

Original Article



Parent Perspectives of Diagnostic and Monitoring Tests Undertaken by Their Child with Inflammatory Bowel Disease

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Conflict of Interest

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ABSTRACT

Purpose: To assess parent perspectives of the current and potential future tests for their child with inflammatory bowel disease (IBD).

Methods: New Zealand parents of a child with IBD were invited to complete an anonymous online survey. Experiences relating to their child's blood or faecal tests, medical imaging (abdominal ultrasound [US], abdominal computerised tomography [CT] and magnetic resonance enterography) and colonoscopy were collected. Perceived attitudes to potential future testing of urine, saliva, and breath, were sought.

Results: Twenty-eight parents, 93% female completed the survey, and 86% were aged between 35 and 54 years. Baseline information was provided by parents for 27 of 28 children, 70.3% had Crohn's disease with a mean disease duration of 2.67 years. Blood tests were the most requested and completed tests, while CT was the least ordered and most refused test. Colonoscopy was rated as the least comfortable and generated the most worry. Explanation of test significantly improved parent's levels of understanding when their child had blood, faecal, imaging (US) or colonoscopy tests. Providing an explanation, test invasiveness and the impact of the blood results may have on their child's treatment significantly improved parents' comfort levels. However, explanation of colonoscopy generated a significant parental concerns. Saliva, urine and blood tests were chosen as the most preferred disease monitoring tests.

Conclusion: Parents preferred any tests less invasive than colonoscopy for monitoring their child's IBD. Although providing explanation of their child's tests enhanced parents' understanding, it can also affect parents' levels of concern and comfort.

Keywords: Inflammatory bowel disease; Investigative techniques; Perception; Parent; Child; Disease progression; Blood test; Feces; Diagnostic imaging; Colonoscopy

INTRODUCTION

Inflammatory bowel disease (IBD), comprised of Crohn's disease (CD), ulcerative colitis (UC) and inflammatory bowel disease unclassified, is characterised by idiopathic chronic relapsing inflammation of the gastrointestinal tract (GIT) with or without extraintestinal manifestations [1]. The rate of paediatric IBD diagnosis is increasing globally, both in

developed nations such as New Zealand (NZ) and in developing countries [2,3]. Currently, there are many therapies to induce, and then maintain disease remission and prevent disease complications: none of these are curative.

In recent years, the definition of achieving disease remission has shifted from symptom-free remission to mucosal healing (MH) [4]. MH is associated with sustained clinical remission, and reduced risk of hospitalisation and surgery [5-7]. Consequently, endoscopy (gastroscopy and/or colonoscopy) is currently the gold standard for the assessment of the GIT at diagnosis and following therapies. Children having colonoscopy may experience various emotions including frustration, anger, fear, anxiety and stress prior to and during their procedure [8]. These may be accentuated with subsequent endoscopic procedures. Furthermore, endoscopy is also limited by hospital resources and time [9]. Therefore, there is increasing emphasis upon less invasive investigations such as blood and/or faecal tests to monitor disease activity [10]. Recent studies have shown promising outcomes of utilising saliva, urine and breath as disease monitoring markers and have the potential to be implemented as future standard care [11-15].

In addition, various imaging modalities including abdominal ultrasound (US), abdominal computerised tomography (CT), or magnetic resonance enterography (MRE) are commonly requested at diagnosis and subsequently to monitor disease activity over time. US is a useful screening tool in the preliminary work-up of children suspected having IBD, but more sensitive imaging test such as MRE is required as part of the diagnostic assessment [16]. Ordering CT practices as part of paediatric IBD diagnosis investigations or disease monitoring in NZ is unknown. Doctors in the United States of America generally prefer CT for evaluating patients with CD; however, MRE is preferred over CT by paediatricians and gastroenterologists, especially for disease activity surveillance [17].

The diagnosis of IBD places a significant burden on children and their parents [18-20]. The child's disease activity is closely associated with parental stress and the child's quality of life [21]. A recent study noted that parents of children with IBD desire to become more active in the decision-making process for their child's care [22]. However, little is known of parent perspectives of the current diagnostic and monitoring tests ordered for their child with IBD. Parents of diverse educational backgrounds may have different perceptions of these investigations and how their physician explains these tests to them. A cross-sectional survey was conducted in parents reporting the frequency of IBD tests requested, completed and reasons for refusal. Parents were also asked to rate their levels of comfort, understanding and worry about each test undertaken by their child. Their perspectives about potential future non-invasive tests (saliva, urine or breath) were also sought.

