Crohn's & Colitis 360, 2026, 8(3), otag062
https://doi.org/10.1093/crocol/otag062
Published: June 23, 2026
Innovations in Care Delivery

School life in children with inflammatory bowel diseases: from a national survey to a patient-driven awareness initiative

Laura Gianolio, MD*[,1,2], Valentina Silvera, MD[1], Alice Bianchi, MD[1], Francesca Penagini, PhD[1], Enrica Previtali[3], Salvo Leone[3], Gianvincenzo Zuccotti, MD[1,2], Lorenzo Norsa, PhD[1,2]

[1]Pediatric Department, Vittore Buzzi Children's Hospital, Milan 20154, Italy
[2]Department of Biomedical and Clinical Science, University of Milan, Milan 20157, Italy
[3]National Association for Inflammatory Bowel Diseases (AMICI Italia), Milan 20125, Italy
*Corresponding author: Laura Gianolio, MD, Pediatric Department, Vittore Buzzi Children's Hospital, via Castelvetro 32, Milan 20154, Italy (laura.gianolio@unimi.it).

Abstract

Background: **School plays a crucial role in the daily life of pediatric patients with inflammatory bowel disease (IBD). Our study aimed to evaluate patients' perspectives on school environment and identify improvement areas.**

Methods: **An anonymized patient-driven school survey was distributed via an online platform between February and November 2024 to all pediatric IBD patients and families registered with the Italian IBD patient association (AMICI).**

Results: **Overall, 362 IBD patients responded, of whom 326/362 (90%) were in secondary school. Most respondents reported being aware of their disease (327/342, 96%). While the majority expressed a positive attitude towards school (269/342, 79%) and had disclosed their condition to at least 1 person at school (286/318, 90%), challenges were identified. Only 91/308 (30%) and 84/318 (26%) felt often understood by teachers and peers, respectively. Toilet access was problematic, with 225/318 (71%) expressing fear of using school bathrooms. Additionally, 80/313 (26%) experienced at least occasionally physical/verbal bullying. More than half (172/310, 55%) attended school despite feeling unwell to avoid criticism, with a minority having opportunities to catch up on missed lessons (95/261, 36%). To address these issues, patients' suggestions included training programs to educate teachers/peers and practical improvements in restroom access and absence management.**

Conclusions: **This national patient-driven survey highlights substantial unmet needs in the school environment for children/young adults with IBD, underscoring the need for targeted interventions to improve inclusion and quality of life. Patient associations play a key role in identifying everyday challenges and fostering collaboration among clinicians, institutions, and policymakers to implement meaningful change.**

