

# Coping Strategies of Parents with Cleft Lip and Palate Children

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## ABSTRACT

**Objective:** To evaluate the coping strategies employed by parents of children born with cleft lip and palate.

**Methods:** Consenting parents or guardians of children born with cleft lip and/or palate children presenting at Armed Forces Specialist Hospital Kano participated in the study. These caregivers were interviewed using the Profile of Mood State (POMS) and Family Stress Coping (FSC) questionnaires.

**Results:** One hundred and fifty (150) caregivers participated in the study. Most (63.6%) participants had not received prior information on how to care for a child with a cleft lip or palate. Only 6.7% had a history of a cleft child in their extended family. Majority (89.3%) however only had mild mood affectation while 7.3% had severe mood affectation.

**Conclusion:** Social support from family members plays a major role in helping parents and guardians cope with a cleft child. More emphasis should be given to community education on caring for babies with cleft lip and/or palate in the study region.

**Keywords:** cleft, coping strategies, caregivers, parents

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## INTRODUCTION

Many parents look ahead to the birth of their children and therefore form fantasies and images of the expected infant.<sup>1</sup> Following child delivery therefore, a quick visual inspection to ascertain the well-being of the child and gender check are paramount, words may therefore not be enough to describe the emotional swing of the expectant mother, whose fulfillment of being a mother is turned to devastation after being confronted with a child with orofacial

cleft deformity.<sup>2</sup>

A study has suggested that mothers of children with orofacial clefts experience great stress and handle marital conflicts poorly when compared to control groups.<sup>2</sup> Despite the existence of these psychosocial problems, the exact nature and extent of the difficulties experienced remains undefined. Effective parental adaptation via coping strategies is critical in helping the deformed child adjust to his or her condition. The potential role of the parent(s) and

support system in these regards have received only cursory attention in relevant literature, hence the need to explore the applicability and psychosocial impact of this framework to the cleft population.<sup>3</sup>

The birth of a child with a defective facial structure therefore has significant stressful impact on the parents, who have to cope with the physical and social demands of parenthood.<sup>2</sup> Most parents are often not prepared for the birth of a child with a facial cleft deformity and generally do not have the necessary knowledge on how to deal with the unexpected deformity. The severity of the cleft and the overbearing impact on the parents therefore may cause myriads of conflicting emotions.<sup>3</sup> A study had suggested the development of separation and strained relationships between parents, likewise development of mental disorders related to the stress involved in bringing up a child with cleft lip (CL).<sup>4</sup>

Most parents are often not prepared for the birth of a child with facial deformity, hence the need for readjustment from denial, depression and anxiety, to parental adaptation or establishment of a coping strategy. This strategy can be derived from strong social support systems, such as positive extended family, communication network and adequate health care, which prevent the parents from feeling overwhelmed by their responsibilities to a child with a congenital anomaly.<sup>5</sup>

The family environment is an important factor in the rehabilitation of a child with orofacial cleft. The attitudes, expectations and degree of support shown by the parents are likely to have an enormous influence on a child's perception of their cleft impairment.<sup>6,7</sup> 'Coping with stress, is defined, as "constantly changing cognitive and behavioral efforts required in managing specific internal and external demands that are appraised as taxing or exceeding the resources of the person".<sup>8</sup> If one partner has to bear the entire child caring responsibilities, feelings of frustration and resentment may develop and this will impact negatively on the parents' relationship.<sup>9</sup> The birth of a child with facial deformity therefore is a notable stress factor that may severely strain family's coping mechanism, additional stress factors being the family attitudes, myths and prejudices.<sup>10</sup>

When the typical coping activities are inadequate, the family system must restructure and organize itself to find new ways of dealing with the problem. Indeed some parents have indicated interest in sharing their feelings and getting emotional support

from experienced professionals at the time of diagnosis<sup>11,12</sup> It is important that the parent(s) succeed(s) at coping because research has consistently linked strong parent-child interactions to the child's adjustment in many areas of life.<sup>13</sup> The dominant coping strategies reported by parents were "approach-oriented" (which involves actively thinking and trying to resolve a problem) rather than "avoidance oriented" strategies. The approach-oriented strategy has shown an appreciable positive adjustment in parents of cleft patients<sup>14,15</sup> while avoidance coping is associated with negative family impact and psychological distress. Mutual support between parents helps to develop a healthy adaptation which demonstrate that the facial anomaly of their child is not viewed as a situation which is likely to threaten the stability of their relationship and hence cannot lead to divorce or separation.<sup>16</sup> Parents have also reported using emotion-focused strategies such as maintaining a hopeful attitude for the future and a belief in their own competence as parents.<sup>11,17</sup>

