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Perspectives and attitudes of young patients with inflammatory bowel disease: symptoms, burden of disease and communication with their healthcare professionals

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ABSTRACT

Introduction Inflammatory bowel disease (IBD) affects a significant proportion of young patients in the UK. The role of the healthcare professional, and their relationship with the young patient is particularly important at this difficult stage of their life, when education, social integration and career planning, can be dramatically affected by this consuming condition.

Objectives To address the attitudes, experiences and perspectives of young patients suffering from IBD, focusing particularly on the relationship between sufferer and healthcare provider.

Methods Crohn's and Colitis UK invited its young members to respond to a detailed internet based questionnaire addressing various aspects of patients' disease and their relationship with respective healthcare workers.

Results 1081 patients aged 29 years or less responded. Self reported burden of illness was high with only 12% respondents free from a disease flare in the previous 12 months with almost half being hospitalised in the same period. Quality of communication with healthcare providers was generally high, with three-quarters of patients feeling appropriately empowered in their healthcare decisions. The IBD nurse specialist was highlighted as a particularly valuable member of the team, scoring the highest of the professional groups in communication comfort scores, as well as being nominated by the patients as the preferred professional group to discuss their disease with.

Conclusions The results emphasize the considerable impact of the disease that this group is encumbered with, and identifies areas in the patient-professional relationship that can be augmented to improve the overall healthcare of this complex and fragile subgroup of patients.

INTRODUCTION

Inflammatory bowel disease (IBD) includes a group of chronic gastrointestinal conditions that affects more than a quarter of a million people in the UK. They are characterised by relapsing and remitting periods of inflammation of the alimentary tract, which can manifest as a variety of symptoms including bloody diarrhoea, abdominal pain and weight loss, as well as a host of extra-intestinal complications. The two commonest forms of this group include ulcerative colitis (UC) and Crohn's disease (CD) which have an approximate UK prevalence of 240/100 000 and 145/1000 population, respectively.¹ Although there are many disease associations, there remains no recognised aetiology, and current concepts regarding causality centre around a combination of genetic predisposition associated with an exaggerated immune reaction to the normal bowel flora. Unfortunately, with the exception of pan-colectomy in UC, there remains no cure for either disease, and medical management is directed at dampening bowel inflammation and preventing subsequent disease progression.

Unfortunately, these diseases are not uncommon in young patients. Up to 10 000 young people are diagnosed each year and the incidence in this group is rising.² Younger age at diagnosis is often associated with more aggressive disease patterns, including the need for surgery.

Younger sufferers may have to contend with considerable psychosocial consequences

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of their chronic condition. Educational development or career progression may be seriously affected. When surveyed, young sufferers subjectively reach fewer social and psychosexual milestones, compared with healthy peers.³ Although such concerns are appreciated by healthcare providers, they can often be sidelined, with the focus during encounters being predominantly clinical. Gaining a deeper insight into patient concerns and anxieties, which may not always be clinically based, should provide a platform to improve communication between both parties, and ultimately improve patient support, understanding and experience.

Crohn's and Colitis UK (CCUK) is a nationwide charity that supports patients with IBD. With the incidence of young sufferers increasing, the charity was keen to survey attitudes and perspectives of this patient group, with a particular focus being communication between patient and healthcare provider.

METHODS

CCUK offered all its 31 000 members the opportunity to partake in this internet based survey, entitled 'Me and IBD—Facing the Future, School and Beyond'. The survey ran from February to April 2013. It included 60 detailed questions inquiring into a variety of issues affecting young sufferers including demographic data and clinical data into disease type, course and treatment. It also included questions regarding education and employment status. A large bulk of the questions focused on communication aspects between patient and healthcare provider, with patients encouraged to rate these interactions using standardised scoring systems. A copy of the full questionnaire is available in the online supplementary material.

The results were collected and analysed by NSM Research, an independent research agency based in Oxford. The study was carried out in accordance with the Data Protection Act and the Market Research Guidelines. Consent was implied by voluntarily taking part in the process, with respondents made previously aware that the data were to be used by CCUK for the purposes of addressing and improving communication between young sufferers and their healthcare

professionals. Statistical comparisons, where appropriate, were performed with the Student's *t* test.

