

# The Status of Orofacial Cleft Care in Ghana

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## Abstract

Orofacial Clefts (OFC) are common congenital facial anomalies. The study seeks to determine the status of care for OFC patients in Ghana. Currently, in addition to the Ministry of Health, there are six Non-Governmental Organizations, which are dedicated to the provision of logistics for the management of cleft patients. As it is possible there could be OFC endemic areas in Ghana, sensitization of the population of the condition and management of this anomaly should be promoted. Persons of OFCs are faced with known challenges, which result in negative self-image that affect their quality of life. Hence educating the general public, in particular pregnant women who access antenatal care in health facilities may reduce ill effects associated with the anomaly. Genetic studies of the anomaly should also be encouraged to help decrease the incidence.

*Key Words: Orofacial Clefts, Care, Status, Non-Governmental Organization, Negative Self-image*

## Introduction

### Incidence and predisposing factors

Orofacial cleft is one of the most common congenital abnormalities affecting people worldwide with high prevalence especially in Asians, native American population and Caucasians; prevalence in the African population is however recorded as low [1,2]. Cleft Lip and Palate (CLP) is the most prevalent congenital birth anomaly in live births [3-5] with an incidence of cleft lip with or without palate (CL ± P) 1 in 600 live births [6]. Causes of CL ± P have been attributed to genetic and environmental factors [7]. Smoking, vitamins and folic acid deficiencies, alcohol consumption and use of non-prescription medication by pregnant women are predisposing factors of CL ± P [8,9].

Cleft lip occurs more commonly in males than females (2:1 ratio) whereas cleft palate is more frequent in females than males (2:1 ratio) [10]. A descriptive hospital based study conducted in Gorgan, Northern Iran to determine incidence of oral clefts showed results of an incidence of 1.05 per 1000 live births [11]. Elahi et al. in their study reported an incidence of 1.91 per 1000 live births based on population data obtained from the birth registry in Northern Pakistan [12]. Agbenorku et al. reported an incidence of 1.31/1000 live births out of 27,449 births in eleven selected health facilities in Kumasi, Ghana, of which 36 orofacial anomalies were recorded [13]. Agbenorku et al. again reported of a prevalence of at least 6.3 per 1000 people in Wudoaba community in South East Ghana [14].

From 2004 to 2006, data from 14 states in the USA showed cleft prevalence of 6.35 per 10,000 live birth for cleft palate only and 10.63 per 10,000 live births for cleft lip with or without palate [15]. A prevalence of 1.39 per 1000 live births with CL ± P was obtained in a study conducted in Jordan over an eleven year period [16]. According to Suleiman et al. [17] 1 per 2500 African American is born with a cleft. A prevalence of 0.7 per 1,000 live births has been reported in Malawi [18]. Prevalence of 0.9 per 1,000 live births was reported among group of newborns in Khartoum, Sudan [17]. More so, prevalence of 9.7 per 10,000 live births has been reported in Mestizo [19] and 1.23 per 1,000 live births in Sucre, Bolivia [20].

### Effects and management

Management of OFCs requires comprehensive approach from professionals in specialties such as plastic surgery, maxillofacial, orthodontics, nursing, speech therapy and dental surgery among others who work together and ensure quality care for the patients. The psychosocial stress experienced by both persons with the anomaly and parents has also been documented; they are unable to 'be themselves' and take part in normal social activities of their peers and as a result develop a negative self- image [21,22]. Kapp reported in his study on the low perception these persons have of themselves to an extent that they are unusually angry, anxious and sad [23].

Cleft lip repair surgery is usually recommended at 10-12 weeks while palate surgery is from nine to twelve months old [24-27] to aid in good speech outcome [26] as delayed surgery has been reported as a cause of poor speech outcome [27]. A study carried out in Wudoaba community in Ghana by Agbenorku et al. revealed lack of finance (47.5%) as the main cause for delay in repair of OFCs [28]. A study carried out in Nigeria by Adeyemo et al. reported lack of money (56.7%), health services nearby (18.4%) and awareness of treatment availability (13.3%) as reasons why people presented late to health facilities for various CL ± P surgeries [29]. In developing countries, factors such as cultural beliefs, superstition, unawareness of treatment availability, lack of time have been reported to contribute to delayed presentation of CL ± P cases [30,31].

