Children and young people with inflammatory bowel disease attend less school than their healthy peers

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CB, JJA and RMB conceived the study. The study was designed by CB, JJA, DMW and RMB. Data were collected by CB with help from JJA, FB and MC. Data were analysed by CB and JJA. CB wrote the manuscript with help from all authors. All authors approved the final version prior to submission

Conflicts of interest

The authors have no conflicts of interest to declare.

Data sharing

All data relevant to the study are included in the article or uploaded as supplementary information

**Abstract**

**Objective**: Chronic diseases, such as inflammatory bowel disease (IBD), can impact negatively on education and social development. Examining the impact of IBD on school/college attendance for children and young people (CYP) is vital to provide targeted support to patients, families and schools.

**Methods**: We performed a cross-sectional survey to determine the school/college attendance rates, the reasons for absence related to IBD and facilitators/barriers to school/college attendance. In a subset followed-up locally, we performed a detailed review of hospital attendance data, to assess the healthcare burden.

**Results**: Two-hundred-and-thirty-one questionnaires were given to CYP with IBD aged 5-17 years. Response rate was 74% (final sample 169). The median school/college attendance rate was 92.5%; significantly lower than all children in England (95.2%). 39.6% of children with IBD were persistently absent, defined nationally as missing 10% or more of school. Only five children (3%) had a 100% attendance record. Increasing age and use of monoclonal therapy were predictors of poor school attendance. Concerns about feeling unwell at school/college, access to toilets, keeping up with work, and teachers’ understanding of IBD are the main issues for CYP with IBD. There was a significant negative correlation between number of days in hospital and school attendance.

**Conclusion**: IBD has a significant impact on school/college attendance, with hospital attendance, disease burden, and school difficulties being major factors. Employing strategies to minimise health care burden and developing a partnership between health and education to support children with IBD will serve to facilitate school/college attendance.

**Introduction**

Inflammatory bowel disease (IBD) is a chronic, multifactorial condition, encompassing Crohn’s disease, ulcerative colitis and inflammatory bowel disease unclassified (IBDU). An estimated 25% of IBD presents in childhood or adolescence [1] [2], with a twofold increase in incidence in the past 20 years [3] [4]. This chronic condition can place a significant burden on children and adolescents, impacting physical, social, psychological well-being and education. [5][6][7][8][9]. IBD may adversely affect school or college attendance which is associated with a negative effect on development[10] [11] [12][13][14]. Regular school attendance helps shape later life outcomes [11].

Multiple studies examine the impact of IBD on health-related quality of life [15][16] [17][18][19], showing that the symptoms and complications can have a negative impact on the daily lives of CYP and their families, affecting all domains of health. However, some data suggests that health-related quality of life and education attainment is not always impaired in children with IBD, if coping and support strategies are effective[20][21][22].

Studies examining children with chronic illness, including those with cancer, asthma, heart disease, cystic fibrosis, and gastrointestinal disease show lower school attendance [10][23]. Considerable differences in education exist between illnesses, although significant themes emerge across the spectrum, including worse school experiences, performance, outcomes, and lowered attendance rates [14] [24]. Studies that specifically examine IBD also demonstrate these patients miss more school than their healthy peers [25][26] [27], although this is not necessarily linked to poorer educational outcomes [28]. Lower school/college attendance rates are correlated with disease, demographic, and psychosocial variables [25][29][30]. However, disease factors/treatments are not predictive of worse educational outcomes [25] [28] [30][31].

The aim of this study was to examine the extent to which IBD affects school/college attendance for children, determine contributing factors for absences and perform thematic analysis of CYP comments.

**Methods**

Study population

The Paediatric Gastroenterology Service at University Hospitals Southampton (UHS) provides specialist care for over 650,000 children, covering 12 regional hospitals. CYP are managed in conjunction with local clinical teams as part of a network. CYP with IBD are typically seen 3 monthly in the year following diagnosis, with well controlled patients seen 6 monthly, or, if very well, yearly. Patients with IBD diagnosed prior to 1st January 2018 and of school/college age were identified from our in-house IBD database.

Questionnaire

A questionnaire (supplementary file 1) was constructed to determine the school/college attendance rates in the last year, the reasons for absence related to IBD, facilitators/barriers to school/college attendance, and current treatments. As no validated tool is available, a questionnaire was designed with input from several CYP with IBD and their families, a head teacher and members of the paediatric gastroenterology team. All school children in England receive their attendance as a percentage on a yearly school report, enabling accurate and reliable collection of attendance figures. All eligible patients and their families were invited to complete the questionnaire while attending hospital for clinic, day case or inpatient management. Any IBD patients who had not been given a questionnaire within 4 months of data collection commencing, were mailed with a covering letter and enclosed pre-paid return envelope. All questionnaires were returned in a sealed envelope to a tray in the clinic or ward, or to the post room. This was to ensure that CYP answers were not influenced by giving completed questionnaires to members of the clinical team.

