worries (Calsbeek et al., 2002). Although

there is little in the adolescent literature regarding employment, adult research suggests that IBD is a major factor when making decisions regard location and type of employment, and it brings with it the fear of having to explain the situation to employers (Casati & Toner, 2000).

Psychological and emotional health

Understandably the effects of IBD on adolescents – the lack of control, the vulnerability, the unpredictability and the realisation that the illness will never go away – invoke many emotions, e.g. frustration, embarrassment, depression, anger, self-blame and guilt (Daniel, 2002; Lynch & Spence, 2008; Nicholas et al., 2007; Savard & Woodgate, 2009). The issue of stress was raised in a number of studies and, given that it is a known trigger for exacerbations, can be a major factor in a vicious cycle of events. Stress frequently arose from the fears and anxieties that accompany IBD – either physical (pain), practical (knowing where the nearest toilet is, getting behind at school) or worries over their future (relationships, employment, need for surgery) (Lynch & Spence, 2008; Savard & Woodgate, 2009).

Ostomy

Having ostomy surgery and a pouch brings with it additional and different problems for young people. While there may be benefits (alleviating pain, better health) (Savard & Woodgate, 2009), the effects of a stoma and pouch are emotionally profound. Those affected reported feeling 'very different' (Savard & Woodgate, 2009) and expressed anxiety and fears related to body- and self-image. They often did not want others to know about their pouch (Nicholas et al., 2008) and spoke of the restrictions it brings in not being able to wear the same type of clothing as their peers, their ability to take part in particular sports (e.g. swimming), and about intrusion on their bodies (Nicholas et al., 2008) and fears related to intimacy (Savard & Woodgate, 2009). A further challenge was the need to take on responsibility for the care of their stoma and appliance.

Resilience and IBD

Despite the challenges they face most young people with IBD indicate that they cope well with life and a number of positives are highlighted by them, such as the potential for better relationships with others. Many find that it has helped them to mature, encouraged a sense of acceptance, provided them with skills, and with greater sensitivity and tolerance towards others (Daniel, 2002; Nicholas et al., 2007; Nicholas et al., 2008; Savard & Woodgate, 2009). Some see it as a challenge to overcome and find that it has provided them with new and different opportunities, (Nicholas et al., 2007; and personal communication; van der Zaag-Loonen, Grootenhuys, Last, & Derkx, 2004).

Conclusions

For young people, having IBD has a profound impact on their lives at a time when they are already undergoing developmental changes in their lives (Lynch & Spence, 2008). Not only is there an exaggeration of the challenges that typical adolescents face (e.g. body image, social development, etc.) (Nicholas et al., 2007) to cope with, but

some of the impacts, e.g. unpredictability, restricted living space, feeling 'different', etc. exceed normal adolescent issues and provide young people with additional major challenges to overcome (Brydolf & Segesten, 1996; Nicholas et al., 2007). Furthermore there may be consequential effects such as delays in social development and becoming independent (Nicholas et al., 2008).

Ethnicity and IBD

The findings of the two adult IBD and BME studies cited earlier in this review focused on the social and economic aspects of IBD in relation to ethnicity, and suggest that it is an area that merits further investigation. Both studies (of Black African Americans) found a negative impact of ethnicity in relation to career choices, awareness of support organisations, internet use for IBD-related information, absenteeism and healthcare, the latter frequently related to health insurance (Finlay et al., 2006; Straus et al., 2000). Differences were even greater in terms of social support in that African Americans with IBD were far less likely than their White counterparts to tell employers, colleagues or friends about their condition (Finlay et al., 2006).

In view of the paucity of literature on IBD and young people from BME communities, the literature review was broadened to other long term conditions (asthma and diabetes) in order to gain insight into how people from BME groups experience other conditions requiring long-term management.

BME Young People and Long Term Conditions (LTCs)

Health services

Evidence from asthma and diabetes research highlights the need for improvements in the cultural appropriateness of health services and the development of cultural awareness by staff (Asthma UK, 2008; Chaudhuri, 2008; Davies, 2006; Lawton et al., 2008). The provision of services and appointments needs to be culturally appropriate: for example, South Asian patients may be unable to attend clinic on certain days or at certain times, speak frankly to members of the opposite sex, and women may be unable to attend clinic appointments alone (Hanif & Karamat, 2009).

Over recent years emergency admissions among all young people for long term conditions have increased (Coleman & Brooks, 2009). However it appears that BME groups also experience high rates of hospital admissions for LTCs; for example, South Asian people are three times more likely and black people twice as likely to have emergency hospital admissions for asthma in the UK. Explanations for these disparities include unequal access to high quality care (Asthma UK, 2007), variations in health-seeking behaviour (Netuveli et al., 2005), lack of awareness of services, language barriers and 'cultural insensitivities' when interacting with ethnic communities (Asthma UK, 2005a).

Cultural awareness

Community support for people from BME backgrounds is an important and complex issue. For example, many people of Indian culture and origin have been found to welcome someone from their community to provide information and assist with access to services (Asthma UK, 2008). However, cultural preconceptions can also be misleading, and access to large networks of family and community based support should not be assumed by health care providers (Asthma UK, 2008).

Diet and food practices

Food management is a core issue for people with diabetes, and cultural knowledge by professionals of differences in diet can have a positive effect on self-management and care through the recommendation of culturally sensitive dietary alternatives (Davies, 2006). Moreover in cultures with a strong emphasis on social 'sharing of food' changing dietary habits and modifying eating patterns in order to successfully manage a LTC such as diabetes can isolate individuals from their community and increase the stigma of having a LTC (Lawton et al., 2008; Patel, Morrissey, Goenka, James, & Shaikh, 2001). The difficulties of dietary change may also be doubly amplified for young people in school who may face intense social marginalisation or even bullying if they eat differently from their peers, and, as a result, they may not adhere to healthy eating regimes (Khunti, Stone, Bankart, & al., 2008).

Quality of life

Overall the evidence from the diabetes and asthma literature suggests that the quality of life for some people from BME backgrounds with a long term condition may be lower than that of the rest of the population with the same condition. Just under a third of the BME respondents in Asthma UK's survey experienced their LTC as negatively impinging on their social life, family relations and employment progression. Moreover, the result of the stigmatising effects of having a LTC may mean that important treatment and self-management strategies are forsaken in preference for self-protection through social concealment. However cultural and religious perspectives can have additional beneficial effects on care and self-management. For instance, the philosophy of balance in life advocated by Hinduism could contribute favourably to diabetes management (Patel et al., 2001). Furthermore, the support given to South Asians with diabetes by their family and religious leaders can be a means of assuaging illness-related anxiety (Stone & Lloyd, 2009).

As this review clearly indicates, age and ethnicity are crucial factors to take into consideration when addressing support for specific conditions. Given the apparent absence of any UK-based research into social inclusion and young people from BME groups who have IBD, together with the increasing prevalence of the illness within these communities, the research reported here is both necessary and timely. The evidence-based outcomes will contribute towards informing the development of ethnically sensitive support services and will also hopefully go some way towards raising awareness and understanding among health professionals, policy makers, and the wider community.

Chapter 3

BACKGROUND TO THE RESEARCH

Literature search (Chapter 2)

Literature searches were conducted through the Web of Knowledge, Scopus and Pubmed. The keywords were combinations of: IBD, inflammatory bowel disease, Crohn's, colitis, adolesc*, young people, youth, Minority Ethnic, Black, BME, Asian, social inclusion, social exclusion. Seven core studies were selected as addressing a broad and varied range of issues related to young people and IBD (Brydolf & Segesten, 1996; Calsbeek et al., 2002; Daniel, 2002; Lynch & Spence, 2008; Nicholas et al., 2007; Nicholas et al., 2008; Savard & Woodgate, 2009). Other articles related to specific areas of concern, e.g. coping strategies and quality of life (MacPhee et al., 1998; van der Zaag-Loonen et al., 2004). Of the seven core studies the majority were qualitative with sample sizes ranging from four to 80. Only one study was quantitative (IBD n = 305) and examined social functioning in adolescents with chronic digestive disorders including IBD (Calsbeek et al., 2002). Ethnicity was not identified in any of the core studies, although two papers indicated samples of 'diverse' origin (Nicholas et al., 2007; Nicholas et al., 2008).

Field research methodology

The study was guided by an initial pilot interview and the steering group. The research comprised one-to-one interviews with young people who met the criteria for the research and who consented to take part. They were recruited through collaborative consultant IBD specialists at three hospitals, two in London and one in the South West of England.

Pilot Interview

A pilot interview to inform the research was conducted with a young woman (20y) of British Black African background heritage, with CD. The interview highlighted a number of inter-related themes, some typical of young people with IBD and some ethnicity-specific, such as social isolation from other sufferers and the desire to avoid conflict with cultural values and traditions.

Steering Group

The research was guided by a Steering Group which comprised three university-based researchers, a representative from the funding body, two gastroenterologists from two of the collaborating NHS Trusts and two young people from BME groups with IBD. Input was also received during the early stages of research from two community members with health outreach expertise in BME communities and a dietician. Further input, external to the steering group, came from the third gastroenterologist. A key aim of the Steering Group was to facilitate the project's collaborative research methodology. Quarterly meetings during the 15-month project allowed for the cyclical feeding back of progress and emergent findings as the study developed.

Ethics

Ethical consideration for the patients was paramount and NHS ethical approval for the study was received from the Outer North London Research Ethics Committee, REC No. 10/H0724/2 (12.02.10). Both field researchers were subject to CRB approval, and obtained appropriate contracts to allow access to NHS patients at all three sites.

The researchers (a psychologist and a sociologist) were experienced interviewers and were sensitive to the nature of the discussion taking place, the age of the participants and to the interviewees' ethnic backgrounds. Both interviewers were White and whilst there are advantages to ethnically matching interviewer and interviewee, there are equally disadvantages (Elam & Fenton, 2003). Shared cultural references may, for example, enable ethnically matched interviewers to understand cultural norms and values. Conversely, in an ethnically unmatched interview, respondents may be more inclined to admit to cultural deviance and dissent of cultural norms and our fieldwork interviews accord with Carter's (2004, p.348) observation that interviewing across ethnic differences can protect against ethnic suppositions:

“it is the gap in experience between interviewer and interviewee that creates a space for respondents to describe and tease out meanings and assumptions that may otherwise remain unspoken.”

The interviewees in our study were very open with the researchers and felt able to talk freely, sometimes more so because they were strangers – a number said they did not talk to family or friends about their condition and yet they were remarkably frank with the researchers. Furthermore, one young Asian woman stated that she would have felt less able to be open in her responses had the researcher been of her own ethnicity.

Sample

The criteria for the study were:

- to be aged 16-24 years old,
- to have been diagnosed with either Crohn's Disease or Ulcerative Colitis,
- and to have a Black or South Asian ethnic background.

