

A Comparative Study of Quality of Life of Families with Children Born With Cleft Lip and/or Palate before and after Surgical Treatment

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Abstract

Background: Cleft lip and palate (CLP) is treated in a multidisciplinary manner, incorporating both surgical and non-surgical specialties. Surgical reconstruction of OFCs is a common treatment performed by oral and maxillofacial surgeons and other surgical professionals, and it entails the repair of both the lip and the palate. Several strategies for CLP repair have been documented in the literature. When the infant is roughly 3 months old, the lip is repaired, and the major palate is repaired between the ages of 6 and 14 months. OFCs may have an impact on family functioning and, as a result, are likely to lower QoL in school-aged children and their parents. **Aim:** The purpose of this study was to assess the quality of life (QoL) of parents/caregivers of children with cleft lip and/or palate before and after surgical correction. **Materials and Methods:** Families of individuals who needed either primary or secondary orofacial cleft repair and met the inclusion criteria were invited to participate. The 'Impact on Family Scale' (IOFS), a preoperative and postoperative health-related QoL questionnaire, was used to assess the affected family's subjectively assessed QoL before and after surgical intervention. A paired t-test was used to compare the mean pre- and postoperative total scores. The mean pre- and postoperative total scores were compared using paired t-test. **Results:** Before surgery, over ninety-six percent of families' quality of life was impacted. The economical and social sectors had the biggest impact preoperatively. Families with children who had bilateral cleft lips saw QoL consequences mostly in the social domain and in the domain of "impact on siblings." The mean overall QoL score after surgery was considerably lower than the mean QoL score before surgery, indicating a significant improvement in QoL (P<0.001). In all domains, the mean postoperative QoL score was considerably lower than the mean preoperative QoL score. Only 3% of the families said the surgery had a negative impact on their quality of life. The domains of mastery (almost sixty-two percent) and finance (nearly forty-five thousand) had the most postoperative impact. After treatment, the proportion of families whose QoL was impaired by orofacial cleft was significantly different. **Conclusion:** Caring for children with orofacial clefts has a considerable negative impact on parents' and caregivers' quality of life in all dimensions. Surgical intervention, on the other hand, dramatically enhances the quality of life of these children's parents and carers.

Keywords: Orofacial cleft, Caregivers, Quality of life, Surgery

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Introduction

Health is defined as a condition of complete physical, mental, and social well-being, rather than the absence of disease or infirmity. It has been proposed that evaluating health should not be limited to the use of only clinical normative measures based on this idea. Health-related quality of life (HRQoL) assessments are increasingly being used to assess aspects of health that are not addressed by other measures, such as psychological and social factors. 2. In persons with surgically curable illnesses, quality of life (QoL) is being increasingly recognised as an important health outcome.

A patient's assessment of and contentment with his or her current level of functioning is referred to as QoL [1,2].

The most frequent orofacial congenital deformity among live infants is orofacial clefts (OFCs), which account for 65 percent of all head and neck anomalies. OFCs afflict roughly 1 in 500 (Asian or Amerindian heritage) to 2,500 newborns, depending on geographic ancestry (African ancestry). OFCs are assumed to be the product of a

complicated interaction between hereditary and environmental factors. Asian and Native American communities have the highest documented birth prevalence rates of OFCs, typically as high as 1/500, European populations have prevalence rates around 1/1,000, and African populations have prevalence rates around 1/2,500 [3-4]. Cleft lip and palate (CLP) is treated in a multidisciplinary manner, incorporating both surgical and non-surgical specialties. Surgical reconstruction of OFCs is a common treatment performed by oral and maxillofacial surgeons and other surgical professionals, and it entails the repair of both the lip and the palate. Several strategies for CLP repair have been documented in the literature. When the infant is roughly 3 months old, the lip is repaired, and the major palate is repaired between the ages of 6 and 14 months. OFCs may have an impact on family functioning and, as a result, are likely to lower QoL in school-aged children and their parents [5-6]. Children with OFCs may face psychosocial challenges as a result of their altered speech and facial appearance, which may influence their quality of life and family functioning. The occurrence of OFC, according to Kramer et al, is a cause of significant shock for the parents of an affected baby. In Sub-Saharan Africa, where cultural beliefs contribute to psycho-social instability and infanticide, the impact of having CLP is of special relevance. OFC is not reported to be a leading cause of death in affluent countries; however, it produces significant morbidity in affected children and poses a significant financial risk to families, as well as a social cost [7-8]. Thus, this study was designed to compare

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the QoL of families of children with cleft lip and/or palate before and after surgical repair.

