Paediatric Special Interest Group: British Society of Haematology

1189

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

1190

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.