The researchers hoped to include some patients who had undergone stoma surgery and, ideally, the sample would have been equally divided by gender, illness and ethnicity. However, due to the narrow criteria and the means of accessing patients, the study necessarily relied on an opportune sample within the constraints of the criteria. In total 29 referrals were made to the researchers. However a number did not wish to take part or failed to respond to calls, and two were outside the age range. The final sample comprised 20 young people of Black or South Asian heritage and Table 1 provides a detailed analysis of the sample. The demographic characteristics of the sample is

likely to reflect the location of the collaborating hospitals as, of the 29 patients referred to us, only four were of Black British origin and two of these patients failed to respond to our requests.

Table 1:
Details of the sample of young people interviewed.

SAMPLE OF 20 YOUNG PEOPLE INTERVIEWED		
Age	Number	%
17-19	8	40
20-24	12	60
Gender	Number	%
Male	13	65
Female	7	35
Ethnicity	Number	%
Asian or Asian British	17	85
Mixed Asian and White	1	5
Black or Black British	2	10
Diagnosis	Number	%
Crohn's	13	65
Colitis	6	30
Both Crohn's and Colitis	1	5
Stoma	Number	%
Stoma	2	10
Reversed stoma	1	5
Religion	Number	%
Christian	2	10
Hindu	1	5
Hindu/Buddhist	1	5
Islam	13	65
Mormon	1	5
Agnostic/No religion	2	10
Age when diagnosed	Number	%
Under 10	2	10
11-15	13	65
16-20	2	10
20+	3	15
Place of Birth	Number	%
UK	18	90
Non UK	2	10

Conduct of interview

Patients who met the criteria were introduced to the study through the collaborating consultant gastroenterologist or the IBD nurse and were provided with information about the study. With patient consent, contact details were passed on to the researchers. For those who agreed to take part in the study, semi-structured one-to-one interviews of up to one hour took place at a time and location convenient to the participant, and this included coffee shops, their homes, or at the hospital. Four interviews took place by telephone as the participants were unable to travel due to ill-health or time constraints. The interviews were open-ended and flexible in terms of questioning strategy to allow the key issues from the participants' perspective to emerge. These started from the question "How does IBD affect your daily life?" and went on to cover issues such as diagnosis and treatment, access to information, healthcare services, education and employment, family, cultural and religious issues, peer relationships, etc. At the end of the interview participants were provided with a £15 gift voucher as a thank you for their time. The recorded interviews were transcribed for analysis.

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 were cross-coded by the researchers and analysed thematically. We initiated follow-up email and telephone calls with some respondents in order to clarify analytical themes arising since they were initially interviewed.

Aside from the original pilot interview, only two participants were of British Black background. As no specific differences were identified between these participants' experiences and those of the others no indication is given with regard to individual ethnicity in the following chapters in order to ensure anonymity and confidentiality.

Chapter 4

CULTURE, ETHNICITY AND IBD: THE EXPERIENCES OF YOUNG PEOPLE

Analysis of the interviews against the baseline of existing research indicated that young people with IBD from BME backgrounds shared many commonalities with their non-BME peers with IBD, with reports of secrecy, restricted living space, and social isolation, for example. Like their non-BME counterparts, many respondents used the internet for more information about IBD and, in general, found it helpful, although some found the amount of information on the internet rather overwhelming. Two-thirds of interviewees were aware of Crohn's and Colitis UK (or NACC), either as members, past members or as visitors to the website. However, the prime focus of the findings reported here will be on those factors that appeared to be related to issues of culture and ethnicity. In addition, delays in diagnosis or misdiagnosis and interrupted or abandoned educational paths featured heavily in the interviews. While these experiences were not directly attributed by individual participants to their ethnicity, young people's cumulative accounts suggest they merit discussion as areas of concern and are addressed in Chapters 5 and 6 respectively.

The interviews explored the extent to which the young people's ethnicity and IBD interact, particularly in the context of their age. Many of the young people interviewed reported that their ethnicity had not affected their own primary experience of IBD, for example, they were proficient in English and had no problem accessing information and understanding their condition. However, for most of the participants, their lives are cross-cultural in that they are part of families, extended families and the local community, all of which have strong ethnic identities and influences. One interviewee succinctly expressed this aspect of life as a young person from a BME background in the following comment,

“I mean, any ethnic minority sort of family ... you do have a slightly harder upbringing because your family want you to stick to your cultural roots and you're sort of rebelling against that because you've grown up in a western society so it's very difficult because you're torn both ways.”

(young man, aged 24, CD)

It was predominantly in relation to this cross-cultural aspect of their experiences with IBD that our interviewees reported specific challenges and two key areas emerged. One was the apparent paucity in the provision of culturally appropriate information for those young people's parents for whom English is a second language, and the other was diet-related. These issues and how they can negatively impact on the lives of BME young people with IBD are examined later in this chapter. However, before addressing them in more detail it is important to note that the effects of any ethnicity-related issues may be strengthened or compounded by other factors and two specific moderating factors arose from the interviews.

Firstly, there were reports of a lack of familiarity with IBD, both generally and, according to our interviewees, specifically among the wider community of the ethnic minority groups included in this study. Indeed, this was an underlying feature of many of the challenges that faced them,

“... some awareness would be nice, just so I don't have to sort of ... [explain myself all the time]”

(young man, aged 20, CD)

One mother who accompanied her son to the interview confirmed this unfamiliarity within her community and indicated that raising awareness was the main reason for her son taking part in the research. Her experiences as the mother of a young person with IBD from an ethnic minority community reflected those of the young people in this sample and provided an alternative, but concurring, perspective. She reported finding that she needs to repeatedly explain her son's condition to their wider family, and this was in part to defend her role as his mother as some believe that his stomach problems arise from what she is feeding him. Whilst acknowledging Crohn's and Colitis UK's determination to raise awareness, she suggested that still more awareness was needed, particularly in education. However, she was also aware that she and her son tended to hide his condition and, as such, were complicit in maintaining the secrecy around IBD.

At the same time, a greater awareness and understanding of IBD may help to alleviate any problems that arise from the other moderating factor, the cultural importance of respect for one's elders. In particular, this factor was felt by some participants to create tensions over diet and eating. For example, one young man whose IBD was exacerbated by certain foods reported the difficulties he experienced in disobeying his elders, despite it being the correct behaviour for his health,

“since my family say “eat this, eat that”, you know I wouldn't say, I wouldn't be saying no, I'd just be eating it so that they're not shouting at me ... it's a little bit difficult saying no to adults when you are supposed to [laughs] and I have to sort of build up the courage each time to say no I won't eat”

(young man, aged 24, CD)

He explained how this affected him emotionally and practically,

“since I'm the youngest I have to listen to what all the older people say, I have to do what all the older people say and since I'm not doing that they kind of get angry with me at times. ... easier to hang around with kids than with the adults since it's, ... you know it's just less stressful.”

For others, challenges arising from the need for respect for elders came in other forms such as blunt and ‘hurtful’ comments about personal appearance and weight, comments which, for the young people, simply had to be accepted and not questioned. A wider awareness and understanding of IBD would perhaps alleviate some of these issues and promote empathy.

Information, understanding and social support

Information equals understanding: a key to social support

As indicated in the wider literature, parents can provide invaluable social support for young people with IBD and this encompasses practical, emotional and psychological help. Indeed, many of our interviewees reported examples of this and, while they spoke of both parents supporting them, mothers tended to be mentioned more frequently in this role. For example, mothers would accompany young people to hospital appointments, act as confidantes, help with diet, and prepare meals separately for them. Fathers were notably found to play a greater role when they too experienced problems, as was the case for three participants whose fathers had either IBD or diabetes. However, there was evidence that this parental support was not always available and that this was specifically associated with those parents who had a poor understanding of IBD. The following presents the background to this poor understanding and the impact that it had, and continues to have, on interviewees’ lives.

Nine of the twenty interviewees reported that their parents had limited proficiency in English, and yet none mentioned being provided with information in alternative languages. This paucity in the provision of culturally appropriate information at diagnosis meant that the information parents in this situation received was, for most of them, through their son or daughter, for example,

“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 to them and try and explain as much as I can about the illness and the sort of progression that it might take and sort of treatments”

(young man, aged 21, UC)

As the number of participants affected by this represents very nearly half of our sample, it suggests that a significant proportion of parents of young IBD patients from BME backgrounds may be deriving their knowledge about IBD from a lay source such as their son or daughter, rather than directly from a healthcare professional or a professionally-informed health communication. None indicated that they had referred to Crohn’s & Colitis UK’s translated leaflets.

Moreover, whilst young people may discuss their condition with their parents and be their source of information on IBD this can, at times, result in mis-information. For example, young people often do not disclose everything and, in common with research findings from non-BME young people with IBD, we found evidence of censorship

specifically related to not wishing to worry their families. This occurred both when they are feeling unwell,

“... but I’m not really open about it because I don’t want them to worry too much.”

(young man, aged 20, CD)

but, perhaps more crucially, when conveying key messages about the nature and prognosis of IBD,

“This thing isn’t curable so I don’t really want to say that to them, it’s like I don’t want to really get them worried too much.”

(young man, aged 18, CD)

In addition, some young people admitted that they were, on occasion, not forthcoming with information in order to avoid generational conflict over differing views, while others found it simply difficult to explain,

“and my mum like she knows what it is but because I think she’s like, she can’t speak English like it’s not really clear to her, all she thinks it’s like an ulcer or something in my belly but she doesn’t know the medical like thing behind it at all and I can’t explain it.”

(young woman, aged 20, CD)

As a result, the parents of some interviewees were inadequately informed about IBD and this affected their perception and understanding of the true nature of the condition, including its effects on eating and the reality that it is a long-term condition.

Interviewees’ experiences revealed the profound effects that can arise from this situation. For example, it can lead to a parental ‘denial’ of the illness,

“And I think for a very long time, I think they were in denial that I have this disease. They just thought it was just gastric problems. And I think I’m pretty sure my Dad and Mum are probably still in denial, they think it’s some gastric problem... That will go away if I eat every single day loads and gain a bit of weight, it will be gone.”

(young woman, aged 23, CD)

or, quite typically, the belief that it is a short term, finite, illness as reflected in the following comment by one young man when talking about his father,

“he cares but he doesn’t show it the best way, he just sort of gets a bit angry, he’s like ‘Well this is ridiculous, why aren’t you better yet? and these doctors aren’t...?’ ... You have been going to that hospital for how long? Why haven’t they fixed you?”

(young man, aged 20, CD)

Being under-informed also means that parents may have difficulty in providing appropriate or optimal support for their child or young adult. For example, one young woman reported that her father believes that her medical problems arise from not eating properly and keeps buying milk and bananas for her, despite the fact that she would have problems digesting them. Similarly, of her mother, she recounted,

“ [she’s] just concentrating, ‘eat, eat, eat’ but, you know, sometimes she doesn’t understand that you can’t eat. ”

(young woman, aged 23, CD)

This young woman was not alone in her experiences and other respondents reported similar instances. One young man, now aged 23, had been diagnosed with Ulcerative Colitis at the age of 14, and felt the effects keenly of having under-informed parents. He recalled his experience of coping alone in early adolescence and how the sense of isolation that often accompanies IBD was not alleviated in his home life due to his parents not understanding the severity of his condition.

