SATISFACTION AMONGST PARENTS/GUARDIANS OF CHILDREN WITH CLEFT LIP AFTER REPAIR AT KOMFO ANOKYE TEACHING HOSPITAL

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ABSTRACT

BACKGROUND: Orofacial clefts are a group of congenital deformities commonly presenting as cleft lip with or without cleft palate or solitary cleft palate. Cleft lip and palate (CL/P) is one of the world's most frequent congenital birth abnormalities. It is estimated that 400 babies are born with orofacial cleft in Ghana every year.

AIM: This study aimed to assess the level of satisfaction amongst parents/guardians of children who underwent cleft lip repair at Komfo Anokye Teaching Hospital (KATH) and the effect of cleft lip repair on their psychosocial status.

MATERIALS AND METHODS: A cross-sectional survey was conducted, and data were collected from 73 parents/guardians of children who underwent cleft lip repair at KATH. The survey assessed parental satisfaction with the aesthetic outcome, the impact of the procedure on social interactions and family dynamics, and the overall psychosocial effect of cleft lip repair using the modified Cleft Evaluation Profile. The data was captured in Excel and analysed with the Statistical Package for the Social Sciences (SPSS) version 25.0.

RESULTS: The majority of parents/guardians expressed overall satisfaction with the outcomes of cleft lip repair, with 67.1% reporting that the appearance of the lip was "Very satisfactory." However, there were concerns regarding other facial features, such as teeth (21.9% unsatisfactory) and the face profile (35.6% very satisfactory). Despite these concerns, a significant proportion of respondents reported positive psychosocial effects, including improved relationships with spouses (15.1% strongly agreed, 15.1% agreed), increased social interactions (41.1% strongly agreed, 47.9% agreed), and enhanced confidence in the child (30.1%stronglyagreed, 34.2% agreed). Notably, 34.2% of respondents were neutral about the child's confidence in interactions after the repair.

CONCLUSION: The findings indicate that cleft lip repair at KATH positively impacts parental satisfaction and overall psychosocial well-being. While parents/guardians expressed overall satisfaction with the appearance of the lip, other facial features may require more attention during surgical planning and post-operative care to enhance overall outcomes. Addressing parental concerns and providing tailored support services can further optimise the psychosocial effects of cleft lip repair and promote positive family dynamics. Continued research and comprehensive support programs are essential to improve the care and satisfaction of parents/guardians of children with cleft lip after repair at KATH.

KEYWORDS: cleft, satisfaction, parents, guardian, Psychosocial well-being.

INTRODUCTION

Orofacial clefts (OFC) are a group of congenital deformities commonly present as cleft lip with or without cleft palate or solitary cleft palate. Cleft lip and palate (CL/P) is one of the world's most frequent congenital birth abnormalities. Cleft lip and palate affect roughly 1 in 600 to 800 live births (1.42 in 1000), with isolated cleft palate affecting approximately 1 in 2000 live births. Thus, the typical cleft-type distribution is 15% for cleft lip alone, 45% for cleft lip and palate, and 40% for isolated cleft palate.[1] A cleft lip is classified based on its laterality and extent. Laterality is noted (left, right, bilateral), with unilateral deformity being more common than bilateral. The cleft's extent is classified as complete or incomplete. Other classification systems include Davis and Ritchie, Veau, Kernahan, Stark, and the International Confederation of Plastic and Reconstructive Surgery. However, the most commonly used classification is the Veau classification[2]. Orofacial clefts can occur alone or as an associated feature in over 300 identified syndromes. Some of these syndromes include Pierre Robin syndrome, Van der Woude syndrome, Down syndrome, Treacher Collins syndrome, and Apert syndrome. However, approximately 70% of cleft lip and palate cases are non-syndromic[3]. Its complex aetiology includes both hereditary and environmental factors. Risk factors include folic acid deficiency, maternal smoking, alcohol intake, drug usage, and chemical exposure [4] The treatment of cleft lip entails a commitment to the child's care throughout the child's growth into adulthood. However, a skilled surgeon is needed for this group of patients; a multidisciplinary cleft and craniofacial team is best suited to meet the unique demands of children with clefts[5]. Improvements in the appearance of the lip and nose are the most frequently desired aspects for further treatment by patients with clefts and their parents[6]. Unfavorable outcomes in unilateral and bilateral cleft lip repair are often simple to identify, but they are not always as simple to prevent as to treat. In the case of unilateral cleft lip repair, dehiscence and scarring are immediate unfavorable outcomes that occur [6]. Delayed blemishes include vermillion notching, a short lip, white roll malalignment, an oro-vestibular fistula, a cleft lip-nose deformity, and a small nostril. In the case of bilateral cleft lip repair, immediate unfavorable outcomes usually include dehiscence and loss of premaxilla or prolabium. Unfavourable delayed outcomes included a central vermillion deficiency, a tight lip, bilateral cleft lip nose deformity, issues with the premaxilla, and maxillary growth disturbances[6] Several studies have emphasised the significance of parental satisfaction in healthcare settings. For instance, Smith et al. found that parental satisfaction positively impacts treatment adherence and the child's psychosocial well-being in paediatric

