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The everyday school experiences of children and young people with Inflammatory Bowel Disease

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ABSTRACT

Inflammatory Bowel Disease (IBD) is a chronic condition increasingly affecting children and young people. While research often focuses on the impact of IBD on attendance and attainment, little is known about pupils' everyday school experiences of IBD in the UK. This qualitative study explored how seven pupils with IBD navigate school life. Semi-structured online interviews were thematically analysed, revealing daily negotiations around medication, diet, toilet access, hospital appointments, and physical education. Fatigue, brain fog, and invisible symptoms compounded challenges, and were often misunderstood by teachers, wider school staff and peers. Supportive measures were inconsistently applied, and social relationships offered both protection and stigma. Findings highlight the need for consistent accommodations, teacher training, and peer education.

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Introduction

Inflammatory Bowel Disease (IBD), encompassing Crohn's disease (CD), ulcerative colitis (UC), and IBD-unclassified (IBD-U), is a chronic inflammatory condition of the gastrointestinal tract (Nakase et al. 2021). In children and young people, IBD is characterised by recurrent episodes of active disease and remission, with symptoms such as abdominal pain, diarrhoea, and fatigue often persisting even when the disease is inactive (Bouhuys, Lexmond, and van Rheenen 2023). The incidence of IBD has risen sharply in recent years, with approximately 25% of patients diagnosed before the age of 20 (Henderson and Dobson 2024). Overall diagnosis rates have nearly doubled, rising from 13.1 per 100,000 people in 2000 to 25.4 per 100,000 in 2020 (Pasvol et al. 2020). This chronic condition not only affects physical health (Werner et al. 2017), but also influences health-related quality of life (Silva, Seixas, and de Carvalho 2020), social development (Mählmann et al. 2017), self-esteem (Capilla-Díaz et al. 2019), mental health (Barnes et al. 2024; Cooney et al. 2024), and body image (Gasparetto and Guariso 2014).

Schools play a central role in children's social, emotional, and academic development (Pervez and Galea 2024). For young people living with chronic illnesses, including IBD, school can be both a source of support and a site of stress. Despite the importance of these experiences, research examining how IBD impacts school life, particularly from the perspectives of children and young people themselves, remains limited. Existing studies, as we detail below in this paper, have often focused on quantitative measures of absenteeism, academic attainment, or health-related quality of life, leaving

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a gap in our understanding of the nuanced ways in which IBD shapes everyday educational experiences. This study seeks to address this gap by qualitatively exploring the school experiences of pupils with IBD in the UK. Such insights are critical for informing interventions, policies, and educational practices that can support pupils with IBD to fully participate in school life.

This paper is structured as follows. We begin with a review of existing literature on IBD and school life, highlighting key findings and gaps. We then outline our research methods and approach to analysis. Findings are then presented around themes identified from participant narratives, followed by a discussion of practice-based implications and recommendations for future research.

IBD and school life

Schools are a central context in children's lives, and research to date has often focused on how IBD affects attendance. Pupils with IBD are more likely to be absent from school due to symptoms and frequent medical appointments (Barnes et al. 2020). UK data shows that nearly 40% of pupils with IBD are persistently absent (≥10% of school days), a rate three times higher than the national average (Carreon et al. 2018). Limited school support, including restricted bathroom access, can exacerbate absence (Barnes et al. 2020; Freckmann et al. 2018). For example, Barned et al. (2022) found that pupils denied bathroom use during lessons often missed extended periods of school. However, absenteeism is not universal; some pupils sustain regular attendance when their condition is well managed, and schools provide support (Barnes et al. 2020). While quantitative studies offer insight into the scale of absence, less is known about its consequences for peer and teacher relationships, confidence in learning, and reintegration after time away from school.

Educational outcomes for pupils with IBD show similarly mixed patterns. On average, large-scale studies suggest that pupils achieve results comparable to healthy peers, particularly when in remission and supported by schools (Freckmann et al. 2018; Mackner, Bickmeier, and Crandall 2012). Yet for some, severe disease activity, repeated hospitalisation, or prolonged absence increase the risk of lower academic attainment or repeating a school year (Freckmann et al. 2018). Psychosocial challenges such as anxiety, depression, and family stressors may compound these risks (Mackner, Bickmeier, and Crandall 2012). Older pupils appear especially vulnerable during transitional stages of schooling, when reduced attainment is more likely (Malmborg et al. 2019). Together, while IBD may not directly impair educational outcomes for many, indirect effects through health disruptions and psychological challenges can place some pupils at a disadvantage.

Beyond attendance and attainment, IBD also shapes pupils' social and emotional experiences in school (Wilkinson and Budworth 2025). Many children and young people report feelings of isolation or misunderstanding in school (Freckmann et al. 2018). Decisions about whether to disclose their condition can be complex: some hide their diagnosis to avoid stigma, while others who are open face unwanted attention (Freckmann et al. 2018). Furthermore, there is evidence to suggest that children and young people may feel stress and embarrassment around bathroom needs, which can further undermine classroom confidence (Barnes et al. 2020). Young people also describe exclusion from activities, which is often linked to food or exercise, with fatigue and dietary needs restricting participation (Barned et al. 2022). Studies also indicate some fear missing key milestones, while others recount bullying related to frequent bathroom use or dietary requirements (Byron et al. 2020). Such experiences can contribute to low self-esteem or depression, though supportive peers and empathetic teachers can provide protection and foster resilience (Zhu et al. 2025). However, much of this evidence comes from outside the UK, leaving gaps in understanding local school contexts.

Appropriate accommodations play a critical role in shaping pupils' school experiences. Support such as unrestricted bathroom passes, flexible deadlines, modified physical education (PE), and targeted assistance during absences are widely recommended (Barnes et al. 2020). In the UK, Individual Healthcare Plans (IHPs) can formalise such arrangements, yet their implementation for children with

IBD is inconsistent. Parents often report dissatisfaction with teachers' understanding of the condition, noting that IBD's fluctuating and invisible nature is underestimated (Carreon et al. 2018). Pupils similarly describe feeling unsupported when teachers and peers fail to recognise the impact of fatigue or medication side effects (Freckmann et al. 2018).

Rationale for the current study

Current literature highlights both challenges (absenteeism, stigma, inconsistent support) and resilience (academic success despite illness, supportive school environments) in pupils' school experiences with IBD. Yet existing literature remains dominated by quantitative studies and from parental perspectives. Far fewer studies capture lived experiences, particularly in the UK, leaving important questions about how IBD shapes children's everyday school lives. Recognising this, the aim of this study was to explore the everyday school experiences of children and young people with IBD in the UK. By foregrounding their lived experiences, this study seeks to go some way towards addressing a gap in the literature and offers new insight into how schools can better support children with IBD not only to attend, but to feel included and able to thrive.

