

## Psychological Experiences of Parents having a Child with Cleft Lip and Palate

SMT Laksrini, WAD Dilrukshika, YMJM Yapa, AAI Sirimanna, MAR Saumika#, N Liyanage and KGPK Munidasa

*Department of Nursing, Faculty of Health Sciences, The Open University of Sri Lanka*

#rasodasaumika@gmail.com

**Abstract:**-Cleft Lip and Palate (CLP) is one of the most common congenital craniofacial conditions globally. Parents' who are having Children with CLP are facing various types of experiences. A qualitative study was conducted to explore the parent's psychological experiences of having a child with CLP. Twenty parents who take care of children with CLP more than three months were purposively recruited for this phenomenological study. The study was conducted at Dental Teaching Hospital, Peradeniya and ethical approval was obtained from the Faculty of Allied Health Sciences, University of Peradeniya. Data were collected using semi-structured interviews and data analysis was done using thematic analysis method. Three major themes were emerged from the data as excessive sorrow, fear towards the surgery and coping with the child's birth defect. Not having the child that parents expected to have, low body weight of the child and sadness towards child's future with CLP were perceived as reasons for excessive sorrow. Probable complication of the surgery and lack of knowledge regarding the surgery were reasons for fear towards the surgery. Follow up treatments and family supports were helped parents to coping with the child's birth defect. These main negative adverse experiences and drawbacks help to understand several hidden unpleasant experiences of parents having a child with CLP. Hence, it is needed to ensure the importance of arranging social support services for these parents which are one of the

neglected areas within the health care context of Sri Lanka.

**Keywords:** Cleft Lip and Palate, Parents, Experiences

### Introduction

The CLP are among the most common congenital craniofacial birth defect globally. The CLP is referred to an abnormal opening of the lip and roof of the mouth (Revezes, 2013). A cleft lip and, on occasions a cleft palate, may be visualised antenatally by ultrasound scan and if identified early allows an opportunity to inform parents prior to birth. However, a facial cleft lip may also remain undiagnosed until the birth, when the full extent of the anomaly becomes apparent at delivery (Beaumont, 2006).

Child with CLP can be emotionally, socially, traumatic for parents (Johansson, 2004). The worldwide parents have so many experiences with CLP children. Johansson (2004) further explained parents slowly adapted to this situation. Most of the time, there is no major difficulties or problems with feeding a newborn child with Cleft Lip whereas a child with Cleft Palate has feeding problems because of its incapability to produce effective oral suction. According to clinical standards advisory group in United Kingdom (1998), the CLP may affect to child's capability such as feeding, chewing, breathing, and hearing along with cause to disorders of dental, facial, speech and even in language development.

Addressing about the 'loss', 'mourning' and 'correcting' have been common aspects in

research viewpoints in surrounding the diagnosis of a child with a cleft, which informed by the assumptions of previous theoretical perspectives (Olshansky 1962; Solnit & Stark 1962; Drotar et al., 1975). Both pre- and post-natal, across countries and cultures, parents' feelings of shock, anger, grief and worry have been identified equally in surveys and in qualitative studies (Bradbury & Hewison 1994). Coy et al. (2002) found that some mothers of children with CLP or CP showed extraordinary protectiveness and responsiveness towards their children, as they viewed them as vulnerable.

There are many studies in worldwide regarding parents' experiences having child with cleft lip and palate. However, it is hard to find published studies related to this area in local context. Therefore, this study was aimed to determine the experiences of parents who are having children with CLP and identifying what kind of humanistic nursing care that should be provide to these parents

## METHODOLOGY

This is a qualitative phenomenological study. Semi- structured interviews were used to collect data on parents' experiences and close observations to observe their expressions and responses. A sample of 20 participants was selected purposively considering the characteristics of population and objectives of the study. Parents who take care of children with CLP more than three months were recruited to the study and child should be diagnosed with CLP by a pediatrician and Oro Maxilla Facial surgeon and record should be available. This study conducted at the Dental Teaching Hospital, Peradeniya. Ethical approval was obtained from the ERC of Faculty of Allied Health Sciences, University of Peradeniya. Data analysis was done using thematic analysis method.

