

TRANSITION SERVICES IN PAEDIATRIC INFLAMMATORY BOWEL DISEASE: A SINGLE TERTIARY CENTRE EXPERIENCE

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BACKGROUND

- Transition from paediatric to adult care is a critical phase for adolescents with inflammatory bowel disease (IBD).
- 20-30% of patients are diagnosed with IBD before the age of 20, and paediatric-onset illness has shown to be associated with greater disease severity(1,2,3).
- It is essential to optimise management prior to transfer to adult services.
- Transition services provide pivotal opportunities to empower patients with greater responsibility and autonomy within a well-supported environment.

AIM

- To evaluate the current IBD transition service at a single tertiary centre and identify any recurring themes and targets for improvement within service delivery.

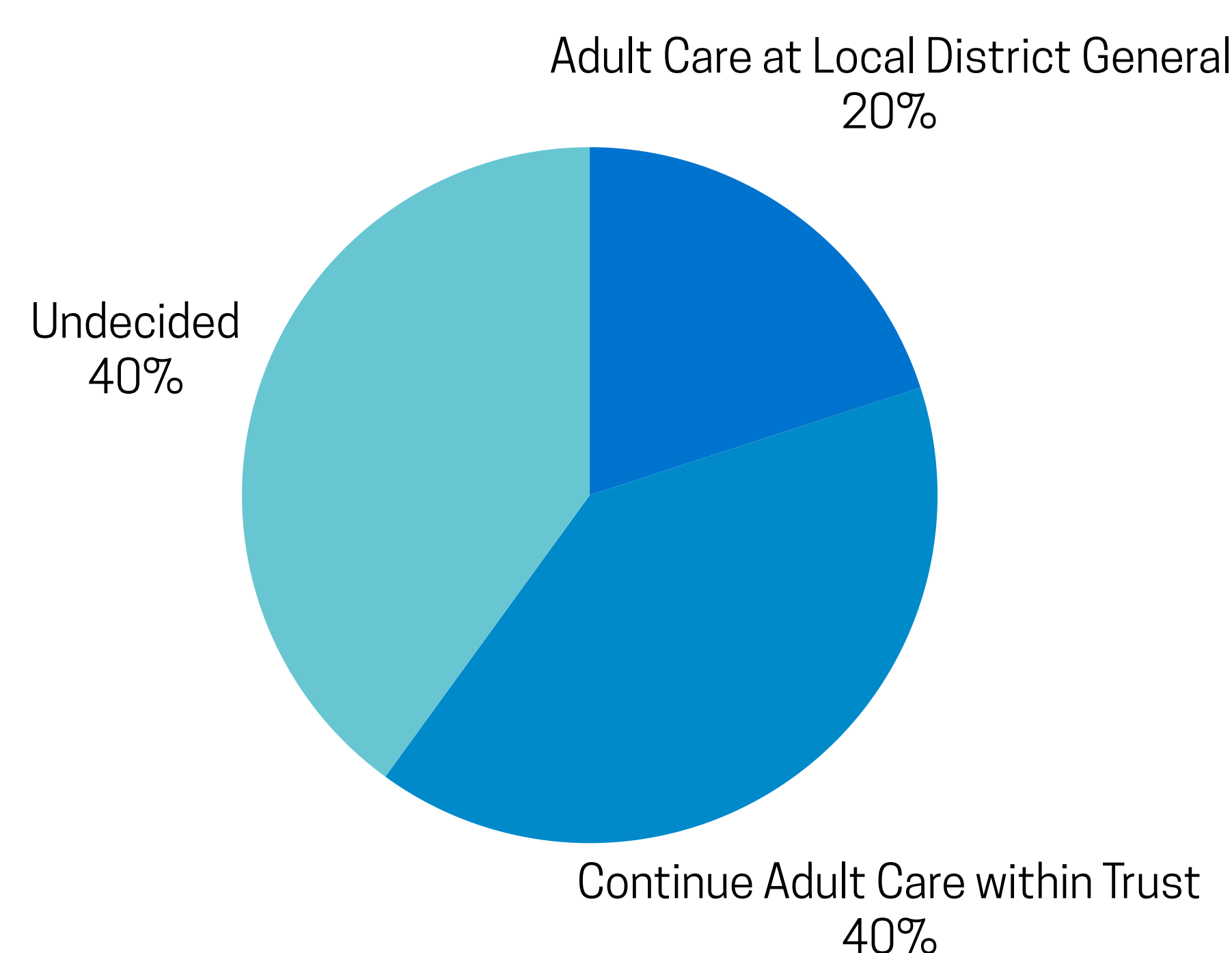
METHODS

- 50 patients aged 16-18 were selected retrospectively from the departmental IBD database.
- Electronic patient notes were evaluated and data collected on age, sex, diagnosis and treatment.
- Thematic analysis using open coding was performed on consult notes and letters to identify transition-related themes.

