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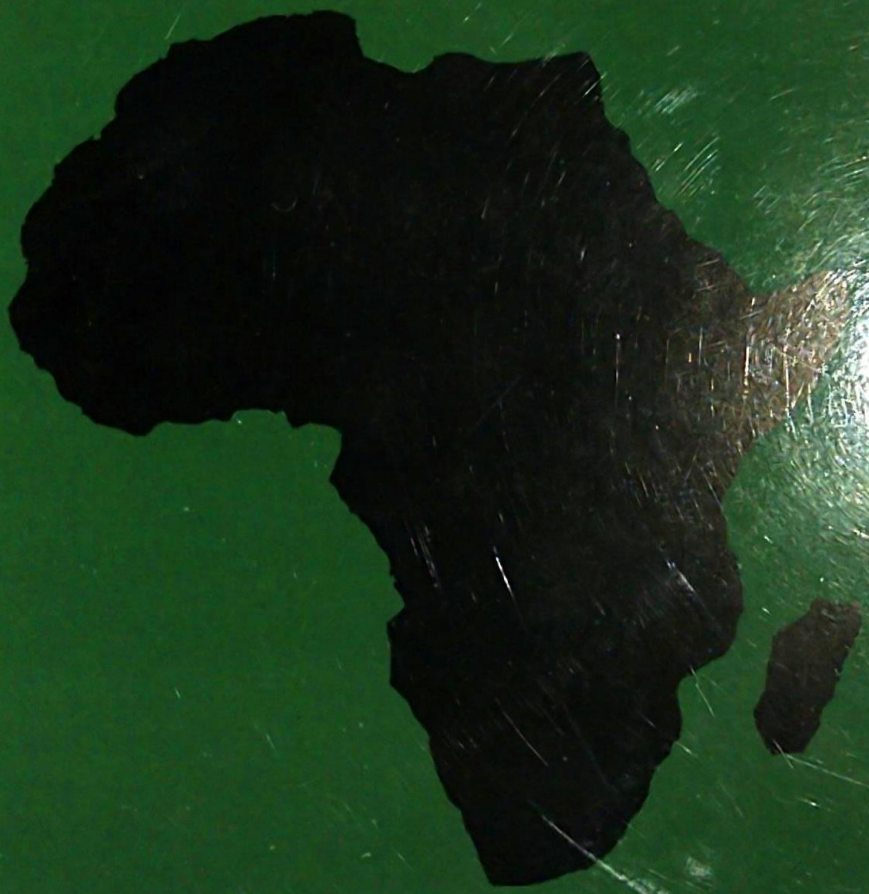

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Challenges of cleft care in Africa.

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Summary
Professionals involved in the care of patients with clefts in Africa face unique challenges when compared with what obtained in western countries. It is the purpose of this paper to review some of the challenges of cleft care in Africa. A computerized literature search using electronic databases; Ovid MEDLINE, EMBASE and AJOL databases was conducted for published articles from 1965 to 2006. Mesh phrases used in the search were: Cleft lip, Cleft palate, Cleft care, Management, Challenges and Africa. The search produced 46 articles. A critical evaluation of the 46 articles using the inclusion and exclusion criteria led to selection of 20 articles for the review. The findings were: (1) No reliable data on incidence of cleft; (2) Strong traditional beliefs system exist regarding etiology of cleft; (3) Health problems attributed to clefts common at presentation; (4) Patients with cleft commonly present late; (5) Lack of multidisciplinary approach to care. The chance that a child born with a cleft tomorrow in Africa will receive the best care possible can not yet be guaranteed. The need to formulate basic strategies to improve the standard of cleft care in Africa and the rest of the developing world is overdue. We hope that the findings in this review will provoke solutions that might ultimately improve the standard of cleft care in Africa and the rest of the developing world.

