had VSD, 3 had PDA, 1 had pulmonary stenosis, 4 had asymmetric septal hypertrophy, 4 had aortic root dilatation, 2 had LV non-compaction cardiomyopathy and 1 had Hypertrophic Obstructive Cardiomyopathy (HOCM). 92 (41%) were completely discharged, 87 (39%) had arranged follow-up, 11 (5%) referred to adult cardiology and 34 (15%) were to be re-referred 3 years after initial review.

Conclusions Despite clear national guidelines (references) for referral of children with FHx of CHD or ICC in CUHFT, early inappropriate referrals have overburdened the service with the ongoing follow-up of physiological or non-significant findings. We need to develop robust referral pathways to decrease inappropriate referrals and avoid 'too early' clinic attendance to reduce the detection of normal physiological findings (PDA and PFO) in otherwise well children. Onward referral pathways to the national ICC service also need to be agreed to optimise patient care.

Paediatric Educators' Special Interest Group

1108 CIVILITY SAVES LIVES: EDUCATING COLLEAGUES ABOUT THE IMPACT OF INCIVILITY WITHIN A PAEDIATRIC DEPARTMENT

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Background There is increasing recognition within Paediatrics and wider healthcare settings, of the demonstrable impact of uncivil behaviour upon clinical performance and subsequently upon patient care. It has been repeatedly observed that uncivil behaviour reduces the quality of work of the recipient and surrounding team members; and reduces both diagnostic and procedural performance.

Incivility is not always pronounced. It can be subtle and undermining, the impact of which can be destructive to the individual, the team and those that they care for. It can be challenging to confront and when poorly managed it can lead to preventable complications and cause harm to our patients, even if unwittingly.

With the growing evidence of these detrimental effects to both teamwork and patient care, we implemented novel changes within our paediatric department to educate our colleagues on the impact of incivility and how these behaviours can be addressed.

Objectives The primary aim of this campaign was to increase staff awareness of the impact of incivility on patient care from 70% to 100%. Secondary aims were to increase team members' confidence in managing observed or endured incivility at work and decrease the number of colleagues experiencing or witnessing uncivil behaviour.

Methods Preceding interventions, we captured baseline quantitative and qualitative data surrounding staff perceptions of uncivil behaviour via questionnaire. Three interventions within the department were then introduced.

To improve awareness and accountability, staff were invited to sign a 'Civility Charter' in which they commit to supporting an open and encouraging ward environment. 'Civility Saves Lives' workshops were held face to face and virtually, educating staff regarding the importance of civility

within the department and encouraging constructive management of uncivil encounters. Lastly, a 'Supporting kindness in Paediatrics' badge was distributed to team members to initiate discussions and serve as a visual reminder of the importance of the campaign. Post interventional surveys were collated one month after the workshops to enable comparison.

Results Prior to the implementation of the 'Civility Saves Lives' campaign in the department, only 70% of 90 surveyed staff members reported awareness that incivility can impact patient care. Following intervention, this increased to 100%.

On initial surveying, 69% of staff members reported having witnessed or experienced incivility in the last month, with 47% reporting it having had a negative impact on their work. Only 47% of those experiencing incivility had addressed the issue directly, with 33% feeling unconfident to act upon it at all.

One month post interventional workshop, a similar 75% of workshop attenders reported experiencing civility. However, 67% had addressed the issue directly with only 17% feeling unable to do anything about it.

Conclusions An active anti-incivility campaign within the department using workshops, charters and visible badges is effectively raising staff awareness of the impacts of incivility. The campaign is empowering our paediatric colleagues to recognise and challenge uncivil behaviours and helping change our ward culture, to the benefit of our staff wellbeing and our patient care.

British Society for Rheumatology

1110 A CASE SERIES OF THIRTEEN PATIENTS WITH HEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS

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Background Hemophagocytic lymphohistiocytosis (HLH), is an uncommon, life-threatening hyperinflammatory syndrome caused by severe hypercytokinemia with excessive activation of lymphocytes and macrophages due to a highly stimulated but ineffective immune process. It may be primary or secondary to infection.

Objectives To study the clinical and laboratory profile and outcome of children with HLH.

Methods Type of study: Retrospective case series. Data were retrieved from medical records and the data collected included details of clinical and laboratory features, treatment and outcome.

Period of study: March 2015 – August 2016 (18 months)

The diagnosis of HLH was based on the criteria laid down the Histiocytic Society

[HLH 2009 protocol].

Total no of cases – 13

Results Total no of cases 13 – 7 boys & 6 girls

Youngest one was 1 month old & oldest one was 11 years old & 4 were infants.

