impairment of the brain and/or neuromuscular system and create functional limitations. Impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour.

Using the list of patients we then contacted the parents via telephone or in person to gather the information. We developed a proforma for our parent discussions to provide a standardised approach as well as a parent information sheet to enable consent. Proforma included asking about

- GI issues experienced
- Treatments felt to be most effective
- Effect of GI issues on patient
- Effect of GI issues on family

An online survey was also created and completed by senior clinical staff to compare clinical view with parental responses. The survey for senior clinical staff included questions on

- Which GI problems do they encounter
- How significantly they believe the GI problems affect them
- Which treatments they find most effective
- How confident they feel managing GI problems

Results Age range for patients was from three months to thirteen years.

The most common GI issues experienced were:

- Constipation
- swallowing issues
- GORD

Treatments deemed most effective were:

- PEG insertion
- PPI use
- laxatives

Quality of life most affected by:

- poor weight gain
- device placement and maintenance
- Pain and discomfort

The survey data mirrored proforma information. From the completed surveys 46% respondents stated lack of confidence when managing GI problems in Neurodisability and 100% respondents felt that a formal guidance document would aid the management of these children.

Conclusions GI issues have a significant impact on both patients and family's quality of life. A larger cohort and data is needed in this field and production of a guideline to standardise care would be beneficial. Always remember the importance of treating the child holistically and by managing the simple things well can make a profound difference to the child.

Quality Improvement and Patient Safety

1610

PAEDIATRIC CEREBRAL VENOUS SINUS THROMBOSIS (CVST): A SINGLE-CENTRE AUDIT AND DISCUSSION OF BEST PRACTICE

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Background Cerebral venous sinus thrombosis (CVST) is a rare but serious condition that typically affects children and young adults. Its presentation is variable and non-specific, making diagnosis difficult. Systemic anticoagulation is the first-line treatment, but many patients deteriorate despite this and there is a lack of clear guidance on the management of these patients.

Objectives To characterise the patient population at our institution and evaluate their diagnosis, management and prognosis.

Methods We performed a retrospective, single-centre audit of 29 patients with CVST who were aged between 1 month and 16 years at diagnosis between 2014 and 2021. Patients' time of admission/discharge, presenting symptoms/signs, diagnostic imaging, treatment modalities and follow-up outcomes were recorded via review of electronic patient records. These were compared to a set of standards based on the American Heart Association/American Stroke Association and the British Journal of Haematology guidelines for paediatric CVST.

Results 29 patients (15 female, 14 male) were identified with a mean age at diagnosis of 7.5 years (range 30 days to 15.8 years). 12 presented acutely within 4 days, 10 subacutely and 6 chronically after 14 days of symptoms. The most common signs and symptoms were nausea/vomiting (18/29), decreased responsiveness (14/29) and headache (14/29). The most common risk factor was anaemia (15/29). 11/29 patients had thrombophilia testing with 1 testing positive. Most patients were diagnosed with CT venography and the sigmoid sinuses were most commonly involved. 24/29 patients underwent heparinisation, with 19 of these receiving a full-dose for 7 days. Some patients deteriorating despite anticoagulation were treated with decompressive craniotomy (3/29) and/or endovascular interventions (2/29). Average follow-up time was 19.6 months. 17 patients (59%) achieved full symptom resolution and 5 had complete radiological recanalisation. 1 patient had a recurrence and 4 patients died.

Conclusions Children with CVST at our institution were a heterogeneous population. Most patients received and fully recovered on systemic anticoagulation with heparin. Efforts should be made to switch patients to warfarin once stable and to de-escalate anticoagulation after resolution of thrombus or risk factors. Patients not responding to anticoagulation may be offered decompressive craniectomy or endovascular treatment, but the precise indications for these are undefined.

Paediatric Special Interest Group: British Society of Haematology

1614

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Background Cerebral venous sinus thrombosis (CVST) is a rare but serious condition that typically affects children and