“ they [parents] can see what I was going through, you know, I was going to the toilet a lot, things like that, they could see that, but they thought it was just, just a phase thing, they didn’t really understand ... growing up could have been better if I had better support. But I don’t blame them, you know, ... I did as much... myself to look after myself, you know, just changing my food, just, and my lifestyle, food, things like that, but it was hard, because when you’ve got no-one to talk to in an everyday situation... ”

(young man, aged 23, UC)

The evidence suggests that parents clearly wish to support their sons or daughters and are acting in what they believe to be a positive way, however, their inaccurate perceptions and lack of understanding about IBD seriously hamper their efforts.

The parent as advocate

Reports also indicated that being poorly informed and lacking proficiency in English impacted on the ability of some parents to provide advocacy for their sons and daughters. For one young man this had profound effects on both his education and his healthcare. Despite being on a high dosage of steroids over a period of three years and yet still experiencing symptoms, this young man attended a secondary school which remained unaware of his illness. Failing to comprehend the severity and nature of their son’s condition meant that the parents did not inform the school, and the young man did not feel in a position to be able to tell staff,

“ I wasn’t a person who could just approach my teachers and just tell someone like that, because ... they might not take it forward or do the right thing, ... so for me personally it was really, I was really on my own with it, I did have to suffer in silence. ”

(young man, aged 23, UC)

Likewise, he believed the health advocacy that some parents could offer was not available to him,

“ Parents, the way, they, because they didn’t understand ... it could’ve been better, but ... they didn’t know what questions to ask, they didn’t know what was going on ”

Moreover, healthcare professionals spoke to his parents, but neglected communicating with him directly because he was under paediatric care and was treated as a child, despite being 14 years old.

“ they don’t tend to talk to you, they tend to talk to your mum and dad, and you feel, you know, very indirect about what’s going on ”

It seems unfortunate that the opportunity for him to engage with healthcare professionals was missed, and raises the question as to whether healthcare professionals recognise that some parents are in a position of being unable to properly understand the nature of their son’s or daughter’s condition.

For many young people with IBD their home life and parents are regarded as “safe” at a time when they may be feeling vulnerable and isolated, and it was no different for participants in this study when parents had a clear understanding of the nature of IBD. However, as the previous examples illustrate, for some young people with IBD from BME backgrounds, when parents have a poor understanding of the condition tensions can result and life at home can, conversely, become a source of stress or place of isolation. Currently there appears to be a significant gap in support for these young people which could be effectively addressed with culturally appropriate information for those parents who need it and with strategies on how to explain their long-term condition to their parents. Equally, age-appropriate responses in the UK health care system would benefit young people and create greater understanding.

Improving the situation – young people’s solutions

The interviewees were forthcoming with positive suggestions for addressing the challenges that they and their families encountered through the lack of culturally- and age-appropriate information. These ranged from producing leaflets in appropriate languages to ensuring that health professionals make more attempts to include young people in this situation in their care, as in the case above.

“ I thought if I had someone talking to me I would’ve been a lot more comfortable asking questions, ... even though you are a kid, you know, at that age, you’re still, you know, you’re intelligent enough to speak to an adult, you know, in a formal situation ”

(young man, aged 23, UC)

Furthermore, the young man’s experiences in education led him to propose that liaison with schools should be a feature of joined-up care for young people.

“ if [a kid’s] been diagnosed I think the hospital should be obliged to tell the school, the school should be obliged to know that one of their kids is going through this and they should have support. ”

This does occur among some teams with responsibility for young people with long-term conditions but appears not to be something that the participants in this study uniformly experienced. This suggests an inconsistency in policy by different NHS trusts and is something which could be readily addressed.

Harnessing experience was seen as a useful tool by one of the older participants who had been diagnosed at the age of 11. He put forward the suggestion that a mentoring service could provide valuable extra support for young people,

“ a service for people like myself who understand and have managed their condition very well, to support people who haven’t ... some form of I think peer to peer sort of support, not necessarily same age, would be really good. I know it would have been useful for me when I was... ”

(young man, aged 24, CD)

The value of a peer support or ‘expert patient’ type of programme would, no doubt, be a useful service for young people in general with IBD and, indeed, echoed a number of interviewees’ positive comments about the value of social support from those in similar circumstances. However, for those whose parents have English as a second language, this type of supplementary support could prove essential in helping them to cope with everyday life and reducing their sense of isolation.

For many the view was that professionals need to understand the potential benefits of ensuring that families were fully informed and our participants offered suggestions with regard to cultural norms that would engender better receptivity to information and, thus, greater understanding. This included enlisting the help of healthcare professionals as figures of authority who would be seen as trustworthy and knowledgeable or ensuring that there was someone available to interpret for the parents and to reassure them,

“ if they’re having a bit of trouble whether it’s getting their parents to understand or communicating with their parents, whether it’s about explain what their illness means or what exactly is involved in colitis or Crohn’s, for them to maybe speak to somebody who can maybe translate for them if they don’t speak English, or just for maybe a doctor or a nurse or somebody to speak to them just to say ... this is what’s happening, and just to sort of give them a bit of time to get used to it and ... don’t be, don’t feel upset or don’t feel you know, if they’re unable to take part in certain cultural events or if they can’t eat the food ”

(young woman, aged 20, UC)

One young woman, acknowledging that sometimes Asian parents are older than non-Asian parents, proposed that counselling should encompass family members too.

“ like the parents might be quite old to understand it, especially in Bengali culture I think it’s really hard to understand as well, so like yeah, I think they should ask them about counselling and stuff like that so they can also talk to the family as well, as well as the patient that’s ill and just make them understand what this illness is about and it’s affected them. ”

(young woman, aged 20, CD)

The interviewees’ expertise in this area is invaluable. Not only were they aware of the problems associated with under-informed parents, but they recognised that there are specific, culturally appropriate, ways in which to redress the situation, for example, by employing figures in positions of authority as sources of information. Furthermore, they are aware of, and can identify, issues which will be important to older generations.

Key Findings: Information, understanding and social support

- The parents of nearly half of the participants in the study had limited proficiency in English, and a paucity in the provision of culturally appropriate IBD information for these parents meant that they had a poor understanding of the condition.
- Inaccurate perceptions of the nature of IBD had a profound negative impact on the social, emotional and practical support that these parents were able to offer.
- The young people participating in the study were able to provide valuable ethnically-sensitive suggestions for improving the current situation with regard to culturally appropriate information, which included alternative formats for communication.

Diet and culture

Restrictions, restrictions, restrictions

Problems associated with diet and eating were key issues for all participants and affected daily life, even during periods of remission. Participants reported difficulties, for example, with the physical act of eating and with a loss of appetite. However, it was the imposition of dietary restrictions that featured in most interviews and which presented a serious challenge for most of the young people, producing comments that suggested a sense of social exclusion.

“I can’t have proper food like everybody else, I’ve got kind of, not a strict diet but a diet that I sort of follow so that I don’t have stomach pains ...”

(young woman, aged 20, CD)

Many found that they could no longer tolerate certain foods or food groups. However, the key diet-related issue for the ethnic minority groups in this study was that around three-quarters of the participants were unable to tolerate the spicy, ‘hot’, food which is typical of Asian and Black cuisines. Challenges and difficulties related to dietary restrictions of this nature touched many aspects of our interviewees’ lives, from the practical side to the social consequences associated with this in societies where food and food sharing have high cultural importance.

With regard to their home experiences, two participants mentioned that their parents sometimes cook or provide ‘modern’ or British foods such as pasta or fish and chips. However, this was the exception. Far more common was the finding that spicy food was the norm, for example,

“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”

(young woman, aged 23, CD)

Comments such as this capture the dual nature of the problem: not only is spicy food the daily norm in South Asian and some Black cultures, but it also has a negative impact for those from BME backgrounds who have IBD,

“food wise, Asian food isn’t... Pakistani, Indian food isn’t quite suited to people with Crohn’s disease”

(young man, aged 20, CD)

As this suggests, young people with IBD from BME backgrounds experience additional dietary restrictions to those of their peers with IBD.

While the majority of our interviewees found that spicy food either triggered IBD attacks or exacerbated their symptoms, the inability to tolerate spices and chilli varied by individual. For example, one interviewee only experienced problems during a flare-up. However, for

many, the intolerance was far more general, but sometimes related to the amount or strength of the spice used. For others, the issue of not being able to eat spicy food was very clear cut,

“spicy foods and stuff never have done me any good so I don’t have anything with any significant spice in or hot food in any way, shape or form.”

(young man, aged 24, CD)

There was also the suggestion that difficulties with tolerating spicy foods could intensify the problems faced by those who have surgery. One interviewee who had not experienced problems with the mild spices that were regularly used by her family, was aware that problems may arise now that she has a stoma and pouch,

“... after the last operation some people have said that once they can go, pass stools, normally it is hard when they’ve had spicy food, so I don’t know if that’s a factor that could affect me later in the future”

(young woman, aged 18, UC)

While the interviews revealed the individual challenges posed for participants by their traditional, cultural cuisines, a key finding of this research was the proportion of the sample that were affected. Of the participants in this study, only six of the 20 interviewees reported being able to tolerate spicy food at all times and two of these six have only mildly spiced food as part of everyday life. Given that this was an opportune sample within the criteria, it suggests that this may be a common challenge for those with IBD from Asian and Black communities.

Managing the restrictions

In order to manage dietary restrictions and, specifically, to avoid hot spicy food for the young people from BME communities, meals were cooked separately for them without spices or with a greatly reduced amount of spices,

“I told my mum, she makes special food for me. Basically what she does, she cooks it normally for everyone but she doesn’t put spices at all, she doesn’t put in all the spices. She’ll probably put it like half a spoon or something which I can’t taste that much which is cope-able but I won’t get ill over it and all that.”

(young man, aged 20 CD)

However, food consumption is not simply a matter of gaining sufficient nutrients to ensure physical health, it also contributes to emotional and psychological well-being. While reports indicated that the issue of spicy food was managed, and managed successfully, by families or by individuals, there were consequences of this. For example, in not eating the same food as the rest of their immediate family, some participants reported feeling excluded and most were aware of creating a burden of extra work for their families in producing separate dishes.

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 [feel excluded] because I'm obviously having to eat something different to them so, and it's extra work for my parents as well. ”

(young man, aged 21, UC)

Furthermore, food frequently has special attachments either evoking links to childhood or to a strong cultural attachment. Having IBD meant that these young people were denied food that they enjoyed and which had been a regular part of their daily life. Participants in interviews conveyed a sense of personal loss and described the tensions they faced in meeting their emotional needs for such foods against the consequences to their physical health.

