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Title: Factors influencing treatment preferences in steroid resistant ulcerative colitis – a qualitative interview study

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Word count: 2502 characters (with spaces) – but need to save 397 for authors and affiliations

Background

The best treatment option for people whose ulcerative colitis (UC) is resistant to steroids is not clear. Importantly, understanding of patient preferences for available treatments in this setting is also limited. Therefore, the objective of this study was to explore patient experiences of different treatment options, their approaches to decision making, and preferences for available treatments for steroid resistant UC.

Methods

Qualitative interview study with adults living with UC recruited from three Inflammatory Bowel Disease (IBD) services in the North of England, undertaken between 4th June and 31st October 2019. Data were collected during telephone interviews, digitally recorded and transcribed. Inductive thematic analysis was performed by two researchers using NVivo software. Codes were cross-checked and data saturation was confirmed prior to study close.

Results

A total of 33 adults participated (51% female, median age 39 years, median time since diagnosis 6 years). Thematic saturation was confirmed. Four key themes were identified in the data. (1) Treatment effectiveness: this was the primary concern of all participants when choosing a new treatment. Participants explained that alleviating symptoms improving quality of life was the most important driver of their treatment preferences. (2) Influence of healthcare professionals: treatment discussions and choices were heavily guided by IBD healthcare professionals (HCPs). Most participants in this study described the valuable relationships that they have within IBD nurses and medics, and how they trust and respect their clinical expertise. (3) Other influences: whilst important to treatment choices, participants placed limited value on the route of administration and side effects relative to treatment effectiveness overall. (4) Changes over time: there was an increased willingness to try alternative

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treatments, and eventually surgery over time, in accordance with the severity and duration of symptoms, and crucially, as medical treatment options are exhausted.

Conclusion

The importance of treatment efficacy and the influential role of HCPs when patients choose treatments for steroid resistant UC has been highlighted – with a willingness to consider different treatments over time. Less value was placed on side-effects and route of administration. This study provides a qualitative perspective on patient preferences which should be considered in practice guidelines and trial design.