healthcare[7]. Therefore, assessing parental satisfaction after cleft lip repair is crucial for optimising treatment outcomes and providing comprehensive care. In Ghana, Komfo Anokye Teaching Hospital is a leading healthcare institution providing comprehensive cleft care services through a multidisciplinary cleft clinic. However, limited studies specifically examined parental satisfaction at this facility. Understanding the satisfaction levels and factors influencing satisfaction among parents or guardians is vital for enhancing the care provided to children with cleft lip and/or palate and ensuring their holistic well-being[8]. Beyond the aesthetic abnormalities, cleft lip and cleft palate may also be accompanied by other complications, such as feeding problems, ear infections and hearing loss, speech difficulties, and dental and orthodontic problems[9]. The emotional impact on parents when their new baby with CL/P is born can be devastating, especially for mothers[10]. Orofacial clefts are associated with various meanings and repercussions in various cultures. For instance, cleft lip is sometimes regarded as punishment in some Nigerian societies for parental misdeeds such as witchcraft. Hence, infants born with CL/P are kept from the public eye[11]. Many of these misconceptions affix blame to the parents. As a result, OFC may cause emotional and social trauma in mothers in various parts of the world where religion, culture, beliefs, and demographic characteristics have been demonstrated to have a significant influence in modeling the individual's attitude and behaviour towards children with OFC [10]. Cleft care comprises more than just surgical closure of the cleft; it also aims for an aesthetically and functionally ideal outcome in infancy and adulthood[12]. This research aimed to assess the satisfaction and the effect of surgery on the psychosocial status of parents of children with cleft lip after repair and the common complications associated with cleft lip repair.

METHODOLOGY

This was a descriptive cross-sectional study of three months (August to October 2023) duration among parents/guardians of children born with CL/P who underwent cleft lip repair at the Komfo Anokye Teaching Hospital Kumasi. All children born with non-syndromic CL/P who had undergone cleft lip repair and whose parent/guardian consented to the study were included in the study, including lip revision (re-do cases). Parents of children with CL/P with hearing, speech, and or mental health challenges were however excluded from the study.

After obtaining ethical clearance from Kwame Nkrumah University of Science and Technology Committee on Human Research, Publication and Ethics (CHRPE/AP/545/23), a self-administered questionnaire with assistance from trained research assistants was distributed to 73 parents/guardians at KATH and collected by the distributor before or after consultation. Assistance was provided for any literacy problems, including translating the questionnaire to the local dialect for better understanding. The questionnaire consisted of 5 parts. The first two sections looked at the socio-demographics of the parent and child. The third section assessed the parents/ guardians' perceived satisfaction aesthetic outcomes (appearance of the lip, teeth and nose, and profile of the face) using a modified "cleft evaluation profile" (originated from the Royal College of Surgeons Cleft Lip and Palate Audit Group and was used to assess perceived satisfaction for individual features related to cleft care[13].) This modification was made by scaling the 7-point Likert scale to a 4-point Likert scale, ranging from very satisfactory to very unsatisfactory. This made it easier for participants to answer. The fourth section compared the psychological status of the parents before and after the surgical repair. The parameters assessed before repair were the guardian, spouse, and family's reactions after being informed of the child's condition. However, after the surgical repair, a psychological assessment was performed. Parents/guardians were asked if the surgical repair improved their relationship with their spouse, resulting in confidence in attending social gatherings with the child, whether the family and friends interact with the child often, and whether the child shows confidence in interactions. Participants used a 6-point Likert scale ranging from strongly agree to not applicable to answer the questions. The fifth section assessed the complications following the cleft lip repair (notching, scarring, short lip, and wound dehiscence). The data was captured in Excel and analysed with the Statistical Package for the Social Sciences (SPSS) version 25.0. A descriptive statistics was done, and the data was summarised using proportions and percentages for all variables.