Methods

Research design

A qualitative study employing semi-structured online interviews was conducted. The study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury, and Craig 2007) and received approval from the institutional ethics committee (25/EDN/017).

Research positionality

A relative ontological perspective was adopted, acknowledging that reality is personally constructed and interpreted through individual experiences (Guba and Lincoln 2005). This perspective allowed the research to capture diverse perspectives and authentically represent participants' personal experiences of attending school with IBD. The lead author has professional experience working with children and adolescents, and experience of interviewing children and young people. This background facilitated sensitive engagement with participants, helping to create a supportive environment where they felt comfortable sharing their personal experiences of attending school with IBD. The second author brings extensive experience of conducting research with children and young people, including those living with long-term health conditions. Her professional expertise is complemented by lived experience, having been diagnosed with Crohn's disease in adulthood. This personal experience of navigating a chronic condition, alongside her role as a parent whose daughter was undergoing investigations for a bowel condition at the time of the study, informed a heightened sensitivity to the complexities that framed participants' experiences. These positionalities no doubt shaped her interpretive lens, and she has reflected on this elsewhere (Wilkinson 2025).

Sampling strategy

Recruitment was conducted between May and August 2025 using purposive sampling, whereby participants were selected based on characteristics aligned with the study's aims. This approach was supplemented with convenience sampling, as participants were also recruited through platforms where they were readily accessible. Social media advertisements were posted through the authors' networks and in collaboration with relevant IBD charities (e.g. ERIC, The Children's Bowel and Bladder Charity, Crohn's and Colitis UK, Crohn's in Childhood Research Association (CICRA), and GetYourBellyOut).

Sample

Seven children and young people with IBD took part in the study (85.7% female). Two participants were in primary education (Key Stage 2, ages 5–11), three were in lower secondary education (Key Stage 3, ages 11–13), and two were in upper secondary education (Key Stage 4, ages 13–16). The eligibility criteria were: (1) aged 5–16 years, (2) confirmed or suspected diagnosis of IBD, or another bowel condition with urgency and frequency of bowel movements, (3) current or recent (within the past year) school attendance in the UK, and (4) provision of written informed consent from parents or legal guardians, alongside child assent. These criteria were chosen to ensure that participants could meaningfully reflect on their school experiences with a chronic bowel condition.

Tools of data collection

Semi-structured interviews were chosen as the data collection method to allow participants the flexibility to share personal narratives while ensuring key areas of inquiry were addressed. Age-appropriate interview guides were developed for three groups – young children (5–7 years), middle childhood (8–11 years), and young people (12–16 years) to ensure that the language, question framing, and examples were tailored to participants developmental levels. All guides covered the same topics relating to school experiences and the impact of IBD on daily school life, while prompts and follow-up questions were used flexibly to encourage elaboration and sustain engagement.

Data collection was conducted through semi-structured interviews held online via Microsoft Teams (version 7.6.2, Microsoft Corporation) between July to August 2025. Online interviews were recognised as a care-full method (Budworth 2023) and were selected to reduce participant burden for chronically ill participants, to increase accessibility for geographically dispersed families, and provide a comfortable environment for children and young people to participate from their own homes (Wilkinson 2025). Guidance was taken from previous recommendations for interviewing children and young people with chronic health conditions (Rogers et al. 2021).

Process of data analysis

Semi-structured interviews were audio-recorded and transcribed verbatim for qualitative data analysis. Data from the interviews were analysed using Braun and Clarke's (2019, 2021) six-phase reflexive analysis. This approach was appropriate for this study due to its flexibility and capacity to provide rich and nuanced accounts of the data (Braun and Clarke 2021). Analysis began with familiarisation, during which the lead author listened to the audio recordings and read the transcripts several times, making preliminary notes on recurring issues. Inductive coding was then conducted, without applying a pre-existing framework, to prioritise the meaning communicated by participants (Braun and Clarke 2021). Reflecting on these initial codes, initial themes were generated through an iterative process of reading, writing and reflection. Provisional themes were subsequently reviewed by the authors and refined, with subthemes developed to capture more specific patterns within broader themes. Throughout this process, reflexivity was supported through discussions with critical friends, to provoke further reflexivity and understanding of the rich data (Morse 2015). Final themes were defined and agreed, and participants voices were retained through the use of illustrative quotations. This flexible approach ensured a transparent analytic process that centred the everyday school experiences of children and young people with IBD (Nowell et al. 2017).

Ethical considerations

All ethical protocols relating to research with children and young people, particularly those with chronic illnesses, were carefully observed (Budworth 2023). Families who expressed interest in the study were sent a recruitment pack, which included information sheets for parents and children, a

consent form for parents or legal guardians, and an assent form for the child or young person to complete. The information sheets were designed to be age-appropriate, ensuring accessibility for younger children. Written parental consent and child assent were obtained before participation. Conducting interviews online was also an ethical decision, reducing participant burden by supporting comfort and privacy (Budworth 2023; Wilkinson 2025). As part of promoting agency and respecting children's participation rights, participants were invited to select their own pseudonyms. Allowing children and young people to choose how they wished to be represented in the study supported autonomy and fostered a sense of ownership over their contributions (Wilkinson and Wilkinson 2017; Pretorius and Patel 2025).

Findings and discussion

Following data analysis, five themes relating to participants' everyday school experiences of IBD were developed: (1) managing IBD in the school environment, (2) the hidden impact of IBD, (3) supportive and unsupportive school practices, (4) navigating social relationships, and (5) resilience and identity. Each theme is explored respectively below.

Managing IBD in the school environment

A central theme among participants was the practical management of IBD within school, with participants describing how they navigated medication, diet, medical appointments, and academic expectations. These accounts corroborate previous findings that IBD can disrupt educational routines and require significant self-management within the school day (Barnes et al. 2020; Freckmann et al. 2018). Medication was a daily feature that required careful consideration. Ella described the disruption caused by leaving lessons to take tablets: 'sometimes I have to go out of my lessons to take my tablets, and that can feel disruptive.' For Thomas, the availability of pain relief provided reassurance: 'sometimes I might have a paracetamol from reception to see if the pains go away.' Managing diet was another area requiring close management, particularly when school canteen food was considered unsuitable for their dietary needs. Tegan expressed mistrust of school meals: 'I don't always trust what they're serving, so I take food from home', while Sienna noted limited options: 'some days there's nothing really I can eat, so I just use my shakes from medical.' These findings contribute to existing literature (Bramuzzo et al. 2022) about the dietary beliefs of children and young people with IBD, whereby some adopt restrictive diets.

