THE1

“Hello to Adults”: How well are we preparing our young people for transition from paediatric to adult renal services?

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INTRODUCTION

Transition from paediatric to adult renal services can be a challenging time for young people (YP). The "Ready Steady Go” (RSG) programme built around structured questionnaires, is widely utilised as a tool to support this process so at the point of transfer, YP are ready to “go” and have the confidence and skill set to take charge of their healthcare in the adult world. Despite widespread adoption, its effectiveness at point of transfer remains underexplored. This study aimed to validate the effectiveness of the RSG programme in preparing YP for transfer and to identify areas requiring further support in adult services.

METHODS

A single-centre, qualitative study was conducted using the “Hello” questionnaire (mirroring the RSG structure) to assess YPs knowledge across 6 domains at point of transfer: 1) understanding of condition, medications and accessing medical support; 2) self-advocacy; 3) importance of lifestyle factors in maintaining health; 4) independence in daily living; 5) educational/vocational planning; and 6) psychosocial well-being. The questionnaire comprised 34 statements with binary responses: “Yes” or “I need more help with this,” with optional free-text elaboration. We used a “traffic-light” system to summarise the results: over 90% “Yes” answers (green), 80–90% (amber), and below 80% (red), Free-text comments were reviewed qualitatively. YP unable to complete the questionnaire independently were excluded.

All YP who transferred between June 2022, and June 2025 completed the “Hello” questionnaire at their transfer visit supported by the adult youth worker (YW). Completion implied consent, and responses were uploaded anonymously to the RSG dashboard for evaluation. A retrospective analysis was conducted to assess the duration of YW involvement for YP identified as needing additional support in the 12 months post transfer. Support levels were coded as: a single contact, one hour/week, one hour/fortnight, or one hour/month.

RESULTS

72 YP participated (54% male, 46% female, mean age 18.4 years) with 100% completion rate. Of 34 statements, 28 (82%) “Yes” answers were rated green, 3 (9%) amber, and 3 (9%) red. Three key areas emerged where YP expressed a need for further support:

1) Confidence in healthcare engagement: 20% lacked confidence attending clinic alone, 25% struggled with organising prescriptions, and 20% were unsure about contacting the hospital when unwell.
2) Psychosocial wellbeing: 13% reported difficult managing their emotions, commonly citing anger, sadness, or anxiety.
3) Body image concerns: 11% felt uncomfortable with their appearance, primarily due to excess weight.

The analysis of YW support levels revealed the following: single contact (27%), one hour per week (10%), one hour per fortnight (23%), and one hour per month (40%).

DISCUSSION

This qualitative study identified that implementation of the RSG transition tool plays a key role in preparing YP for transition with >90% YP at transfer demonstrating a good understanding of their condition and its management, including the importance of medication compliance and lifestyle factors in maintaining health. However, there are key areas around emotional well-being, self-management and body image that require ongoing YW support to encourage the holistic development of the YP during their early adult years.

THE2

Neurodiversity and psychosocial problems in young people with chronic kidney disease: an emerging pandemic or simply under-recognised?

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INTRODUCTION

Young people (YP) with chronic kidney disease (CKD) are known to exhibit a higher prevalence of neurocognitive and psychosocial challenges than their age-matched peers, including difficulties with social interaction and emotional regulation, traits common in neurodivergent profiles such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). Despite these overlaps, neurodiversity is rarely screened for in YP. This may lead to under-recognition and inadequate psychosocial support for YP faced with the challenge of managing their health care in the adult world. This study explored the prevalence of confirmed or self-reported ASD/ADHD and associated psychosocial factors in YP with CKD.

METHODS

A single-centre, pilot, qualitative study was conducted using an electronic survey to explore the experiences of young people (YP, 18–25 years) after their transition to adult services, with a focus on individual well-being and psychosocial factors. Basic demographic data were collected, including age, gender, type of kidney condition, and education/employment status.

The survey evaluated four key areas: 1) overall satisfaction with the transition process and experiences within adult services since transfer; 2) psychosocial factors, including confirmed or self-reported diagnoses of ASD or ADHD; 3) interest in socialising with peers, including reasons for avoiding social interaction; and 4) the level and impact of youth worker (YW) support.

20 consecutive YP who had an interaction with the YP service either through a clinic appointment or an appointment with the YW were asked to complete the survey at the end of their consultation. Participation was voluntary and anonymity was offered as an option. Completion of the survey implied consent to the analysis of responses with the intention of informing a future study involving a larger patient cohort.

RESULTS

The responses of 20 YP (48% male, 52% female, mean age 21 years) were analysed. YP were happy with their transition to adult care, reporting satisfaction with 1) preparation for transition (90%) and 2) clinic appointments meeting expectations (95%). 13 YP (65%) had

regular contact with the YW (defined as > 1 hour per month) with 83% finding the support helpful.