Key words: pediatrics, inflammatory bowel diseases, school, quality of life

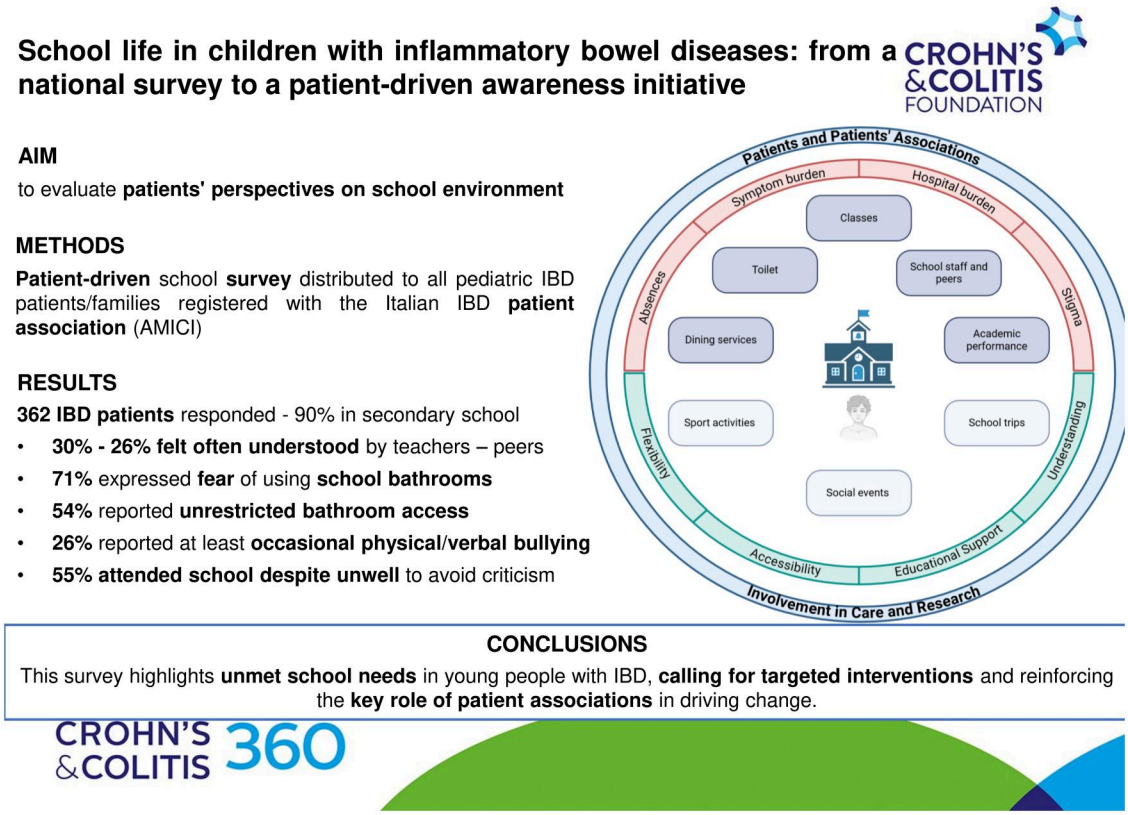
Lay Summary

A nationwide patient-promoted survey of Italian children/young adults with inflammatory bowel disease revealed substantial unmet needs at school, including limited disease understanding and restricted restroom access. Patient associations may facilitate targeted educational interventions to improve inclusion and quality of life.

Received: February 4, 2026. **Accepted:** May 28, 2026
© The Author(s) 2026. Published by Oxford University Press on behalf of Crohn's & Colitis Foundation.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (https://creativecommons.org/licenses/by-nc/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact journals.permissions@oup.com.

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

Graphical abstract



Introduction

Inflammatory bowel diseases (IBD) are chronic, immune-mediated conditions of the gastrointestinal tract characterized by a relapsing–remitting course. Common gastrointestinal symptoms include diarrhea, abdominal pain, and bowel urgency, while fatigue represents the most frequent and debilitating extra-intestinal manifestation.[1]

Both disease-related symptoms and the associated healthcare burden—encompassing hospitalizations, medical visits, and pharmacological treatments—have a documented impact not only on the physical functioning but also on the psychosocial dimension, during both active and remission phases.[2]

Approximately 10%-20% of IBD cases present during childhood, a developmental stage in which school plays a central role in social integration, emotional development, and future academic and professional pathways.[3] Despite this relevance, the literature has mainly focused on increased school absenteeism, without consistent evidence of poorer educational outcomes in children/young adults with IBD.[4–7]

Given the inherently patient-centered nature of school experiences, understanding how children and adolescents with IBD perceive and navigate the school environment is essential to identifying unmet needs and guiding targeted interventions. This study represents the first published initiative to explore school-related challenges, arising directly from priorities expressed by a national IBD patient association and disseminated within its community. Our goal was to capture patients' lived experiences to outline concrete strategies to promote an inclusive and supportive educational environment for young people with IBD.

Materials and methods

A cross-sectional anonymized survey was designed by the Italian IBD patient association (AMICI), reflecting patients' needs, and distributed via an online platform between February and November 2024 to all pediatric IBD patients and families registered with AMICI.

The questionnaire consisted of 30 items exploring: sociodemographic characteristics, extracurricular activities (sports and social activities), disease-related awareness, perceived support from teachers and peers, school bathroom use, experiences of bullying and discrimination; school absenteeism, and academic performance. All questions were closed-ended, except for a final open-ended item on patient-identified priorities. In line with the patient-driven design, all questions were optional, allowing participants to respond only to items they felt relevant or comfortable answering, thereby maximizing accessibility and participation. Eligible participants were children and adolescents (6-18 years) with a diagnosis of IBD, attending primary or secondary school. Parents were invited to assist younger children, while adolescents ≥12 years were encouraged to complete the survey independently.

