Childhood inflammatory bowel disease: Parental concerns and expectations

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Abstract

AIM: To document the concerns and expectations of parents of children with inflammatory bowel disease (IBD) within the context of a multidisciplinary IBD clinic, and to highlight the importance of a holistic approach to the care of these children.

METHODS: The parents of 60 children with IBD were surveyed by mailed questionnaire. Parents were asked to provide details of their concerns regarding their child's condition and to express their expectations of medical care. In addition, enquiry was made in respect to the respondents' learning about IBD.

RESULTS: Forty-six questionnaires (77%) returned. Fifty-two percent of the patients were male. Patients were aged a mean of 10.9 (±4.1) years and diagnosed at an average age of 2.1 (±1.8) years previously. The most common concerns expressed by the parents related to the side-effects of medications and the future prospects for their child. Overall, parents were satisfied with aspects of care within the IBD clinic but many suggested additional personnel such as counselors or educators should be available. Parents also reported the need for continuing education and easy access to up-to-date information.

CONCLUSION: Parents of children and adolescents with IBD have many common concerns regarding their child's condition. On-going attention to holistic care, including psychosocial and educational elements for patients and families, is appropriate in the context of the chronic and unpredictable nature of IBD.

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Key words: Children; Inflammatory bowel disease; Parents; Clinic

INTRODUCTION

Inflammatory bowel disease (IBD) appears to be increasingly common in children and presenting at earlier ages[1]. IBD, comprising ulcerative colitis and Crohn's disease, is a chronic condition, which features periods of remission and episodes of relapse. Although most commonly presenting in the second and third decades, IBD may present prior to 10 years of age, including infancy. Because of differing ages at diagnosis, patients (and their families) may have varying understanding of their disease, and hence will differ in their ability to adjust to a chronic illness. In addition, nutrition and growth are vital aspects of managing children with IBD, with many children presenting weight loss prior to diagnosis, and potential compromise of weight and height affecting the onset of pubertal development and acquisition of final adult height. Consequently, children with IBD and their parents comprise a distinct group with specific medical, nutritional and emotional needs[2].

These issues have been highlighted by several reports delineating quality of life in children with IBD. Other investigators have shown that a child with IBD may place extra stress and concerns upon siblings and parents. For instance, parental focus groups conducted in a British population showed that parents of children with IBD have many concerns, such as the impact of disease on their child's future, difficulties with school attendance, concerns about the side effects of medicines, and restrictions upon the family lifestyle[2,3].

In order to provide focused care for children with IBD, a specialized multidisciplinary IBD clinic was established in 2001. This clinic aims to provide a disease-specific facility for children and adolescents with IBD and to ensure that patients and families are provided with medical, nutritional, educational and psychosocial resources to ensure optimal care. The current study was conducted to determine the parental concerns regarding their child's illness, within the context of the multidisciplinary clinic. Additional enquiry was directed towards the parent's impressions and expectations of their medical care and further aims were to understand how patients and parents learn about their disease.

MATERIALS AND METHODS

Patients

Children and adolescents who attended the Inflammatory...
Bowel Disease Clinic, Sydney Children’s Hospital (SCH), over 12 mo from commencement of the clinic in March 2001 were identified from clinic booking records and the clinic database. Children who were seen within the clinic schedule, but later diagnosed with a condition other than IBD (such as celiac disease) were excluded. In addition, children cared for at SCH but who were still seen in their gastroenterologist’s primary general follow-up clinic (i.e. not yet seen in the IBD Clinic) were not included.

Questionnaire
The questionnaire was developed for the purposes of this study (copies available from the authors upon request). The survey was mailed to each family with a covering letter, which explained the rationale for undertaking this process, provided appropriate contact details and invited individuals to make direct contact with the investigators if questions or confusion arose. The questionnaires were directed to the parents of children with IBD, and, hence reflecting parental impressions primarily, where appropriate parents were asked to consult with their child or to take their child’s impressions into account.