Treatment for cleft lip is between 2-3 months post surgery with the need of following the rule of 10 (i.e., babies about 10 weeks old, weighing about 10 lb (4.5 kg) and haemoglobin level of about 10g/dl) [13]. However, depending on the degree and extent of cleft lip such as in bilateral cases, two surgeries may be required. The most common procedure employed for cleft lip is the Millard's procedure [32]. For cleft palate, surgery is carried out between 6-12 months with the aim of helping the affected to produce a normal speech without any nasal effect. Surgical procedure employed for the correction of the palate is Lagenbeck procedure. In a study by Agbenorku et al. [13] Millard's rotation advancement repair, straight line procedure were employed for unilateral and bilateral CL respectively while Lagenbeck variant methods were employed for cleft palate victims.

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## Cleft Care in Ghana

Ghana is a country located in West Africa with a population estimated to be 25,000,000 [33] in 2012 and well noted for her longstanding peace stability. The country has attracted investors from all around the globe. She is bounded in the north, east and west by Francophone countries: Burkina Faso, Togo and La Cote d'Ivoire, respectively and in the south by Gulf of Guinea. There are ten regions in the country [34].

### Cleft care supporting organizations in Ghana

Cleft surgeries have been carried out in the past by a variety of surgeons, especially general pediatric surgeons, Ear, Nose and Throat (ENT) surgeons and Oral surgeons but have been poorly documented. Presently, there are six main Cleft Care Organizations in Ghana: *Smile Train*, partnering with the Komfo Anokye Teaching Hospital (KATH) in Kumasi, *Transforming Faces Worldwide*, partnering with the Cleft Lip and Palate Management Project Team at the Korle-Bu Teaching Hospital, *Operation Smile*, partnering with the Ghana Ministry of Health and the Ghana Health Service, *Nanenu Missions* (a completely indigenous effort) partnering with the Global Evangelical Mission Hospital, Apromase-Ashanti and the Sogakope District Hospital, *ReSurge International*, partnering with individual local surgeons and the *Ghana Cleft Foundation*, also partnering with the KATH Multidisciplinary Cleft Clinic.

**Smile Train:** The world's largest Cleft charity organization based in New York founded in 1999 aims at providing free safe surgeries for cleft lip and palate patients who cannot fund these surgeries themselves. Currently their services are in 87 developing countries, including Ghana, providing support for persons who need to undergo surgery without the patient or family burdened with any costs at all. The organization also provides training, organizes conferences to equip professionals on modern ways to be able to better manage patients with the anomaly [35].

**Transforming Faces Worldwide (TFW):** A cleft charity based in Canada also provides funds for cleft lip and palate care in developing countries. Made up of professionals from the various specialties, the TFW team coordinates with the locally based cleft teams as well as medical teams and assists them with funds [36].

**Operation Smile:** A non-profit organization which aims at providing free medical training to health professionals as well as medical care to people with facial anomalies. The organization works with the Ministry of Health and the Ghana Health Service to provide free reconstructive surgeries to patients who need them. The organization includes persons in the various specialties involved in the surgery and management of patients even after surgery [37].

**Nanenu Missions (now Charis Missions International):** The implementation of outreach programs by an NGO known as Nanenu Missions has been very beneficial in the sensitization of persons in the rural communities in parts of the Volta Region and in the Ashanti Region of Ghana. Owing to the fact that surgery is indispensable in persons with the condition, this NGO is responsible for all the costs involved in the surgery and management of persons who undergo surgery. In the past, individuals with CL ± P were seen as being punished by ancestors and parents of such babies and were subsequently treated with scorn and even sometimes banished from the community. The Nanenu Missions also discovered that sometimes OFC babies were deliberately killed or thrown away in 'sacred forests' to die [38]. The lack of knowledge of the causes and possible interventions has been a problem for rural populations in particular. Wudoaba in the Volta Region is one of the rural

communities which has benefited immensely from interventions by Nanenu Missions, including studies and clinical work carried out by Agbenorku et al. which has brought much relief to affected persons in these communities [14]. The high prevalence recorded by this NGO in the Wudoaba community [14] could imply that this community could be an 'endemic zone' for OFCs in the Volta Region of Ghana. It is thought that this could be a resulting factor for the long standing existence of regular every 5th- day night market in the area where OFC patients do their petty trading and shopping under the cover of almost total darkness except for miniature kerosene lamps [38]. Through various sensitization programs using the radio, durbars, churches, community opinion leaders Nanenu Missions has been a channel of hope to under-privileged persons who have been living with the anomaly for years, many into late adulthood, and may have resigned themselves to their fate as a result of lack of finances, access or awareness of interventions.