Despite the majority of YP reporting being “happy with life” (average rating 8/10), 3 key themes emerged:

1) Psychosocial well-being: YP reported a high incidence of anxiety (32%), depression (21%), and loneliness (10%) during the preceding 12 months.
2) Neurodiversity: 20% YP had a confirmed diagnosis of ASD or ADHD, however, 50% of those without a diagnosis suspected they may have either / both condition
3) Social interaction: 52% YP reported not wishing to socialise with peers with 25% citing anxiety / shyness as a reason.

DISCUSSION

This study suggests that neurodiversity may be more prevalent in YP with CKD than previously recognised, however, this observation needs to be confirmed from evaluation of a larger cohort. If this holds true, transition planning should consider both formally diagnosed and self-reported neurodivergent needs such that support can be tailored to individual requirements. Involvement of professionals with expertise in managing neurodiversity may also enhance psychosocial well-being for YP during early adulthood and beyond.

THE3

Learning disabilities amongst UK children on kidney replacement therapy and its association with all-cause mortality: a national historical cohort study of survival outcomes

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Introduction
Children with learning disabilities (LD) experience a four-fold higher mortality risk than the general population, according to statistics published by NHS England in 2020. Neurocognitive and executive function impairments are also disproportionately prevalent in children with chronic kidney disease. Yet, no prior research has examined the association between LD and mortality in children with kidney failure undergoing kidney replacement therapy (KRT), a high-risk population. This research addresses a critical but neglected knowledge gap fundamental to paediatric nephrology by investigating whether children on KRT with LD experience higher mortality compared to children without LD.

Methods
A historical cohort study of routinely collected UK Renal Registry (UKRR) and Hospital Episode Statistics/Patient Episode Database for Wales (HES/PEDW) was used to examine the association of LD and all-cause mortality in UK children <18 years on KRT between 1st January 1996 and 31st December 2022. Kaplan-Meier survival curves and Cox proportional hazards models were employed to compare survival differences, adjusting for demographic and clinical covariates. Sensitivity analyses assessed time-specific effect estimates and exposure misclassification risk from time-differential LD ascertainment.

Results
Of 3015 children, 20.66% had ≥1 documented LD. Over a mean 7.97 years (SD=0.38) of follow-up, 338 deaths occurred. Crude Cox analysis revealed strong evidence ($p<0.001$) for a 71% higher death hazard in children with LD relative to children without (HR: 1.71; 95% CI: 1.35, 2.15). The effect of LD on mortality remained after adjusting for age at KRT initiation, sex, ethnicity, deprivation, primary renal diagnosis, KRT modality, and year of KRT initiation. Extended time-stratified Cox model, accounting for non-proportional hazards, revealed strong evidence of the hazard of death increasing substantially to 148% between years 7 and 14 from KRT initiation (HR: 2.48; 95% CI: 1.48, 4.17, $p=0.001$), and remaining elevated at 115% beyond years 14 (HR: 2.15; 95% CI: 1.20, 3.87, $p<0.001$). No evidence of increased

mortality was observed in the first seven years (HR: 1.31; 95% CI: 0.92, 1.86, p=0.14). Results were consistent across sensitivity analyses.

Discussion

This study was the first to demonstrate increased mortality risk in children with LD undergoing KRT. The findings highlight the impact of LD as an independent risk factor of mortality, with clear implications for clinical and policy-related aspects of holistic renal care strategies for this neglected but high-risk sub-group. It underscores the importance of routine screening, and optimising tailored care pathways and early interventions in survival trajectories. Generalisability may be limited for paediatric populations outside the UK.

THE3

Constipation and laxative use in children with chronic kidney disease: a retrospective cross-sectional study

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Introduction

Constipation is common in adults with chronic kidney disease (CKD), with a reported prevalence of approximately 30% in non-dialysis patients and up to 90% of those on dialysis. It is independently associated with CKD progression, cardiovascular morbidity, and mortality, although the precise mechanisms are unclear. Yet, its prevalence in children with CKD is largely unknown. Moreover, although general paediatric guideline for constipation is available, evidence-based recommendations specific to children with CKD, who have multiple CKD-related risk factors, are lacking. This study aimed to describe constipation prevalence and laxative prescribing patterns in a UK tertiary paediatric CKD cohort.

Methods

We conducted a retrospective cross-sectional study using electronic health records from a UK tertiary paediatric nephrology centre between 1st January and 31st December 2024. Inclusion criteria were children aged 1 month to 18 years with estimated glomerular filtration rate (eGFR) <60 ml/min/1.73 m², including those receiving peritoneal dialysis (PD) or haemodialysis (HD). Period prevalence was defined as the proportion of unique patients with clinician documentation of bowel movement discussion in the clinical notes together with a recorded laxative prescription at any time within the study period, with each patient contributing once. Prescribing patterns analyses were stratified into incident initiation and prevalent ongoing laxative therapy.

