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

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Models of care;
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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
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. Recent studies have identified psychological stress as one of the strongest predictors of symptomatic disease course in IBD, while treatment of stress and depression has been reported to improve the course of IBD.

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. Consequently, IBD is associated with a very significant emotional burden, with rates of depression ranging from 10 to 8%. 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, and variable access to funded psychological support in other settings. Consequently, psychological symptoms in IBD remain largely undertreated.

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. 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”) may improve clinical and psychosocial outcomes and is cost-effective. However, since the published data on models of care in IBD are limited – only nine research papers have been published to date – 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. 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
model of care in which they work, and their perceived ideal model of care. The survey contained a variety of question formats: single choice, multiple-choice and open-ended. Responses were not forced to avoid falsely endorsed data and thus participants could choose to omit some questions.

2.5. Analysis

Results were summarised using descriptive statistics, with means and standard deviations, medians and ranges, and frequencies and percentages presented. Open-ended questions were reported using a simple content analysis25.

2.6. Ethical considerations

The study was approved by the Royal Adelaide Hospital Research Ethics Committee and the University of South Australia Human Research Ethics Committee in September 2012. HCPs gave informed consent.

3. Results

Overall, 161 HCPs accessed the survey and 159 indicated consent. After consenting, 24 did not complete the questionnaire and were thus removed from the analysis. Results for 135 respondents were analysed.

3.1. Respondents’ demographics

Of the 135 included respondents, 76 (56%) were female, with the median age of 44, ranging from 23 to 69 years. The majority of respondents were specialist GI physicians (50%), followed by nurses (34%), psychologists (8%), dieticians (4%), surgeons (2%), psychiatrists (1%) and physiotherapists (1%). The majority of respondents came from the United Kingdom, followed by Australia, The Netherlands and the USA (see Fig. 1).

On average respondents reported being involved in IBD care for 9 years (a range of less than 1 year to 40 years) since completing their training and spending a mean of 60% of their clinical time in IBD. They had contact with an average of 32 (SD = 27) IBD patients weekly (face to face, via phone or email), of whom four (SD = 7) were new patients. Of 135 participants, 81 (60%) reported supervising trainees in IBD care.

3.2. Context of work

The setting of respondents’ practices was typically a university hospital (51%) or general hospital (39%), with 18% working in a private practice. In those working at a hospital, 33 (24%) worked at a specialty hospital, 72 (53%) in a metropolitan location and 100 (74%) in a teaching hospital.

On average the respondents spent 62% of their time in clinical care, 16% on administration, 16% on research, 9% on teaching and 9% in other activities (e.g. self-education, management). Overall, 105 (78%) respondents reported that they regularly attend IBD/GI specialist meetings (e.g. the European Crohn’s and Colitis Organisation Annual Congress or the Digestive Disease Week). Of the 135, 127 (94%) respondents reported having a special interest in IBD.

Respondents reported that the healthcare system in which they work was predominantly public (79/58%), 29 (21%) reported a mixed public and private system and 9 (7%) reported a private healthcare system, with 18 (23%) not answering this question. Respondents’ practices cared for an average 900 (SD = 1142) IBD patients in the previous year (a median of 525, ranging from two to 7800). Ninety five (82%) respondents reported treating adults (>17 years old), 14 (12%) treated both children and adults and six (5%) treated children only. Only 54 (40%) respondents reported that their practice had formal transition arrangements from child to adult care in place.

3.3. Model of care and IBD service characteristics

Overall, 73 (54%) respondents considered their IBD service to apply the integrated model of care (i.e. a model in which several health practitioners are located at the same site and manage patients collaboratively and where patient’s perspective and needs are included in the treatment). Forty seven (35%) respondents considered the model in which they work a mixture of the biomedical and biopsychosocial approaches, but favouring biomedical care, while 24 (18%) reported working in the predominantly biopsychosocial model. Only 5% reported that they had worked exclusively using the biomedical model. However, 40 (30%) respondents did not answer these questions.

The majority of respondents reported including informal mental health assessment in their standard IBD care (65%); questionnaires were reportedly rarely used for screening (29%). The majority of respondents expressed a positive (34%) or neutral (32%) attitude to complementary medicine, with the free text comments illustrating a positive attitude as long the complementary treatment is combined with the usual care and does not harm patients.

Many respondents (44%) reported that their IBD service utilised an electronic database to monitor patient outcomes, with the majority of respondents’ IBD services conducting research (61%). However, respondents reported that their patients rarely (22%) had access to electronic or telemedicine.
There was also a low rate of formal links with social support agencies (24%). However, there were well established mechanisms for following patients up (61%). Thirty six percent of respondents reported that their IBD patients had been involved in design and provision of patient care via patient panels or surveys. The majority of the described IBD services provided regular patient education sessions (56%).