Electronic informed consent for participation and processing of personal data was obtained by submitting the completed

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

questionnaire, in accordance with the EU General Data Protection Regulation (Reg. EU 679/2016). Categorical variables were summarized as absolute frequencies and percentages, whereas continuous variables were reported as medians with interquartile ranges (IQR). For each survey item, percentages were calculated using the number of respondents to that specific question as the denominator.

Results

Overall, 362 children/adolescents (195/362 females, 54%; median age 16 years, IQR: 13-18) completed the survey. Ulcerative colitis (UC) was the commonest diagnosis (173/318, 54%), followed by Crohn's disease (CD) (136/318, 43%). Disease duration ranged from <1 year (31/318, 10%) to >5 years (83/318, 26%), with the majority (204/318, 64%) reporting a disease-duration of 1-5 years. Most respondents were aware of their condition (327/342, 96%) and its chronicity (311/318, 98%); 36/362 (10%) were in primary school, and 326/362 (90%) in secondary school. Disclosure at school was frequent, with 286/318 (90%) informing at least one teacher or peer.

Perceived empathy at school

Most respondents (269/342, 79%) reported "enjoying going to school." However, perceived empathy was limited: 91/308 (30%) felt "often understood" by teachers, whereas 143/308 (46%) felt "sometimes" or 74/308 (24%) "never understood." Peer understanding showed a similar pattern (Table 1). Bullying related to IBD at school was reported by 80/313 (25%) of respondents at least occasionally, including 14/313 (5%) describing "frequent physical or verbal bullying."

Absenteeism and educational support

Most participants reported missing school "sometimes" (190/313, 61%) or "often" (103/313, 33%) due to IBD, mainly because of medical visits (177/283, 62%) and disease-related malaise (81/283, 29%).

Conversely, 172/310 (55%) reported "attending school despite feeling unwell to avoid criticism." Support measures were limited: 54/312 (17%) had a support teacher, and 95/261 (36%) were regularly allowed to catch up on missed lessons.

Bathroom access

Unrestricted bathroom access was reported by 172/318 (54%) participants, while 225/318 (71%) expressed fear of using bathrooms, mainly because of discomfort or embarrassment in shared facilities and concerns about poor cleanliness.

Academic outcomes

Academic performance remained stable for most respondents (211/310, 68%), with a small proportion (27/310, 9%) reporting repeating at least one school year due to IBD.

Engagement in sports and extracurricular activities

One-third of respondents (125/362, 35%) did not engage in any sport, with "fatigue" (71/123, 58%) as the main reason. Participation in extracurricular social activities was high, with 233/318 (73%) students taking part in school trips.

Patient-identified priorities

Participants highlighted priorities for improving school experience: "targeted educational programs for teachers and peers" (60/207, 29%), "improved bathroom facilities and accessibility" (29/207, 14%) and better management of absences, including "remote learning options" (27/207, 13%).

Discussion

This national, patient-driven survey provides novel insights into school experiences among Italian children and adolescents with IBD, highlighting unmet needs that, if addressed, may substantially improve quality of life, beyond the clinical goal of achieving disease remission.

School absenteeism remains a major challenge for PIBD patients. Over 90% of respondents reported missing school at least occasionally, and one-third reported frequent absences, mainly due to medical appointments and disease-related malaise. These results align with previous studies[8]: Mackner et al. reported >3 weeks of annual school absence in 20% of PIBD patients versus 4% of healthy peers[5]; Assa et al. observed 64% of PIBD patients versus 3% of controls missing >3 weeks annually[4]; Barnes et al. documented absenteeism in 46% of patients, with older age and monoclonal therapy predicting poorer attendance.[6] Within this context, it is particularly striking that 55% of participants reported attending school while unwell to avoid criticism, highlighting substantial psychosocial pressure alongside gaps in educational support. This behavior, likely driven by fear of judgment and stigma, may ultimately negatively impact both physical health and overall well-being. Notably, formal support measures were limited, suggesting that structured catch-up mechanisms remain inconsistently implemented and insufficiently integrated within school systems.

