

Causes Of Delayed Presentation In Patients With Hydrocephalus

¹Ozor II, ¹Chikani MC*, ¹Dada OA, ¹Mezue WC,
²Ohaegbulam SC, ²Ndubuisi CA.

¹Neurosurgery Unit, Department of Surgery, University of Nigeria Teaching Hospital, Ituku Ozalla, Enugu, Nigeria.

²Memfys Hospital for Neurosurgery, Enugu

*Author for Correspondence: markochikani@yahoo.com

ABSTRACT

Hydrocephalus is one of the common neurosurgical conditions that present to neurosurgeons in our environment. Delay in presentation for neurosurgical care can result insignificant morbidity and mortality. Early diagnosis and prompt treatment is important to reduce morbidity and mortality in these patients. This study set out to determine the causes of delay in presentation of patients with hydrocephalus for treatment in our environment. A prospective cross-sectional study of all patients with hydrocephalus that presented between January 2012 and December 2014 was carried out. The relevant data were recorded prospectively in clinical summary forms and an electronic spreadsheet. Data was analyzed using SPSS version 22.0 (SPSS, Chicago, IL) for statistical analyses. Of the 72 patients, 50 (69.4%) experienced a delay of >4 weeks from onset of symptoms to definitive presentation to the neurosurgeon. Occurrence of neurological deterioration in those that experienced delay was statistically significant compared to patients who did not experience delay (chi square $\chi^2 = 2.967, p = 0.002$). Of the 50 patients with delayed presentation, it was due to lack of fund in 29 (58%) patients, ignorance in 11 (15.3%), religious beliefs in 7 (9.7%) and delayed referral in 3 (6.0%) patients. Barriers exist that prevent early patient presentation for neurosurgical treatment of hydrocephalus. These are all preventable and efforts should be geared towards this.

Keywords: Delayed presentation, hydrocephalus, awareness, caregivers, healing centres.

INTRODUCTION

The availability and provision of neurosurgical surgical care in Sub-Saharan Africa has improved significantly in the past few decades. However, there remains a problem with regards to early accessibility of care, resulting in devastating and irreversible consequences for many patients. (Cadotte et al. 2010; Heinsbergen et al. 2002; Tarcan et al. 2006). Hydrocephalus is one of such conditions where significant morbidity and mortality can follow late assessment and management. Generally, developing countries face a greater burden of care for hydrocephalus likely due to a combination of factors including higher poverty, cultural beliefs about health, poor infrastructure, unstable and fragile politics, and limited access to neurosurgical treatment. (Warf, 2010; Biovin et al. 2015; Stagno et al. 2015). Therefore, patients with hydrocephalus in low- and middle-income countries are faced with significant barriers to early treatment. (Aschoff et al. 1999; Warf et al. 2013; Warf et al.

2015; Weil et al; 2015). Unfortunately these societies have little capacity to cope with the consequences of delayed management particularly the morbidity in terms of management of grossly enlarged heads and poor cognitive function.

There is considerable data in literature to suggest that early surgical intervention results in less neuronal damage and better cognitive outcomes (Weil et al. 2015; Mezue et al. 1992; Afolabi et al. 1993). This has been associated more with the cerebral mantle thickness at the time of definitive surgery than the type of CSF diversion procedure. Weil et al (2015). A significant morbidity that has not been as frequently researched is the social and psychological consequences of bringing up a child with very large head and craniofacial disproportion. Some studies have addressed the stigmatization the children face at school (Mezue et al. 1992; Afolabi, 1993). However, there are little available studies on the stresses the mothers go through with a neonate with such

disproportionate cranial size. In our environment such parents are frequently from the lower socio-economic classes with low literacy rates and little support from health services and social welfare.

This study was designed to determine the causes of delayed presentation in patients with hydrocephalus. This will provide a basis to understanding the challenges these parents face and a basis for planning health interventions.

MATERIALS AND METHODS

This was a prospective descriptive analysis of all cases of hydrocephalus seen at the University of Nigeria Teaching Hospital, Ituku-Ozalla and Memfys Hospital for Neurosurgery in Enugu, Enugu State of Nigeria. Ethics approval for the study was obtained from the institutions' ethics committees. It was conducted over a period of 3 years from January 2012 to December 2014.

