symptoms managed were pain, breathlessness, nausea, vomiting, and constipation.

Conclusions Patients with LLC are referred to palliative care from a number of paediatric subspecialties, with the majority of referrals coming from cardiology and oncology. SMPs and SDPs are written for a significant number of patients referred to palliative care. Perhaps not surprisingly, often only a few drugs from the SMP/SDP were required at the end of life, particularly opiates and midazolam.

Further study including the perspectives of all stakeholders –parents and professionals- to better understand the purpose, use and impact of SMP/SDP on symptom control, particularly at the EoL.

Of note this project took place during the coronavirus pandemic, and hence bears repeating when circumstance change.

Paediatricians with Expertise in Cardiology Special Interest Group

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A CASE REPORT OF RE-INVESTIGATION OF A PATIENT TRIGGERED DUE TO THE PANDEMIC- DIAGNOSIS OF AORTOPULMONARY (AP) WINDOW WITH PULMONARY HYPERTENSION

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Background Abstract:

The unprecedented COVID situation has led to a steep learning curve. This is a case report of a patient who previously known to have a diagnosis of innocent murmur was re-investigated and found to have a rare congenital heart disease – aorto-pulmonary window (AP window).

Objectives Introduction:

‘No question is simple’. Alert parents and an astute GP aided in the re-investigation of a murmur which led to the re-visiting the diagnosis from an innocent murmur to Aortopulmonary window (APW).

APW is a rare congenital heart defect occurring as an isolated cardiac lesion or with other cardiac anomalies and rarely with abnormal coronary arteries. Its clinical presentation is dependent on the size of the defect and the associated lesions.

Methods Case report:

A 4.5-year-old boy referred to PEC(Paediatrician with expertise in cardiology) clinic due to the query raised by parents - ‘What are the implications of the pandemic on my child with a murmur?’

This murmur had which was previously investigated when he was a toddler and found to be innocent, was assessed by the GP during the pandemic. Apart from mild difficulty breathing at rest on occasion, the parents posed no other concerns. Parents on reflection comprehend why he did not enjoy physical sports like his peers.

On clinical examination, he had frontal bossing, prominence of the left chest wall and engorged vein in the upper part of chest. He had visible apical impulse, hyperdynamic impulse, gallop rhythm. The P2 was loud and 4/6 pansystolic murmur that radiated all over the precordium and back, loudest at the left lower sternal edge. Rest of his examinations were normal.

Results A further ECHO confirmed AP window with pulmonary hypertension. He had an initial device closure but a residual shunt was identified following a diagnostic cardiac catheterization. He has now had corrective surgery was performed with no intraoperative complication and good echo results. Pulmonary hypertension has persisted and he will be under continued to be followed up in cardiac clinic.

He is going to be followed up in 4–6 weeks in a cardiology clinic.

Conclusions Discussion:

No question is simple and although it has been an unprecedented time last year, it led to re-visiting the child's clinical condition and thus a rare diagnosis.

APW consists of a communication between the ascending aorta and the pulmonary trunk and/or the right pulmonary artery. Some literature suggests a majority of the APW is associated with other cardiac anomalies. Our patient was a case of isolated APW.¹

Literature also suggests APW can be confused with other defects. Clinical findings associated with an adequate echocardiogram can provide the information for the correct diagnosis.

APW has similar hemodynamic features to a patent ductus arteriosus or, even more so, to a common truncus arteriosus (CTA).

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Paediatricians with Expertise in Cardiology Special Interest Group

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OUTCOME OF ADOLESCENT ONSET POTS (POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME)

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Background POTS (Postural Orthostatic Tachycardia Syndrome) is an autonomic dysfunction associated with symptoms of dizziness, headaches, palpitations, fatigue, pre-syncope feelings etc. This is diagnosed with a positive tilt table test which shows a increase in heart rate of more than 40 beats per minute on tilt with stable blood pressures or a sustained heart rate of more than 120 beats per minute in the first 12 minutes of tilt. In children this is commonly diagnosed in the adolescent age group and there is currently not much information on the long-term outlook in this subgroup of children. This case series looks at a cohort of 20 adolescents with POTS and their long-term outcome.

Objectives To look at the clinical course of children with tilt positive adolescent POTS to assess symptom resolution or progression.

Methods Review outcomes with 20 children with adolescent POTS and their clinical information. Children with diagnosis of chronic fatigue syndrome were not included in this study. Clinic follow up letters were reviewed.