3.4. Specialists involved in IBD care

On average respondents reported that 12 (SD = 9) health professionals were involved in IBD care in their IBD service (not including research staff positions, only paid clinical employees). Commonly listed specialists contributing to IBD care included gastroenterologists and IBD nurses followed by colorectal surgeons and dieticians (see Table 1). Other less commonly listed specialists included: stoma nurses, endoscopy nurses, paediatric surgeons, obstetricians and gynaecologists and Aboriginal (indigenous) liaison officers (in selected jurisdictions). The funding used to support the work of these specialists in the majority of cases was via the caring institution (hospital/university) (Table 1).

Respondents were also asked about which HCPs are essential for providing good quality IBD care. The majority indicated gastroenterologists, IBD nurses, colorectal surgeons, dieticians, psychologists and radiologists as essential to meet this goal. These roles were also typically represented at multi-disciplinary meetings at respondents’ IBD services (Table 1). Most respondents reported that their IBD service held regular multi-disciplinary meetings (72%), which most commonly occurred weekly (46%) or monthly (20%).

Respondents were asked to discuss the role of nurses and psychologists in their services. IBD nurses were perceived as providers of direct patient care (33%), the first point of contact for patients (23%), educators (22%), administrators of biologics (12%) and providers of social support (8%). Mental health providers were seen as helpful in supporting patients in coping with IBD (47%), treating co-morbid mental illness (18%) and providers of direct patient care (33%), the first point of contact for patients (23%) and educators (22%).

When asked about features of an ideal IBD service, respondents suggested a fully multi-disciplinary clinic, with a significant role for IBD nurses, routine psychological and nutritional assessment and care for every patient rather than just for those reporting problems in these areas, and easy-access drop-in clinics offering care 24 h a day (Fig. 3).

4. Discussion

This is one of very few studies which have explored models of care in IBD. Uniquely, the survey involved both GI physicians (50%) and other HCPs engaged in IBD care, bringing together their extensive shared experience in caring for IBD patients in Europe, Australia and North America, albeit admittedly limited to respondents working predominantly in specialty IBD clinics within hospital based models. The most important finding of the survey was the shared view that an ideal IBD service should be fully integrated, involve significant roles of IBD nurses (doing ‘the nursing job’ rather than dealing with a huge workload of administrative tasks), psychologists and dieticians (for every patient to prevent the development of serious problems), should be run in specialist clinics, be easily accessible to patients and funded publicly. The ideal model is, however, rarely the reality in these respondents’ services, with clear gaps in

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Specialists commonly involved in IBD care in the respondents’ IBD services.</th>
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<tbody>
<tr>
<td>Current involved n (%)</td>
<td>Considered essential for good quality care</td>
</tr>
<tr>
<td>Gastroenterologists</td>
<td>92 (68)</td>
</tr>
<tr>
<td>IBD nurses</td>
<td>85 (63)</td>
</tr>
<tr>
<td>Colorectal surgeons</td>
<td>77 (57)</td>
</tr>
<tr>
<td>Dieticians</td>
<td>75 (55)</td>
</tr>
<tr>
<td>Psychologists</td>
<td>44 (33)</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>15 (11)</td>
</tr>
<tr>
<td>Pathologists</td>
<td>54 (40)</td>
</tr>
<tr>
<td>Radiologists</td>
<td>57 (42)</td>
</tr>
<tr>
<td>Eye specialists</td>
<td>16 (12)</td>
</tr>
<tr>
<td>Dermatologists</td>
<td>23 (17)</td>
</tr>
<tr>
<td>Rheumatologists</td>
<td>29 (21)</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>36 (27)</td>
</tr>
<tr>
<td>Social workers</td>
<td>18 (14)</td>
</tr>
</tbody>
</table>

*Approximately 30% of respondents did not provide an answer to these questions.*
providing adequate and holistic nursing, psychological and nutritional care to IBD patients.

In particular, according to these respondents, current treatment teams largely comprise GI physicians, nurses, colorectal surgeons and dieticians. Less commonly the care team comprises mental health practitioners whom the majority of respondents considered essential for good quality care. Access to psychologists is still problematic world-wide despite the evidence that unmanaged mental symptoms may impact disease activity, thus leading to preventable suffering and increased healthcare costs. In the models of care described by this survey’s respondents, psychological care is at times provided by nurses considered to be providers of psychosocial support. Yet, this responsibility adds to already large nursing workloads, their other tasks including acting as providers of direct patient care, the first point of contact for patients, providing drug infusions and administrative duties. Clearly, there is room for improvement in current models of care in this respect as indicated in the current national UK IBD Standards, which list access to psychologists as a particular challenge and area for addressing in the coming years.