MATERIALS AND METHODS

Participants

Parents with a child (up to 16 years of age) with IBD living in NZ were invited to complete an anonymous online survey that was posted for six weeks, from 5 July till 18 August 2019. Parents with more than one child with IBD were allowed to complete the survey for each individual child with IBD, and both parents were allowed to complete the survey for the same child with IBD if desired.

Survey

The survey was hosted by Qualtrics, Version 2019 (Provo, UT, USA) and advertised via the social media platforms of Crohn's and Colitis New Zealand (CCNZ). Parent's perceptions of their child's previous encounters with various tests (general blood tests, faecal tests, medical imaging [including US, CT or MRE] and colonoscopy) were collected. If the doctor did not request any of the described tests, not applicable was applied. Parents rated their levels of comfort, understanding and worry using a visual analogue scale (VAS). In regards to comfort, for example, this was scored as 0 being most uncomfortable and 100 being most comfortable when their child undertook a test.

Other questions asked whether any explanation was provided to the parents by the referring doctor for the ordered test, and if any of the following specific explanations were included: the impact of the test's result affecting the child's treatment, risks associated with the test, test invasiveness, that test results may not reflect their child's IBD activity (false positive or negative) and alternative testing options.

Participants were also asked to rank their preference of current and potential future non-invasive tests (such as tests using saliva, urine or breath) for their child. Descriptions of what collection of potential saliva, urine and breath samples would involve were also provided in the questionnaire (**Supplementary Table 1**).

At the end of the survey, parents had the option of providing demographic details, including those of the child with IBD. This study was approved by the University of Otago Ethics Committee (Health), reference number HD19/016.

Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics for Windows, Version 25.0 (IBM Co., Armonk, NY, USA). Results, including VAS were expressed as mean±standard deviation (SD). ANOVA test was used to analyse the difference between the understanding of VAS scores and education. Correlations between understanding and comfort or worry VAS were analysed using Pearson's correlation. Student *t*-test was used to analyse the difference between the VAS means. Ranking of test preference was analysed by summing the ranking preference. Statistical significance was assumed when $p < 0.05$.

RESULTS

Participant's background

Twenty eight parents completed the survey, including baseline data. Almost all responders (92.9%) were female and most (85.7%) were between 35 to 54 years of age (**Table 1**). Parent participants were equally distributed between the North and South Islands of NZ. Twenty-seven of 28 parents provided their child's baseline data, 40.7% were female and 70.3% had CD (**Table 1**). The mean (±SD) reported disease duration was 2.67±2.63 years. The age of the children with IBD was available for 25 children and almost three-quarters (72.0%) were adolescents (11–15 years of age).

Current IBD test requested and reasons for refusal

General blood tests were the most requested test (n=28; 100.0%), followed by colonoscopy (n=27; 96.4%), then faecal tests (n=25; 89.3%). None of these tests were refused (**Table 2**).

Table 1. Baseline information of parent respondents and their child with IBD

Characteristic	Value (n=28)
Parents	
Female	26 (92.9)
Age group (y)	
16–34	2 (7.1)
35–54	24 (85.7)
>55	2 (7.1)
Ethnicity	
New Zealand European	24
Maori	2
Others	3 [†]
Location	
North Island	14 (50.0)
South Island	14 (50.0)
Education level	
Secondary school	6 (21.4)
College	10 (35.7)
University*	8 (28.6)
Postgraduate	4 (14.3)
Civil status	
Married/civil partnership	22 (78.6)
Divorced/separated	4 (14.3)
Single	2 (7.1)
Children with IBD**	
Female	11 (40.7)
Age group (y)	
<6	2 (8.0)
6–10	5 (20.0)
11–15	18 (72.0)
IBD subtype	
Crohn's disease	19 (70.3)
Ulcerative colitis	5 (18.5)
IBD-unclassified	2 (7.4)
Duration of IBD (y)	2.67±2.63
General health VAS (reported by parents)	63.7±21.2

Values are presented as number (%), number only, or mean±standard deviation.

IBD: inflammatory bowel disease, VAS: visual analogue scale.

*Including Bachelor's Degrees, Graduate Certificates or Graduate Diploma. **Twenty-seven of 28 parents provided information about the baseline characteristics of their child. Only 25 parents provided their child's age. †Others: Other European (n=1), Romani (n=1), South African (n=1).