Everyone's used to, like in Bengali families you're really used to having hot, heavy food like curries and stuff like that so sometimes, even though I'm not meant to have it, sometimes I just get so weak I just want it you still feel like having your curries because you're used to it, I've had it ever since I was a kid ”

(young woman, aged 20, CD)

For those of Islamic faith, there was the added challenge of needing to conform to religious food practices which, because of their condition, intensified the feeling, for some, that their relationship with food was primarily about restriction.

And it is sometimes, it's, um, it is sort of difficult and you feel like Muslim and then you've got Crohn's as well, because you're a Muslim certain foods they won't eat, is restricted and then with Crohn's it's even more restricted ”

(young man, aged 24, CD)

As the literature review indicated, diet and eating constitute a major influence in terms of social exclusion for all IBD patients. However, for these young people from BME communities, IBD appeared to create dietary restrictions and tensions in the way they respond to food and food consumption practices that far exceed those of their non-BME peers.

The social and cultural consequences of dietary restrictions

The consequences for our interviewees of dietary restrictions went beyond immediate family level to impacting on extended kinship relationships, particularly for interviewees of South Asian heritage. Many encountered difficulties at social occasions, at cultural events with family and extended families, or at weddings. The following description by one young man presents an overview – and a young person's view - of the importance and centrality of food at social occasions within South Asian culture.

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. ”

(young man, aged 20, CD)

However, as this indicates, it is the sharing of food that is culturally important: just as important as the courtesy of providing food, is the courtesy of accepting and eating it. It is with the latter aspect that our Asian interviewees reported experiencing problems when socialising within their communities. The terms 'awkward', 'frustrating' and 'tricky' recurred frequently in this respect, and the following is representative of comments about socialising.

you have to be very, very picky especially when I, say if I visit a relative they will sort of serve all these sort of dishes and I have to pick which one I can or can't eat and if they want me to eat some foods I can't ... they would like suggest ..you eat some other type of food. If there are other things on the table they might say "have some of these" or "have some of that" and I usually just say no way, you know most of the time. So it's, um, it is sort of frustrating because I'm off visiting a relative and it is, um, you know I'm sort of denying some of the food that they're offering me and I kind of feel bad for doing that. ”

(young man, aged 24, CD)

The extent of the social challenges posed by culturally-related dietary restriction was identified by the one interviewee who was adamant that ethnicity was not a factor that required consideration with regard to IBD, when even he admitted experiencing problems,

whenever I've gone to sort of family weddings and that sort of thing, that's where the ethnicity does come into a bit of an issue because I won't eat when we go there ”

(young man, aged 24, CD)

Moreover, as mentioned earlier in this chapter, the challenges facing young people with IBD of Black or Asian heritage in social situations such as these can be intensified by the need to pay heed to social and cultural norms, such as respect for one's elders.

Furthermore, for some, the problems with eating as part of a social occasion were compounded by the secrecy that often surrounds IBD. While large extended kinship networks were an important feature of familial life, participants did not always wish to disclose details of their condition to everyone. As one young woman reported,

“my immediate family know about it, but there’s no point, you know, having the extended... And being Asian you have very extended families, you know, everyone’s close so, I don’t know. I mean, I just don’t want to really talk about it to the whole world.”

(young woman, aged 23, CD)

Thus, members of the extended family networks were frequently unaware of the true nature of the young person’s condition. In some situations they were aware that the young person had gastric problems, but rarely knew that it was a long-term condition or that it was specific medical condition. In view of the potent combination of cultural norms, secrecy and dietary restrictions, particularly those related to spicy food, it is not surprising that young people with IBD from BME backgrounds might experience problems and be aware of feeling, and being regarded, as ‘different’ in social situations within their cultural community.

However, dietary restrictions were not confined to affecting life in the UK but also influenced young people’s ability and desire to travel. For example, a number of interviewees reported that they had vetoed the possibility of visiting extended family members overseas because of concerns over the food they would be expected to eat. The centrality of food within a society which can experience hunger or starvation through poverty or food scarcity means that attitudes towards food differ markedly to those in the UK. This clearly influenced one young man in light of his experience on a previous visit to family abroad.

“If I refuse it, um, basically it’s kind of like to sort of eat, um, it’s like some of each dish basically so you taste everything so, um, so basically, I try to do that but there are certain things I can’t eat. I remember once I was in Bangladesh and they had these, um, I don’t know how to translate them, but there was something but basically they were trying to force it into my mouth basically, like trying to force the food into my mouth with their hands so, um, so I really don’t want to go through that again.”

(young man, aged 24, CD)

Moreover, decisions not to travel abroad to see extended families were not taken lightly as participants were aware of the difficulties that it created, in terms of conflict or social exclusion, with families being split during holiday periods.

Diet and culture – addressing the social consequences

Our interviewees had developed a variety of ways of overcoming the difficulties associated with their IBD and socialising within Asian society. Taking or making sandwiches or packed lunches was mentioned by several interviewees and certainly resolves the issue of being hungry.

“you make 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.”

(young man, aged 24, CD)

However, as the phrase ‘get out the way’ suggests, the dietary issue related to spicy food does suggest feelings of exclusion. An alternative solution for many was not to eat at all, as one young man put it,

“now it’s been so many years I’m used to going places and not eating anything”

(young man, aged 20, CD)

For some, like the young man mentioned earlier who kept refusing his relatives’ attempts to persuade to try different foods, this situation makes them feel awkward and frustrated. However, one interviewee, was far more confident and very objective about his refusal to eat spicy food and to cede to persuasion at social events,

“if I’m going to have an issue with the food, I will tell them. I’m not going to be ashamed to say, well sorry, I can’t eat this. They’re like, no, go on, try some. Do you want to sit with me and be sick with me tomorrow? Then yeah, I’ll eat your food, otherwise shut-up, basically. And you become a bit brutal with it, you become a bit blunt and you do make some enemies with it but it’s like, well I’m sorry, it’s my body, it’s me that’s going to suffer, not anyone else. What’s the point in appeasing them just to eat some food so that I can suffer tomorrow? They’re not going to see it, they’re not going to be interested, they won’t ring me up to check I’m okay tomorrow.”

(young man, aged 24, CD)

Another young man was creative about the way in which he dealt with the issue of spicy food on social occasions as, in his words,

“... you don’t have to make a big deal about it, you don’t have to make a fuss about it, just be smart about it and don’t draw [attention]...”

(young man, aged 20, CD)

He would get his brother to taste test items to ascertain how hot they were or would have sandwiches. Normally though he would avoid eating. However, rather than simply not eating he employs techniques, some of which he learned from friends with anorexia, to cover the fact that he is not eating.

“... I’ll try and eat something because I don’t want to be like... I’m just sitting there and being like ‘Yeah, I’m not eating anything.’ I’ll eat a little ... make it look as if... yeah, and I’ll have to talk a lot so they don’t notice I’m not eating, and just little things and people won’t notice.”

Clearly, some young people develop pro-active ways in which to handle difficult situations successfully with regard to diet in social situations and some are more adept at it than others. Overall, negotiating and managing social situations was a key challenge for the young people in the study.

Key Findings: Diet and Culture

- Around three-quarters of interviewees experienced problems in being able to tolerate the spicy food typical of traditional Asian and Black cultural cuisines.
- An inability to tolerate the traditional cultural cuisine resulted for many in practical and emotional challenges on a daily basis.
- The dietary restrictions further impacted negatively on the young people’s ability to take part in family, social and cultural activities.
- Young people expressed a sense of loss and of social exclusion.

Religion

Religious identity has often been eclipsed by ethnicity in the context of health policy and research (Mir & Sheikh, 2010). While an examination of religion does not detract from health inequalities along ethnicity and ‘race’ lines, the aim of this section is to take account of BME young people’s religious identities in order to gain a more holistic understanding of their experiences of IBD.

The sample in this study shows a high rate of young people with religion, namely 18 out of 20 interviewees. They described their religious affiliations as Christian, Hindu, Hindu/Buddhist, Mormon, Roman Catholic, and Islam, the latter being the religion of 13 respondents. The following analysis examines the connections between young people’s religious perspectives and IBD experiences which includes a preponderance of data related to Islam reflecting the profile of those interviewed.

Ramadan

Ramadan was a significant time of the year for Islamic interviewees who spoke about their varying abilities to fast. Since Ramadan is a month of charitable giving, fasting during Ramadan is said to facilitate empathy with the poor and hungry which may thus enhance charitable donation. One view is that compensation for failing to fast due to ill-health can take the form of increased charity giving such as feeding and clothing people in need.

Compensatory deeds of this kind chime with the experiences of an interviewee in this study whose colitis prevented her observance of fasting. She explained how her family had been understanding:

“Like my family, especially my parents, they didn’t mind. What we do instead is we just either give some money to charity or we just sort of just give some money to the less well-off people who you know, maybe in other poorer countries, so yeah, and then just, yeah, my family they were okay with it.”

(young woman, aged 20, UC)

There was a sense in which young Islamic people in this study wished to undertake Ramadan fasting where possible. One respondent revealed his ability to fast depended on the time of year when Ramadan fell, with longer Summer days proving more problematical than the shorter daylight hours of Winter. Three respondents were pleased they were able to take their IBD medication at sunrise and sunset during Ramadan thereby keeping their fasts. Of 13 Muslim respondents, eight did not fast, two undertook a “mini fast” lasting a few hours rather than the full fasting time span, and three were able to fast.

Patients with IBD can be vulnerable to the risks of fasting during Ramadan. For example, the three-day fasting endeavours of an interviewee with Crohn’s disease had resulted in her becoming very ill which prompted her to

consult her Imam. He reassured her that her health came first and that if it caused her damage then she should not undertake fasting. She had also found an explanatory leaflet about Ramadan beneficial:

“... in our surgery they had like these leaflets as well for that month, people that are ill like what reasons they can't fast and when they should fast and what breaks the fast, things like that. I read that leaflet so it really helped.”

(young woman, aged 20, CD)

In terms of dietary intake, only one Muslim interviewee spoke of the restrictions of Halal food. Given the widespread availability of Halal food, especially in interviewees' residential localities, the dietary intake of young Islamic people with IBD in this sample does not appear to be significantly restricted.

Dietary requirements pertaining to other religions, such as periods of vegetarianism, were fulfilled without difficulty by respondents in this sample.

Public Worship

IBD has the potential for obtrusiveness on public forms of worship especially during periods of exacerbation. Attending mosque proved problematical for some male interviewees, particularly when they had less control over their symptoms and had to ensure they were clean for mosque. One interviewee had been unable to attend mosque as often as he wished as a child due to soiling his clothes. Another interviewee was mindful of the location of toilets in mosques. In instances of bowel urgency at mosque, sometimes mid-prayer, bathroom usage was acceptable, as in the words of one young man:

“It's not looked down upon”

(young man, aged 18, UC).

