

## REVIEW ARTICLE

## Tackling the problem of delayed presentation of congenital central nervous system anomalies in Africa

Taophee B RABIU

## AFFILIATION

Division of Neurological Surgery  
Department of Surgery  
Ladoke Akintola University  
of Technology Teaching  
Hospital Osogbo  
Osun State, NIGERIA

## CORRESPONDING

## AUTHOR

Taophee B RABIU

Division of Neurological Surgery  
Department of Surgery  
Ladoke Akintola University of  
Technology Teaching Hospital  
Osogbo, Osun State, NIGERIA

E-mail: [eshohealth@gmail.com](mailto:eshohealth@gmail.com)

Phone: +234 803 495 4806

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DISCLOSURES: NONE ELSE

## ABSTRACT

**Background:** Children, adolescents and adults with paediatric congenital neurosurgical conditions appear to be increasing in Africa.

**Objective:** This study evaluates the problem of late presentation of congenital central nervous system (CNS) anomalies in Africa.

**Methodology:** Pubmed and AJOL databases were examined for publications addressing the issue. The findings were pooled and descriptive analysis was done.

**Results:** Reported age at presentation was as high as 47years. The identified lesions included congenital hydrocephalus, encephalocele, spina bifida, microcephaly and dermoid cyst, which were obvious at birth. Social, cultural and economic factors and deficient-healthcare systems were responsible for the late presentations. Increased rates of infection and overall morbidity and mortality in the patients presenting late for care are reported. Suggested solutions include improvements in public health education as well as social and health services.

**Conclusion:** Late presentation of gross congenital CNS anomalies is a major issue in Africa. Advocacy, aimed at increasing the awareness of the problem, is canvassed.

**Keywords:** Birth, definitive care, six months, malformations, neurosurgeons

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## INTRODUCTION

Congenital malformations of the central nervous system (CNS) represent an important group of conditions treated by neurosurgeons. They, like other malformations, represent major contributors to disability.<sup>1</sup> Although they could become apparent in adulthood, such as adult-onset aqueductal stenosis, they are often present at birth. Many of them such as spina bifida and encephalocele, and to a lesser extent, hydrocephalus, are obvious at birth and as such early presentation to a neurosurgical centre for treatment should be expected.

Late presentation is taken as presentation to the centre of definitive care (neurosurgery) at or after 6 months of age or after 6 months since it was first noticed.<sup>2</sup> Delayed presentation (and/or delayed treatment) is a major contributor to morbidity in a wide variety of disease conditions and presents growing concerns in hospital care in several parts of the world.<sup>3,4,5</sup>

The number of older children, adolescents and adults diagnosed as having paediatric congenital neurosurgical conditions appears to be on the rise in Africa. Several reports abound in the literature of delayed presentation to neurosurgical services for congenital conditions that were obvious at birth.<sup>2,6,7</sup>

This study evaluates the problem of late presentation of congenital central nervous system anomalies in Africa with a view to determining the pattern of anomalies and the factors responsible for the delay in seeking care.

## METHODOLOGY

### Data Collection

A search of the published literature was done (initially in 2010; repeated in 2012) to identify studies addressing the issue of late presentation in congenital anomalies of the

central nervous system in the African population. Pubmed and African Journals Online (AJOL) databases were searched for publications addressing the issue. The search terms employed included "late presentation in Africa", "delayed hospital presentation", "congenital malformations in Africa", "central nervous system malformations", "Africa", "hydrocephalus" and "spina bifida". Abstracts of the retrieved publications were examined for relevance to the research topic. Only articles published in English were considered.

Seven relevant publications were identified and included in this study. They were analyzed to determine the pattern of anomalies with late presentation, problems associated with late presentation, reasons for late presentations and authors' suggestions for tackling the problem of late presentation of congenital anomalies of the central nervous system in Africa.

### Data Analysis

Findings in the identified studies such as the age at presentation, types of anomaly, reasons for the late presentation and associated problems, were pooled. Simple descriptive analysis was performed.

## RESULTS

### Geographic Distribution

The identified studies (including their countries of origin) are as set out in Table 1.<sup>2,6-11</sup> The studies were from East and West Africa.

### Age at Presentation

The reported age at presentation for the identified congenital anomalies was as high as 47 years. The reported age of the oldest patient in each study is as set out in Table 1.

Table 1: Details of studies and age at presentation of the oldest patients

S/N	Authors	Country	Oldest Patient (Yrs)	Publication Yr
1.	Adeleye, <i>et al</i>	Nigeria	5	2009
2.	Munyi, <i>et al</i>	Kenya	15	2009
3.	Bickler, <i>et al</i>	Gambia	13	2000
4.	Komolafe, <i>et al</i>	Nigeria	47	2008
5.	Idowu, <i>et al</i>	Nigeria	2	2008
6.	Alatise, <i>et al</i>	Nigeria	NS	2006
7.	Binitie	Nigeria	NS	1982

NS: Not Stated

### Reported Anomalies

The reported anomalies with late presentation were congenital hydrocephalus, microcephaly, encephalocele, spina bifida, and dermoid cyst.

### Problems Associated with Late Presentation

All the authors reported increased morbidity and mortality as major consequences of late presentation of congenital CNS anomalies in Africa. The other problems included difficulty with repair and increased risk of intracranial sepsis. For hydrocephalus, increased risk of blindness and raised ICP were reported. Increased risk of infection was reported as common to both hydrocephalus and spina bifida when the patients presented late (Table 2).

