Paediatric Special Interest Group: British Society of Haematology

1394 HYDROXYCARBAMIDE THERAPY AMONGST CHILDREN WITH HOMOZYGOUS SICKLE CELL DISEASE IN LARGE DISTRICT GENERAL HOSPITAL – A QUALITY IMPROVEMENT PROJECT

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10.1136/archdischild-2021-rcpch.612

Background Sickle cell Disease (SCD) is a chronic debilitating disease associated with recurrent vaso-occlusive crises, progressive organ damage, and other life-limiting complications. Hydroxycarbamide has been proven to be of clinical benefit in children with SCD and should be offered to all children with SCD who are aged 9 months and above irrespective of their disease severity. It reduces the incidence of vaso-occlusive crises, transfusion requirements, hospitalization and ultimately gives better quality and longer lives.

The clinical efficacy of hydroxycarbamide is achieved by dose escalation, compliance, and laboratory monitoring of toxic effects. Despite the proven benefits of hydroxycarbamide, it is usually underutilized by patients due to fear of side effects and lack of confidence by caregivers to comply with therapy.

Objectives Our study was set out to evaluate our practice of offering and monitoring hydroxycarbamide against the guideline produced by the British Society of Haematology in 2018 for the use of hydroxycarbamide in children with SCD. We also looked at the admission rate, quality of life and improvements in providing the service with the help of the specialist nurse.

This study highlights shortfalls of hydroxycarbamide dose escalation in clinical practice, logistic approach to overcoming barriers to therapy utilization and cost benefits of the appropriate use of hydroxycarbamide therapy amongst children with SCD.

Methods Retrospective single-centred study to evaluate how effectively children with SCD are offered hydroxycarbamide, treatment doses, and monitoring of the effects of the drug against current best practice guidelines. Data was collected by retrieving information from medical notes, electronic blood records, annual review documents, team hydroxycarbamide planner, and discharge summaries.

A qualitative arm of the study was also carried out by telephone interviews of parents by specialist nurse practitioners to understand barriers to the use of hydroxycarbamide and how obstacles were overcome.

Results All eligible children were offered treatment. 62% were started on the appropriate starting dose of 20 mg/kg. 76% had blood monitored within 2–4 weeks of commencement. 90% had regular blood monitoring every 3 months. Only 20% had appropriate dose escalation to the maximum tolerated dose. Only 25% of children had their quarterly review.

A significant reduction of 80% in hospitalisation with SCD related complications. An average increase in haemoglobin of 20–30 g/L was also noted.

An improvement in the quality of life was reported universally with increased parental confidence in medication.

Before the appointment of a specialist nurse into our service, 20% of eligible patients were treated with hydroxycarbamide. We overcame the barrier of poor uptake and communication gaps with the support of the specialist nurse.

Conclusions The guidance has helped us to offer hydroxycarbamide and help families to improve uptake. The role of a specialist nurse is invaluable in supporting the families and monitoring the toxic effect of medication. The quality of life of children has improved significantly with reduced hospitalisation and thus saving cost to NHS.

A nurse-led Hydroxycarbamide clinic is being introduced to further improve our service. We hope that this study will inform paediatricians on simple ways of improving therapy compliance and consequently provide better cost-effective care to children with SCD.

Quality Improvement and Patient Safety

1396 UNCOVERING THE ROLE OF A TELEHEALTH DEVICE IN PROVIDING QUALITY PAEDIATRIC CARE REMOTELY

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10.1136/archdischild-2021-rcpch.613

Background Innovation that improves the quality of care children and young people (CYP) receive is a major theme of the RCPCH 2040 vision. Paediatricians are being challenged to move beyond the virtual consultation adopted during the COVID-19 pandemic and utilise new technology to monitor, care for and treat CYP; empowering them to access services in a way that achieves this.

Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) is the first NHS site in the UK to pilot the use of a handheld Telehealth device called TytoCare. The device enables healthcare professionals, CYP or their carers to link with clinicians remotely, in real time or offline, to enable examination of the heart, lungs, skin, ears and throat.

Objectives Our pilot aimed to assess the usability and potential benefit of TytoCare in CYP with chronic respiratory or life-limiting conditions to reduce face to face reviews by health care professionals, acute admissions and the burden of illness for these CYP and their families.

Methods 1. Stakeholder engagement with the BTHFT Executive, the Paediatric multidisciplinary team, Informatics, Information Governance Department, Clinical Engineering and the TytoCare Company.

2. Workflow design:

a. Professional workflow: a device was utilised by the specialist nurse in each team when a review from a senior doctor, other speciality or other allied health care professional was needed.

b. Patient workflow: families were chosen according to where the clinical team felt there would be greatest benefit