A retrospective audit of referral and triage pathways of paediatric patients with constipation and soiling.

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The authors have no conflicts of interest.

Abbreviations:
GP – general practitioner
IRSAD – Index of Relative Advantage and Disadvantage
RCH – The Royal Children’s Hospital
MAINTEXT

Abstract

Aim
This study aimed to explore referral and triage pathways for paediatric patients referred to an Australian hospital with bowel dysfunction (isolated or mixed bowel and bladder).

Methods
We conducted a retrospective audit of patients who attended their first clinic appointment during April to June 2014. Patients were included if they: (1) were a new patient referred for symptoms of constipation, soiling, daytime urinary incontinence, or enuresis; and (2) attended the Encopresis, General Medicine, Continence, Gastroenterology, Paediatric Surgery, Urology, Renal, or Child and Adolescent Mental Health clinic. Patients with an organic cause (e.g. Hirschsprung Disease) for their dysfunction were excluded.

Results
Of 1485 new patients seen at our targeted clinics, 281 (18.9%) had symptoms of bowel and/or bladder dysfunction. After excluding patients aged under 3 years (n = 43) and those with isolated bladder dysfunction (n = 130), 56 were referred for isolated bowel dysfunction and 52 for mixed bowel and bladder dysfunction. The median wait time from referral to first appointment was 3.8 months. Median wait times varied across symptom groups (Isolated bowel, 4.6 months; Mixed 3.4 months) and clinics (Encopresis, 7.7 months; General Medicine, 2.5 months). Over a 12-month period, patients attended an average of 3.5 appointments (Isolated bowel, mean 3 appointments; Mixed, mean 4 appointments).

Conclusions
Paediatric patients with symptoms of bowel and bladder dysfunction wait several months to be seen in a public tertiary referral hospital. Alternative pathways for care, such as community based primary care, need to be explored to improve timely management.
Keywords:
Constipation, faecal incontinence, referral, triage, outpatient clinic

What is already known on this topic:

1) Functional constipation affects 0.5% to 32.2% of children worldwide.
2) In Australia, approximately 6.7% of Victorian hospital admissions were for childhood constipation.
3) Paediatric constipation places a heavy financial burden on the healthcare system, costing Victorian hospitals approximately $5.5 million annually.

What this paper adds:

1) The median wait time from referral to first appointment was 3.8 months (115 days), which varied between symptom groups and clinic specialties.
2) Patients with mixed dysfunction attended more clinic appointments in comparison to those with isolated bowel symptoms.
INTRODUCTION

Constipation and faecal incontinence (encopresis or soiling) are highly prevalent conditions within the paediatric community. The prevalence of paediatric constipation ranges from 0.5% to 32.2%,\textsuperscript{1-3} whilst 1.0% to 4.1% of school-aged children suffer from soiling.\textsuperscript{4, 5} Several studies have documented the detrimental effects of soiling on an individual’s well-being, such as decreased quality of life and increased behavioural problems.\textsuperscript{6-9} The negative impact also extends to the family.\textsuperscript{10}

Research exploring health service utilisation offers an insight into the care pathways of children. In general practice, Australian registrars revealed 23% of general practice encounters comprised of patients aged birth to 19 years.\textsuperscript{11} However, due to limited data, the proportion of bowel-related presentations in general practice is unknown. In 2013, a national survey of Australian paediatricians revealed 5.1% of all private, community or outpatient specialist consultations were for constipation and 2.5% were for soiling.\textsuperscript{12} Across secondary and tertiary care, wait times for specialist appointments are problematic. In Canada, median wait times for paediatric specialist appointments have been reported to range from 1.5 to 2.1 months.\textsuperscript{13, 14} Recent internal data from The Royal Children’s Hospital in Melbourne demonstrated that the median wait time across three specialities (General Medicine, Encopresis or Gastroenterology) for all patient conditions was 2.1 months (range 0 to 23 months).\textsuperscript{15} Such prolonged wait times are not ideal, particularly for this cohort who are not prioritised as “urgent” and at risk of impaction and Emergency Department presentations if constipation is left untreated.\textsuperscript{16}

Despite the prevalence of constipation and faecal incontinence, very little is known about referral wait times and triage within Australian tertiary paediatric centres. This study aimed to investigate referral and triage pathways for children with bowel dysfunction referred to specialist clinics at The Royal Children’s Hospital (RCH), Melbourne.
METHODS

Study design

A retrospective chart review was undertaken to investigate referral and care pathways of patients with symptoms of bowel and/or bladder dysfunction who attended a new appointment between April 1st and June 30th 2014. The data included basic demographics, referral information, and a subsequent 12-month review of constipation and soiling related appointments, documenting evaluation and treatment recommendations.