RESULTS

Demographics

In all, 1081 patients responded to the survey, of which 74.5% were female. Overall, 36.3% stated they had UC and 63.2% had CD. Mean age of survey participants was 23.3 years. The age range of respondents is shown in figure 1.

Educational experience

The majority of respondents had completed their education (figure 2). Patients were asked about how their illness had affected their education and learning experience. The results indicate a significant proportion of young sufferers who felt their education was seriously compromised by their illness. Overall, 17% of respondents claimed to have missed significant amounts of school or college. In all, 12% alleged that they were too tired or fatigued to study, with 4% stating that they were in too much pain to study or concentrate. Overall, 11% missed out on attending university because of the burden of their disease, and 6% subsequently had to leave their place of education and 7% felt that their grades were affected as a result of their illness while 4% of respondents could not take or struggled to take exams because of symptoms.

Disease activity and profiles

Self-reported disease activity was high in this patient group, with almost 40% reporting 1–3 disease flares in the previous 12 months. A quarter of those with subjective disease activity reported that they were continuously ill over this period. The breakdown of disease burden in the patient group is demonstrated in figure 3.

Extreme fatigue was highlighted as the predominant symptom (75.9% of respondents). Pain (49.4%) and diarrhoea (44%) were also common, with 16% reporting a variety of other symptoms.

A total of 665 responded to questions about previous IBD related surgery. In the 12 months prior to the survey, 14% revealed that they had had between one

Figure 1 Age of survey participants.

Figure 2 Current educational status of survey participants.

Figure 3 Self-reported disease burden of survey participants.

and two surgeries, and 3% had had three or more surgeries. In all, 27% of patients answering the same question, but about the previous 5 years, needed surgery at least on one occasion. Overall, 43% of respondents had at least one inpatient admission in the previous 12 months.

Outpatient burden was equally taxing with 34% of patients responding they had had six or more visits to see a specialist (gastroenterologist/surgeon/IBD nurse specialist (IBD-NS)) in the previous 12 months. The breakdown of these clinic visits is shown in figure 4.

In the preceding 12 months, 62% had taken oral steroids, 23% 5-ASA treatment, 55% azathioprine, 10% methotrexate, 2% cyclosporine, 18% infliximab and 13% adalimumab. Of note, 7% claimed they had been on parenteral nutrition over this period. Despite the heavy pharmaceutical use of this patient group, only 61% of respondents felt that the medication they were taking was effective at keeping them well.

Healthcare providers

The gastroenterologist appears to play the most significant role at the point of diagnosis with 81% patients reporting it was a physician who made their initial diagnosis (surgeon 13%, general practitioner (GP) 6%, IBD-NS 4%).

Overall, 76% of respondents had access to a nurse specialist. The importance of their role is further highlighted when the patients were questioned as to which

Figure 4 Hospital outpatient appointments over 12 months prior to survey completion.

Figure 5 Communication comfort levels as rated by survey participants.

healthcare professional they had most contact with. In all, 57% (from a base of 820 who had access to an IBD-NS) reported nurse specialist for most contact, with 54% (base 1081) gastroenterologist, 14% surgeon (from a base of 599 who had had contact with a surgeon) and 36% GP. More importantly, an IBD-NS was reported as the first point of contact during an acute flare (71% from base of 820) followed by the gastroenterologist (45% from 1081), GP (38% from 1081) and surgeon (8% from 599).

Quality of communication between patient and healthcare professional

Patients were asked to gauge the relative levels of comfort when communicating with their healthcare professionals using a scale whereby 5 corresponded to 'very comfortable' and 1 represented 'difficult to talk to'. Figure 5 shows the mean comfort score for all healthcare professional subgroups as scored by the survey respondents. There was marked variation in the time respondents felt that they had with their healthcare professional to answer all their questions (figure 6).

Figure 6 Proportion of respondents who felt they were given adequate time to answer all their questions during the consultation with their respective healthcare professional.

Respondents to the survey were also asked as to the level of support they experienced when they discussed their disease with their respective healthcare professional. They were given qualitative options to describe their opinions ('understanding', 'helpful', etc) (table 1).

The patients were subsequently asked which healthcare profession, when given the option, they would most prefer to discuss their condition with. In all, 61% preferred to speak with their gastroenterologist. A similar amount (61% from a base of 820) chose IBD-NS as first choice. Only 12% (from a base population of 599) chose their surgeon, and 14% opted for their GP.

