Challenges of congenital malformations: an African perspective

Victor C. Emordi and David O. Osifo

Background **Congenital malformations are defects of morphogenesis of organs or body regions identifiable during the intrauterine life or after birth. The etiological factors proposed have varied in history based on prevailing understanding, culture, and religion. Worldwide historically, the role of the supernatural had been in the forefront of etiological considerations but has changed with advances in embryology and teratology. It has, however, remained a part of many societies and cultures especially in Africa.**

Purpose **The aim of this review article is to highlight the psychosocial and economic impact, as well as the ethical and management challenges, posed by congenital malformations in the African setting.**

Materials and methods **A literature search was done using PubMed, African Journals Online, HINARI, and Google Scholar, regarding issues and challenges faced by parents who have children with congenital malformations, the affected children, and the healthcare workers who manage them. Focus was on the peculiarities of the African society.**

Result **Superstitious beliefs about congenital malformations bred negative attitudes toward these children and their parents. Chronic illness, long-term disabilities, and overall poor quality of life were associated with congenital malformations. These problems in a background of negative sociocultural beliefs created enormous psychosocial challenges for the parents and children. This was further complicated by economic challenges posed by the absence of health support systems in most African settings. Furthermore, the healthcare teams caring for these children were faced with challenges of difficult ethical and medicolegal considerations, as well as paucity of appropriately skilled manpower and facilities.**

Conclusion **The role of the supernatural in the etiology of congenital malformations still has a stronghold in the many African settings and poses an enormous psychosocial challenge for the affected. It is hoped that this review can influence policy formulations to support affected parents and improve outcomes of affected children.** ***Ann Pediatr Surg*** **14:1–7 © 2018 Annals of Pediatric Surgery.**

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Introduction

Congenital malformations are defects of morphogenesis of organs or body regions identifiable during the intrauterine life or after birth [1]. All races, cultures, and socioeconomic groups are affected 2. Although they comprise a leading cause of infant mortality worldwide, they also lead to chronic illness and long-term disability, which often constitute enormous challenges for the parents, caregivers, healthcare systems, and the affected individuals [2–4]. In addition, congenital malformations account for a majority of infanticide cases globally, as most of these children are killed or left to die by either their parents or enforcers of cultures, which abhor their existence [5–9].

The expectation of every parent is to hold in their arms a 'bundle of joy' in the form of a healthy newborn after the period of pregnancy. Therefore, the birth of a child with a malformation, or prenatal diagnosis of such, is often devastating [10]. The wide range of emotions experienced is often similar to that experienced following the loss of a child. This is often complicated by existing negative societal and cultural attitudes toward infants with malformations, as well as unavailability of support systems especially in developing countries [11]. These parents thus experience several psychological, emotional, social, and economic challenges while caring for the child [12].

Children with major congenital defects often require multiple complex surgical procedures and technologically advanced monitoring devices, which are often unavailable in developing countries. This places a huge strain on the healthcare system. In addition, difficult ethical and legal implications associated with these cases often complicate the managing team's capacity to care for the patient and the family [10].

Some common malformations that pose major challenges to the aforementioned include congenital heart defects, neural tube defects, anterior abdominal wall defects, facial clefts, anorectal malformations, and esophageal atresia. Despite the advances made in the field of neonatology and pediatric surgery to cater for these infants, these challenges are often overlooked during policy formulations, resulting in poor outcome.

Materials and methods

A literature search was undertaken using PubMed, African Journals Online, HINARI, and Google Scholar, regarding issues and challenges faced by parents who have children with congenital malformations, the affected children, and the healthcare workers who manage them. Focus was on the peculiarities of the African society. Keywords such as 'Congenital malformations', 'challenges of anomalies', 'birth

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defects', 'Surgical neonate', and 'parenting challenges' were used in combinations. References of retrieved articles, as well as relevant newspaper articles and reports, were also reviewed.