The least prescribed test was an abdominal CT scan (n=3; 10.7%): this was the most refused test (by two parents). One parent refused this test rating the risks of the test, that the test may find more problems and may affect the child (VAS 100 for each reason). The other parent rated refusal by their child (VAS 80) as the primary reason (**Table 3**).

Table 2. Parents' report on their child's IBD tests ordered and completed, including refusal

Test	Total test ordered	Test completed	Test refused	Test not ordered
General blood test	28 (100.0)	28 (100.0)	0 (0.0)	0 (0.0)
Faecal test	25 (89.3)	25 (89.3)	0 (0.0)	3 (10.7)
US	15 (53.6)	14 (50.0)	1 (3.6)	13 (46.4)
CT	3 (10.7)	1 (3.6)	2 (7.1)	25 (89.3)
MRE	16 (57.1)	15 (53.6)	1 (3.6)	12 (42.9)
Colonoscopy (including biopsies)	27 (96.4)	27 (96.4)	0 (0.0)	1 (3.6)

Values are presented as number (%).

IBD: inflammatory bowel disease, US: ultrasound, CT: computerised tomography, MRE: magnetic resonance enterography.

Parent Perspectives of Their Child's IBD Diagnostic and Monitoring Tests

Table 3. Reasons provided by parents for refusal of investigations

	US	CT	MRE
Reason(s) provided using VAS (N)	(1): Concern of the test results affecting the child (VAS 100), of finding more problems (VAS 100) and risk of the test (VAS 74).	(1): Risks of the test (VAS 100), fear of finding more problems (VAS 100), concern of the test results affecting the child (VAS 100). (1): Refused by the child (VAS 80), concern of the test results affecting the child (VAS 74), too painful (VAS 72), risks of the test (VAS 5).	(1): Fear of finding more problems (VAS 46)
No reason provided (N)	(0)	(0)	(0)
Total patients	1	2	1

US: ultrasound, CT: computerised tomography, MRE: magnetic resonance enterography, VAS: visual analogue scale, N: sample size.

Table 4. Twenty-eight parents preferred choice of current and potential IBD tests for their child with IBD

Rank*	Current IBD tests	Current and potential† IBD tests
1	Blood test	Saliva test
2	Faecal test	Urine test
3	US	Blood test
4	CT	Breath test
5	MRE	Faecal test
6	Colonoscopy	US
7	-	CT
8	-	MRE
9	-	Colonoscopy

IBD: inflammatory bowel disease, US: ultrasound, CT: computerised tomography, MRE: magnetic resonance enterography.

*Analysed by summing the ranking preference. †Potential tests include saliva, urine and breath tests: saliva test requires approximately 5 mL of saliva collected into a container, urine test requires approximately 20 mL of urine collected into a container, and breath test requires the participants to breathe out into a bag for up to 5 minutes.

Preferred choice of current and potential IBD tests

When parents were given the option to rank their preferred choice of current standard IBD tests for their child, having a blood test was the most preferred choice followed by faecal test, US, CT, MRE and lastly, colonoscopy. When other potential tests using saliva, urine or breath samples were included with the current tests, saliva, urine and blood tests were the three most preferred tests, while colonoscopy remained the least preferred test (Table 4).

Levels of understanding of why tests were requested

Parents reported having a reasonable understanding of the current IBD tests except for CT: mean understanding VAS ranged from 68.33 to 90.69 (Table 5). Notably, only three parents reported that a CT was ordered for their child. Parents' understanding of these tests was not influenced by their educational background (ANOVA, $p > 0.05$). A moderate correlation was found between parents' understanding and comfort VAS, and an inverse correlation between parents' understanding and worry VAS when their child had general blood tests (Pearson's $r = 0.60$, $p = 0.001$ and $r = -0.39$, $p = 0.04$, respectively). No correlations were found between understanding and worry or comfort VAS for other tests (Supplementary Table 1).

Table 5. Parents' VAS levels of comfort, understanding and worries when their child took the tests

Test	N	Comfort VAS	N	Understanding VAS	N	Worry VAS
General blood test	28	86.29±19.68	28	84.68±23.22	28	53.86±31.43
Faecal test	25	88.80±21.12	25	87.36±24.35	25	50.92±36.17
US	14	92.71±11.40	15	81.53±31.56	15	59.80±31.28
CT	1	100	3	68.33±54.85	3	35.00±56.35
MRE	15	67.33±34.34	16	90.69±11.01	16	46.94±37.12
Colonoscopy (including biopsies)	27	47.11±34.92	27	88.85±21.01	25	72.24±33.61

Values are presented as number only or mean±standard deviation.