## RESULTS

Sample was comprised with 85% of Sinhalese, 5% of Muslims and 10% of Tamils. They were

belongs to three age groups as 40% in 18 - 25 years, 35% in 25 - 35 years and 25% over 35 years. As level of education 60% parents had completed Ordinary level (O/L), 30% had completed Advanced level (A/L) and 10% were graduates. Furthermore, 10% of them were employed, 90% were unemployed. Considering the gender of the child 70% were male and 30% were female. Within the sample only 10% was diagnosed pre-natal stage. Among 20 children 5% diagnosed as Cleft lip, 15% children were diagnosed as Cleft palate and 80% diagnosed as both cleft lip and palate. From those 20 children 15% had family history of cleft lip or palate. When considering the birth order of child 55% were first child of the family.

Three major themes were emerged from the data as excessive sorrow, fear towards the surgery and Coping with the child's birth defect.

Excessive sorrow: Not having the child that parents expected to have, low body weight of the child and sadness towards child's future with CLP were perceived as reasons for excessive sorrow.

*"When I saw her, I didn't know what I could do with her. I thought there would be nothing anyone can do to my child. I was feeling something terrible" (Participant 06).*

*"This is my first baby. We were looking for three years for a baby. We never thought our baby will be like this. When the nurse has shown my baby to me, I felt like this baby is not mine. I cried lot" (participant 8).*

*"When compared to other children, my baby is having low body weight. it's always make me sad" (participant 2).*

*"She is a girl; I really worry about her future with this condition" (Participant 5).*

Fear towards the surgery: Probable complication of the surgery and lack of knowledge regarding the surgery were reasons for fear towards the surgery.

*"I saw my baby lay on the theatre bed unconsciously. I was afraid. The doctor said that the baby is sleeping. But I had a fear that my baby will not be recovered after surgery" (participant 14).*

*"I searched about surgery via online. And I saw photos of babies before and after surgery. Then I strongly decided to go to the surgery as soon as possible. Before that I wasn't that much sure about the surgery" (participant 1).*

Coping with the child's birth defect: Follow up treatments and family supports were helped parents to Coping with the child's birth defect.

*"When I took her to the clinic, I saw some children who were in the same condition. I understood that this is common, and I saw the pictures before and after treatment. I felt guilty that I hid my child in the beginning. I saw a nurse with the same condition and I was more encouraged that my daughter also will have bright future" (Participant11).*

*"When I came to the hospital I saw many children with cleft lip and palate with their mothers, and I found that very strengthening. It helped me keep on track. I saw some children who have got treatment. I got new hope" (Participant3).*

*"As I went to hospital, I met many in the same condition. I became strong and even encouraged them. When I am there, I forget things that bother me and I feel am in a better position where treatments are available." (Participant14).*

Most of participants worried of their family acceptance. There were many complaining, comparing with other children and not supportive from their extended family such as mother, mother in law, grandmother, sisters and sister in law.

*"My mother in law said me that I was the first lady to give birth a child like this in their family" (participant 09).*

*"My sister in law always comparing her two children with my little one. She said again and again try to emphasise my baby is giving an extra burden to the family" (participant 12).*

However, some participant has good family acceptance.

*"My mother was with me until I got stronger and emotionally stable. Even in the hospital, she was the first one who came to see my baby. I was very happy to have her standing by my side" (Participant 4)).*

*"I think my mother in law is a great woman. She never complained me. She supports me always. She kept lot of hopes of her granddaughter. She always said with me that all the things happened according to the karma and we have to accept it. She participated to the bodhi puja to bless my child" (participant 09).*

## DISCUSSION

All most all participants of this study had great sorrow due to their children's condition. They were shocked when they were showing their baby at the first time. Similar findings were identified in other studies done in South Africa and Nigeria (Hlongwa & Rispel2018; Fakuade et al., 2012). This study was identified that most of the participants were denial to accept unfortunate condition and appearance of their child. Nidley (2016) also stated that the most parents of child with CLP in United States had denied.