Despite notable absenteeism and limited access to educational support in our cohort, most participants perceived their academic performance as stable. This aligns with evidence indicating that PIBD does not necessarily impair long-term educational outcomes.[5,9] Singh et al. demonstrated comparable grade-12 achievement between adolescents with and without IBD, with socioeconomic status and mental health, rather than disease activity, predicting poorer academic results.[7]

Regarding extracurricular and social participation, our findings mirror those of Assa et al. showing that social activities were less disrupted than school attendance and sports.[4] This likely reflects adolescents' efforts to preserve participation in less physically demanding social engagements.

A key finding of our analysis is the limited perception of understanding and support from both teachers and peers, despite high rates of disease awareness and disclosure. Nearly 30% of

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

Table 1 Overview of selected questions from the 30-item school questionnaire, including missing data.

School questionnaire	Answer choices	*N* (%) Total *N* = 362
Do you like going to school?	Yes	269/342 (79%)
	No	73/342 (21%)
	Missing	20
Do they know at school that you have a chronic disease?	Yes	144/318 (45%)
	No	32/318 (10%)
	Someone	142/318 (45%)
	Missing	44
Do you feel that your teachers understand your condition?	Often	91/308 (30%)
	Sometimes	143/308 (46%)
	Never	74/308 (24%)
	Missing	54
Do you feel that your peers understand your condition?	Often	84/318 (26%)
	Sometimes	148/318 (47%)
	Never	86/318 (27%)
	Missing	44
Do your teachers allow you to go to the bathroom when you ask?	Often	172/318 (54%)
	Sometimes	131/318 (41%)
	Never	15/318 (5%)
	Missing	44
Are you afraid to go to the bathroom at school because of your disease?	Often	103/318 (32%)
	Sometimes	122/318 (39%)
	Never	93/318 (29%)
	Missing	44
Do you play any sports outside of your school physical education classes?	Yes	237/362 (65%)
	No	125/362 (35%)
	Missing	0
If you answered "no" to the previous question about sports, why do you not play any?	I feel uncomfortable	13/123 (10%)
	I feel fatigued by it	71/123 (58%)
	I do not feel accepted by my peers	2/123 (2%)
	I do not like sport	37/123 (30%)
	Missing	239
Do you take part in extracurricular group activities (e.g. playing in a band, other)?	Yes	77/342 (23%)
	No	265/342 (77%)
	Missing	20
Do you meet with your classmates outside of school (e.g., in the afternoon, at the weekend, or other)?	Often	111/313 (35%)
	Sometimes	147/313 (47%)
	Never	55/313 (18%)
	Missing	49
Do you take part in school trips?	Yes	233/318 (73%)
	No	27/318 (9%)
	Sometimes	58/318 (18%)
	Missing	44
Have you been teased at school because of your disease?	Often	13/316 (4%)
	Sometimes	76/316 (24%)
	Never	227/316 (72%)
	Missing	46
Have you experienced bullying (physical or verbal) because of your appearance or disease?	Often	14/313 (5%)
	Sometimes	66/313 (21%)
	Never	233/313 (74%)
	Missing	49
Do you miss school because of your disease?	Often	103/313 (33%)
	Sometimes	190/313 (61%)
	Never	20/313 (6%)
	Missing	49

(continued)

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

Table 1 (continued)

School questionnaire	Answer choices	*N* (%) Total *N* = 362
Do you go to school even when you don't feel well to avoid criticism?	Often	53/310 (17%)
	Sometimes	119/310 (38%)
	Never	138/310 (45%)
	Missing	52
Do you have a support teacher?	Yes	54/312 (17%)
	No	258/312 (83%)
	Missing	50
Do teachers allow you to catch up on missed lessons when you are absent from school?	Often	95/261 (36%)
	Sometimes	96/261 (37%)
	Never	70/261 (27%)
	Missing	101
Are you performing well at school? Is your academic performance consistent?	Yes	211/310 (68%)
	No	55/310 (18%)
	I don't know	44/310 (14%)
	Missing	52
Do you believe you have ever failed a school year because of your disease?	Yes	27/310 (9%)
	No	283/310 (91%)
	Missing	52

