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Cleft Lip and/or Palate (CLP): Parents’ Experiences and Perceived Impacts on the Quality of Life of Their Child and Families.

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Objectives: To describe Malaysian parents’ experiences of having a child born with CLP (their reaction to the diagnosis, coping methods, social reaction and support, health care cost and utilization); to assess parents’ perceived impact of CLP on the QoL of their affected child and families; and its impact by family factors and clinical details.

Methods: A mixed-method study was employed using ‘in-depth’ interviews and ‘face-to-face’ interview with PedsQL™. Twenty parents from various backgrounds (qualitative) and a convenient sample of parents from CLAPAM Registry or who attended Combined Cleft Clinic at UMMC/UKMMC (quantitative) were recruited.

Results: Parents’ reaction towards clefts varied with mostly feelings of shock and being upset. Getting information and learning from others’ experiences were among their coping methods. Family and community support influenced parents’ coping ability. The mean scores of all dimensions were above 80.0 for child’s QoL and 60.0 for families’ QoL. The children’s ‘Psychosocial Health’ was lower compare to ‘Physical Health’ while The ‘Family Functioning’ summary scores were higher than ‘Parent HRQoL’. Both the children’s and families QoL were higher among the 25-59 months old children. CLP children of parents with lower income, and Muslim (1-12 months old) had higher QoL. Families with Malay mothers’, having lower education levels, and Muslim mothers’ (1-12 months old) showed better QoL.

Conclusions: Findings indicated that parents’ reaction as well as their coping methods varied. Social reaction and support were important for parents to adapt to the condition. Demands for treatment at public hospitals were higher compared to private ones. CLP children aged younger than five years were less affected compared to their families. The impacts were more on the children’s ‘Psychosocial Health’ and ‘Parents HRQoL’ for families. Household income and child’s age influenced the child’s QoL while mothers’ ethnicity, education level and child’s age influenced the families’ QoL. Types of cleft and treatment status also influenced both children’s and their families’ QoL.