



# Perspectives on the state of cleft lip and cleft palate patient care in Africa

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## Purpose of review

Patients with cleft lip -palate (CLP) experience morbidity and social stigma, particularly in low-income and middle-income countries (LMICs) such as those of sub-Saharan Africa (SSA). Delays in treatment secondary either to lack of awareness, skills, equipment and consumables; poor health infrastructure, limited resources or a combination of them, has led to SSA having the highest rates of death and second highest rates of disability-adjusted life years in patients with CLP globally. Here we review current perspectives on the state of comprehensive cleft lip and palate repair in Africa.

## Recent findings

To bridge gaps in government health services, nongovernmental organizations (NGOs) have emerged to provide care through short-term surgical interventions (STSIs). These groups can effect change through direct provision of care, whereas others strengthen internal system. However, sustainability is lacking as there continue to be barriers to achieving comprehensive and longitudinal cleft care in SSA, including a lack of awareness of CLP as a treatable condition, prohibitive costs, poor follow-up, and insufficient surgical infrastructure. With dedicated local champions, a comprehensive approach, and reliable partners, establishing sustainable CLP services is possible in countries with limited resources.

## Summary

The replacement of CLP 'missions' with locally initiated, internationally supported capacity building initiatives, integrated into local healthcare systems will prove sustainable in the long-term.

## Keywords

cleft lip and palate, low-income and middle-income countries, short-term surgical interventions, sub-Saharan Africa

## INTRODUCTION

Orofacial cleft lip and palate (CLP) is the most common congenital craniofacial deformity. The estimated worldwide prevalence is 1.4 per 1000 live births with the highest rate in Asia at 1 per 500 live births [1–3]. In contrast, the prevalence of CLP in sub-Saharan Africa (SSA) is less than 1 per 1000 live births. Variation exists between African countries, ranging from 0.3 per 1000 in South Africa to 1.5 per 1000 in Ethiopia [4–7]. Despite the lower prevalence, SSA retains the highest rates of death and second highest rates of disability-adjusted life years (DALYs) related to CLP. These adverse second-order effects result from poverty and inadequate access to care, highlighting the disparity in CLP care between low-income and middle-income countries (LMICs) and high-income countries (HICs) [1,8]. Here we review the current state of cleft care in SSA and lay out future directions [9,10].

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## KEY POINTS

- Delayed repair of cleft lip and palate contributes to adverse functional and psychosocial outcomes among patients and their families across sub-Saharan Africa (SSA).
- Barriers to comprehensive cleft care in SSA include lack of awareness that treatment exists, geographic barriers to access, financial burdens, scarcity of training opportunities, and the inadequate surgical workforce.
- Short-term surgical interventions (STSI) historically emphasized surgical delivery but should notably be shifted to surgical teaching and support of domestic health infrastructure.
- Effective care for patients with CLP in SSA requires improved surgical infrastructure, surgical education, and creative contextual solutions that integrate human capital with technology.
- The role of Ministries of Health will be imperative for these changes in the coming decades.

## CLEFT LIP: PALATE DISEASE BURDEN

Repair of a CLP deformity is listed by the World Bank as one of the 44 essential surgeries to which resource allocation and health infrastructure design should be prioritized to avert substantial death, disability, and cost [11]. Functional consequences of delayed CLP repair related to craniofacial development, dental growth, speech, nutrition, and upper respiratory infections impose a significant economic burden [12,13]. The total global burden of disease due to delayed CLP repair was estimated to be 191 000–457 000 DALYs and that 2.1–4.7 million DALYs were averted at an operating cost of \$196 million USD, emphasizing that early diagnosis and timely treatment are imperative [13]. However, even the most accurate economic modeling fails to capture the human impact of inadequate surgical care for the patient with CLP. The authors have more than once called families to schedule their child's long-awaited surgery only to be told the child has died. Furthermore, it is not uncommon to meet elderly patients with unrepaired CLP who have suffered from the long-term comorbidities [14].

The psychosocial impact of CLP has long been a source of concern. Children born with CLP in SSA may be stigmatized as malevolent spirits and considered an act of divine retribution for the immorality of their mothers, who are in turn heavily criticized and shamed [15–17,18<sup>\*\*\*</sup>,19,20]. In this context, the presence of a visible deformity (i.e. cleft lip) can trigger child abandonment and neglect. An unseen deformity (i.e. isolated cleft palate) can

result in delays in diagnosis and deferment of treatment, thereby transitioning CLP from a surgically 'curable' condition to a long-term 'incurable' condition of chronic speech disability [11,21,22]. Caring for a child with a craniofacial deformity may also negatively impact family well being and resources, with resultant fracturing of family sub-units [11,23]. Additionally, as children with CLP reach school-age, the social ramifications of an unrepaired deformity can prompt withdrawal from school, placing them at a disadvantage for jobs and predisposing them to a lower socioeconomic status in the future. Therefore, the first step to addressing comprehensive treatment of this vulnerable patient population is to understand the human, economic, and psychosocial burden of CLP.