The patients were given the opportunity to convey how they preferred to be communicated with by healthcare professionals in an open narrative question. The top four responses included: 'Use a friendly manner', 'Treat me respectfully, as an equal', 'More time please' and 'Be honest'.

In the subgroup of patients who had undergone surgery, the surgeon appeared to be the commonest healthcare professional who undertook explanation of the procedure (87% respondents), although the gastroenterologist seems to have an important role here as well, with 46% of respondents also having discussed surgical procedures with a physician. In all, 88% responded that explanation of the surgical procedure was either 'adequate' or 'thoroughly explained'. With regard to surgery timing, the majority of patients had little say in this aspect, primarily because of clinical need. However, 46% did feel they were able to have some control of operation planning to accommodate important life events (exams, work priorities, etc). When asked about where patients sought other information (non-healthcare professional) regarding surgery, 49% used friends, 16% used Facebook, 9% used an alternate social media website, and 10% used one of the Crohn's and Colitis information portals (meetings/online forum/helpline, etc).

Respondents were asked as to whether they felt sufficiently involved in the decisions regarding all aspects of their disease. Three-quarters responded in the affirmative, but a quarter still felt they did not

have the full control they wanted in the decision making process.

DISCUSSION

This is the largest survey of its type in the UK, looking specifically at IBD sufferers' insight into their disease, with particular focus on the relationship and communication between patient and healthcare professional.

Of particular note is the high level of disease burden in this young patient group. Almost 80% of respondents described varying levels of illness over the previous 12 months. This was coupled with a high dependence on healthcare professionals. Around two-fifths of patients required admission in the previous year, whereas about a third of patients had six or more outpatient appointments. This level of disease burden will undoubtedly have an impact on various aspects of the patients' lives, including the ability to work. In a US study, symptomatic IBD sufferers were twice as likely to be out of the labour workforce than healthy individuals.⁴ Although the majority of our population were no longer in education, the results of this study clearly indicate a deleterious effect of disease on patients' participation in education and learning. The results echo those of a similar study by CCUK in 2011, in which 67% of IBD sufferers felt that their illness had or was delaying their education progression.⁵ In the same study, 69% of respondents felt they had failed to achieve their full educational potential because of their condition. There is however some conflicting evidence in the literature. Data exist from the USA that indicate, on balance, IBD sufferers probably attain a similar level of education compared with their healthy peers.⁶

This survey addressed the relationship and quality of communication between sufferer and healthcare professional. Patient empowerment in decision making has been highlighted as an important factor in previous studies.⁷ In this survey, about 75% of respondents were satisfied with the level of their involvement in the decisions regarding their healthcare, which is promising, but leaves plenty of room for improvement. Patient empowerment is derived from effective and appropriate communication between sufferer and healthcare professional, and this must be optimised by the healthcare professional. This may be difficult to achieve as patients' expectations continue to rise as they derive information from alternate sources (media/internet). Another limitation in communication highlighted by this study was the perception that sufferers felt they were not given enough time to cover all their questions. Although no healthcare professional group performed particularly well in this field, surgeons fared particularly poorly. This apparent 'lack of time' could be addressed by ensuring that patients with IBD are given longer slots in outpatient appointments, although this provision could be difficult in an already financially restricted health

Table 1 Qualitative statements regarding the level of support by individual healthcare professionals

	Gastroenterologist (%)	IBD-NS (%)	Surgeon (%)	GP (%)
Understanding	66	56	20	41
Supportive	59	57	18	42
Positive	57	49	18	33
Helpful	69	53	20	40
Dismissive	13	4	6	18
No reply	4	17	35	15

GP, general practitioner; IBD-NS, inflammatory bowel disease nurse specialist.

service. A potential solution to this, which has been adopted in several larger teaching hospitals, is to hold dedicated IBD clinics in which the patient has potential access to a gastroenterologist, surgeon and nurse specialist in one visit.

On the whole, respondents to our survey were generally satisfied with the quality of communication with the various healthcare professionals. Communication comfort scores were encouragingly high across the board, and there were only limited reports of unfavourable communication.