RESULTS

The study included a total of 73 parents/guardians of 73 patients. The parents/guardians consisted of 18 (25%) males and 55(75%) females. As shown in Table 1, most of the parents/guardians were within 30-39 years, representing 49.3%, with the least age distribution being less than 20 years, representing 5.5%. However, children with CL/P comprised 30 (41%) males and 43 (59%) females. 43(59%) of the cleft children were between 3 months to 1 year, 13(18%) in the 2 to 3 years range. 8(11%) 4 to 5 years and 9(12%) between the ages of 6years and above.

Table 1: Socio-demographic Characteristics

Age	Frequency (%)
< 20	4 (5.5)
20-29	23 (31.5)
30-39	36 (49.3)
40+	10 (13.7)
Total	73 (100.0)

From Table 1 above, most parents/guardians were within 30-39 years, representing 49.3%, with the least age distribution being less than 20 years, representing 5.5%.

Above, 75.0% of the parents/guardians were females, with 25.0% being males(Fig 1)

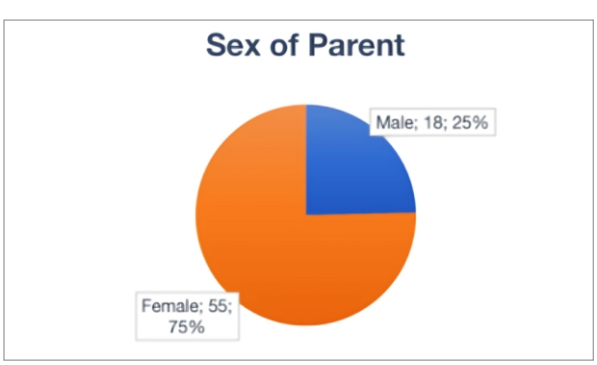

Figure 1: The Sex of Parents/Guardians

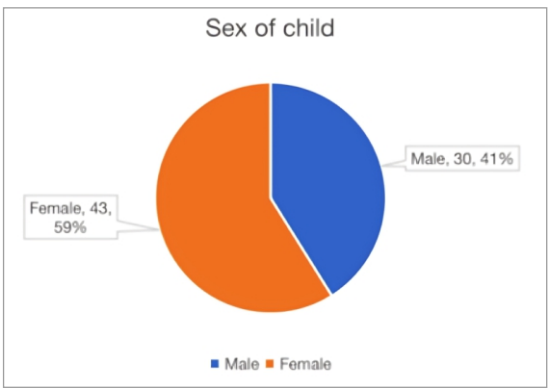

Figure 2: The Sex of the Child

From Figure 2 above, 59.0% of children with cleft lip and palate were females, with 41.0% being males

Table 2: Summary showing the distribution of the Laterality of Cleft Lip and Completeness of Cleft Lip amongst the sample

Variable		Frequency (%)
Laterality of cleft lip	Bilateral	14 (19.2)
	Unilateral	59 (80.8)
	Total	73 (100.0)
Completeness of cleft lip	Complete	39 (53.4)
	Incomplete	34 (46.6)
	Total	73 (100.0)

Table 2 above presents data on the laterality and completeness of cleft lip occurrences based on a sample of 73 cases. It shows that 19.2% of the cases had bilateral cleft lips, while 80.8% had unilateral cleft lips. Regarding completeness, 53.4% of the cases had a complete cleft lip, and 46.6% had an incomplete.

