Making the Neonatal Unit Accessible for Camptodactyly-Arthropathy-Coxa Varra

A survey for parents of children with a BMI centile of ≥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

Rebecca Trenear, Catherine Warnick. Barts Health Trust

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 of being transgender and 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

1Anupama Mallappa, 2Gulshan Malik. 1Royal Aberdeen Children’s Hospital, 2Royal Aberdeen Children’s Hospital

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.