CYP and their families were asked for the percentage school attendance for the previous academic year, or if unknown, the number of school/college days missed. For those patients/families who did not know the exact percentage, an estimate of school attendance was calculated based on the number of school days missed. For those missing >38 days per year, attendance was assumed to be 80%; a likely over estimate of attendance, to avoid biasing results to lower attendance.

Free text comments on the questionnaire were collated and manually searched for recurrent themes. Following classification of themes, a correlation/enrichment of these themes in different groups were identified through structured thematic analysis.

Review of hospital attendance data for local patients

Detailed review of hospital attendance was performed for all patients with IBD whose local hospital was Southampton Children’s, i.e. receiving specialist and local care from the same unit. For each patient, all hospital clinic appointments, admissions, reviews and investigations from September 2017 to August 2018 inclusive, were identified and recorded from the patient’s electronic health record. These data were used to calculate the number of days of attendance for each category of healthcare. An overall total number of days of hospital attendance for the year was calculated; removing duplicates where children had more than one attendance per day (e.g. clinic and radiology on the same day). This data was then compared to school attendance data.

Statistical analysis

To assess differences between our IBD patients and the general population, school attendance figures for England were obtained from the Department for Education [32]. These data were converted into number of school days missed across England for all children and compared to the number of days missed by children in our IBD sample using a 2 test (supplementary table 1). The number of children who were persistently absent from school (defined by the Department for Education as missing 10% or more) were compared to the number persistently absent across England through a 2 test (supplementary table 2). National attendance figures are not available for students aged >15 years at the start of the academic year. Following discussion with the statistics team at the Department for Education, data for school attendance was used as a comparison for college attendance.

Median values were compared using the Kruskal-Wallis Test. A stepwise forward multivariable linear regression was used to assess factors associated with school attendance. Pearson’s correlation was used to assess the relationship between hospital attendance and school attendance.

All statistical analysis was performed with SPSS (IBM v25). Statistical significance was considered to be p=<0.05.

Ethical approval

The study was registered as a service evaluation following review by UHS Research and Development Department. Ethical approval for the study was obtained from the University of Southampton.

**Results**

Questionnaires were distributed to 231 patients; 151 in hospital, and 80 by post. There was an overall response rate of 74% (97% for questionnaires distributed in hospital, and 30% postal). Two patients were excluded as one was home-schooled, and one had dropped out of school and went into employment, giving a final sample of 169. Table 1. The majority of questionnaires were completed with direct input from CYP, with 64% of questionnaires completed by the parent and child, 30% by CYP alone and 6% by the parent. The only significant differences between the questionnaires returned in hospital and returned by post were the duration of disease; 2.32 years vs 4.53 years, p=0.007, and the proportion of patients on immunomodulator therapy, 69.9% vs 45.8%, p=0.02. Supplementary table 3.

School attendance

State educated school children in England are expected to attend 191 days of school per year. The median school/college attendance rate overall for CYP with IBD was 92.5%. This is significantly lower than average attendance in England where the attendance rate is 95.2% [32] (2 test=515.02, p<0.0001). Supplementary table 1. The median attendance for primary school children was 95% versus 92.5% for secondary school/college students. This difference was not significant (p=0.071).

Children classified as persistently absent

39.6% (n=67) of patients missed 10% or more of school/college, meeting the Department of Education criteria for being persistently absent [32]. This is significantly more than all primary and secondary school children in England, where the rate is 11.2% [32] (=137.492, p=<0.00001). In our dataset 33% (8/24 patients) of primary school children were persistently absent versus 40% (58/145 patients) of secondary/college students; greater than the rate of 8.7% and 13.9%, respectively, in the general school population [32]. Only five CYP (3%) had 100% attendance rates, 45.6% (77 patients) missed >3 weeks of school (<92% attendance). Almost half (44%, n=74) of respondents reported that all their absences were due to IBD, 18% (n= 30) reported ¾ or more absences due to IBD, 13% (n=22) reported 50-74% absences due to IBD, and the remainder (n=43) less than 50%.

Factors associated with school attendance

Following multivariable linear regression, the significant predictors of reduced school attendance were increasing age (β-coefficient -0.203, 95% CI -0.350 to -0.057, p=0.007) and use of monoclonal therapy (β-coefficient -0.212, 95% CI -0.358 to -0.066, p=0.005) - table 2. Non-significant variables were, age at questionnaire, age at diagnosis, sex, thiopurine/methotrexate treatment, diagnosis, and time with disease. Regarding monoclonal therapy, 80% (n=57) were on Infliximab, 11% (n=8) Adalimumab, 8% (n=6) Ustekinumab and 1% Vedolizumab (n=1). This reflects >81% of patients receiving therapy as an infusion, including all Infliximab patients, the single patient on Vedolizumab (who had also been on Adalimumab during the year) and induction therapy with Ustekinumab. When separating monoclonal usage into infusions and injections, neither was significant in the regression model, infusion β-coefficient -0.142 p=0.06, injection β-coefficient -0.136 p=0.073.