Participants

The study was conducted at the RCH, Melbourne, a tertiary referral centre for paediatric patients in Victoria, Australia. A manual review of all new appointments was undertaken to identify potential participants. The following outpatient clinics were screened for eligible patients: Encopresis, General Medicine, Continence (General Medicine clinic dedicated to continence), Gastroenterology, Paediatric Surgery, Urology, Renal, and Child and Adolescent Mental Health Services. Drop-in clinics for General Medicine and Gastroenterology were also reviewed. Each patient record was screened according to the eligibility criteria (Figure 1).

A socio-economic ranking was assigned to each patient, using the Australian Bureau of Statistics Index of Relative Advantage and Disadvantage (IRSAD) and assigned according to patient postcode of residence. The IRSAD provides a measure of advantage and disadvantage using economic and social information of areas.

All patients were followed for a 12 month period, regardless of the clinics that they attended.

Ethics

The study was granted approval by The Royal Children’s Hospital Human Research and Ethics Committee to access relevant clinical records of RCH patients (DA006-2015-10).
Data analysis

Bivariate analysis was used to compare the outcomes of patients with different subgroups of bowel dysfunction in the various clinics. Sample size and outliers were used to determine the statistical test used and how data were presented.

Clinical data were entered into REDCap, a secure web-based application designed to support data capture for research studies. Recruitment and demographic data were entered into Microsoft Access (Microsoft Corporation, Seattle, Washington, USA). Stata Statistical Software (Stata Corp, College Station, Texas, USA) was used to analyse the audit data.

Measures

The Rome III Classification of Paediatric Functional Gastrointestinal Disease was used to define paediatric functional constipation and soiling. The International Children’s Continence Society (ICCS) standardisation document was used to classify bladder dysfunction. Information from the referral and clinical notes was used to categorise each patient’s symptoms against the Rome III and ICCS criteria. Any uncertainty was discussed with the project team.

Wait time was calculated using data from the referral and patient record. It represents the time period from date the referral was written to the date of the first appointment.

RESULTS

Screening and patient characteristics

Over a 3-month period, a total of 1485 new patients attended appointments at one of twelve specialist clinics at the RCH. Of these, 281 (18.9%) patients aged birth to 18 years were referred for a primary diagnosis of functional bowel and/or bladder dysfunction.

Patients aged less than four years (n = 43) and patients referred for only symptoms of bladder dysfunction (n = 130) were excluded from final analysis. The remaining cohort comprised of 56 patients with isolated bowel symptoms (constipation and/or soiling) and 52 patients with mixed dysfunction (bowel and bladder symptoms). A detailed outline of screening and eligibility is provided in Figure 1.
The median age of all new patients was 5.5 years (IQR 1.5 to 9.2 years) (Table 1). A very small proportion required an interpreter (5.6%, n=82) and approximately 70% were living in areas of greater relative socio-economic advantage (IRSAD quintile 3-5, n=1030). The General Medicine clinic saw 716/1485 (48.2%) of all new patients referred to our selected specialist clinics. One third (n = 35/108) of patients with symptoms of isolated bowel dysfunction or mixed dysfunction were first seen in General Medicine. A further 31 (28.7%) patients were seen in the Encopresis clinic, which focuses on children with soiling.

Referral and wait time

The majority (92/108, 85.2%) of referrals originated from providers outside the RCH and mostly general practitioners (GPs) (80/92, 87.0%) (Table 2).

The median wait time between referral (date written) to the first clinic appointment was 139 days for patients with isolated bowel symptoms and 104 days for patients with mixed dysfunction (Table 2). Wait times varied across clinics (Figure 2). For patients with isolated bowel symptoms, the longest wait time was observed for the Renal clinic, followed by the Encopresis clinic (median 324 days and 230 days, respectively). The Encopresis clinic also had the highest wait time for patients who attended for symptoms of mixed dysfunction (median 233 days).

Diagnosis and triage

Of the 56 patients with isolated bowel dysfunction, 25 (44.6%) had symptoms of constipation and soiling, 25 (44.6%) had constipation alone, and the remaining 6 (10.7%) had soiling alone. Symptom combinations for patients with mixed dysfunction are presented in Figure 3.