Historical background

Congenital malformations have been part of human existence from the beginning [13]. This is evidenced by ancient cultures that depicted them in the form of paintings, carvings, and written documents. The tablets of Nineveh, which dated back to the seventh century BC, contained the first written records of congenital malformations. A total of 62 different malformations were described, each bearing prophetic meanings [14]. Other archeological relics depicting the existence of malformations have been described in several countries and cultures. A notable example is the statue of the conjoined twins, the goddess of Antolia, dating back to 6500 BC, which was discovered in southern Turkey in 1962 [13].

Etiological factors proposed for congenital malformations have varied in history based on prevailing understanding, culture, and religion. Broadly, it can be divided into two eras – the ancient era of superstitious beliefs, which showed man's rudimentary concepts, persisting to the 17th century, and the era of modern thought, which began during the 18th century and has continued to evolve until now [7,14].

Ancient theories of etiology

The Monster theory was probably popularized by the Babylonians [15]. They believed that the future was predicted by stars and malformed infants were reflections of the stars. This was passed into the Roman and Greek civilizations. Thus, the Latin word *monstrum* derived from *monstrare*, meaning 'to show' or *monere* meaning 'to warn', is inferred from the concept of monsters having the ability to predict the future. Infants with congenital malformations were therefore regarded as monsters. Following the first treatise on monsters written in the sixth century AD, several books on monstrous births were published between the mid-16th and 17th centuries [14].

The etiological theory of maternal impressions or fright was based on the assumption that by photographic engraving a growing fetus could be affected by what the mother sees or her state of mind during pregnancy [13,14]. For example, cleft lip and palate in some climes was thought to result from a woman being frightened by a rabbit during pregnancy, whereas microcephaly and anencephaly were attributed to a pregnant woman looking at monkeys [7,13].

Another theory associated with congenital malformations was the theory of demons and witches. Parents of such children were accused of being evil and were thus often killed along with the child. Twin infants, for example, even without any birth defects, were considered as evil and nonhuman in parts of Nigeria and subsequently killed and their mothers ostracized [7,16]. Closely linked to this was the theory of supernatural causes. Birth defects were seen as punishment from the gods for past wrongdoings in several cultures and religion. With Christianity came the theory of cross-hybridization wherein it was believed that congenital malformations resulted from intercourse between a woman and the devil or a male beast [13,14,17].

Although these theories or myths have been overtaken by advances in knowledge of embryology and teratology in the modern era, they are still being held in several communities and cultures today. This is prominent in Africa where they constitute a major challenge in the management of congenital malformations [6,8,9,16,18]. This historical background gives an insight into some responses that greet children with congenital malformations including awe, terror, anguish, and abandonment [13]. One of the most dreaded direct consequences of some of these myths is infanticide, which is still prevalent in some cultures. Thus, the contribution of congenital malformations to infant mortality is twofold: direct effect of the pathology and infanticide carried out by their parents or communities [4,5,7,9].

Overview of congenital malformations

Embryology

In utero development can be divided into three time periods: the pre-embryonic, the embryonic, and the fetal periods. The pre-embryonic period, which extends from fertilization to the end of the second week, is characterized by the presence of pluripotent cells that proliferate rapidly. Teratogenic insults during this period produce an 'all or none' effect – i.e. expulsion of the embryo or have no effect [2]. The embryonic period, which spans from the third to eight week, is characterized by the development of the three germ layers and subsequent formation of all major organs and systems. During this period, the embryo is most susceptible to insults. Indeed, most major congenital malformations are due to insults at this stage [2,19]. The fetal period is mainly that of growth of already laid down organs. Vulnerability to teratogens is less during this period; however, external mechanical forces can lead to malformations [1,2].

Etiology

Despite advances in embryology and teratology, over 50% of congenital malformations have no known specific cause [3]. Known causes and risk factors include the following.

Genetic factors

These include chromosomal abnormalities and single gene defects [20]. The role of genes in the etiology of congenital malformations is speculatively by coding for an anomaly or mutation [3]. Also related to genetic factors is the concept of consanguinity wherein parents are blood relations. It increases the prevalence of rare genetic mutations, which results in higher risk of birth defects including cardiac malformations [3,21,22].