Just as there was variability among young people as to whether they informed teachers at school of their IBD diagnosis, so too was there variability concerning whether religious figures and scholars were privy to this information. There was inclination towards non-disclosure among a small minority of young men, one of whom explained how he showered each time before attending mosque and therefore did not feel the need to inform his Islamic teacher:

“he didn't know my problem but to what he saw I was like a normal, perfect student who used to come to mosque every day.”

(young man, aged 20, CD)

These sentiments are reminiscent of Williams' (2002) research which documents the tendency among young men to treat long-term conditions as episodic and therefore separate from their core identities. This is

analogous to young men in our study keeping IBD outside their religious personae and conforming to masculine ideals of being 'normal' and 'perfect', untainted by long-term illness.

Buffering Effects of Religion

Religious beliefs and practice can have beneficial effects on the management of long-term illness. A number of interviewees held religious beliefs concerning IBD causation which improved their ability to cope, as in the case of a young woman with Crohn's:

“Because I'm a Muslim and I'm actually trying to practice, I do believe in Allah and I strongly believe that, you know, he's given me that and I can cope with that, so I just know that he's there for me so I'll be able to deal with it. So my faith has actually grown stronger because yeah, it hasn't gone down at all.”

(young woman, aged 20, CD)

Research shows that believing in fate is not synonymous with an abdication of healthcare practices, but rather can signify the coexistence of religious beliefs and active self-management (Mir & Sheikh, 2010). This mirrors the accounts of some young people in this study who relied on God and derived strength from their faith in parallel to experiencing medical procedures, IBD medication and dietary therapy.

With stress prone to exacerbating symptoms, religion was regarded as having a beneficial effect on IBD, as mentioned by several interviewees for whom Buddhism, Hinduism and Islam had respectively helped them to stay calm and positive. Similarly, talking to her priest had proved helpful for a Catholic interviewee's adjustment to IBD:

“I told the priest about it and had a prayer meeting... so I've talked to him quite a bit about it... I think talking helps, certainly helps. Before I'd just block everything out, pretend I didn't have it.”

(young woman, aged 17, CD)

Religious Requirements and Hospital Healthcare Provision

There was evidence of hospital care services responding well to young people in terms of their religion. Inpatient dietary requirements, such as vegetarian and Halal food, were catered for by hospitals in this study. Praying facilities, including multi-faith prayer rooms, were also available in the hospitals where interviewees had been inpatients, although patients did not always make use of such facilities if IBD symptoms were not permitting.

On the subject of physical examinations at hospital, both male and female doctors were present at IBD clinics, as borne out during our observations at two of the collaborating hospitals. This enabled healthcare professionals to meet the needs of patients based on gender and/or religion. A gastroenterologist, whose clinic we attended for observation, informed us that occasionally

female patients did not wish him to examine them and occasionally they were Muslim, but this was rare. Nurse chaperones were also available where necessary for intimate examinations.

During the course of our research we noted the implementation of awareness raising measures in reference to heeding medical advice during Ramadan. In the month preceding Ramadan one of the collaborating NHS Trusts in this study ran information sessions for Imams and senior scholars about exemptions to fasting and adherence to medical treatment during Ramadan (BBC London News, 01/08/10). The Trust disseminated leaflets to this effect in multiple languages and is continuing to work with the local Islamic community. Heeding interview data elicited from young people in this study, such awareness raising endeavours are likely to be welcomed.

Religious Intersection

Some young people in this study seemed to be positioned at the crossroads of traditionalism and modernity. For example, one respondent wore an amulet of spiritual significance to ward off evil spirits as advocated by his parents who were of the opinion that black magic could have caused their son's IBD. As a Pharmacology student the interviewee in this instance appeared located at the intersection of traditional and modern-day healthcare beliefs. This is not to suggest that such intersection is a source of tension or conflict; indeed the interviewee appeared accepting of these intersecting perspectives, indicative of their capacity for coexistence.

Key Findings: Religion

- Interview data indicate predominantly positive connections between young people's religious perspectives and experiences of IBD.
- Measures are being taken to increase awareness of the implications of fasting and non-adherence to medication during Ramadan.
- Healthcare provision in hospital was commonly deemed responsive to IBD patients' religious needs.
- Improved understanding among healthcare practitioners of the religious context of some BME young people's lives may facilitate patient self-management practices.

HEALTHCARE SERVICES AND DIAGNOSIS

Primary Care

General Practice is often the first point of contact with health services for young people in their journey to being formally diagnosed with IBD. The interviewed sample had experienced a variety of encounters with GPs, and so too was there variety in the length of time young people had been ill for since initially contacting primary healthcare services until formal diagnosis was reached. These time periods spanned one month to three years, with two interviewees reporting ill-health for several years. It is their experiences of primary healthcare services in the course of diagnosis which form the main focus of this section, although reference to experiences of secondary care is included briefly at the end of the chapter.

Naming the Pain

Of the 20 people interviewed for this study, eight reported no adverse experiences during the process of being diagnosed. Their GPs had shown understanding towards their symptoms and had referred them to hospital for specialist tests. However, the remaining 12 interviewees, spread across the three NHS Trusts, had experienced difficulties and delays in being diagnosed. It was not uncommon for these young people to be told they may have other conditions such as Irritable Bowel Syndrome, stomach bug, stress related diarrhoea, or that they had consumed something disagreeable, or that they were dismissed as a picky eater.

Other incorrect diagnoses were tuberculosis (TB) as reported by two interviewees, and a tropical disease as in the case of one interviewee. These diagnoses are suggestive of 'cultural diagnostic stereotyping' (Dein, 2006, p.56), whereby symptoms are attributed to known cultural conditions while other, potentially serious, diagnoses are missed.

Delayed IBD diagnosis may exacerbate problems since inflammation of the digestive system can damage the lining further, and affect some of the concomitant symptoms of diarrhoea, passing blood, abdominal pain, malnutrition and fatigue. This was evidenced by a young woman in this study who recalled how she had suffered from stomach pain over a prolonged, three-year period before eventually being referred for tests and diagnosed with Crohn's:

“ I had a pain in my stomach and it wasn't normal, it wasn't like period pain or just normal pain, it was really painful. So my mum called, and I fainted once I think because I couldn't eat, every time I ate I'd vomit, so I fainted and an ambulance came and they took me in and they didn't know what was wrong with me. So it went on for about three years and I lost a lot of weight and then I started getting abscesses. ”

(young woman, aged 17, CD)

Although she visited her GP surgery, they told her that she was not eating properly. When there was no improvement in her condition other medical advice was sought and she was informed by two doctors and two different hospitals that she may have bowel cancer which had had the effect of “scaring” her and her family.

The very nature of IBD symptoms sometimes contributed to the length of time taken to reach diagnosis. A number of young people reported they had received unfavourable treatment from their GP from scepticism towards patient perspectives through to refutation of physical symptoms. One interviewee, for example, recollected how she saw her GP repeatedly over several months with severe abdominal pain, but the GP doubted she was 'really ill':

“ I used to go in as emergency and then she would be like, you know, 'People like you are wasting time'. ”

(young woman, aged 23, CD)

Her GP eventually referred her for tests which led to her being diagnosed with Crohn's. She reflected on the time, subsequent to being diagnosed, when she covered IBD in her own Pharmacy Degree studies:

“ I think the GPs need to be aware. And it's so funny because once I came across that in my course, I realised it's such a... like all the symptoms fitted it and I'm sure GPs they've got that standard training. And you know, like IBD is quite common in that sense, these symptoms and stuff and I'm surprised that she'd assume I'd be faking it. ”

(young woman, aged 23, CD)

Young people's delayed diagnosis can have a profound physical as well as emotional effect. The psychological impact of misdiagnosis was evinced during an interview with a young man who likewise encountered GP incredulity towards his ongoing symptoms of stomach pain and passing blood:

“ I went back there 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. ”

(young man, aged 24, CD)

After prescribing him various drugs which did not improve his condition, his GP suggested he see a psychiatrist. An Asian relative, also a GP, concurred with the psychosomatic diagnosis. In the meantime, the patient's worsening symptoms of constant vomiting and vomiting blood led his GP to give him anti-sickness pills. These did not work either and his continual vomiting culminated in his going to Accident and Emergency (A&E). After leaving A&E a different GP at the surgery referred him to hospital for tests where he was subsequently diagnosed with Crohn's.

“ I just kept taking all sorts of drugs which I don’t think I should have in the first place. And basically I just got very frustrated as none of the medicines [was] working. I remember, I think I just started crying after a long time since nobody seems to know what’s wrong with me and I’m in all this pain all the time and basically they just thought I have to see a psychiatrist because of that, um, yeah it was a very unpleasant experience for me during that time. ”

(young man, aged 24, CD)

Faced with deteriorating, untreated symptoms, some young people inevitably felt a sense of isolation, intensified in some cases by the doubt cast on their experiences by traditional first points of contact with primary healthcare services.

These interview narratives chime with research conducted by Mir and Sheikh (2010) into Pakistani Muslim patients in the UK with long-term illnesses. Patients in their study perceived their integrity was undermined when medical practitioners rejected their accounts of pain and deferred pain relief accordingly. Research has also documented evidence of white patients being more likely to be offered pain relief than Pakistani patients, supporting the contention that ‘practitioners deny credibility to these patients’ (Mir & Sheikh, 2010, p.335). In addition young people who experience pain may also be marginalised and seen as likely to be ‘acting out’ or ‘attention seeking’ consequently.

In relation to the current study it was not only young people who encountered scepticism from primary healthcare personnel but sometimes their parents too, redolent of the cultural stereotype pertaining to some ethnic minority patients’ inability for self-analysis (Said, 1995, cited in Mir & Sheikh, 2010). An illustrative example here is the account of a young, female interviewee who spoke of her frustration when both her and her mother’s concerns appeared to be disregarded during successive visits to her GP surgery:

“ ...maybe they didn’t believe that there was something wrong with me at first and it was constantly going back and forth to them. It really did annoy me because I knew there was something wrong, mum knew there was something wrong but no-one actually did anything to help me. ”

(young woman, aged 18, UC)

After she had been ill for a year her father informed the GP practice of his dissatisfaction:

“ I think it was my dad that put his foot down and said, ‘We need to get a proper answer now’. ”

(young woman, aged 18, UC)

She was eventually referred to hospital where she underwent an endoscopy and latterly required a reversible stoma.