The relevant data were recorded prospectively in clinical summary forms and an electronic spreadsheet. Information in each proforma consisted of patient's age, sex, presenting symptoms, duration of symptoms, interval between onset of symptoms and deterioration, place of initial care, other places of care previously attended, reasons for referral, initiator of referral, duration of previous care before presentation and duration of delay. Socio-demographic data of the patient's caregivers obtained included occupation, level of education attained, religion and acquaintance with a doctor or nurse or any other health workers.

All caregivers whose educational status was below tertiary were grouped as lower-level educational status. Occupations other than civil service, students in tertiary institutions and graduate entrepreneur were put under the category artisans. Artisans included farmers, traders, painters, hair stylists and commercial bus drivers. Artisans and students were placed into the group of non-salary earners while civil servants and business entrepreneurs were salary earners. The patients and caregivers were also asked about who convinced them to present to hospital, the surgical specialty of the referring doctor, reasons for deciding to present, reasons for delay and whether there was any awareness

of the need to present early. Delay was defined as time lag of four weeks and above between onset of symptoms and presentation to neurosurgeons for definitive treatment.

The database was analyzed using the SPSS version 22 (SPSS, Inc, IL). Descriptive data are presented in frequencies / proportions, means (\pm standard deviations, SD) and medians. Tests of associations were performed using the Pearson's Chi-square test for categorical variables. Statistical significance was set at p value < 0.05.

RESULTS

A total of 72 patients were recruited for this study. This included 53 males and 19 females with male: female ratio 2.8:1 (table 1).

Table 1: Patients' and Care-Givers Socio-Demographics

CHARACTERISTICS	FREQUENCY	PERCENTAGE
No of patients	72	100
Age		
Range 3weeks-18years	72	100
Neonate	3	4.2
Infant	44	61.1
1 – 5 years	17	23.6
> - 5 years	8	11.1
Mean 3.7 \pm 4.6 year		
Gender		
Male	53	73.6
Female	19	26.4
Care-givers' occupation		
Artisan	27	37.5
Students	13	18.1
Civil servants	32	44.4
Care-givers' educational status		
Primary school	14	13.9
Secondary school	48	66.7
Tertiary	10	19.4

The age range was 3 weeks to 18 years with a mean of 3.7 ± 4.6 years. The most common presentation was macrocephaly seen in 46 (63.9%) patients followed by abnormal gait in 14 (19.4%) as depicted in **table 2**.

Table 2: PATIENTS' CLINICAL FEATURES AND CARE PARAMETERS

Main symptoms		
Large head	46	63.9
Poor vision	6	8.3
Abnormal gait	14	19.4
Headache	6	8.3
Initial place of care		
FMC	5	6.9
General hospital	6	8.3
Private hospital	41	56.9
Teaching hospital	8	11.1
Medicine dealer	3	4.2
Traditional healer	9	12.5
Reasons for referral		
No personnel	58	80.5
No facility	1	1.3
No improvement	13	18.1
Other places of care attended		
Medicine dealer	2	4.5
Other clinics	25	56.8
Traditional healer	12	27.3
Religious healers	5	11.4
Care-givers' acquaintance with hospital staff		
Yes	14	19.4
No	58	80.6
Reasons for delay		
Lack of fund	29	58.0
Ignorance	11	15.3
Religious belief	7	9.7
Delayed referral	3	6.0

A significant number of patients 50 (69.4%) presented late for care. Reasons for delayed presentation included lack of fund, ignorance, religious beliefs and delayed referral (**table 2**). Majority of patients that presented late did so with complaints of neurological deterioration and unacceptable head size before the caregivers decided to bring them. There was a statistically significant difference between patients with delayed presentation and those with no delayed presentation in terms of onset of deterioration prior to presentation (Chi-square $\chi^2=2.967$, $p=0.002$).

Among the parents and caregivers were 13 (18.1%) Students and others who were unemployed, 27 (37.5%) irregular income earners (artisans including seamstress, peasant farmers, petty traders, hair-stylists and house painters), and 32 (44.4%) regular income earners (civil servants). There was no statistically significant difference between the salary earners(civil servants) and irregular and non-income earners (artisans and students) in terms of delayed patient presentation (Chi square $\chi^2=0.689$, $p=0.160$) as shown in **table 3**.