Keywords: *Craniofacial, cleft, palate, challenges, Africa*

Résumé
Les professionnels impliques dans les soins de sante aux patients ayant les fentes en Afrique soufre des défis uniques lorsque comparée avec ceux des pays développés. Le but de cette étude était de revoir certaines défis des soins des fentes en Afrique. Une revue littéraire informatisée sur les banques des données électroniques, Ovid Medline, Embase et AJOL a conduit aux articles entre 1995-2006. les phrases utilisées pour la recherche inclue : lèvre de la fente, soins de la fente, soins, défis en Afrique , produisant 46 articles. Une évaluation critique de ces articles avec des critères d'inclusion et d'exclusion conduisaient a 20 articles seulement.ces résultats inclus (1) pas des données sur l'incidence de la fente, (2) Système de croyance traditionnelle existe sur l'étiologie de la fente, (3)les problèmes de sante attribues a la fente commune a la présentation,(4) patients ayant une présentation tardive, (5) manque d'approche multidisciplinaire aux soins. Le chance qu'un nouveau ne en Afrique ayant la fente recevra des meilleurs soins possibles ne peut pas être garantie. La nécessite de formuler des stratégies de base afin d'améliorer le standard des soins de la fente en Afrique et les autres pays sous développés reste important. Nous espérons que ces résultats provoqueront des solutions qui peuvent ultimement améliorer le standard des soins en Afrique et dans d ;autres pays sous développés.

Introduction

Craniofacial anomalies, most especially cleft lip and palate (CLP) are major human birth deformities with world wide incidence of 1 in 700 and associated substantial clinical and psychosocial impact [1,2]. Studies have shown that cleft management in developing region of the world lags behind that of United States [3]. Attainment of the minimum standards of cleft care services in Africa and the rest of the developing world are undoubtedly challenging. Due to many factors, professionals involved in the care of patients with clefts in Africa face unique challenges when compared with what obtained in western countries.

These challenges may vary from country to country within Africa and even between hospitals and regions in the same country; however majority of these challenges are commonly encountered by professionals in their daily care of patients with CLP in this continent. In this paper we review some of the challenges of cleft care in Africa. We propose that this might provoke solutions that might ultimately improve the standard of cleft care in Africa and the rest of the developing world.

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Materials and methods

A computerized literature search using electronic databases; Ovid MEDLINE, EMBASE and AJOL databases was conducted for published articles from 1965 to 2006. Mesh phrases used in the search were: Cleft lip, Cleft palate, Challenges, Management and Africa. In addition, a combination of the following terms was also used: Cleft lip and Africa; Cleft care and Africa; Cleft care and Challenges; and Incidence of cleft and Africa.

All identified published prospective and retrospective studies on cleft care in any country in Africa and other developing countries were considered for inclusion in the review. The studies included report on incidence of orofacial clefts; beliefs and altitudes concerning congenital defects including orofacial clefts; late presentation of patients with cleft, unoperated cleft and management of patients with cleft.

Studies limited to cleft patterns and clinical features only as well as reports on congenital anomalies without mention of orofacial clefts were excluded.

Result

The search combination in the databases produced 46 articles which refer to cleft care in Africa and other developing countries. A critical evaluation of the 46 articles using the inclusion and exclusion criteria led to the exclusion of 26 articles leaving 20 articles selected for the review.

Lack of data on the incidence of facial clefts in Africa

In most African countries, there are no national statistics and there is limited data related to cleft incidence [4,5]. The few studies available on the incidence of cleft are hospital-based [6,7]. The data from these studies indicates that orofacial clefts disorders are at least as important in this region as in more industrialized regions of the world. For example, in Egypt (1998), the frequency of cleft lip and/or palate (CLP) has been reported as 1.66 in 1000 live and still births [8]. In Gambia (2000), CLP rank second among reasons for paediatric hospital admissions [5]. In Kenya (2004), the most common craniofacial birth defects are CLP, estimated to affect 1/1,000 live births [9]. Hospital-based surveys in some developing countries have also revealed markedly higher frequencies of orofacial clefts [10]. Population-based prevalence figures are however, not yet available for most African countries [4,7,8]. To a large extent, reports from countries in Africa could not highlight the true incidence of clefts because of non-availability of reliable birth and death registers [4].

