Association of Paediatric Palliative Medicine

1050 INTEGRATING A MODIFIED PAEDIATRIC PALLIATIVE CARE SCREENING (MPAPAS) TOOL AS A STEP TOWARDS GOAL-CONCORDANT CARE AT A PAEDIATRIC CARDIORESPIRATORY UNIT

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Background Goal-concordant care for children with complicated critical illness requires balancing multidisciplinary teams (MDT) input, decisional conflicts, and communication challenges that are team-based (opportunities, effectiveness) and family-based (goals, understanding).

The Paediatric Palliative care Screening scale (PaPaS) for stratifying palliative care benefit in children was originally designed for a general paediatric population.

Objectives To help us navigate relationship with specialist MDT and families, we developed a modified (mPaPaS) tool in 2019 to communicate our multidisciplinary assessment. Three domains were modified relevant for our patient cohort with complex cardiorespiratory diagnoses and treatments, reflecting length of stay in hospital, category of life-limiting or life-threatening conditions, and institution of extracorporeal-membrane-oxygenation (ECMO) resuscitation in the event of cardiac arrest.

We describe our pilot use of integrating mPaPaS tool with our multidisciplinary assessment proforma (MAsPro) from focus group discussions to define holistic needs under 5 domains of disease burden, treatment burden, life expectancy, symptom burden and patient/parent preference.

Methods We examined domains of illness from mPaPaS and outcome, indicating stepwise approach to monitor needs, explore understanding or refer for palliative care.

Results From September 2019 to January 2021 (excluding the March-July 2020 pandemic period), 90 children have been discussed at our weekly complex care meetings.

26 children, median age 7.6 months (range 5days to 16years), had completed mPaPaS. In-hospital stay was over 30 days in 13 (50%) patients, of whom 3 were beyond 6 months length of stay.

Treatment burden was high in 31% (n=8), which included ECMO, multi-organ support for chronic lung disease of infancy or staged palliative surgery. These treatments were clustered within first 2 weeks of hospital admission, and 180-day survival was 75%.

Of the 5 children where the screening question ‘would you be surprised if the child were to suddenly die in 6 months’ time’ replies were ‘no’, 2 died by 90 days, 1 had lung transplant at 4 months, 1 died at 14 months (accrued time at home less than 6 months) and 1 was discharged home by 18 months.

Psychological distress of parents relating to child’s symptoms scored moderate-high in 65% (n=17), and 3 parents expressed wish to formulate needs that are best met by palliative care.

Based on high mPaPaS score, 5 patients were referred for specialist palliative care, one subsequently received lung transplant as part of parallel planning, 1 referral to hospice for carer respite and 3 advanced care plans were completed.

Integrating mPaPaS with MAsPro led to clinical psychology input for parents and/or patient as part of anticipatory care for withdrawal of life support (n=2), and enhance engagement with therapists for rehabilitation (n=1) with play therapy.

Conclusions For children with complex and/or multistage interventions, including palliative surgery and potential long-term organ support, the framework of integrating mPaPaS tool with focus on multidisciplinary assessment can help distil complex needs into achievable goals to be responsive to patients and families.

Quality Improvement and Patient Safety

1051 PREHOSPITAL PAEDIATRIC BURN CARE: A RE-AUDIT. THE ADEQUACY OF COOL RUNNING WATER FIRST AID

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Background Appropriate initial management of paediatric thermal burns is key to the prevention of complications and improvement in patient outcomes. Interestingly, research revealed significantly poorer knowledge of burns first aid (FA) management among healthcare workers, when compared with non-healthcare workers. Guidelines recommend all patients receive twenty minutes of cool running water up to three hours following injury. The administration of cool running water not only serves an analgesic function but is also associated with significantly reduced odds of skin grafting. The present re-audit evaluates the FA care of paediatric burn patients with a focus on the adequacy of cool running water.

Objectives Our aim is to determine the adequacy of cool running water FA provided in the management of children with thermal burns. The FA treatment of paediatric burns was specifically examined in the context of pre-hospital and
SLEEP DISTURBANCES IN PRESCHOOL CHILDREN WITH AUTISM SPECTRUM DISORDER AT A MALAYSIAN TERTIARY HOSPITAL

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Background Children with autism spectrum disorder (ASD) have a myriad of associated health problems which affect their overall quality of life. These include sleep disturbances, which may have been under-recognised previously. Recent research have indicated that children with ASD have more sleep problems compared to their typically-developing peers. However, there is limited information regarding the prevalence of sleep problems among preschool children with ASD. The Sleep Disturbance Scale for Children (SDSC) was originally validated on a sample of healthy children 6–16 years old, but it has been proven to have a good level of internal consistency (Cronbach’s alpha: 0.83) for preschool children between the ages of 3–6 years old. This questionnaire has also been validated in the Malaysian children population in previous studies.

Objectives This study aims to determine the prevalence of sleep problems and associated factors in a group of Malaysian preschool children between the age 3 and 6 years old, with autistic spectrum disorder (ASD) diagnosed as per DSM-5.

Methods Patients who fulfilled the inclusion criteria were recruited from the Child Development Clinic, Universiti Kebangsaan Malaysia Medical Centre (UKMMC). Demographic data was obtained and the Sleep Disturbances Scale for Children (SDSC) questionnaire was completed by the main caregiver. Logistic regression analysis was used to determine factors related to higher total SDSC scores.

Results A total of 56 preschool children were recruited (48 boys) with a median age of 5 years (IQR = 9 months). Twenty-one of them (37.5%) obtained a pathological score for at least one subtype of sleep disturbances on the SDSC with eleven children (19.6%) scoring high for overall sleep disturbances. For each sleep disturbance subtype: DIMS 23 (41.1%), PAR 10 (18%), SBD 2 (3.6%), DOES 17 (30.4%), DA 8 (14.3%), NRS 6 (10.7) while no participants achieved pathological score for SHY. Majority of them had insufficient night sleep duration of less than 8 hours (35.7%) and prolonged sleep latency beyond 30 minutes after bedtime (46.4%). A significant proportion of the preschoolers with ASD had co-morbidities (39.3%) in which more than a quarter (26.8%) had attention-deficit hyperactivity disorder (ADHD). The practice of co-sleeping was common in a majority of the households (94.6%). Using logistic regression analysis, four factors were significantly associated with higher total SDSC scores; female gender (p = 0.032), insufficient sleep length (p < 0.001), prolonged sleep latency (p = 0.021) and the practice of co-sleeping (p < 0.001).

Conclusions Sleep disturbances are prevalent in Malaysian preschool children with ASD, especially DIMS. Female gender, insufficient sleep length, prolonged sleep latency and household practice of co-sleeping were found to be significant factors associated with sleep disturbances. Evaluation of sleep problems should form part of the comprehensive care of preschool children with ASD. Individuals at risk for sleep problems could then be directed to appropriate avenues for support and therapy.

Abbreviations: DA, disorders of arousal; DIMS, disorders of initiating and maintaining sleep; DOES, disorders of excessive somnolence; NRS, nonrestorative sleep; PAR, parasomnias; SBD, sleep breathing disorders; SDSC, Sleep Disturbance Scale for Children; SHY, sleep hyperhidrosis.