Journal of Crohn's and Colitis (2014) **8**, 1668–1674

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How can we improve models of care in inflammatory bowel disease? An international survey of IBD health professionals

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Received 25 June 2014; received in revised form 15 July 2014; accepted 23 July 2014

KEYWORDS
Biopsychosocial;
Health practitioners;
Holistic;
Integrated;
Models of care;
Survey

Abstract

Background and aims: Few studies have specifically examined models of care in IBD. This survey was designed to help gather information from health professionals working in IBD services on current care models, and their views on how to best reshape existing models for IBD care worldwide.

Methods: An online mixed-methods survey was conducted with health professionals caring for IBD patients. Recruitment was conducted using the snowballing technique, where members of professional networks of the investigators were invited to participate. Results of the survey were summarised using descriptive statistics.

Results: Of the 135 included respondents, 76 (56%) were female, with a median age of 44 (range: 23–69) years, 50% were GI physicians, 34% nurses, 8% psychologists, 4% dieticians, 2% surgeons, 1% psychiatrists, and 1% physiotherapists. Overall, 73 (54%) respondents considered

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http://dx.doi.org/10.1016/j.crohns.2014.07.009

their IBD service to apply the integrated model of care, and only 5% reported that they worked exclusively using the biomedical care (no recognition of psychosocial factors). The majority of respondents reported including mental health assessment in their standard IBD care (65%), 51% believed that an ideal IBD service should be managed in specialist led clinics, and 64% wanted the service to be publicly funded. Respondents pictured an ideal IBD service as easy-access fully multi-disciplinary, with a significant role for IBD nurses and routine psychological and nutritional assessment and care.

Conclusions: Health care professionals believe that an ideal IBD service should: be fully integrated, involve significant roles of nurses, psychologists and dieticians, run in specialist clinics, be easily accessible to patients and publicly funded.

1. Introduction

The aetiology of inflammatory bowel disease (IBD) is unclear but it likely involves a deregulated immune response to the intestinal microbiome or other environmental factors, in those with a genetic susceptibility. A psycho-neuro-immunological concept of IBD is a relatively new addition to the already complex view on pathophysiology and arises from studies demonstrating that psychological status can directly influence inflammatory lesions in the gut[1]. Recent studies have identified psychological stress as one of the strongest predictors of symptomatic disease course in IBD[2], while treatment of stress and depression has been reported to improve the course of IBD[3,4].

As a consequence of IBD's incurability, unpredictability, severity of symptoms, the possible need for surgery and potential for medication side effects, patients' quality of life (QoL) may be profoundly impaired. IBD is usually diagnosed in young adults, and sufferers are therefore affected for many years[5]. Consequently, IBD is associated with a very significant emotional burden, with rates of depression ranging from 10 to 8%[6–11]. However, models of care for IBD rarely specifically address the psychosocial aspect of the disease, typically operating within the biomedical paradigm, where services are run independently of each other rather than being integrated into comprehensive holistic care. Current IBD Standards list access to psychologists as a particular challenge and show that the provision of psychological support to IBD patients remains at very low levels, with only 24% of adult services in the UK having access to a psychologist with an interest in IBD[12], and variable access to funded psychological support in other settings[13]. Consequently, psychological symptoms in IBD remain largely undertreated[14].

We believe that the currently prevalent biomedical model of care does not address the needs of patients, and the previous studies have indicated that care models should be modified to recognise and address complex patient needs[13]. In particular, recent studies have demonstrated that an integrated model of care (i.e. a model that "brings together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion"[15]) may improve clinical and psychosocial outcomes and is cost-effective[16,17]. However, since the published data on models of care in IBD are limited — only nine research papers have been published to date[16–24], the current survey was designed to help gather information more broadly from health care professionals (HCPs) working in IBD services on the characteristics of existing models. A second aim was to collect their opinions on how to best reshape or redesign existing models for IBD care worldwide.

2. Materials and methods

2.1. Design

A cross-sectional mixed-methods online survey was conducted (see Appendix A).

2.2. Participants

Participants were recruited via the professional networks of the investigators using the snowballing technique, which is a well-established recruitment technique in qualitative and mixed-methods studies[25]. In particular, members of the European Crohn's and Colitis Organisation, Australian IBD practitioners' network and both the UK and Australian IBD nursing networks, Canadian IBD practitioners, and other IBD experts known to the investigators were invited via email. An invitation to participate was also included in a British Society of Gastroenterology email circular to its membership.

2.3. Procedure

The initial survey was piloted (for readability and face validity) with 5 HCPs (IBD physicians and nurses) at the Royal Adelaide Hospital, and the wording of some questions subsequently amended. The survey was then distributed by emails as described above. The emails contained a link to the survey and interested professionals accessed the survey directly. Survey Monkey was used as it allows confidential access and facilitates data analysis. Study information and the contact details of researchers, in case any queries arose, were provided at the commencement of the survey (Appendix A). Participants' responses were analysed by AMW.

2.4. Measurement

The survey (see Appendix A) was anonymous and asked about HCPs' demographics, their professional environment and