Cultural factors and local perception of etiology of facial clefts

Myth and superstitions commonly accompanied the birth of a physically defective child in most African countries [11,12]. Beliefs with regard to etiology of clefts may not always be grounded in empirical science; sociocultural views have been found to play an important role in the belief systems concerning the etiology of CLP among Africans [12]. Reports from Lesotho indicated that the birth of a disabled child is usually perceived as negative [13]. The mother in particular feels responsible, and desperate to discover the cause. When a group of 20 South African adults with repaired facial clefts were interviewed, majority attributed the cause of their clefts to *sangona* (an ancestral spirit); while others mentioned that their mothers had handled sharp objects during an eclipse [11]. Olasoji *et al* [12] in a recent study that identified the perceptions concerning the causation of clefts and in particular belief systems that might be responsible for such perception among 36 Nigerian mothers of children with CLP, reported that only one mother attributed the etiology of child's defect to hereditary and environmental factors. Majority of these parents were of the opinion that their child's deformity was caused by supernatural forces (evil spirits and ancestral spirits), or the 'will of God'.

Cleft and associated health conditions.

Few reports available from Africa indicated that a large percentage of children with orofacial clefts are diagnosed at presentation with associated health problems which could be directly attributed to the deformity [14,15]. Undernutrition coupled with infections had been reported as the most common associated health problem. Ojofeitimi and Oyefeso [16] in Nigeria found that some parents of children with birth defect were least favourable attending hospital immunization centres for child vaccination against six known tropical childhood killer diseases, probably due to the feeling of shame associated with this deformity in the community.

Late presentation of patients with cleft lip and palate

In developing countries patients with CLP often present to the hospital for treatment of the deformity far past the optimal time for closure [17,18]. The precise reasons for this varied from culture to culture,

but the common reasons were found to be similar in many countries in Africa.

Because majority of patients with CLP that were seen in the North Eastern Nigeria were from low socioeconomic group, Olasoji *et al* [19] hypothesized that lack of money for surgery might be a principal reason for late presentation in this society. Using a cross-sectional survey method to find the reasons for late presentation among patients who presented after 3 months of age (79%) in Nepal, Schwarz and Khadka [18] found that lack of knowledge of availability of service for repair (31%), and lack of accessibility to service centers (29%) were the two commonest reasons for late presentation. Other studies from Africa [5,10] have identified factors such as lack of money for treatment, unavailability of service, superstition and lack of time as potential reasons for late presentation of patients.

Some of the reported challenges faced by cleft care givers in Africa in the management of patients presenting late for treatment include;

(1) Impaired family and societal relationships with potential long-term psychological effects on the child [20]
(2) Prominent distortion of the lip and nose, with well displaced premaxilla and prolabium in some cases of unrepaired clefts in adults [17]
(3) Established speech defect in late closure of the palate [17].
(4) Anterior fistula formation as may often be observed following late repair of the palate [17]

Organization of cleft care in Africa and the developing world

A review of the literature concerning cleft care in African indicates the following; Cleft care is provided in most hospitals by individual clinicians, working in isolation. There are many examples of two or more surgeons operating cleft independently in the same hospital [24]. Orthodontics and speech therapy services are not available in majority of the centres [17,20,21].

There are not much diversity in the type of technique used by most surgeons in lip/nasal deformity and palatoplasty, alveolar bone grafting is rarely carried out [17,20,21,22]. Cleft protocol is essentially the same in most of the centres; lip is closed at first operation and hard and soft palate together at second operation [17,21,23].

Professional cleft association is not common and there are no pressure groups such as parent's organizations [17,20,23].

There is a general lack of responsiveness from the health authorities at local and national level in the care of patients with cleft deformity [20].Many hospitals are severely under funded and many lack basic essentials such as surgical instruments for cleft surgery, reliable electricity and running water [20].

Cleft management in Africa like most developing world is presently based on the old philosophy regarding cleft care; that simple surgical intervention alone can produce quality outcome, in other words, the present mode of cleft management in most of the health institutions in this continent seems to be purely an aesthetic rather than a functional undertaking.