TABLE 3: FACTORS SIGNIFICANTLY ASSOCIATED WITH DELAYED PATIENT PRESENTATION

FACTORS (No)	DELAYED PRESENTATION		Chi square χ^2	P-value
	YES	NO		
Care givers Occupation (72)				
Salary earners (32)	23	9	0.689	0.160
Non salary earners (40)	27	13		
Level of education (72)				
Lower (62)	46	16	4.745	0.029*
Higher (10)	5	5		
Initial place of care (72)				
Hospital (60)	47	13	6.702	0.010*
Non hospital (12)	7	5		
Other places of care				
Non – hospital (44)	28	16	1.799	0.180
No other places (28)	22	6		
Health worker acquaintance (72)				
Yes (14)	8	6	0.952	0.329
No (58)	41	17		

***Significant association**

Only 10 (13.9%) parents or caregivers attained tertiary level of education while 62 (86.1%) had lower level education. Attaining a tertiary education was significantly associated with earlier patient presentation compared to other levels of education (Chi square $\chi^2=4.745$, $p=0.029$). This means that caregiver's educational status lower than tertiary education had a higher tendency of delayed presentation. Initial place of care was a private hospital in 41 (56.9%) patients, 6 (8.3%) in general hospital, 5 (6.9%) in Federal Medical Centres, 8 (11.1%) in a Teaching hospital while 3 (4.2%) went for complimentary/alternative medicine (CAM). There was a statistically significant difference between patients whose initial care was in a hospital before being referred and those who did not go to a hospital first in terms of delayed presentation (Chi square $\chi^2=6.702$, $p=0.010$). This showed that when the initial place of care was a hospital, majority of the patients still presented late for treatment. The reasons for referral from health institutions to neurosurgery were because of no facilities or lack of neurosurgeons in majority of patients (59, 81.8%). The reasons for the delay is because of need to optimize patients (rehydration and nutrition)

Forty-four (44) patients accessed CAM at one point or the other and subsequently reached neurosurgical units through referral from those hospitals. These places included medicine dealer's shop (2, 4.5%), traditional healers (12, 16.7%), religious healer (15, 34.1%) and other clinics (25, 56.8%). However, attending other places of care was not statistically significantly associated with delayed patient presentation for care (Chi square $\chi^2=1.799$, $p=0.180$).

Another important finding was that 14 (19.4%) of our patients' caregivers had relations who work in a hospital especially doctors, nurses and other health workers. When compared with those who did not have relations working in a hospital, there was no statistically significant difference as they both had high occurrence of delayed presentation to the neurosurgeon for care (Chi square $\chi^2=0.952$, $p=0.329$).

When questioned about their personal desires for early treatment, majority (65, 90%)

of care-givers agreed that early presentation was important for care. That most of them nevertheless presented late suggests failure of the health care system in the society.

DISCUSSION

Delayed treatment of hydrocephalus is a recognized poor prognostic factor. Patients who present late to a neurosurgical department have poorer outcomes irrespective of the form of definitive treatment offered and other variables. Late presentation to the appropriate health facilities for treatment adversely affects outcome of patient management for a wide variety of clinical conditions in many parts of the world. (Ameh et al. 2000; Kidanto et al. 2002; Dogo et al. 2006; Elzawawy, 2008; Fehmy et al. 2007; Ingarfield et al. 2005).

The findings of this study corroborate some of the findings of some previous studies (Mezue et al. 1992; Afolabi et al. 1993; Alatisie et al. 2006; Adeleye et al. 2010). Factors identified in our study to be responsible for delayed presentation of hydrocephalus for management included low or no income earning, low level of education, religious beliefs, lack of funds, ignorance and delayed referral from peripheral centres.

Majority of caregivers only realized an urgent need to present the children to hospital following neurological deterioration. This behavior definitely would impact adversely on the outcome of treatment in such patients. Parents or caregivers' financial standing contributed largest to the reasons for delayed presentation. Majority of these patients had parents who were artisans such as seamstress, hairstylists, petty-traders and peasant farmers, and students who were either low-income or non income earners. ¹⁷This affects the initial decision to present for health care as well as the treatment timelines once in hospital. Adeleye et al (1992). This is inevitable in a society where poverty and literacy are well below the WHO recommended levels and where complete absence of social support ensures that health burdens must be borne by the individuals and their families. A significant number of the caregivers of the patients in our study had low-levels of education that could have contributed to their ignorance of the need for early

presentation of the patients for care.