For many participants, toilet passes were viewed as essential tools for managing urgency and preventing embarrassment. Lucy explained: 'I have a pass that I can either show a teacher or leave on my table if I need to leave quickly', whilst Thomas told: 'I've got a toilet pass so that I may be excused to leave the room'. The reliance on ad hoc strategies (toilet passes), places responsibility on pupils to self-advocate, while inconsistency in teacher response often undermined pupils dignity and exacerbated anxiety (Green et al. 2025). For example, Sienna recalled being challenged in class: 'a teacher asked, 'do you need to go *now* though?', and I thought would I be asking if I didn't need to go now?' Schools remain largely built around assumptions of 'healthy bodies' (Ropski 2023) and standardised routines, rendering chronic illness as an inconvenience rather than a norm to accommodate (Wilkinson and Budworth 2025). As such, this may reflect a broader issue of conditional compassion, where accommodations are subject to teacher discretion rather than treated as a right (Carreon et al. 2018; Green et al. 2025).

The uncertainty of unfamiliar environments also contributed to stress and anxiety, as Kiera describes: 'if I don't know where the toilets are, that makes me anxious.' This could be avoided in schools, by providing a tour highlighting where all of the toilets are situated, as was the case for lucy: 'Before I started secondary school, the teachers gave me a tour and showed me where all the toilets were across the school, including the more private ones'. This is supported by wider literature on Irritable Bowel Syndrome, for instance a participant in White's (2023, p. 861) study

notes 'I have to know where I can go'. Together, these accounts highlight how anticipatory planning around toilet access becomes a fundamental strategy through which young people with IBD negotiate dignity and participation in school life.

All participants highlighted how hospital appointments interrupted schooling, with Ruby explaining she sometimes missed whole days at school due to appointments and struggled when teachers did not send work. Thomas noted the impact of infusions (medical care needed by some patients with IBD): 'I might miss school all day for certain medical appointments, like when I've got to have an infusion.' This echoes the findings from Freckmann et al. (2018) who found pupils are often left to catch up on work without adequate support, arguably compounding educational disruption. Placing the responsibility on the pupils rather than the teacher reflects a structural imbalance of responsibility, at the disadvantage of those with IBD. Although, given existing teacher workload pressures, it could be argued that they may lack the time and capacity to organise and send missed work, which helps explain why this support is often inconsistent (Stacey et al. 2024). Despite these challenges, many participants attempted to mitigate the impact themselves. Sienna, for instance, described trying to minimise disruption caused by medical appointments: 'I still go to school the next day after my infusion … I try to minimise the amount of time I have off.' This reflects wider evidence that children with chronic conditions often engage in proactive self-management to reduce the educational consequences of their illness, frequently assuming responsibility for continuity of learning when structural support is insufficient (Barnes et al. 2020; Freckmann et al. 2018). Such strategies illustrate the extent to which pupils compensate for systemic gaps, reinforcing arguments (e.g. Spencer et al. 2024) that young people with long-term conditions are required to shoulder disproportionate responsibility for managing the intersection of health and schooling.

PE lessons also represented a particularly complex site of negotiation, where some pupils felt unable to participate due to their IBD. Thomas stated: 'Since I got diagnosed, I haven't done any PE lessons. I just go to a breakout area to catch up on missed work.' In contrast, Lucy described selective participation depending on her health: 'sometimes I can't always join in PE, but if I'm not well enough, there's no point being in the lesson'. While some existing research has explored how to support young people with chronic illness during PE (e.g. Lepore-Stevens 2024), no research has yet examined how children with IBD navigate PE specifically, despite evidence that physical activity, a core component of PE, has substantial benefits for children with long-term conditions (Dimitri, Joshi, and Jones 2020). These findings therefore offer a novel contribution, identifying PE as an overlooked but significant context in which pupils with IBD must negotiate symptoms, expectations and inclusion. Ruby explained that she often needed frequent breaks and adapted activities due to the intensity of the lessons, but when required to sit out, she felt she 'missed out on playing with her friends.' This differs from the earlier accounts, which focused primarily on physical limitations or symptom management, by highlighting the social cost of non-participation and the importance of PE as a space where friendships are formed and maintained (Piñeiro-Cossio et al. 2021). Her experience demonstrates that exclusion from PE affects not only physical activity but also pupils' sense of belonging and connection to peers. That said, our findings highlight that with flexibility and adaptation, PE can become a site of inclusion and resilience rather than marginalisation for those within IBD (see Giese and Ruin 2018 writing on ableism and PE).

The hidden impact of IBD

Alongside visible disruptions, pupils emphasised invisible burdens related to their IBD – such as fatigue, brain fog, and the psychological weight of being misunderstood – that negatively impacted their everyday school experiences. Invisible symptoms were central to how participants navigated lessons, workloads and interactions with staff. A particularly salient aspect involved managing the pervasive fatigue and cognitive difficulties associated with their IBD. Consistent with wider research documenting hidden symptom burden in paediatric chronic illness (Barnes et al. 2024; Capilla-Díaz et

al. 2019), participants described fatigue as qualitatively distinct from ordinary tiredness. Lucy emphasised this difference clearly: 'sometimes I can get really tired and it's not like normal tired; it's like *really* tired', and Sienna shared: 'one of my biggest things with Crohn's is I'm so tired all the time'. Ella also noted how this fatigue can impede her learning: 'If I get too tired, I just can't take anything in'. Despite the severity of these symptoms, participants noted that teachers and peers often overlooked or minimised them, leading to classroom disengagement being misinterpreted as a lack of interest rather than an illness-related limitation. These accounts reinforce concerns within the literature that fatigue remains one of the most underestimated and under-accommodated symptoms in school-aged children with long-term conditions (Lum et al. 2017).

Cognitive difficulties, commonly referred to by participants as 'brain fog', were also frequently reported. Thomas explained that 'sometimes I might forget about stuff…it might just slip my mind a bit,' while Tegan described moments where 'it's hard to concentrate…my mind just goes black.' Sienna expressed particular worry about the implications of brain fog during exams, fearing it would undermine her academic performance. These concerns echo earlier work documenting attentional and memory challenges among young people with IBD, particularly during disease flares (Mackner, Bickmeier, and Crandall 2012). However, in line with critiques that mainstream school systems rarely account for illness-related cognitive variability (Lum et al. 2017), participants reported that these lapses were often misread as disengagement or, in some cases, behavioural non-compliance. Even benign coping strategies, such as resting one's head on the desk or pausing to refocus, were sometimes penalised, illustrating how school environments can inadvertently pathologise or sanction illness management.