Discussion

Currently available data on the incidence of CLP in Africa are from hospital-based studies [6,24,25]. Hospital-based studies are associated with a high tendency for under ascertainment of cases, and are more liable to bias when compared to population-based studies [7]. Determining the exact epidemiological data of orofacial clefts in Africa is important for public health reasons. Reliable data on incidence rates can stimulate genetic and epidemiologic investigations of heritable and environmental factors involved in CLP in this population. Prevalence rates may help identify cluster areas and can be used to document current clinical needs and project future caseloads of facial clefts in the continent [7].

There is now an urgent need for both local and international researchers to establish accurate and reliable data on the incidence and prevalence of facial clefts in Africa. Accurate ascertainment of cases may be difficult in an environment where a high proportion of births are known to occur in areas remote from structured healthcare systems [26]. For an improved ascertainment of CLP cases, WHO in 2003 [27] recommended the setting up of a birth defects surveillance system in countries in Africa. Such surveillance system may probably start with hospital-based birth defects surveillance system and gradually work towards a regional and national population-based birth defects registry.

Reliable epidemiological data on cleft deformity in Africa are potent tools that can be used in influencing health decision makers and government to provide adequate facilities for cleft care, especially in the face of many agents competing for limited and scarce resources on the continent [4].

Various authors have noted the relationship of culture and religion to a variety of health behaviours

including concept of disease causation, illness behaviours, health utilization pattern and relationship with health professionals [11]. The cultural factors most often determine the labels, the explanations and the treatments that followed [11]. The traditional beliefs regarding the etiology of cleft in Africa have wide ranging implications as regards cleft care in the continent and other developing world. Firstly, this cultural factor seems to influence the attitude towards this deformity. Studies have shown that though patients, families, and the general population may hold a variety of beliefs rather than one common belief about the causes of CLP, the idea of fixing blame for the condition on the behaviour of one or both parents seems to be a common factor in all the belief systems [11,12]. Therefore the birth of a child with CLP is usually considered a 'shame to the family' in some African communities [12,28]. This traditional parental blame or fatalistic 'causation belief' has been reported to inhibit parents from coming forward to seek help for their children [12,28]. Infanticide following the birth of a child with a birth defect has been reported in some cases [28]. There is a need for a strong and clear health education message at the community level that includes an explanation of the causes of this anomaly. Providing a 'scientific' explanation does not necessarily eliminate the traditional belief, as this traditional belief may continue even while the population begins to accept a biomedical explanation, the negative attitude and the daily lives of individual with CLP may however gradually improve with time.

Secondly, the traditional beliefs with regard to the causation of clefts have been reported to play an important role in the treatment approaches to CLP in Africa. In the developing world, there are two main types of health treatment traditions, the modern approach that is located in western medical paradigm and the traditional approach that is based on indigenous belief system [1,11]. In a study among the Yoruba ethnic group in Nigeria, 12 out of 16 parents of a child with CLP consulted traditional healers for treatment of the child's condition before coming to the hospital [12]. Moreover, majority of those who consulted the traditional healers did so because of the belief that the traditional healers treat supernatural causes. It is currently estimated that there are 150,000 to 200,000 traditional healers in South Africa and 8 out of every 10 black South Africans rely on traditional medicine only or in combination with Western medicine for treatment of diseases or deformities [11]. The fact that traditional healers are likely to be consulted first for the treatment of CLP underlines the need for greater collaboration between the Western-trained practitioners and traditional healers and recognition of the strengths and weaknesses of both approaches in cleft care in this continent [11]. By giving traditional healers information regarding CLP through health workshops, targeting areas such as the etiology from a modern medical perspective and basic care issues such as feeding and nutrition, the referral and rehabilitative process in cleft care could potentially be managed in a more effective way in Africa. This could in the long run results in a complementary and holistic system of cleft care that incorporates both the physical and spiritual dimensions [11,12].

Cleft care givers in Africa and the developing world needs to understand that patients with CLP in this environment exists in a sociocultural matrix in which the meaning of the condition they have and the future they face are determined by a host of factors over and above the specific surgery itself [29].