The factors that may contribute to psychosocial strain between parents of a cleft patient include: feelings of guilt, blame and antipathy, such therefore may culminate in reduced emotional intimacy, relational and communication problems.<sup>16</sup> Many parents also feel socially isolated and do not enjoy sufficient support from their families and friends; hence an increased feeling of loneliness. The day to day care of a child with physical anomaly often requires time re-budgeting, parental role renegotiation, finances and dynamism which should be without prejudice to the care required for the other children.<sup>18</sup>

The objective of the study was to evaluate the coping strategies employed by parents of children born with cleft lip and palate.

### MATERIALS AND METHODS

This is a cross sectional study of parents of patients with orofacial cleft attending the Armed Forces Specialist Hospital (AFSH). The AFSH is a secondary health facility, attended by two major groups of patients, which include the immediate military community and the general civilian population. It serves as a referral center for cleft lip and palate (CLP) patients referred from the Kano State hospitals to the Grassroots Smile Initiative clinic (a Non-Governmental Organization) and from the hospitals of the bordering states like Jigawa, Zamfara, Yobe and Bauchi states. Many of the patients attending

this facility consist of a heterogenous group of people from various ethnic and socio-economic groups. Since there is no standard instrument or questionnaire on the coping strategies of parents of children with CLP, a similar instrument used among parents of autistic children was modified.<sup>19</sup> The instrument used was an interviewer-administered questionnaire which consists of 72 items with four major components namely, Profile of Mood State-SF (POMS-SF), Family Stress Coping Questionnaire (FSCQ), Psychological Impact of Cleft on Parent-Questionnaire (PICP-Q), Cleft Severity Scale (CSS). For this study, POMS-SF and FSCQ were used.

**POMS-SF** was coded to measure the emotional well-being of the parent using a 3- point Likert scale ranging from 0 ('not at all') 1 (moderate) and 2 (extreme). The higher the score, the higher the emotional disturbance. The variables were further regrouped into mild mood affectation = good mood, moderate mood affectation = fair mood and severe mood affectation = poor mood. These variables were later dichotomised into mild-moderate and severe mood, mild-moderate mood = 1 while severe mood = 2.

**FSCQ-A** was coded to measure the coping strategies of the parents using a 3-point Likert scale with 0 (Not stressful) 1 (Moderately stressful) and 2 (Extremely stressful). The lower the score, the better the coping strategy. The variables were also stratified into stressful = 1, and not stressful = 0.

Parents of live CLP children ranging between birth and early adolescent (birth-10 years) who consented to participate in the study and relative/guardian/foster parent or anybody close enough to the patient from birth to childhood, to such an extent that there is social and emotional connection. Excluded in the study group are parents of CLP patient who did not consent, or parents of children diagnosed to have other severe congenital anomalies e.g mental retardation. The study protocol (Ref No MORHREC/APP/002/12) was approved by the Ethical Committee of Ministry of Defense Health Research and Ethics.

## RESULTS

A total of 150 parents or guardians of children with cleft lip and/or palate participated in the study.

### Parents' Emotional Response to the Cleft Child

Four percent of the respondents had previous life birth of a cleft child in the nuclear family and 6.7% indicated that they had cleft children in their extended family. The maternal extended family had a higher incidence (4.7%) while the paternal extended family had only (2%) of the cleft patients. Most of the parents (63.6%) had never had any prior information about clefts, Among the parents who had prior information about clefts only (46%) of them knew that treatment was possible.

Table 1 shows parent's emotional response POMS-SF, Majority (89.3%) of the respondents had mild mood affectation (good), 3.3% had moderate (fair), while 7.3% had a severe affectation (poor).