These experiences reflect a broader structural landscape in which the invisible nature of IBD contributes to misunderstanding and misattribution within educational settings. Just as research on stigma and disclosure highlights the emotional labour young people invest in managing how their illness is perceived (Freckmann et al. 2018; Rouncefield-Swales et al. 2020), participants in our study described the continuous work required to justify or explain symptoms that are not outwardly visible. The mismatch between symptom severity and external recognition not only amplified feelings of frustration and anxiety but also reinforced a school environment where the legitimacy of pupils' needs depended on visible evidence of illness. Such findings point to the ongoing necessity for school-level policies that more explicitly acknowledge the fluctuating and hidden dimensions of chronic illness, and that equip staff to distinguish between illness-related disengagement and behavioural issues. Without such adaptations, pupils with IBD remain responsible for navigating misunderstandings that are, in practice, systemic rather than individual. Integrating targeted staff training within these policies would be a crucial step, enabling teachers to recognise and respond appropriately to the everyday implications of IBD, including fatigue and concentration difficulties (Berger et al. 2018; Lum et al. 2017).

Supportive and unsupportive school practices

Participants' accounts revealed a mixed picture of school responses to their IBD, ranging from highly supportive to indifferent or punitive. Several participants praised teachers and schools who demonstrated flexibility. Lucy appreciated staff who consistently checked in with her and provided work when she was absent: 'they've been amazing with sending me the work [when I am off of school] and wishing me well,' while Tegan valued individualised exam adjustments: 'They let me do exam in a separate room, so I don't feel stressed about needing the toilet.' Ella similarly valued responsive teacher communication: 'most of my teachers have been really good when I email them about appointments.' Such practices reduced barriers and fostered a sense of care that participants found important. Research suggests that children with chronic conditions are better able to self-manage in school when they have a designated or trusted member of staff to turn to (Uhm & Choi 2023), a finding consistent with the positive experiences described by participants in this study.

Participants also placed considerable importance on the availability of dedicated spaces and practical adjustments. Consistent with findings in early education contexts, safe spaces, when available, were particularly valued for pupils offering a sense of agency and security (Musgrave and Levy 2020). Lucy described 'the hub' as the safe place she could retreat to when feeling unwell: 'They are happy for me to come out my lessons if I don't feel well … I can sit and relax for a bit.' Sienna recalled supportive administrative staff who took her concerns seriously: 'If I say I need to go home, they will straight away ring my grandparents.' For Thomas and Tegan, formal 'access plans' helped clarify entitlements, such as reduced timetables or extensions for incomplete work. These accounts illustrate how both formal and informal spaces can provide a vital sense of safety and control for pupils managing unpredictable health conditions, echoing findings that accessible and trusted spaces enhance pupils' sense of agency and belonging (Musgrave and Levy 2020). Such adjustments align closely with best-practice recommendations for supporting young people with chronic illness, which emphasise predictable support, flexibility and personalised accommodations (Lum et al. 2017). More broadly, these findings reflect evidence that consistent, supportive school practices are central to promoting academic engagement, regular attendance, and psychosocial wellbeing among children with long-term conditions (Lum et al. 2019).

However, alongside these positive experiences, participants emphasised inconsistency across staff responses. Sienna described being sanctioned for illness-related behaviour, 'I had my head on the desk … I got given a low-level disruption. I wasn't disrupting anyone', while Thomas recounted moments where teachers were unaware, he had IBD: 'One teacher didn't know I had Crohn's, so my friends had to explain.' As Sienna summarised, 'Some teachers know about it and are great, others just don't seem to get it.' These accounts resonate with wider findings (e.g. Berger et al. 2018) that teachers' knowledge plays a crucial role in mediating the relationship between chronic illness and school participation, and that misunderstandings can lead to inappropriate disciplinary responses or unmet needs.

The variability described by participants reflects a broader pattern in chronic illness research, where support frequently depends on the practices of individual teachers rather than a coherent whole-school approach (Carreon et al. 2018; Uhm & Choi, 2023). In this context, pupils' accounts resonate with critiques of a 'postcode lottery' in school provision for health-related needs, whereby access to effective support is shaped by local resources, staff training and wider institutional culture (Schnabel 2025). Such inconsistency can leave children uncertain about how they will be received in different classrooms – a burden that is particularly heavy for those managing largely invisible symptoms. Research on the invisibility of chronic illness shows that when symptoms such as fatigue, pain, or cognitive fog are not outwardly evident, children often feel compelled to explain, justify or defend their needs, a pattern previously reported among chronically ill university students (Toller and Farrimond 2021). Participants' experiences mirror this dynamic, with some relying on informal peer advocacy to ensure staff understood their condition.

Navigating social relationships

Social interactions with peers were central to participants' school experiences, encompassing both positive support and experiences of stigma. A key element of these interactions involved decisions about whether, when, and how to disclose their IBD. Consistent with wider research showing that young people often manage disclosure strategically to balance openness and self-protection (Barned et al. 2016; Freckmann et al. 2018), participants described adopting differing approaches depending on their circumstances and levels of trust. Lucy chose to be open, using a charity event as an opportunity to explain her condition: 'I decided I'd do a bake sale … and explained what was going on.' Others were more cautious. Ella described limiting disclosure: 'only my closest friends know, because I don't want everyone asking questions', while Sienna noted that she sometimes denied having IBD altogether, stating, 'Depending on who it is, I'll say no I don't have IBD.' One participant had chosen not to disclose at all, reflecting, 'I don't want people to see

me for my illness, but for me.' These accounts illustrate the delicate balance children with IBD navigate between seeking understanding and avoiding unwanted attention or stigma. As identified in previous studies, concerns about others' reactions, illness visibility, and the desire to maintain a sense of normalcy strongly shape disclosure practices among young people with chronic conditions (Rouncefield-Swales et al. 2020). The varied strategies used by participants here reflect reports in wider literature (Denny et al. 2014; Lum et al. 2017), highlighting both the emotional labour involved in managing personal information and the importance of supportive peer environments in making disclosure feel safe.

Negative responses from peers were evident in several accounts. Ruby described how 'they thought I was contagious at first', highlighting how misconceptions about IBD can shape children's social interactions. Similar assumptions have been reported among older age groups (14–21 years) (Rouncefield-Swales et al. 2020), where peers assume that IBD is transmissible or contagious. The emergence of these misconceptions in younger children suggests that such beliefs arise long before adolescence, underscoring wider systematic gaps in health education within school settings (Byron et al. 2020). These misconceptions often manifested as teasing and bullying. Lucy recalled being mocked by peers who confused her Crohn's disease with COVID-19: 'Some people got confused … and teased me a bit.', while Thomas described peers making repeated comments to him: 'There was a kid who kept making comments … I had to speak to the Head of Year'. Although teasing and bullying in school extend far beyond IBD (Barned et al. 2016), evidence indicates that students with chronic health conditions are disproportionately targeted compared with their healthy peers (Runions et al. 2020). These findings highlight the need for clearer school-based strategies to prevent illness-related bullying, including consistent staff responses and the integration of chronic illness into existing anti-bullying frameworks. Misinformation surrounding symptoms also influenced children's willingness to disclose their condition to their friends. Ella described how comments such as 'you just poo yourself' fuelled stigma and heightened her anxiety about telling friends she had IBD. These experiences reflect wider evidence (Freckmann et al. 2018) that children with chronic conditions often manage disclosure carefully to avoid ridicule or negative reactions. Alongside these challenges, participants emphasised the protective role of supportive friendships. Thomas explained that classmates assisted him when he felt unwell: 'If I'm not well, they help me get to reception.' Lucy described close friends visiting her at home with a gift box whilst she was unwell, and Tegan noted that her friends: 'always make sure I'm not left out.' Such accounts mirror findings (Silva, Seixas, and de Carvalho 2020) that peer support can buffer psychological distress, promote a sense of belonging, and mitigate the negative effects of stigma among children with long-term conditions.