Environmental factors

These include agents that pregnant women are exposed to, which are capable of inducing structural anomalies in a developing fetus. They are termed teratogens, derived from

the Greek words *teratos* (monster) and *gen* (producing). Examples of teratogens include alcohol, tobacco, certain pesticides, radiation, and drugs such as antiepileptics and anticoagulants [2,3,20,23]. The precise mechanisms by which these agents cause malformations are not clearly understood but include alteration in gene expression, cell migration and differentiation, and histogenesis [2].

Nutritional factors

Deficiencies in folic acid and other vitamins and minerals such as zinc have been implicated in the etiology of some congenital malformations [24–27]. Notably, periconceptional folic acid deficiency has been associated with the occurrence of neural tube defects – spina bifida and anencephaly [26,27].

Infectious diseases

Viral infections such as influenza, rubella, and syphilis in pregnancy have been found to be significant causes of congenital malformations including cleft lip and palate, neural tube defects, and cardiac malformations [3,28]. More recently, maternal Zika virus infection has been found to be associated with microcephaly and ocular malformations in the newborn [29,30].

Socioeconomic factors

Low income has been associated with increased occurrence of congenital malformations as there is a disproportionate affectation of children in low-income countries [31]. This may be due to poor access to nutritious food during pregnancy, increased exposure to viral infections, poor healthcare systems, and sociocultural factors [3,31].

Demographic factors

Maternal age has also been found to play a role, as advanced age increases the risk of chromosomal abnormalities such as Down syndrome, whereas young maternal age increases the risk of malformations such as gastroschisis [3,32].

Classification

Congenital malformations are broadly classified based on the timing of insult, histological changes, pathogenesis, or medical and social consequences (Table 1) [1,2].

On the basis of timing, primary malformations arise from intrinsic errors of the developmental process occurring during the embryonic period. Disruptions occur when organs develop abnormally from a normal primordium because of environmental interference. Deformations are anomalies that result from distortion of normal structures by aberrant mechanical forces. In contrast to primary malformations, disruptions and deformations occur in the fetal period.

On the basis of pathogenesis, syndromes refer to combinations of developmental defects sharing a common etiology. Sequences are characterized by developmental defects resulting from a cascade of events originating from a primary morphological defect. Associations are two or more anomalies usually occurring together more often without any etiological relationship such as the VACTERL. In sequences, a single primary malformation initiates a series of events that results in multiple malformations such as is seen in Potter's sequence. Complexes or developmental field defects refer to a group of malformations affecting organs that share a common anatomical location – for example, epispadias–exstrophy complex [1,2,33].

Table 1 Classification of congenital malformations

Classification basis	Types
Timing	Primary malformation
	Disruption
	Deformation
Histological changes	Aplasia
	Hypoplasia
	Hyperplasia
	Dysplasia
Pathogenesis	Single system defects
	Multiple malformation syndrome
	Associations
	Sequences
	Complexes
Medical consequences	Major malformations
	Minor malformations

Major malformations are anomalies that reduce life expectancy and cause significant functional impairment such as congenital heart defects and bladder extrophy. Minor malformations, in contrast, do not affect functional capacity or affect life expectancy and may be left without treatment – for example, polydactyly.

Challenges

Parents and family

Children with congenital malformations have an enormous direct impact on their parents and family beginning from the prenatal period, spanning through the entire life of the child in some cases.

Preknowledge of a malformation

Advances in prenatal ultrasound, as well as other prenatal diagnostic tools, have improved the detection of malformations *in utero*. However, foreknowledge that a pregnancy is bearing a malformed child has its own challenges for an affected couple. Parents are suddenly confronted with life-changing decisions: terminate a much awaited and cherished pregnancy or continue and give birth to a child who may die shortly after birth or live with deformities and functional impairments. It is often an awful and disappointing reality; hopes are dashed, and emotions of guilt, intense sadness, and anguish are evoked [34]. These feelings are aggravated in parents in whom the pregnancy has been tagged 'precious' following years of infertility, parents in developing countries where expertise and facilities for surgical intervention are largely unavailable, and those living in communities where existing culture abhors such infants. There is evidence of increased psychological distress and grief among parents who receive prenatal diagnosis compared with those who do not [35,36].

