

Making the Invisible Visible: The Hidden Cost of Paediatric Inflammatory Bowel Disease



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Abstract

This year, the European Society for Gastroenterology Hepatology and Nutrition (ESPGHAN) joined forces with the European Federation of Crohn's & Colitis Associations (EFCCA) to drive awareness of the hidden costs of paediatric inflammatory bowel diseases (IBD) and make the invisible visible. This feature puts the hidden cost of paediatric IBD in the spotlight and the author makes the case for policy makers to recognise the invisible cost of paediatric IBD. He pledges to take four key steps to reduce the burden of the diseases on society and improve the lives of children and their families.

INTRODUCTION

Europe has the leading prevalence rates of inflammatory bowel diseases (IBD) in the world. It is estimated that 2.5–3.0 million people on the continent bear the condition,¹ and the associated costs are on the rise. Up to 20% of IBD cases develop during childhood which equates to a pan-European figure of 500,000–600,000 children affected by IBD. This has led to substantial direct costs, such as medications, admissions, surgeries, and various healthcare expenses. To make matters worse, indirect costs of IBD include lost working and school days as well as reduced productivity of the child and the immediate family circle. Moreover, the 'invisible' costs such as anxiety, depression and loss of motivation, as well as lost family time are often left unnoticed but heavily exacerbate the issue.

THE PROBLEM

The direct healthcare costs of IBD are posing a significant challenge with reports of €5.6 billion across Europe each year. With pan-European prevalence rates of IBD on the rise, this figure is expected to further increase.¹ Park et al.² showed that IBD patients incurred a direct cost of care bill that was over three times higher than that of non-IBD patients,² and for paediatric IBD patients the cost is on average even higher than for adults.³ Furthermore, while incidence rates are declining in adults, they are rising amongst children.⁴ This is reflected in healthcare services, where the utilisation of adult gastroenterologists and surgeons for IBD is decreasing but their use in paediatrics is increasing. In the extreme

context, it has been reported that the risk of death amongst children with IBD when followed through adulthood is up to three times greater when compared with the general population.⁵

In short, IBD is associated with a substantial strain on the healthcare of western countries, but perhaps the biggest burden is associated with the tremendous indirect and 'invisible' costs to the individual, families, and society. It is noteworthy that the costs of IBD, in children and in adults, are not exclusively rooted in a healthcare setting. Studies have suggested that the economic burden of IBD per patient on society (indirect costs) account for up to 68% of the total cost, with the annual direct cost to the patient of around €750 being dwarfed by the €2,300 cost to society per year.⁶ Based on this calculation it may be speculated that the true cost of IBD is in the region of tens of billions of euros per year. On average, parents and carers of children with IBD take an additional week off from work to provide care for their child,⁷ and people with IBD lose up to 20 days of recreational time every year due to their condition. Indeed, IBD patients are sick approximately 4 weeks a year on average and are 50% more likely to take sick leave.¹

Multiple studies indicate that IBD frequently leads to issues associated with work or school absence, in addition to social life and psychological problems such as anxiety and depression. This is often a consequence of the burdens of IBD, such as flares, admissions, surgeries, emotional and body image challenges, issues around growth, and osteopenia. The ramifications of these costs may be more significant in children given the additional age-specific considerations. The impact on children, living with the condition at such a key stage of their physiological, social, physical, mental, and educational development, can be detrimental. In a recent study, 52% of IBD patients indicated that their condition negatively affected their education.¹ Many paediatric patients find the symptoms of IBD embarrassing and humiliating, which in turn can cause psychological issues.⁸ These form part of the invisible costs that are difficult to quantify but exist on top of both the direct and indirect costs. When it is considered that 72% of patients report that they are worried about their IBD, even when in remission,⁹ we can begin to understand not just the physical, but

the psychological battle that many children with IBD face, and how this struggle can spill over into their education and every day life. It is thus intuitive to grasp how important effective management of those children is, in the goal of achieving complete and sustained deep remission.

POSSIBLE SOLUTIONS

Solving the issue is not a quick or easy process but it is realistic if policy makers commit to taking swift and appropriate action. To achieve this, four key steps are suggested to help reduce the burden of IBD on society and improve the lives of children and their families. Firstly, policy makers must recognise the true cost of paediatric IBD and also incorporate the indirect and invisible costs into economic modelling and public health decision-making. Acknowledging the real disease burden will undoubtedly justify more investments into paediatric IBD and actively facilitate improved management of the condition in childhood.¹⁰ Optimal paediatric treatment has been proven to reduce both the direct and indirect costs of IBD.¹¹

Secondly, implementation of education and workplace policies that better consider the needs of children with IBD and their caregivers. Schools could play a central role in this motion by providing flexible food options, cleaner and readily accessible bathrooms, and a secure environment where children are comfortable with their disease, such as when asking to exit the class to go to the bathroom or going home as needed. Moreover, schools should provide extra examination time to children with IBD to account for the associated multi-level burdens that they experience. Similarly, workplaces should be educated about the disease to provide parents with the necessary flexibility for managing their child's chronic disease.