Parents were requested to complete the questionnaire and return it to the investigators using the enclosed stamped addressed envelope. Forms were not numbered and parents were asked not to add any identifying information upon the surveys, in order to ensure complete anonymity. This questionnaire was followed 2 mo later by a second letter. This generic letter was sent to all participants thanking those who had replied, and reminding those who were yet to complete the questionnaire to do so and return it.

Basic background data requested included the child’s age and gender, the specific IBD diagnosis and date of diagnosis. Parents were asked to detail their child’s current prescribed medications. The questionnaire asked the respondents to detail their concerns about their child’s condition within two categories: firstly, concerns held in the past and, secondly, their current concerns. In addition, parents were asked to provide comments regarding the care of their child within the IBD clinic, and their expectations for this clinic. Parents were asked to provide details of their experiences learning about IBD. A second questionnaire also was included, directed to the children’s use of complementary and alternative therapies, and would be reported separately.

Prior to the commencement of the study period, 6 parents were asked at random to review each of the questions with subsequent amendments as appropriate. The study was conducted following institutional guidelines and approved by the Research Ethics Committee, South East Sydney Area Health Service.

Statistical analysis
Averaged data are expressed as mean±SD. Student’s t test was utilized in comparison between the groups of data. GraphPad InStat was employed for the analysis of data (GraphPad InStat version 3.00 for Windows 95, GraphPad Software, San Diego, CA, USA, http://www.graphpad.com).

RESULTS

Patient descriptions
Sixty-five patients were seen against 148 appointments in the IBD Clinic over a 1-year period from March 2001. A further 10 children with IBD managed at Sydney Children’s Hospital over this period, but who had not yet been seen in the IBD clinic, were not included.

Of the 65 children, 60 were appropriate for inclusion in this study (remainder were not diagnosed with IBD) and questionnaires were mailed to each of these families. Forty-six questionnaires (77%) were returned by mail.

The average age of the patients, whose parents completed the questionnaire, was 10.9±4.1 years (range 1-18 years) with 24 (52%) of the patients being male. Thirty-five (76%) were identified as being diagnosed with Crohn’s disease and 7 (15%) had UC. The remaining 4 (9%) were classified as indeterminate colitis. Children were diagnosed with IBD a mean of 2 (±1.8) years previously (range 0.25-7 years). Children were receiving an average of 1.7 (±0.8) prescribed medications. Thirty-three (72%) children were prescribed maintenance aminosalicylate compounds and 20 were taking azathioprine (4 having azathioprine alone). Seventeen (37%) children were on oral steroids at the time of the questionnaire (1 on budesonide, 16 on prednisone). At the time of this survey, 3 children were taking antibiotics and 1 on tacrolimus.

Parental concerns regarding their child’s illness
Parents expressed numerous concerns about their child and his or her illness (Table 1). The most commonly mentioned concerns that parents had felt in the past were regarding the side-effects of medications (n = 37), prospects for their child’s future (n = 36), and the use of medicines for their child (n = 33). Parents held similar current concerns about their children. These included concerns about the future of their child’s illness (n = 32), side effects of therapies (n = 23), and their child’s current symptoms (n = 22).

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Parents reported their past and current concerns.

Parental experiences of IBD Clinic
Forty-five parents reported that the clinic was useful for them (19 extremely, 21 very and 5 fairly useful). One
respondent felt that the clinic was not useful for him. Most (35 of 46) parents reported that their expectations of the clinic were met. Two parents felt that their expectations were not met and the remaining parents were unsure. Forty-four (96%) of 46 respondents reported that their children also found the IBD Clinic useful (20 extremely, 20 very and 4 fairly useful). Of the two parents who did not find the clinic useful, one commented that nothing worked for their child, and the second said their child attended clinic only on one occasion.

