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Original Article

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Agreement Level of Inflammatory Bowel Disease Symptom Reports between Children and Their Parents

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ABSTRACT

Purpose: Children with inflammatory bowel disease (IBD) frequently undergo clinical assessments, involving triadic communication between clinician, parent, and child. During such encounters parents are traditionally the main communicator of information on their child's IBD, including subjective symptom reports. The level of agreement between children and their parents for IBD symptoms is poorly understood, and this study aimed to examine this factor.
Methods: This was a cross-sectional study among children with IBD, and one parent. A validated paediatric IBD symptom report tool (IBDnow) enabled children and their parent to rate seven pain, well-being, and stool metrics, with dyads completing the tool concurrently. Results were assessed using: Individual agreement: proportion of identical symptom reports by each dyad (ideal score >0.7); Category agreement: percentage of identical reports for IBDnow metrics for the cohort; Inter-rater reliability: Gwet's AC1 coefficient with higher scores indicating better reliability (maximum=1).
Results: Seventy-four parent/child dyads participated; child's mean age 12.2 years (standard deviation [SD] 2.9, range 6-16), mean time since diagnosis 2.8 years (SD 3), 54% female, 73% had Crohn's Disease. Mean individual agreement level was 0.6, with 27% of dyads agreeing on ≥6/7 IBDnow metrics. Category agreement was reported by 61% of dyads, 20% of parents overestimated, and 19% underestimated, their child's symptoms. Inter-rater reliability ranged from fair to good.
Conclusion: These results should improve clinician awareness of how IBD symptom reports from parents may introduce bias. Children should be considered the most important source of symptom reports, and tools such as IBDnow utilised to enhance communication.

Keywords: Inflammatory bowel disease; Agreement; Subjective symptoms; Child; Parents

INTRODUCTION

For children with inflammatory bowel disease (IBD) clinical encounters are an essential component of their management. These may be required to assess disease activity, evaluate response to treatment, or monitor growth and development trajectories. Communication during paediatric clinical encounters typically takes the form of a triadic process between clinician, the child, and their parents, which will continue until the child's cognitive and emotional development allows for health autonomy [1,2].

Conflict of Interest
The authors have no financial conflicts of interest.

The complex processes involved for clinicians in interpreting symptom reports relayed by parent-proxy, as well as the child, may lead to discrepancies in understanding [3]. There may be bias in the parent proxy-report who may unknowingly relay their own impression of their child's symptom burden [4-6], while the child expresses symptoms as they relate to their own perception and concept of health and disease [3]. There is increasing recognition that self-reporting is the gold standard for subjective health status indicators during clinical encounters, with patient self-reporting associated with improved disease management, patient-provider communication, and patient health status [7].

A symptom self-report tool for children with IBD (IBDnow) has been developed that enables quantified, structured reports of subjective disease activity metrics such as pain, well-being, and stool variables using a series of text and picture Likert scales [8]. The tool was developed to help teach self-regulation via symptom reflection and evaluation, as well as to be used as an aid to enhance communication between the child with IBD, their parents, and clinicians. During development of IBDnow the tool was validated by comparing children's self-report using IBDnow against clinician assessments using subjective report items from the Pediatric Crohn's Disease Index [9], and the Pediatric Ulcerative Colitis Index [10]. As such, IBDnow has been shown to produce symptom reports with a good level of agreement with the clinical assessment carried out by their paediatric gastroenterologist [8], with data indicating a tendency to underestimation of IBD symptoms by clinicians compared to the child's self-report [8,11,12]. Little is known of the level of agreement between the symptom reports given by children with IBD and their parents. The objective of this study was to utilise the symptom report tool IBDnow to compare child and parent reports of IBD symptoms, with the aim of assessing congruency between child and parent reporting.

MATERIALS AND METHODS

Participants and centres

This cross-sectional study was conducted in two tertiary sites: Christchurch Hospital, New Zealand and Sydney Children's Hospital, Australia. Participant inclusion criteria were children aged four years and over with a confirmed diagnosis of IBD, with at least one parent also willing to participate.

Outcome measures

Demographic and disease specific information for each child was collected relating to age, sex, IBD classification, time since diagnosis, and parent history of IBD. Demographic information collected on each parent included age, sex, education level, personal history of IBD, and whether they belonged to an IBD parent support group.

The outcome measure for symptom assessment was IBDnow, a paediatric IBD symptom reporting tool shown to have validity between child and clinician symptom reports, and generalisable between the two study sites [8]. IBDnow is a 7-scale symptom report tool that facilitates children reporting their IBD symptom metrics using a series of picture and text four-item Likert scales for the categories; pain, tiredness, feeling poorly, stool blood, stool consistency, and a whole number entry for stool frequency (day and night).

