ABSTRACT

Knowledge, Attitude and Practices of Parents/Caregivers of Children with Sickle cell Disease Toward the Management of Painful Crises

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Sickle cell disease (SCD) is one of the most common inherited genetic disorders, which results from an abnormality in the β globulin portion of haemoglobin. Under stressful conditions the red blood cells undergo structural changes that leads to microvascular and macrovascular occlusion, the most common manifestation of which is an acute painful crisis or veno- occlusive episode. Sequalae of recurrent painful crises may include restriction of daily activities, decreased school attendance and performance, decreased participation in hobbies, maintenance of social contacts, sleep and appetite and disturbed emotional state. It also increases utilisation of health services. The majority of these recurrent severe painful crises can be managed in a home setting. Therefore it is important that parents/caregivers have good knowledge of SCD and its management in order to improve the quality of life of their child/ward.

The aim of this study is to determine the knowledge, attitude and practices of parents/ caregivers of children with sickle cell disease toward the management of painful crises.

Parents/caregivers of children in the new cohort followed up at the Sickle Cell Unit (SCU) who attended the unit during the study period were invited to participate in this study. A questionnaire divided into 3 domains: 1) Basic Knowledge of SCD, 2) Knowledge of painful crisis and its management 3) Attitude and Practices of painful crises management was administered while they were attending the SCU in Kingston, Jamaica W.I.

Ninety-one parents/caregivers were interviewed, 89% of which were mothers. Though basic knowledge was good only 10% obtained a passing knowledge score. Knowledge scores were better for parents/ caregivers of older children, those who received a pain management sheet and persons who knew their sickle status. Most caregivers knew common triggers of painful crises. Panadol and Cataflam were the most frequently used drugs. Non-pharmacological methods were well known and used by parents/ caregivers though distraction techniques were underutilized. A disparity was found between the knowledge and practices of the parents/caregivers in some areas The majority of caregivers (91%) were willing to be further educated about managing pain at home. Sixty-three percent of parents/caregiver believed they were coping well with their child's/ward's painful crisis.

The findings of this study indicate that though there were some deficiencies in parental knowledge and practise with regards to the management of painful crises in SCD, parents believed that they were coping well and were willing to receive further education.

Keywords: Sickle Cell Disease, Painful Crisis, Knowledge Attitude and Practise, Mara Hosang