The majority (37 of 40) of parents reported that they always felt comfortable asking questions to the clinic staff. Similarly, most parents reported that the time allocated for clinic appointments was always (n = 25) or mostly (n = 18) sufficient. The other 3 felt that appointments were sometimes not long enough. Thirty (67%) of 45 respondents reported that they were always well-informed about their child's progress. Eleven replied that they were mostly informed, whereas 3 said sometimes and 1 was unsure. In addition, parents reported on receiving the information they needed about their child (19 always, 23 mostly, and 2 sometimes). One parent reported as never receiving all the information they required.

When asked about the team-based approach of the clinic, all but one respondent were pleased. Twenty-six of 45 respondents found the approach of the clinic to be excellent and 14 commented that the clinic approach was good. Three parents were indifferent. Fifteen of the 19 parents, whose child saw the clinic dietitian within the clinic structure, were pleased with being able to do this. Three were unsure whether this was beneficial or not, one was indifferent, and none felt that it was not helpful. Similarly, most parents (27 of 42) felt that it was helpful to have all children with IBD coming to a specialized clinic and 26 (60%) of 43 respondents felt that the advent of the IBD Clinic had positive effects on their child. Four felt the clinic did not make any change to their child's care and 13 were either unsure or indifferent.

Parents also made a number of additional comments about their child's experiences in the IBD Clinic. These included comments about the timing of clinics (in relation to time off school), the team approach (helpful that more than one gastroenterologist was aware of the child's condition and ideal to see dietitian at the same visit), and the awareness of new issues for the parents.

**Parental psycho-social and educational expectations**

The most common suggestion made by the parents was that the clinic should provide easy access to a counselor or psychologist (23 parents). Seven parents requested further opportunities to improve knowledge and education about IBD. Improved access to peer support for their children and adolescents with IBD was considered an important issue for 23 parents. Other parents (n = 20) reported that increased peer supports could possibly be useful for their child. In addition, parental support was mentioned by several parents as an important aspect of managing and coping with their child's condition.

**Parental comments regarding learning about IBD**

Parents commented on their initial experiences of learning about IBD following their child's diagnosis. Most reported that they were initially educated about IBD by multiple individuals, most frequently by their pediatric gastroenterologist. On the majority of occasions, parents felt this initial education experience was positive: 37 said this was excellent, 4 felt it was reasonable and 2 were indifferent. Only one parent reported inadequate initial education (from their general practitioner).

Parents rated the amount of information transmitted in initial education sessions as just right (n = 26), not enough (n = 16), or inadequate (n = 3). Areas that respondents felt were not provided sufficiently were predominantly diet and nutrition (13 parents), the impact of IBD upon their child's life (n = 13) and the side effects of treatments (n = 11). In addition, areas that some parents felt they would have liked to learn more about, were initial psychological effects of the disease and the impact of the child's disease upon the rest of the family.

A number of parents expressed the view that their education was an on-going process and that the initial sessions were of limited benefit as a consequence of the stress of the new diagnosis. Common sources for further or on-going information about IBD included the IBD Clinic (30 responses), the internet (n = 27) and the hospital (n = 21).

Formal education meetings were emphasized as essential by a number of parents. Nineteen respondents attended such a meeting in the previous year and all expressed that they found this event useful in understanding and learning about IBD. Other parents suggested that other mechanisms to distribute information (such as newsletters or handouts) could also be useful for them and their child ren.

**DISCUSSION**

This report describes the concerns and issues facing the parents of young people with IBD. These parents expressed a wide range of concerns regarding their child’s illness and had many expectations for their child’s care. Many similar aspects were expressed commonly by these parents. The data gathered in this report are representative of the study population with satisfactory return of questionnaires by mail. Anonymous parental responses were provided for, by the study design. These data demonstrate that the parents are satisfied with the multi-faceted care provided to their children with chronic gastrointestinal illness. This care may help to ensure optimal quality of life outcomes, in addition to medical and nutritional outcomes. Further study is required to establish such outcomes.