Results Of the 20 children in the study there were 15 girls and 5 boys. All of the patients were diagnosed following a positive tilt table test. The age range at diagnosis were

between 13–15 years. The symptoms experienced included dizziness, near syncope, headaches, palpitations, abdominal pain, fatigue, cold hands and feet and low mood. All 20 patients were managed with non-pharmacological advice and pharmacological treatment. Of the 20, only 5 reported complete resolution of symptoms at an average age of 17 years. 12 cases had only mild symptoms (at 17 years) with intermittent exacerbation but were still on medications. 3 patients still had moderate ongoing symptoms at 17 years with ongoing medical management needing transition to adult physicians.

Conclusions Adolescent POTS have a good prognosis with 85% of the patients reporting significant improvement by their 17th birthday. 15% patients unfortunately still continue to experience disabling symptoms which necessitates ongoing care in adulthood. This information is useful in counselling of children with newly diagnosed POTS and understanding long term outlook.

Association of Paediatric Emergency Medicine

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IMPACT OF THERAPEUTIC LIVE MUSIC ON PAIN AND DISTRESS LEVELS DURING INTERVENTIONS WITHIN THE PAEDIATRIC EMERGENCY DEPARTMENT

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Background Music is known to have therapeutic benefits and is frequently used in healthcare. For children in emergency settings, it may reduce stress and pain. There is little evidence evaluating the effect of live music in an emergency setting. This innovative study explores the effect of live music on children undergoing a painful procedure in a Paediatric Emergency Department (PED).

Objectives

- Whether live music helps to decrease pain and distress in children undergoing a painful procedure in the PED.
- Whether these procedures can be carried out with greater ease from a clinician's perspective and whether staff experience is impacted by the presence of live music.
- Overall impact on the PED experience from the patients, families and clinicians' perspectives.

Methods A mixed methods study, designed with input from the local Young Persons Advisory Group (YPAG). Patients between 6 months - 16 years of age undergoing a painful procedure (eg cannulation) in PED were recruited after written consent. All patients received 'standard' distraction techniques and appropriate analgesia eg Ametop. The intervention group received live music (Musicians playing clarinet & guitar) within the cubicle whilst they underwent the procedure and the control group no live music. Data on physiological measures (Heart rate), self-reported pain (Wong-Baker Faces scale >3years of age) & observed pain (FLACC Scale in younger children) were collected in real time by an independent observer. Following the procedure parents, children & clinicians completed a written questionnaire. Questions included 'How did you feel the music affected the

child's distress before, during & after the procedure' and 'Can you tell me about how the live music helped or hindered the procedure'.

Results 110 participants were included in the study. Qualitative responses were overwhelmingly positive, but quantitative results showed no significant positive interaction between music and reduced pain and distress. Qualitative data indicated that live music in an ED setting is reported to make children, parents and staff feel more at ease, creating distraction and change of focus for children undergoing procedures and enhancing wellbeing in the department. Quotes included: 'Thumbs up and special, I was a little bit worried but the music made me happy. I was really brave' (Child). 'My experience today has been positive, I believe the music is beneficial to the children during stressful times' (Parent). 'I think it makes the A&E department a more pleasant environment. Children and staff love it'(Clinician).

Conclusions A ground-breaking study of this nature looking at the effect of live music on children undergoing painful procedures is possible in a busy PED. The qualitative data is overwhelmingly positive and indicates across all groups that live music is beneficial to children, parents and clinicians. COVID-19 has brought further challenges for musicians working within the healthcare setting but this study shows the positive value of their work in an acute clinical environment and that research in this area is vital to patient and staff wellbeing.

British Academy of Childhood Disability

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RAPID DISCHARGE OF CHILDREN WITH MEDICAL COMPLEXITY (CMIC) FROM A SPECIALIST CHILDREN'S HOSPITAL DURING THE FIRST WAVE OF THE CORONAVIRUS PANDEMIC

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Background CMIC are well described to have high health care use and long lengths of time in hospital.¹ In our specialist children's hospital. Our specialist discharge team usually have 18–30 children with the most complex journeys on our case-load. A significant proportion of these children have non-medical barriers to discharge which include care and commissioning, housing, parental training and need for adaptations.² Many of them were perceived to be at increased risk of deterioration should they have caught the SARS-CoV-2 variant.

Objectives We undertook to provide a rapid discharge for this group of children during the first wave of the pandemic.

Methods Rapid discharge was undertaken using the creation of a virtual telephonic and then zoom space to bring together key stakeholders. It was led by silver command and fed into organisational architecture during the pandemic. Stakeholders included clinical teams across institutional boundaries, therapies, social care colleagues and voluntary sector collaborators. Rapid PDSA cycles enabled us to adapt to the changing landscape. Initially the meetings were three times a week, decreasing in frequency to once weekly until the present time. We relied on existing relationships and built new connections.