Commonly reported factors impacting on school/college attendance included; hospital appointments, feeling unwell, and access to a toilet. Improved access to after school appointments, better teacher/school education, and sending work home were all reported as facilitators to improve school attendance.

The heat map (Figure 1) illustrates the frequency of responses, highlighting factors influencing school attendance.

Thematic analysis of free text comments

Free text comments were included on 38% of questionnaires. Figure 2 illustrates a word cloud of the comments and table 3 illustrates the main themes with direct quotes.

Review of hospital attendance data for Southampton patients

A review of hospital attendance data for all local patients with IBD included 39 patients. The questionnaire response rate for this group of patients was 87% (n=34).

In this group there were a total of 416 hospital attendance days from September 2017 to August 2018. Hospital attendance rates for individuals ranged from 2-38 days, with a median of 9 days (supplementary table 4). Clinic appointments accounted for the most days (n=275), then day case admissions (n=117). The least number of days was for inpatient admissions (n=24). Inpatient admission days reflect all unplanned admissions and account for only 5.8% of the total hospital attendances. The median number of days attended per patient for monoclonal treatment/review was 7 days; 5 days for attending clinics and 1 day for endoscopy, radiology investigation, day case or inpatient admissions.

There was a significant negative correlation between the number of days in hospital and school attendance, Pearson’s correlation coefficient -0.373, p=0.037.

Based on these data we hypothesised that if days off for hospital attendance are excluded, school attendance would increase by a median of 9 days per child, or 4.7% attendance, based on 191 school days per year. This would increase the median attendance to 97.2%, exceeding the national average in the general population.

**Discussion**

Median school attendance is significantly reduced in children with IBD, compared to the general school attendance in England. Almost 40% of children with IBD are classified as persistently absent, missing 10% or more of school/college; significantly greater than the rate for school children in England (11.2%). Only five with IBD achieved 100% attendance rates. Poor school attendance is largely driven by attending hospital for appointments and treatments. Patients requiring monoclonal therapy/older age have a significantly lower school attendance in the multivariate analysis. Self-reported factors associated with inability to attend school were frequent appointments, lack of toilet access, and feeling unwell. Respondents felt improved school attendance may be achieved with better teacher/school education, better toilet access, and hospital appointments after school .

These findings are in line with other studies showing that children with IBD miss significantly more school than their healthy peers [25][26] [27]. Mackner *et al* [25] found that 20% of those with IBD missed >3 weeks of school (<92% attendance) compared to 4% of healthy adolescents, whilst Assa *et al* [26] found that the difference was greater, with 64% of those with IBD missing >3 weeks compared to 3% of healthy adolescents, although they had a relatively small sample of IBD patients. In our study 45.6% (77 patients) missed >3 weeks of school (<92% attendance). Nevertheless, Eloi *et al* [27] found that IBD patients were absent 4.8 days per year on average, versus 3.2 for the non-IBD group.

If days off for hospital attendance were excluded the school attendance rates were increased to 97.2% exceeding the national average in England, although these data are hypothetical at this stage and would require validation by moving hospital appointments to outside school hours in a cohort. Similarly, Eloi *et al* [27] found after excluding absences for scheduled care, the rate of school absenteeism of IBD patients was significantly lower than the non-IBD group.

Increasing age and the use of monoclonal therapy are predictors of reduced school attendance. This is consistent with Carreon *et al*’s [30] study examining adolescents with IBD; greater disease activity (p=<0.01 in child report and p=0.03 for parent report), and older age (p=0.03 for child report and parent report p=0.02) were the most significant predictors of poorer school attendance.

Monoclonal therapy is a marker of greater disease severity which leads to a higher healthcare burden. When separating infusions in hospital and injectable monoclonal therapy at home, neither was independently predictive of school attendance, indicating that it is not only the increased number of hospital attendances for infusions that contributes to worse attendance. This is revealed in the detailed review of the local hospital attendance data, with monoclonal therapy being the second most common reason for hospital attendance. Likewise, Eloi *et al* [27] showed greater absenteeism in those on biologic treatment. This has implications for practice in terms of which type of monoclonal treatment is used and when infusions should take place (evenings or weekends). Injected forms of treatment such as adalimumab and ustekinumab, can be administered at home, reducing time off school/college. Only 19% of our patients were on an injectable form of monoclonal, with 81% attending hospital 6-9 times per year for infusions, accounting for a large number of missed school days. Facilitating shared care with regional hospitals reduces travelling time and minimises time out of school.