Being diagnosed with IBD during adolescence comes at a significant developmental and transitional phase in young people’s lives (Heath, Brooks, Cleaver, & Ireland, 2009). Physical and behavioural changes regarded as characteristic of adolescence, such as being a choosy eater or anxious about school, can divert attention away from a young person’s medical symptoms. The process of ‘normalising’ a young person’s behaviour as typical for this life stage was revealed at interview with a young man whose GP described him as a “picky eater”. The interviewee explained how he had diarrhoea and started losing weight rapidly by the age of 12 but his GP simply thought he was “a bit thin” and would gain weight. He was critical of the tendency of his GP to “fob you off and send you home” and recalled the exasperation he and his mother felt during his prolonged route to being diagnosed with Crohn’s. Concerned about her son’s deteriorating health, it was incumbent on the interviewee’s mother to exact a more effective medical response, as the respondent explained:

“ ...when I was 13, I mean I was going 8, 9, 10 times a day to the bathroom and I was bleeding and all the rest of it and I’m going, ‘Oh my God, why am I bleeding, what’s going on?’ And so that summer I got really ill and my mother was just like, ‘No, this is taking it too far,’ and she went to the GP and said, ‘Look, I want him to go to hospital, I need to get him checked out,’ and they were like, ‘Oh, OK, right.’ And they still weren’t overly happy, they were like ‘Oh, it will fix itself, it’s probably just like a stomach bug’. ”

(young man, aged 20, CD)

The tendency to normalise and rationalise young people’s conduct as typical for their age also came to light during an interview with a young man who was diagnosed with Crohn’s aged 11 at a time when he was having problems at school. His GP initially attributed his ill-health and school absenteeism to the stress he was experiencing there. This case also illustrates the important role that parents play as advocates for their children and without this level of support they were unlikely to obtain a diagnosis.

“ ...my mum kind of got in such a state about it and she was like, oh, but we kept going back because she knew something wasn’t right. And then we went to this one doctor who she knew was good and he like, as soon as I walked into the room he like knew something was wrong with me. ”

(young man, aged 19, CD)

Tenacity and proactivity on the part of some parents clearly played a vital part in securing answers to their children’s unresolved medical problems.

When a young person's continuing symptoms enter a diagnostic impasse, their pathway to diagnosis may be forced to take an alternative route to that of traditional GP referral. This was evidenced in the case of a young woman who had been ill for over a year and a half. Despite describing herself as "getting very, very weak," her GP prescribed her medication for diarrhoea. Upon developing a swollen foot she went to a medical walk-in-centre and it was from there they referred her to hospital for more tests where she was finally diagnosed with colitis.

Even in cases where there was a family history of Crohn's or colitis, young people presenting IBD symptoms still encountered delays in being referred for further tests. A young, male interviewee, whose father had colitis, was ill for six months to a year during which time his GP thought he had a stomach bug. Although the GP knew his father had colitis, he said that colitis was rare. His parents suspected he had colitis and suggested their lay-diagnosis to the GP. Their son was eventually referred to hospital by the GP.

Formal diagnosis of IBD did not necessarily ease the process of referral from primary to secondary healthcare for ensuing treatment. An interviewee, recalling the "aggro" she had with her GP, experienced delays in being referred despite her considerable weight loss and difficulty eating and sleeping. Even after being formally diagnosed with Crohn's, her GP continued to be reluctant to refer her to hospital for treatment of a Crohn's related symptom:

“...they would not even refer me to hospital, six months I was struggling like with a boil you know, in my back passage and everything and they wouldn't refer me, and then after six months I had an operation without knowing what it was but they had to get this out.”

(young woman, aged 20, CD)

She later moved house and GP surgery. She praised the effective and frequent two-way communication between her new GP and hospital healthcare personnel.

For other interviewees trust in their GP had been damaged irrevocably and, following diagnosis, they preferred to bypass non-specialist healthcare practitioners and consulted hospital clinicians instead. The young woman, cited above, who visited her GP surgery over the course of three years prior to being diagnosed with Crohn's, was understandably inclined to make direct contact with the gastroenterologist at hospital in times of need:

“...whenever I have a problem I call her, I don't even think about calling the GP.”

(young woman, aged 17, CD)

Some interviewees were critical of the continued lack of awareness of IBD among GPs:

“I don't even think they know what Crohn's is.”

(young woman, aged 23, CD)

When diagnosis of IBD was finally reached, a common theme running throughout the young people's narratives was that of relief, especially when life threatening conditions such as cancer had been feared. Relief was, however, sometimes mixed with disappointment and shock at being diagnosed with a life-long condition that could only be managed rather than remedied. With diagnosis usually came the commencement of appropriate treatment, albeit in some cases long overdue.

Patient-GP Relationships

The GPs cited above were of varying ethnic backgrounds, though, when questioned, neither GP ethnicity nor patient ethnicity were regarded by any interviewees as having a bearing on the way they had been treated. Incidents of delayed and misdiagnosis could be interpreted as young people not being taken seriously by GPs, even in cases of severe, enduring physical symptoms.

This raises the question concerning how interaction dynamics impact on patient-doctor relationships. According to Helman (2000), patient-doctor interaction is influenced by the power differential that exists between them structured by variables including social class, ethnicity, age and gender. Factors such as these influence who wields power in the consultation and who does not, thereby affecting the form and content of communication between patient and doctor:

“...they help to determine what is said in the consultation, how it is said, and how it is heard and interpreted.”

(Helman, 2000, p.106)

This resonates with the diagnosis biographies of some of the young people in this study. Discourses of interaction revealed at interview indicate that young people were often disempowered by the consultation process. These concerns may also be present among other patient groups, but are possibly amplified in relation to young people of BME background because of their relative powerlessness within the medical context. Given that research has documented power imbalances which frequently attend relationships between GPs and patients, the sway of power could be even more one-sided where the patient is young and of a BME background. Power imbalances of this kind may emerge in subtle rather than overt forms and, as interview data suggest, could be influenced further by patients' temporal location in young adulthood and its attendant issues. This is not to suggest that young people in this study were passive recipients of medical services. Indeed, data discussed here show that unsatisfactory lay-professional interaction often necessitated recourse to self-directed action from young people and their parents.

As young people's customary first point of contact with primary healthcare services, GPs tend to occupy the relatively powerful position of gatekeepers concerning accessibility of referral pathways and setting in motion diagnostic procedures. The high rate of delays in referral for specialist tests among this cohort of interviewees, namely 60%, is particular cause for concern in view of this study's small-scale, opportune sample, and may be indicative of delayed diagnoses among the wider population.

Secondary care

The majority of participants had excellent relationships with the healthcare professionals in secondary care and the predominance of White healthcare professionals in IBD care was not perceived by our interviewees to be an issue that needs addressing. For the young people in our study, the ability to provide good healthcare is far more important than ethnicity. Moreover, one young Asian woman stated that she would find it difficult dealing with a healthcare profession from her own cultural background as she would feel that she was being judged. This concern only arose, by chance, with one interviewee, therefore it may be worth pursuing this further with a greater number of patients from BME backgrounds to ascertain whether this finding can be generalised.

IBD Specialist Nurses

IBD nurses were highly valued by interviewees particularly at times of disease exacerbation and their prompt response to patient need was commended. Even if correspondence with the specialist nurse took the form of telephone or email rather than face-to-face contact, these channels were much appreciated and well-suited to young people's mobile means of communication. Seeing the same IBD nurse in the paediatric clinic and in the adolescent and young adult clinic was highlighted by multiple respondents as good for continuity of care.

Dieticians

Dietician referral was, in the main, offered to those young people who needed nutritional therapy. However, there were some gaps in provision and not all young people in need of expert dietetic advice were referred. Receiving guidance from a dietician helped to a certain extent in young people's self-care management, particularly in the early period following diagnosis.

Counselling

Although not all young people felt the need for counselling, with a small number declining offered services, some respondents by contrast regretted that counselling had not been made available to them. Those interviewees who had received counselling spoke about its benefits such as dealing with both teenage issues and IBD issues. A respondent with orofacial symptoms of Crohn's had found counselling especially helpful for coping with adverse comments from other people.

Key Findings: Healthcare Services and Diagnosis

- 8 young people had positive encounters with primary healthcare services.
- 12 young people experienced difficulties and delays in being diagnosed.
- A significant barrier to young people's referral pathways was lack of awareness of IBD among GPs.
- Some GPs interacted in a negative way with young people and appeared to lack the necessary communication skills for consultations with young people.
- In general secondary care was seen positively.

Chapter 6

SCHOOLS, EDUCATION AND EMPLOYMENT

This section firstly explores the extent to which young people's education and employment experiences are influenced by having IBD. It latterly considers some of the financial implications of living with IBD raised by interviewees. Young people spend a substantial proportion of their time in education and it is important to examine the role played by school and university in shaping their experience of daily life with IBD.

While many of our research findings apply to young IBD patients in general, the analysis below additionally explores the interconnections between ethnicity, education, employment and long-term illness among the interviewed sample. The focus here is therefore on young people's experiences of IBD in the spheres of education and employment and, where applicable, on ethnicity as a mediating factor of their experiences.

IBD as Educational and 'Biographical Disruption'

Chronic illness has been seen as creating for many people major 'biographical disruption' in that it interrupts the usual life course that most people can expect (Bury, 1982). Disruption in the life course during adolescence and early adulthood can have the most profound implications for long term life chances. The concept of their illness creating significant disruption to their life plans resonated with young people's narratives in this study and in particular with their educational experiences.

Only five (a quarter) of the interviewees had not experienced any major interruptions to their education and had kept pace with contemporaries. This subgroup of five comprised three respondents who had hitherto completed school and two who had completed university with no illness-enforced gaps. These young people spoke of understanding educational staff who knew of their IBD. One young man, for example, was appreciative of his teachers:

‘They were supportive through it, they were like, ‘If you need the time off and everything, then we can do that and then we can make sure that the work is ready for you so when you do come back, the teacher can go through it with you so you can catch up on work.’

(young man, aged 18, CD)

These research participants valued understanding school and university staff who gave them special dispensation during exams to sit closer to the door and permit them extra time. Some interviewees also praised the fact that hospital consultants provided them with letters to give to school explaining the symptoms and needs of students with IBD. This was verified by our fieldwork observations at an IBD clinic where explanatory letters for school were offered to patients to help allay patient and parental anxieties concerning educational matters.

The fact that five young people in this sample were able to sustain continuous education was partly due to having IBD symptoms under control and partly due to the approach of educational staff, but was also testament to their own determination to manage the impact of IBD, as conveyed by one young female respondent who retained her position in the education system in spite of absences:

‘If I was ill and I didn't go to school I'd do work at home so I just, even if I'm in bed I'd be doing work.’

(young woman, aged 17, CD)

Just as there were various factors contributing to young people's educational continuation, there were conversely multiple causes of disruption, as evidenced by the remaining 15 research participants (three-quarters) experiencing significant interruptions to their education. Disruption of this kind was heightened in some cases where educational staff had not been informed of a student's IBD condition. Even if young people and their parents notified school staff about a diagnosis of IBD teachers did not consistently receive this information, highlighting the need for effective communication procedures across relevant educational personnel:

‘I told the head of year and we wrote a letter and she was like, ‘Oh yeah, well, you know, you can take time off,’ but they never told the teachers and if I'd mentioned it to the teachers they were like ‘What?’