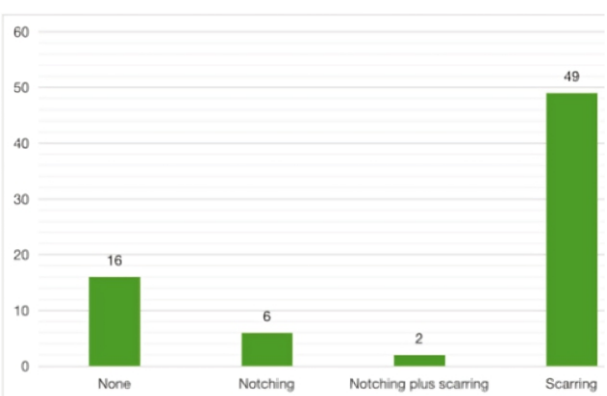

Figure 3: Complications After Repair

From Figure 3 above, lip scarring was the most common complication representing 67.1% with the least being notching and scarring representing 2.7%

Table 3: Perceived Aesthetic Outcome after Cleft Lip Repair

	Appearance of lip	Appearance of teeth	Appearance of the nose	Profile of the face
Very satisfactory	49 (67.1%)	15 (20.5%)	33 (45.2%)	26 (35.6%)
Satisfactory	16 (21.9%)	34 (46.6%)	34 (46.6%)	38 (52.1%)
Unsatisfactory	8 (11.0%)	22 (30.1%)	6 (8.2%)	8 (11.0%)
Very unsatisfactory	0 (0.0%)	2 (2.7%)	0 (0.0%)	0 (0.0%)
Total	73 (100.0%)	73 (100.0%)	73 (100.0%)	73 (100.0%)

Note: 1 Very satisfactory, 2 Satisfactory, 3 Unsatisfactory, 4 Very unsatisfactory

From Table 3 above, 67.1%, 45.2%, and 35.6% were very satisfied with the lip appearance, appearance of the nose, and profile of the nose of their children, respectively

Table 4: Psychosocial Effect Before Repair

	Guardian's reaction	Spouse's reaction	Family's reaction
Not worried	2 (2.7%)	6 (8.2%)	3 (4.1%)
Slightly worried	4 (5.5%)	7 (9.6%)	14 (19.2%)
Fairly worried	12 (16.4%)	10 (13.7%)	6 (8.2%)
Worried a lot	15 (20.5%)	16 (21.9%)	25 (34.2%)
Very worried	40 (54.8%)	34 (46.6%)	15 (20.5%)
Not applicable	-	-	10 (13.7%)
Total	73	73	73

Note: 0 Not applicable (family doesn't know), 1 Not worried, 2 Slightly worried, 3 Fairly worried, 4 Worried a lot, 5 Very worried.

From Table 4 above, 54.8% of the guardians were very worried. This was followed by 46.6% of very worried spouses and 20.5% of the family who were very worried about seeing and being informed of the child's cleft lip and palate.

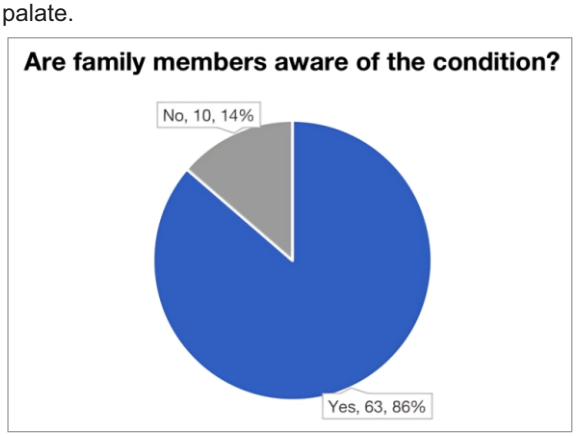

Figure 4: Knowledge of Family Members on the Child's Cleft Lip Condition

From Figure 4 above, the majority of the family members (86.0%) were aware of the child's cleft lip and palate condition.

Table 5: Table Summary for Responses on How the Cleft Lip Condition Affected Their Marriages and Relationships with Friends

Variable		Frequency (%)
Has the condition affected your marriage in any way?	Yes	5 (6.8)
	No	44 (60.3)
	Not applicable	24 (32.9)
	Total	73 (100.0)
Has it affected your relationship with friends?	Yes	20 (27.4)
	No	53 (72.6)
	Total	73 (100.0)

From Table 5 above, 60.3% of marriages were unaffected by the child's cleft lip and palate condition. Moreover, 72.6% of relationships with friends were not affected negatively.

