

Exploration of the Lived- in Experience of Mothers of Infants with Oral Facial Clefts

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Reprint Request

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Received on November 15, 2017

Accepted on December 08, 2017

Abstract

The present study was conducted to explore the lived- in experience of mothers of infants with oral facial clefts in selected Hospital, Thrissur. Objectives of the study were to elicit the lived- in experience of mothers of infants with oral facial clefts and to prepare a coping module for those mothers. Qualitative research approach with phenomenological design was used. Ten samples were selected by using convenient sampling technique. Content validity of the tool was done with the help of experts and the reliability was based on trust worthiness of the data. The data were collected with a semi structured interview and analyzed using thematic analysis. Five themes were derived from exploring the lived- in experience of mothers of infants with OFC. The themes were divided into physical dimensions, psychological dimensions, social dimensions, spiritual dimensions and economical dimensions. Various subthemes were derived from these themes. The results of the phenomena studied have helped to develop a conceptual frame work. The study concluded that the mothers of infants with oral facial clefts had both positive as well as negative experiences.

Keywords: Lived-in Experiences; Mother; Infant; OFC; Coping Module.

Introduction

Birth of the child is a greatest moment in a mother's life. But after the child's birth, if it becomes apparent that something is wrong with the child, the beautiful moment is replaced with shock and disappointment. When children are born with oral facial clefts (OFC), the stigma of OFC affects not only the individual but also the family and society. No congenital anomaly has more complexity and diverse than cleft lip and palate. When child born with OFC mother is under shock and distress [1].

It is estimated that overall global prevalence of oral facial clefts is one individual in every 600 new born babies. Assuming 15,000 births per hour worldwide, a child is born with cleft somewhere in the world in every 2 minutes. The Indian subcontinent remains one of the most populous areas of the world with an estimated population of 1.1 billion, in India alone.

This yields an estimated 24.5 million births per year and birth prevalence of clefts is somewhere between 27,000 and 33,000. Cleft lip and palate occur in about 1-2 per 1000 births in the developed world [2].

Statement of the Problem

A study to explore the lived- in experience of mothers of infants with oral facial clefts in selected Hospital, Thrissur

Objectives

- To elicit the lived- in experience of mothers of infants with oral facial clefts.
- To prepare a module on coping strategy for the mothers of infants with oral Facial clefts

Operational Definitions

- *Lived- in experience*: Refers to the expressed experiences of mothers while taking care of infants with oral facial clefts.
- *Oral facial clefts (OFC)*: It is the congenital anomalies of the face which includes cleft lip and palate.
- *Mothers*: Refers to mothers of infants affected with oral facial clefts (OFC).
- *Infants*: Refers to the age group of children between 1 month to 1 year, who is affected with cleft lip and palate.

Assumptions

Mothers of infants with oral facial clefts may have both positive experience and negative experience.

Methodology

Design

Qualitative design with phenomenological approach.

Setting

Charles Pinto Center at Jubilee Mission Medical College, Thrissur.

Sample and sampling technique

Convenient sample of 10 mothers of infants with OFC who is admitted in Charles pinto Centre for surgery.

Sampling Criteria

Inclusion criteria

- Mothers who are able to speak and understand Malayalam.
- Mothers who are willing to participate in the study.
- Mothers who are available during data collection period.

Exclusion criteria

- Mothers with hearing problem.
- Mothers who are not willing to participate in the study.
- Mothers of infants with both cleft lip and palate.

Instruments

Section A: Demographic profile of mother

Demographic profile of infant

Clinical profile of infant

Section B: Semi structured interview schedule regarding the experience of mother of infants with OFC.

Data Collection

Ethical clearance was obtained from the ethical committee constituted by the institution on 8/4/2016. The investigator obtained a written informed consent from authorities of Jubilee Mission Hospital, Thrissur.

After obtaining permission from the concerned authority, the procedure for data collection was explained to the study participants. The informed consent was obtained from the samples to audiotape the interview.

An in depth interview was conducted using a semi structured questionnaire. Each sample took 30-45 minutes for the completion of interview schedule. Coping module was administered after the completion of interview. Some of the mothers discussed their doubts briefly.

Data Analysis

Taped interview dialogue were listened to and transcribed in to verbatim. Thematic content analysis was done by Colaizzis analysis. It includes: -

- Read all the subjects description to acquire a feeling for them.
- Return to each protocol and extract significant statements from each transcript.
- Spell out the meaning of each significant statement, known as formulating meanings.
- Organize formulated meanings into clusters of themes.
- Results so far are integrated into an exhaustive description of the phenomenon under study.
- Formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification as possible.
- A final validating step can be achieved by returning to each subject and asking about the findings so far [3].

Themes and subthemes in exploration of lived- in experience of mother of infants with OFC.

