particularly high, significantly higher than males (34.6 (95% CI 25.3–43.9%) v 25.5 (95% CI 21.0–30.0))

A survey for parents of children with a BMI centile of $\geq 95\%$ revealed that a significant proportion (48%) of parents were 'not worried' about their child's weight. Themes included a restrictive eating pattern, a lack of appropriate physical activity options and a lack of acknowledgement of weight by professionals including doctors and dieticians

Conclusions Although limited somewhat by sample size and a more variable age range than the comparison groups. The service evaluation highlights that the incidence of obesity locally was significantly higher among children with confirmed ASD and that there are some factors and challenges for children with ASD and their parents that justify further research and consideration when aiming to reduce the overall incidence of childhood obesity.

British Association of Perinatal Medicine and Neonatal Society

998 MAKING THE NEONATAL UNIT ACCESSIBLE FOR PARENTS WHO ARE TRANSGENDER AND NON-BINARY: A LITERATURE REVIEW AND LOCAL GUIDELINES UPDATE

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Background 1% of people are thought to identify as transgender and non-binary and yet case reports of openly transgender and non-binary people accessing the neonatal unit as parents is scarce. Anecdotal evidence suggested that people were concerned with accessing obstetric and neonatal services whilst presented as themselves for fear of being misnamed, misgendered or otherwise treated by a system who did not understand their experience. It is likely that people are either not becoming pregnant or presenting as cis-gendered throughout pregnancy and infant care.

Objectives This was a literature review of data available on the wishes of transgender and non-binary people with the aim of writing guidelines for neonatal units within the trust for when openly transgender and non-binary parents access our services

Methods HDAS was used to access medline, pubmed and EMBASE. The search strategy used in each was 'transgender' and 'obstetric or pregnancy or neonatal'. Papers were included which had conducted a survey of transgender and/or non-binary people who had accessed or were considering accessing obstetric and neonatal services. This was further narrowed by only including studies which had questions on the impact being transgender had on accessing postnatal and neonatal services, from lactation specialists to admission of a child to a neonatal unit.

Results By using this HDAS search strategy, 180 published papers were found. Of these 10 met the stated criteria of publishing original surveys of transgender and non-binary people. These papers spoke to a total of 394 people about their experiences considering being pregnant or having been pregnant; 210 in quantitative studies and 184 in qualitative studies. They took place in the USA, Canada, Sweden, 'Western Europe' and Australia. The papers discussed the unique needs

of the transgender and non-binary population, such as inclusive spaces and language, as well as healthcare professionals having a basic understanding of medical needs such as hormone therapy and chestfeeding.

Conclusions The wishes of transgender and non-binary people to enable them to feel comfortable accessing services were education for staff on their health needs and clear ways of communicating name, pronouns and parent nouns. A simple joint perinatal guideline was designed with multi-disciplinary team involvement from antenatal booking as well as a table for parents to fill out to communicate their personal details. It also incorporated information on offering chestfeeding and locating further support as recommended by Stonewall.

The postnatal period and having a baby on the neonatal unit is an incredibly stressful experience for any parent and it is imperative that we mitigate stress where we can by ensuring our parents are able to present the whole selves to their child and those caring for them.

British Society for Rheumatology

999 CAMPTODACTYLY- ARTHROPATHY-COXA VARA-PERICARDITIS (CACP) SYNDROME IN TWO CAUCASIAN SIBLINGS- A CASE REPORT

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Background CACP (Camptodactyly arthropathy coxa -vara pericarditis syndrome) is characterized by early onset non-inflammatory arthropathy with synovial hyperplasia, congenital or early onset camptodactyly, progressive coxa vara deformity and non-inflammatory pleural or pericardial effusion.

Objectives Non-responsive JIA -think of alternate diagnoses

Methods Electronic case records was used to collect data

Results 7-year-old Caucasian boy and his 4-year-old sister were recently diagnosed with CACP syndrome.

7-year-old brother had history of joint swelling in early infancy, but was referred at 3 years of age. He presented with knees, ankles, wrists swelling. He was diagnosed with juvenile idiopathic arthritis (JIA). Despite significant treatment with steroid joint injections, methotrexate and biologics, there was no improvement.

As was the case with his younger sibling, she had presented with flexion contracture of the index fingers of both hands at early infancy which was initially thought to be trigger finger. Following this she presented with bilateral knee and wrist swelling. Ultrasound of knees showed synovial thickening and was diagnosed with JIA at 2 years of age. Despite significant immune-suppression treatment, including intra-articular steroid injections, methotrexate and biologics there was no improvement.

Mutation in the PRG4 gene was detected in both. Parents are awaiting genetic testing.

