

# Expectations of Caregivers of Patients with Cleft Lip and Palate Attending the Cleft Clinic of KATH for the First Time

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## Abstract

**Background:** Cleft lip and palate (CLP) is one of the most prevalent congenital malformations affecting the face worldwide, with high prevalence in Asians, Americans, and Caucasians and low in Africans. Orofacial Clefts (OFCs) are among the causes of perinatal death in Ghana. The children often experience difficulties in swallowing, feeding, and speaking. These children often face problems in cognition, education, and communication. Caregivers' ignorance of treatment, poverty, and noncompliance with follow-up schedules are obstacles to optimal cleft care. Most studies focus on the incidence of cleft, but not much is known about caregivers' expectations. **Methodology:** An exploratory qualitative study design was used for this research between October and November 2020. The study site was the Komfo Anokye Teaching Hospital, (KATH), Kumasi, Ghana. The respondents were recruited from the oral health clinic. Included in the study were all CLP caregivers attending the cleft clinic for the first time. Purposive sampling was used to select fifteen caregivers who met the inclusion criteria. Face-to-face interviews with a semi-structured interview guide were used to collect data. The data were analyzed using NVivo software. Three major themes and six sub-themes emerged from the data analysis using thematic analysis. Ethical clearance was obtained for data collection. **Results:** Most caregivers were expecting their babies to be operated on, and they were certain that the cleft would be repaired at the end of the treatment, but they were unfamiliar with the process and cost of treatment. Less than half of the caregivers reported that they were oblivious to what to expect the first time visiting but had hopes that the healthcare professionals would be able to close the cleft for their babies. **Conclusion:** The majority of the caregivers expressed fear and disappointment at the diagnosis of their child. Some caregivers were very scared to the level where they had to

hide the babies from the public. Others reported being already in financial difficulties, so their children's conditions would compound them.

## Keywords

Cleft Lip and Palate, Caregivers, Congenital, Abnormalities, Malformation

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## 1. Introduction

Cleft lip and palate are among the most prevalent congenital malformations affecting the face worldwide, with high prevalence in Asians, Americans, and Caucasians and low in Africans [1] [2].

The etiology of this malformation is multifactorial and includes genetic predisposition, in-utero teratogen exposure, or maternal viral infections. In addition, environmental factors such as smoking, vitamins, and folic acid deficiencies, alcohol consumption, and use of non-prescription medication by pregnant women are considered predisposing factors for CLP [3] [4] [5].

A CLP results from a failure of fusion of the maxillary, medial and lateral processes, which typically happens around the 6<sup>th</sup> and 10<sup>th</sup> weeks of gestation. They can present alone or as a combination of multiple birth abnormalities [6] [7].

The lip forms within the fourth and seventh weeks of pregnancy. As a baby develops during pregnancy, body tissue and special cells from each side of the head grow towards the center of the face and join together to make a face. This tissue joining forms the facial features, like the lips and mouth. [8].

A cleft lip (CL) occurs if the tissue that makes up the lip does not join completely before birth resulting in an opening in the upper lip. The opening in the lip can be a small slit, or it can be a large opening that goes through the lip into the nose. A CL can be on one or both sides of the lip or in the middle, which rarely occurs. Children with a CL also can have a cleft palate (CP) [8].

The palate is formed between the sixth and ninth weeks of gestation. A CP occurs if the tissue that makes up the roof of the mouth does not fuse completely during pregnancy. For some babies, the front and back parts of the palate are open. For other babies, only part of the palate is open. [8]

The prevalence of clefts may be affected by socioeconomic, geographic, racial, and ethnic factors. [9] Current knowledge indicates that cleft lip and palate occur in approximately 1 in 700 live births [10] [11].

Meanwhile, there is much information about OFC prevalence, incidence, long-term patterns, and disparity in Ghana; nonetheless, the results have not been consistent [12] [13]. This may be described by differences in the syndromic condition, differences in the underlying population, indistinct classification of clefts, time, and geographic coverage. Agbenorku *et al.* reported an incidence of 6.3 per 1000 live births in Ghana [14].

Again, in Ghana, OFCs are among the causes of perinatal death [15]. The children often experience difficulties swallowing, feeding, hearing, and speaking dif-

faculties. In addition, these children often face problems in cognition, education, and communication.

