The Economic Impact and variability of managing Distal Renal Tubular Acidosis (dRTA) in the UK healthcare setting

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Objectives

To explore and uncover the cost of managing distal Renal Tubular Acidosis (dRTA) in the United Kingdom.

Introduction

dRTA is a rare but serious type of kidney disease that can be inherited (primary dRTA) or be caused by another disorder or medication (secondary / acquired dRTA) leading untreated to metabolic acidosis. In the UK dRTA management is poorly defined or documented, which leads to difficulty in assigning costs to disease management. Late diagnosis and sustained metabolic alterations may lead to short stature, significant bone deformities, Nephrocalcinosis and even chronic kidney disease (CKD) in some patients. Alkali replacement therapy must be permanently used in genetic forms of dRTA, however, the treatment is not capable of avoiding deafness. (Soares, Silva, Mrad, & Silva, 2019)

dRTA prevalence is estimated at between 0.46 (diagnosed) and 1.6 (diagnosed and suspected) per 10,000 people (CPRD Gold UK database). With estimated UK population of 66,400,000 people we see dRTA population estimates ranging from 3,054 to 10,624 patients..

Methods

A process of face to face and telephone interviews were conducted with seven nephrologists, and one urologist in six leading UK centres to discuss management pathways for distal Renal Tubular Acidosis (dRTA). A number of patient cases were collected, all considered to be typical cases by managing physicians. Both adult and paediatric cases were included, however paediatric cases dominated the sample. Additionally we have sought to use the Clinical Practice Research Datalink database to give use of additional information on resource utilisation. Costs were assessed utilising NHS Reference costing and Healthcare Resource Group (HRG) costing to fairly gauge the real cost of managing dRTA. We quantified costs of inpatient stay, consultations, diagnostics, and pharmacotherapy, all related solely to dRTA management.

Results

Cost of diagnosis is dependent on the patient pathway and age of presentation (e.g. paediatric failure to thrive Primary dRTA verses recurrent stone former with Acquired dRTA). Diagnosis phase costs dominate where there is no familial linkage. Treatment costs vary dependant on therapeutic choice.

Costs of managing dRTA ranges from £2,434 to £22,717 for 12 months of treatment. Costs differ between adult and paediatric dRTA and genetic and acquired forms. Highest costs relate to hospital admissions and percutaneous nephrolithotomy (removal of renal stones) which has an NHS cost of £5,516 (NICE, 2018). Clinician interviews reported that adult patients forming stones can require up to 2 stone removals each year.

Because of low level compliance, current management methods do not remove the risk of stone formation. On average, hospital, pharmacotherapy and diagnostic costs vary significantly between centres and cases. However for more severe cases (as described by clinician), the hospital costs related to inpatient stay contributed to 33% of total costs and interventional procedures contributed to 40% of costs. Pharmacotherapy, despite the very poor levels of compliance contribute to 27% (10-40%) of costs.