Resilience and identity

Despite challenges, participants consistently articulated resilience and a desire to construct identities that extended beyond their illness. Many emphasised determination to 'keep going', with Thomas explaining, 'When I'm well enough to go join in on the lessons, yeah, it'll be nice.' Tegan linked perseverance to enjoyment – 'It makes me more determined to do the things I enjoy' – while Ella framed her motivation in academic terms: 'I don't want Crohn's to be the reason I don't do well in my GCSEs.' Such accounts illustrate how perseverance operated as both a coping strategy and a form of identity work (Sveningsson and Alvesson 2003), enabling pupils to retain a sense of continuity despite the disruptions associated with IBD.

Hobbies and future aspirations played an important role in sustaining this sense of continuity. Sienna foregrounded her passion – 'I've always wanted to be a dancer…I try not let it [IBD] get in the way' – while Ruby insisted: 'I still want to do everything my friends do.' These accounts align with broader research (Mählmann et al. 2017) showing that young people with chronic illness often resist being defined by their diagnosis, instead emphasising interests, relationships, and ambitions that affirm identities beyond illness. Engagement in valued activities for children with long-

term conditions has been found by Medforth and Boyle (2023) to provide psychological continuity and support self-esteem among children.

Participants also reflected explicitly on the importance of not being reduced to their illness in school contexts. Lucy noted, 'Normally I'm fine with my Crohn's and it definitely doesn't affect who I am as a person,' while Kiera emphasised, 'I want teachers to see me for what I can do, not just my condition.' Their reflections echo longstanding critiques that children with chronic illness often feel 'over-medicalised' or narrowly categorised within institutional settings (Blackwell et al. 2019). The desire to be recognised as whole individuals resonates with research on identity negotiation in chronic illness (Kirk and Hinton 2019; Slothouber and Lindsay 2025), which highlights how children engage in active work to counteract assumptions of frailty, difference, or limitation.

However, these narratives of determination should be interpreted with caution. While participants' resilience was striking, celebrating individual perseverance risks reinforcing neoliberal discourses that valorise coping while obscuring the structural inequities that necessitate such coping in the first place. As scholars have argued, young people's resilience often illuminates the shortcomings of institutional environments rather than compensating for them (Hart et al. 2014). In other words, pupils' efforts to 'keep going', should not be viewed as evidence that existing support is adequate; rather, their determination exposes the gap between what children need and what schools currently provide. This perspective aligns with critiques (e.g. Ferguson and Walker 2014) urging educators and policymakers to shift from expecting children to adapt to inflexible systems, towards reshaping systems to meet the needs of children with long-term conditions.

The aim of our study was to qualitatively explore the everyday school experiences of pupils with IBD in the UK. While existing research has largely focused on attendance rates and academic attainment (Barnes et al. 2020; Eloi et al. 2019), our findings suggest that the impact of IBD in the school environment extends beyond these outcomes. Several positive aspects of school were identified, including some supportive teachers and wider school environments, the provision of flexible adjustments, strong peer support, and pupils' resilience and determination to maintain a sense of identity beyond their condition. Nevertheless, the findings also revealed significant challenges, exposing systemic gaps in awareness, understanding, and the inconsistent implementation of appropriate support within school environments.

Implications

This study makes several important contributions to the education and wider social sciences literature. The findings extend existing research by providing qualitative insights into the everyday school experiences of pupils with IBD, a context underrepresented in UK-based studies and often overlooked in favour of quantitative measures (Peng et al. 2025). The study highlights the hidden and emotional impacts of IBD including fatigue, brain fog, and stigma, that remain insufficiently explored, and it exposes inequities created by inconsistent school support and reliance on individual teacher discretion. Crucially, it foregrounds children's voices, showing how they actively negotiate and adapt within school environments.

Several practical implications emerge. First, teacher training should be implemented in schools and emphasise the unpredictable and often invisible nature of IBD. Such training would equip staff to respond appropriately to fatigue, concentration difficulties, and flexible toilet access needs (Berger et al. 2018; Lum et al. 2017). Second, academic continuity during medical absences should be supported through accessible online materials, helping pupils remain on track with their peers and reduce anxiety about falling behind (Freckmann et al. 2018). Third, PE should adopt flexible participation models, including adapted activities or alternative roles, to enable inclusion without compromising health (Vanhelst et al. 2020). Finally, schools should address the wider social environment by implementing peer awareness initiatives to reduce stigma and by providing safe spaces and

pastoral support, offering reassurance and security during symptom flare-ups (Byron et al. 2020; Musgrave and Levy 2020).

Limitations and future research

This study has several limitations that must be acknowledged. The small ($n = 7$); predominantly female sample limits generalisability, though children and young people with IBD are an underrepresented population that may experience barriers to participating in research. Future research should continue to use care-full methods (Budworth 2023) to undertake research with larger and more diverse cohorts to examine potential gendered and cultural differences. Longitudinal designs could explore how school experiences change across educational transitions (e.g. from primary to secondary school). Comparative studies with other chronic conditions would also help to identify shared challenges and inform the development of more inclusive school policies for pupils with chronic illness.

Conclusion

Our findings show that pupils with IBD encounter challenges in schools that often lack the awareness, policies and infrastructure to meet their needs. Supports such as toilet passes, safe spaces, and access plans were valued but inconsistently applied, highlighting systemic gaps and inequities. Hidden burdens (fatigue, brain fog) remained largely misunderstood by teachers and peers, while pupils' resilience and determination to sustain identities beyond illness, though admirable, must not be seen as a substitute for adequate provision. Schools require systemic accommodations, teacher training, and peer education to reduce stigma and to promote inclusive environments for pupils with IBD. Importantly, this study makes a distinctive contribution to existing literature by centring the everyday experiences of children and young people with IBD – voices rarely heard in UK research – and by illuminating how they navigate not only medical needs but also social relationships, disclosure decisions, participation in PE, and identity work within school environments. By revealing the emotional labour, structural barriers, and inconsistent practices that shape these pupils' daily lives, the study shifts attention from individual coping to institutional responsibility, offering an evidence base that can inform more equitable, consistent and rights-based approaches to supporting pupils with chronic, invisible conditions.