Table 2: Problems associated with late presentation

Author	Problems associated with late presentation*
Alatise	Spina bifida: Increased mortality, infections
Bickler	Difficulty with repair
Idowu	Intracranial sepsis
Komolafe	Hydrocephalus: Blindness, raised intracranial pressure, infection Spina bifida & Encephalocele: Rupture, infection

\*All authors reported increased morbidity and/or mortality

### Reasons for Late Presentation

The studies identified the following reasons as being responsible for late presentation of congenital CNS anomalies in Africa:

- Lack of hope for child's survival*
- Shame*
- Abandonment of child*
- Poverty*
- Delayed or wrong referrals*
- Poor access to health centers*

### Suggested Solutions

The solutions to the problem as suggested by the authors were:

- Improved public health education*
- Provision of social support*
- Improved access to health care*

### DISCUSSION

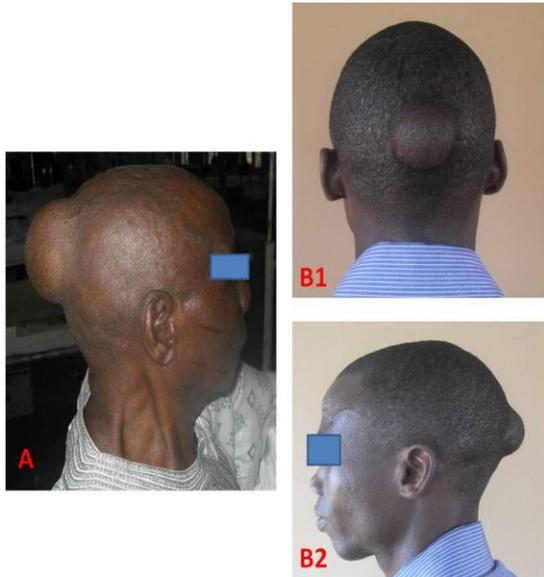
Late presentation to the appropriate health facilities is a major problem which adversely affects outcome of healthcare for a wide variety of disease conditions in many parts of the world.<sup>12-17</sup> The issue is of particular importance in developing countries, of which African countries are a major part.

Congenital CNS anomalies are often obvious at birth or shortly after. As such, it would be expected that early presentation for care should be the rule. As observed by many authors, however, delayed or late presentation of congenital CNS anomalies has become an issue of concern in different parts of the world.<sup>3,4,5</sup>

The highest age at presentation as documented by the authors is 47 years. While the authors did not state or define what age constitutes late presentation, it was generally expressed that presentation beyond 6 months of age contributes significantly to morbidity and mortality. In fact, this author was encouraged to carry out this study following the presentation of two male adults with

congenital cranial lesions that had been present and obvious since birth (*Figure 1*).

Figure 1: Occipital dermoid cysts in A: 83-year old man; B1 & B2: 32-year old intending groom



It is instructive to note that the identified studies were from East and West Africa. These are regions of Africa where there is a low ratio of neurosurgeon per population.<sup>18</sup> As such, there is a high likelihood of poor access to neurosurgical services by the inhabitants of such regions which may contribute to the observed problems of late presentation. South Africa and many countries in North Africa, especially Morocco and Egypt, have a higher ratio of neurosurgeons per population, and may not have the problem of late presentation of congenital CNS anomalies as much as is obtained in East and West Africa. Until very recently, many Central African countries did not have neurosurgeons and this may account for the absence of relevant publications from that region.

More than four decades ago, Sharrad, *et al*, reported that early repair of spina bifida

results in improvement of the morbidity and mortality associated with that condition.<sup>19</sup> It is not surprising, therefore, that the authors of the identified studies all listed increased morbidity and mortality as major problems of late presentation.

The various reasons listed by the authors as being responsible for late presentation all reflect the extreme poverty level ravaging the pockets and minds of the poor in Africa. Poverty has been correctly adduced to be behind most of the health problems facing Africa.<sup>20</sup> Therefore, finding solutions to the economic woes of Africa would help to improve this ugly picture of congenital CNS malformations.

The authors suggested that improved public health education, provision of social support and improved access to health care would help to reduce this burden. In addition, international organizations involved in neurology/neurosurgery healthcare such as the World Health Organization (WHO), the World Federation of Neurology (WFN), the World Federation of Neurosurgical Societies (WFNS), and the International Society for Pediatric Neurosurgery (ISPN), all have important roles to play in helping African children. There is also an urgent need to equitably redistribute public health spending in Africa so as to solve the health problems confronting the down-trodden members of Africa.<sup>21</sup>

The identified studies did not specify the exact number of patients presenting late with the congenital CNS conditions. Also, the authors did not indicate if the observed complications were age-related or not. Perhaps, the understanding of the exact burden of the issue would have been better if these were addressed. In our neurosurgical unit, we have commenced a prospective

study which may address some of these limitations in the near future.

While the data presented, most likely, give a true picture of the problem in Africa, it is possible that the extent of the problem would have been broader if articles published in, for example French, which is the official language in Francophone African countries, were also included. The author also recognizes the limitation of conducting an online search for African literature. It is not impossible that some articles on this subject were not indexed by the major databases examined. Nonetheless, it might also be possible that the overall picture would not have been anything but gloomier if the non-indexed papers were included.

## CONCLUSION

Late presentation of gross congenital central nervous system anomalies is a major issue in neurosurgical care in East and West Africa. Advocacy aimed at increasing the awareness of Africans and African governments about congenital neurosurgical problems are urgently needed.

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