Study process

Children with IBD and their parents were approached to participate in the study while waiting for specialist IBD out-patient clinics at each hospital. Each dyad was approached in the waiting room prior to their out-patient appointment. Once informed assent and consent were obtained the subjects were required to complete the outcome measures before their specialist consultation so that no discussion relating to symptoms had been observed by either the child or parent. Each child/parent dyad were asked to complete IBDnow concurrently while sitting separate from each other. Once both IBDnow reports were completed, the parent was asked to provide demographic and disease characteristic information for their child, and demographic information for themselves. Researchers were permitted to help the children with reading the IBDnow text if it was required, but not with completion of the tool. Outcomes were completed either in paper format, or electronic format on a tablet device.

Ethics

Ethical approval was granted by the University of Otago Human Ethics Committee (Health), New Zealand (H16/116), and the Sydney Children's Hospitals Network Human Research Ethics Committee, Australia, (2020/ETH00562), respectively.

Analysis

The level of agreement between child and parent reports using IBDnow were assessed in three ways:

Individual agreement was measured as the proportion of identical symptom reports by each child/parent dyad. This was calculated by dividing the number of congruent pairs of symptom severity reports by the number of total possible pairs, with perfect agreement being a score of 1, and no agreement being a score of 0. The ideal agreement level score is considered to be above 0.75, or the equivalent to agreeing on at least 6 of the 7 items in IBDnow. A univariate general linear model determined whether any single independent variable could predict the degree of agreement between the scores.

Category agreement was determined by the percentage of identical symptom reports for each symptom metric in IBDnow for the cohort overall. Each symptom category was examined using contingency tables to determine the percentage of identical agreement, underestimation and overestimation of reported symptom severity between the participants and parents.

Inter-rater reliability for the category agreement between the children and parents was then calculated using Gwet's AC1 coefficient [13,14]. The levels of agreement for reliability coefficients are considered as follows: 0–0.2 poor, 0.21–0.4 fair, 0.41–6 moderate, 0.61–8 good, 0.81–1.0 very good [15].

A sample size calculation was not possible as IBDnow is not scored, however, it was considered by a biostatistician that a sample size of 70–80 child/parent dyads would be sufficient to explore the stated outcomes. Demographic and disease characteristic data are presented as means and standard deviations for linear variables and number plus percentage for categorical data. Results were considered significant at $p<0.05$. Statistical analysis was performed using IBM SPSS statistics for Windows (Version 27.0; IBM Co.) [16].

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RESULTS

Demographics

Seventy-four parent/child dyads completed the study (**Table 1**), 60 from Christchurch and 14 from Sydney.

Individual agreement

The mean agreement level between child/parent pairs was 0.6 (SD 0.24), which is considered below the acceptable level. Twenty (27.0%) of the pairs had an individual agreement level over 0.75, equating to exact agreement on ≥6 of 7 items (**Fig. 1**). The agreement level between children and their parents was not associated with any independent variable (**Table 2**). To further examine the trend towards significance of child age group on the number of items in agreement the previously defined age groups (**Table 1**) were utilised to ascertain the percentage of each age category agreeing on items (**Fig. 2**). Children in the youngest age group (6–10 years) and their parent most frequently agreed on 6/7 items, while those in the 11–14 year age group agree on 3/7 items, and those in the 15+ year age group agreed on 5/7 items.

Category agreement

When the levels of agreement between the children and parent reports for the categories overall were examined, they were highest for the night-time stool frequency (85.0%), stool blood (73.0%), and pain (59.5%) (**Fig. 3**). The majority of child/parent dyads agreed on their rating for each IBDnow category, with little difference to be seen on visual inspection between over and under-estimation of symptom severity by parents.

Table 1. Background demographic and IBD-specific data for all participants completing IBDnow reports

Variable	Value (n=74)
Child age (yr)	12.2±2.9 (6.1–16.6)
Child age group (yr)	
6–10	17 (23)
11–14	34 (46)
15+	23 (31)
Child sex	
Female	40 (54)
Child diagnosis	
CD	54 (73)
UC	14 (19)
IBDU	6 (8)
Child age at diagnosis (yr)	9.6±3.7
Child time since diagnosis (yr)	2.8±3.0
Parent age (yr)	45±7.1
Parent sex	
Female	59 (80)
Parent education level	
High school	27 (36)
College	12 (16)
University	24 (33)
Post-graduate	11 (15)
Parent has IBD	
Yes	10 (14)
Parent in IBD parent support group	
Yes	29 (39)

Values are presented as mean±standard deviation (range) or number (%).
CD: Crohn's disease, UC: ulcerative colitis, IBDU: inflammatory bowel disease unclassified.