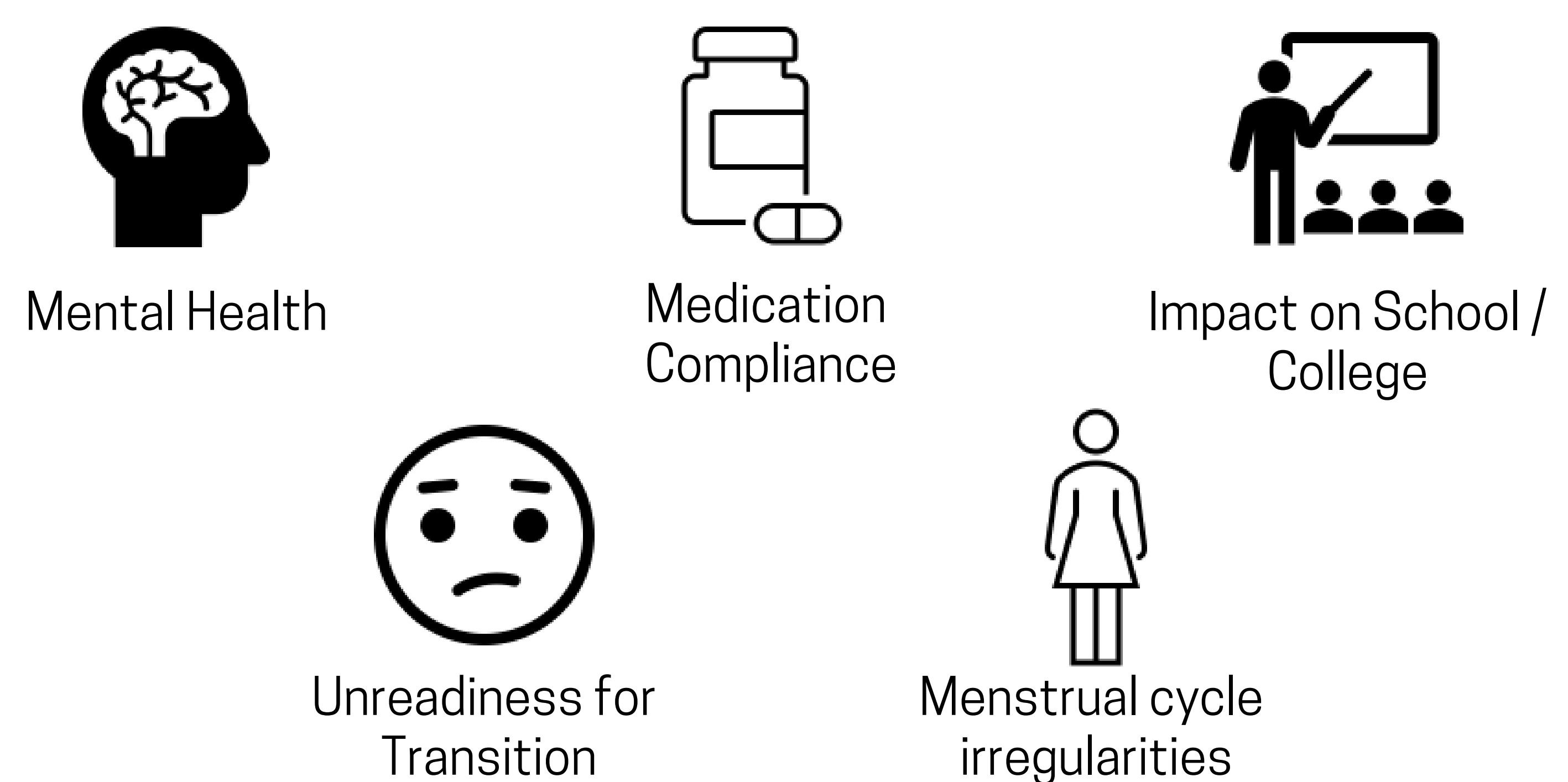
RESULTS

- Mean age was 16.5 years with 26/50 (52%) male and 24/50 (48%) female.
- 35/50 (70%) had Crohn's disease, 10/50 (20%) had IBD-unclassified and 5/50 (10%) had ulcerative colitis.
- 34/50 (68%) were on thiopurines, 31/50 (62%) were on aminosaliclates and 19/50 (38%) were on biologics. 2/50 (4%) were on no maintenance therapy.
- 32/50 (64%) were in clinical remission.
- 31/50 (60%) had a completed transition clinic appointment.
- In 4/31 (13%) the parent was present without the patient.
- 6/50 (12%) had failed to attend at least 1 transition appointment.
- 4/50 (8%) explicitly expressed they did not feel ready for transition, most commonly due to active disease.
- Mental health issues affected 12/50 (24%); 5/50 (10%) reported anxiety, 3/50 (6%) reported eating disorder/poor self-image behaviours and 4/50 (8%) reported autism as having a significant effect on their well-being and disease management.
- 9/50 (18%) reported school absences having a substantial effect upon their work and examinations. Future education or work was discussed in 36% of consultations.
- When prompted, 8/13 (62%) had medication compliance issues with reasons including poor understanding and forgetfulness quoted.
- Menstrual cycles were broached in 25% of female consultations, with 80% of these patients reporting irregular periods.
- 1/50 recorded discussion of smoking.
- Sex, relationships, alcohol and substance use were not discussed.
- 20/50 (40%) wanted to continue care within the Trust's adult services, 10/50 (20%) at a local district general hospital (DGH) and 20/50 (40%) had not indicated a preference yet.

FIGURE 1: A PIE CHART SHOWING THE LOCATIONS OF ADULT IBD CARE CHOSEN BY PATIENTS DURING TRANSITION CLINIC APPOINTMENTS



KEY THEMES IDENTIFIED IN CONSULTATIONS:



CONCLUSIONS

- Key issues at the time of transition to adult IBD services include mental health, school and education, and medication. Particular consideration should be given to these in clinic.
- Prevalence of mental health issues is comparable to reported rates of 22% in the general adolescent population(7).
- Relationships, sex, substance use, alcohol and smoking were rarely discussed. Incorporating a structured tool into clinic review such as the HEADSSS assessment(8) can help clinicians structure discussion of these and mental health issues.
- Barriers to patient attendance at clinic and patients' views on service design should be sought to ensure young people attend key clinic appointments