Research letters

Prospective survey of childhood inflammatory bowel disease in the British Isles

A Sawczenko, B K Sandhu, R F A Logan, H Jenkins, C J Taylor, S Mian, R Lynn

The incidence of inflammatory bowel disease in children in western countries may be rising. Since there is no prospective national data on the incidence of inflammatory bowel disease in the UK and Republic of Ireland (ROI), we undertook a prospective survey to determine this incidence. The incidence during 1998 and 1999 was 5·2/100 000 per year in children aged younger than 16 years. Those from an Asian background were over-represented and more likely to have ulcerative colitis.

Retrospective surveys have suggested that the incidence of childhood inflammatory bowel disease might have increased in the British Isles during the past two decades.[1,2,3] There has been debate as to how much of this increase is real and how much could be attributable to changes in referral patterns or diagnostic criteria.

We prospectively identified cases of inflammatory bowel disease for 13 months, from June 1, 1998, to June 30, 1999, via the British Paediatric Surveillance Unit (BPSU). 1852 paediatricians, paediatric gastroenterologists, surgeons, and pathologists in the UK and ROI were sent surveillance cards each month. To identify any children that were cared for by adult services, the British Society of Gastroenterology Research Unit (BSGRU) also prospectively sent surveillance cards to 1395 adult gastroenterologists and surgeons in the UK. The British Society of Paediatric Gastroenterology and Nutrition maintains a Register of Paediatric Inflammatory Bowel Disease (RPIBD) that receives notifications from 53 UK paediatric centres. All three surveys obtained data anonymously.

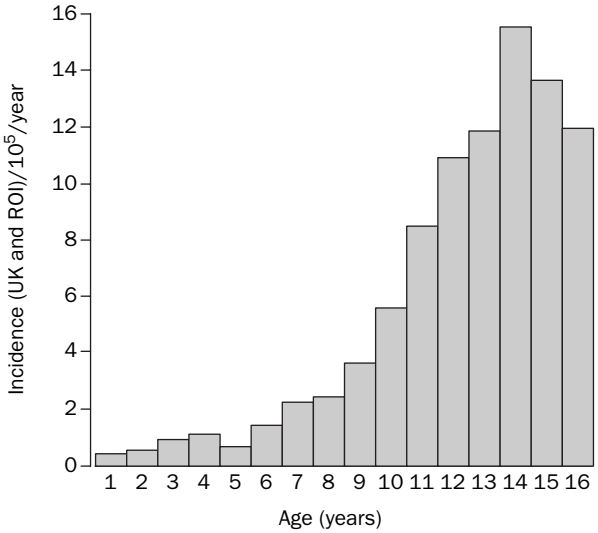
Participants in the BPSU and BSGRU surveys were sent a surveillance card at the end of each month to be returned whether or not they had a case to report. We asked reporters to notify any individuals aged less than 20 years who had been newly diagnosed with inflammatory bowel disease. The initial diagnosis of inflammatory bowel disease was made by the reporter, based on clinical, radiological, and histological features, and confirmed by a detailed postal questionnaire. Data were obtained on date of diagnosis, mode of presentation, results of investigations (including endoscopy, radiology, and histology), and details of initial management. The RPIBD received details of new inflammatory bowel disease cases from contributing centres on a monthly basis.

The mean monthly return of reporting cards was 94% in the BPSU survey and 46% in the BSGRU survey. The BPSU, BSGRU, and RPIBD received 972, 641, and 422 reports respectively, during the 13 months. We excluded 1250 reports because they were duplicates or they included children: aged older than 16 years at diagnosis; diagnosed outside the study period; who were foreign; or whose final diagnosis was not inflammatory bowel disease. In 46 cases despite repeated attempts, follow-up of the initial card report was not possible. Of the total of 739 valid reports, 88%, 8%, and 4% came from the BPSU, BSGRU, and RPIBD surveys, respectively. Using ANOVA there was no significant seasonal variation in the number of monthly reports.

The overall mean age at diagnosis was 11·9 years with 4% being aged under 5 years and 17% aged between 5 and 10 years (figure). 58% of cases were reported as Crohn's disease, 2% orofacial granulomatosis, 29% ulcerative colitis, and 12% indeterminate colitis. The proportion of boys was higher in the Crohn's disease than ulcerative colitis and indeterminate colitis groups (62% *vs* 51% *vs* 47%, respectively; χ^2 test, p=0·005).