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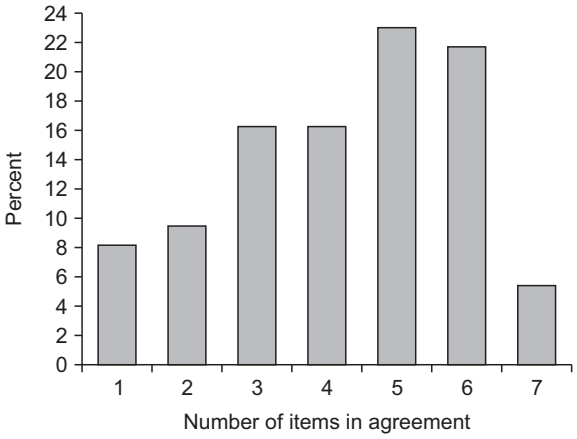

Fig. 1. Level of individual agreement between child/parent pairs for IBDnow categories.
IBD: inflammatory bowel disease.

Table 2. Association between individual variables and agreement scores of parent/child pairs

Variable	Association	*p*-value
Child age group		0.083
Child sex	MD 0.009	0.870
Child diagnosis		0.859
Parent sex	MD −0.017	0.805
Parent education level		0.627
Parent has IBD	MD 0.038	0.464
Parent in IBD support group	MD −0.019	0.744
Child age	R 0.168	0.152
Child age at diagnosis	R 0.143	0.238
Child time since diagnosis	R 0.151	0.209
Parent age	R 0.131	0.265

IBD: inflammatory bowel disease, MD: mean difference, R: correlation coefficient.

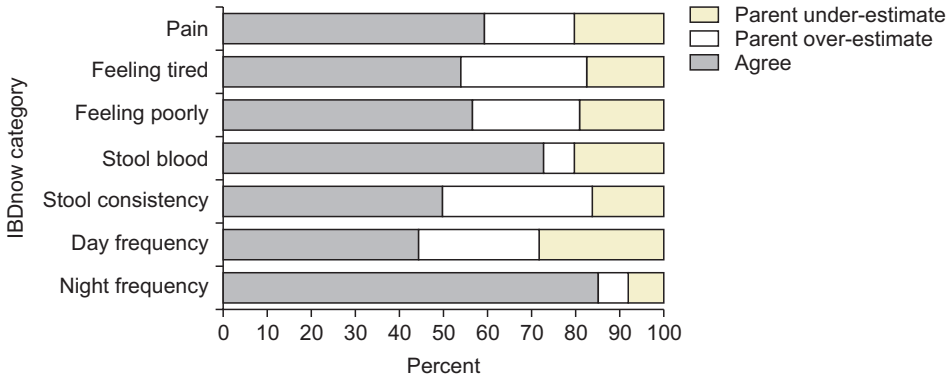

Fig. 2. Individual agreement between child/parent pairs. Data presented as a percentage of each age group to account for different group sizes.
IBD: inflammatory bowel disease.

When the agreement levels were studied as a whole it was seen that overall, 61.0% of pairs agreed on their category ratings, 20.3% of parents over-estimated their child's symptoms, and 18.7% of parents under-estimated the severity (**Table 3**). When the degree of over and under-estimation were further examined it could be seen that while 60% were in exact agreement, 32% were within one category rating, and 8% ≥ two category ratings. The level of

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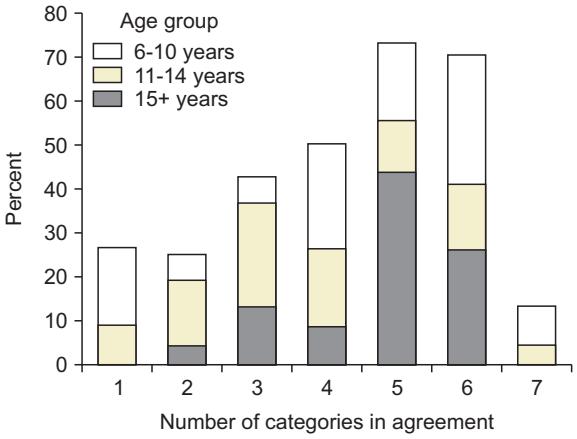

Fig. 3. Level of category agreement, under, and over-estimation for IBDnow categories.
IBD: inflammatory bowel disease.