According to the World Development Report 1993, congenital malformations constitute 6.5% of the total disease burden for children under 5 years of age in developing countries and 4% of all deaths during 0-4 years of age [1,30]. Among other factors, disability at birth has been reported to lower the life expectancy of a child born in Sub-Sahara Africa by 15% [31]. One of the most important issues surrounding the care of children with CLP in Africa is the associated health problems with the deformity, especially undernourishment and infections [14,15]. It has been shown that most children with palatal clefts have problem with feeding, especially during the first few months of life when they may demonstrate a reduction in weight gain [32]. In the first 6 months of life, all patients with CLP require adequate nutrition to maintain normal physical and neurological development [32]. Unfortunately, cleft care professionals in most cases in developing countries are not empowered with enough information to give lactation education and other feeding techniques to parents with CLP children. Babies with CLP in Africa may therefore face major nutritional challenges leading in most instances to delay in surgery. The traditional method of feeding babies among the Yoruba ethnic group in West Africa will certainly kill a child with cleft palate. The baby lies supine on the mother's lap with the head turned to a side, the mother's hand is then cupped over the baby's mouth, her fingers partially occluding his nostrils occasionally, food is poured into her cupped hand from there into the baby's mouth [28].

Studies [32] in developing countries have

demonstrated that constant supervision and feeding by trained professionals can reduce the incidence of undernourishment and failure to thrive in babies with palatal cleft. The need to provide cleft care givers in Africa with adequate training on the various feeding techniques for patients with orofacial clefts, especially at the community level cannot be overemphasized.

There is a general consensus among professionals working in the field of cleft deformity that early assessment and commencement of counselling and treatment, whether surgical or with other methods, improves the overall outcome of patients with cleft deformity from speech, cosmetic, and psychological perspectives [18]. The commonly observed late presentation of patients with cleft deformity in Africa and the developing world indicate that services such as surgery, counselling and others that optimize cleft care may not be available to majority of these patients at an appropriate time. To optimize the results of treatment, it is essential to understand the reasons for late presentations in this continent and direct public health policy in a way to address these issues.

The problem of lack of finance for treatment as a reason for late presentation is endemic throughout developing countries, especially among the rural poor [18]. The present role that overseas charity organization such as The SmileTrain is playing to alleviate this problem by providing free cleft treatment to indigenous children with clefts in developing world is commendable; however, government policies in Africa that will directly improve the socioeconomic conditions of the populace may be necessary to minimize this problem on a long term basis.

Lack of knowledge of availability of service for repair and lack of accessibility to service centres were other factors found to be responsible for late presentation of patients for treatment. This would suggest that increased access to primary health care services combined with providing primary health care workers with information regarding the availability of cleft services would reduce the rate of late presentation in developing countries [17-19]. Permanent cleft services are presently available only in very few centers in the continent. Bringing cleft services to district hospitals may alleviate problems associated with accessing far-removed centers, and this approach may also lessen the financial and time cost associated with traveling long distances for treatment.

Regarding the management of patient with CLP, It is widely accepted that highly specialized corrective surgery in the early months of life of a patient with cleft is necessary to improve function and appearance. Subsequent impairment of facial and dental development, speech and hearing are common [33]. Also, a large number of service specialists are often required if the child's potential is to be maximized. These include neonatal nursing and community nurse services, surgery, speech, hearing, otolaryngology, dentistry, orthodontics, psychology and genetic counselling [33].

In light of these observations, two important challenges may readily come to mind as regard the organization of cleft care in Africa and the rest of the developing world.

1. Interdisciplinary team approach for cleft care in Africa.

During the past three decades it has become increasing clear that successful cleft management requires a multidisciplinary, long term, team approach [33,34]. In spite of the many documented short and long term benefits of an affective team-based cleft care service in the Western world [34]. the acute shortage of manpower/specialists in most African health institutions will certainly be a big impediment to the implementation of an interdisciplinary team service for patients with CLP. With a real prospect of improving the standard of cleft care in the developing world in the face of this challenge, what should therefore be the minimum number of specialists to constitute a cleft team in this environment? The minimum number of professionals in most joint clinics in the United Kingdom were reported to be three; a surgeon, an orthodontics and a speech therapist [33]. This probably may be an appropriate starting number for cleft Team in Africa.