participants reported bullying related to their IBD. Although pediatric literature on this topic remains limited, it is well recognized that the socially stigmatizing nature of symptoms, combined with the burden of a chronic, unpredictable disease and demanding treatments, may heighten psychosocial vulnerability.[1,10,11] Roberts et al. further demonstrated that peer victimization contributes to reduced social belongingness and increased depressive symptoms, particularly when disease-related stigma is high.[12] In the latest PIBD meta-analysis pooled prevalence estimates were 16% (95% CI, 7%-27%) for anxiety symptoms and 15% (95% CI, 6%-25%) for depressive symptoms.[13] Given this evidence, efforts should focus on early identification and mitigation of psychosocial distress in the school environment, as reducing stigma, enhancing support, and preventing peer victimization may help prevent anxiety and depression.

Regarding school toilet use, only half of respondents reported unrestricted access to school bathrooms, and over 70% expressed fear of using them. These findings highlight two distinct but interrelated challenges: institutional barriers, such as limited recognition of the need for unrestricted bathroom access, and patient-related concerns regarding the usability of school facilities. Insights from the only open-ended question on patient-identified priorities indicate that fear is driven by embarrassment in shared facilities and poor hygiene. Permission alone is therefore insufficient, requiring environmental improvements and targeted awareness interventions. Similar concerns have been reported in other countries; Freckmann et al. described low satisfaction among German PIBD families with school facilities while in the US, Schwenk et al. reported that bathroom access/condition was among the cited challenges by college IBD students.[14,15]

From a practical standpoint, these findings underscore the need for structured school-based interventions: (1) Targeted education of teachers and peers regarding IBD, its chronic nature, and its invisible burden; (2) Guaranteed unrestricted toilet access, alongside improved bathroom infrastructure that ensures accessibility, privacy, and hygiene; (3) Academic accommodations, such as flexible catch-up mechanisms, and access to remote learning during flares or hospitalizations to minimize school disruption.

This study has several limitations. Distribution through a patient association likely introduced selection bias, as respondents may have higher disease awareness and stronger self-advocacy skills. Data were self-reported and not externally validated. In line with the patient-driven design, all survey items were optional, which may have contributed to missing data. Clinical variables, including disease severity, treatment regimens, and socioeconomic factors, were not collected and may have influenced the interpretation of school experiences. In addition, validated mental health screening tools were not included, reflecting the patient-led design without direct clinical involvement, and representing a relevant limitation given the recognized psychosocial burden of IBD. Finally, the absence of a control group precludes comparison with healthy peers, and generalizability may be limited by differences in school systems and support structures across countries. Despite these limitations, this survey provides the first national patient-derived overview of school experiences and offers actionable insights. Importantly, the initiative directly informed real-world advocacy: based on these findings, the Italian patient association AMICI strengthened *IBD Bridge*, a nationwide awareness campaign aimed at reducing stigma and promoting inclusion at school. Targeting both students and school staff in secondary schools, the initiative delivers interactive sessions led by patients, clinicians, and psychologists to raise awareness on the daily challenges of IBD and improve support within the school environment. The awareness campaign is ongoing, with a formal evaluation planned at its completion. This translation of patient-reported needs into concrete interventions offers a