## THE SURGICAL WORKFORCE CRISIS

Africa bears 25% of the global burden of disease but only 2% of the global workforce to combat it [24]. In SSA, there are insufficient numbers of qualified cleft surgeons who are unequally distributed. There are few training programs for CLP within SSA and within these existing programs, training is often disrupted or compromised by scarce resources and inadequate infrastructure [25]. Consequently, trainees are faced with training options such as: international programs in HICs, programs in SSA with visiting expertise, SSA programs funded by regional organizations such as the College of Surgeons of East, Central, and Southern Africa (COSECSA), and programs in nearby SSA countries [25].

Another deleterious effect on the surgical workforce is the so-called 'brain drain', when healthcare workers leave the continent to pursue higher paid employment. The majority of trainees in SSA, however, remain within SSA for employment [25–30]. Barriers exist to attend training programs in a different country even within the subcontinent [25]. These barriers include the need to self-fund salary during training, a feeling of trivialization with regards to rotation scheduling and choice of operative cases, and a lack of academic support and opportunities compared with local trainees [29].

More commonly, an 'internal brain drain' occurs when surgeons appointed to government hospitals supplement their lower salaries with private practice. Faculty surgeons within the government hospital system maintain that this allows them to subsidize their public hospital teaching positions and in essence offer charity care. Although understandable, this splits the attentions of surgeons and hampers the full development of the public teaching hospital faculty roles. Regulations to hinder this along with more competitive government hospital salaries will

foster faculty surgeon development within the government health system. This ‘internal brain drain’ will be a force that ministries of health will have to address, affecting cleft surgeons and the surgical workforce in general.

In addition, the existing cleft surgical workforce is unevenly distributed across SSA. Qualified surgeons tend to concentrate within large academic centers that are centrally located in urban areas, where there is comparatively more staff, equipment, and educational and research opportunities [25]. Consequently, this renders them inaccessible by much of the population who reside in more rural and remote areas. Creative alternatives to bringing surgical care to remote areas including outreach programs, the use of active case finding, task sharing, remote surgical mentorship, and telecommunication solutions [31,32].

## THE GLOBALIZATION OF CLEFT CARE

The field of global surgery has evolved into more emphasis on collaboration with local health systems and thus older terminology is no longer sufficient. Efforts to improving CLP care in SSA have historically taken the form of short-term surgical interventions (STSIs), conventionally referred to as ‘mission’ trips. The term ‘mission’ reflects the origins of global health alongside colonial and religious goals of the 16th century. This later expanded to include surgical care trips in the 18th century [33]. By the 19th century, surgical trips were largely taken over by more secular nongovernment organizations (NGOs) with persistence of the term ‘mission trip’ [34]. These short, service-based trips emphasize efficiency and surgical volume and arrive with large numbers of international staff. Other names for these surgical teams, which can be led by local or visiting surgical teams, are brigades or camps. Successful STSIs share the expertise of visiting surgeons, provide educational opportunities for local surgeons, and foster long-term relationships over many years. Learning is bidirectional as visiting surgeons learn different systems of care and witness the surgical challenges of operating within a more resource-limited setting.

Despite the best intentions, the ethics of these STSIs have recently been called into question, arising from the observed divergence of perspectives between local and visiting physicians [35–37]. These STSIs may disrupt the routine workflow of the hospital where they occur, diverting already scarce operating rooms and inpatient units away from potentially more critically ill patients. Cleft surgeons who work in SSA are faced with a dilemma of using their limited operating room time for

trauma, oncology cases, high-risk infections, or cleft. In addition, even the most comprehensive, well intentioned STSIs have difficulty achieving adequate follow-up required for comprehensive cleft care. Complications are left to surgeons who have not been trained to handle these delicate and critical events. Furthermore, the amount of skill transfer during STSIs is limited by the short period of time they are present.

Exacerbating this issue is the lack of understanding of local language, traditions, and culture from the visiting team. The most salient criticism, however, is that there is a lack of focus on sustainability and effort to strengthen internal systems. In response, the 2000s saw an intentional shift in dialogue toward capacity building of local surgical expertise.