Discrimination is disadvantageous to people with disabilities and may affect their self-image and realization of their life goals [16]. Moreover, these discriminations among individuals indirectly or directly affect their socioeconomic life and invariably jeopardize their health.

In Ghana, many studies have been done on CLP. However, most of these studies focus on the incidence of cleft [17], but not much is known about caregivers' expectations.

Therefore, this study explored the expectations of caregivers of patients with CLP attending the cleft clinic of KATH for the first time to help inform future policy direction.

## **2. Methodology**

### **2.1. Study Design**

The study was an exploratory qualitative study conducted between October and November 2020.

### **2.2. Study Setting**

The study was conducted at KATH, Kumasi, Ghana. The respondents were recruited from the oral health clinic in the hospital.

### **2.3. Sampling and Data Collection Techniques**

Purposive sampling was used to select twenty caregivers who met the inclusion criteria.

Face-to-face interviews were conducted using a semi-structured interview guide to collect data from the consulting room at the oral health clinic. All verbal information was obtained in either Asante Twi or English based on the caregivers' preference.

Socio-demographic features, including age, sex, occupation, level of education, residence, and religion, were also taken as part of the data collection.

Interviews were digitally recorded, and the researchers took field notes. Permission to use a tape recorder was obtained from the participants to enable data extraction. Information received was transcribed word for word to ensure accuracy. Each interview lasted between 30 and 45 minutes.

### **2.4. Inclusion Criteria**

- Caregivers of patients with CLP.
- Caregivers attending the cleft clinic for the first time at KATH.
- Fluency of the caregiver, either in English or Asante Twi.

### **2.5. Exclusion Criteria**

- Patients with other maxillofacial conditions.

- Caregivers who were not first-time attendees.

## 2.6. Data Analysis

The data were analyzed using NVivo software. Data were transcribed verbatim and then coded. Codes generated were given themes that made meaning in exploring caregivers' expectations of patients with CLP. Three major themes and six sub-themes emerged from the data analysis using thematic analysis. The research team examined the themes to confirm that data were represented accurately.

## 2.7. Ethical Clearance

Before data collection, ethical clearance was obtained from the Komfo Anokye Teaching Hospital Institutional Review Board (KATH IRB) with reference number KATH IRB /AP/152/20. The human data performed were per the Declaration of Helsinki. Before their enrollment, the participant signed a written consent form explaining the purpose of the research and assuring confidentiality of the information to be collected. The rights of the caregivers who declined to participate in the study were respected. All caregivers were further informed that the data collected was only used for the purposes for which it was collected. Only the researcher and supervisors will have access to the raw data.

## 3. Results

Socio-demographic features of the cleft lip and palate patients and caregivers.

### 3.1. Socio-Demographic Features of the CLP Caregivers

The socio-demographic data of the respondents are shown in **Table 1**. Twenty respondents were recruited for this study, with twelve being females and eight being males. Eleven cleft patients had an age range between 0 and 3 months while two were above 12 months. The age of the guardians ranged from 20 and 40 years. With the guardian's relationship to the cleft patient, fourteen were mothers, and two were grandmothers. Sixteen respondents had basic education, whereas two had SHS and tertiary education. Thirteen of the respondents were self-employed, with four being unemployed. Nine respondents had an income between 50 - 500 Ghc, whereas five had an income higher than 500 ghc.

Three major themes with six sub-themes were found in the expectations of caregivers of patients with cleft lip and palate attending the Cleft clinic of KATH for the first time as illustrated in **Table 2** below.

### 3.2. Emotional Experiences

#### 3.2.1. Fear

The caregivers were asked to share their experiences and reactions when they realized their child was diagnosed with a CLP. The majority of the caregivers expressed fear, perplexity, and self-disappointment.