Population ethnic data were available for England, Scotland, and Wales in the BPSU survey 78% and 75% of reports respectively gave details of maternal and paternal ethnicity. 39 (7%) of 532 mothers were recorded as Asian (relative risk 1·5, 95% CI 1·1-2·1, p=0·01). In children from an Afrocaribbean background the overall incidence of inflammatory bowel disease as well as the proportion of Crohn's disease to ulcerative colitis and indeterminate colitis was the same as that of white children (20 [4%] of 532 mothers; relative risk 1·1; 95% CI 0·7–1·7). For the UK and ROI as a whole a greater proportion of Asian children had ulcerative colitis than other children (20 [42%] of 48 *vs* 191 [28%] of 691; 1·5; 1·1–2·2, p=0·03).

We calculated the overall incidence of inflammatory bowel disease in the UK and ROI with population estimates for mid-1998 from England (10 308 344), Wales (599 092), Scotland (1 008 244), and ROI (903 600), and for mid-1997 from Northern Ireland (411 942; Office for National Statistics, London; Central Statistical Office, Dublin; and the Northern Ireland Statistics and Research Agency, Belfast). The overall incidence of inflammatory bowel disease in the UK and ROI was 5·2 (95% CI 4·8–5·6)/100 000 children per year. This



Incidence of childhood inflammatory bowel disease in the UK and ROI during 1998 and 1999

All figures are incidence per 100 000 children (95% CI) aged younger than 16 years.

	All inflamatory bowel diseases	Crohn's disease	Ulcerative colitis	Indeterminate colitis
UK	5·2 (4·8–5·6)	3·1 (2·8–3·5)	1·4 (1·2–1·7)	0·6 (0·5–0·8)
England	5·2 (4·7–5·6)	3·1 (2·7–3·4)	1·4 (1·2–1·7)	0·7 (0·5–0·9)
Scotland	6·5 (5·1–8·3)	4·2 (3·0–5·6)	1·8 (1·1–2·8)	0·6 (0·2–1·3)
Wales	5·2 (3·5–7·3)	3·2 (1·9–5·0)	1·7 (0·8–3·1)	0·3 (0·0–1·2)
Northern Ireland	3·6 (2·0–6·0)	2·4 (1·2–4·5)	1·0 (0·3–2·5)	0·2 (0·1–1·4)
ROI	4·4 (3·2–6·0)	2·3 (1·4–3·6)	2·0 (1·2–3·1)	· ·

Incidence of inflammatory bowel disease by country

incidence figure is substantially greater than that retrospectively collected in South Glamorgan[2] from 1983 to 1988 of 2·2 (1·1–4·1). The British respondents reported an incidence of Crohn's disease twice that of ulcerative colitis (table), as has been noted before.[1,2] The increased risk we have shown in Asian people is in accord with findings from limited regional adult data.[4]

The incidence of inflammatory bowel disease we reported in Scotland of 6·5 (5·1–8·3) is greater than the retrospective figure from 1983[1] of 3·9 (95% CI 2·8–4·6), and from 1990 to 1992 of 4·5 (3·5–5·3; reference 3 and E Armitage, personal communication). The current incidence of Crohn's disease in Scotland of 4·2 (3·0–5·6) is almost twice that from 1983[1] of 2·3 (1·5–3·3) and is also greater than that from 1990 to 1992[3] of 2·9 (2·4–3·6).

Clearly definitive comparisons cannot be made between our and previous studies because of differences in data collection and possible changes in clinical practice. The high incidence in Scotland could reflect a heightened awareness of inflammatory bowel disease resulting from repeated surveys, but it is of note that the apparent rate of increase during the last decade is similar to that reported in Sweden during a similar time period.[5] Most BSGRU reports were in older children and the overall peak in incidence of inflammatory bowel disease at around 13 years is likely to indicate the lower response rate in this survey and thus contribute to some underestimate of the true incidence.

We plan to repeat a similar survey in 3 years time to document any changes in the epidemiology of paediatric inflammatory bowel disease.

We thank members of the Royal College of Paediatrics and Child Health, the members of the British Society of Gastroenterology, and others who reported cases. Our study was funded by donations from the National Association of Crohn's and Colitis, SHS International, and the Bristol Paediatric Gastroenterology Fund.