## CLEFT CARE BARRIERS AND SOLUTIONS

### Awareness

The path to comprehensive and accessible cleft care in SSA is fraught with patient and systemic barriers [38]. Fundamentally, there is a lack of awareness in the population of why CLP occurs. In some areas, CLP may be viewed as spiritual retribution with shifting of blame onto the mother, leading to a sense of shame that further hinders the seeking of timely care [15,16,18]. Furthermore, populations may be unaware that CLP is a treatable condition [14,39,40]. Traditional healers often predominate as the first line source of medical care, particularly in rural regions, and may be less likely to refer a child with CLP to a surgeon [41,42]. Additionally, patient literacy rates vary widely within SSA, with half of caregivers in Nigeria having a secondary education whereas half of caregivers in South Africa are either illiterate or only having a primary school education [15,23,43]. Strategies aimed at raising awareness must take into account the education level and literacy of the local population.

Cleft education should target both prospective parents as well as physicians, nurses, and community health workers [44]. Initiatives should focus on capturing those caregivers with the highest potential for early CLP identification and referral, including hospital staff in maternity wards, midwives, community health workers, and specifically in SSA, traditional healers. The challenge to maximizing awareness is reaching those who live in more rural and remote areas. One innovative strategy using mobile scouts has been piloted in Nepal, where trained laypeople were sent to remote districts of Nepal on foot to screen and refer patients for surgical care [32]. Additionally, the rise of mobile phones and the expansion of internet access bring

promise for more efficient information delivery, democratization of health education, and ultimately lower the barrier to surgical care. There has been a steady increase in mobile connectivity in SSA and is estimated that by 2025, approximately 88% of the SSA population will have access to a personal mobile phone [45]. Leveraging high mobile phone penetration rates in Zimbabwe, Shaye *et al.* [31] conducted a prospective study in Zimbabwe whereby automated 'blast' text messages containing the date and location for the surgical screening clinic were sent to 25% of subscribers to the largest cellular service provider in Zimbabwe, 1 week prior to a STSI. Seventy-three percent of patients presenting to the clinic learned of the surgical team through the text message and in a follow-up study, it was found that patients were significantly more likely to have learned of the team through their mobile phones after implementation of the blast text message compared with the years prior [31,46].

### Financial barriers

Financial barriers to care permeate all aspects of healthcare in SSA, including care for the CLP patient. The majority of caregivers are from low-income families, yet a majority of payments for pediatric surgery in SSA are made out-of-pocket by the parent or guardian [43,47,48]. Although STSIs may offset the surgical cost for operated patients, substantial cost is incurred before and after surgery in the form of transportation, housing, hospitalization, and nutrition [18<sup>11</sup>]. In conjunction with the lack of referral to timely CLP care and low medical literacy, limited financial resources lead to delayed repair with speech, aesthetic, surgical, and psychological consequences [49–51]. Furthermore, longitudinal care is often cost prohibitive, with reported follow-up rate of less than 50% in the region [52]. Although partially attributed to financial constraints, many caregivers of patients with CLP carry the perception that only surgical treatment is required, ignoring other associated functional outcomes [4<sup>11</sup>,17,53,54].

Solutions should be sought to reduce the financial burden of perioperative and longitudinal care for families. Although funding from NGOs can mitigate some of the perioperative costs, the impact is limited to a subset of patients and often not sustainable [48]. Instead, the focus should be shifted internally with the expansion of national health insurance to cover more aspects of comprehensive cleft care, as currently exhibited by Ghana's National Health Insurance Scheme [18<sup>11</sup>]. Another example is Rwanda, where national health insurance has reduced out-of-pocket health spending from 28 to 12%, which makes healthcare access more financially feasible for a significant number of citizens [55].

### Geographic barriers

A database study of 48 SSA countries found that only 29% of the population were located within a 2 h travel time to the nearest public hospital, far below the international recommendation of 80% [56,57]. Moreover, there is no standardization of services provided by these public hospitals, many of which function largely to provide emergency care without the capability for subspecialty surgical care. Although the travel barrier to a primary hospital alone can be daunting, the need for additional travel to a referral/tertiary hospital located even farther away in capital cities may render specialty care geographically prohibitive. In a study from Rwanda, patients reported a median of 1.6 days in reaching the referral hospital, with over a third reporting delays in accessing care [58]. The private sector also plays a significant role in health delivery; however, their centralized locations make them largely inaccessible for geographically and financially marginalized populations.