Discussion CACP syndrome is a rare condition which causes non-inflammatory joint swelling (arthropathy), permanent bending of fingers (Camptodactyly) and sometimes changes in hip joints resulting in shortened legs and possible limb (coxa -vara). It can also cause fluid in the pericardium or pleura.

Autosomal recessive mode of inheritance

Camptodactyly in CACP is usually bi-lateral & congenital, but in some cases, it develops in early childhood. The degree of contracture need not be equal in both & the deformity may progress or not improve.

Arthropathy principally involves large joint such as elbows, hips, knees and ankles. Histopathologic analysis of synovial tissue reveals pronounced hyperplasia of synovium without evidence of inflammatory cell infiltration or vasculitis, while synovial hyperplasia in rheumatoid arthritis is associated with chronic inflammation.

Non-inflammatory pericarditis is reported in 30% of CACP, this may be mild and self-limited. The presence of coxa vara is noted in 50% of published CACP cases.

Diagnosis is based on clinical findings and confirmed by genetics. Patients with CACP have mutations on the gene PRG4 which encodes the secreted protein called lubricin. Lubricin is a protein that lubricates joints and works as a lubricant between the two layers of the pleura and pericardium.

CACP is often mis-diagnosed as JIA because both present with joint swelling.

At present there is no cure or specific treatment for CACP. Much of the research to date is investigating mechanical benefits of lubricin allowing lubrication of joints. Treatment options are physiotherapy and analgesia focusing on relieving symptoms of the disease.

Conclusions CACP mimics JIA due to similar presentation hence causing a delay in diagnosis & probably unnecessary treatment with anti-rheumatic drugs including biologics. Although it is very rare condition, if there is no or poor response to various immuno-suppression treatment in patients with JIA, we recommend looking into non-inflammatory arthropathy and possible CACP.

British Association for Community Child Health

1001

ADVANCE CARE PLANS FOR CHILDREN WITH LIFE-LIMITING CONDITIONS ADMITTED TO PAEDIATRIC CRITICAL CARE

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Background With advances in medical therapies, and increasing use of long-term ventilation, the number of children living in the UK with life-limiting conditions is increasing. Advance Care Plans (ACPs) allow families and, if appropriate the child themselves, to make important decisions about their care in an unpressurised environment. ACPs are essential to providing quality care for children with life-limiting conditions¹ but are often initiated later than considered optimal.

Objectives I aimed to investigate how many children admitted to Paediatric Critical Care (PCC) with a life-limiting condition already had an ACP in place and for those children without an ACP, if their deterioration could have been pre-empted and ACP discussions started earlier in a more appropriate setting.

In addition, I looked into the accessibility of ACPs on Electronic Patient Records (EPR) to assess the sharing of information between the teams involved in the child's care.

Methods Over a 6 month period, the records of children admitted to PCC with a pre-existing life-limiting condition were reviewed to determine the following:

1. Evidence of an existing ACP
2. Documentation of ACP and resuscitation status on EPR
3. Any ACPs completed during PCC admission
4. Discussions regarding ACP during PCC admission
5. Previous number of PCC admissions

Results 32 patients with a life-limiting condition were admitted to PCC over the 6 month period. Their diagnoses included Rett syndrome, hypoxic-ischaemic encephalopathy and neuro-degenerative disorders. 10 out of 32 children had an ACP in place prior to admission. Three children had ACPs completed during admission, following which one child died after withdrawal of care, and discussions about initiating ACPs occurred in three further patients. Of the patients with ACPs, 70% were for full resuscitation. The number of previous admissions to PCC ranged from zero to ten. Two-thirds of children without an ACP had at least one previous admission to PCC. The ACPs were often difficult to locate within our digital patient records and only two ACPs were recorded on the electronic Carevue system specific to PCC and four on hospital-wide EPR.

Conclusions The majority of children with ACPs were for full resuscitation, and all were admitted to PCC, highlighting that not all ACPs equate to ceilings of care or 'do not resuscitate' decisions, but can instead be used to express the family's wishes for their child's care. Overall 20% of families were involved in ACP discussions during their child's admission to PCC. This is a stressful and time-pressured environment in which to expect families to make such important decisions. We need to empower general and community paediatricians to start ACP discussions with families earlier, which would allow families the time and space to make these decisions. In addition, earlier implementation of ACPs can serve as a platform for further discussions in the event of the child being admitted to PCC acutely unwell. However, for ACPs to be fully effective we need a facility to allow ACPs to be easily located on EPR in order to facilitate sharing of information between teams involved in the child's care.

REFERENCE

1. The End-of-Life Care Strategy, Department of Health, 2008.

British Society of Paediatric Endocrinology and Diabetes

1005

STUDY OF VISFATIN AND FETUIN-A IN TYPE 2 DIABETES MELLITUS IN CHILDREN

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