Southampton hospital attendance data showed a significant negative correlation between number of days in hospital and school attendance. Most absences for IBD are for hospital appointments (supplementary table 3). This is consistent with previous studies [26,30,33,34], demonstrating IBD related clinic visits were the most frequent form of health care utilisation. Overall the majority (62%) report that at least ¾ of their absences were due to IBD. This is a likely underestimation of the true figure, as families may not have linked certain absences, such as symptoms of stress or infections due to immunosuppression to IBD.

These findings illustrate the need for after school/college appointments; a measure identified by respondents as the most important factor that would improve attendance. Also, patients are likely to benefit from tailored clinic appointment intervals, or perhaps telephone appointments, depending on their disease activity [41].

Feeling unwell at school/college is the biggest concern for these patients (Figure 1). The Children and Families Act [35] outlines the duty of schools’ to ensure pupils with medical conditions are supported [36]. However, the literature indicates a gap in the knowledge of schools about chronic diseases, such as IBD [37] [38]. This illustrates the vital role of effective liaison between health and education, with the provision of training/support; further highlighted by many responses indicating nurse specialists educating teachers could result in improved attendance (Figure 1). Other school-related issues can be addressed by the provision of toilet passes, sending work home, and IT portals to access lessons missed. Nevertheless, there are contrasting reports from families on their experiences; some describe a lack of awareness, understanding and support, which is congruent with research [31]. Others reveal that schools are accommodating and supportive and this may reflect better sharing of information by health. A significant proportion reported no issues with IBD and school/college. Absenteeism at diagnosis and early treatment is common; associated with the lower health-related quality of life, and increased disease severity [16].

The 74% questionnaire response rate of the questionnaire is comparable to previous studies, and constitutes a relatively large sample size. School attendance, medication use and disease subtype data was not present for those who did not return a questionnaire. We have compared those returning questionnaires in hospital vs post, with the only significant differences between groups being time with disease and immunomodulator use. However, despite this, it was not possible to compare those not returning questionnaires in both groups as data and implied consent was not available, potentially meaning that the higher return rate of hospital questionnaires may have introduced a bias. There was typical representation of disease severity indicated by the proportion of patients on monoclonal (42%) or thiopurine/methotrexate treatment (66.9%). Assessing longitudinal disease activity is complex and lacks a validated score to reflect disease activity over a whole year. We have therefore used medication usage as a proxy of disease severity; however we recognise that many patients on monoclonal therapy will have well controlled disease. The questionnaire relied on self-report, with the potential for recall bias, without external validation of school attendance. We were unable to compare to local attendance data as the 12 regional hospitals covered by our service are situated in Hampshire, Dorset, Isle of Wight, West Sussex, Surrey, Wiltshire and the Channel Islands; there is no single education authority reporting figures for this area. Some responses may have been affected by fears that their reasons for missing school were not good enough, with the consequent risk of further action from schools. It was not possible to control for factors such as income inequality, lone parenting or young carer responsibilities; factors known to impact school/college attendance [39] [40]. There were relatively low numbers of young people attending college (11.8%) and a significantly smaller proportion attending primary school (14.2%) compared to secondary school/college (85.8%). We recognise a lower response rate from postal questionnaires leads to potential confounding of attendance figures; however characteristics of responses from both patients returning questionnaires by hand and by post are highly comparable.

Conclusion

IBD negatively impacts on school/college attendance, with hospital attendance, disease burden and school difficulties being major barriers. Needs of children with chronic illnesses must be addressed by ensuring effective partnership between education and health and targeting those with risk factors for poor attendance with preventative measures. Utilising strategies to minimise healthcare burden and provide more integrated care can directly impact service provision and facilitate school/college attendance for CYP with IBD.

What is already known on this topic

* Children and young people with inflammatory bowel disease miss more school than their healthy peers.
* There is a strong link between school absenteeism and underachievement.
* Disease, demographic and psychosocial factors contribute to lower school/college attendance rates.

What this study adds

* Significantly more children and young people with inflammatory bowel disease are persistently absent from school/college (39.6%) compared to all children in England (11.2%).
* Concerns for those with IBD attending school/college include feeling unwell, access to toilets, keeping up with work, and teachers’ understanding of IBD.
* Important measures identified as helping with school/college attendance include; appointments/treatments after school, gastro nurses educating teachers on IBD and school sending work home when absent.

**References**

1 Griffiths AM. Specificities of inflammatory bowel disease in childhood. Best Pract. Res. Clin. Gastroenterol. 2004. doi:10.1016/j.bpg.2004.01.002

2 Beattie RM, Croft NM, Fell JM, *et al.* Inflammatory bowel disease. *Arch Dis Child* 2006;**91**:426–32. doi:10.1136/adc.2005.080481

3 Ashton JJ, Coelho T, Ennis S, *et al.* Presenting phenotype of paediatric inflammatory bowel disease in Wessex, Southern England 2010-2013. *Acta Paediatr Int J Paediatr* 2015;**104**. doi:10.1111/apa.13017

4 Ashton JJ, Cullen M, Afzal NA, *et al.* Is the incidence of paediatric inflammatory bowel disease still increasing? *Arch Dis Child* 2018;:archdischild-2018-315038. doi:10.1136/archdischild-2018-315038

5 Decker JW. The effects of inflammatory bowel disease on adolescents. *Gastroenterol Nurs* Published Online First: 2000. doi:10.1097/00001610-200003000-00003

6 Mackner LM, Crandall W V., Szigethy EM. Psychosocial functioning in pediatric inflammatory bowel disease. Inflamm. Bowel Dis. 2006. doi:10.1097/01.MIB.0000217769.83142.c6

7 Hummel TZ, Tak E, Maurice-Stam H, *et al.* Psychosocial developmental trajectory of adolescents with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 2013.