Poor prenatal diagnostic facilities

Despite the psychological disadvantage of prenatal diagnosis, it helps some parents to seek appropriate

medical help and plan for the future [36]. For many parents in developing countries in Africa prenatal screening for congenital malformations is not often done because of nonavailability/nonaffordability [37]. Thus, the diagnosis of a major malformation immediately after birth without a prenatal foreknowledge is often seen as a disaster [37,38]. Expectations of joy are suddenly cut short, and fear of the unknown sets in.

Postnatal hospital care

Children with major malformations, who have the benefit of being born or transferred to a center with facilities and expertise for resuscitation and care, are often admitted for variable periods, requiring multiple invasive procedures. Some may require emergency operations in the first few days of life – e.g. patients born with gastroschisis, esophageal atresia, bladder extrophy. These provoke more anxiety for the parents who may find it difficult understanding why their tender newborn has to be subjected to so much pain [39].

Poor mother–child bonding

Following the birth of a child with a malformation, parents, especially mothers, go through several stages of emotional reactions. The initial stages are characterized by shock, denial, sadness, and anger, preceding adaptation and reorganization [40]. During the initial stages, hesitance toward affection to the child is often seen as the parents are overwhelmed by emotions of guilt, self-pity, and uncertainty about the child's future [40,41]. In addition, certain newborn care practices foster maternal bonding such as breastfeeding, and strapping of an infant to the mother's back (a common practice in Africa). These may be initially inhibited by some malformations such as esophageal atresia and anterior abdominal wall defects, respectively.

Financial challenges

Poor or absent health insurance policies, as well as out-of-pocket payments for healthcare, are commonplace in many African countries [42,43]. Thus, even when centers with facilities and expertise for neonatal surgical care are available, the challenge of paying a deposit fee before treatment and paying directly for utilities and other cares are enormous. This results in some parents discharging the child against medical advice or completely abandoning the child in the hospital [44]. Because of these financial constraints, some mothers resort to giving birth to their children without supervised antenatal care such as in churches, traditional doctors' homes, or in health facilities, which cannot provide care or appropriate neonatal transport to specialized centers for those with malformations [31,44,45]. These adversely affect the outcome of management of these patients and increase the mortality rate.

Family acceptance

For parents who can afford treatment bills in a specialized facility, the challenges of caring for a child with special needs at home, as well as family acceptance, arise after discharge. In most sociocultural settings in Africa, for example, the role of grandmothers in the care of the newborn and the mother is sacrosanct. In southern Nigeria, during the postpartum period called *omugwo*, the grandmother sponge-bathes the infant and stimulates the child with various exercises to enhance motor development [46]. These may be inhibited by the presence of major malformations, as well as acceptance, considering that the infant may be viewed as evil or a bad omen by the extended family [5,8,18,46,47]. The care of the newborn may thus be left for the mother who is still recuperating from the process of childbirth.

Marital strain

In some cultures, a woman who gives birth to a child with a malformation may be abandoned by the husband as these cultures accuse the woman of infidelity following the birth of such a child [18,47]. In the African setting where the extended family has a huge impact on the affairs of the nuclear family, men are often put under pressure to abandon their wives with claims that she is evil, and her evil acts have caused her to bring forth such a child. Thus, the birth of a child with a congenital malformation may trigger the onset of marital strain, and eventual broken marriage [18,31,40]. Some families are evicted from their homes and ostracized from their communities. These evoke intense emotions of guilt and shame [6,8].

Increased parenting stress

Parents especially mothers who have children with major malformations requiring special needs face significant stress [11,41]. This results from the extra care given to the index child, abandonment of the other healthy children, and the associated feeling of anger and despair that pervades during the care of the child with the malformation. In addition, family support, which is a part of the African family system, may be absent because of cultural beliefs that abhor such children. Parenting becomes a hideous task.