1 Barton JR, Gillon S, Ferguson A. Incidence of inflammatory bowel disease in Scottish children between 1968 and 1983; marginal fall in ulcerative colitis, three-fold rise in Crohn's disease. *Gut* 1989; **30:** 618–22.
2 Cosgrove M, Al-Atia RF, Jenkins HR. The epidemiology of paediatric inflammatory bowel disease. *Arch Dis Child* 1996; **74:** 460–61.
3 Armitage E, Drummond H, Ghosh S, Ferguson A. Incidence of juvenile-onset Crohn's disease in Scotland. *Lancet* 1999; **353:** 1496–97.
4 Probert CS, Jayanthi V, Rampton DS, Mayberry JF. Epidemiology of inflammatory bowel disease in different ethnic and religious groups: limitations and aetiological clues. *Int J Colorectal Dis* 1996; **11:** 25–28.
5 Lindberg E, Lindquist B, Holmquist L, Hildebrand H. Inflammatory bowel disease in children and adolescents in Sweden, 1984–1995. *J Ped Gastroenterol and Nutr* 2000; **30:** 259–64.

Department of Gastroenterology, Bristol Children's Hospital, St Michael's Hill, Bristol B52 8BJ (A Sawczenko MRCP, B K Sandhu FRCP); **Department of Public Health and Epidemiology, University of Nottingham Medical School, Queen's Medical Centre, Nottingham** (R F A Logan FRCP); **Department of Child Health, University Hospital of Wales, Heath Park, Cardiff** (H Jenkins FRCP); **Institute of Child Health, Children's Hospital, Western Bank, Sheffield** (C J Taylor FRCP); **British Society of Gastroenterology Research Unit, London** (S Mian PhD); **and British Paediatric Surveillance Unit, London** (R Lynn MSc)

Correspondence to: Prof B K Sandhu (e-mail: sandhu@i.am)

UK collaborative randomised trial of neonatal extracorporeal membrane oxygenation: follow-up to age 4 years

*Charlotte C Bennett, Ann Johnson, David J Field, Diana Elbourne, for the UK Collaborative ECMO Trial Group**

Extracorporeal membrane oxygenation (ECMO) is a supportive intensive-care technique used for babies with acute respiratory failure. We examined morbidity at age 4 years in surviving children recruited to the UK Collaborative ECMO Trial, and provide long-term data on ECMO support compared with contemporary conventional care. The neonatal ECMO policy resulted in improved survival and a favourable outcome. We therefore advocate the safety and efficacy of this intervention.

The safety of and potential treatment-related morbidity associated with new technologies must be assessed to develop guidelines for their appropriate use. Neonatal extracorporeal membrane oxygenation (ECMO) is an intensive-care technique used to stabilise and support critically ill newborn babies who develop acute, but potentially reversible, respiratory failure. The UK Collaborative ECMO Trial is assessing the safety and effectiveness of this treatment.

Over 3 years, from January, 1993, 185 babies (gestational age ⩾35 weeks, weight ⩾2 kg, oxygenation index ⩾40) from 55 hospitals were entered into a randomised controlled trial comparing a policy of transfer for consideration for ECMO support in one of five ECMO centres, with conventional care, normally in the neonatal intensive-care unit to which the neonate was admitted. ECMO support was given to 78 (84%) of the infants assigned to that trial group, 50 of whom received venoarterial (VA) cannulation, 23 a veno-venous (VV) circulation, and five had both. Primary analysis, by intention to treat, showed that an ECMO policy was clinically effective and cost effective in terms of improved survival without a rise in severe disability at age 1 year.[1–3]

Information about long-term morbidity is essential when assessing any intervention related to neonatal intensive care, since the full range of disability and potential economic implications cannot be assessed by age 1 year. Therefore, we did a follow-up of babies entered into the UK Collaborative Trial to describe mortality and morbidity at age 4 years.

Of the 99 children (62 in the ECMO group and 37 in the conventional group) assessed at age 1 year, one child in the ECMO group subsequently died. She had a congenital diaphragmatic hernia treated by patch repair, and gastro-oesophageal reflux requiring Nissen's fundoplication. When assessed at age 1 year she had hypotonia with motor delay and was classified as impairment with functional loss. She collapsed at age 2 years with endotoxic shock and died as a result of small bowel obstruction and ischaemia associated with adhesions.

Two children in the conventional group were lost to follow-up. One family moved to Nigeria and no information is available on the child's status, but she was judged normal at age 1 year. The second child was thought of as impaired at age 1 year because of motor asymmetry. He is known to be alive at age 4 years but the family declined further follow-up. We did not fully assess three other children (all in the ECMO group) at age 4 years, but had sufficient clinical information on two of them to allow outcome classification, with limited information on the third. In the analysis of overall outcome, we assume that the children lost to follow-up are alive and do not have severe disability.

A single paediatrician (CCB), who was unaware of treatment allocation and original diagnoses, visited 93 of the