

What If the Cleft Child is Yours?

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ABSTRACT

Every 3 minutes, a child is born with a cleft lip or cleft palate and make the child to suffer from hunger and thirst, difficulty with speech and social stigma (Operation Smile, n.d.). Yes, Cleft (lip/palate) is usually accompanied with stigma from the society especially when they lack information about it. When a baby is born into the world the whole family rejoices but in the case of the cleft (lip/palate) child the parents end up in shock and sadness. It even makes the parents and their families think that having a cleft child is a curse in itself. One of the factors that the parents' of cleft (lip/palate) child limit themselves from taking their cleft (lip/palate) child to social gathering as they are scared that the society may have a negative attitude towards them. Assumptions about its cause make the parents difficult to adjust to the situation. People would talk behind them discussing about the cause of cleft (lip/palate) saying that their parents did something wrong that is the reason why their cleft child is the consequence. Twelve year old twins from a small state (Meghalaya) in India do not want to go to school or play with the other children because they were named as daughters of the devil and ugly simply because they were born with a cleft lip.

Key words: cleft (lip/palate), problem, family and social stigmatization.

INTRODUCTION

The cleft lip is an opening in the bones of the upper jaw and/or the upper gum and the cleft palate happens when the tissue that makes up the roof of the mouth does not join together completely during pregnancy (Mersch, 2014; Redett, 2009; Operation smile, n.d.; Nordqvist, 2009).

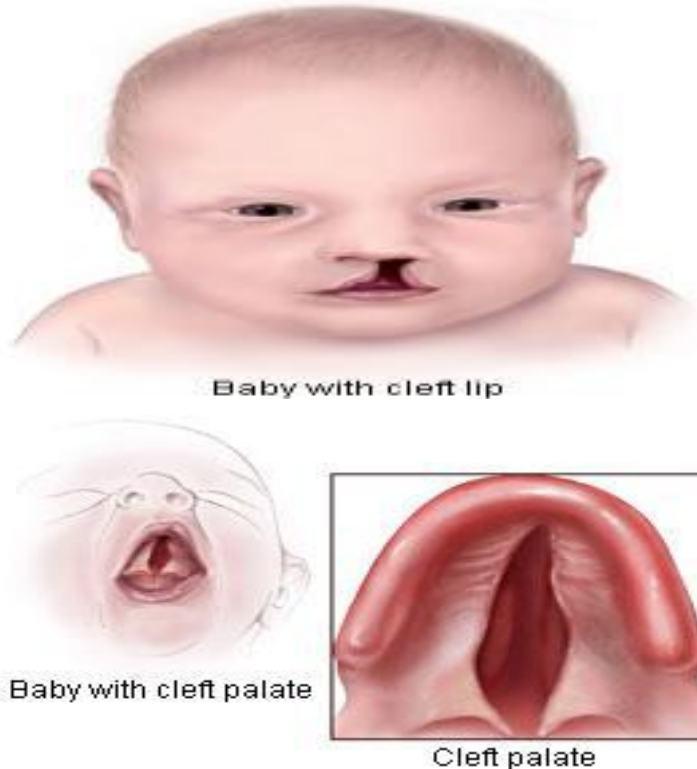


Figure 1

Figure 1 - Source: Centers for Disease Control and Prevention, 2015

Having a child with cleft lip and / or cleft palate birth condition can be very challenging and traumatic. Studies also showed that a person is considered to be attractive regardless of the physical or facial appearance as long as he has a healthy physical appearance. Thus, living with a change in appearance of one's face as a result of injury or disease is a very challenging task. This also implies to children with cleft and their parents who have to adjust to this challenge (Devare et al. 2009). Hence, most of them may face issues of self-esteem if they are concerned with visible differences between other children and themselves. Cleft can be repaired and with right and timely treatment; children who have cleft lip or/and cleft palate can still lead a very normal, healthy and happy life (Better Health Channel, 2014; Centers for Disease Control and Prevention, 2014).

DIFFICULTY IN FEEDING

Parents of such deformity find difficulty in feeding such children and thus most of them are victims of malnutrition mainly caused by partial starvation. But with the right feeding method this can be addressed, thus awareness about it, is essential.