8 Brooks AJ, Rowse G, Ryder A, *et al.* Systematic review: Psychological morbidity in young people with inflammatory bowel disease - risk factors and impacts. *Aliment Pharmacol Ther* Published Online First: 2016. doi:10.1111/apt.13645

9 Werner H, Landolt MA, Buehr P, *et al.* Changes in health-related quality of life over a 1-year follow-up period in children with inflammatory bowel disease. Qual. Life Res. 2017.

10 Moonie S, Sterling DA, Figgs LW, *et al.* The relationship between school absence, academic performance, and asthma status. *J Sch Health* Published Online First: 2008. doi:10.1111/j.1746-1561.2007.00276.x

11 Commons C. The Longitudinal Study of Australian Children Australian Institute of Family Studies. 2013.

12 Tollit MA, Sawyer SM, Ratnapalan S, *et al.* Education support services for improving school engagement and academic performance of children and adolescents with a chronic health condition. *Cochrane Database Syst Rev* Published Online First: 2015. doi:10.1002/14651858.CD011538

13 Emerson ND, Distelberg B, Morrell HER, *et al.* Quality of Life and School Absenteeism in Children With Chronic Illness. *J Sch Nurs* Published Online First: 2016. doi:10.1177/1059840515615401

14 Lum A, Wakefield CE, Donnan B, *et al.* Understanding the school experiences of children and adolescents with serious chronic illness: a systematic meta-review. Child. Care. Health Dev. 2017. doi:10.1111/cch.12475

15 Calsbeek H, Rijken M, Bekkers MJTM, *et al.* Social position of adolescents with chronic digestive disorders. *Eur J Gastroenterol Hepatol* Published Online First: 2002. doi:10.1097/00042737-200205000-00012

16 Otley AR, Griffiths AM, Hale S, *et al.* Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. *Inflamm Bowel Dis* 2006.

17 Varni JW, Bendo CB, Nurko S, *et al.* Health-related quality of life in pediatric patients with functional and organic gastrointestinal diseases. J. Pediatr. 2015.

18 Ganz ML, Sugarman R, Wang R, *et al.* The economic and health-related impact of Crohn’s disease in the United States: Evidence from a nationally representative survey. Inflamm. Bowel Dis. 2016. doi:10.1097/MIB.0000000000000742

19 Diederen K, Haverman L, Grootenhuis MA, *et al.* Parental Distress and Quality of Life in Pediatric Inflammatory Bowel Disease: Implications for the Outpatient Clinic. *J Pediatr Gastroenterol Nutr* Published Online First: 2018. doi:10.1097/MPG.0000000000001756

20 Nicholas DB, Otley A, Smith C, *et al.* Challenges and strategies of children and adolescents with inflammatory bowel disease: A qualitative examination. *Health Qual Life Outcomes* Published Online First: 2007. doi:10.1186/1477-7525-5-28

21 Rogler D, Fournier N, Pittet V, *et al.* Coping is excellent in Swiss Children with inflammatory bowel disease: Results from the Swiss IBD cohort study. *J Crohn’s Colitis* Published Online First: 2014. doi:10.1016/j.crohns.2013.10.004

22 Mayberry MK, Probert C, Srivastava E, *et al.* Perceived discrimination in education and employment by people with Crohn’s disease: A case control study of educational achievement and employment. *Gut* 1992;**33**:312–4. doi:10.1136/gut.33.3.312

23 Crump C, Rivera D, London R, *et al.* Chronic health conditions and school performance among children and youth. *Ann Epidemiol* Published Online First: 2013. doi:10.1016/j.annepidem.2013.01.001

24 Pinquart M, Teubert D. Academic, physical, and social functioning of children and adolescents with chronic physical illness: A meta-analysis. J. Pediatr. Psychol. 2012. doi:10.1093/jpepsy/jsr106

25 MacKner LM, Bickmeier RM, Crandall W V. Academic achievement, attendance, and school-related quality of life in pediatric inflammatory bowel disease. *J Dev Behav Pediatr* Published Online First: 2012. doi:10.1097/DBP.0b013e318240cf68

26 Assa A, Ish-Tov A, Rinawi F, *et al.* School attendance in children with functional abdominal pain and inflammatory bowel diseases. *J Pediatr Gastroenterol Nutr* Published Online First: 2015. doi:10.1097/MPG.0000000000000850

27 Eloi C, Foulon G, Bridoux-Henno L, *et al.* Inflammatory Bowel Diseases and School Absenteeism. *J Pediatr Gastroenterol Nutr* Published Online First: 2019. doi:10.1097/MPG.0000000000002207

28 Singh H, Nugent Z, Brownell M, *et al.* Academic performance among children with inflammatory bowel disease: A population-based study. *J Pediatr* 2015.