Results

Among 225 children (median age 10 years (IQR 4–14); 64% male), the period prevalence of constipation with laxative use was 40.4% (91/225). Prevalence rates by CKD stages/dialysis modality were 25.9% (G3a), 29% (G3b), 47.5% (G4), 43.8% (G5), 100% (PD), and 53.3% (HD). Constipation with laxative use were significantly associated with lower eGFR ($p<0.01$). Case and non-cases also differed by primary renal diagnosis, with a higher proportion of congenital anomalies of the kidney and urinary tract among cases (73.6% vs 56.7%; $p=0.033$). Phosphate-binder use was more common in cases: calcium-based 33.0% vs 17.9% ($p<0.009$) and non-calcium-based 6.6% vs 0% ($p<0.003$). Among 33 incident initiations, osmotic laxative monotherapy was the most common first-line regimen (69.7%), followed by stimulant laxative monotherapy (12.1%); the remaining 18.2% started combination regimens with two or more laxatives. Over a median follow-up of 110 days (IQR 34–227), the median number of regimen changes was 2 (range 0–7); among PD patients (n=6), the

numbers of changes were 0, 0, 2, 5, 6, and 7, respectively. In prevalent cases (n=58), the number of regimen changes ranged between 0 and 18 (median 0); all patients remained on laxatives at their last follow-up visit (median 281 days; IQR 189–316).

Discussion

Constipation is common in children with CKD and, consistent with adult data, its prevalence increases as kidney function declines. This study provides the first characterisation of real-world laxative prescribing in this population, highlighting therapeutic challenges reflected in frequent regimen changes, particularly among children receiving PD. These challenges are likely multifactorial, relating to CKD-associated risk factors such as fluid and dietary fibre restriction, polyuria, reduced physical activity, uraemia-associated intestinal dysbiosis, polypharmacy, and dialysis-related effects. Collectively, the findings identify constipation as a clinically important burden and underscore the need for improved, evidence-based, CKD-specific management.

THE5

Use of mycophenolate mofetil and gastrointestinal adverse effects early post-kidney transplant: experience of a national paediatric centre, and relationship with feeding methods.

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Standard post-renal transplant immunosuppression in our national paediatric renal unit follows the TWIST regimen; Mycophenolate Mofetil (MMF) 600mg/m2 twice daily, tacrolimus and a short 5-day course of corticosteroids. MMF dosage is halved to 300mg/m2 BD from day 15 post-transplant. If adverse effects occur, dose alterations may be made earlier, or further dose reductions later post-transplant. Many patients are fed enterally to meet fluid and nutritional targets. This study explores the adverse effects of MMF early post-transplant, primarily GI intolerance and leukopenia, and possible linkage between patient feeding routes with rates of GI effects.

Aims

1. To assess the incidence of MMF intolerance and requirement for early or multiple dose reductions of MMF.
2. To assess the efficacy of MMF dose reduction and alterations in the resolution of GI intolerance in affected patients.
3. To assess if different feeding routes pre-transplant influence rates of MMF intolerance.

Methods

All paediatric renal transplant recipients from January 2015 to April 2025 were identified. The following data was collected from the electronic patient record:

1. Changes in MMF dose post-transplant as per protocol or not
2. Documentation of GI adverse effects [diarrhoea, nausea +/- vomiting, or abdominal pain disparate from surgical site pain]
3. White cell counts and presence/absence of leukopenia or neutropenia
4. Time taken for GI intolerance improvement following final recorded MMF dose alteration per feeding route group.
5. Type of feeding

Results

90 patients were identified. 5 patients' were excluded as they were not started on MMF. Of the 85 patients, GI intolerance was documented in 35 (41.2%) .This included: diarrhoea (n=31, 36.5%), abdominal pain 10.6% (n=9, 10.6%), nausea +/- vomiting (n=6,7.1%). Leukopenia and/or neutropenia affected 18 patients (21.1%).

Six patients (7%) had MMF dose reduction prior to day 15 and 13 patients had a change in dose frequency (15%). 18 patients (21%) who received the scheduled dose reduction subsequently had further dose alterations during the 90 day window post-transplant.

41 patients (48%) did not have a dose reduction at day 15 and continued on the higher dose initially. These patients were considered as a sub-group (Group B) for some analyses. 12 patients (14% cohort) had the dose reduced within the 90 days post-transplant, and 11 patients (13% cohort) had a change in dose frequency.

Analysis by type of feeding route is illustrated in Table 1.