(young man, aged 20, CD)

Educational Curtailment

So severe were some educational disruptions that educational curtailment ensued. This fate befell one interviewee who explained that she missed so much college that she reluctantly gave up her course:

‘...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.’

(young woman, aged 20, CD)

IBD did not always permit mainstream schooling and three research participants had been home tutored. However for two of them home tutoring it did not provide an adequate alternative to full time school attendance leading to increased social isolation, gaps in knowledge and skills and delay in taking key public examinations. The remaining home tutee spoke favourably of the hospital home teaching programme she had enrolled on through a hospital where she had previously received IBD treatment and not one involved in this study. Her older sister had been instrumental in initiating her referral to the programme.

Stress in Educational Settings

Education pressures can impact on young people's health and an increase in school tests coupled with widespread higher attainment expectations have arguably added weight to the strain put on young people in recent years (West, 2009). Young people in this study identified the stress of worrying about management of their condition in school and college as a major factor triggering their IBD symptoms. Apprehension about ill-health was itself a source of stress:

“ I think during exam times, just the stress and getting scared like because you're stressed you're going to get ill, so I think that's the most difficult thing. ”

(young woman, aged 17, CD)

Another interviewee, whose teachers had not been informed of his IBD diagnosis, referred to the stress of examinations and the potential to arouse suspicion if visiting the toilet frequently during an exam.

Higher Education

Educational disruption permeated higher education too. As discussed in the diagnosis section, the effects of delayed IBD diagnosis can be far reaching, evinced by one young man's thwarted aspirations of a university education:

“ if I had completed my course then I might have gone to university and maybe, I might have done a bit better than what I am doing right now but that's, I just wish I was diagnosed a lot earlier on than giving me all these sorts of drugs and telling me that it's all in my head. That's the only thing that's really bothered me. ”

(young man, aged 24, CD)

Overall there was a tendency for colleges and universities to show greater understanding of the needs of students with IBD in comparison to schools which may be related to young people themselves being better able to manage their disease and articulate their needs to educational personnel. Nevertheless, four interviewees had repeated part of a year or taken a year out of university for health reasons which necessitated getting to know a new cohort of students.

Informal Aspects of Managing IBD in School

In addition to formal aspects of schooling, informal aspects affected young people's educational progress as borne out in interviews with IBD patients. Accessing school toilets, for example, had a bearing on young people's physical and emotional well-being. Concentrating during lessons proved difficult for one young man:

“ I'm like literally doing a countdown in my head to the end of the lesson, so I know that I can get out and use the bathroom. ”

(young man, aged 18, UC)

Fear of soiling themselves at school naturally led to disease-specific coping strategies such as wearing incontinence pads and constant survey of where the nearest toilets were. Reaching toilets in time was not always the end of student worries though. One young male interviewee explained that some of the toilets at his secondary school did not have locks on the doors and other students kicked them open while he was on the toilet, or tried to climb over the top of the doors and asked him why he was in the toilet for so long. Together with his parents this young man negotiated the use of staff toilets at school. On occasion he has shown his Crohn's and Colitis UK 'Can't Wait' card to teachers at school when using the staff bathroom.

While interviewees often gained support from friends, in order to stay below the radar of adverse attention in school some passed off their physical complaints as having eaten something disagreeable. The very nature of IBD meant that school-based concealment of physical manifestations had limitations and interview data show that being bullied affected four respondents though for different reasons. Bullying for some of them had the dual origin of racism and disease discrimination,

“ 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. ”

(young man, aged 24, CD)

Being bullied straddled primary and secondary school for another interviewee who discerned the multi-factorial causes changed over time:

“ They were bullying me from the beginning because I was thin, that was the bad thing, they didn't even know me, they just straight away it's because I was thin, and then once they realised I was actually coming top of the class and all of that, and then they start picking on you for that, and then as I'm getting a bit older, sort of 13/14, then the race stuff starts coming out. ”

(young man, aged 20, CD)

Schools, however, were not always responsive when informed of bullying, as in the case of a young woman whose sustained bullying throughout secondary school led her to write a letter of complaint to her school. She had subsequently written a letter, in electronic form, to her current college informing them of her condition to which she had attached a guide for universities and colleges from the Crohn's and Colitis UK website, in response to which her college had been very supportive.

The Politics of Immigrant and BME Education

When analysing health-related biographies it is essential to situate personal narratives within broader structural contexts (Scambler, 2009), just as the personal accounts of young people with IBD from BME communities require contextualisation against a wider ethnic and social backdrop. For example, first-generation migrants' endeavours to overcome economic adversity may be foregrounded, while other issues, such as health, may recede into the background as noted by one young man in this study:

“ I had ill health, but things at home were difficult as well. So when your top priority is to, you know, to get out of a poverty situation your health, your health is just as important but it's not really in the spotlight. ”

(young man, aged 23, UC)

Free education is often viewed as a potential route out of poverty, yet concerns including ill-health could be perceived as impeding economic self-sufficiency. This was revealed at interview by the same young man cited above who understandably conceptualised illness in these circumstances as a 'weakness':

“ I had the motivation to go to school because, you know, there are a lot of factors where, you know, where your mum and dad are immigrant, you have to... free education is, you just can't take granted for that. And someone with an illness, you know, I just could not, you know, have that as a weakness. ”

(young man, aged 23, UC)

It is, perhaps, not surprising that the secondary school attended by this research participant had not been informed of his IBD diagnosis. Another interviewee likewise told of his father's strong work ethic when he immigrated to the UK in his late teens and of his tendency to equate his son's illness with weakness:

“ When he came to this country he had two jobs and he put himself through school and all the rest of it... so he's used to hard graft and not having time to sort of get ill and so he's just sort of like, 'You're being a bit weak, just deal with it. ”

(young man, aged 20, CD)

Failure to fulfil educational potential due to ill-health can clearly negatively affect any young person, but may be felt more acutely where parental pressure to succeed is allied to overcoming economic hardship and where siblings have achieved university education and enhanced career prospects.

Sometimes the benchmark for educational success was set high by first-generation migrant parents who had not been afforded the educational opportunities now on offer to their children. This came to light during an interview with a

young man who explained that his parents did not see educational success in the dichotomous terms of pass and fail:

“ There was an expectation for me to perform, it was just a given, it wasn't a: 'You're not going to fail', there really wasn't an option. But failure wasn't a fail, failure was like a C. It wasn't an actual fail and those are just expectations that you have because they've had it really hard, they've had it really tough when they were growing up and stuff, they didn't have someone to push them so they believe that they need to push their children to make sure that they excel better. ”

(young man, aged 24, CD)

When examining the politics of BME students' education it is important to take into account home-school relations. Communication with the family is vital in a school's endeavours to support students with long-term illness. Certainly from data revealed in this study, there were instances of a lack of communication between students, parents, schools and available healthcare services. An interview with a young woman, whose persistent bullying was not addressed by her secondary school, attested to poor home-school communication. She had assumed her school were aware of her Crohn's condition due to her physical symptoms and frequent hospital appointments but realised that her mother had not formally informed the school of her diagnosis:

“ I think my Mum just didn't know to tell them that I was sick or anything like that. So, my sister helped and she helped me with work and stuff. She got me referred to the hospital teaching programme. ”

(young woman, aged 18, CD)

The experiences of this respondent resonate with research findings from Crozier and Davies (2007) which show that it is schools themselves who sometimes restrict accessibility for BME parents. Lack of interaction with school on the part of BME parents may be erroneously interpreted as a lack of support for, or indifference towards, their children's education. In reality it could signify a lack of awareness of, inhibition towards, or disaffection from, the process of parent-teacher relations within the education system. Given the tendency for some BME parents to seldom initiate contact with schools (Crozier & Davies, 2007), inhibition to make further demands on the school may be heightened where a student of BME heritage has health-related special needs.

Drawing on data from our own study, perhaps second and third generation Britons are better placed, both linguistically and in terms of help-seeking abilities, than earlier migrants when mining for information and gaining access to available educational services, such as hospital teaching programmes, and healthcare provision, such as stoma surgery. Eliciting information of this kind is essential

given that lack of progression in education can have the knock on effect of hampering progression at work as discussed next.

Employment

Like young people more generally, many research participants in this study were building up their CV and a number of them were undertaking voluntary work as a means of gaining work experience, especially if IBD precluded them from undertaking potentially more exacting paid employment.

Lack of entry into the world of paid work can be keenly felt among those with long-term conditions (Green, Todd, & Pevalin, 2007). Post-education transitions proved problematic for a number of young people in this sample as IBD impacted on their ability to gain and sustain paid employment. Fatigue was a perennial obstacle to working even in times of disease inactivity when IBD patients are known to still suffer from fatigue (Banovic, Gilibert, & Cosnes, 2010). In the event of full-time employment proving too demanding, flexible working hours and part-time work appealed to some young people. Drawing on previous work experience, interviewees sought work according to their abilities and sometimes with low physical impact.

A number of interviewees whose education had ended prematurely due to IBD lamented their restricted employment opportunities. Even research participants yet to enter the world of work foresaw limited employment opportunities in the absence of educational qualifications. Yet there was equally evidence of hope that future employers would be understanding about their IBD condition. Indeed, one interviewee spoke favourably about his current employer's flexibility concerning his attending hospital appointments.

Financial Implications

Education Maintenance Allowance payments proved beneficial for a minority of young people in this study as a way of helping them continue in education and training beyond compulsory schooling, though the scheme is currently being phased out. Two interviewees were unable to work and were receiving benefits. Although they were managing financially, they had to budget for additional costs associated with IBD as in the case of a young man who had arthritis:

“I’m on benefits at the moment, so, and sometimes I’ve got to take cabs a lot because of my joints and everything like that.”

(young man, aged 22, CD&UC)

His benefit co-beneficiary described her allowances as “just about enough” as she needed to budget for medical supplies not provided by her doctor.

Applying for benefits was not without its problems, however, as in the case of one young female interviewee who had to withdraw from the final year of her degree due to her IBD. During her enforced gap year she was able to depend financially on her family. Although she thought she would qualify for disability benefit she was too “scared” to sign on, the exertion of regularly visiting the Job Centre being too great for her to contemplate given her debilitating IBD symptoms:

“...it would probably be something like disability [benefit] but I know you have to keep going back and forth for that. And even though it’s right at the end of my street, literally at the end of the street, I knew I can’t leave the house.”

(young woman, aged 23, CD)

Some respondents had additional dietary costs if particular foods were bought conducive to their illness management. Life-long prescription costs were a source of contention for a minority of interviewees and were compounded in some cases by the impact of few qualifications on employment prospects.

Positive Consequences of IBD?