Although the gastroenterologist still maintains an important role in diagnosis and provision of information, the increasing role of the IBD-NS has been particularly highlighted in this survey. This group of professionals were deemed the first point of contact during a flare for the majority of patients, as well as the highest scoring group of professionals in the communication comfort scores. Patients seemed to be as happy to discuss their treatment with an IBD-NS as they were with a physician. This encouraging feedback with regard to the IBD-NS role in patient care should not detract from the positive reports in the patients' qualitative statements about gastroenterologists (table 1). The physicians outperformed all other specialists in the favourable qualitative statements ('understanding', 'supportive', etc), but surprisingly, and worryingly, had a 13% response rate of appearing dismissive. These findings should encourage physicians (as well as other clinicians) to reflect carefully about their interactions with IBD patients in future consultations.

Another key finding of the survey was that significantly more patients have access to an IBD-NS than in a similar study 6 years previously, when only 49% had access to an IBD-NS (compared with 76% in this survey).⁸ The IBD-NS forms a key part of the integrated multidisciplinary team looking after patients with IBD. Whereas a physician or surgeon will have a number of commitments outside the realm of IBD, the IBD-NS can direct all their efforts to IBD. As well as addressing patients' symptoms, concerns and worries, they can offer management advice, and also highlight sick patients to the attention of the physician/surgeon. They are also more likely to be readily contactable than their doctor counterparts, with a number of trusts having now set up IBD hotlines/email addresses to ensure swift and direct access to the nurses. In one study, IBD-NS follow-up of patients resulted in patient reported outcomes similar to that of gastroenterologists.⁹ The true value of the IBD-NS as part of the IBD multidisciplinary team, with particular reference to cost benefit and disease outcome, needs to be addressed more closely, but the results of our patient survey indicate that this group of healthcare professionals is very much used and appreciated by young patients with IBD.

A final point from the survey is the apparent ascending role of social media as tools for young

sufferers to gather more information about their condition and treatment. In all, 25% of patients undergoing surgery in our survey used social media websites in this way. Whereas young patients should be encouraged to search information from a variety of sources, caution must be advised by the healthcare professional, as there remain plenty of sites on the worldwide web that provide incomplete or inaccurate information about IBD.¹⁰ On a different front, social media websites could be used in the future by the healthcare providers to reach out to less accessible patient groups. Previous work has highlighted some of the difficulties faced by non-Caucasian young patients with IBD¹¹, in particular the language barriers faced by these patients and their families. Establishing improved links between the various websites, and offering material in a variety of other languages will facilitate the interaction between healthcare provider and such minority group patients.

There are a number of limitations to this study. First, it is prone to selection bias, given that it is an internet survey, and therefore only accessible to those with access to the web. The presumption that the majority of young patients have access to such technology coupled with the large number of respondents will hopefully counter any such bias. The apparent sex bias, with three-quarters of respondents being female, may skew results, but is a recognised problem of online surveys in general. Future online surveys will need to address this disparity, although increasing male survey response rates could prove challenging. Perhaps, promoting such surveys through potential male role models in the world of sport or entertainment could help. Certainly, in recent years, a successful premiership footballer and a world champion rower have been highlighted as suffering from IBD. Finally, as a survey, all the data are self-reported and therefore difficult to verify. However, whereas this might be a problem when considering symptom severity, for the key findings of the report, which was the patients' assessment of their communication and relationship with their healthcare professional, a subjective opinion is warranted.

In conclusion, this large internet based survey has demonstrated that young patients feel that they receive a reasonable quality of communication with their healthcare professionals. There is some variance in the quality of communication provided by the various specialty teams, with definite room for improvement, but on the whole the majority of patients feel they are in control of their disease management. Of note, from the perspective of the patient, the IBD-NS has been highlighted as an extremely valuable care provider, and this survey provides further supporting evidence in the quest to establishing this position in the IBD multidisciplinary team.

What is already known on this topic

- ▶ The incidence of IBD in young people is generally increasing, and is associated with significant hardships, both physically, socially and psychologically.

What this study adds

- ▶ This is one of the largest surveys to date focusing on young patients' subjective attitudes and experiences of living with IBD, focusing particularly on their relationships with healthcare providers.

How might it impact on clinical practice in the foreseeable future

- ▶ The survey highlights the positive role of the IBD nurse specialist, and identifies areas in the patient-professional relationship that can be augmented to improve the overall healthcare in this patient group.

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Competing interests None.

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