**Table 1.** Demographics of caregivers.

Variable	Frequency (%)
<b>Gender of cleft patient</b>	
<i>Male</i>	8 (40%)
<i>Female</i>	12 (60%)
<b>Age (months) of cleft patient</b>	
0 - 3 months	11 (55%)
4 - 6 months	3 (15%)
7 - 12 months	4 (20%)
Greater than 12 months	2 (10%)
<b>Age(years) of the guardian</b>	
Less than 20 years	2 (10%)
20 - 29 years	5 (25%)
30 - 39	9 (45%)
Greater or equal to 40	4 (20%)
<b>Relation of caregiver to child</b>	
Mother	14 (70%)
Father	4 (20%)
Grandmother	2 (10%)
<b>Level of education of the caregiver</b>	
Basic	16 (80%)
SHS	2 (10%)
Tertiary	2 (10%)
<b>Occupation of caregiver</b>	
Self-employed	13 (65%)
Unemployed	4 (20%)
Employed by other	3 (15%)
<b>Level of income of caregiver/month</b>	
Less than 50 cedis	6 (30%)
50 - 500 cedis	9 (45%)
Greater than 500 cedis	5 (25%)

**Table 2.** Major themes and sub-themes based on thematic analysis.

EMOTIONAL EXPERIENCES	THE EXPECTATION OF TREATMENT	SUCCESSFUL TREATMENT OUTCOME
Fear Acceptance Isolation	Expectations at the cleft clinic for the first time Expectations of health professionals' attitude	A desire for normality

I was afraid, scared, and cried a lot P1, 5, 6, 7, 9, 15, and 16.

The fear of a caregiver led to her having high blood pressure postnatally when she saw her child.

P 11 reported *I was scared and had a rise in blood pressure.*

P4 and 5 were so scared that they initially refused to see their children. *i.e., I was very scared and sad and could not go near the child.*

### 3.2.2. Acceptance

Some of the respondents were indifferent to the diagnosis and were not afraid but embraced it at the initial glance of it. *P8 I am indifferent to the child's condition.*

There were varying reasons for their acceptance.

Some indicated they had seen some of the condition before, and others were hopeful of repair. *P13 I was not discouraged as I have seen some before.*

*P14 I was hopeful that it could be solved.*

*P12 was not afraid because I was told doctors could fix it.*

### 3.2.3. Isolation

Caregivers were asked to share their sentiments toward the condition of their baby. However, emotionally speaking, it was very difficult for many of them to accept this lifetime fate for their children.

*It was difficult to take it, and I was shy to take the baby out. P1, 2, 3, 16, 19.*

Some were very scared to the level where they had to hide the babies from the public.

*Emotionally, I was very worried and had been thinking about it and could not show the child P7, 9 but P11 I was a bit withdrawn and only allowed family members to see my child.*

As the process of grief differs for every individual, some of the caregivers indicated that they were not worried at all.

*Emotionally, not worried P10, 12, 13, 14, 16, 17, 20.*

## 3.3. The Expectation of Treatment

Caregivers were asked to share their expectations since it was their first time visiting the multidisciplinary cleft clinic. This theme had two subthemes: expectations of treatment and expectations of health professionals' attitudes at the specialist clinic.

### 3.3.1. Expectations at the Cleft Clinic for the First Time

Most of the caregivers were expecting their babies to be operated on. They were certain that the cleft would be repaired at the end of the treatment, but they were unfamiliar with the process and cost of treatment.

*'For the child to be operated on 'no idea' 'no idea' 'for the doctors to close the palate and the child to talk normally' P18, 19, 20.*

Less than half reported that they were oblivious of what to expect the first time visiting the specialist cleft clinic but had hopes that the doctors would be able to close the cleft for their babies. So, their response was *'no idea' 'no idea'*

'no idea' 'for the doctors to be able to close the cleft' P5, 7, 8, 9, 11, 15, 16, 17.

Only P3 could make a suggestive amount on the cost of treatment, *not more than 2000 cedis*.

### 3.3.2. Expectations of Health Professionals' Attitude

It was seen in the caregivers' responses that they had good expectations of the attitude of the health workers at the cleft specialist clinic.

*To be communicated to and help me to understand the process well and nicely* P1, 7.

*To be talked to politely and professionally* P2, 3, 4, 5.

Some of the caregivers expected the attitude of the staff to be normal toward them.

P18, 19, 20 'normal'.

### 3.4. Successful Treatment Outcome

#### A Desire for Normality

The caregivers were to respond to what they considered a successful treatment outcome for their child, and various responses were given. Most of their answers were when the cleft was repaired, and the child's mouth appeared normal, like a child without a buccal deformity.

*When I see that the cleft is gone and the child's mouth is normal* P2, 4, 5, 9, 10, 11, 12, 13, 15, 16, 19, 20.

Some reported the child's ability to cry well or have a good speech delivery would indicate a successful surgery.

