

The spectrum of disease in children with end-stage kidney disease using registry and linked electronic health record data.

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Background: Children with end-stage kidney disease (ESKD) may have additional medical conditions that can impact upon care and outcomes for their kidney disease. This data is often not collected as part of a core dataset by renal registries, resulting in data capture of variable completeness and accuracy which limits adjustment for case-mix in renal research [1]. The aim of this study was to audit data on coexisting disease held by the UK Renal Registry (UKRR) against national electronic health record (EHR) data using Hospital Episode Statistics (HES) in England and Patient Episode Database for Wales (PEDW).

Methods: This study included children aged <18 years receiving RRT for >90 days in England and Wales on 31/12/2016. Prevalent disease data held by the UKRR, not including primary diagnosis, was reported and compared where possible, to HES and PEDW data, using disease groupings based upon the International Classification of Diseases, 10th revision.

Results: As of 31/12/2016, 1001 children in England and Wales were receiving RRT for ESKD (62.1% male). The median age as of 31/12/2016 was 12.1 years (IQR 7.8-15.3). Linked HES/PEDW data was available in 833 children (83.2%). Using UKRR data, 24.8% of children had no reported additional diagnoses, although about 25% of data were missing; the most commonly reported were congenital anomaly (n=323, 45.6%), followed by developmental delay (n=152, 24.2%), prematurity (n=138, 23.6%) and syndromic diagnosis (n=159, 22.6%). All children bar one with linked HES/PEDW data had at least one non-renal disease code listed. The most commonly reported disease groupings were factors influencing health status and contact with health services (n=772, 92.7%) abnormal clinical findings not otherwise classified (n=715, 85.8%), genetic, congenital or chromosomal conditions (n=596, 71.6%), certain infectious and parasitic diseases (n=539, 64.7%) and endocrine, nutritional and metabolic diseases (n=535, 64.2%). Some gender differences were noted by disease group: using HES data (figure 1), a strong male preponderance was noted among gastrointestinal, genetic, respiratory, perinatal diseases and factors influencing health status categories ($p \leq 0.02$). UKRR submitted data showed a female predominance for malignancy (65.4%, $p=0.002$) and chromosomal anomalies (55.2%, $p=0.03$) while prematurity, congenital anomalies and congenital heart disease affected males more frequently (73.2% $p=0.02$ and 72.8% $p<0.01$, respectively).

Conclusion: This is the first study to report the spectrum of disease for UK children with ESKD receiving RRT using both registry and EHR data. Using EHR-linkage, a substantial burden is seen, with almost all patients identified as having one or more additional disease codes. A high proportion of congenital and genetic anomalies as well as early life disease is seen using both UKRR and HES data, which predominantly affects males. The fact that much of this disease manifests in early life needs to be recognised by clinicians preparing children and their families for RRT, to ensure this does not limit access to optimal kidney disease care.