Themes	Subthemes
Physical dimension	Sleep disturbance Insomnia Difficulty to feed her child Tiredness Headache Breast engorgement Breast tenderness
Psychological dimension	Disappointment Mal adjustment Anxiety Fear to feed the child Guilty feeling Sadness Withdrawal from society Worries about Child’s condition Neglect the child
Social dimension	Support from partner Support from family members
Spiritual dimension	Blaming God Strength from prayers
Economical dimension	Financial difficulties Inability to continue employment

Physical Dimension

Difficulty to feed her child

Most of the mothers 8(80%) experienced difficulty to feed her child. Some of the mothers Expressed that they experienced difficulty to feed her child due to less production of milk.

“I felt the child is not fed properly because of the milk secretion is less.”

Few mothers expressed that difficulty to feed her child due to aspiration of milk coming through the nose.

“I can’t feed the child, because while I am feeding the child, milk is coming through the nose, the child can’t breathe and also the child becomes blue in color.”

Sleep disturbance

The majority 6(60%) of mothers had sleep disturbances. Some mothers expressed that they had disturbed sleep due to tension.

“Thinking about my child’s condition and future I had disturbed sleep.”

One mother told that she had experienced disturbed sleep due to the child’s condition.

“During the first few days after delivery, I was little tensed about my child, even though my mother

was beside me, a slight noise made by the child would wake me up.”

Insomnia

The most of the mothers 7(70%) experienced insomnia. Majority of mothers expressed that they had lack of sleep due to anxiety.

“I had tension about the condition of my child and her future which disturbed my sleep.”

“Day and night seemed to be same for me. Since I was sleepless throughout as I had given birth to a girl baby, suffering from cleft lip. I am always thinking about the child. Whether the disorder would affect her for the whole life and whether due to this, she will have to face many problems in life.”

Tiredness

Majority of mothers 6 (60%) felt tired. Some of the mothers expressed that they felt tired due to repeated hospitalization of the child and also due to lack of sleep.

“My child was admitted in ICU because he had cleft lip. Due to the admission of the child in ICU, I often had to go to feed the child that I had no time to take rest.”

One of the mothers verbatim is as follows

“As per our customs and tradition, we got traditional treatment after delivery. But as my child has cleft lip, I was unable to take care of myself. I was deprived of the traditional treatment as others. It may be the only reason why I am tired Most of the time when compared to others.”

Headache

6(60%) of the mothers experienced headache. Few mothers said that they felt headache due to the tension about child's condition.

“Thinking about child's condition, I used to experience headache.”

“When I realized about the condition of the child, I was so tensed that I had a Severeheadache. In many situations it will subside only with T. Paracetamol.”

One mother commented that she had giddiness followed by headache.

“I was concerned most of the time about my child. Due to that tension I had severeheadache. Mean while I experienced giddiness. It was difficult for me to remain constant for a single minute. I tend to be off balance. I was on Medication.”

Breast engorgement

Few mothers 2 (20%) felt breast engorgement because of accumulation of milk in breast.

“During first few months, baby had not sucked the breast properly because of cleft lip. The breast became enlarged so I squeezed the milk to remove it from the breast.”

One mothers complaints that fullness of breast

“During first few months, the child did not sucking the breast because of cleft lip. So I felt fullness of breast that the milk was accumulated in the breast and the breast became hard.”

Breast tenderness

Few mothers 2(20%) experienced tenderness over the breast.

“My child had opening in his lip, so he was unable to suck the breast. Because of that the milk was accumulated in the breast, I felt slight pain in the breast during initial period.”

One mother said “I didn't notice the tenderness around the breast because of my tension.”

“Although I felt pain over the breast, I didn't notice the tenderness around it because I was always

bothered about how to feed my child carefully without the entry of the milk into the gap.”

Psychological Dimension

Disappointment

Some of the mothers 3(30%) expressed that they felt disappointment due to the facial deformity of the child.

“When I saw my child for the first time, I was so shocked, mentally down and imbalanced that I did not recover from the shock.

Even I wasn't able to accept my child. I didn't allow my child to lie near by my side. Due to this I sought counseling and I have undergone many counseling sessions.”

One mother said that she faced lots of mental problems after delivery.

“Since I had to face many mental problems after the delivery of cleft lip baby. I was mentally down, imbalanced and had not shown any interest in any activity.”

Maladjustment

Most of the mothers 5 (50%) had maladjustment to the unexpected situation (child with cleft lip).

“It was new experience to me. It took fifteen days to adjust with the situation. After fifteen days only I could hold the baby in my arms. “

Few mothers told that they had adjustmental problems in feeding the child.

“I had fear to feed the child. I couldn't adjust with the situation, so my mother used to help me to feed the child.”

Anxiety

All mothers 10 (100%) experienced anxiety and worries regarding the child's condition.

“When I thought about child's condition, I was so anxious about how to take care of my child and what can I do for my child.”

“After child's birth, I experienced anxiety regarding his condition and health.”

Fear to Feed the Child

Majority 9(90%) of mothers had fear to feed the child due to aspiration of milk. Several mothers experienced that they had the fear during the time of feeding the child.

"While feeding the child, milk comes through the nose. Due to that the child can't breathe and turns blue. Due to this, I had difficulty to feed the child."

Some mothers said that they had less knowledge about child's condition and related to feeding.