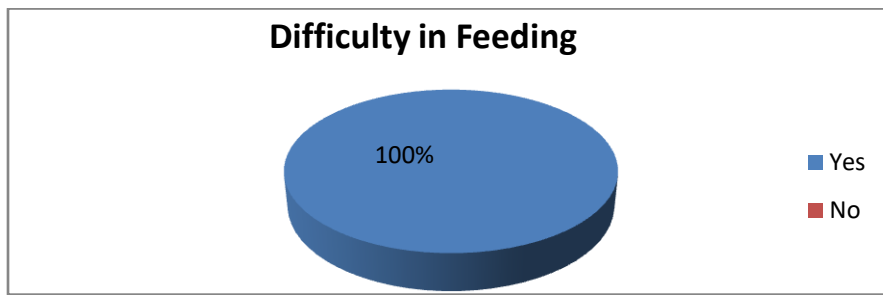


FIGURE 2

Figure 2 indicate that all the 100% of the respondents encountered challenges in feeding the cleft (lip/palate) child. Studies also show that malnutrition is a well-documented problem associated with cleft lip and palate. It is mainly because of partial starvation because cleft children often get fatigue easily and their inability to create negative pressure inside the mouth and the lack of a hard palate to press the nipple against to initiate lactation (Foote, 1925; Cubitt et al, 2011). Thus briefing about the feeding method and how to care for the cleft child is necessary for the parents because their cleft child cannot eat like the other children.

FIRST REACTION OF PARENTS

100 parents of cleft were asked about their first reaction when they first saw their cleft (Lip/Palate) child, 18% of them accepted whatever has happened when they first saw their cleft child, 36% felt sad, 13% felt bad , 9% questioned God and 7% questioned themselves what wrong they have done. And 17% just lay in awe because they were shocked seeing their child having a facial deformity (Figure 3).

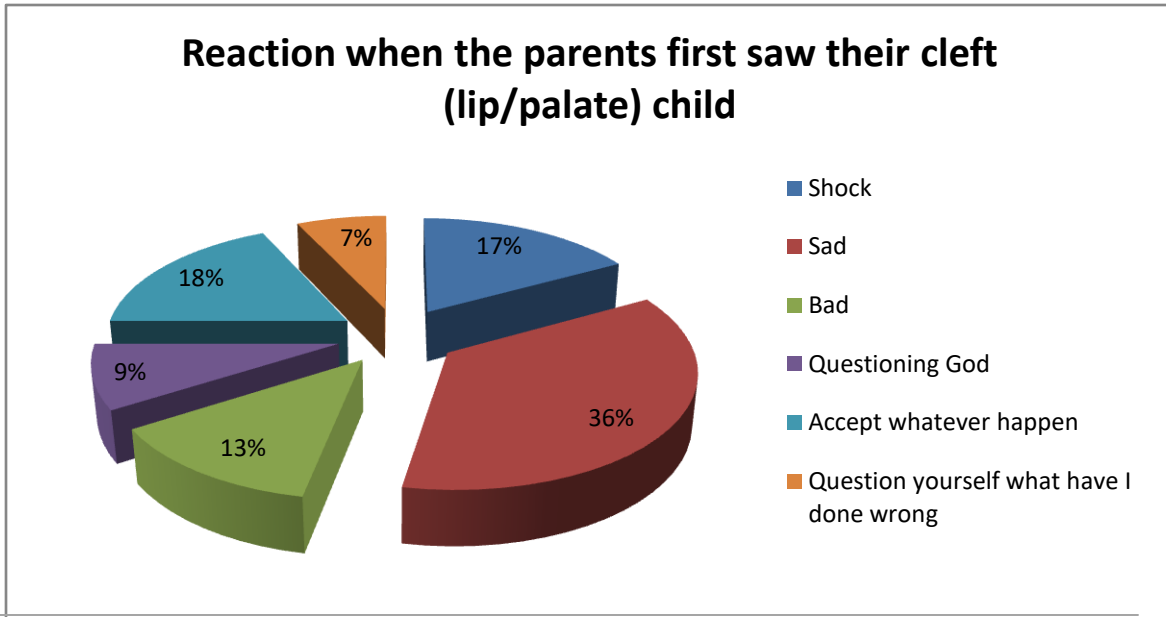


Figure 3

Some of the prominent feelings of mothers at the time of the birth of the cleft lip/palate child such as anxiety, confusion, depression, disappointment, disbelief, frustration, grief, guilt, hurt, inadequacy, rejection, resentment, shock, stigmatization, and withdrawal (Vanpoelvoorde, 1986) are seen in this study.

AWARENESS AND FEELING OF FRUSTRATION

Lack of Awareness regarding Cleft (Lip/Palate) can be a contributing factor that leads to feeling of frustration by the parents and family members of the cleft child.