VAS: visual analogue scale, N: sample size, US: ultrasound, CT: computerised tomography, MRE: magnetic resonance enterography.

The parents' mean understanding VAS improved significantly when their doctor provided an explanation of the ordered test compared to none ($p < 0.01$ for each comparison) (**Supplementary Tables 2 and 3**). Analysis of parents receiving test explanation or specific test explanations were not possible for CT due to small sample size (similarly for analysis of comfort and worried VAS levels). Statistical analysis was also not possible for MRE, as all parents reported an explanation was provided to them for this test.

When the child's doctor provided parents with specific explanations about the impact the test results may have on their child's treatment, the parents' mean understanding VAS significantly improved in all, except CT (not analysed) and MRE. In contrast, when other specific explanations about risks associated with the test, test invasiveness and that test results might not reflect IBD activity (false positive/negative) were discussed, parent's mean understanding VAS did not achieve a statistical difference, depending on the referred test (**Supplementary Tables 2 and 3**).

Comfort levels of having tests

Overall, parents rated US to be the most comfortable test for their child (comfort VAS, 92.71 ± 11.40), while the least comfortable test for their child was a colonoscopy (comfort VAS, 47.11 ± 34.92) (**Table 5**). Interestingly, one parent rated comfort VAS 100 for their child having a CT.

When parents were questioned about whether any test explanation provided by the referring doctor influenced their comfort levels when their child had a test, a general blood test was the only test that was reported to have a significant improvement in their mean comfort VAS levels, compared to those who did not (89.24 ± 13.27 vs. 61.67 ± 45.76 , $p = 0.02$) (**Supplementary Tables 4 and 5**). Moreover, parents' mean comfort VAS levels were rated significantly higher when the clinician's explanation specifically included the possible impact of the child's general blood test results on treatment and general blood test invasiveness.

Worry levels regarding test results

Parents reported being least worried about receiving their child's CT results (mean SD worry VAS, 35.00 ± 56.35); however, this included only three parents. MRE also had low worry scores ($n = 16$, mean SD worry VAS, 46.94 ± 37.12). Parents were most worried about their child's potential colonoscopy findings (mean SD worry VAS, 72.24 ± 33.61) (**Table 5**).

Test explanations provided by a physician did not change parents' mean worry VAS levels upon receiving results across all tests, except for colonoscopy findings, which increased worriedness with explanation, compared to none (mean SD worried VAS, 93.52 ± 9.97 vs. 30.50 ± 41.72 , $p < 0.001$) (**Supplementary Tables 6 and 7**). Similarly, mean worry VAS levels concerning tests results increased significantly if their child's doctor specifically mentioned the impact the general blood test results may have on their child's treatment and discussing alternative testing option for MRE ($p < 0.05$ for each comparison). Parent worried levels were not statistically different when other specific explanations were provided across other tests.

DISCUSSION

This survey found that general blood tests were reported to be the most requested and had the highest completion rate. CT was the least ordered and most refused test. Colonoscopy was rated as the least comfortable and generated the most concern for parents. Parents

preferred any non-invasive tests over colonoscopy for monitoring of their child's disease. Test explanations by a referring clinician significantly impacted on parents levels of understanding when their child had a general blood test, faecal test, US or colonoscopy. General explanation including invasiveness and the impact a general blood test may have on their child's treatment significantly improved parental discomfort. However, explanation of colonoscopy caused a significant increase in parents' concerns.

The two most ordered tests for children with IBD, as reported by their parents in the current study, are similar to those undertaken by adults with IBD, where general blood tests were the most ordered test by their clinician (97%), followed by colonoscopy (93%) [23,24]. Furthermore, in the Canadian study, medical imaging (not specified) was the least frequently ordered test (58%) [23].

The reason for low rates of medical imaging requests in the current study was unclear, given that small bowel imaging is considered a key diagnostic test in children [16]. CT imaging was referred to by three of the respondents, although it was the least ordered and most refused test of those listed. Reasons for refusal to proceed with CT included concerns about the risks of the test itself, although it was not clear if this was specifically related to the risk of radiation exposure.