While not denying the many difficulties posed by long-term illness such as IBD, tangential benefits may be experienced by some patients (Nettleton, 2006), as noted by two interviewees in this study with reference to education and employment. The experience of IBD contributed to improved educational engagement for one interviewee who now worked harder at college and no longer took education for granted. Another research participant likewise identified IBD as a contributory factor in his educational and career progression:

“I strongly believe with education and the way that the Crohn’s sort of was there, it’s made me the person that I am today and I wouldn’t be in the position that I am both financially, life-wise as well as education and sort of job-wise, if it wasn’t for the Crohn’s. I think it’s got me to where I am so I wouldn’t take it away, it would be quite nice not to have it but I don’t think I’d be the person I am today if it wasn’t for it so.”

(young man, aged 24, CD)

Although these cases are outliers in this sample and represent exceptions rather than the norm, they are worthy of note as illustrative of the diversity among young people of BME background with IBD.

Key Findings: Education

- The majority of young people, namely 15 out of 20, had experienced significant interruption or curtailment to their education due to IBD.
- The response from schools to BME students with IBD was found at times to create difficulties for students in both managing their condition in schools and in pursuing their education.
- A few young people experienced a 'double whammy' in terms of being victimised at school. Bullying in school occurred in an inter-related way as a result of their illness and because they were from a BME community.
- Improved signposting for available educational and health provision is essential for young people's successful navigation of support services.

CONCLUSIONS AND THE WAY FORWARD

As an investigation of a previously under-researched area, the findings presented in this report offer a critical insight into the specific challenges posed for young people of Black and South Asian heritage who have been diagnosed with IBD and live in the UK. While participants in the study reported many experiences which echoed those of young people with IBD generally (see Chapter 2), there was a clear indication during the interviews of issues that were specific to the heritage of the young people being interviewed. In addition, negative experiences of IBD diagnosis and disrupted educational paths were reported by the majority of interviewees, although neither was directly attributed to ethnicity by individual respondents. Nonetheless their extensive collective reference across interviews and resonance with existing health and educational research literature determine that they are areas of concern in need of address.

In this section we summarise the findings and what they mean for young people with IBD of BME heritage, and offer suggestions for the way forward. While most of the recommendations are specific to individual aspects of life, two are more generic in nature and are primarily associated with the situation in which young BME people find themselves. As inhabitants of a cross-cultural society, interviewees reported experiencing tensions between, on the one hand, their need to respect traditional cultural norms and generational differences, and on the other, their need to ensure they act in the best interests of their health, all within a society that is largely unfamiliar with IBD and its requirements.

- Participants' experiences highlighted the importance of raising awareness of IBD within primary care, education and, particularly, among Black and South Asian communities. This would help communities to develop an understanding of the condition, and, as a result, would promote empathy with young people with IBD and a greater acceptance of the dietary restrictions they face.
- Healthcare professionals and support organisations need to be informed and made aware of how cultural norms impact on the ability of young people of BME heritage to manage their condition.

Culture, ethnicity and IBD

Information, understanding and support

The IBD literature stresses the importance and value of social support in helping patients to cope with their condition and, for young people, the prime providers of this support are their parents. However, the experiential data presented here indicated that some young people with IBD from BME backgrounds did not have the same access to parental support as their peers with IBD. This arose through paucity in the provision of culturally appropriate information for those parents who had limited proficiency

in English and which meant that their ability to understand the nature of the condition was severely restricted. This led, in some instances, to stressful conditions at home, the one environment that many young people with IBD typically regard as 'safe', and meant that parents in this situation were not always able to provide optimal support for their son or daughter at the very time when they needed extra support. Given that stress is a known trigger for relapse in IBD, any ways of redressing shortcomings arising from a lack of appropriate information should be sought.

A major concern is that the number of participants negatively affected by their parents' limited proficiency in English represents very nearly half of what was an opportune sample within the criteria for the research. This suggests the possibility that the problem may affect a significant number of young people with IBD from BME groups. Identifying those who need such support and providing appropriate information would be a step forward and beneficial for all involved, as would developing and providing other, supplementary, support networks to ensure that these young people are given the same opportunities as their peers with IBD.

- Key to resolving some of the challenges facing young people with IBD of BME heritage is identifying, at diagnosis, those young people whose circumstances warrant additional support for specific issues arising from their ethnicity.
- For parents to be able to offer appropriate support to their sons and daughters, parents themselves need to be supported and provided with culturally appropriate information about IBD. Possible formats could include:
 - Booklets in appropriate languages
 - Verbal presentations by people in authority
 - Meeting other parents in a similar situation
 - A short DVD, Youtube video or a video presentation on the Crohn's and Colitis UK website aimed specifically at the BME community.
- Informal mentoring by others who have had similar experiences may offer a supplementary means of support, and prove particularly valuable for young people with IBD from BME communities.
- Healthcare professionals should be encouraged to recognise that young people in paediatric care wish to be involved with their care, and need to be involved, especially when their parents' have limited proficiency in English.
- IBD counsellors should be apprised of the issues related to ethnicity that have emerged from this research, such as the potential for parents to be less informed, that schools may not be aware, and the social challenges faced by dietary restrictions. In this way they can tailor counselling to meet specific needs.

Diet and Culture

Eating difficulties and dietary restrictions represent key areas of social exclusion for most young people with IBD. However, participants' experiences showed clearly that the dietary restrictions for many Asian and Black young people exceeded even those of non-BME young people, with many reporting that their IBD was either triggered or exacerbated by the spicy foods which are typical of Asian and Black cuisines and of their daily, family life. Moreover, the young people's inability to tolerate spicy foods had far wider implications within a community that places high cultural importance on the value of sharing food. In situations such as these young people can feel socially excluded insofar as the restrictions affect their ability to participate in daily life and ways of addressing inclusivity would prove beneficial. As Asian and Black cuisines are unlikely to change substantially, a more pragmatic approach is necessary to address how young people with IBD from BME communities manage social situations in terms of diet, and to help them cope with any negative emotional responses to feeling excluded.

- Raising awareness with dieticians of the specific dietary restrictions facing IBD patients from BME backgrounds, and the social consequences of these, should give a very specific and effective focus to any advice offered.
- Ensure that young patients with IBD from BME backgrounds are referred for counselling with the aim of helping them to develop skills and techniques to manage specific social situations, particularly in relation to avoiding or refusing food without offending and without making them feel awkward.
- Counselling should also focus on addressing any of the negative emotions of exclusion related to dietary restrictions within the home.
- Consider encouraging debate and input on the Crohn's & Colitis UK 'IBD & Me' forum with regard to dietary restrictions so that young people can share techniques that they have found successful in refusing food without causing offence.

Religion

Interview data indicated a buffering effect of religion and showed a continuum of religious perspectives. On the one hand, some young people appeared to be resourceful mediators of religious and cultural heritage while simultaneously embracing contemporary healthcare practices. On the other hand, religious discourse at odds with modern-day healthcare practices was resisted and contested.

- By taking into account the diversity of religious context of BME young people's lives, healthcare professionals may be better equipped to engage with the health beliefs and self-management practices adopted by IBD patients.

Healthcare and Diagnosis

Young people's entry into secondary care came through various forms of referral, mainly through their GPs, but also through self or parental advocacy for referral, a walk-in clinic, and GP referral following hospitalisation or A&E admission. As well as significant physical effects, misdiagnosis can have profound emotional consequences. Young people in this study catalogued a series of unfavourable patient-professional interactions, commonly borne of insufficient GP knowledge of IBD yet with varying degrees of culpability. While some GPs lacked understanding, perhaps unwittingly, of their patients' conditions, other GPs were more prone to discrediting patient experience and thereby attract greater suspicion of culpability for delayed diagnosis.

- If access to secondary care is governed by gatekeepers of the primary healthcare kind, raising GP awareness of the wide ranging symptoms and related conditions of IBD appears to be a key factor in unlocking potential barriers to referral pathways and accelerating the route to formal diagnosis.

Education

In some instances the educational and employment experiences of young people in this sample were shaped by varying intersections of ethnicity, culture and disease. Interview data showed the heterogeneity of young people's educational and employment trajectories, as well as experiential commonalities evidenced in most research participants' education being disrupted, in both the short and long term, by IBD. Improved signposting for education and healthcare services, such as home hospital teaching programmes, would be beneficial.

Some teachers were less adept at supporting students than others and increased awareness and integrated working among teachers would be welcome. However, one model of practice would not fit all schools and individual schools will need to adapt their provision based on students' personal and age-appropriate requirements. To this end, the voices of BME students and parents need to be accorded greater legitimacy within dominant educational discourses in order to facilitate this group of young people in reaching their full, rather than partial, educational potential.

Although most of them undoubtedly experienced IBD as disruptive to their education and employment, there is also evidence of interviewees engaging in biographical revision and continuity in the advent of effective disease management.

- Hospitals and education need to develop joined-up thinking so that, with consent, schools are routinely informed and advised following a diagnosis of IBD to ensure that young people are not left to cope alone within the education system.

- Our findings indicate the need for greater proactivity on the part of schools in evaluating the specificity of BME students' personal needs. Personalised support in school, developed in consultation with students, parents and, where appropriate, medical clinicians, could enhance the emotional well-being and educational performance of young people with IBD from BME communities.

Study Parameters

We would suggest that, with normal cautions, the data can be generalised. Although small for some studies, a sample size of 20 within the very narrow constraints of the research criteria for this study meets the needs of the research, especially in view of the qualitative nature of the study, the rich data gathered and data saturation point being reached. However, Black African and Caribbean young people with IBD were underrepresented in this study sample and there is potential for further research to expand on this, if only to confirm that there are no additional needs to be addressed. Future research could also address the health needs of other ethnic minority groups such as the new migrant communities which often remain below the radar of formal healthcare provision.

Final thoughts ...

The prime aim of this report was to provide Crohn's and Colitis UK with information to allow the development of inclusive policies for young people with IBD of Black and Minority Ethnic heritage. The findings reported here will contribute to this, highlighting previously overlooked social and cultural processes which affect how young people from BME communities in the UK experience IBD. Moreover, they indicate the need to ensure that matters related to ethnicity and cultural identity are taken into consideration in the management of IBD in young people of BME heritage. Key to this is greater provision of more culturally-appropriate information, raising awareness of IBD and providing extra support where necessary. The research was also successful at highlighting factors such as the buffering effect of religion and the largely positive experiences within secondary care.

The recommendations included in the report are intended primarily for Crohn's & Colitis UK, but we believe they will also be of interest to others involved in the care of young people with IBD from BME communities, such as healthcare professionals and schools. However, there is also the potential for applying some of the core outcomes to the care of young people from other minority ethnic groups. Moreover, as with the diabetes and asthma research which informed this study, the findings may have implications for the care of young people of BME heritage with other long term conditions.

Finally, many of the interviewees welcomed the opportunity to talk about IBD and how it affects their lives and for the majority, when asked, the principal reason for their participation was to help others in similar situations and to raise awareness through the outcomes of the study. We hope that publication of this research and the continued work of Crohn's & Colitis UK will contribute to that end.

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