Further to this, while previous studies have shown that less than 40% of IBD patients with high levels of anxiety and/or depression receive treatment for these mental disorders, 65% of the present survey’s respondents reported that they had assessed mental health as part of their usual practice, although informally rather than using screening tools. Routine screening for mental disorders and symptoms has been recommended for IBD patients by the recent review of IBD guidelines, and particularly at the time of diagnosis, which support the dualism of body and mind; it is a single-factor model which explains illness as a biological malfunction rather than recognising that a variety of factors (only some biological) may be responsible for its development; and it emphasizes illness over health so it focuses on abnormalities that lead to illness rather than on factors promoting health. Further to this, a relatively low rate of patient engagement in diagnosis and provision of care identified by these respondents (36%) is of concern and a confirmation that the biomedical approach to care, which is doctor- rather than patient-centred, is still very much present in IBD clinics worldwide. An effort should be made to involve patients in decision-making regarding their care as studies have shown large discrepancies between patients’ and doctors’ perceptions of disease and treatment, which may have implications for treatment compliance and response to overall care.

A moderate uptake of ehealth/telemedicine (approx. 30%) reported by the respondents is worth highlighting. This mode of care is increasingly becoming popular in gastroenterology, with a recent systematic review indicating that ehealth may improve quality of life, treatment adherence, and knowledge about the disease, and reduce healthcare costs in IBD, although more studies are needed to confirm these preliminary observations. From the survey it seems that there is a scope for improvement in the use of etherapy/telemedicine, which can potentially reduce queues, improve access to healthcare and be cost-effective.

Finally, obstacles to establishing better services are according to these respondents not only financial but also very much administrative and political, with current governing systems in hospitals in many countries poorly suited to supporting integrated models of care and with inadequate referral mechanisms for psychological and nutritional care. As previously documented by us, the perception of a significant cost associated with changing care towards an integrated model is flawed, as the care becomes reorganised rather than more expensive. In fact, a recent study with an IBD population has shown that integrated care not only improves patient outcomes but also significantly decreases healthcare costs. More studies into cost and benefit of changing existing treatment paradigms are needed not only to facilitate changes to the status quo but also to address the increasing demand of the ageing population and the rising incidence of IBD in some parts of the world.

4.1. Limitations

Important limitations of the study include (a) an unknown response rate (given the snowballing technique used we had no control over the actual number of people who received our invitation); (b) a probable participation bias (only those with an interest in IBD and those working in a secondary or tertiary care setting, and possibly those unhappy with the status quo and access to the Internet participated); (c) a social desirability bias (possibly over-reporting working within the biopsychosocial paradigm); (d) reliance on
self-report (as per any survey design); (e) a potential recall bias when asked to report on some characteristics of models of care, and (f) reliance on the English language, which may have deterred non-medical respondents in particular from countries where English is a second language. While these are all important to consider, the bias towards involving those interested in IBD only can also be considered this study’s strength as these providers are best informed as to what current care is lacking. In addition, the survey was limited to respondents working in specialty IBD clinics within hospital based models as evidenced by a proportionally large subsample of nurses. It would be thus interesting in future studies to poll private practitioners who work in single or small group practices as well as primary care providers and patients as to what they think the optimal way to deliver care would be. In addition, health professionals who responded to the survey may have been more interested in models of care and the biopsychosocial medicine (particularly likely given large subsamples of nurses and psychologists) than those who ignored our invitation, and thus may not be representative of the larger population of health professionals. However, the sample characteristics make us believe that those who participated in the survey clearly understand the system as they have worked in it for many years treating large numbers of patients, and have ideas on what can be improved in the standard care of IBD, which was our interest in pursuing this study.

Outside of this study, AMW has received payment for lectures from MSD-Schering Plough; travel grants from Ferring, Orphan, Nycomed and Abbott; and royalties from the Authors’ Licensing and Collecting Society.

JMA has been a consultant for Abbvie, Takeda, Janssen, Ferring, Abbvie, Janssen and Abbott; received payment for lectures from Abbvie, Janssen, Takeda, Shore, Ferring, AstraZeneca, MSD, Nycomed, Orphan; received payment for development of educational presentations from Shire, Ferring, Abbvie, Abbott and Janssen; and is currently running sponsored trials for Amgen.

JvW has been a consultant for MSD and Abbvie; received grants from Falk Benelux, Janssen & Janssen; and payment for lectures from Ferring, Falk and Abbvie.

CB is a Board Member for Abbvie Canada, Takeda Canada, Forest Canada, Shire Canada, Pfizer, Vertex Pharmaceuticals, Hospira; has given expert testimony for Mylan Pharmaceuticals, Cardinal Health, Ranbaxy Pharmaceuticals; and received grants from Abbvie Canada, Takeda Canada, Shire Canada and Aptalis.

Conflict of interest

None in relation to this study.

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AMW conceived of the study, designed it, collected, analysed and interpreted the data, and drafted the paper. JMA conceived of the study, designed it, contributed to data collection and interpretation, and provided feedback on drafts. DR, JG, JvW and CB contributed to study design and interpretation of the data, and provided feedback on drafts. All authors have read and approved the final manuscript.

Appendix A. Supplementary data

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.crohns.2014.07.009.

References