Materials and Methods

The researchers conducted a prospective longitudinal study to examine the quality of life of parents and carers of children with cleft lip and/or palate before and after surgical procedures. Before each subject was enrolled in the trial, the parents/caregivers provided written informed consent. Prior to this, each parent or guardian was given extensive information and explanations about the study. During the permission procedure, parents/guardians were also permitted to express questions and get clarifications. Each parent or caregiver was informed of their right to withdraw at any time during the trial without being victimised or denied treatment. The study included parents/caregivers of infants born with non-syndromic cleft lip and/or palate who required surgical therapy to address the deformities. This study did not include parents or caregivers of children with syndromic clefts or oblique facial clefts. Parents/caregivers of 94 participants who needed primary or secondary OFC repair and met the inclusion criteria were eventually recruited. Each subject's age and sex, kind of cleft defects (lip and/or palate), type of cleft repair (lip or palate), and surgical technique were all gathered and recorded in a proforma prior to surgery. CLP were classified according to Kernahan and Stark in 1958 [14]. At least one week before surgery, each subject's parents/caregivers were given a preoperative HRQoL questionnaire (Appendix 1). The 'Impact on Family Scale' (IOFS) [15,16] was used to assess the afflicted family's subjectively assessed quality of life. The IOFS was created as a self-report tool in the Anglo-American literature to quantify the consequences of chronic illnesses and

disability in childhood on the family. It consists of 33 items organised into five dimensions (Appendix 1), including financial consequences (4 items), social ties (15 items), personal consequences (5 items), coping mechanisms (3 items), and siblings' worries (if present; 6 items). The parents must mark whether the item was "absolutely true," "true in most areas," "not true in most aspects," or "not true at all." Summing the scores of all items yielded a total impact score. The lowest possible total score was 33, and the highest possible total score was 132. The QoL was not influenced if the score was between 1 and 66, however it was affected if the score was more than 66. At least 2 months after surgical repair, each parent/caregiver was given the same HRQoL questionnaire (Appendix 1) to complete. SPSS for Windows was used to examine the data (version 17.0; SPSS Inc., Chicago, IL, USA). Tables are used to present the information. As needed, other descriptive and inferential statistics were applied. A paired t-test was used to compare the mean pre- and postoperative total scores. The IOFS's five domains' mean scores were also compared before and after surgery. P<0.05 was used as the criteria for establishing statistical significance in all comparisons.

Results

A total of 95 families with OFC who met the inclusion criteria and agreed to take part in the study were enlisted. One family, on the other hand, elected to stop the study in the middle for personal reasons, and their data was removed from the analysis. As a result, 94 of the 95 recruited families were accessible for final analysis. Unilateral cleft lip (52.1%) was the most common kind of OFC, followed by cleft lip/palate (23.4%) and bilateral cleft lip (23.4%). (13.8 percent). (See Table 1)

Table1. Sex distribution according to cleft type

Type of cleft	Male (%)	Female (%)	Total (%)	P-value
Unilateral cleft lip	18.1	34.0	52.1	0.48
Bilateral cleft lip	5.3	8.5	13.8	0.41
Cleft lip/palate	11.7	11.7	23.4	<1.00
Cleft palate	7.4	3.2	10.6	0.35
Total	42.6	57.4	100	0.23

The pattern of cleft distribution between boys and females did not change statistically significantly (P=0.179). The average age of OFC patients was 5.78.5 months, with a range of 1 to 48 months.(Table 2)

Table2. Preoperative mean score in each domain

Domain	Total possible score	Mean score	Affected (%)
Financial impact	16	11.8±1.6	73.6
Social impact	60	41.1±3.8	68.5
Personal impact	20	13.4±2.1	67.0
Impact on mastering/coping	12	7.8±1.5	64.8
Impact on sibling	24	15.5±2.2	64.6
Total	132	89.6±2.4	67.9

The bulk of the participants (78.0 percent) were between the ages of one and twelve months, with the majority of them falling within the three-month range. There were 54 females and 40 men among them, for a female-to-male ratio of 1.4:1. The families' average total QoL score before surgery was 89.62.4. 95.7 percent of families had their quality of life impacted. The financial domain, with a mean score of 11.81.6, and the social domain, with a score of 41.13.8, had the highest influence; both domains were affected in 73.6 percent and 68.5 percent of families, respectively. (See Table 2). Table 3 compares the percentage of families whose QoL was impacted prior to surgery based on the kind of OFC. The bulk of the participants (78.0 percent) were between the ages of one and twelve months, with the majority falling within the three-month range. With a female-to-male ratio of 1.4:1, 54 of these were females and 40 were males. The families' total QoL score was 89.62.4 at the time of surgery. 95.7 percent of families had a negative impact on their quality of life. The financial domain had the highest influence, with a mean score of 11.81.6, and the social domain had a score of 41.13.8; 73.6 percent and 68.5 percent of families, respectively, were affected by these domains.