29 Almadani SB, Adler J, Browning J, *et al.* Effects of Inflammatory Bowel Disease on Students’ Adjustment to College. *Clin Gastroenterol Hepatol* Published Online First: 2014. doi:10.1016/j.cgh.2014.03.032

30 Carreon SA, Bugno LT, Wojtowicz AA, *et al.* School Functioning in Adolescents with Inflammatory Bowel Diseases: An Examination of Disease and Demographic Correlates. *Inflamm Bowel Dis* Published Online First: 2018. doi:10.1093/ibd/izy026

31 Freckmann M, Seipp A, Laass MW, *et al.* School-related experience and performance with inflammatory bowel disease: Results from a cross-sectional survey in 675 children and their parents. *BMJ Open Gastroenterol* Published Online First: 2018. doi:10.1136/bmjgast-2018-000236

32 Department for Education. Statistics at DfE - Department for Education - GOV.UK. https://www.gov.uk/government/organisations/department-for-education/about/statistics (accessed 17 Jun 2019).

33 Kappelman MD, Porter CQ, Galanko JA, *et al.* Utilization of healthcare resources by U.S. children and adults with inflammatory bowel disease. *Inflamm Bowel Dis* Published Online First: 2011. doi:10.1002/ibd.21371

34 Wojtowicz AA, Plevinsky JM, Poulopoulos N, *et al.* Examining predictors of healthcare utilization in youth with inflammatory bowel disease. *Eur J Gastroenterol Hepatol* Published Online First: 2016. doi:10.1097/MEG.0000000000000540

35 Legislation.gov.uk. Children and Families Act 2014. *Child Fam Act* 2014.

36 Supporting pupils at school with medical conditions Statutory guidance for governing bodies of maintained schools and proprietors of academies in England. 2015.

37 Berger C, Valenzuela J, Tsikis J, *et al.* School Professionals’ Knowledge and Beliefs About Youth With Chronic Illness. *J Sch Health* Published Online First: 2018. doi:10.1111/josh.12646

38 Kim ES, Kwon KT, Kim SK, *et al.* Impact of Education on School Nurses’ Knowledge of Inflammatory Bowel Disease. *Gut Liver* Published Online First: 2018. doi:10.5009/gnl18139

39 Morrissey TW, Hutchison L, Winsler A. Family income, school attendance, and academic achievement in elementary school. *Dev Psychol* Published Online First: 2014. doi:10.1037/a0033848

40 Gottfried MA. Can Neighbor Attributes Predict School Absences? *Urban Educ* Published Online First: 2014. doi:10.1177/0042085913475634

41 Akobeng AK, O’Leary N, Vail A, *et al.* Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine* 2015;**2**:1251–6. doi:10.1016/j.ebiom.2015.08.011

Table 1 – Demographic and disease characteristics of study population and subgroup of local Southampton patients

|  |  |  |
| --- | --- | --- |
| **Demographic and Disease Characteristics** | **Study sample (n=169)** | **Subgroup of local Southampton patients (n=34)** |
| Median Age at Questionnaire (years) | 15.3 | 15.1 |
| Median Age at Diagnosis (years) | 11.5 | 11.1 |
| Median Time with Disease (years) | 2.7 | 3.3 |
| No. female (% total) | 59 (35%) | 16 (47%) |
| Median School Attendance (IQR) | 92.5% (81-96%) | 93.5% (81-96%) |
| Number of patients with 100% attendance | 5 (3%) | 2 (6%) |
| Number of patients missing 10% or more of school/college | 67/169 (40%) | 13/34 (38%) |
| Percentage on monoclonal therapy | 42% | 35% |
| Percentage on thiopurine/MTX therapy | 67% | 62% |
| Patient diagnosis | CD- 108 (64%)  UC- 56 (33%)  IBDU- 5 (3%) | CD – 24 (71%)  UC – 10 (29%)  IBDU – 0 (0%) |
| Percentage attending school | 87% | 92% |
| Percentage attending college | 12% | 9% |
| Number not attending school or college | 2 | 0 |

Table 2 – Multivariable linear regression for school/college attendance

Increasing age and use of monoclonal therapy (infliximab, adalimumab, ustekinumab or vedolizumab) are predictors of reduced school attendance.

|  |  |  |
| --- | --- | --- |
| **Independent variable** | **β-coefficient (95% CI)** | **p value** |
| Monoclonal therapy | -0.212  (-0.358 to -0.066) | 0.005 |
| Age at response to Questionnaire | -0.203  (-0.350 to -0.057) | 0.007 |

Dependent variable: School Attendance (%). Independent variables: age at questionnaire, age at diagnosis, sex, thiopurine/methotrexate treatment, diagnosis (CD, UC or IBDU) and time with disease.