Discussion

Early issues with GI intolerance (i.e. within 2 weeks post-transplant) were commonest in enterally fed children, then those on mixed feeds. The impact of feeding was less significant where higher doses of MMF were continued beyond day 15. A similar trend was seen for lymphopenia and neutropenia. Patients being enterally fed also had the most dose adjustments compared to those feeding orally or mixed. Determining the date of resolution of GI intolerance was challenging as this was often poorly documented or unclear. An exclusive enteral diet may increase the likelihood of adverse effects from MMF.

THE6

Exploring the use of blended diets in paediatric patients with chronic kidney disease who are tube-fed – a mixed method approach

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Chronic kidney disease (CKD) has significant consequences on nutritional status and often requires use of a feeding tube (FT) to provide adequate nutrition and optimise growth. Sub-optimal nutrition in CKD is multifactorial and gastrointestinal (GI) symptoms are a key contributor. Blended diet (BD) is a novel approach in providing real food via FT to improve GI symptoms of patients, more often used in children with neurodevelopmental disorders. The aim of this study was to review the effects of introducing BD to children with CKD.

Patients were included if they were aged under sixteen years, had a clinical CKD diagnosis, attended the Scottish national service, and received some or all their nutritional requirements through BD TF. The data were gathered through a parent-completed questionnaire and review of patient notes. The mixed-method approach allowed collection of qualitative (parent/carer perspectives) and quantitative datapoints. Thematic analysis was used to analyse the qualitative data, through inductive methods after single-author coding of themes. The GI symptoms were analysed through comparison of parental perceived symptoms and stools (via Bristol stool chart) pre and post the initiation of BD. Weight was analysed by comparison of z-score 6months-pre, initiation and 6months-post BD.

Eleven participants were recruited, nine of whom completed the required questionnaire.

Four themes were identified:
(1) Health and Wellbeing: Parents/carers reported improvement in their child's bowel motions and overall GI symptoms, e.g. "BD was life changing for my son, it gave him energy, improved his stool"

(2) Practical Challenge: The time management of making up the blends was an adjustment to families, losing the convenience of using a ready to feed formula, but still described positively; "finding the time to dedicate to batch cook every few weeks...definitely worth it". The added consideration of fluid management caused a new challenge; "easier to manage on the weekend when there is more time".

(3) Emotional impact: Psychological and social benefits were highlighted, demonstrated by the experience of caregivers. The opportunity to feed children "real food" fostered a sense of inclusion and parental empowerment.

(4) Individualised Nutrition: Reflected the necessity of flexibility and adaptation in blended feeding regimens, especially considering fluid allowance, describing "it's trial and error. But the flexibility is good for us".

The findings indicate that there is a benefit of the GI symptoms, with a reduction of constipation and nausea/vomiting. During blends, 6/9 participants reported “no symptoms”, compared to 0/11 pre-blends. Additionally, stooling consistency improved from type 1-type 7 (Bristol stool chart) pre-blend, to what is considered a healthier bowel motion of type 3-5 post-blends. BD does not appear to significantly increase z-score but does allow weight maintenance.

Use of BD is a rational treatment for TF patients with CKD who are struggling with GI symptoms, though our data does not support the use if weight-gain alone is the goal. The results support the wider observations, that BD provides an emotional benefit that families may strive on.

THE7

A Retrospective Look at Coping and Chronic Illness in Young People through Immunology and Neurobiology

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BACKGROUND: In young people, coping is inherently interconnected, playing an important role in adaptation processes to stress triggers. Investigations surrounding coping in young people and chronic illnesses are unique and challenging.

AIM/ METHODOLOGY: This review investigates central coping mechanisms in young people and chronic illness and the importance of opportunity to raise awareness and encourage educational perspectives.

CHRONIC ILLNESS: The available understanding supports the claim that young people with chronic illnesses have access to a broad repertoire of coping strategies. One limitation of most investigations is that coping data has been collated quantitatively—surveys lack situational detail, which limits the likelihood of capturing the multifaceted ways that young people appraise different types of stress triggers to deal with them.

CENTRAL MECHANISMS: Understanding coping in chronic illness populations (including young people) is important, since many tend to be clinical. It may be that young people, and coping strategies adapted, influence neurobiological and immunological pathways.

RESULTS: Laboratory investigations are essential to understanding coping and to identifying how particular immune cells are influenced in chronic illness populations. Collaborative efforts should encourage positive attitudes and empowerment. Including young people in aspects purporting healthcare and Patient and Public Involvement (PPI) practices can help prompt best practices.

CONCLUSION: Here, an effort has been made to form a review interlinking broader mechanisms of coping in young people living with chronic illnesses. Components of immunology and neurobiology are generated endogenously by stress or in reaction to coping and stressors.