Paediatric Special Interest Group: British Society of Haematology

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EXPLORING THE ANXIETIES AND EXPERIENCES OF CHILDREN WITH SICKLE CELL DISEASE DURING THE COVID PANDEMIC

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Background Sickle cell disease (SCD) results in functional hyposplenism and impaired immunity with risk of respiratory infections and pulmonary complications.¹ During the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic, patients with SCD were identified as 'high risk' and received shielding advice.² Health related anxiety in the general population has been great throughout this unprecedented global health crisis, and this survey was carried out to evaluate how these anxieties have affected a specific vulnerable patient group with SCD.

Objectives This project aimed to gain an understanding of parent's views and experiences of the COVID-19 pandemic when they have a child with an immunocompromising health condition such as SCD. The secondary aims were to encourage timely hospital presentation by allaying their fears through explaining new infection control set up.

Methods A telephone survey of the local cohort of families with one or more children with a diagnosis of SCD was carried out between April and August 2020 at a district general hospital using a questionnaire entitled 'COVID-19 - How are you doing and how can we help you?'. 11 questions were asked of one parent from each family and the answers collated and analysed. Additional responses were obtained during the clinic consultations, virtually or in person.

Results 45 families with 54 children (27 male) were successfully contacted and supported during the pandemic. 32 of these families gave responses on behalf of 42 children to all 11 survey questions. The age of patients ranged from 10 months to 16 years, 15 were adolescents and contributed to responses. 57% had HbSS genotype, of which 16 were on hydroxycarbamide and 28% had HbSC. 53% of families reported worrying about attending hospital during the coronavirus outbreak, 34% felt significantly isolated and half felt that the virus outbreak had significantly changed how vigilant they are regarding their child's symptoms. However, no family made unscheduled changes to their child's regular medications in response to the virus, with no significant difference between HbSS or HbSC cohorts found (p -value >0.05). All but one participating family felt that they had received sufficient information about the pandemic from the clinical team and 81% felt no additional support was required. In particular, those on hydroxycarbamide were satisfied with the provision of home blood monitoring and prescription delivery. 7 families reported trusting information provided through social media, however they verified this with known hospital teams. During the study period there were 3 admissions for sickle crises, all testing negative for coronavirus.

Conclusions The survey indicated the positive role that the community sickle cell nurse specialist played in liaising with the families throughout the pandemic, informing and educating them and attempting to resolve any anxieties or concerns that they had. It further helped to identify any specific queries

regarding prescriptions and missed appointments and allowed the community team and the local consultant paediatrician with haematology expertise to provide extra support and information where needed, helping to reduce hospital attendance related anxiety and minimise delays in presentation throughout the COVID-19 pandemic.

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Child Protection Special Interest Group

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THE AWARENESS OF ADVERSE CHILDHOOD EXPERIENCES FOR PRACTITIONERS IN TRAINING

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Background The term ACES (adverse childhood experiences) was first recognized in 1988 by the Kaiser Permanente study that identified three main areas that related to premature death in adults, abuse, neglect and household challenges (Bryan:2019).

The concept of childhood adversity was further explored by Felitti et al (1988) cited by Olsen and Warring (2018) who suggested that there are ten categories of abuse and family dysfunction that were linked to a variety of poor health outcomes; physical abuse, sexual abuse, emotional abuse, physical neglect, emotional neglect, violent treatment of the mother, household substance abuse, household mental illness, parental separation or divorce, incarceration of a household member.

It is apparent that Adverse Childhood Experiences are a significant public health concern (Olsen and Warring: 2018). Frontline health professionals particularly medics and nurses will require knowledge around the topic of adverse childhood experiences in order to carry out an assessment for the mitigation of risks to children and their families. Furthermore, Gill et al (2018) argues that many health professionals have highlighted their unmet needs about the knowledge of adverse childhood experiences in their education and work.

Following a literature review exploring 'How does education support students with adverse childhood experiences?' (Turner: 2020) This literature review highlighted:

1. Professional knowledge and awareness of childhood adversity and how this effects children and young people across the life course is a work in progress
2. Adverse childhood experiences have long term consequences at population level, and in turn this effects health, educational and social outcomes
3. Inter professional learning can be valuable to share knowledge and learn new information and skills
4. Importance of awareness and knowledge of childhood adversity has been identified within the literature and it is evident that literature pertaining to this is also lacking and requires further development (Turner:2020)

Objectives To ascertain the levels of knowledge and whether there are gaps in knowledge of practitioners in training.

To assess the current knowledge and understanding of trauma informed care.