The potential impact of chronic IBD upon children and adolescents with IBD has been clearly delineated by a number of investigators recently. Akobeng et al. utilized focus group meetings and a questionnaire to delineate some of these issues in 16 young people with IBD. Depressive symptoms and school absenteeism were reported by 12 of 16 subjects. Inability to do school sports was expressed by 8, worry by 14 and anger/frustration by 12. A further common observation was of difficulty taking holidays and staying at friends’ houses. This study, conducted in the United Kingdom, is complemented by several other reports from North America and Europe of issues affecting
young people with IBD\textsuperscript{[10-11]}. The nature of IBD may have multiple effects upon the ability of children or adolescents to perform normal age-related activities. Such effects include managing symptoms related to their gut diseases such as frequent diarrhea, and effects on growth and puberty, schooling, career choices, social and sporting activities, and peer interactions. The impact of disease upon the children was not investigated directly in the current report, which focused more upon parental concerns and expectations.

Parental quality of life issues were illustrated clearly by the respondents in the current study. Issues such as, what the future may hold for their child, psychological implications and social consequences were commonly expressed. Several investigators have explored the consequences of a child’s chronic gut disease upon siblings and parents\textsuperscript{[8,10]}. One employed parental focus groups involving 20 parents of children with IBD\textsuperscript{[8]}. Two-thirds of the parents were concerned about impact of disease on their child’s future (job, independence, etc.). Half of them worried about school problems and a number of others expressed feelings of guilt, concerns about the side-effects of medicines, and restrictions upon the family lifestyle. Although the current study did not include the same techniques to assess family concerns, the impact of the disease reported by parents was similar. In addition, this report did not consider the impact of the patient’s illness upon siblings. Siblings also reported that they had fears about diseases (that they may develop) and feelings of jealousy (related to the time and attention devoted to the sick child)\textsuperscript{[22]}

Education can be considered an essential tool for coping with new situations, such as that presents following the diagnosis of IBD in a child. The quality of the initial educational process may impact upon subsequent outcome, compliance and patient or family quality of life aspects\textsuperscript{[3]}. Specific education in the setting of instituting nutritional interventions in patients with IBD has been demonstrated to alter outcome\textsuperscript{[4]} but the outcome is not formally considered in the current study. The design of the study to maintain anonymity of parental responses did not permit detailed collection of data regarding disease severity, nutritional progress or current disease activity.

The educational goals and expectations of patients with IBD have been considered by several authors\textsuperscript{[5-8]}. This study highlights that information distribution is vital in the management of children with chronic gastrointestinal conditions such as IBD. Parents had a common desire for greater access to information. Although most parents noted satisfactory initial experiences in learning about IBD after diagnosis, some remarked that education about IBD was an ongoing process. Many reported their continuing use of the Internet to obtain information and to answer questions about IBD. The reliability of information from various sources may vary. The impact of educational activities and identification of areas of ignorance may be measured by specific tools, such as those developed and validated by Eaden et al\textsuperscript{[2]} and Haaland and Otley\textsuperscript{[13]}.

Educational activities are considered as one of the essential roles of the IBD Clinic, upon establishment. The clinic is set up as a multi-disciplinary, team-based clinic for children and adolescents with IBD. Prior to the institution of the clinic, children diagnosed with IBD were managed by one of the two pediatric gastroenterologists in general follow-up clinics at Sydney Children’s Hospital, without coordination or focus of care and without easy access to other health professionals. The advent of the clinic permits team-based care with medical, surgical, nutritional and nursing personnel. Holistic care, with the consideration of all the aspects of a child’s condition, is considered an important focus of the clinic.

The parental responses detailed here suggest that such a clinic format is appropriate and well received. There are, however, no data regarding parental impressions of their child’s care prior to the commencement of the clinic format that could be used as a comparison. The implications of the findings of the current study are to ensure that any facility directed towards managing children with IBD should consider the multiple and complex issues faced by these young people and their families. Further study is required to ascertain how a multi-disciplinary IBD clinic format impacts upon outcome and parental quality of life and expectations.

REFERENCES