All of participant initially had fear and confused for surgery. most of parents had reduced the fear in second time in palate surgery. These findings are also consistent with another study done by Chuacharoen et al., (2009).

Coping with the child's birth defect is a major finding that was identified in this study. Follow up treatment and family support were the sub themes in coping with condition. Most participants said that regular follow up treatment was help them coping with the child's birth defect and reduce psychological

discomfort. In a study done by Young *et al.*, (2001) also found similar situation in their study which highlighted that follow up treatment was a good coping strategy.

## CONCLUSION

Majority of the parents who are having children with CLP had negative experiences that they had to face in their life. The findings of this study can be used in staff education to promote understanding of Parents' experience and how best to help them to recover from psychological issues. And also counseling program will be started in the hospital for parents with cleft lip and palate child for reduce psychological disturbances.

## ACKNOWLEDGEMENTS

We wish to express our appreciation to the entire participants of the research project for their valuable co-operation and, the consultant and nursing staff of the Dental Teaching Hospital, Peradeniya

## REFERENCES

Beaumont, D., (2006) Exploring parental reactions to the diagnosis of cleft lip and palate. *Paediatric Nursing* 18(3):14-8.

Bradbury, E. T. & Hewison, J. (1994) Early parental adjustment to visible congenital disfigurement. *Child: Care, Health and Development*, 20, 251–266.

Chuacharoean, R., Rithugol, W. Hunsrisakhun, J. & Nilmanat, K. (2009). *Felt needs parents have 0 to 3-month-old child with a cleft lip and palate*. Scholarly article. Faculty of dentistry, Prince of Songkla university, Karnnjanavanitrd, Hat Yai, Sonngkla, Thailand.

Clinical Standards Advisory Group (1998) Cleft Lip and/or Palate. Report of a CSAG Committee. The Stationery Office, London, UK

Coy K., Speltz M.L. & Jones K. (2002) Facial appearance and attachment in infants with

orofacial clefts: a replication. *Cleft Palate-Craniofacial Journal* 39(1), 66–72.

Drotar, D., Baskiewicz, A., Irving, B., Kennell, J. & Klaus, M. (1975) The adaptation of parents to the birth of an infant with a congenital malformation: a hypothetical model. *Pediatrics*, 56, 710–717.

Fakuade, B. O., Efunkoya, A. A., Adebayo, A. M., & Adisa, A. O. (2018). Psychosocial impact of cleft lip and palate children on their parents. *Nigerian Journal of Basic and Clinical Sciences*, 15(1), 50.

Hlongwa, P., & Rispel, L. C. (2018) "People look and ask lots of questions": caregivers' perceptions of healthcare provision and support for children born with cleft lip and palate. *BMC public health*, 18(1), 506.

Johansson, B. & Ringsberg, K. C. (2004). Parents' experience of having a child with cleft lip and palate. *Journal of Advanced Nursing* 47(2), 165–173.

Nideley, B. A. (2016, January). Psychological wellbeing of parents of children with oral cleft. *Child care Health Development*, 15, 42-50.

Olshansky, S. (1962) Chronic sorrow: a response to having a mentally defective child. *Social Casework*, 43, 190–193.

Revezes, L. J. (2013). Incidence of orofacial cleft in Ghana. *Journal of ISRN Plastic Surgery*, 10, 1-6.

Solnit, A. & Stark, M. H. (1962) Mourning and the birth of a defective child. *The Psychoanalytic Study of the Child*, 16, 9–24.

Young, J. L., O'Riordan, M., Goldstein, J. A., & Robin, N. H. (2001). What information do parents of newborns with cleft lip, palate, or both want to know?. *The Cleft palate-craniofacial journal*, 38(1), 55-58.