Methods A questionnaire pilot study, sampling pre-registration BSc nursing students in the first year of a three-year pre-registration degree

Results The results of this pilot study identify two clear themes:

1. Students identify not knowing enough about trauma informed care and wish to learn more.
2. Students identify a clear learning need around adverse childhood experiences. Requesting to attend a workshop with service user involvement which focuses on the lived experience and the effect of childhood adversity.

Conclusions Following evaluation of the research I wish to introduce the concept of trauma informed care for the second-year student nurses. Furthermore, work with the undergraduate medical school to introduce trauma informed care to medical students.

Conduct further research with other allied health professional students to ascertain their knowledge and understanding. For example, with samples of allied health professionals, paramedics and midwives.

Further research to be conducted with trained health care professionals to ascertain their understanding and knowledge.

This pilot study will be preparatory work for a larger scale study as part of a professional doctorate.

Children's Cancer and Leukaemia Group

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CHILDHOOD, TEENAGERS AND YOUNG ADULT CANCER SYMPTOM AWARENESS AMONGST FUTURE DOCTORS

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Background Child Cancer Smart (<https://www.cclg.org.uk/child-cancersmart>) is a UK public and professional awareness campaign aiming to raise awareness of the symptoms and signs of children, teenagers and young adult (CTYA) cancers. In seeking evidence for the campaign to enhance public and professional awareness, a series of systematic literature reviews of symptomatology of common cancer clusters of childhood are being conducted. The campaign is also assessing awareness amongst different target populations in order to inform the development of key messages as well as tailored educational resources.

Objectives To assess the level of knowledge and awareness on the symptomatology of childhood cancer amongst undergraduate and graduate-entry medical students at the University of Nottingham.

Methods The online cross-sectional questionnaire survey was carried out in October 2020. Inclusion criteria were all medical students who were in their 3rd, 4th or 5th years (Clinical Phase CP2-CP3) during the study period and consented to take part in the survey. Study questions covered respondents' perception about cumulative cancer risk across childhood and early adulthood, confidence in recognising signs and symptoms of CTYA cancers, factors which would potentially influence

clinical decision making, and the awareness of childhood cancer signs and symptoms.

Results A total number of 163 (90 CP2 and 73 CP3) clinical years students at the University of Nottingham took part in the survey. About 77% (126) of the respondents felt the quoted cumulative risk (1/200 by the age of 25) were higher than they expected. Only 6.7% felt confident to recognise the signs/symptoms of childhood cancer.

Factors likely to influence decision making included worsening of symptom (159, 98%), persistent/recurrent symptom (152, 93%), family history of cancer (148, 91%), accumulation of symptoms (145, 89%), gut instinct (140, 86%), multiple symptoms at presentation (119, 73%), multiple visits to healthcare professionals (109, 67%), parental concern (94, 58%), patient's age (70, 43%) and communication barrier (54, 33%).

On average, respondents identified 35.2 out of the 43 signs/symptoms. Top ranked signs/symptoms recognised by >95% of respondents were persistent/recurrent headache, lump or swelling in chest wall or armpits, abdominal distention or mass, persistent/recurrent tiredness or fatigue, visual abnormality, lump or swelling in face, jaw and skull, fever and night sweats and seizures or fits. The least recognised symptoms were torticollis (58%), leukocoria (59%), persistent earache (60%), developmental delay in young children (60%), slow growth (61%) and early/delay puberty (61%).

Conclusions This project provides the first insight into a gap in awareness of childhood cancer amongst medical students. This is important and further work is needed to understand whether this is a regional or national gap which could be improved through changes in the medical school curriculum nationally.

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IS HHV-6 ASSOCIATED WITH INCREASED MORTALITY IN PAEDIATRIC STEM CELL TRANSPLANT PATIENTS?

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Background Human Herpes Virus Type 6 (HHV-6) is a beta herpes virus which infects nearly 100% of people in early childhood and establishes lifelong latency in the host. Infection with HHV-6 in children seldom leads to severe disease or requires treatment.¹ However, in immunocompromised paediatric patients, such as those who undergo haematopoietic stem cell transplantation (HSCT), research has shown a significant association between reactivation of HHV-6 and severe clinical complications.² Despite this, there is insufficient evidence to decipher whether infection with HHV-6 in paediatric HSCT patients leads to an increased rate of mortality after transplantation.

Objectives We set out to examine the mortality rate in paediatric HSCT patients with and without HHV-6 infection as the first step of a wider project aiming to develop guidelines for HHV-6 screening paediatric SCT patients.

Methods We performed a retrospective, cross-sectional analysis of patients aged 0–18 years undergoing HSCT in Leeds Children's Hospital within the time period of October 2015 - December 2019. This data was cross-referenced with a list of all the patients who had HHV-6 detected in a BAL, Blood or