Awareness and Feeling of Frustration		Awareness about Cleft before the cleft child		Total
		Yes	No	
Feeling of Frustration for having a Cleft Child	Not at all	18	14	32
	Sometimes	12	31	43
	Most of the time	5	16	21
	Always	1	3	4
Total		36	64	100

Table 1

Table 1, indicates that out of the 64 respondents who have no awareness about cleft lip and palate; only 14 of them do not feel frustrated of having a cleft child while the rest 50 of them feel frustrated of having a cleft child. And out of the 36 respondents who are aware of cleft; 18 of them feels that they do not feel frustrated of their cleft child. Here in the “yes” column the number of respondents’ feeling of frustrated descended from not at all (18) and sometimes (12) while in the “no” column the number of respondents’ Thus the more the respondents are aware about cleft the lesser they will feel frustrated ascended from not at all (14), Sometimes (31). Thus from the table it can be inferred that the more the respondents are aware about cleft the lesser they will feel frustrated.

DISCRIMINATION FROM THE SOCIETY

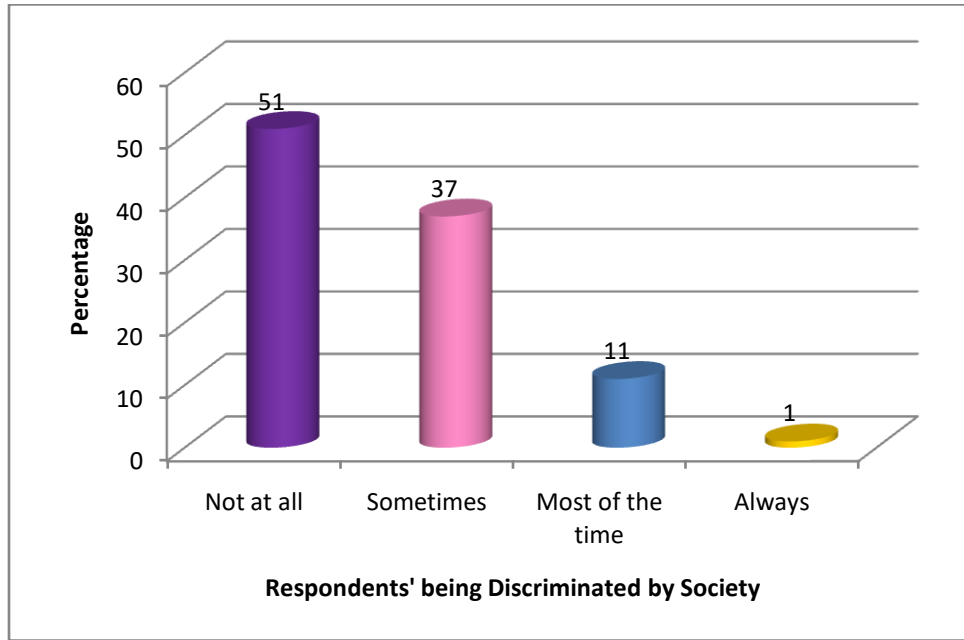


FIGURE 4

Figure 4 shows that out of 100% respondents, many do not feel that they are being discriminated (51%) by the society and the rest (49 %) feels that they sometimes, most of the time or always feel that they are being discriminated by the society. The respondents expressed that their cleft children are being teased as sons and daughters of demons, ugly and parents blamed themselves for the wrong things they did. According to a study conducted by Kot and Kruk, 2007 shows that parents are often worried that the disorder may be caused by something they have done and eventually suffer a stigma from their extended families and communities. According to Cleft Lip and Palate Association (CLAPA), a child who is born with cleft might look different to their peers, and this might be noticed and pointed out by other children and a child who is bullied may suffer low self esteem and have an effect on general confidence level, class participation and sensitivity to comments from other children.