To date, there is no national orofacial database; in their recent study in Kumasi, Agbenorku et al. [13] expressed hope of extending their study to other cities in the country in order to be able to create a national database. The Charis Missions International (CMI) in its focus on preventive measures to curtail the cleft menace in the Wudoaba communities is planning on genetic studies. Even though funds have still not been secured the CMI is still working hard on establishing a world-class medical research center to tackle the problem.

**Others:** Additionally, *ReSurge International*, a US NGO that provides free reconstructive surgeries for the poor is partnering with local surgeons to treat cleft patients on outreach programs at selected areas. OFC patients who otherwise may not receive cure benefit from this generosity to receive free treatment.

Also, the *Ghana Cleft Foundation*, in collaboration with the KATH Multidisciplinary Cleft Clinic, runs community programs to sensitize the public on OFCs in addition to the provision of human and logistics resources for outreach cleft surgeries.

### Cleft Care at the Korle-Bu Teaching Hospital, Accra

Since the year 2003, Transforming Faces Worldwide (TFW) has partnered with the Cleft Lip and Palate Management Project of the Reconstructive Plastic Surgery and Burns Center (RPSBC) of the Korle-Bu Teaching Hospital, Accra, to manage patients with orofacial clefts. This multidisciplinary team includes plastic surgeons, dental surgeons, an orthodontist, speech therapists, anesthetists, a clinical psychologist, pediatricians, otolaryngologists, nutritionists and both community and clinical nurses. Services rendered include reconstructive surgery, nutritional support, dental care, orthodontics, speech therapy, and counseling. In addition transport and accommodation expenses are reimbursed where needed. The team also undertakes outreach programs to identify new patients and educate the public to dispel myths and reduce stigmatization of these individuals. Monthly Panel Clinics are held where patients are examined, diagnosed, treatment plans formulated, appointments given for surgeries and referrals made to the various specialists for their expert management at their respective departments. Orthodontic management is undertaken at the University of Ghana Dental School where mainly fixed appliances are used. On the average, multidisciplinary treatment begins at three months of age and may continue until 21 years; 50% of them are being treated before their first birthday and 75% are treated before their fifth birthdays. TFW also provides training to the members of the multidisciplinary cleft team [39].

## Cleft Care at the Komfo Anokye Teaching Hospital, Kumasi

The Multidisciplinary Cleft Clinic in Komfo Anokye Teaching Hospital (KATH) consists of specialists such as plastic and maxillofacial surgeons, pediatricians, an orthodontist, nutritionists, ENT specialists, anesthesiologists, speech and language therapists and nurses. Weekly once, multidisciplinary clinics are held where the cleft patients are seen. Here, their parents are counseled, appropriate diagnoses are made and bookings are done for surgeries. All the professionals at the Clinic in their various fields of specialty help to put smiles on faces of persons with OFCs as well as their parents and families as a whole. In managing patients after surgery, follow up is done at 1 week and after 3 weeks; within this period, parents are taught how to massage scars to quicken scar maturity and prevent formation of contractures. During the first year, follow up is done quarterly and then yearly until the child turns 20 years when all secondary and improvement surgeries, functionally and aesthetically are completed. In a study undertaken to review the activities of the

KATH Multidisciplinary Cleft Clinic from 2006-2009 a total of 158 surgeries were performed, with patients' age ranging from 1-25 months; also, there was increase in cleft lip cases from 2006-2009 whilst cleft palate cases decreased towards 2009 [40]. Smile Train largely sponsors the KATH work.

## Conclusion

There is a need for more studies to be carried out, especially in the field of cleft genetics. The management of OFC requires a multidisciplinary approach to produce an excellent outcome and those affected are usually unable to fund their care themselves. There is therefore a need for all responsible stakeholders, including the Ministry of Health of Ghana and Non-Governmental Organizations involved in the management OFC management, to work together to ensure that there is adequate funding for the care of OFC patients.

There is also the need to increase awareness of this anomaly so that affected persons may seek and receive early treatment.

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