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Conflict of interest statement

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References

Barned, C., A. Fabricius, A. Stintzi, D. R. Mack, and K. C. O'Doherty. 2022. "The Rest of My Childhood Was Lost: Canadian Children and Adolescents' Experiences Navigating Inflammatory Bowel Disease." *Qualitative Health Research* 32 (1): 95–107. https://doi.org/10.1177/10497323211046577.

Barned, C., A. Stinzi, D. Mack, and K. C. O'Doherty. 2016. "To Tell or Not to Tell: A Qualitative Interview Study on Disclosure Decisions among Children with Inflammatory Bowel Disease." *Social Science & Medicine* 162:115–123. https://doi.org/10.1016/j.socscimed.2016.06.023.

Barnes, A., B. Toson, R. V. Bryant, S. Mukherjee, J. M. Andrews, P. Spizzo, and R. Mountifield. 2024. "Latent Profiles of Fatigue in Inflammatory Bowel Disease." *BMC Gastroenterology* 24 (1): 148. https://doi.org/10.1186/s12876-024-03239-2.

Barnes, Claire, James John Ashton, Florina Borca, Mick Cullen, Dawn-Marie Walker, and Robert Mark Beattie. 2020. "Children and Young People with Inflammatory Bowel Disease Attend Less School than Their Healthy Peers." *Archives of Disease in Childhood* 105 (7): 671–676. https://doi.org/10.1136/archdischild-2019-317765.

Berger, C., J. Valenzuela, J. Tsikis, and C. Fletcher. 2018. "School Professionals' Knowledge and Beliefs about Youth with Chronic Illness." *Journal of School Health* 88 (8): 615–623. https://doi.org/10.1111/josh.12646.

Blackwell, Courtney K., Amy J. Elliott, Jody Ganiban, Julie Herbstman, Kelly Hunt, Christopher B. Forrest, and Carlos A. Camargo. 2019. "General Health and Life Satisfaction in Children with Chronic Illness." *Pediatrics* 143 (6): e20182988. https://doi.org/10.1542/peds.2018-2988.

Bouhuys, M., W. S. Lexmond, and P. F. van Rheenen. 2023. "Pediatric Inflammatory Bowel Disease." *Pediatrics* 151 (3): e2022058037. https://doi.org/10.1542/peds.2022-058037.

Bramuzzo, Matteo, Federica Grazian, Veronica Grigoletto, Alessandro Daidone, Stefano Martelossi, Federica Mario, Eleonora Maurel, et al. 2022. "Dietary Beliefs in Children and Adolescents with Inflammatory Bowel Disease and Their Parents." *Journal of Pediatric Gastroenterology and Nutrition* 75 (3): e43–e48. https://doi.org/10.1097/MPG.0000000000003527.

Braun, V., and V. Clarke. 2019. "Reflecting on Reflexive Thematic Analysis." *Qualitative Research in Sport, Exercise and Health* 11 (4): 589–597. https://doi.org/10.1080/2159676X.2019.1628806.

Braun, V., and V. Clarke. 2021. "One Size Fits All? What Counts as Quality Practice in (Reflexive) Thematic Analysis?" *Qualitative Research in Psychology* 18 (3): 328–352. https://doi.org/10.1080/14780887.2020.1769238.

Budworth, P. 2023. "Care, Comfort, and Capacity: The Importance of Being Flexible in Research with Disabled and Chronically Ill People." *SSM – Qualitative Research in Health* 4:100352. https://doi.org/10.1016/j.ssmqr.2023.100352.

Byron, C., N. Cornally, A. Burton, and E. Savage. 2020. "Challenges of Living with and Managing Inflammatory Bowel Disease: A Meta-synthesis of Patients' Experiences." *Journal of Clinical Nursing* 29 (3–4): 305–319. https://doi.org/10.1111/jocn.15080.

Capilla-Díaz, Concepción, Candela Bonill-de las Nieves, Sandra Milena Hernández-Zambrano, Rafael Montoya-Juárez, José Miguel Morales-Asencio, María Nieves Pérez-Marfil, and César Hueso-Montoro. 2019. "Living with an Intestinal Stoma: A Qualitative Systematic Review." *Qualitative Health Research* 29 (9): 1255–1265. https://doi.org/10.1177/1049732318820933.

Carreon, S. A., L. T. Bugno, A. A. Wojtowicz, and R. N. Greenley. 2018. "School Functioning in Adolescents with Inflammatory Bowel Diseases: An Examination of Disease and Demographic Correlates." *Inflammatory Bowel Diseases* 24 (8): 1624–1631. https://doi.org/10.1093/ibd/izy026.

Cooney, R., D. Tang, K. Barrett, and R. K. Russell. 2024. "Children and Young Adults with Inflammatory Bowel Disease Have an Increased Incidence and Risk of Developing Mental Health Conditions: A UK Population-Based Cohort Study." *Inflammatory Bowel Diseases* 30 (8): 1264–1273. https://doi.org/10.1093/ibd/izad169.

Denny, Simon, Mandy de Silva, Theresa Fleming, Terryann Clark, Sally Merry, Shanthi Ameratunga, Taciano Milfont, Bridget Farrant, and Sarah A. Fortune. 2014. "The Prevalence of Chronic Health Conditions Impacting on Daily Functioning and the Association with Emotional Well-Being among a National Sample of High School Students." *Journal of Adolescent Health* 54 (4): 410–415. https://doi.org/10.1016/j.jadohealth.2013.09.010.

Dimitri, P., K. Joshi, and N. Jones. 2020. "Moving More: Physical Activity and Its Positive Effects on Long Term Conditions in Children and Young People." *Archives of Disease in Childhood* 105 (11): 1035–1040. https://doi.org/10.1136/archdischild-2019-318017.

Eloi, Clémentine, Gauthier Foulon, Laure Bridoux-Henno, Estelle Breton, Cecile Pelatan, Emilie Chaillou, Isabelle Grimal, et al. 2019. "Inflammatory Bowel Diseases and School Absenteeism." *Journal of Pediatric Gastroenterology and Nutrition* 68 (4): 541–546. https://doi.org/10.1097/MPG.0000000000002207.

Ferguson, P., and H. Walker. 2014. "'Getting on with Life': Resilience and Normalcy in Adolescents Living with Chronic Illness." *International Journal of Inclusive Education* 18 (3): 227–240. https://doi.org/10.1080/13603116.2012.676082.