Patients with isolated bowel symptoms were further stratified according to the first clinic they were triaged to and subsequently attended. A large proportion of patients with symptoms of constipation and/or soiling had their first appointment with a general paediatrician in the General Medicine, Continence, or Encopresis clinic (43/56, 76.8%). However, 13/56 (23.2%) patients were seen by clinicians with sub-specialty training in Gastroenterology, Urology, Nephrology, or Paediatric Surgery.
Appointment pathway

Appointment data were reviewed over a 12-month period after the date of the first clinic appointment. During that time, patients had attended a total of 1 to 13 appointments (mean 3.5, SD = 2.2). Patients with isolated bowel symptoms attended less appointments compared to those with mixed dysfunction (mean 3.0 versus 4.0, \( P = 0.017 \)). Within the isolated bowel cohort, patients with constipation and soiling attended a mean of 4.0 appointments, in comparison to those with only constipation (mean 2.0, \( P = 0.0001 \)).

DISCUSSION

Our findings revealed 7.3% of patients aged 4 to 18 years were referred to our targeted clinics for symptoms of isolated bowel dysfunction or mixed bowel and bladder dysfunction. The pathway from referral to first appointment was lengthy, with patients waiting an average of 3.8 months. The majority of patients were triaged to a general first-line clinic such as General Medicine, but 20% were seen by a paediatrician with sub-specialty training (e.g. Gastroenterology or Urology). Over a 12-month period, patients had attended an average of 3.5 appointments, with a higher number of appointments for patients with symptoms of mixed dysfunction.

The proportion of patients who attended our outpatient clinics is comparable to a previous nationwide study of Australian paediatricians\(^{12}\) and confirms that bowel dysfunction, with or without associated bladder symptoms, continues to be a common reason for paediatric care. However, the most significant obstacle in provision of timely management for constipation, a relatively low morbidity chronic condition, is wait time. Several factors may contribute to increased wait times, such as high volumes of incoming referrals, referral management and acceptance parameters, triage and scheduling procedures, and prioritisation based on severity.\(^{22}\)

The importance of timely management for this cohort cannot be overestimated, where delays in management may result in patients suffering from psychological and social complications arising from their condition. For families experiencing disadvantage, the need for timely and low-cost care in the public setting is important to ensure all children receive quality care and socio-economic disparities do not impact child outcomes. Community
providers, such as GPs, are in an ideal position to be able to intervene early and monitor treatment. According to an audit of GP availability, 78% of appointments for non-urgent paediatric conditions could be offered on the same day.\textsuperscript{23} While access to care is important, reasons behind why GPs refer to secondary care must be considered. Research has suggested GP knowledge about managing the condition are one of the key drivers for referral.\textsuperscript{24} Other factors influencing GP referral decisions included: parental requests for referral to a paediatrician; wanting a second opinion; and treatment failure.\textsuperscript{24} These findings highlight the importance of ensuring GPs are adequately supported to manage these patients in the community setting. In 2017, the Primary Care Network launched the HealthPathways constipation guideline. This platform has been developed for GPs and aligns with current recommendations for constipation. Moreover, prior to 2015, the RCH did not have any clinical practice guidelines for the evaluation and management of bladder dysfunction. In order to fill this gap, recent work was undertaken at the RCH to produce clinical practice guidelines for daytime urinary incontinence and enuresis. These guidelines have been adapted for use across all clinical settings (primary, secondary and tertiary care) and are available online. The impact of these guidelines is unknown, but may streamline treatment approaches for patients with symptoms of bladder dysfunction, thus improving outcomes.

Constipation is typically a relatively straightforward condition that may be managed by GPs or general paediatricians. Our audit revealed sub-optimal triage pathways for a small proportion of patients who were triaged to various sub-specialty clinics. Ideally, patients referred for ‘simple’ constipation (no comorbidities and no previous treatment trial) should be seen in a general outpatient clinic for their initial consultation. After evaluation of symptoms and treatment history, a general paediatrician will determine whether patients need referral to a sub-specialty clinic. Resources are wasted when new patients are initially triaged to sub-specialty clinics and then re-referred to more appropriate first-line clinics for management.