TAKING THE CHILD FOR OUTING

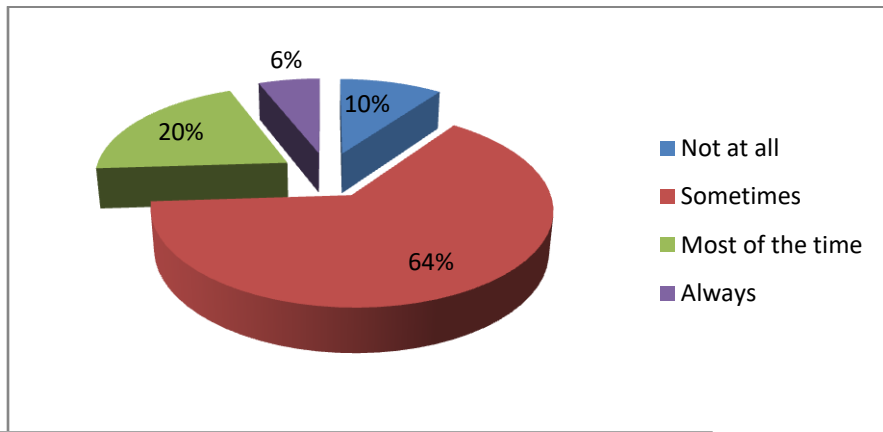


FIGURE 5

Figure 5, indicates how often the respondents take their cleft child out like social gathering in the community. About 10% says not at all, 64% says sometimes they do take them out, 20% take them out most of the time and only 6% takes them always.

GIVING MORE THAN EXPECTED

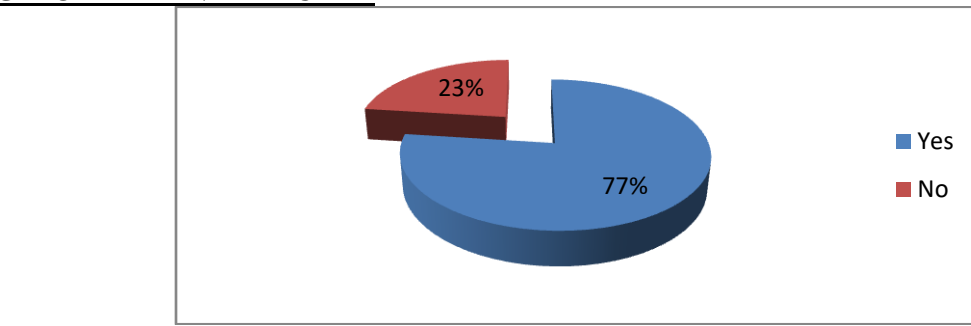


FIGURE 6

Figure 6 shows that out of the 100% respondents, 77% of them felt that they are giving up more of their life for the cleft child needs than they ever expected as compared to the rest (23%) who did not feel like giving up more than they expected.

Parents of cleft (lip/palate) often use different parenting style with them and try their best for the betterment of their children. They tend to give more of their time to them than to the others. This makes the other children feel neglected because their parents give more attention to the cleft child than to them. This means that by having a cleft child the parents face a challenge in managing their time because they have to give more time to their cleft child and this created a feeling of neglect among the other children. This is a challenge as expressed by the parents because they want to treat everyone equally and cater to all their needs but by having a cleft child their concern automatically leaned more to their cleft child because of their needs, thus they sometimes feel bad of it. And according to Lemacks et al, 2013 it states that parents feel guilty for they are unable to spend time that much with their other child like they do with their child with birth defect and siblings sometimes feel neglected because of that.

CLEFT AS A CURSE TO THE FAMILY

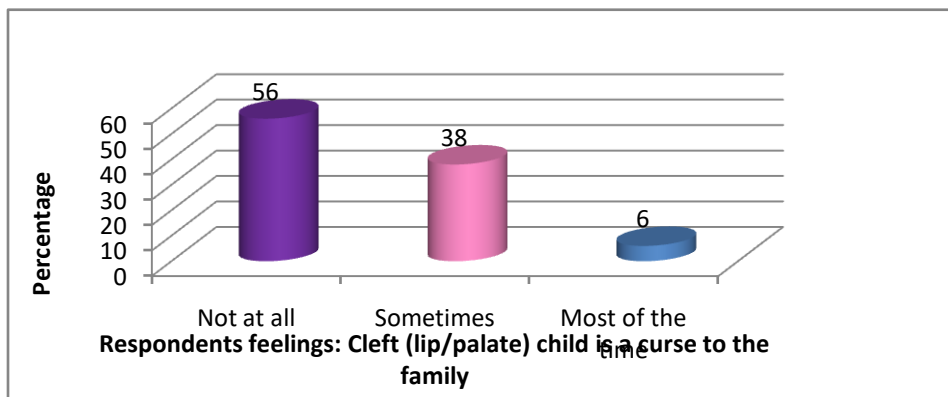


Figure 7

Figure 7, shows that many of the respondents (56%) do not feel that having a cleft (lip/palate) child is a curse to the family though 38% of them sometimes feels that they are a curse to the family and 6% of them felt that most of the time they feel that their cleft (lip/palate) child is the curse to the family. They expressed that no one in the rest of their family has a cleft (lip/palate) child and their child is the first cleft child in the whole family and everyone starts questioning what they could have done wrong for giving birth to a child with cleft (lip/palate) and thus blame them for it. As per the study done by Indian