Freckmann, Magdalena, Alexander Seipp, Martin W Laass, Sibylle Koletzko, Martin Claßen, Antje Ballauff, Jenny Peplies, and Antje Timmer. 2018. "School-Related Experience and Performance with Inflammatory Bowel Disease: Results from a Cross-Sectional Survey in 675 Children and Their Parents." *BMJ Open Gastroenterology* 5 (1): e000236. https://doi.org/10.1136/bmjgast-2018-000236.

Gasparetto, M., and G. Guariso. 2014. "Crohn's Disease and Growth Deficiency in Children and Adolescents." *World Journal of Gastroenterology: WJG* 20 (37): 13219.

Giese, M., and S. Ruin. 2018. "Forgotten Bodies: An Examination of Physical Education from the Perspective of Ableism." In *Sport and Disability*, edited by F. Kiuppis, 152–165. Routledge.

Green, M. J., C. Haines Lyon, A. Little, and J. Telford. 2025. "Teachers', Parents', and Pupils' Perceptions and Described Experiences of Toilet Provisions and Practices within English Schools." *British Educational Research Journal* 51 (6): 2683–2699. https://doi.org/10.1002/berj.4198.

Guba, E. E., and Lincoln, Y. S. 2005. "Paradigmatic Controversies, Contradictions, and Emerging Confluences." In *The SAGE Handbook of Qualitative Research*, edited by N. K. Denzin and Y. S. Lincoln, 191–216. 3rd ed. Thousand Oaks, CA: Sage.

Hart, A., B. Heaver, E. Brunnberg, A. Sandberg, H. Macpherson, S. Coombe, and E. Kourkoutas. 2014. "Resilience-building with Disabled Children and Young People: A Review and Critique of the Academic Evidence Base." *International Journal of Child, Youth and Family Studies* 5 (3): 394–422. https://doi.org/10.18357/ijcyfs.harta.532014.

Henderson, P., L. Dobson, and PINPOINT Collaborators. 2024. "DOP50 PINPOINT: The Epidemiology of Paediatric-Onset Inflammatory Bowel Disease in the United Kingdom – a Prospective, National, Cohort Study." *Journal of Crohn's and Colitis* 18 (1): i162. https://doi.org/10.1093/ecco-jcc/jjad212.0090.

Kirk, S., and D. Hinton. 2019. ""I'm Not What I Used to Be": A Qualitative Study Exploring How Young People Experience Being Diagnosed with a Chronic Illness." *Child: Care, Health and Development* 45 (2): 216–226. https://doi.org/10.1111/cch.12638.

Lepore-Stevens, M. 2024. "Supporting Students with Chronic Illnesses during Physical Education and Sport." *Palaestra* 38 (2): 43–50.

Lum, A., C. E. Wakefield, B. Donnan, M. A. Burns, J. E. Fardell, and G. M. Marshall. 2017. "Understanding the School Experiences of Children and Adolescents with Serious Chronic Illness: A Systematic Meta-Review." *Child: Care, Health and Development* 43 (5): 645–662. https://doi.org/10.1111/cch.12475.

Lum, Alistair, Claire E. Wakefield, Barb Donnan, Mary A. Burns, Joanna E. Fardell, Adam Jaffe, Nadine A. Kasparian, et al. 2019. "School Students with Chronic Illness Have Unmet Academic, Social, and Emotional School Needs." *School Psychology* 34 (6): 627–636. https://doi.org/10.1037/spq0000311.

Mackner, L. M., R. M. Bickmeier, and W. V. Crandall. 2012. "Academic Achievement, Attendance, and School-Related Quality of Life in Pediatric Inflammatory Bowel Disease." *Journal of Developmental & Behavioral Pediatrics* 33 (2): 106–111. https://doi.org/10.1097/DBP.0b013e318240cf68.

Mählmann, Laura, Markus Gerber, Raoul I. Furlano, Corinne Legeret, Nadeem Kalak, Edith Holsboer-Trachsler, and Serge Brand. 2017. "Psychological Wellbeing and Physical Activity in Children and Adolescents with Inflammatory Bowel Disease Compared to Healthy Controls." *BMC Gastroenterology* 17 (1): 160. https://doi.org/10.1186/s12876-017-0721-7.

Malmborg, Petter, Natalia Mouratidou, Michael C Sachs, Ulf Hammar, Hamed Khalili, Martin Neovius, Anders Hjern, et al. 2019. "Effects of Childhood-Onset Inflammatory Bowel Disease on School Performance: A Nationwide Population-Based Cohort Study Using Swedish Health and Educational Registers." *Inflammatory Bowel Diseases* 25 (10): 1663–1673. https://doi.org/10.1093/ibd/izz040.

Medforth, N., and C. Boyle. 2023. "Challenges, Complexity, and Developments in Transition Services for Young People with Disabilities, Mental Health, and Long-Term Conditions: An Integrative Review." *Comprehensive Child and Adolescent Nursing* 46 (3): 180–200. https://doi.org/10.1080/24694193.2023.2245473.

Morse, J. M. 2015. "Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry." *Qualitative Health Research* 25 (9): 1212–1222. https://doi.org/10.1177/1049732315588501.

Musgrave, J., and R. Levy. 2020. "Including Children with Chronic Health Conditions in Early Childhood Education and Care Settings." *Journal of Early Childhood Research* 18 (2): 159–173. https://doi.org/10.1177/1476718X19875776.

Nakase, Hiroshi, Motoi Uchino, Shinichiro Shinzaki, Minoru Matsuura, Katsuyoshi Matsuoka, Taku Kobayashi, Masayuki Saruta, et al. 2021. "Evidence-Based Clinical Practice Guidelines for Inflammatory Bowel Disease 2020." *Journal of Gastroenterology* 56 (6): 489–526. https://doi.org/10.1007/s00535-021-01784-1.

Nowell, L. S., J. M. Norris, D. E. White, and N. J. Moules. 2017. "Thematic Analysis: Striving to Meet the Trustworthiness Criteria." *International Journal of Qualitative Methods* 16 (1): 1609406917733847. https://doi.org/10.1177/1609406917733847.

Pasvol, T. J., L. Horsfall, S. Bloom, A. W. Segal, C. Sabin, N. Field, and G. Rait. 2020. "Incidence and Prevalence of Inflammatory Bowel Disease in UK Primary care: A Population-Based Cohort Study." *BMJ open* 10 (7): e036584.

Peng, Keyuan, Pingting Zhu, Xinyue Gu, Chenglei Hu, Yi Teng, and Zhie Gu. 2025. "Listening to the Voices of Adolescents with Inflammatory Bowel Disease after Returning to School: A Qualitative Study." *Archives of Disease in Childhood* 110 (7): 533–538. https://doi.org/10.1136/archdischild-2024-328010.

Pervez, A., and E. Galea. 2024. "Primary Schools: Spaces for Children's Social and Emotional Learning." *Psychology of Education Review* 48 (1): 68–76. https://doi.org/10.53841/bpsper.2024.48.1.68.