Table 3. Level and direction of agreement of IBDnow categories overall and by diagnosis, and inter-rater reliability

Category	Symptom agreement	Overestimation by parent	Underestimation by parent	Gwet's AC1
Pain	44 (59.5)	15 (20.3)	15 (20.3)	0.42
Feeling tired	40 (54.1)	21 (28.4)	13 (17.6)	0.51
Feeling poorly	42 (56.8)	18 (24.3)	14 (18.9)	0.34
Stool blood	54 (73.0)	5 (6.8)	15 (20.3)	0.53
Stool consistency	37 (50.0)	25 (33.8)	12 (16.2)	0.56
Day frequency	33 (44.6)	20 (27.0)	21 (28.4)	0.64
Night frequency	63 (85.1)	5 (6.8)	6 (8.1)	0.75
Overall	313 (61.0)	96 (18.7)	104 (20.3)	
CD	225 (59.5)	77 (20.4)	76 (20.1)	
UC	61 (62.2)	24 (24.5)	13 (13.3)	
IBDU	27 (64.3)	8 (19.0)	7 (16.7)	

Values are presented as number (%).
CD: Crohn's disease, UC: ulcerative colitis, IBDU: inflammatory bowel disease unclassified.

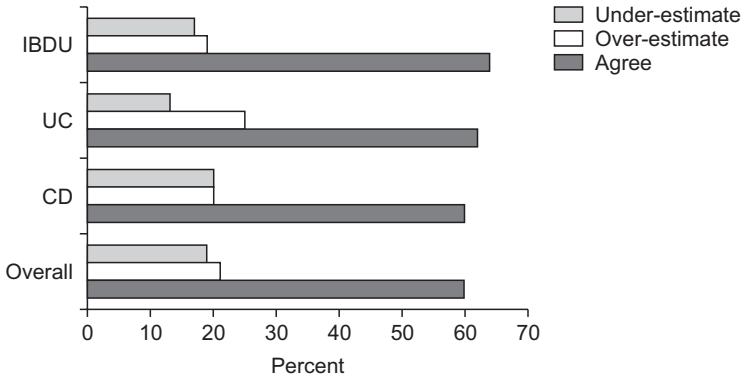

Fig. 4. Level of overall agreement between children and parents to all IBDnow categories, stratified by diagnosis.
CD: Crohn's disease, UC: ulcerative colitis, IBDU: inflammatory bowel disease unclassified.

under and over-estimation were divided by diagnosis to show that there were similar levels of exact agreement for all diagnoses combined, equal distribution of over/under-estimation for children with CD, a higher level of overestimation by parents of children with UC, and marginally higher overestimation for those with IBDU (**Fig. 4**).

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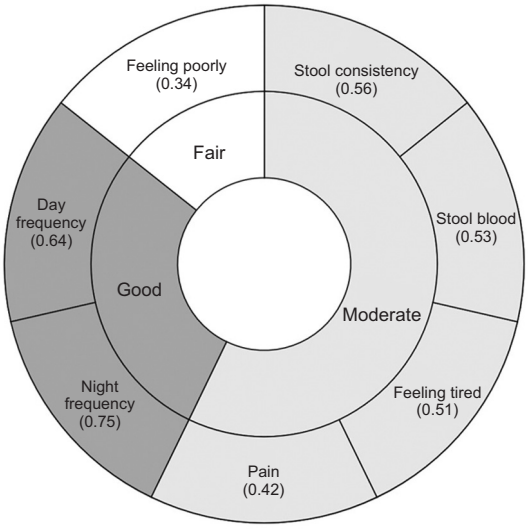

Fig. 5. Inter-rater reliability between child and parent symptom ratings for IBDnow categories. Outer wheel presents IBDnow categories with Gwet's AC1 result in brackets. Inner wheel presents corresponding level of agreement for the reliability coefficient.
IBD: inflammatory bowel disease.

Inter-rater reliability

When Gwet's AC1 was calculated for each category, the score showed that inter-rater reliabilities for each IBDnow metric were 'good' for night and daytime stool frequency, 'moderate' for stool consistency, feeling tired, stool blood, and pain, and 'fair' for feeling poorly (**Fig. 5**).

DISCUSSION

This study aimed to examine the congruence of IBD symptom reports between children and their parents. The results show that child/parent dyads had a level of individual agreement below the considered acceptable range. When studied at the category level, there was a trend towards overestimation overall, mainly driven by particular IBD metrics that may be considered more subjective, and between children with UC and their parents. Inter-rater reliability was good to fair, highlighting the importance of seeking child self-report for subjective IBD symptoms in the clinical setting.