Stigmatization

As the child grows older, social challenges emerge. Because of existing sociocultural beliefs regarding congenital malformations, and the consequent shame, parents often find themselves isolated from friends and family. These beliefs create a platform for stigmatization of the parents of such children. Obvious malformations may prevent the parents from socializing with their child because of fear of being derided or becoming a center of undue attraction from strangers [48]. Thus, the child is seldom taken out for social ceremonies, which are commonplace in most African settings. Some children are permanently locked indoors out of shame 6. These result in repressed self-esteem [41]. Relocation to places where they are not known becomes an option with the aim of trying to 'reset' their lives.

Economic challenges

Extra finances are often required to care for most children with major congenital malformations, creating an enormous burden on the parents and caregivers. This is accounted for by the need for multiple surgeries, expensive radiologic investigations, as well as frequent

and often long-term follow-up visits; the cost of these are directly borne by the parents with no government assistance in many African countries. In addition, some parents may have to travel long distances from remote areas with poor transport facilities because of paucity of specialists [43,49]. In some cases, the mother may have to quit her job to properly cater for the child, further aggravating the financial constraints on the family [12,31,41]. Where available, the child may require a special school, creating an extra burden on the parents. These factors have been reported to be a cause of increased rate of killing of newborns, toddlers, and preschool-age children who have congenital malformations [9].

The child

The challenges faced by these children vary depending on the severity of the malformation, the organ or body region affected, and the family support system. Common to most of them, however, is the increased tendency toward emotional and behavioral problems and reduced self-esteem.

Child abuse and neglect: role of superstitious beliefs and ignorance

As a result of prevalent illiteracy and ignorance, outrageous superstitious beliefs regarding children with congenital malformations are easily perpetuated by acclaimed pastors, prophets, and traditional doctors who are usually numerous in African settings. The child is seen as evil, a witch or wizard, or a sign of impending doom for the family and community. These beliefs often prevent parents from seeking appropriate treatment and result in a wide spectrum of child abuse: delayed presentation to the hospital, masterly inactivity, starvation, mutilation, preferential maltreatment in the home, refusal to give consent for surgical procedures, discharge against medical advice, abandonment in refuse dumps and hospitals, and in some cases outright killing of the child [5,6,9,42,47,50,51]. Even in death within the hospital setting, some infants' bodies are abandoned by their parents to avoid giving birth to another child with a similar malformation [17].

Withdrawal and depression

Survival of infancy period appears to be the dawn of a new series of challenges for a child born with malformations. He becomes more aware of his surroundings, and those around him. The realization that he or she is 'different' could induce several negative emotions. Malformations that cannot be obscured with clothing such as craniofacial and limb malformations lead to the feeling of anxiety and inferiority complex, and consequently hinder peer relationships [39]. Urinary and fecal incontinence associated with conditions such as spina bifida, bladder extrophy, and anorectal malformations lead to seclusion and withdrawal as the child is often an object of scorn. These may precipitate psychiatric tendencies such as depression [39]. These are also more prevalent in African countries in which, owing to poverty and unavailability of health resources, children are often left with these conditions, unattended [6,39,42].

Exploitation by parents

In some communities, parents see their children with major congenital malformations as 'money making' opportunities. They use them for alms begging from unsuspecting well-wishers [42]. They therefore refuse treatment of such conditions because begging is seen as a source of economic survival. This thrives in African countries because of poverty and poor health support systems [8]. This exploitation by the parents increases morbidity and precipitates severe psychosocial maladjustment.

Defective learning

Cognitive and learning problems are associated with cardiac and neurological malformations 39. In addition, teasing from peers, teachers, and disfiguring malformations inhibit learning and sometimes often lead to children refusing to go to school. Some parents also prevent their children from attending school as they are often 'concealed' because of shame [8].

Parental dependence

In some conditions, especially neurological malformations, children are often dependent on their parents and caregivers for their entire lives as they may be unable to carry out basic self-care. This leads to poor social functioning [52]. This, in addition to other long-term complications associated with certain malformations, lead to overall poor quality of life.

Lost career opportunities

For the children who survive to adulthood, dreams are unfulfilled, stigmatization and marginalization continues, careers opportunities are lost, and the vicious cycle of segregation, seclusion, and eventual depression continues [13,52–55].