Piñeiro-Cossio, J., A. Fernández-Martínez, A. Nuviala, and R. Pérez-Ordás. 2021. "Psychological Wellbeing in Physical Education and School Sports: A Systematic Review." *International Journal of Environmental Research and Public Health* 18 (3): 864. https://doi.org/10.3390/ijerph18030864.

Pretorius, L., and S. V. Patel. 2025. "What's in a Name? Participants' Pseudonym Choices as a Practice of Empowerment and Epistemic Justice." *International Journal of Research & Method in Education* 48 (4): 371–388. https://doi.org/10.1080/1743727X.2024.2432271.

Rogers, L. G., K. Shearer, S. S. Hryniuk, L. Ray, and G. R. Rempel. 2021. "Beyond the Interview Guide: Experiences of Practically and Mindfully Implementing Interview Guidelines When Conducting Research with Children and Adolescents with Chronic Conditions and Their Siblings." *International Journal of Qualitative Methods* 20:1609406920982148. https://doi.org/10.1177/1609406920982148.

Ropski, S. S. 2023. "*'But You Don't Look Sick … ': Shedding Light on the Socially Constructed Problems of Invisible Chronic Illness and the Benefits of Shifting to a Dynamic Illness Framework*." Master's thesis, Loyola University Chicago.

Rouncefield-Swales, Alison, Bernie Carter, Lucy Bray, Lucy Blake, Stephen Allen, Chris Probert, Kay Crook, and Pamela Qualter. 2020. "Sustaining, Forming, and Letting Go of Friendships for Young People with Inflammatory Bowel Disease (IBD): A Qualitative Interview-Based Study." *International Journal of Chronic Diseases* 2020 (1): 1. https://doi.org/10.1155/2020/7254972.

Runions, K. C., R. Vithiatharan, K. Hancock, A. Lin, C. G. Brennan-Jones, C. Gray, and D. Payne. 2020. "Chronic Health Conditions, Mental Health and the School: A Narrative Review." *Health Education Journal* 79 (4): 471–483. https://doi.org/10.1177/0017896919890898.

Schnabel, J. 2025. "A Postcode Lottery in Education? Explaining Regional Inequality in Multilevel Systems." *Policy Studies Journal* 53 (2): 263–284. https://doi.org/10.1111/psj.12565.

Silva, L. C., R. B. M. Seixas, and E. de Carvalho. 2020. "Quality of Life in Children and Adolescents with Inflammatory Bowel Disease: Impact and Predictive Factors." *Pediatric Gastroenterology, Hepatology & Nutrition* 23 (3): 286–296. https://doi.org/10.5223/pghn.2020.23.3.286.

Slothouber, V., and S. Lindsay. 2025. "Identity Negotiations of Multiply Marginalized Disabled Youth." *Disability & Society* 40 (11): 3104–3128.

Spencer, B. K., S. Hugh-Jones, D. Cottrell, and S. Pini. 2024. "The INSCHOOL Project: Young People with Long-Term Physical Health Conditions: An in-Depth Qualitative Study of Their Needs at School." *Journal of Adolescence* 96 (2): 337–349. https://doi.org/10.1002/jad.12278.

Stacey, M., M. Gavin, S. Fitzgerald, S. McGrath-Champ, and R. Wilson. 2024. "Reducing Teachers' Workload or Deskilling 'Core' Work? Analysis of a Policy Response to Teacher Workload Demands." *Discourse* 45 (2): 187–199.

Sveningsson, S., and M. Alvesson. 2003. "Managing Managerial Identities: Organizational Fragmentation, Discourse and Identity Struggle." *Human Relations* 56 (10): 1163–1193. https://doi.org/10.1177/00187267035610001.

Toller, L., and H. Farrimond. 2021. "The Unpredictable Body, Identity, and Disclosure: Identifying the Strategies of Chronically ill Students at University." *Disability Studies Quarterly* 41 (2). https://doi.org/10.18061/dsq.v41i2.7049.

Tong, A., P. Sainsbury, and J. Craig. 2007. "Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups." *International Journal for Quality in Health Care* 19 (6): 349–357. https://doi.org/10.1093/intqhc/mzm042.

Uhm, J. Y., and M. Y. Choi. 2023. "School Health Teachers as Partners in Diabetes Caring: Maternal Perspectives." *Western Journal of Nursing Research* 45 (10): 942–952.

Vanhelst, Jérémy, Florian Vidal, Dominique Turck, Elodie Drumez, Djamal Djeddi, Eve Devouge, Claire Spyckerelle, et al. 2020. "Physical Activity Is Associated with Improved Bone Health in Children with Inflammatory Bowel Disease." *Clinical Nutrition* 39 (6): 1793–1798. https://doi.org/10.1016/j.clnu.2019.07.018.

Werner, Helene, Markus A. Landolt, Patrick Buehr, Rebekka Koller, Andreas Nydegger, Johannes Spalinger, Klaas Heyland, Susanne Schibli, and Christian P. Braegger. 2017. "Changes in Health-Related Quality of Life over a 1-Year Follow-Up Period in Children with Inflammatory Bowel Disease." *Quality of Life Research* 26 (6): 1617–1626. https://doi.org/10.1007/s11136-017-1513-9.

White, L. 2023. "'I Have to Know Where I can go': Mundane Mobilities and Everyday Public Toilet Access for People Living with Irritable Bowel Syndrome (IBS)." *Social & Cultural Geography* 24: 851–869.

Wilkinson, C. 2025. "Towards Painless and Productive Research Relationships: Reflections on Study Design by a Researcher with Chronic Pain for Participants with Chronic Pain." *Frontiers in Pain Research* 5: 1450667.

Wilkinson, C., and P. Budworth. 2025. "Pooh-poohing School Toilet Policies: (more Than) Leaky Bodies as Resistance for School Children with Inflammatory Bowel Disease (IBD)." *Children's Geographies* 23 (3): 413–420. https://doi.org/10.1080/14733285.2025.2467276.

Wilkinson, C., and S. Wilkinson. 2017. "Doing it Write: Representation and Responsibility in Writing up Participatory Research Involving Young People." *Social Inclusion* 5 (3): 219–227.

Zhu, Yangfan, Yueyue Chen, Yuman Tang, Xin Zhang, Qiao Shen, Fei Li, Hao Wang, and Xianlan Zheng. 2025. "The Association between Perceived Social Support and Self-management Behaviors in Adolescents and Young Adults with Inflammatory Bowel Disease: The Chain Mediating Role of Basic Psychological Needs and Anxiety/Depression." *Frontiers in Psychology* 16:1483021. https://doi.org/10.3389/fpsyg.2025.1483021.