Streams Research Journal, 2014 it shows that they consider it as a guilty condition, a curse from God or because of some bad things they might have done in the past and they also blame their parents for giving birth to such a child. As such both the child and the parents undergo a series of problems; starting from the family to the society, which in turn becomes the victim of emotional problems such as worries, guilt and depression (Thamilselvan, 2014)

PARENTS NOT ABLE TO FOCUS ON WORK

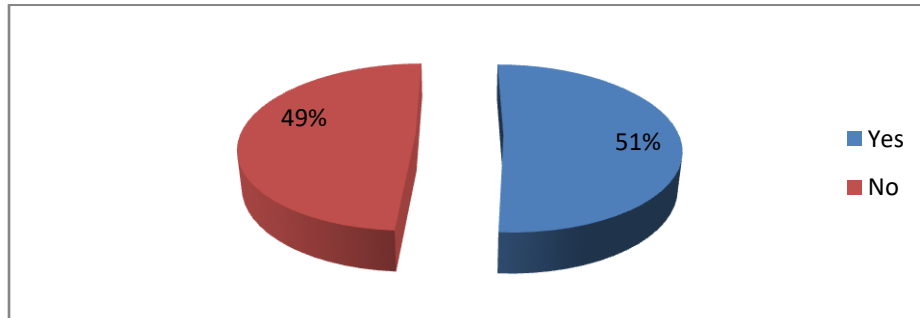


FIGURE 8

From the figure 8 out of 100% respondents (Figure 4.5), majority (51%) of them feel that their job performance is affected by just having a cleft child as compared to the rest (49%) who do not feel that it affects their job performance out of which most of them are housewives. Thus these show that many of those who are working feel that having a cleft child affects their job performance. This means that the economic status of the family will be affected by just having a child with cleft. And as per the Study conducted by Lemacks et al. 2013, employment can be impacted for those families which have children who have birth defects which also includes cleft because it is one of the birth defects as their performance is being disrupted

CONCLUSION

Parents of cleft (lip/palate) children face many challenges while parenting them. Parents of cleft (lip/palate) do consider their cleft (lip/palate) child as a curse to their family. It is mainly contributed by the discrimination from the society so if this decreased then the parents tend to decrease their consideration of their cleft (lip/palate) child as a curse. Discrimination from the society is mainly caused by the myth that they have regarding the causes of cleft like sons and daughters of the devil, parents have sin, etc.

Parents sometimes avoid taking their cleft (lip/palate) child for social gathering and outing because of the stigmatization that the society have on them and their family as a whole. They are being teased by children, questioned by elders and their self-esteem is being pulled down because the society looked down on them simply because they have a cleft child. Parents of the cleft child had to give up more of their life and they had to spend more time with their cleft child as compared to their non-cleft child and this disrupts their relation with their other children who tend to feel neglected because they invest most of their time with their cleft child than with them. The marital relationship is not disturbed simply because of having a cleft (lip/palate) child. Sometimes parents of cleft (lip/palate) children do have conflict with their spouse regarding their cleft (lip/palate), but it is quite natural for them because it is not possible for them to always agree on everything. Job performances are often disrupted with the birth for their cleft (lip/palate) child because they have to cater to their needs and this consequently affects their income. And with low income and high expenditure and additional expenses, caring for the cleft (lip/palate) child increases the rate of financial problems.

When it comes to social support, the family support is very essential to help the parents to cope with the situation of having a cleft (lip/palate) child and it will help them to avoid burn out issue. The source of financial support for the treatment of cleft (lip/palate) child comes from different sources like the family members, non-governmental organization, neighbours, etc and not only from themselves this shows that the parents of cleft children is being financially supported from all level of social support. Lack of information and awareness about the situation, cleft will increase the parents' distress and decrease the level of handling the situation. It also shows that the lack of awareness about cleft will increase the level of feeling of frustration of having a child with cleft (lip/palate).

As social workers and educated people we should spread awareness about Cleft lip/palate so that it will reduce the stigma that is attached to it and this will help them live in a welcoming environment that will bring alive their beautiful smile.

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