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Original Research

An exploratory study of socio-emotional experience and coping in mothers of cleft lip and palate children

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Abstract

The aim of the present study was to understand the emotional and social experience of mothers of children with a congenital cleft lip and palate condition including an assessment the coping responses employed in dealing with the stressful condition. The research was designed primarily in the qualitative mode because it caters to a subjective experiential realm of the mothers. The participants were 14 housewife mothers with their affected child in the age range of 0 to 5 years residing in Delhi and its outskirts through purposive sampling. The measures included an Interview Schedule designed specifically for the study and Coping Responses Inventory Adult Form. The interviews were transcribed and thematically analysed. The results show that most mothers experienced disbelief and denial with gradual acceptance of child as destiny but associated with physical and financial stresses. Presence of good social support resulted in attributing the cause to external factors and improved the quality of life. But the gender constructions produced differential anticipated consequences for a cleft affected girl compared to a boy. Avoidance coping responses were observed to be observed primarily. The study has mental health implications. Interventions need to be developed to help parents deal with the impact the social stigmatization and physical concerns of the cleft lip and palate condition.

INTRODUCTION

When the newborn is held by the mother for the first time, the mother-child relationship is created, thus beginning the psychosocial development and attachment of the mother to the child.[1] The classical ethological viewpoint [2] hypothesized that specific features including physical attractiveness of the infants impact upon caregiver approach as well as nurturing behaviour.[1,3-8].

One in 500 children (under 16 years) have a facial disfigurement which significantly affects their ability to lead a normal life.[9] One of the most common conditions of cleft involving the lip and/or palate or isolated clefts of the palate requires complex long term treatment and has lifelong implications for the individuals affected.[10] The etiology of the cleft condition is thought to be multifactorial involving interplay between genetic and environmental factors like teratogens, medications, maternal smoking and drinking especially during pregnancy.[11,12] In India, cleft lip/palate occurs in nearly 1 in 500 live births.[13]

The cognitive behavioural model talked about appearance anxiety resulting in perceived stigma leading to coping in order to reduce the anxiety in case of physical abnormalities.[14] The impact on the affected person was taken into account by the model but the social impact included in it is of importance for the caregivers too. Apart from the physical consequences like lengthy & tiring feedings [15], nasal quality in speech[16] and abnormally shaped teeth[17], the congenital condition of cleft lip and palate has been considered a chronic stressor emotionally as well.[18,19] There is anxiety, confusion, depression, disappointment, disbelief, frustration, grief, guilt, hurt, shock, hysteria, resentment, rejection, stigmatization, and withdrawal feelings arising from self blame in some mothers after viewing their cleft affected child.[20-24] Some parents tend to blame others, chance, God's will or environmental factors like starvation in the village, a previous miscarriage and prematurity for causing the condition.[23,25] The diverse reactions to the cleft condition give way to more everyday concerns in living with the affected child. Parents have reported fears that the child may choke during feeding or possible mental retardation in the child.[26] Parental concerns also included managing other people's reactions to their child's appearance resulting in social isolation[27-31], overprotectiveness, developmental concerns and treatment decisions[32-34]. The socio- cultural impact of male and female gender roles and stereotypes in society has also been discussed, cited as more problematic in case of cleft affected females due to the issues of difficulty in marriage prospects in case of girls.[22,23]

But, with despair of seeing the malformation, there was happiness too for some parents with no adverse impact on maternal attachment.[22,35] Some studies reported no significant difference between parents of children with cleft lip/palate and parents of children who are physically normal.[23,36,37]

Thus, it can be seen that the way of dealing with the situation or coping plays a significant role in the parental handling of the condition. Many researchers have highlighted factors like a caring and consistent parent figure, socioeconomic advantage, a positive extended family network, family management, good communication, effective coping, and family cohesion that ease the difficulties in life with a cleft lip and palate child and foster growth as well as resilience.[38-45]

Most of the studies that have been carried out in this area have tried to assess the attachment securities and insecurities that arise out of the reactions and attitudes towards the cleft lip and palate child largely in the medical field without addressing the emotional experience as well as the coping strategies used by the mother of a cleft child. Therefore, the need for the research arose with the following objectives

- To explore the emotional and social reaction of mothers of a child with cleft condition
- To understand the coping responses of mothers of a child with cleft condition

METHOD

Participants

Due to the low prevalence of cleft lip and palate condition, 14 mothers (7 mothers of sons and 7 mothers of daughters affected by cleft lip and palate both) coming to a private hospital for its free of cost treatment, falling in the age range of 24 years to 30 years, with cleft affected child being 3 months to 5 years old, living in Delhi or its outskirts, were selected through purposive sampling. These mothers were housewives, not formally educated above grade ten with the husband's income being approximately not more than Rs 5000-7000 per month belonging to a low socio economic status.