2. Centralized or decentralized cleft care centres for the developing countries?

The original Eurocleft intercentre study suggested that decentralized care by low volume operators may be associated with inferior outcomes [33]. Therefore, fully comprehensive teams (located in regions or national centres) provided with adequate facilities/ funds and with sufficiently large caseload is been advocated for cleft care to optimize clinical experience and outcome evaluation. Cleft services are still fragmented in most countries in Africa, and the concept of centralization of care is yet to be adopted [22]. Securing adequate funds and clinical resources for the implementation of such programme in the developing countries of the world may be challenging. The implementation of a very effective health information dissemination policy will also be necessary for the centralized model of cleft care to

succeed in Africa, since majority of the populace live in rural areas [33].

Despite the obvious benefits of a centralized cleft care, it has also been argued that small centre which are geographically accessible and have accessible team members can provide a more supportive and cost effective service than large, distant, geographically inaccessible centre, that in themselves can have problems with patient follow-up and compliance [33]. The need for African cleft care givers and health policy makers to determine the organization of cleft care that will best meet the needs of children with CLP in Africa can not be overemphasized.

Cleft service delivery model for Africa.

The greatest challenge to the delivery of adequate cleft care across much of Africa appears to be better organization and improvement of the existing cleft services in such a way as to be accessible and affordable to majority of the populace. As local surgeons in developing nations become more interested in cleft surgery, teaching local surgeons the multidisciplinary approach to cleft care should be paramount.

We describe a three-level cleft care model for establishing a safe and accessible cleft service for Africa and developing world.

MODEL.

Primary level of care is directed towards the early detection, cure and amelioration of problems once a child with CLP is born. Interventions include providing adequate feeding and nutrition information to parents, monitoring weight gain, height and growth. It also includes routine paediatric care including immunization and parental social support. Counselling including information on the role of hereditary-environmental factors in the etiology of CLP and the availability of service for medical treatment of clefts are to be provided to parents, community leaders and possibly traditional healers at this level of care. Services at this level are to be provided by trained community health officers and nurses at primary and comprehensive health centres. A simple and workable referral system should be available at these health centres.

Secondary level aims to provide a form of comprehensive (multidisciplinary) cleft care for patients with CLP. Services at this level will include speech-language services, orthodontics and surgical correction of CLP. The services will depend on the availability of different specialists involved in the different areas of cleft care. The care is expected to take place in General/district hospitals which are classified as secondary level of health care in most Africa countries. An important aspect at this secondary level is that overseas volunteer surgical teams can direct their attention at this level to share their skills and train more local surgeons the act of cleft management preferably in conjunction with local colleagues on ground that are already repairing clefts. Working together with local colleagues will allow for longer term follow-up of patients, as well as possible development of rehabilitation services, thereby ensuring maximum benefits from the intervention performed [35-36]. International charity organization can direct funding into areas such as transportation and cleft repair of indigenous patients, supply of equipments and surgical instruments and training of more local surgeons.

Tertiary level is expected to take place in teaching hospitals and specialist hospitals expected to be manned by highly skilled local and international professionals. The complex nature of many types of craniofacial anomalies often necessitates multiple operative procedures at different stages of development. Services at this level will be directed at longitudinal follow-up of patients with CLP and other craniofacial anomalies after the secondary level intervention has been successful with respect to anatomical defects. Procedures necessary to correct residual deformities of the mandible, maxilla, orbits, zygoma, forehead and the nose will be attended to at the tertiary level.

Conclusion

Attainment of the minimum standards of cleft care services in Africa and the rest of the developing world is undoubtedly challenging. The chance that a child born with a cleft tomorrow in Africa will receive the best care possible can not yet be guaranteed. Multiple challenges are recognized but these are not to be viewed as obstacles to improving cleft care in this continent. The need to formulate basic strategies to improve the standard of cleft care in Africa and the rest of the developing world is overdue.

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