Table3. Quality of life (QoL) of the family before surgical intervention according to cleft type

Types of cleft	QoL affected (%)	QoL not affected (%)	Total
Unilateral cleft lip	98.0	2.0	100
Bilateral cleft lip	100	0	100
Cleft lip/palate	90.9	9.1	100
Cleft palate	90.9	9.1	100
Total	95.7	4.3	100

Table 3 compares the percentage of families whose quality of life was impacted prior to surgery by kind of OFC.(Table 4)

Table4. Comparison of the mean quality of life before and after surgery in each domain

Domain	Mean before surgery	Mean after surgery	P-value
Financial impact	11.8±1.6	7.2±1.6	0.001
Social impact	41.1±3.8	22.1±4.3	0.001
Personal impact	13.4±2.1	8.3±1.8	0.001

Impact on coping	7.8±1.5	7.4±1.8	0.01
Impact on sibling	15.5±2.2	9.2±1.7	0.001
Total	89.6±2.4	54.2±1.6	0.001

In each domain, Table 5 compares the proportion of families whose QoL was impaired before and after surgery. All domains except "effect on coping domain" showed a statistically significant difference. The domains of coping/mastering, with a mean score of 7.41.8, and money, with a mean score of 7.21.6, had the biggest influence following surgery, with 61.3 percent and 45.1 percent of families' QoL affected, respectively.

Table5. Comparison of proportion of families whose quality of life was affected before and after surgery according to domain

Domain	Affected preoperative (%)	Affected postoperative (%)	P-value
Financial impact	96.8	22.3	0.03
Social impact	95.7	1.1	0.001
Personal impact	88.3	10.6	0.03
Impact on coping	73.4	69.1	0.70
Impact on sibling	83.0	4.3	0.001

Table6. Quality of life (QoL) of the family after surgical intervention

Type of cleft	QoL affected (%)	QoL not affected (%)	P value
Unilateral cleft lip	4.1	95.9	0.001
Bilateral cleft lip	0	100	0.001
Cleft lip/palate	0	100	0.001
Cleft palate	10.0	90.0	0.001
Total	3.2	96.8	0.001

(See Table 6) Furthermore, 10.0 percent of families with children who have a cleft palate indicated that their QoL was impaired following surgery, whereas only 4.1 percent of families with children who have a unilateral cleft lip reported a QoL effect.

1. Financial impact domain

All families of children with bilateral cleft lip and cleft palate (100%) acknowledged that caring for the cleft youngsters had a negative impact on their finances prior to surgery. However, only 15% of them reported a decline in financial capacity after surgery. For all forms of OFC, there was a statistically significant improvement in family financial condition after surgery.

2. Social life domain

All families of children with bilateral cleft lip (100%) acknowledged that caring for their cleft child had a detrimental influence on their social life prior to surgical surgery. Only one family, however, stated that caring for their child had a detrimental influence on their social life after surgery. This was similar to the experiences of families who had children with unilateral cleft lip and palate. Overall, after surgery, the social lives of families with cleft children improved statistically significantly.

Personal impact domain

Before surgery, all families of children with bilateral cleft lip claimed that caring for the cleft kid had a significant negative impact on their quality of life; however, just two families in this category reported the same effect after surgery. Furthermore, 90 percent of families with cleft palate children said that caring for their cleft child had a detrimental impact on their personal lives, while no family in this category said the same thing following surgery. In the personal effect area, surgical intervention was related with a statistically significant drop in the proportion of families reporting "affected."

Coping ability domain

Prior to surgery, 82 percent of families of children with unilateral cleft lip said that caring for a child with cleft lip had a negative impact on their capacity to cope. After surgical intervention, this figure only dropped to 67 percent. Notably, following surgery, a higher proportion of families of children with bilateral cleft lip and those with cleft lip/palate felt that their quality of life was impacted than before surgery.

Impact on sibling domain

Almost every family with an OFC child indicated that caring for the child with OFC had a detrimental influence on the sibling before surgery. For unilateral cleft lip, the impact was the smallest (76 percent).However, after surgery, there was a statistically significant reduction in the proportion of families who reported that caring for a

child with OFC had a negative impact on the siblings.