Table 3 – Thematic analysis of questionnaire free text comments

|  |  |
| --- | --- |
| Side effects of IBD | “Feeling unwell makes college very off putting and not very desirable as it causes me not to be able to focus on the lesson properly.”  “I worry that I will need the toilet urgently during lessons or exams and feel embarrassed.”  “He found getting to school tricky as he was often fatigued, felt unwell and worried constantly that he wouldn’t make the toilet in time and soil himself in front of peers” |
| Measures to improve attendance | “Whilst missing large periods of time off school due to having a flare up, I had virtual learning to help keep up with school work; this helped a lot.”  “Treatments and appointments at closer hospitals. Southampton is quite far away making me miss more school time.”  “Gastro nurse speaking to the school was a huge help”  “Appointments outside of college would be most helpful & alleviate the stress incurred in catching up on missed work” |
| Schools are not accommodating | “Very clear none of them understood the impact of Crohn’s on everyday life. A case of if you cannot see an illness you are not ill. A teacher commented on his school report that if he improved his attendance it would help his school work!”  “She fetches a key every day at school as the toilets are locked during lessons”  “The school need information relating to IBD despite being constantly given information from me via emails etc – this info never seemed to be shared amongst staff though and caused real stress for my son at times” |
| Schools are understanding | “Generally, both schools have been excellent and very understanding. 1 school went to the effort to help her sit her SATs while in hospital, so she didn’t miss out.”  “School really good at understanding her needs and has free toilet pass when needed. Without this school would be hard to attend.”  “The primary school he was attending at the time were great – very supportive especially when he was taking modulen.” |
| No issues with IBD & school/college | “At the moment my IBD is under control therefore it doesn’t affect my school life much.”  “Nothing makes it difficult to attend school currently”  “IBD v school is not a question/problem that has consistently arisen as yet” |
| Need for more awareness of IBD | “Schools & employers need more awareness of IBD and its impact on family life, student well-being.”  “I feel schools need to be more aware of the effects of Crohn’s disease in order to meet the needs of children, especially those who may find it difficult to speak up”  “My son missed school on many days due to flare ups and was reluctant to attend school due to the lack of awareness shown by many teachers.” |

The table illustrates the main themes from the questionnaire free text comments, with direct quotes from patients/families to illustrate each theme.

Figure 1 – Heat map to illustrate factors affecting school/college attendance

Heat map demonstrating the frequency of responses for 4 questions – the deeper the colour red, the higher the frequency.