Clinical features:

We have found HLH in cases like enteric fever (3), other blood culture proved sepsis(2), pneumonia(1), primary immunodeficiency related(1), pyrexia of unknown origin(1), sJIA(2), acute pancreatitis(1), Infectious mononucleosis(1), congenital cytomegalovirus (CMV) infection associated(1).

Fever and hepatosplenomegaly were present in all the cases & other findings like rash (5), respiratory distress (4), lymphadenopathy (3), jaundice (1), bleeding (2) & seizures (2) were also present.

Laboratory features:

Anaemia (four needed blood transfusion) & thrombocytopenia and hyperferritinemia were present in all cases. Neutropenia present in 4 cases but others also showed gradual fall in total counts from leukocytosis towards normal range with clinical deterioration.

Other lab features like low fibrinogen level (10), high triglyceride (9), raised liver enzymes (12), hyponatremia (7) were also present. Fall in ESR present in 6 cases including the sJIA cases.

Bone marrow showed evidence of hemophagocytosis in seven cases.

Treatment:

All patients received supportive treatment including the treatment of cause.

Total 10 cases were infection related of which 4 were treated with IVIG and 3 were treated with steroid and rest 3 responded with treatment of the cause only.

One case was primary immunodeficiency (PID) related [leukocyte adhesion defect] which was treated with IVIG.

All of the sJIA (2) cases received steroid for macrophage activation syndrome and one was treated with cyclosporine also

Outcome:

Most of the cases (8) recovered with specific treatment (gamma/steroid) but three cases recovered with supportive treatment only. Unfortunately two children died - the case of immunodeficiency died of liver failure & the case of CMV infection died of profuse bleeding due to altered coagulation profile not responding to treatment with fresh frozen plasma and both of them died within one week of diagnosis.

Conclusions

- HLH not that uncommon in hospitalized children.
- A mind of suspicion for HLH - In a case of non remitting fever despite the appropriate treatment, Deterioration of clinical condition despite the appropriate treatment.
- Timely diagnosis & intervention can save lives.

Young People's Health Special Interest Group

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CHALLENGES TO THE TRANSITION OF YOUNG PEOPLE WITH COMPLEX HEALTH CONDITIONS TO ADULT SERVICES

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Background Transition to adult services is a critical time in a young person's life. NICE guidelines include five quality statements, which are; planning transition, an annual meeting, a named worker, introduction to adults' services and missed first appointments after transfer. Paediatrics as a speciality is becoming increasingly complex, with significant advances being made in medical care, such as gene therapy for spinal muscular atrophy, developments in neonatal resuscitation and non-invasive ventilation strategies being frequently used for respiratory failure. As a consequence, children are now surviving into adulthood with conditions that would have been previously fatal, many of which are rare and equally complex to manage, involving input from numerous members of the multi-disciplinary team (MDT). For this reason, the transition period for young people with complex conditions is challenging, not only for them but also for their families and needs to be appropriately managed at a time of vulnerability.

Objectives To compare the transition practice in a tertiary children's hospital using the NICE guideline for transition to adult services, NG43.

Methods Data was collected using a SurveyMonkey questionnaire, with twelve questions sent to all consultants in the Trust. Qualitative data was collected from four different specialities via focused interviews.

Results Of approximately 400 consultants, 68 responded over a wide range of specialities: 60.3% have a speciality specific transition pathway, 5.9% have a CNS designated to transition, 50% have a dedicated transition clinic (61.7% are held at the paediatric centre, 23% are held at both paediatric and adult centres and 14.7% are held at the adult centre). One service runs an out of hours transition clinic. 37% of transition discussions begin between the ages of 12 and 15 years. 26.5% start the process after 16 years. Barriers to the management of transition were clinic capacity and administration time, lack of a dedicated co-ordinator, and lack of an equivalent adult service to refer to. 38% of respondents reported negative consequences after transition, such as patient disengagement, anxiety and lack of input from other health professionals.

Interviews were carried out with 4 specialities: Cardiology, Epilepsy, Renal and ENT. Cardiology has the most clearly defined pathway, with a dedicated transition consultant and CNS. Starting at 12 years of age, there are 3 transition appointments with the majority of young people transferred to the designated the adult service by 16 years. The Renal and Epilepsy teams aim for a similar model, however begin transition discussions later and transfer by 18 years. ENT has a specific pathway only for young people with cochlear implants, but no transition CNS. The greatest challenge for all specialities was time available in the appointments and subsequent loss to follow up after transfer.

Conclusions There is considerable variation in the transition process across specialities within a tertiary children's hospital managing complex conditions in childhood. Variability in meeting NICE guidelines is evident. Key concerns are having an identifiable adult service to transfer to, patient disengagement and patient anxiety. A dedicated team for the speciality suggests improvement in successful transition.