Table 1: Distribution of parent's emotional response using POMS-SF

Emotional response	Frequency	Percentage (%)
Mild Mood	134	89.3
Moderate Mood	5	3.3
Severe Mood	11	7.4
Total	150	100

Table 2: FSCQ-A

FSCQ-A	Frequency	% FSCQ-A
Not Stressful	146	97.3
Stressful	4	2.7
Total	150	100

### Parents' Coping Strategy

All the respondents indicated that the support from the medical facility was helpful and most of them also indicated that they got support from the family and encouragement from friends. Only 2.7% of the respondent indicated it was stressful for them caring for a cleft child (Table 2). Of all the respondents 46% were from polygamous family settings and of these 36.0% had two wives, 8.0% had three wives while 5.3% had four wives or more.

### DISCUSSION

From this study most of the respondents indicated that social support was helpful in adjusting to the care of their cleft child, because most families lived with their extended family as opposed to the nuclear models in other climes. Most of the family models in this study were polygamous, hence, an elaborate support system, which might have reduced the stress of caring for cleft children alone. Indeed, many of the parents in this study indicated little or no stress in the care of the cleft children.

Few respondents indicated that they were having problems with their spouse (4% divorce and 3% separation) while a study by John *et al.*,<sup>20</sup> reported a 6.8% divorce and 4.9% separation. Also reported in the Vanderbilt University Medical Center weekly journal was 11.25% divorce rate in congenital malformations.

It can be deduced from this study that most parents were not ashamed of their cleft children as more than 80% of such children who were of school age were already attending school, this indicates that the parents had a positive psychosocial outlook as shame or guilt are indices of reduced self-esteem or negative psychosocial value.

Failla *et al.*<sup>21</sup> and Risdal *et al.*<sup>22</sup> have reported negative mood affectation in parents of children with disability. This was not the case in this study, as up to 89.3% of respondents claimed they had only mild to moderate affectation. This may be because of the parental beliefs and or culture, which adduces events to faith or Gods will<sup>23</sup> in northern Nigeria. The stress in parent was higher amongst those of children having bilateral than the unilateral cleft (though not statistically significant), contrary to a study by Kumar *et al.*,<sup>24</sup> wherein they reported that the psychosocial impact of orofacial cleft is not easy to define and quantify hence the difficulty in correlating it to the severity of the problem. However, a Denmark study corroborated this assertion by highlighting the increased adult suicide rate<sup>25</sup> in cleft lip and palate

patient and also the increase in number of school dropouts among orofacial cleft patients.<sup>26</sup> It is therefore logical that the bilateral cleft patient with worse facial deformity is likely to result in more negative impact on the parent. Parent's mood was not affected by severity or type of cleft, probably because a good number of the parents knew about free cleft treatments via already-treated members of the clan, radio jingles, clan heads and local health workers.

The level to which orofacial cleft child affects the parent is more in female parents than the male (although not statistically significant). This is corroborated by an Umweni & Okeigbemen<sup>27</sup> study and also underlined in a study by Lemwik in an Ethiopian society, where he concluded that a child's condition is believed to have been caused by the mother's wrong deed in the past.

### CONCLUSION

That high number of the respondents (97.3%) from this study indicated social support from polygamy and extended family models as coping strategies, from having CLP children is further evidenced in few numbers of divorce and separation. Also reported in some studies was negative mood affectation in parents of children with disability, but this was not the case in this study because a good number of the parents (89.3%) claimed they were mildly affected. The pattern of coping strategies presented in this study requires further investigation using larger sample size and other instruments capable of further minimizing bias.

### REFERENCES

1. Huber CH. Parents of the handicapped child facilitating acceptance through group counseling. *Personnel and Guidance J* 1979; 57(5): 267-269.
2. Speltz ML, Armsden GC, Clarren SS. Effects of craniofacial birth defects on maternal functioning post-infancy. *J Pediatr Psychol* 1990; 15(2):177-196.
3. Mac Donald, SK. Parental needs and professional responses: A parental perspective. *Cleft Palate J* 1979; 16(2):188-192.
4. Turner SR, Thomas PW, Dowell T, Rumsey N, Sandy JR. Psychological outcomes amongst cleft patients and their families. *Br J Plast Surg* 1997; 50:1-9.

