Correspondence

Assessing quality of care in paediatric inflammatory bowel disease: Focusing on self-reported outcomes

Dear Editor,

Unlike other chronic childhood conditions, suitable quality outcome measures for paediatric inflammatory bowel disease (IBD) have proved much more difficult to establish and hence only limited data is available. Just as important are the subjective symptoms experienced by children with IBD, as well as their perceived quality of life and measures of wellbeing. Agreement between self-reported and medical assessed health status has rarely been investigated in paediatric IBD. To promote transparent and open reporting of service quality we tested a panel of outcome measures in our patient cohort. In addition to objective clinical measures, we aimed to evaluate quality of care from a patient and parental perspective with a prospective patient questionnaire. Patients attending the Paediatric IBD outpatient clinic at Addenbrooke’s Hospital in Cambridge were consecutively enrolled between November 2012 and February 2013. The first 80 patients admitted to our clinic were invited to participate and 76 patients returned the questionnaire (96%) and were prospectively included in the study. Overall these included 48 children with Crohn’s disease (CD), 13 with ulcerative colitis (UC) and 15 with a diagnosis of inflammatory bowel disease unclassified (IBDU). Clinical outcomes were collected from medical notes and electronic records and patient reported outcomes were extracted from a questionnaire designed aiming to assess patient/parent views on quality of care, treatment outcomes and perceived wellbeing. Disease’s activity and remission status were defined using the weighted Paediatric Crohn’s Disease Activity Index (w-PCDAI) for CD [1] and the Paediatric Ulcerative Colitis Activity Index (PUCAI) for both IBDU and UC [2].

Results show that 39% of our patients were found to be in clinical remission, as defined by a w-PCDAI of <12.5 or PUCAI of <10, with 31.7% in steroid-free remission and only 7.8% of them not receiving steroids for >6 months. There was no significant difference between children with CD, UC or IBDU. Asking patients/parents to indicate their health status the vast majority of patients reported “good health” in the previous 3 months, with 33.3% of patients reported their wellbeing as “very good” or “excellent”. However, in comparison to the previous year, 5% of subjects reported their health as being “much better” or “better” (Fig. 1a). When correlating ‘subjective’ wellbeing with ‘actual’ disease activity (assessed by disease activity index), a strong statistical correlation was observed ($r = -0.4133, p = 0.0007$). Finally we enquired about the “awareness of disease status” by asking patients/parents whether they felt their disease was currently in remission or not. We provided a “not sure” option as an alternative answer, and then matched up ‘subjective’ disease activity with the actual disease activity index score (i.e. w-PCDAI or PUCAI). Interestingly, the majority (72%) of patients in remission were found to be “correct” in their assessment that their disease was inactive. In contrast, a substantial proportion (63%) of patients with active disease incorrectly thought they were either ‘in remission’ or were ‘not sure’ (Fig. 1b).

Fig. 1. Self-reported health status in paediatric inflammatory bowel disease patients. Panel A: Reported health status during 3-month period prior to enrolment as well as present status compared to one year prior (on a five points scale). The vast majority of patients reported “good health” in the previous 3 months and 50% of subjects reported their health as being “much better” or “better”. Panel B: Awareness of own disease status in patients in remission compared to those not in remission; 72% of patients in remission were found to be “correct” in their assessment that their disease was inactive, whereas 63% of patients with active disease incorrectly thought they were either ‘in remission’ or were ‘not sure’.

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It is important to assess clinically relevant outcomes in order to improve care. The availability of such data provides an essential benchmark against which future service change can be assessed. It is critical that interventions are validated against patient outcomes, as cost-effective use of resources is ever more important in healthcare. Our findings also demonstrate that parents and patients with IBD are still relatively poor judges of their own disease activity. Although this is more accurate when they are in remission, the high false-positive rate during active disease indicates that additional clinical parameters must be used to guide treatment decisions. Although self-reporting constitutes an important part of evaluating disease status, we must better understand the factors that inform this personal assessment before abandoning other, more objective, measures of disease activity.

**Conflict of interest**
None declared.

**References**


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