Table 6: Psychosocial Effect After Repair

	Improved relationship with spouse	Attend social gatherings with child	Family interacts with the child often	Friends interacts with the child often	The child shows confidence in interactions
Strongly agree	11 (15.1%)	30 (41.1%)	22 (30.1%)	21 (28.8%)	22 (30.1%)
Agree	11 (15.1%)	35 (47.9%)	42 (57.5%)	20 (27.4%)	15 (20.5%)
Neutral	25 (34.2%)	4 (5.5%)	6 (8.2%)	28 (38.4%)	6 (8.2%)
Disagree	2 (2.7%)	3 (4.1%)	1 (1.4%)	3 (4.1%)	6 (8.2%)
Strongly disagree	0 (0.0%)	1 (1.4%)	2 (2.7%)	1 (1.4%)	5 (6.8%)
Not applicable	24 (32.9%)	-	-	-	-
Total	73	73	73	73	73

Note: 0 Not applicable, 1 Strongly agree, 2 Agree, 3 Neutral, 4 Disagree, 5 Strongly disagree.

From Table 6 above, 57.5% agree that the family's interaction with the child improved after the surgical lip. About half of the guardians (47.9%) were comfortable attending social gatherings with their children after the surgical repair.

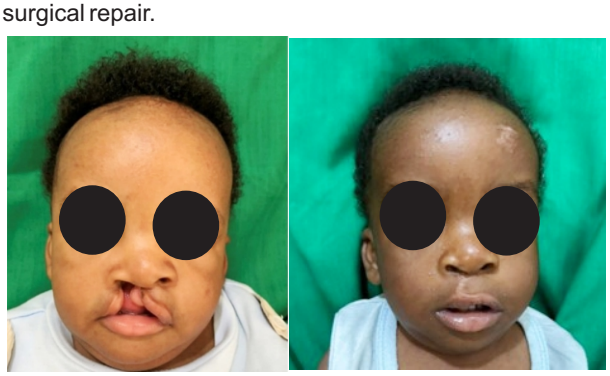

Figure 5: A patient with right unilateral complete cleft lip and palate Before and After

Figure 6: A patient with bilateral complete cleft lip and palate Before and After

DISCUSSION

The study reveals that cleft lip repair improves the psychosocial status of parents/guardians and the child with a cleft. Most parents/guardians were satisfied with the aesthetic outcome of the cleft lip repair.

Demographically, most of the parents/guardians were in the fourth decade, as shown in Table 1. The one-fourth of guardians being males is a positive sign that the mothers are now receiving support from their husbands or male figures in their families. Of the children with cleft, the majority were female; most had unilateral cleft lip in laterality, and the majority were complete.

Moreover, in this study, scarring is the most prevalent complication, occurring in about two-thirds of cases, followed by notching. However, about one-fourth of cases reported no complications. A study in Nigeria found similar results, with scarring being the most frequently reported complication[21]. Although scarring is an expected outcome of any surgical procedure, efforts should be made to minimize its severity and long-term impact on patients' aesthetics and self-esteem. Notching is another complication that requires careful attention during cleft lip repair. A study on early surgical complications after primary cleft lip repair investigated the incidence of notching following different surgical techniques. It emphasized that notching varied based on the surgical approach utilized. [22]. Preventive measures and surgical refinements are essential to minimize the occurrence of notching and ensure more favourable outcomes for patients. The observation that 21.9% of cases [Figure 3] reported no complications in this current study is encouraging and suggests that a significant proportion of patients experienced a successful cleft lip repair with minimal complications. However, a similar study conducted in Nigeria by Abdurrazaq et al. (2013) reported a higher surgical success rate. 68.8% of cleft lip and palate repair cases showed good outcomes, while 67.9% of lip repairs had favourable lip and nose scores[23]. This is likely due to the larger sample size in their study. They further emphasised the importance of surgical expertise and post-operative care in reducing complications and achieving favourable outcomes[23]. The findings of this current study underscore the need for continuous improvements in surgical techniques and post-operative care to achieve better outcomes and reduce the incidence of complications in cleft lip repair.