Measures

A *semi structured interview schedule* was developed for the purpose of the study. The first part of it ascertained the socio-demographic information of the parent and the second part elicited information about the emotional and social experience of the mother living with a child having a cleft lip and palate.

Coping Responses Inventory Adult Form (CRI-A) [46] was used to assess the coping responses of the mothers emerging due to the condition of cleft lip and palate associated with their child. The author reported Cronbach's alpha coefficients fluctuating between .74 and .61 for men (average alpha= .67) and between .71 and .58 for women (average alpha .64). The association among the eight scales was in general positive and moderate (average r for men= .29 and for women r= .25). The average stability of coping scales after 12 months was r= .49 for men and r= .47 for women.

Procedure

The protocol cleared by Ethical Review Committee was followed by data collection. 14 participants were selected through purposive sampling method. After introducing the research objectives and obtaining a written informed consent from the participants, the interviews were carried out lasting for an hour and a half using the semi structured interview schedule which was audio recorded. The recorded interview was then transcribed for further analysis. Analysis of data was carried out by thematic analysis. Relevant and meaningful features and content of the data were used to generate the initial codes. The codes were then sorted into potential themes by looking at how different codes were combining to form an over arching theme [47]. It was followed by administration of Hindi translation of CRI-Adult form.

RESULTS

Results of the present study are represented in major themes and sub-themes in Table 1 to Table 4.

Table 1. Major themes and Sub-themes identified in mothers' emotional experience

Major theme	Subthemes	N
Immediate reaction	Disbelief and denial	4
	Sense of detachment	3
	Sadness	3
	Anxiety	2
	Sense of betrayal and anger	2
Affect over time	Acceptance as fate	6
	Acceptance by positive reappraisal	4
	Acceptance out of pity	3
	Anxiety about cognitive deficits	1

Table 2. Major themes and Sub-themes identified in mothers' social experience

Major theme	N
External attribution	8
Internal attribution	6
Gender related concerns	9
Child related concerns	5

Table 3. Major themes and Sub-themes identified in meaning of cleft condition from the mothers' perspective

Major theme	N
Suffering for mother and child	6
Physical and financial pressure	6
A strengthening condition	1
A lucky charm	1

Table 4. Major themes and Sub-themes identified in mothers' coping responses

Major theme	N
Positive reappraisal	3
Seeking guidance and support	3
Cognitive avoidance	3
Emotional discharge	3
Acceptance or resignation	2
Problem solving	1
Seeking alternative rewards	1
Logical analysis	0

DISCUSSION

To begin with for most mothers, the very first look at the child evoked disbelief and denial on the part of the parents because of the novelty of the event [20] and collapse of the perfect baby image for the parents [18]. A sense of detachment inclusive of rejection, resentment and feeling that the baby will not survive showed the difficulty experienced by the affected parents in accepting the condition. [21,48] Some mothers experienced traumatic feelings of sadness, grief and disappointment suggestive of futility of the efforts of the parents on not having a normal baby.[22,24] There was anger towards God and a sense of having been betrayed that emerged as something new in the present study. It probably was reflective of perceived feelings of unfairness and injustice of God towards parents for having given them an abnormal child. The socio cultural context brought in a new angle to the study too that involved the immediate desire of the parent to know the sex of the child after getting to know the cleft condition. There are future concerns of marriage associated with a girl's birth compared to later concerns mentioned in reviewed literature.[22,23] Talking about the affect experienced by the mothers over a period of time, most of the mothers accepted the child as a part of their destiny, expressed love arising out of pity for the child's state or even positive reappraisal of the situation for having got a girl as desired. The long term affective experience of the mothers was not something taken up by the previous researches. Parents mentioned feeling happy and attuned to provide love to their child even after despair as well.[22,49]

With regards to attributing a cause to the condition which later has a role to play in the parents' attitudes towards the child and their quality of life, 50% of the participants assigned an external cause to it.[23,25] The external attribution was possible due to the supportive family environment[40] taking it up as a collective family responsibility, sins of the child or curse of a spirit or God's will. The distribution of responsibility reduced the guilt feeling and improved the quality of life [43,50,51] But at the same time, quite a few mothers assigned an internal cause to the condition with the society accusing them for the condition like not avoiding exposure to eclipse.[23] Blaming resulted in poorer levels of adaptation reducing the quality of life.[27,30] Most mothers addressed the condition as a difficult time for a girl child that is gender related concerns than the child related apprehensions for the condition because of the value society places on the physical appearance of the girl being thin, having good features, being fair. The burden of marriage, increased dowry to compensate for the appearance were the concerns parents reported, adding the socio economic status factor to it as well.[22,23]