Although the ultimate solution to reducing geographic barriers is a more robust rural health infrastructure, existing health resources can be maximized in the meantime through decentralization. One such example is task sharing, whereby tasks are shared between different health workers. A model for task-shared speech therapy has already been piloted in Nepal, in which nursing midwives were trained as speech assistants by licensed speech and language pathologists during 1-week cleft speech camps [59]. Task sharing can also occur within the same profession, such as providing training courses that enable general practice physicians to undertake some specialty roles. This endeavor can be further enhanced through telesurgery, whereby less experienced surgical teams can take on surgeries under the virtual supervision of specialists [60]. Actions such as these require a careful balance between improving surgical access to patients in need and ensuring quality of care. Another example of decentralization is through active case-finding targeted toward remote regions. In Nepal, mobile scouts, consisting of laypeople who underwent 1 week of training, travelled to remote districts on foot over a period of 5 months to screen and refer patients for CLP surgical care [32]. This initiative led to an increase in the number of patients from remote districts presenting to a large CLP center, from 3.5 to 8.2%, and up to 13.5% when transportation was provided. Finding patients where they are is the first step to providing surgery.

### The cleft surgical workforce

The lack of human resources is being addressed by programs that focus on increasing local training

opportunities and by improving the quality of existing training programs. Local initiatives led by universities and regional professional bodies such as the College of Surgeons of East, Central and Southern Africa (COSECSA) have increased the number of resources and workshops for the health workforce. COSECSA, through collaboration with international NGOs and university hospitals, has established traveling scholarships to fund fellowships for surgical trainees [61–63]. Across surgical training programs, the shift from time-based to competency-based outcome measures for trainees has shown improvement in procedure-specific competency scores in a shorter time compared with traditional time-based training [64]. This shift in the pedagogical paradigm may expedite training without jeopardizing surgical competency.

Furthermore, international cleft NGOs (e.g. Operation Smile, Smile Train) fund training sessions for surgeons and other members of a multidisciplinary cleft team, relying on local or regional trainers. They also support scholarships and grants to attend national and international conferences. A 2015 study of 12 partner hospitals over 5 years found that after such partnership, there was an increase in cleft surgeons and active trainees, secondary surgeries, and ancillary services offered, the most common additions being speech therapy, dentistry, and orthodontics [65].

Lastly, there is an emerging role for technology in interdisciplinary, international cleft discussion forums and education. Examples of speech applications tailored to caring for CLP patients are yet another example [66]. Technology may also democratize education by breaking down language barriers across SSA. However, although technology may help decrease barriers to specialized education, it is, in its current form, largely supplementary and insufficient to replace traditional educational models.

### **The fragmentation of cleft care**

Surgeries performed by visiting teams rely on long-term postoperative care supported by local health infrastructure. Despite data demonstrating that comprehensive cleft care is best achieved by a multidisciplinary team of counsellors/social workers, speech therapists, dentists, orthodontists, nutritionists, and audiologists, cleft surgeons in SSA cite difficulty in accessing these specialists [4<sup>11</sup>,14,52,67–72]. Underlying inadequacies in infrastructure and the healthcare workforce makes multidisciplinary care challenging; however, there have been some breakthroughs [73]. Nonetheless, in a 2007 survey administered to cleft surgeon specialists who attended the Pan-African Congress on Cleft Lip and Palate, only 48% of responders belonged to an established cleft care team and only 20% reported practicing true multidisciplinary care [74].

Short-term surgical interventions should at a minimum include one cleft surgeon, anesthesia provider, and nurse from the country where the intervention is taking place. This helps to bridge the gap in language, consent, medical decision-making, and facilitates continuity of care. STSIs should consciously shift from an emphasis on surgical volume to that of skills transfer, with emphasis on integrating other members of a multidisciplinary cleft team who can provide training and education. Furthermore, initiatives geared towards raising community awareness of CLP should highlight the importance of long-term follow-up and multidisciplinary care in addition to timely surgical repair. Ministries of health across SSA play an important role in guiding STSIs that visit their countries and empowering surgical services from within.

### **CONCLUSION**

Patients with CLP are a vulnerable patient population who require comprehensive and longitudinal care from a coordinated group of specialists. There is global disparity in cleft care that is particularly evident in the low-income and middle-income countries of sub-Saharan Africa. For the past two decades, global cleft organizations have sought to increase access to quality cleft care, initially in the form of short-term surgical trips, that should be transformed to initiatives that prioritize sustainability through local capacity building. Although commendable strides have been made in cleft care in SSA, significant barriers, many of which are coupled to overall surgical care delivery, remain. The strengthening of African initiatives to support African-led comprehensive cleft care will be both imperative and exciting to witness in the coming decades.

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*There are no conflicts of interest.*

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