"I had fear to feed the child because I did not know anything about the feeding technique of my child."

Guilty Feeling

Few mothers 2(20%) felt guilty because of the child's appearance.

"I felt guilty while travelling with my child."

"When we travel, my mother-in-law used to cover my baby with cloth, because my baby had cleft lip."

One mother told that

"I had two abortions. Now I feel stressed that because of me only, my child got Cleft lip"

Sadness

The majority 8(80%) of mothers feel sad. Some mothers expressed that they feel sad due to the child's appearance.

"I cried a lot when I saw cleft lip for my baby which I had not seen in anyone before."

"I was so sad when I saw opening seen in the lip for my baby."

Withdrawal from Society

Most of the mothers 6 (60%) experienced withdrawal from society. Some of the mothers expressed that they experienced withdrawal from society due to guilty feeling.

"I do not even take my baby out even for family functions with us because of the facial deformity and often relatives will ask lots of questions about the Condition of the child."

Worries about Child's Condition

Majority 4 (40%) of mothers had worries about child's condition

"After the birth of the child, I was worried regarding the future and health of my child. I was so worried as to how to take care of my child and what to do."

Most of the mothers experienced worries about child's condition due to poor feeding

"I couldn't breastfeed my child, because of that

the child didn't gain adequate weight."

Neglect the Child

Few mothers 1(10%) neglected the child

One mother expressed that

"When I saw my child for first time, I was so shocked. Even I was not able to accept my child. I didn't allow my child to lie by my side. It was new experience to me; I took fifteen days to adjust with the situation. After fifteen days only, I took my baby in my hands."

Social Dimension

Support from Life Partner

Several mothers 4 (40%) had support from partner. Some of the mothers expressed that they got support from partner.

"My husband supported me saying that a baby is a gift from God which we should accept."

Few mothers expressed that support from the partner made her more confident.

"I got psychological support and courage from my husband to face the problems."

Support from Family Members

Some of the mothers 4 (40%) expressed that they got support from family members especially for taking care of the child.

"My family supported me by helping me to take care of my child while feeding, bathing."

Blaming from Family Members

Almost mothers 6 (60%) experienced blaming from family members. Majority of the mothers got blaming from her mother in-law and it made them psychologically down.

"My mother in law always blamed me for the condition of the child saying that in her family nobody had such a deformity and this is due to curse from God."

One mother narrated that

"Because of husband's family's influence, my husband did not even come to see my child and sent me a divorce notice."

Spiritual Dimension

Blaming God

Majority 6(60%) of mothers were blaming God after the birth of the child.

“Before delivery, I used to pray to God for a healthy baby, but I did not get what I wished and became angry with God.”

One mother complaints that

“During pregnancy time, I used to pray with my husband, but now there exists a gap between God and me.”

Strength from Prayers

Few of the mothers 3(30%) were strengthened from prayers

“I prayed to God for the success of the surgery and the good condition of the child.”

“At that time there was a separation from God but now I feel that the baby is a gift from God and I thank him for the baby.”

Economical Dimension

Financial Difficulties

Most mothers 7(70%) experienced Financial difficulties because of the cost of treatment.

“We already spend lots of money for infertility treatment and delivery. Now my baby has undergone surgical treatment due to the cleft lip. So I experienced some financial problems.”

“Although we had some financial problems because of the treatment of the child, we tried to manage it on our own.”

Inability to continue the employment

All of them 10 (100%) belong to the category of home makers. So no one has given the narrative description related to the discontinuing of the job.

Discussion

The present study was undertaken to explore the lived experience of mothers of infants with OFC. The main objectives of the study were to elicit the lived-in experience of mothers of infants with oral facial clefts and to prepare a module on coping strategy for the mothers of infants with oral facial Clefts. In this study 10 interviews were carried out with mothers of

infants with OFC. Totally 5 themes were identified in the analysis such as physical dimensions, psychological dimensions, social dimensions, spiritual dimensions and economical dimensions. During the interview, investigator identified seven sub themes of physical dimension like sleep disturbances, insomnia, difficulty to feed the child, tiredness, headache, breast engorgement and breast tenderness. After the data analysis the researcher categorized psychological dimension into nine sub themes like disappointment, maladjustment, anxiety, fear to feeding the child, guilty feeling, sadness, withdrawal from society, worries about child's condition, and the neglecting of the child. The social dimension was categorized as three subthemes that were support from partner, support from family members and blaming from family members. The subthemes derived from spiritual dimension were blaming God and gaining strength from prayers. The last theme economical dimension was further divided into financial difficulties and inability to continue the employment.

Conclusion

This study explored the lived experience of mothers of infants with OFC. A mother who is having OFC child undergone through various physical, psychological, social, spiritual and economical changes should have positive as well as negative emotions. Findings of this study are useful for nurses in taking care of mothers during the hospitalization. Mothers must be involved in decisions and cares. They must be supported for reducing anxieties and stresses. If nurses understand the stress that mothers experience and adopt the principles of family centered care, mothers will feel supported throughout their journey of the child's treatment and it may alleviate the anxieties that were evident in this study.

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