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## Abstract

**Introduction** A stigma is a deeply discrediting attribute, often contravening social norms and viewed by others as undesirable.<sup>1</sup>People with IBD endure symptoms of diarrhoea and urgency, and 74% have some experience of faecal incontinence (FI).<sup>2</sup>IBD and related FI may lead to stigma through violation of social hygiene rules.

**Method** This qualitative study aimed to: a) understand the experience of stigma in people with IBD and whether stigma derives from the bowel disorder diagnosis or from related FI; b) understand how stigma affects social, personal and emotional wellbeing, and how people with IBD manage these issues. Using purposive stratified sampling, 40 members of a UK IBD charity were recruited. Participants self-identified as having FI or not, and feeling stigmatised or not. Stigma was described as: *being, or feeling that you are being treated differently, feeling ashamed or guilty, worrying that others will find out about your illness, or that others will think badly of you because of your illness*. Unstructured individual interviews took place in participants' homes. Data were analysed using an interpretive method.

**Results** Three themes emerged: *Being in and out of control* (emotional command of one's situation), *Relationships and Social Support* (intimate, family and professional helping networks), and *Mastery and Mediation* (adjusting to/balancing demands of IBD and life). Stigma arises from both IBD and FI due to socio-cultural demands of physical control over bodily functions, causing distress and social isolation. Attitudes towards bodily fluids and functions learnt in childhood, personality, humour, mental health, and perspective affect the stigma experience. Adults who create robust support networks, develop a sense of emotional control, and gain mastery of their situation are more likely to become stigma-resilient over time.

**Conclusion** Clinicians can identify the stigma-vulnerable by asking patients about childhood attitudes towards bodily functions, and assessing personality and self-efficacy mechanisms. Patients can be more rapidly helped towards stigma-resilience and normalisation by learning to assess disease-related risks, e.g. incontinence, and make contingency plans (achieving emotional

control), by learning how to tell others about IBD to secure their help (actively seeking supportive relationships), and by learning to do things differently in order to achieve tasks (mastery of IBD and life). Further research is needed to develop stigma-reduction strategies to improve quality of life for people with IBD.

**Disclosure of interest** None Declared.

## References

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