PARENTAL SATISFACTION TOWARDS THE MANAGEMENT OF CLEFT LIP AND/OR PALATE: AN EXPLORATORY STUDY

Chong Boon Keng

ABSTRACT

Cleft Lip and/or Palate (CLP) is the most common congenital defect of the face. Individuals who are born with cleft may require multiple surgical procedures and frequent outpatient attendance from birth to maturity. While the primary outcomes in the management of CLP are focussed on producing normal facial appearance and function, and normal feeding, hearing and speech; parental satisfaction should also be used to validate the overall quality of care received by children born with CLP. Currently, data regarding the primary outcomes of management of CLP and the subsequent parental satisfaction in Malaysia is unknown. Hence, this qualitative study was conducted to explore the parental satisfaction concerning the management of CLP available in Malaysia. The aim of this study is to determine the factors that influence parental satisfaction towards the management of CLP. Data for this study was derived from semi-structured individual interviews with twenty parents of children with non-syndromic CLP. The interview data was transcribed verbatim and descriptively analysed. Qualitative analysis was used to categorize transcription into themes. The results of this study showed that there were a total of 12 factors that influence parental satisfaction towards management of CLP. All parents agreed that the three main factors were 1) delivery of healthcare services, 2) quality and specificity of information, and 3) implementation of early intervention programme, while over 70% of the parents also agreed that psychosocial aspect of the child and family, timing and results of surgery, existence of parents’ support group, and early feeding management were factors that also played an important role in determining their satisfaction towards the management of CLP. In conclusion, evaluation of the management outcomes must take into account the satisfaction and psychosocial well-being of the parents and the child as well as effects on growth, function and appearance.