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

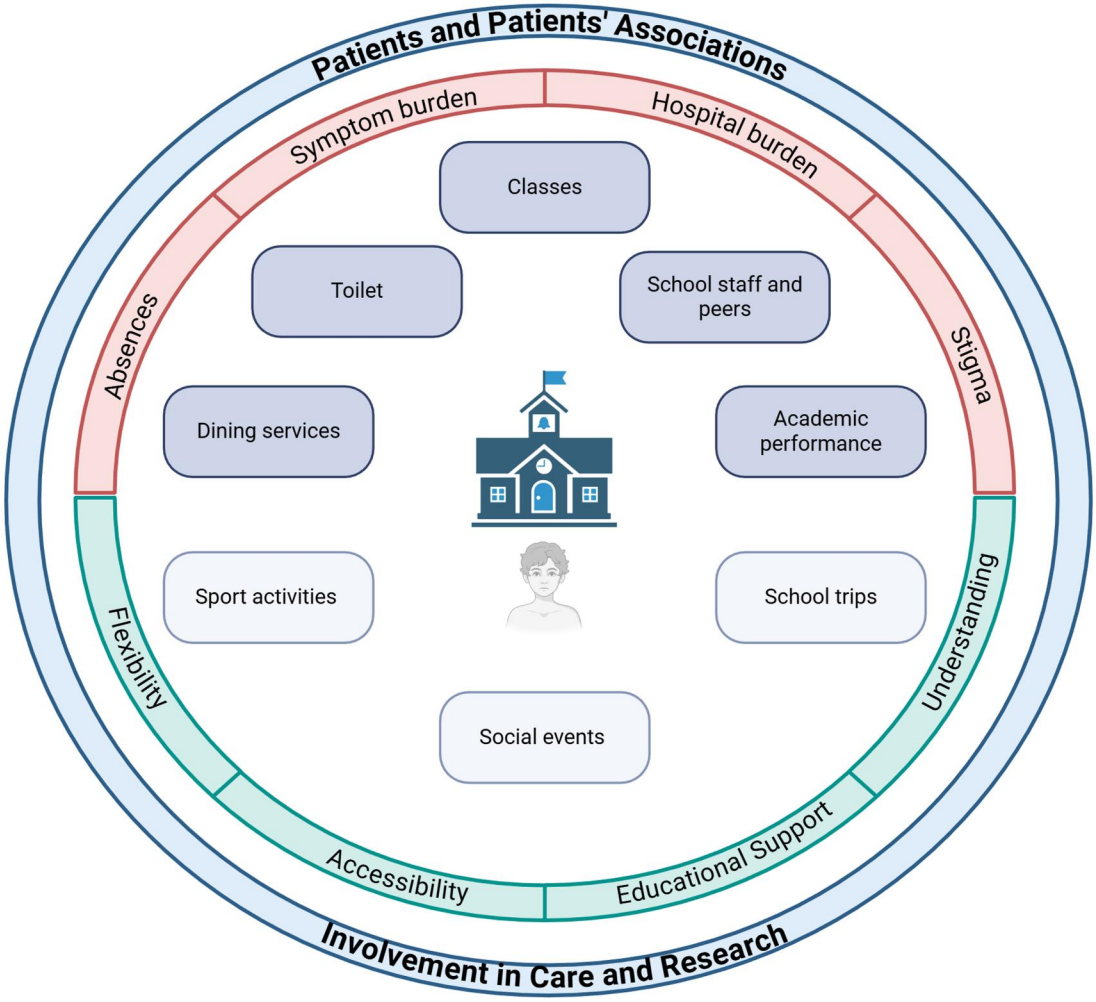


Figure 1 School life challenges in children with IBD and the role of patients' associations. IBD, inflammatory bowel disease.

useful model of collaboration between patient groups, healthcare professionals, and institutions, underscoring the importance of integrating the patient perspective into research, care, and policy (Figure 1).

Acknowledgements

The authors would like to acknowledge the AMICI Patient Association for their valuable contribution to the design and dissemination of the survey, and for their efforts to support individuals living with inflammatory bowel disease.

Funding

This research received no external funding.

Conflicts of interest

L.G., V.S., A.B., F.P., E.P., S.L., and G.V.Z. declare no conflicts of interest related to this study. L.N. received a payment/honorarium for lectures from Takeda, Pfizer, Sanofi, Nestle, and Alfasigma.

Data availability

The authors confirm that the data supporting the findings of this study are available within the article.

Ethical approval and consent to participate

Electronic informed consent for participation and for the processing of personal, including sensitive, data was obtained by submitting the completed questionnaire, in accordance with the EU General Data Protection Regulation (Reg. EU 679/2016). Participants also confirmed that they had read and accepted the GDPR-based Privacy Notice. Participation was voluntary, and participants could withdraw at any time without consequence.

