

Young people and IBD: specific challenges for ethnic minority groups

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Research funded by Crohn's and Colitis UK

Objective: For young people with IBD, learning to cope with their condition represents a major challenge over and above typical adolescent development: the symptoms and side effects of treatment can have a profound impact leading to social isolation, secretive behaviour and delayed independence. Currently there is a lack of research into the impact of ethnicity in young people with IBD, despite significant increases in the incidence of IBD in Black and Asian communities in the UK and research from other chronic disorders which suggests that ethnicity and cultural identity can affect access to services, health management and social inclusion. This study sought to remedy this.

Method: Semi-structured interviews covering a broad range of topics were carried out with 19 young people (16-24y) with IBD of South Asian or Black ethnic backgrounds. The opportune sample was recruited through three NHS gastroenterology departments and was predominantly Asian. Interviews were analysed thematically.

Results: The young people interviewed shared many common experiences with young people with IBD who are not Black or Asian, including significant delays in diagnosis and interruptions to education; however, they faced additional challenges related to their ethnicity. The parents of nearly half the sample were not fluent in English and a lack of appropriate information meant that parents and families were inadequately informed about the nature of the illness and, as a consequence, had a poor understanding of IBD, including perceiving it as a short-term illness. This increased stress for the young people and had a negative impact on social support, health care and education. In addition, spicy food, typical of Asian and Black cuisines, triggered or exacerbated the symptoms of IBD for the majority of participants and presented problems exceeding normal IBD dietary-related issues. These were compounded by cultural norms within Asian and Black communities such as the centrality and social importance of sharing food, and respect for elders, and through a lack of familiarity with IBD.

Conclusion: Young people with IBD from minority ethnic backgrounds have specific needs, some of which could be readily addressed by healthcare professionals and support organisations. Ensuring that parents have access to appropriate information and raising awareness of the condition within Black and Asian communities would help these young people to receive greater support and understanding.

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