P8, 14, *the child cannot cry well, so if I see the child can open his mouth and cry, I would consider the whole treatment successful*.

*When the child's speech is restored, I will be okay* P18.

## 4. Discussion

This study found that most respondents were 30 years and above, which is inconsistent with a study in the sub-region where most mothers were less than 30 years of age [18]. This difference may be because the current study used guardians, including grandmothers, fathers, and mothers, while the other used only mothers. Again, almost all mothers were unemployed or worked low-earning jobs [17]. It was similar to the current study, which found that most respondents were doing menial work for survival. Again this may be due to poor economic living and inadequate job availability in Ghana.

This study also found that most caregivers expressed fear and self-disappointment, similar to a study conducted elsewhere [19], where most families expressed concerns about the marriage prospects and educational opportunities but expected their child's life to be better when the facial deformity was corrected.

However, several parents of children with CLP were unconcerned with the palate. Still, they merely wanted the lip repaired [20], similar to the current study where several guardians were indifferent to the cleft but wanted it repaired with

no buccal deformity. This optimism could be a result of the education and awareness they had received on CLP repair.

This study indicated that it has been emotionally difficult for many caregivers to accept this lifetime fate for their children and social stigma. This may be societal gestures, sayings, and reduced cultural awareness of cleft victims in our part of the world. Some of the guardians were not afraid and embraced it at the initial glance of the diagnosis, which aligns with another study, where most of the parents did not limit their child's social interaction and were not ashamed to be seen in public. [9] In contrast to the acceptance of the condition upon diagnosis, another study [4] reported that few of their respondents exercised some constraints, kept their children isolated, and did not permit them to leave the house or attend school. This is consistent with findings from this study, where the respondents were very scared and had to hide the babies from the public. This act may be due to cultural acceptance and the stigma of having a cleft child in our part of the world.

Less than half of the caregivers reported that they were oblivious of what to expect on the first visit but had hopes that the doctors would be able to close the cleft for their babies, while in a study majority had all their pre-operative expectations fulfilled [21]. In another study, almost half of the parents spontaneously expressed their conviction that, after corrective surgery, their child would have a better chance of achieving a more healthy marriage [20].

This study found that some caregivers were already in financial difficulties, so their child's condition was going to compound it. Similar studies showed a lack of finances as the main cause of delay in the repair of CLP [20] [22]. These are all inconsistent with the findings of this study relating to conducting this study in a developing country.

This study reported that most caregivers expected their babies to be operated on, but they were unfamiliar with the process and cost of treatment. These findings were similar to another study where respondents indicated unfamiliarity with surgery [23]. Therefore, these findings could be said to be the reason for the late presentation to the health facilities.

Finally, the ignorance of what to expect at the cleft clinic agreed with a study in developing countries, where factors such as cultural beliefs, superstitions, lack of awareness of treatment services, and lack of time have been reported to contribute to delayed presentation of CL ± P patients [23] [24].

## 5. Conclusions

The majority of the caregivers were females. The modal age of the patients was 0 - 3 months.

Less than half of the caregivers reported that they were ignorant of what to expect on the first visit but hoped that the healthcare team would be able to close the cleft for their babies. Most caregivers expected their babies to be operated on but were unfamiliar with the process and cost of treatment.



The majority of the caregivers expressed fear and disappointment at the diagnosis of their child.

Some caregivers were very scared to the level where they had to hide the babies from the public. Others reported being already in financial difficulties, so their children's conditions would compound them.

Per the findings of this study, it is recommended that; the cleft team at KATH should organize awareness creation programs to educate the general public about the CLP condition and available treatment. This can be done in partnership with community health nurses who go into the communities regularly. It is therefore important to update such staff on their knowledge of the condition.

Community members should avoid stigmatization and discrimination against families with CLP since it compounds the emotional trauma and stress that they go through and further demoralize them. Instead, they should accept them and show love to them.

The findings of this study should be generalized with caution since few participants were selected for this study due to the qualitative approach used.

From this study, it is recommended that the cleft team at KATH must educate the public on possible risk factors for giving birth to a child with CLP and should also organize awareness creation programs to educate the population on the availability of treatment.

Again, the cleft team at KATH should educate parents/caregivers of babies with CLP on various stages of CLP care until complete treatment is achieved.

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## Consent

The authors confirm that informed consent was obtained from the patient for the publication of this article.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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