EMOTIONAL AND BEHAVIOURAL PROBLEMS AND IMPROVING THE MANAGEMENT OF MENSTRUAL PROBLEMS IN YOUNG PEOPLE WITH PHYSICAL DISABILITIES OR LEARNING DIFFICULTIES – INITIAL INSIGHTS FROM A PILOT SURVEY

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Background Puberty and menarche can be a challenging time for young people with additional needs resulting from physical disabilities or learning difficulties. Patients and carers often turn to clinicians for advice for managing anything from normal menstruation to problems including dysmenorrhea and menorrhagia. It is important that doctors who see young people with disabilities have a good understanding of these issues, recognising the distress they may cause. Paediatricians should have skills and knowledge sufficient to initially assess and manage these problems and an awareness of where to signpost or refer to locally.

Objectives To assess current knowledge and understanding of the management of menstruation difficulties in young people including the Child Behaviour Check List (CBCL), the Strengths and Difficulties Questionnaire, and the Development and Well-Being Assessment.

Results Out of more than 300 children invited to the study, the carers of nearly 100 children were initially screened for attachment difficulties using questionnaires, with 67 completing the Disturbances of Attachment Interview. Of these, 30 families proceeded to be recruited into the RCT, from which baseline data was collected (including the measures of children’s emotional-behavioural functioning). Approximately one third of children met criteria for RAD, according to the interview data. However, it is unclear if the prevalence in this sample is representative of the population of children in foster and kinship care in the UK due to low response rate and potential non-randomness of non-responses. Analyses of the remaining findings are still ongoing, but the CBCL results, for example, reveal high levels of emotional-behavioural problems, with many subscales in the clinical range, such as Externalising and Total problems.

Conclusions The study brings to light the challenges of completing research in the foster care context in the UK. However, stakeholders were unanimous that research of this kind is urgently needed. The high levels of social, emotional and behavioural difficulties found highlight the vulnerability of children in care and the need for evidence-based interventions to address them. Feasibility insights for a future trial of the current intervention will be discussed. Regarding children’s psychopathology results, first, the significance of the prevalence of RAD symptoms that we found will be discussed in relation to existing data from children in foster and institutional care worldwide, as well as the limitations of a RAD ‘research diagnosis’ and the difficulties around the RAD clinical diagnosis more broadly. Second, the significance of children’s level of difficulties in the other scales and association between their psychopathology symptoms and attachment problems will be discussed.
The use of cervical auscultation to detect subtle audible wet pharyngeal sounds (SAWPS-CA) as a screening tool for silent aspiration in infants with trisomy 21

Infants with Trisomy 21 (T21) are at a high risk of aspiration, mostly silent, making them susceptible to respiratory conditions. While disorders in the oral preparation and transport are easier to detect, disorders affecting pharyngeal function are not always overt, making identification of at-risk children difficult.

Since establishing the Down Syndrome Health Surveillance (DSHS) in 2015, all infants with T21 are referred for a feeding evaluation by SLT, during which the presence of subtle audible wet pharyngeal sounds on cervical auscultation (SAWPS-CA) is assessed. These subtle sounds can be indicative of oro-pharyngeal dysfunction and are hypothesised to be associated with aspiration leading to respiratory issues.

The sample comprised all children with T21 aged 0–18 months referred to DSHS between 2015-2018 (N=33). Clinical records were reviewed specifically for the presence of SAWPS-CA, at initial and 4–8 month assessments; and aspiration confirmed via VFSS. Four categories of medical comorbidity hypothesised to be indicative of aspiration were reviewed (prenatal, respiratory, cardiac, gastrointestinal abnormalities).

SAWPS-CA was observed in 5 infants at initial assessment (15%), rising to 20 children at 4–8 months (61%). Sixteen of these 20 children were referred for VFSS which confirmed silent aspiration in all cases. The remaining 4 SAWPS-CA-positive children went on to develop chest infections, and were referred for VFSS at this stage. They all aspiration silently during the study. The 13 SAWPS-CA-negative children have remained asymptomatic with no respiratory complications during the study period.

The presence of any one or more of the categories of comorbidity (prenaturity, respiratory, cardiac, gastrointestinal abnormalities) was significantly associated with the presence of SAWPS-CA (using logistical regression; Odds Ratio = 11.9, p=0.035). No individual comorbidity significantly predicted a positive SAWPS-CA for silent aspiration, likely due to the small sample size and limited statistical power.

Results suggest SAWPS-CA at 4–8 months is effective for identification of T21 children at risk of aspiration. Furthermore, the presence of any cardiac, GI, prematurity and respiratory comorbidities may be indicative of greater risk. We propose that infants with T21 be assessed and screened by an SLT by 8 months of age for possible aspiration using this technique. Priority should be given to those who have at least one additional comorbidity. VFSS provides best visualisation of a dynamic swallow, but is invasive, costly and requires a hospital setting. SAWPS-CA by a trained SLT can be used to identify those at greatest risk of oro-pharyngeal dysphagia requiring further evaluation using VFSS. Further work in a larger clinical sample would establish the sensitivity and specificity of SAWPS-CA in T21.

With learning difficulties or physical disabilities in paediatric doctors working at a UK teaching hospital. As a pilot survey, questions will be assessed for their usefulness before potential further dissemination. It is hoped we can then use this information to address gaps in knowledge, ultimately improving the current quality of the care received by this group of patients.

Methods A pilot survey was created and distributed online to paediatricians working at a UK teaching hospital. Confidence and current knowledge were self-rated using 5-point Likert scales (1=No confidence/No knowledge). Results were analysed using descriptive statistics in Microsoft Excel.

Results Twenty-nine responses were received in total. Sixteen of the respondents (55.2%) were general paediatric doctors, the remainder consisted of doctors working in community child health (4/29), neurodisability (5/29) or paediatric sub-specialties. Approximately two-thirds (65.5%, 19/29) of respondents were consultants. Almost three-quarters (21/29, 72.4%) of respondents rated their confidence in managing menstrual difficulties as low (3; only 3/29 (10%) felt very confident. Results were also similar for the question ‘How confident do you feel in discussing and commencing initial management?’ – this question was aimed more towards medical management (e.g. the oral contraceptive pill) and will be re-worded in the final survey to differentiate from general management. Thirteen respondents (38%) were confident (rated ≥4) in both signposting to services and knowing who to refer to for further help. Current training provision was limited with only 5/29 having received formal training in the past. Although training is lacking and confidence is low, 20/29 respondents recognised the significant impact (rated≥4) it can have on quality of life for those affected.

Conclusions This pilot survey provides valuable initial insights into current confidence around the management of menstrual problems in those with learning difficulties or physical disabilities. Paediatricians locally recognise the burden that menstrual difficulties can place on patients and carers. However, exposure to previous formal training is rare and confidence in the initial management is low. Some questions which have been identified as being too similar will be reviewed prior to further dissemination. Moving forwards it is clear more educational opportunities will need to be created, and we will work with local experts to increase provision of this following completion of the finalised survey. After implementing quality improvement measures a repeat survey is planned. Additional qualitative work on patient/carer experiences is also being considered.