The healthcare team

Caring for a child with congenital malformations by a doctor and other members of his team can often be a daunting task. This is because of several factors including medicolegal and ethical issues, unavailability of appropriate facilities for management, as well as emotional care for the parents who may feel 'bereaved' [10].

Communication

The challenge of communication begins in the antenatal period. Communicating a prenatal diagnosis of a malformation to the parents is difficult especially when it is severe or life-threatening. Such disclosure may be associated with worse psychological distress and psychiatric tendencies including suicide. These may have negative effects on the fetus [35,36]. Following the birth of a child with major malformations, the extent of communication of the pathology and prognosis is often a dilemma in most African settings. This is because with prevalent erroneous beliefs concerning malformations, the child may be abandoned in the hospital or discharged against medical advice and killed [42].

'Epileptic' healthcare system

When the child is born, the team is faced with one of three scenarios: a child with correctable major or minor malformations with good prognosis, one with correctable major

malformations with poor prognosis in terms of quality of life, and one with severe major malformations that are noncorrectable or incompatible with life [39]. For several reasons in many African countries, the last two scenarios are more common, resulting in congenital malformations contributing more to infant mortality rate [56]. Some of these reasons include paucity of appropriately skilled and trained pediatric surgeons, manpower shortage, poor facilities for anesthesia and monitoring of infants, lack of basic facilities for newborn resuscitation in many health facilities, and delayed presentation and consent for surgery because of financial constraints among others [31,44,56–58]. In addition, consent for postmortem examination of neonates is often refused leading to under utilization of a useful learning tool in patient management [59]. The refusal to give consent for postmortem examinations is mainly due to many hospital policies, which make it mandatory for the bereaved parents/caregivers to pay directly for such services [17,59].

Medicolegal and ethical issues

There are several ethical and medicolegal issues related to congenital malformations: termination of pregnancy for a fetus with a perceived lethal malformation, the decision to withhold or terminate initial resuscitation for a child with lethal malformations, the definition of a lethal malformation, and the decision to offer surgical intervention for a child whose quality of life after survival may be very poor. This is the dilemma that pediatric surgeons and their team are often confronted with in the newborn period [39,60].

Poor follow-up systems

Beyond the newborn period, follow-up of these children continues for the pediatric surgeon for variable periods depending on the index anomaly – often into adulthood. These follow-up periods are often laden with emotional and psychological challenges especially for children who are not doing well and families struggling to cope with the morbidities associated with their child's malformation. This is further aggravated by poor transport systems from remote areas, and high cost of follow-up consultations in the background of poverty, resulting in the high rate of default from follow-up in most African countries [39]. In addition, home visits are also difficult to arrange, which results in complete failure to locate these children after discharge. The poor data recording on congenital malformations makes it difficult to ascertain the burden in order to formulate policies in many African settings [31].

Conclusion/recommendation

The challenges posed by congenital malformations are enormous. Although everyone involved (parents and caregivers, the child, the healthcare team) has his peculiar challenge, the parents are often the most affected [10,12,39,61]. The morbidity, psychosocial effects, and mortality rates are high. Thus, in ameliorating these challenges, the healthcare providers, and the government and nongovernmental organizations have a role to play.

Campaigns and public enlightenment programs should be sponsored to educate people on the causes and risk factors for congenital malformations including preventable causes such as alcohol consumption and smoking during pregnancy, and folic acid deficiency. This will not only help in reducing the incidence of congenital malformations, but also dissuade practices that castigate mothers who give birth to such children. Fortification of frequently consumed staple foods with folic acid will help reduce the incidence of neural tube defects. Where available, preconception and prenatal screening to help detect genetic defects associated with increased risk of congenital malformations can be done [20].

Every member of the healthcare team caring for children with congenital malformations should be well trained on effective communication and counseling skills, which will aid parental adjustment and coping [61]. Policies that will protect children with congenital malformations from abuse should also be formulated [42]. Reducing the morbidity and disabilities associated with congenital malformations especially in developing countries should be addressed by improving facilities, training of more pediatric surgeons, and funding research and international collaboration aimed at improving infant care [20,44,57].

Conflicts of interest

There are no conflicts of interest.

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