The cost of paediatric constipation and soiling places a heavy financial burden on the healthcare system, costing close to A$5.5million each year.\textsuperscript{16} By identifying areas for improvement and streamlining the referral and triage process, we may be able to reduce the financial burden on the paediatric healthcare system. Redesign of these pathways could also increase timely management, ensuring that there is a reduced risk of relapse in the future.
Limitations

In our study, wait time was calculated using the date of referral (date written) and date of first appointment. We must acknowledge the possibility that in some cases the referral may not have been processed on the date it was written. Therefore, the accuracy of referral wait time data may be improved by use of the date when the referral was processed.

Moreover, our study evaluated data from a targeted sample of specialist clinics in one metropolitan hospital over a three-month period. This may have limited the ability of our results to represent patient numbers and referral characteristics at other centres or across different time periods. Our decision to only sample outpatient clinics which had previously accepted referrals for bowel dysfunction, may have resulted in an overestimation of the overall proportion of children seen for bowel problems. Nonetheless, at a clinic level, the proportion of referrals for bowel dysfunction provide an insight into the load of these conditions upon different clinics.

We were unable to explore the extent to which childhood bowel dysfunction is managed by primary care providers as it was beyond the scope of this study. Future studies would benefit from a prospective nationwide survey across community and private sectors within primary, secondary and tertiary care. Nonetheless, our data highlight the variable wait times for appointments and current load placed upon a hospital tertiary outpatient service.

CONCLUSION

Our audit confirmed patients experienced long wait times, ultimately delaying definitive management. These findings highlight the need to consider alternative pathways of care. One possible solution is further support and encouragement of primary care providers and community paediatricians. This would greatly decrease the current load placed upon hospital outpatient services and expedite access to care for individual families.
REFERENCES

15. RCH. Internal data: Specialist clinic wait time. Melbourne: The Royal Children’s Hospital; 2018.
Table 1 Patient characteristics (screened versus isolated bowel or mixed dysfunction)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients screened</th>
<th>Patients with isolated bowel or mixed dysfunction†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 1485</td>
<td>n = 108</td>
</tr>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>5.5</td>
<td>8.0</td>
</tr>
<tr>
<td>Interquartile Range, Q1 - Q3</td>
<td>1.5 – 9.2</td>
<td>6.7 – 10.8</td>
</tr>
<tr>
<td>Male gender, n (%)</td>
<td>89 (60.5)</td>
<td>50 (46.3)</td>
</tr>
<tr>
<td>Interpreter required, n (%)‡</td>
<td>82 (5.6)</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Socio-economic ranking (IRSAD), n (%)§</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (Most disadvantaged)</td>
<td>201 (13.5)</td>
<td>11 (10.2)</td>
</tr>
<tr>
<td>2</td>
<td>253 (17.0)</td>
<td>22 (20.4)</td>
</tr>
<tr>
<td>3</td>
<td>330 (22.2)</td>
<td>23 (21.3)</td>
</tr>
<tr>
<td>4</td>
<td>375 (25.3)</td>
<td>36 (33.3)</td>
</tr>
<tr>
<td>5 (Most advantaged)</td>
<td>325 (21.9)</td>
<td>16 (14.8)</td>
</tr>
<tr>
<td>Clinic (1st appointment), n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General medicine</td>
<td>716 (48.2)</td>
<td>35 (32.4)</td>
</tr>
<tr>
<td>Continence</td>
<td>49 (3.3)</td>
<td>18 (16.7)</td>
</tr>
<tr>
<td>Encopresis</td>
<td>33 (2.2)</td>
<td>31 (28.7)</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>160 (10.8)</td>
<td>8 (7.4)</td>
</tr>
<tr>
<td>Urology</td>
<td>239 (16.1)</td>
<td>8 (7.4)</td>
</tr>
<tr>
<td>Renal</td>
<td>140 (9.4)</td>
<td>5 (4.6)</td>
</tr>
<tr>
<td>Paediatric Surgery</td>
<td>127 (8.6)</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Mental Health‡</td>
<td>12 (0.8)</td>
<td>1 (0.9)</td>
</tr>
<tr>
<td>Gastroenterology drop-in</td>
<td>4 (0.3)</td>
<td>-</td>
</tr>
<tr>
<td>General medicine drop-in</td>
<td>5 (0.3)</td>
<td>-</td>
</tr>
</tbody>
</table>

† This sub-group comprised of eligible patients aged ≥4 years that were referred for symptoms of isolated bowel dysfunction or mixed bowel and bladder dysfunction. Patients with isolated bladder dysfunction were not included.
‡ Missing data for eight patients.
Sample size = 1480; Socio-economic quintile ranking could not be calculated for an International patient who lived in Indonesia.

