

Introduction

- Coping with inflammatory bowel disease (IBD) as a young person presents major challenges which exceed typical adolescent development.
- The symptoms and side effects can have a profound impact and **parental support can be key to successful coping** for young people.
- Research from other conditions indicates that **ethnicity can negatively influence health management, social inclusion, and access to services.**
- There is an **increasing incidence of IBD among Black and Minority Ethnic groups (BME) in the UK.** However, there is a **lack of research** into the interaction of IBD and ethnicity and how it impacts on daily life for young people of BME heritage.

Aims and methodology

- To understand whether young IBD patients from BME communities experience difficulties which differ to those of their non-BME peers with IBD.
- Semi-structured interviews were carried out with 20 young people (aged 16-24 years) of Black and Minority Ethnic (BME) heritage. 18 British South Asian and 2 Black British patients were recruited through three NHS gastroenterology departments.
- Interviews were analysed thematically.

Findings

The interviewees had many experiences in common with their non-BME peers, but a number of **challenges arose from their ethnic heritage** and cultural identity.

● ● ● Reduced parental support

- Nearly half** the young people interviewed **were unable to access the same level of parental support** as their peers because their parents were not proficient in English and there was a lack of information on IBD in a suitable format for the parents. Instead, these parents obtained their **information from lay sources**, usually sons or daughters. However, the **young people interviewed reported censoring information about their condition** for fear of worrying their parents and, as a result, many **parents had a limited understanding of the nature of IBD** and that it is a chronic condition.

"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." (23y, f)

- The lack of understanding led to **increased stress** in the home which is somewhere normally regarded as 'safe' by young people with IBD.

"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?" (20y, m)

"they (parents) can see what I was going through ... but they thought it was just a phase ... I did as much ... myself to look after myself ... but it was hard, because when you've got no-one to talk to in an everyday situation ..." (23y, m)

- It also meant that parents were far **less able to act as advocates** for their sons and daughters over health and education matters, e.g. informing schools of their son's or daughter's condition, enquiring about appropriate treatments, etc.

"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" (23y, m)

● ● ● Diet and culture

- Traditional spicy food, typical of Asian and Black cuisines, triggered or exacerbated IBD** in most of the young people interviewed. **Daily life was affected** and participants expressed **feelings of loss and social exclusion**, coupled with an awareness of an **added burden for parents** during meal preparation.

"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" (23y, f)

- Socially the **consequences of this intolerance of spicy food were profound** in a culture that places importance on the centrality of food and sharing food socially. Participants indicated that it could be 'awkward' or 'tricky' refusing food in community or extended family situations and that they were concerned about offending their hosts.

"it's just the way the ethnic community is ... obviously food is a big part of the culture ... everything is based around food, ... so it's just the way... it is a different culture and just, you know, you will stand out ... because you're not eating." (20y, m)

"you have to be very, very picky ... 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 ... it is sort of frustrating because ... I'm sort of denying some of the food that they're offering me and I kind of feel bad for doing that." (24y, m)

- Moreover negative impacts were compounded by a **lack of familiarity with IBD within BME communities**, and by **cultural norms, e.g. respect for elders.**

"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" (24y, m)

● ● ● Diagnosis and education

- Delayed or mis-diagnoses at primary care level, and delayed or interrupted educational paths** were frequently reported. As these are also experienced by non-BME young people it is difficult to attribute them solely to ethnicity. However, this highlights further important issues which need addressing.

Conclusions

Ethnicity and cultural issues mean that young people with IBD from BME communities in the UK have needs which exceed those of non-BME young people with IBD, many of which can be readily addressed by healthcare professionals and support organisations. Key points are:

- the **early identification of those young patients** who may need additional support
- the **development and provision of information on IBD for parents** in different languages and in culturally-appropriate formats, e.g. leaflet, videos, interpreters
- the introduction of **peer mentoring and support**
- the **recognition of the social and cultural importance of food** in Asian and Black societies and how traditional diets create challenging situations for young people, especially within 'extended' family situations
- helping young people to cope and **feel socially included within culturally-sensitive contexts** through dieticians and counsellors
- raising awareness and promoting a better understanding of IBD within **primary care, education** and among **South Asian and Black communities.**

Acknowledgements:
The authors would like to acknowledge Crohn's & Colitis UK as the funding body for this research.