For majority of mothers, the cleft condition was both a suffering for child and mother as well as a physical and financial pressure on the parents. The social ostracism and stigma faced by the parents[27-31] as well as the child resulted in parents keeping the child away from the vision of the society.[23] The pain of the mothers and the children for not having breast fed was something unique in the current research findings, mentioned as a suffering for the both. At the same time the expenses involved in treatment as well as lengthy feedings strained the economic conditions of these women belonging to a low socio economic background.[52] Another unique finding of the study was also a handful of participants positively viewing the condition as strengthening because the cleft child brought economic and personal prosperity to the home.

The responses on CRI-Adult Form showed the way the mothers managed the cleft lip and palate condition supplemented with how the level of adjustment reported was achieved by these mothers. Each stressful situation was linked to the stressor of the congenital condition of a facial anomaly-cleft lip and palate and the strategies used were mentioned in terms of above average usage by the mothers. No mother denied the fact that they did not see it as problem requiring management otherwise they would not have come for surgery. Having accepted the fact that they had to live with this condition, the coping of these mothers now focused on managing the situation. Therefore, seeking guidance and support, positive reappraisal, emotional discharge and cognitive avoidance were coping responses reported to be used more than average by the mothers. The mothers were making behavioural efforts to seek information, guidance and support because the situation was unfamiliar to these mothers. They were also reframing the problem in a way to make it appear positive with acceptance of the reality of the situation. At the same time, mothers were also attempting to reduce the tension by expressing negative feelings, scolding the child, not eating food or crying. They wished and fantasised a life without this stressor due to the associated stigma, physical burden and the confusion created by this unfamiliar condition.[53] The next used coping response was that of acceptance and resigning to the condition by not thinking realistically about the problem at times to deal with the chronic stress. Problem solving and seeking alternative rewards was the relatively less used coping response as it required confronting the problem and taking action against it directly or engaging oneself in some other sources of satisfaction and pleasure.[54] None of the mothers was mentally prepared to face a stressor like the one they encountered due to which their attempts to understand the condition cognitively or logical analysis as a coping method could not be used. It could be observed during the interactions that the availability of the surgical correction procedures is supposed to have been a huge way to reduce the stress arising from the situation as.[55] The treating team's statements of management of the child would have provided a lot of assurance to these mothers to begin better coping with the problem.[22,38,56]

Overall, avoidance coping responses were elicited more in comparison to the approach coping responses. This may be because the stress was not just of the child’s condition but the implications of that physical condition on them. Lack of social support and physical assistance in caring for the child could have resulted in difficulties for the mothers to manage the novel situation alone. The approach responses of seeking guidance and problem solving were close as well because having accepted the problem they had to do something about it and their willingness to get the surgery done represented their effort to work on reducing the intensity of the problem. The coping model [57] helps understand the use of coping for these mothers. The stress resulted in bringing in resources like seeking information through a doctor or support from a family member to reduce the suffering that it brings to them.[22,28,42,50] But an additional coping response that emerged in the present study was the emotional discharge coping.

The present exploratory study has its own set of limitations beginning with the sample being that of mothers belonging to low socio economic strata and who were aware of the free surgical rectification procedures available under the Smile Train project. Also, the study was retrospective which is subject to recall bias and memory distortion. The number of participants included was small due to the rare occurrence of this medical condition thus limiting the generalizability of the results. At the same time, the study has mental health implications. The feelings and conflicts of a caretaker as well educating the significant others of the child about the condition are concerns to be addressed by the team involved. The pre and post operative counselling to deal with the anxieties of the parents becomes important. It becomes important to make the parents understand the negative impact of social isolation or overprotectiveness on the child that can be produced by the parents unknowingly.

Since the study was carried out only with mothers who were aware of the treatment of the cleft lip and palate condition, it would also be beneficial to understand the experience of the parents who are not aware of the surgical rectification procedures for the condition; who do not have facility to get free treatment; the fathers' experience of the condition; its impact on the upbringing and personality of the children on a larger group of participants.

CONCLUSION

The study understands the emotional experience of the mothers; attempts to find a cause based on social reaction; meaning of cleft condition from the mother's perspective and gender and child related concerns. The social realm of existence of the mothers explores the attribution of the problem in the child by the parents. The coping responses produced were found to be avoidant in nature primarily to manage the stressor.

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