Satisfaction with the surgical outcome was high for the appearance of the nose, lip, face, and teeth in decreasing order [Table 3, Figures 5 and 6]. These results align with previous research that highlights the positive impact of

cleft lip repair on lip aesthetics. A study done in Uganda reported similar high satisfaction rates among patients and parents after cleft lip repair, emphasising the significant improvement in lip appearance after surgical repair[8]. Moreover, in this present study, regarding the appearance of teeth, about half of the respondents were satisfied, while about a third expressed dissatisfaction. This finding suggests a need to deepen the explanation of the cleft calendar to guardians on regular follow-up visits. A study by Pradhan et al. 2020 highlighted that dental issues are common in patients with cleft lip, and comprehensive dental care is essential for achieving optimal aesthetic outcomes[14]. In terms of the nose's appearance, nearly half of the respondents found it very satisfactory, and about half found it satisfactory. This suggests that cleft lip repair is effective in addressing perceived nasal aesthetics. Another reported a similar finding, emphasising the positive impact of cleft lip repair on nasal aesthetics and the importance of careful surgical planning for optimal results[15].

About half of the respondents found the face profile in this study satisfactory. Only a smaller proportion expressed dissatisfaction. Achieving optimal facial profile outcomes can be challenging in cleft lip repair. Numerous studies stressed the importance of multidisciplinary approaches, including orthognathic surgery, to enhance facial aesthetics and overall patient satisfaction[16,17]. Parents/guardians were satisfied with the aesthetic outcomes following cleft lip repair. However, areas such as teeth appearance and facial profile need improvement to achieve higher satisfaction rates. The findings are consistent with previous research, highlighting the positive impact of cleft lip repair on lip and nasal aesthetics[12,18]. Comprehensive post-repair care, including dental and orthognathic evaluation, should be emphasised[16] to improve patient satisfaction further. Multidisciplinary collaboration and continuous follow-up care are essential to achieve optimal aesthetic outcomes and ensure the well-being of children with cleft lip and their families.

Nevertheless, this current study revealed that cleft lip considerably impacts the emotional well-being of parents/guardians before the surgical intervention. A systematic review on anxiety, depression, and quality of life in caregivers of children with cleft lip and palate found that parents of children with cleft lip experience higher levels of stress and anxiety, especially during the early stages of diagnosis and treatment planning [19]. This current study shows a notable improvement in the psychosocial status of parents/guardians after cleft lip repair. A considerable number of respondents indicated positive outcomes, such as improved relationship with the spouse, attending social gatherings with the child, and family interactions with the child often. These findings suggest that cleft lip repair positively influenced the family dynamics and social interactions, aligning with a study by Byrnes et al., which reported improved family functioning and parental satisfaction following cleft lip repair[20]. The surgical intervention alleviates parental worries and concerns, improving family dynamics and increasing social interactions.

Nevertheless, some parents/guardians still expressed neutrality on certain aspects, suggesting the need for continued support and follow-up care to address potential residual concerns. Healthcare professionals must recognise the emotional impact of a cleft lip on parents/guardians and provide pre- and post-counselling for parents, tailored to their needs based on age. Enhance multidisciplinary approach to surgery and establish support groups for parents of children with cleft lip. This will provide comprehensive support throughout the treatment journey to ensure the best possible psychosocial outcomes for the child and their caregivers.

The limitations encountered in this current study include the small sample size and the study's data collection was conducted within a specific timeframe. This may limit the ability to capture long-term satisfaction trends or changes over time. Long-term aesthetic assessment would have made the in-depth assessment of aesthetics possible.

We recommend comprehensive counselling sessions for parents/guardians before and after cleft lip repair. Moreover, tailored support services must be offered based on the unique needs of different age groups of parents/guardians. Again, there is a need for an improvement in the multidisciplinary approach to cleft lip repair and support groups and peer support networks for parents/guardians of children with cleft lip.

CONCLUSION

The findings demonstrate that most parents/guardians expressed satisfaction with the surgical intervention's outcomes. The positive psychosocial effects reported, such as improved relationships with spouses, increased social interactions, and enhanced confidence in the child, underscoring the effectiveness of cleft lip repair in addressing physical appearance and supporting the emotional well-being of both the child and their caregivers.

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