The current study found that test explanations by a referring clinician significantly improved parents' levels of understanding when their child had a general blood test, faecal test, US or colonoscopy. Moreover, parents' understanding of the current IBD tests was not influenced by their level of education, similar to the finding in adults with IBD [23]. Collectively the present findings build upon the parent's role as an integral partner of patient- and family-centred care [25]. Having a shared decision between clinicians, children and families to achieve a common goal have been found to improve patient health outcomes [26].

Overall, other than the few parents reporting on CT scans, the parents surveyed were most comfortable with US, followed by faecal tests. Of note, the survey studied the preception of a generalised abdominal US rather than an intestinal or small bowel focused US, as this is only available in selected centres. Studies have reported that intestinal focused US is considered to be well accepted by adults with IBD when it is used as a standard IBD test [27,28]. Similar acceptability by parents is likely to be seen when this is also available extensively for children.

Although parents felt comfortable with faecal tests for monitoring their child's disease, a proportion of adolescents may not share the same view. A study by Heida et al. [29] found adolescents with IBD accept the idea of faecal sampling, but three-quarters (75%) of parents were assisting with placement of their child's stool in the container. Adults have variable comfortability and acceptability of utilising faecal tests for monitoring their disease [23,30]. Early introduction of autonomy in faecal collection may be an important process for children, especially as they start to transition to adult IBD care.

Endoscopy (gastroscopy and colonoscopy) is the current gold standard for the assessment of mucosal healing and detection of complications such as strictures, outcomes of endoscopy (including histological assessment of endoscopic biopsies) and undertaken universally in individuals with IBD. Consequently, it is likely to generate the most concern. In the current study, parents rated their child having a colonoscopy to generate the most concern for them. Similarly, the provision of an explanation about colonoscopy by a clinician also significantly

increased their worriedness. When specific explanations of colonoscopy were explored, there were no statistical differences observed. Any other explanations leading to the increased parental concerns is unclear and will need further exploration in future studies.

This study has several limitations. Firstly, the sample size of the survey was small, potentially limiting generalisability of the findings arising. Secondly, the survey was conducted exclusively online, so may have resulted in a bias towards those parents who were more comfortable with this modality. Thirdly, the parents who responded were almost exclusively mothers, with only a few fathers involved. It is possible that the perspectives of fathers may differ from those of mothers: this was not able to be ascertained in the current study. Including parental anxiety scores in future studies may help to understand their attitudes towards these tests. In addition, this study focused on the parents and did not include any data on the perceptions or attitudes of the children with regards to these investigations. Finally, the study methodology may have introduced parental recall bias, given the length of time since their child had the respective investigations. Balancing these limitations, the current survey was designed to be completed anonymously, so that parents' true perceptions and thoughts could be freely voiced. Further, this survey has provided the first such information on parental perspectives of investigations that their children undertake.

In conclusion, these parents of children with IBD preferred any tests less invasive than colonoscopy to monitor their child's disease status. General blood tests were reported to be the most requested tests and had the highest completion rate, while CT was the least ordered and most refused test. Parents are least comfortable with and have the most concern about colonoscopy. Test explanation by referring doctor can enhance parents' understanding when their child had a general blood test, faecal test, US and colonoscopy. In addition, it can also affect parents' levels of concern and comfort. The findings of this study need to be considered by physicians when referring children with IBD for investigations, with particular regards to parent's test preference and allowing adequate test explanations with parents and the child. The increased use of additional or less invasive tests (such as urine or saliva based assays) may change aspects of parental attitudes to various investigations. Future studies should include both parent's and the child's perception of the tests used in the assessment of IBD.

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SUPPLEMENTARY MATERIALS

Supplementary Table 1

Correlation of parents' understanding and comfort or worry VAS when their child had blood, faecal, US, CT, MRE, and colonoscopy tests

[Click here to view](#)

Supplementary Table 2

Impact of test explanation influencing levels of understanding in parents when their child had blood, faecal and colonoscopy tests

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Supplementary Table 3

Impact of test explanation influencing levels of understanding in parents when their child had imaging tests

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Supplementary Table 4

Impact of test explanation influencing comfort levels in parents when their child had blood, faecal and colonoscopy tests

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Supplementary Table 5

Impact of test explanation influencing comfort levels in parents when their child had imaging tests

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Supplementary Table 6

Impact of test explanation on worriedness in parents when their child had blood, faecal and colonoscopy tests

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Supplementary Table 7

Impact of test explanation on worriedness in parents when their child had imaging tests

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