5. Van Staden F, Gerhardt C. Facing cleft deformities: Challenges and coping skills. *Geneeskunde* 1994; 36(7):15-26.
6. Bull R, Rumsey N. The social psychology of facial disfigurement. *J Cross Cult Psychol* 1988; 17:99-108.
7. Strauss RP, Broder H, Helms RW. Perception of appearance and speech by adolescent patients with cleft lip and palate and their parents. *Cleft Palate J* 1988; 25:335-342.
8. Scheper-Hughes N. Difference and danger: the cultural dynamics of childhood stigma, rejection, and rescue. *Cleft Palate J* 1990; 27:301-310.
9. Lauer RH, & Lauer JC. *Marriage and Family: The Quest for Intimacy* (3rd ed.) Madison: Brown & Benchmark: 1997.
10. Berger ZE, Dalton LJ. Coping with a cleft: psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *Cleft Palate Craniofac J* 2009; 46:435-443.
11. Johansson B, Ringsberg KC Parents' experiences of having a child with cleft lip and palate. *J Adv Nurs* 2004; 47:165-173.
12. Martin V. Helping parents cope. *Nurs Times* 1995; 91(31):38-40.
13. Psychosocial impact of CL, palate on individuals in non-Anglo societies <http://www.news-medical.net/news/20110928/Study-examines-psychosocial-impact-of-cleft-lip-palate-on-individuals-in-non-Anglo-societies.aspx>. Accessed on 25/01/2012.
14. Mary-Elizabeth Reeve, Nora E. Groce, John A. Persing, Sheela N. Magge, *J Craniofac Surg* 2004; 15, 170-174.
15. Nelson P, Glenny AM, Kirk S, Caress AL. Parents' experiences of caring for a child with a cleft lip and/or palate: a review of the literature. *Child care, Health Dev* 2011; 38(1): 6-20.
16. Van Staden F, Gerhardt C. Mothers of children with facial cleft deformities: reactions and effects. *South Afr J Psychol* 1994; 25(1), 39-46
17. Klein T, Pope AW, Getahun E, Thompson J. Mothers' reflections on raising a child with a craniofacial anomaly. *Cleft Palate Craniofac J* 2006; 43:590-597.
18. Rosenstein DL, Schulman JL. Family and social problems associated with CLP. *CLP: A System of Management*. Baltimore: Williams & Wilkins 1990; 47-51.
19. Buss DM, Shckelford TK, McKibbin WF. The mate retention inventory-short form (MRI-SF). *Personality and individual differences* 2008; 44:322-334.
20. John D, Pai L, Belfer ML, Mulliken JB, Effects of a child with a craniofacial anomaly on stability of the parental relationship. *J Craniofac Surg* 2003; 14(5):704-708.
21. Failla S, Jones LC. Families of children with developmental disabilities: An examination of family hardiness. *Res Nurs Health* 1991; 14(1): 41-50.
22. Risdal D., Singer GHS. Marital adjustment in parent of children with disabilities: A historical review and meta-analysis. *Res Pract Persons with Severe Disabilities* 2004; 29, 95-103.
23. Oginni, FO, Asuku, ME, Oladele, AO, Obuekwe, ON, Nnabuko RE. Knowledge and cultural beliefs about the etiology and management of orofacial clefts in Nigeria's major ethnic groups. *Cleft Palate Craniofac J* 2010; 47(4):327-334.
24. Kumar P, Hussain MT, Cardoso E, Hawary MB, Hassanain J. Facial clefts in Saudi Arabia: an epidemiologic analysis in 179 patients. *Plast Reconstr Surg* 1991; 88(6):955-958.
25. Slifer KJ, Amari A, Diver T, Hilley L, Kane A, McDonnell S. Self-concept and satisfaction with physical appearance in youth with and without oral clefts, *Child Health Care*. 2003; 32(2): 81-101.
26. Richman LC. Behaviour and achievement of CP children. *Cleft Palate J* 1976; 13:4-10.
27. Umwemi AA, Okeigbemen SA. Gender issues in parenting cleft lip and palate babies in southern Nigeria: a study of the University of Benin Teaching Hospital. *Early Child Dev Care* 2009; 179(1): 81-86.