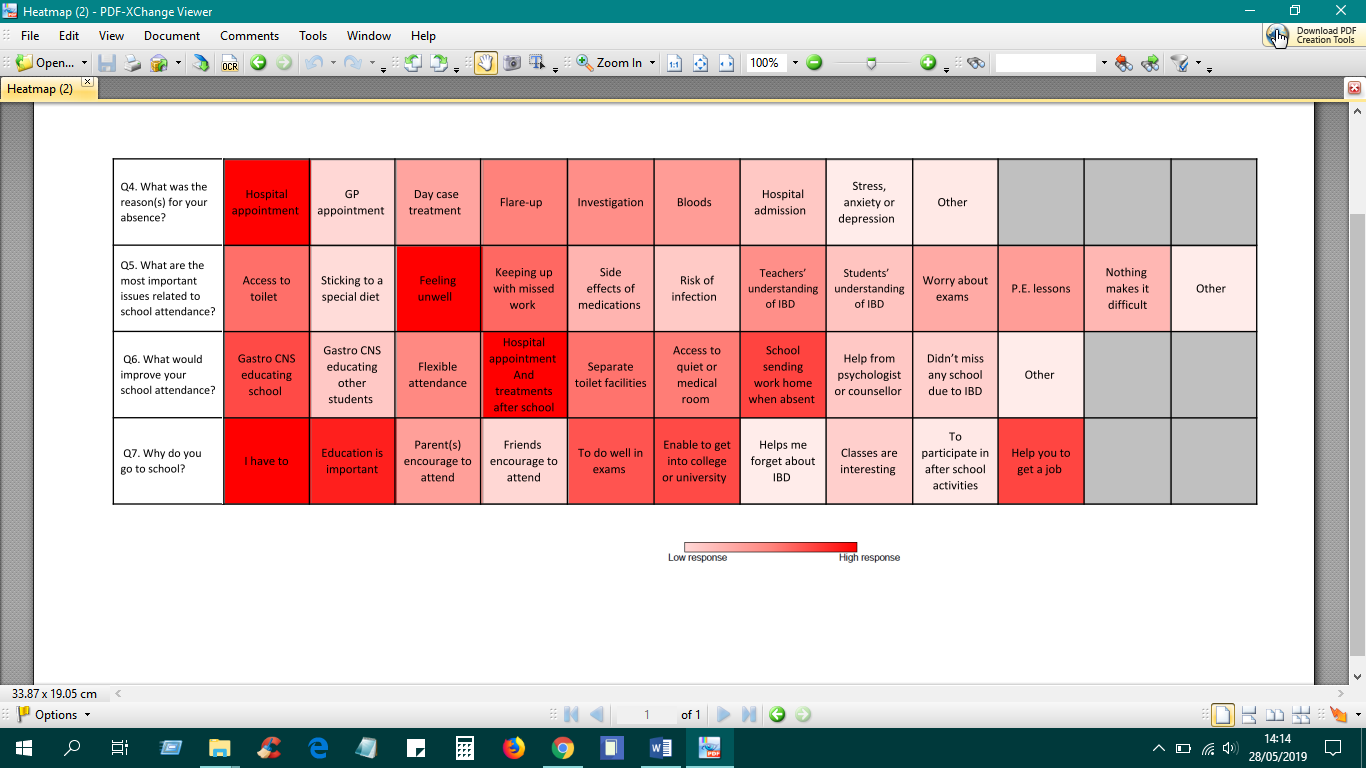


Figure 2 – Word cloud of questionnaire free text comments

A graphical representation of word frequency from the questionnaire free text comments. The size of the word indicates its frequency; the more often a word appears in the text the bigger and bolder it appears in the word cloud.



Supplementary Table 1 – Comparison of school attendance for CYP with IBD to the general school population

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Population | School Days | Attendance | School days total | School days present | School days missed |
| General school population | 6737023 | 191 | 0.952 | 1286771393 | 1217285738 | 69485655 |
| IBD | 169 | 191 | 0.925 | 32279 | 29858 | 2421 |

p=<0.0001

This table shows that CYP with IBD attend significantly less school compared to all CYP in England.

Supplementary Table 2 – Comparison of persistently absent data for CYP with IBD to the general school population

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Population | Proportion persistently absent | Children present | Children persistently absent |
| General school population | 6737023 | 0.112 | 754480 | 5982374 |
| IBD | 169 | 0.396 | 67 | 102 |

p=<0.00001

This table shows that the number of CYP persistently absent (missing 10% or more of school) is significantly greater in those with IBD compared to the general school population.

|  |  |  |  |
| --- | --- | --- | --- |
| **Demographic and Disease Characteristics** | **Hospital questionnaire returned (145)** | **Postal questionnaire returned (24 patients)** | **p value** |
| Questionnaire response rate | 97% | 30% | **p=<0.0001** |
| Median Age at Questionnaire | 15.33 years | 14.87 years | p=0.71 |
| Median Age at Diagnosis | 11.74 years | 10.18 years | p=0.08 |
| Median Time with Disease | 2.32 years | 4.53 years | **p=0.007** |
| No. female (% total) | 51 (35.2%) | 8 (33.3%) | p=0.88 |
| Median School Attendance | 92.5% | 95% | p=0.014 |
| Number of patients with 100% attendance (%) | 4 (2.8%) | 1 (4.2%) | p=0.7 |
| Number of patients missing 10% or more of school/college (%) | 61 (42.1%) | 6 (25%) | p=0.11 |
| Percentage on monoclonal therapy | 64 (44.1%) | 7 (29.2%) | p=0.18 |
| Percentage on thiopurine/MTX therapy | 102 (70.3%) | 11 (45.8%) | **p=0.02** |
| Number with Crohn’s disease (%) | 92 (63.5%) | 16 (66.7%) | p=0.54 |
| Number attending school (%) | 127 (87.6%) | 21 (87.5%) | p=0.95 |
| Number attending college (%) | 18 (12.4%) | 2 (8.3%) | p=0.57 |
| Number not attending school or college (%) | 1 (0.7%) | 1 (4.2%) | p=0.14 |

Supplementary table 3-

Statistical analysis is with Chi-Squared or Kruskal-Wallis test (for median values)

Supplementary Table 4– Hospital attendance data for Southampton patients

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Gastro clinic | Other clinic | Clinic days | Endoscopy days | Radiology days | Monoclonal/  Review | Day case days | Inpatient days | Total days |
| Total no of days | 246 | 29 | 275 | 13 | 19 | 85 | 117 | 24 | 416 |
| Median no of days per patient | 4 | 2 | 5 | 1 | 1 | 7 | 1 | 1 | 9 |

The table illustrates the frequency of hospital attendance for Southampton IBD patients over 1 year for each category of health care.

(Day cases included biologic treatment/medical review, endoscopy and radiological investigations)