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Home and environment survey of children with cleft lips and palates

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Background: Cleft Lips and Palates (CLP) are congenital facial deformities that affect patient's breathing, swallowing, talking and often resulting in unclear communication. These facial defects also limit the ability of intellectualization, socialization and education of the children. At the same time, families are affected by both feelings of loss and regret and have to face those challenges arising from their children due to the facial abnormalities. Restorative care for the patients with CLP requires clear care goals. The care includes correction of the defect and restoration of the physiological functions and also psychological care in order to develop the image that children will have for themselves from adolescence to adulthood. Care and rehabilitation require close coordination of multidisciplinary teams and understanding for patients and families, social context and the disease. Family adjustment, understanding from society around and limitations on access to medical services, is important factor that need to take into account when providing care for the patients with CLP in order to meet the real need of the patients and their families. Tawanchai centre has been trying to improve the care of this group of patient by integrating care of the various sectors. A home visit project was conducted to see family context from the real situation with the aim of making the care team understands the system that links care from families, communities, hospitals and various levels of care. This would lead to a complete care system appropriately for each age group and promptly detect emerging problems from the care in order to be a truly complete care model.

Materials & Method: A preliminary descriptive study was conducted with 20 patients with CLP who were treated at the Srinagarind hospital during the age of 0-12 years which covered all age ranges of major care. A total of twenty home visits were performed. Four research assistants interviewed the patient's caregiver for 45 minutes in three aspects including, 1) the patient's demographic data 2) the caregiver's demographic data 3) the caregiver's attitudes towards caring the patients. The volunteers were also interviewed for 30 minutes for demographic data with structured open ended questions. A 20-minute home and environmental survey was conducted. Quantitative data were analyzed using percentage and content analyses were used to analyze qualitative data.

Result: The results can be divided into four: 1) the patient aspect: data were collected from 10 males and 10 females and the majority of participants were studying in primary school. For nutritional status, 12 patients had normal BMI and 14 patients were underweight whilst 4 patients were overweight; 2) the caregiver aspect: the main caregiver was mother, their common reported occupation was farmers and housewife. The caregivers completed primary or secondary schools, were married, being in an extended family and had good relationship with other family members, had debt, had no concerns about their child with CLP but caring for them more than any other children; 3) volunteer aspect: the majority of the volunteers were the village health volunteers, females predominantly and had completed compulsory school. They reported providing care for this group of children like normal children. There were no guidelines or sufficient knowledge in taking care of the patient with CLP and needed government agencies to provide training for educating and care for the patients with CLP; and 4) environmental aspect: the most of home environment were in good enough level. Only four families had poor environment, was not safe, needed continuing monitoring and corrected.

Conclusion: From home and environment surveys of the patient with CLP, most family members are extended families with poor status. There are concerns about caring for their children. Only four families had poor environment, being not safe, needed continued monitoring and corrections. The community lacks the guidance to care and help the group of patients. The government should provide trainings for educating the proper care in order to prevent further mental health problems.

Biography

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