Mental Health Clinics include: Mental Health Psychology, Mental Health Infant, and Child and Adolescent Mental Health Service (CAMHS) Travancore. CAMHS Travancore patient lists were unable to be screened as they were not accessible through IBA. Screening was undertaken via ICD-10 coding by the CAMHS team.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Isolated bowel dysfunction</th>
<th>Mixed dysfunction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 56</td>
<td>n = 52</td>
</tr>
<tr>
<td>Referral source, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>External provider</td>
<td>46 (82.1)</td>
<td>46 (88.5)</td>
</tr>
<tr>
<td>Internal RCH – ED</td>
<td>2 (3.6)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Internal RCH – other department</td>
<td>8 (14.3)</td>
<td>5 (9.6)</td>
</tr>
<tr>
<td>Type of provider for external referrals, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>41 (89.1)</td>
<td>39 (84.8)</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>2 (4.3)</td>
<td>6 (13.0)</td>
</tr>
<tr>
<td>Other†</td>
<td>3 (6.5)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>Wait time from referral to first appointment, n (%)‡</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median, days</td>
<td>139</td>
<td>104</td>
</tr>
<tr>
<td>Range, days</td>
<td>1 - 542</td>
<td>7 – 390</td>
</tr>
<tr>
<td>Within 30 days</td>
<td>7 (12.7)</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>1 – 3 months</td>
<td>13 (23.6)</td>
<td>18 (34.6)</td>
</tr>
<tr>
<td>3-6 months</td>
<td>13 (23.6)</td>
<td>16 (30.8)</td>
</tr>
<tr>
<td>6-12 months</td>
<td>20 (36.4)</td>
<td>12 (23.1)</td>
</tr>
<tr>
<td>Over 12 months</td>
<td>2 (3.6)</td>
<td>2 (3.8)</td>
</tr>
</tbody>
</table>

† Other providers included: psychologist, gastroenterologist, ED consultant, and surgeon.
‡ Missing data for one patient from the isolated bowel group (n=55).
ED, Emergency Department; GP, general practitioner; RCH, The Royal Children’s Hospital.
Figure 1 Flow diagram of new patients referred to targeted specialist clinics

† Not eligible = ‘new’ patients not referred for bowel and/or bladder dysfunction or patients with organic bowel or bladder dysfunction (e.g. Hirschsprung disease, Neurogenic bladder, Spina Bifida).

‡ Of interest = ‘new’ patients who did not have a referral for bowel and/or bladder dysfunction, but according to clinical notes, symptoms of bowel and bladder dysfunction were discussed, or patients who had previously been seen in the same clinic within the past 12 months for symptoms of bowel and/or bladder dysfunction.

§ Eligible = ‘new’ patients referred to one of the target specialist clinics for functional bowel and/or bladder dysfunction.
Figure 2 Clinic wait times for patients with isolated bowel and mixed dysfunction

† Mental Health Clinics include: Mental Health Psychology, Mental Health Infant, and Child and Adolescent Mental Health Service (CAMHS) Travancore. CAMHS Travancore patient lists were unable to be screened as they were not accessible through IBA. Screening was undertaken via ICD-10 coding by the CAMHS team.

‡ Wait time calculation = date of 1st clinic appointment - date referral written. Missing data for one patient from the isolated bowel group (n=55).

(■) Isolated bowel dysfunction; (■■) Mixed dysfunction.
Figure 3 Illustration displaying the number of patients with each symptom combination (n=108)

† Symptoms of constipation and/or soiling.
‡ Wetting occurring exclusively at night.
§ Combination of bladder symptoms occurring during the day and night: (1) daytime wetting and/or bladder dysfunction such as urgency, and (2) night-time wetting.
¶ Daytime symptoms of bladder dysfunction such as urgency or frequency, without wetting.

(■) Isolated bowel dysfunction; (■) Mixed dysfunction.
New patients identified and screened (April to June 2018)
N=1485

Excluded:
• Not eligible† n=1126
• Of interest‡ n=78

Eligible§ n=281

0 - 3 years of age n=43

4+ years of age n=238

Bowel +/- bladder dysfunction n=108
• Isolated bowel symptoms = 56
• Mixed dysfunction (bowel + bladder symptoms) = 52

Bladder dysfunction only n=130
Bowel symptoms
Daytime urinary incontinence
Monosymptomatic enuresis
Non-monosymptomatic enuresis
Bladder dysfunction (no wetting)
Title Page

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