Discussion

Unilateral cleft lip (52.1%) was the most common kind of OFC in this study, followed by cleft lip/palate (23.4%) and bilateral cleft lip (23.4%). (13.8 percent). Donkor et al. found unilateral cleft lip as the most prevalent kind of OFC in Ghana, and this conclusion is consistent with their findings. A previous study from Nigeria confirmed our findings, indicating that unilateral cleft lip is the most prevalent kind. Cleft lip was likewise the most common kind, according to Onah et al, with 41 percent of cases. In contrast to the current study, other African research have suggested that CLP is the most prevalent form. CLP, on the other hand, was shown to be the most frequent kind of OFC in most Caucasian research [13-14].

Caring for a child with OFC can reduce parents' and caregivers' quality of life. Affected families may have to make financial, social, and personal adjustments before primary treatment is completed, according to reports. OFC has been shown to have an impact on family functioning and to lower QoL in school-aged children and their parents. OFC has also been linked to a number of health issues, including early-life complications such as feeding issues or ear infections, which can lead to high morbidity and mortality concerns, particularly in less developed countries where early systematic paediatric care is not readily available [15,16].

Several of OFC's effects have been observed to last into adulthood, leading to increased mortality and morbidity. The majority of the limited studies on the quality of life of families with children with cleft lip/palate focused on the impact of OFC on the family, rather than the effect of surgical intervention on QoL. The current study examines the impact of surgical intervention on the quality of life of family members and caregivers of children with CLP. The mean preoperative total QoL score as well as the proportion of families whose QoL was affected preoperatively were both high in this study, demonstrating a decline in QoL in families with OFC [17,18].

The findings imply that caring for a child with a cleft lip or palate can negatively affect the family's quality of life. The financial and social areas were the ones that had the most impact. Families with children who had bilateral cleft lip were the most affected, followed by families with children who had unilateral cleft lip. Before surgical intervention, isolated cleft palate had the least impact on the family. In contrast, Weigl et al. used the Short-Form Health Survey (SF-36) to assess HRQoL in mothers of children with CLP [12].

In the domains of personal functioning, bodily pain, and overall health, mothers of CLP patients had better HRQoL than controls, according to Weigl et al. The following explains the discrepancy

between our findings and those of Weigl et al. In addition to the differences in cultural values between Germany and Nigeria, Weigl et al. employed the SF-36, which is ultimately a measure of health status rather than QoL, and only the mother to represent a family. The difference in care quality and cost between a developed economy like Germany with a well-established health insurance system and a developing economy like Nigeria with a poorly developed health insurance system can also explain the contradicting results [13].

Our findings are consistent with those of Kramer et al. and Hunt et al., who showed minor effects on all aspects for parents of children with CLP aged 6-24 months. Impacts were particularly noticeable on the aspects of coping and personal effect. Kramer et al. observed that parents of children with CLP reported less impact on QoL as measured by the IOFS than parents of children with only cleft lip or palate, which is consistent with the findings of our study. In our study, the most affected domains were social relationships, sibling relationships, and financial relationships. Given that many children with CLP have a less beautiful facial appearance or voice than their peers, this is unsurprising [19]. Children born with OFC are seen as a curse in some African tribes, and the family, particularly the mothers are viewed as witches. Such a mother is frequently abandoned by her spouse, family, and friends. This could explain why the sibling and social relationship categories are the most affected. Frequent hospital visits are common when caring for a kid with OFC, resulting in lost work hours, out-of-pocket health-care costs, and, in some cases, job loss owing to frequent time away. All of these reasons could explain why our study found such a high level of financial impact [20,21].

The mean total QoL score after surgery was found to be considerably lower than before surgery in the current study, showing that surgical intervention greatly improved the parents' QoL. Only three patients had a negative impact on their QoL as a result of the surgery. The social and personal effects of surgery were the most noticeable. This significant improvement in parent QoL following surgery could be attributed to the reduction of the considerable physical, financial, psychological, and emotional burden that comes with caring for children with OFC.

The postoperative data in this study were obtained at least two months following surgery. Although the impact of surgery on family QoL was evident within two months of surgery, a longer time of postoperative examination may show the impact of late surgical complications on QoL. This, we believe, is a flaw in this study that can be exploited by others who want to confirm our findings.

Conclusion

Caring for children with OFC has a considerable negative impact on parents' and caregivers' quality of life in all categories. The effects were especially noticeable in the economical and social realms, as well as among individuals who cared for children with bilateral cleft lips. Surgical intervention, on the other hand, dramatically improved the quality of life of these children's parents and carers. In all dimensions except "coping abilities," surgical intervention resulted in a statistically significant reduction in the unfavourable impact of having a kid with OFC. Society, health professionals, and family will need to support caregivers of children with OFC. As a result, research efforts must focus on developing a coping strategy for these families.

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