Gradual transitional arrangements between paediatric and adult care should be a key stage of the care pathway. Policies that build on this will ensure and foster an effective and the least disruptive transition and long-term management. This is particularly important given the concerning statistic that as many as half of adolescents are non-compliant with the recommended treatment and that the transition period is especially vulnerable for disease flares.¹²

Finally, children with IBD must be treated by a competent multidisciplinary paediatric IBD team,¹³ and the healthcare community should play an active role in accomplishing this. Patients with the condition should be managed at the very least by a paediatric gastroenterologist trained in the care of paediatric IBD, a paediatric IBD nurse, dietitian and psychologist, and more paediatric IBD referral centres should be established to provide comprehensive treatment. While a substantial proportion of children are not treated in referral paediatric IBD centres, even the most specialised paediatric IBD centres in Europe and North America do not offer all necessary services to provide comprehensive care to children with IBD.¹⁴ Multidisciplinary teams and being part of quality improvement programmes that monitor disease severity and provide tailored treatment plans, could facilitate clinically important outcomes including remission and

mucosal healing.¹⁵ In addition to providing dietary, social and physiological care, offering support groups and other easily accessible psychosocial interventions in the community are mandatory to enhance coping skills and improve quality of life.

CONCLUSION

The burden posed by paediatric IBD across Europe is becoming an increasingly alarming issue, and a significant proportion of this burden concerns the indirect and 'invisible' societal costs; however, overcoming the problem is achievable. A concerted action towards strengthening paediatric IBD centres and training community paediatric gastroenterologists, as well as facilitating more IBD-friendly environments, are key foundations for making the invisible visible.

References

- Burisch J et al.; ECCO -EpiCO. The burden of inflammatory bowel disease in Europe. *J Crohns Colitis*. 2013;7(4):322-37.
- Park KT et al. The cost of inflammatory bowel disease: An initiative from the Crohn's & Colitis Foundation. *Inflamm Bowel Dis*. 2019;pii: izz104. [Epub ahead of print].
- Kappelman MD et al. Direct health care costs of Crohn's disease and ulcerative colitis in US children and adults. *Gastroenterology*. 2008;135(6):1907-13.
- Benchimol EI et al. Changes to surgical and hospitalization rates of pediatric inflammatory bowel disease in Ontario, Canada (1994-2007). *Inflamm Bowel Dis*. 2011;17(10):2153-61.
- Olén O et al. Increased mortality of patients with childhood-onset inflammatory bowel diseases, compared with the general population. *Gastroenterology*. 2019;156(3):614-22.
- Ruggeri M et al. P.02.22 economic burden of IBD in Italy. *Dig Liver Dis*. 2018;50(2):e141.
- Kuenzig ME et al. The impact of inflammatory bowel disease in Canada 2018: Indirect costs of IBD care. *J Can Assoc Gastroenterol*. 2019;2(Suppl 1):S34-41.
- Devlen J et al. The burden of inflammatory bowel disease: A patient-reported qualitative analysis and development of a conceptual model. *Inflamm Bowel Dis*. 2014;20(3):545-52.
- Wilson B et al. A European Crohn's and ulcerative colitis patient life IMPACT survey. *J Crohns Colitis*. 2012;6(Suppl 1):S171.
- McCartney S et al. Structured transition enhances clinical outcome without an increase in healthcare cost in adolescent patients with IBD: the UK TRANSIT study. *J Crohns Colitis*. 2017;11(Suppl 1):S356-7.
- Sack C et al. A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *J Crohns Colitis*. 2012;6(3):302-10.
- Kasirer Y et al. Management challenges in adolescents with Crohn's disease- Current practice. *J Inflamm Bowel Dis Disor*. 2017;2(1):117.
- Louis E et al. Optimising the inflammatory bowel disease unit to improve quality of care: Expert recommendations. *J Crohns Colitis*. 2015;9(8):685-91.
- Turner D et al. Quality items required for running a paediatric inflammatory bowel disease centre: An ECCO paper. *J Crohns Colitis*. 2017;11(8):981-7.
- Chadokufa S et al. D1.1 successful use of the improvecarenow (ICN) quality improvement tool in paediatric IBD: Our 7 year outcomes and achievements. *Arch Dis Child*. 2017;102(Suppl 3):A5.



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