Figure 1: Most frequent NHS costs of managing dRTA

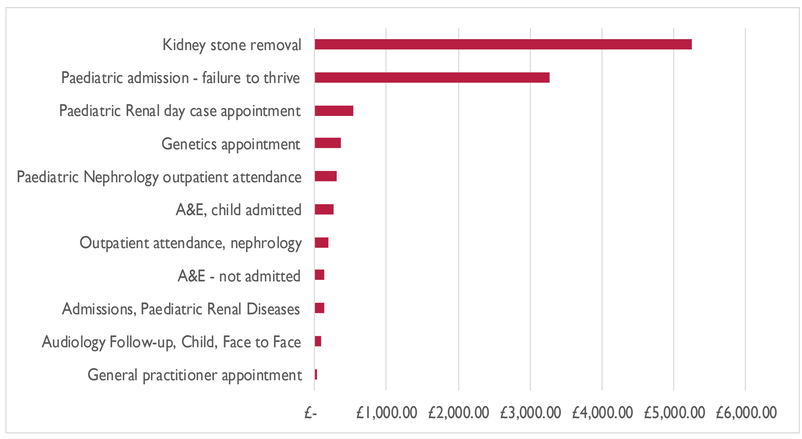


Figure 2: Estimated annual costs of pharmacotherapy in Adults

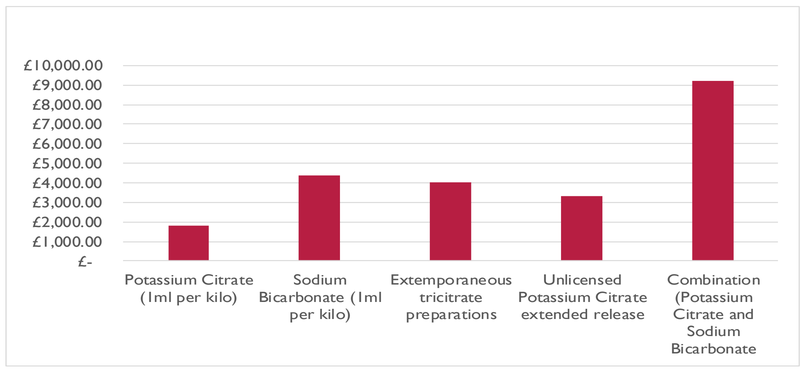


Figure 3: dRTA UK NHS Management Cost Variation

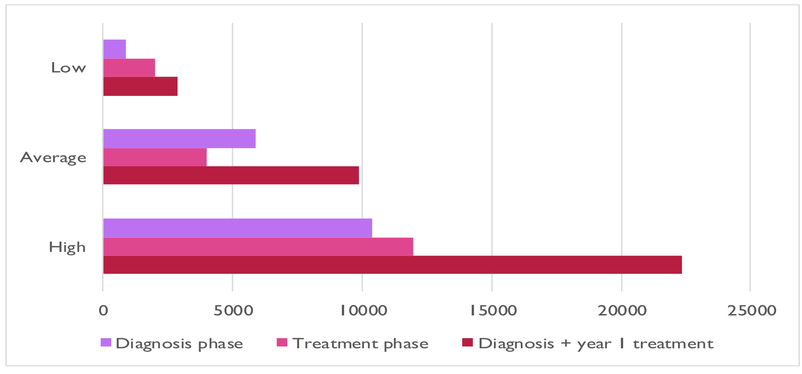
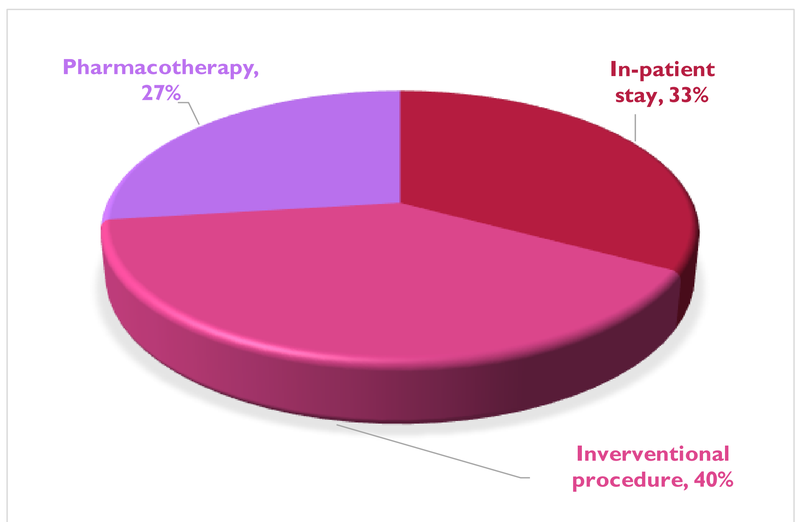


Figure 4: Analysis of hospital costs of dRTA



The total economic burden of dRTA is substantial, particularly where diagnosis is lengthy and undetermined for many years. Direct costs of dRTA include varied alkali therapy that can cost from £100 per year (paediatric) to in the range of £9,200 per year (adult). Indirect costs fall entirely to management of the consequences of poor metabolic control. The major unmet medical need that remains for people with dRTA is that current treatments do not allow an adequate metabolic control to be achieved. Current treatments of dRTA are incredibly difficult to comply with due to the frequency of administration and taste and thus lead to only 49% of patients with dRTA achieving metabolic control. (Lopez-Garcia, 2019). Metabolic control (reversal of acidosis) is identified as critical to reversal or management of the consequences of dRTA, excluding sensorial hearing loss.

Some dRTA patients may have intractable urinary tract infections (UTI) which may or may not be part of their dRTA. The cost of investigation of a UTI with urologist is £1,641.24. Medical therapies range from over the counter treatments to low dose antibiotics for recurrent infections

Due to the complex nature of the condition, clinical management is often disparate and inconsistent across settings. Clinicians reported a higher frequency of out patient appointments for persistently acidotic patients, thus further increasing costs.

Patient pathways may be lengthy with the potential risk of lost to follow up further complicating the economic picture and introducing risk of ongoing complications.

So far, there has been no specific medicine or ready-to-use registered product with a well-defined benefit/risk ratio while various products including hospital/pharmacy-compounded preparations have been routinely used for decades in clinical practice. In spite of currently used treatments (off label or pharmacy/hospital compounded products), patients are not adequately controlled, and treatment compliance is often limited mainly by gastro-intestinal side effects especially in children (Youssef, 2015).

Discussion

The lack of metabolic control in dRTA leads to a number of consequences across the body; and clearly these consequences have considerable cost impacts to healthcare systems. This research did not cover the longer term impact of Osteoporotic fractures or CKD. Given that 14% of dRTA patients suffer fracture neck of femur (Domrongkitchaiporn, et al, 2001) and 82% of adult patients (with dRTA) between 20 and 40 years old had CKD stage 2-4. A third (34.7%) of children (with dRTA) had an impaired eGFR (<90mL/min/1.73m^2), mostly CKD Stage 2 (Lopez-Garcia, 2019), estimating these costs in relation to dRTA will be an important area for future research.

Conclusion

The research demonstrates that the costs of dRTA treatment vary considerably in the UK, ranging from £700 to £22,000 per year for diagnosis and management. Stone forming patients present the highest costs. Metabolic control may not be achieved even in the most expensive to manage cases. These patients cost the healthcare system substantial amounts to manage as a consequence of poor metabolic control of dRTA.

It was noted by clinicians that where a familial link could be established, diagnosis, by genetic testing was both rapid and inexpensive to the healthcare system indicating that routine genetic testing in the disease area may reduce healthcare cost burden.

References

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