The comparison of symptom reports between children with IBD and their parents is studied infrequently, allowing minimal critique for the findings of the current study. The level of category agreement between 60% of dyads in this paper is lower than the 82% reported by Loonen et al. [17], and higher than the 22% reported by Lawton et al. [18]. However, these assessments were not made using tools validated for use by children. The inter-rater reliability of specific symptom categories in the current study are comparable to other reports in that stool categories scored moderate to good in this study (0.53–0.75), and inter-rater reliability for rectal blood loss scored as 'good' in a study by Loonen et al. (0.61) [17], and stool categories as 'good' by Mackner and colleagues (0.61) [19]. For the category of pain this research reported inter-rater reliability as moderate (0.42), similar to other reports that varied between 0.48 and 0.56 [17,19]. The trend towards symptom over-estimation by parents in the current report has also been demonstrated in one article that reported symptom overestimation by 53% of parents

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[18]. This finding has also been demonstrated in comparisons between children with IBD and their parents reporting health related quality of life (HRQoL), whereby parents rated their child's HRQoL as being worse than the child's own self-report [20,21].

In contrast to the child and parent comparisons seen in this study, clinicians have been shown to underestimate IBD symptoms when compared to children with IBD, with overall agreement levels ranging from 60 to 86% [8,11,12,19]. Assumptions may be made that clinicians may underestimate symptoms due to their symptom interpretation accounting for concurrent physical, histological, and haematological markers of disease activity, as well as having previous benchmarks for comparison, whereas the patients expression of symptoms relates to their own experience of health and disease [3]. The reasons for discrepancies in symptom reporting between children with IBD and their parents are likely to be multifactorial. It may be logical to assume that the more observable aspects of IBD symptomatology are easier for a parent to report accurately, such as those metrics with the highest percentage agreement in this study; stool blood and night-time frequency. This has been seen in HRQoL reporting whereby parents and children with IBD agreed most on the observable aspects of the child's HRQOL, and had lower agreement on the more subjective aspects such as social functioning and emotions [17]. However, parents may also report symptoms due to their own interpretation and impression of their child's symptom burden as well as the psycho-social effect on the parent themselves of caring for a child with a chronic health condition.

For parents of children with IBD, higher disease activity has been shown to be detrimental to parental well-being in terms of mental and physical quality of life, family functioning, and work productivity [22-24]. In addition, shorter duration since their child's last flare is associated with increased parental distress [22,24], and parents have elevated anxiety, and significantly more burnout symptoms, than parents of healthy children [25,26]. Their greatest stressors have been shown to be fears about their child's future health, social relations and future employment options [27]. These psychosocial factors have been shown to be associated with parents providing a more negative evaluation of their child's symptoms, as well as elevating parental expectations and beliefs that symptoms would occur, subsequently being associated with an over-estimated parental symptom report [27,28].

This research highlights the importance of encouraging children with IBD to be active participants in conversations about their condition, and to understand their importance in the triadic communication process between the child, clinician and parent. The relatively poor symptom agreement between children with IBD and their parents in this study should be considered significant when it is understood that discrepancies in informant accounts sees clinicians systematically agree more with the parent-proxy report [29]. Using tools such as IBDnow to enable children to self-report their current symptoms helps avoid bias in proxy parental reports, as well as aiding clinician interpretation of perceived symptoms [4-6]. In encouraging children with IBD to become active participants in assessments of their condition they can begin to develop health autonomy by learning self-regulation, a critical skill of self-management.

Strengths

This research utilised a validated, generalisable tool to obtain symptom reports from children and their parents that has previously been shown to have reliability across age groups.

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The study was carried out in two geographically diverse centres, thereby minimising the possibility of these findings being biased for factors relating to the clinical environment.

Limitations

The numbers of child/parent dyads recruited for this study were sufficient to explore the stated outcomes, however, additional numbers would have benefited the analysis and enabled further sub-group analysis. Factors related to coronavirus disease 2019 restrictions in both study centres limited recruitment.

In conclusion, members of multi-disciplinary IBD teams should utilise tools such as IBDnow to encourage children with IBD to self-report symptoms, thereby enhancing communication. The evidence of symptom reporting disparities between children and their parents should make clinicians aware of how different reporters may introduce bias to communicated symptoms. To build on this research further studies will explore the association between parent/child dyad symptom reports and additional psycho-social outcome measures. Children should be considered the most important source of symptom self-reports, but factors associated with report discrepancies should also be examined in order to improve accuracy of the triadic communication process between families and the clinical team.

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