INVESTIGATING THE MODIFIABLE PSYCHOSOCIAL VARIABLES INFLUENCING ACCESS TO AND OUTCOMES AFTER KIDNEY TRANSPLANTATION IN CHILDREN – A STUDY PROTOCOL

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Introduction

Kidney transplantation, compared with dialysis, is often seen as the gold standard in optimising health, reducing mortality and improving quality of life in children with End Stage Kidney Disease (ESKD). We recently surveyed 12 out of 13 UK paediatric nephrology centres on their transplantation plans for all children registered with ESKD. The most commonly cited factors delaying kidney transplantation in these children were: disease-related (36%), availability of a suitable donor (27%) and the child’s size (20%). In 19% of children, psychosocial factors were listed as a barrier. Some factors, including psychosocial, may be modifiable through local or national intervention. To inform future interventions, further study is needed to explore the range and nature of these psychosocial factors.

Aim

To investigate the psychosocial factors that influence access to and outcomes of kidney transplantation among children in the UK.

Methods and Analysis

This is a prospective multicentre (13 UK paediatric nephrology centres) mixed-methods study with QUAL-QUANT and QUANT-QUAL phases. First, we will use thematic analysis to review interviews conducted with NHS professionals, children with ESKD and their families that explore these psychosocial factors. Next, validated questionnaires that measure these psychosocial factors will be distributed to the wider UK cohort of pre-transplant children with ESKD and their families. They will be followed up to 2 years regardless of whether they do or do not receive a kidney transplant. Clinical data will be prospectively collected from local hospital notes and registry data (UK Renal Registry and NHS Blood & Transplant). Families with outlier results will be invited for further interview to explore their findings.

COCATOO: A COHORT COMPARISON TOOL FOR GOSH CLINICAL RESEARCHERS

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When faced with large amounts of data, it can be a challenging and lengthy process for a researcher to identify key differences and trends between different sets of patients. The development of a reporting tool which can be easily adapted to any speciality and patient selection would be advantageous in highlighting and presenting patient group comparisons in a clinical research environment.

By developing standard, reproducible analytics from the core datasets provided by the Digital Research Environment (DRE) team at GOSH, the researcher is able to identify differences in hospital (hospital admissions, ward stays) and clinical (patient laboratory results, demographics and vital signs) trends between user-defined cohort-control patient groups which can accelerate their clinical understanding.

Herein, we introduce COCATOO, a cohort comparison tool that compares and reports distinct sets of patient groups based on defined specifications which are controlled by the researcher. By utilising generalisable analytics developed in R, the tool is able to display a set of predefined exploratory data analytics (EDA) which have the ability to be adapted to any hospital department by incorporating project specific rules.

We present here an example with Chronic Kidney Disease (CKD) comparing stage 5 to stages 1-4. The output report gives an overview of the disease and highlights significant cohort-control differences via the predefined EDA.

CLINICAL AND OPERATIONAL INSIGHTS: WORKING TO EMBED DATA-DRIVEN PROCESSES AT GOSH

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With clinical and operational data for research more easily accessible than ever before through the Digital Research Environment (DRE) in DRIVE, it now is possible to use data-intensive methods and advanced analytics to address many challenges and provide new insights, both clinical and operational. Opportunities for innovation are plentiful and come in many forms, from dashboarding key indicators and trends, to predicting patient needs, forecasting service demand and more. With the expertise and experience gathered within the DRE Team, we are able to leverage key commonalities between projects and focus on particular challenges faced by diverse teams across the organisation.

Herein we introduce our workflow for data extraction, transformation, presentation and analysis and how we can use these to add value for both clinical and operational data use. We also discuss how we can translate requirements and constraints from various teams in order to drive refinements in data presentation and process optimisation. We present two
FEMUR FRACTURES IN CHILDREN WITH CANCERS. WHAT COULD BE THE AETIOLOGY?

Introduction Femur fractures in children are uncommon. Incidence of fractures in leukaemia is about 13.5% and is 6 fold higher than estimate. No prevalence data available on fractures among hospitalized children with cancer. Among the cancer patients femur fractures could be due to various reasons such as non-accidental injuries (NAI), osteoporosis and bone metastasis. We report two patients who had mid shaft femur fractures while receiving chemotherapy as in patients.

Case history Case 01, 17 months old girl diagnosed with Ewings sarcoma (EWSR1-FLI1 type-2) and paraplegia. Whilst receiving chemotherapy she was experienced acute swelling of her left thigh and diagnosed with a spiral femur fracture which was unrelated to disease. Case 02, 4 year old boy with adrenal cortical tumour. During his treatment he sustained a spiral fracture of his left femur. Both these children sustained their fracture while inpatient and extensive review excluded a possible safeguarding issues.

Discussion Case 01 was non ambulatory and case 02 was ambulatory but less able. In multidisciplinary child protection meeting mechanism of the fracture of case 01 was not clear. Child had a habit of trying to bite her toe. But, mum noted she might have caused this when trying to keep her on her side and child refused/rotated – as she did not feel pain therefore the force is difficult to assess – No ill intention was meant. Case 02, he tried to get down from the bed when he falls which leads to the fracture. The conclusion is that there was no evidence of child abuse. Lack of supervision of caregivers was raised as an issue in both cases.

Conclusion Spiral femur fracture in a non-ambulatory child must always raise a concern of NAI. However prevalence of fractures of children with cancers in hospital need more evaluation as those are preventable.

Restructuring of Paediatric Urology Out-patient Workflow During the COVID-19 Pandemic

Aim To audit restructuring of out-patient clinics at GOSH during the COVID-19 pandemic with the aim of evaluating service delivery and business continuity, focussing specifically on the utility of telephonic clinics.

Methods We focussed on paediatric urology out-patient clinics at GOSH. The electronic patient records were accessed to acquire numbers of clinics and patients booked, total face-to-face and telephonic clinic attendances and DNA (did not attend) percentages. Three-monthly blocks were evaluated: April–June 2020, spanning the first peak of the pandemic, April–June 2019 in the preceding year to match activity, and then subsequently the period July–September 2020 to evaluate how the services settled in the post-pandemic phase. The audit was registered with the GOSH Clinical Audit Department. Significance of difference between study groups was examined by Student’s t-test.