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End-stage Renal Disease (Stage 5 Chronic Kidney Disease) in Early Infancy

Background

End stage renal disease (ESRD) in early infancy is rare with an incidence quoted of 0.31 per million UK population per year but presents complex clinical and ethical problems. Controversy continues as to how best care for this population with reports of poor outcome and significant morbidity.

There is anecdotal evidence in the UK of increasing numbers of young infants being treated with dialysis but there is a paucity of data available on the outcome of ESRD during the first 6 months of life.

National ascertainment is required to establish a sufficient cohort, to provide accurate data on this rare but important condition.

It is now possible to support infants with ESRD through Renal replacement therapy (RRT). However, this population differs from older children receiving dialysis in terms of their primary renal diagnosis and are more likely to be diagnosed with renal dysplasia or obstructive uropathy and have more co-morbidities which impact upon long term outcome.

The provision of long term dialysis for neonates with ESRD presents major public health issues with complex clinical, ethical and health-care resource issues. Improvements in neonatal survival and advances in RRT have resulted in higher numbers of infants presenting with ESRD for whom a decision has to made to dialyse or treat palliatively, yet the experience of the infant population has not been reported.

Principal Investigator

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Website

http://bpsu.inopsu.com/studies/current.html

Coverage

United Kingdom & Republic of Ireland

Duration

May 2011 to June 2012

Research Questions

1. To report the incidence of End Stage Renal Disease (ESRD) in infants aged 4 weeks to 6 months (excluding patients with reversible acute renal failure).

2. To characterise incidence by primary renal pathology, age at presentation, gestational age at birth, sex, ethnic origin and region of birth.

3. Clinical presentation
   i. To describe the primary renal diagnosis
   ii. To record the complications and co-morbidities at the time of enrolment in the study and at follow-up at age 1 year

4. Clinical management
   To characterise management from the time of diagnosis of ESRF through to enrolment in the study at follow-up at age 1 year.

5. Outcome
   To describe morbidity and mortality outcomes at age 1 year.

Case definition

Patients from age 4 weeks to 6 months with presumed end stage renal failure who have a serum creatinine of equal to, or greater than 120 micromols/l

Reporting instructions

Please report any infant you have seen for the first time in the UK or the Republic of Ireland since 1st May 2011 who satisfies the case definition regardless of country of birth.

Methods

Paediatricians reporting a case through the orange card system will be sent a questionnaire which explores demographic and clinical information about the infant. A postage paid return envelop will be enclosed with the questionnaire.

Ethics approval

This study has been approved by the Belfast REC (Ref 10/NIR03/32)

Funding

The Childrens' Renal Fund, Belfast

References

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Further Information

If you would like any advice regarding the eligibility of a particular case for inclusion in the study or have any other questions regarding the study please contact Karl McKeever via the details given above