References

1. Farrell D, McCarthy G, Savage E. Self-reported symptom burden in individuals with inflammatory bowel disease.

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

J Crohns Colitis. 2016;10:315-322. https://doi.org/10.1093/ecco-jcc/jjv218
2. Reed-Knight B, Lee JL, Greenley RN, et al. Disease activity does not explain it all: how internalizing symptoms and caregiver depressive symptoms relate to health-related quality of life among youth with inflammatory bowel disease. *Inflamm Bowel Dis.* 2016;22:963-967. https://doi.org/10.1097/MIB.0000000000000686
3. Weber M, Harzer C. Relations between character strengths, school satisfaction, enjoyment of learning, academic self-efficacy, and school achievement: an examination of various aspects of positive schooling. *Front Psychol.* 2022;13:826960. https://doi.org/10.3389/fpsyg.2022.826960
4. 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.* 2015;61:553-557. https://doi.org/10.1097/MPG.0000000000000850
5. Mackner LM, Bickmeier RM, Crandall WV. Academic achievement, attendance, and School-Related quality of life in pediatric inflammatory bowel disease. *J Dev Behav Pediatr.* 2012;33:106-111. https://doi.org/10.1097/DBP.0b013e318240cf68
6. Barnes C, Ashton JJ, Borca F, et al. Children and young people with inflammatory bowel disease attend less school than their healthy peers. *Arch Dis Child.* 2020;105:671-676. https://doi.org/10.1136/archdischild-2019-317765
7. Singh H, Nugent Z, Brownell M, et al. Academic performance among children with inflammatory bowel disease: a Population-Based study. *J Pediatr.* 2015;166:1128-1133. https://doi.org/10.1016/j.jpeds.2014.12.010
8. Eloi C, Foulon G, Bridoux-Henno L, et al. Inflammatory bowel diseases and school absenteeism. *J Pediatr Gastroenterol Nutr.* 2019;68:541-546. https://doi.org/10.1097/MPG.0000000000002207
9. Malmborg P, Mouratidou N, Sachs MC, et al. Effects of childhood-onset inflammatory bowel disease on school performance: a nationwide population-based cohort study using swedish health and educational registers. *Inflamm Bowel Dis.* 2019;25:1663-1673. https://doi.org/10.1093/ibd/izz040
10. Baudino MN, Gamwell KL, Roberts CM, et al. Disease severity and depressive symptoms in adolescents with inflammatory bowel disease: the mediating role of parent and youth illness uncertainty. *J Pediatr Psychol.* 2019;44:490-498. https://doi.org/10.1093/jpepsy/jsy091
11. Guo L, Rohde J, Farraye FA. Stigma and disclosure in patients with inflammatory bowel disease. *Inflamm Bowel Dis.* 2020;26:1010-1016. https://doi.org/10.1093/ibd/izz260
12. Roberts CM, Addante SM, Baudino MN, et al. Stigma moderates the relation between peer victimization, thwarted belongingness, and depressive symptoms in youth with inflammatory bowel disease. *J Pediatr Nurs.* 2021;59:137-142. https://doi.org/10.1016/j.pedn.2021.04.011
13. Stapersma L, van den Brink G, Szigethy EM, et al. Systematic review with meta-analysis: anxiety and depression in children and adolescents with inflammatory bowel disease. *Aliment Pharmacol Ther.* 2018;48:496-506. https://doi.org/10.1111/apt.14865.
14. 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.* 2018;5:e000236. https://doi.org/10.1136/bmjgast-2018-000236
15. Schwenk HT, Lightdale JR, Arnold JH, et al. Coping with college and inflammatory bowel disease: implications for clinical guidance and support. *Inflamm Bowel Dis.* 2014;20:1618-1627. https://doi.org/10.1097/MIB.0000000000000124

Downloaded from https://academic.oup.com/crohnscolitis360/article/8/3/otag062/8714057 by Universita degli Studi di Milano user on 14 July 2026

© The Author(s) 2026. Published by Oxford University Press on behalf of Crohn's & Colitis Foundation.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (https://creativecommons.org/licenses/by-nc/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact journals.permissions@oup.com.
Crohn's & Colitis 360, 2026, 8, 1–7
https://doi.org/10.1093/crocol/otag062
Innovations in Care Delivery