Our study also revealed that a significant number of patients sought care in places other than a tertiary health institution where facilities and personnel for care of hydrocephalus exist. Some of these places include religious places of worship and traditional healing centres many of which are religious based. It is tempting to assume that this is a sign of deep belief in a Supreme Being with power to heal, but often on closer questioning suggests that they were deceived by intense preaching that preys on their need. . There is no doubt that there is a high frequency of increased spiritual beliefs and trust that reflects on the acceptance of any final medical outcomes. Others engaged in use of over-the-counter medications and self-medication hoping for improvement. Idowu et al (2009). They only present to the hospital for care when all they have tried have failed. This group of patients contributed significantly to cases of hydrocephalus that presented late in our study.

A large number of the patients referred from non-specialized hospitals presented late for treatment in spite of early presentation to the referring hospital. The reasons for this were multifaceted including the wrong assumption that the more specialized hospitals must necessarily be more expensive. Another reason is that they have exhausted their financial resources in the referring hospital and need some time to raise more funds. They could also be wary of surgical treatment especially when the first doctor or medical officer encountered gave no details or proper explanation about surgery and related complications. This is also a reflection of the great need for more neurosurgeons and adequately equipped Federal Medical Centres, general and private hospitals in our environment. At the moment Nigeria has only 74 practicing Neurosurgeons for a population of near 200 million people. There is also a need for the Neurosurgeons to engage more with Doctors at primary and secondary centres of care and with the public. Availability of a neurosurgeon at the first time of going to a hospital for care could reduce the incidence of delayed presentation for care.

Having a relation working in a hospital did not improve the occurrence of delayed ct

presentation in our study. Majority of those who had relations working in a hospital still presented late. This could be due to the fact that caregivers with children with big heads may not tell relations of their problems in a timely manner for reasons that may include fear of stigmatization. It could also be due to the fact that some care-givers may be unaware that the non-doctor relation working in a hospital might be of help.

Another significant reason for delayed patient presentation in our environment was delayed referral from peripheral centres. The most common reason given by the patient's relations was an inability to offset their hospital bills at the referring hospital prior to presentation. While it is well recognized that delayed referral may be due to certain behaviors of the referring health worker (Paul et al. 2002; Mehrotra et al. 2002; Reich et al. 2002). All the cases that were referred late in our series were due to factors related to funds to settle hospital bills. This is a societal problem related to lack of social support from the Government and non-existent health insurance scheme. Previous attempts to set up a health insurance targeted primarily civil servants and were not well prosecuted. More recently there has been an attempt to legislate against forcefully keeping patients in any hospital for reasons of non-settlement of bills but this is still to be implemented in any rational manner. It is hoped that studies like this will highlight the disastrous consequences of preventing patients from getting needed health services because of financial difficulties.

CONCLUSION

Delayed presentation of hydrocephalus due to various factors exists in our environment. Cultural and religious beliefs frequently compounded by self-medication and financial constraints are still rampant in our environment. Coupled with low level of education and awareness, these are some of the factors responsible for such delays. Therefore there is need for proper enlightenment of our populace including health workers, improvement in general economic status, increase in manpower, and subsidization of treatment so as to improve on the present situation in our environment.

REFERENCES

- Adeleye AO, Dairo MD, Olowookere KG. (2010). Central nervous system congenital malformations in a developing country: issues and challenges against their prevention. *Childs Nerv Syst.* 26:919-24.
- Afolabi AO, Shokunbi MT. (1993). Socioeconomic implications of the surgical treatment of hydrocephalus. *Niger J Paediatr.* 20:94-7
- Alatise OI, Adeolu AA, Komolafe EO, Adejuyigbe O, Sowande OA. (2006). Pattern and factors affecting management outcome of spina bifida cystica in Ile-Ife, Nigeria. *Pediatr Neurosurg.* 42:277-83.
- Ameh EA, Chirdan LB. (2000). Neonatal intestinal obstruction in Zaria, Nigeria. *East Afr Med J.* 77:510-513.
- Aschoff A, Kremer P, Hashemi B, Kunze S. (1999). The scientific history of hydrocephalus and its treatment. *Neurosurg Rev.* 22: 67–95
- Boivin MJ, Kakooza AM, Warf BC, Davidson LL, Grigorenko EL. (2015). Reducing neurodevelopmental disorders and disability through research and interventions. *Nature.* 527: S155–S160
- Cadotte DW, Viswanathan A, Cadotte A, Bernstein M, Munie T, Freidberg SR. (2010). The consequence of delayed neurosurgical care at TikurAnbessa Hospital, Addis Ababa, Ethiopia. *World Neurosurg.* 73: 270-5.
- Dogo D, Gali BM, Ali N, Nggada HA. (2006). Male breast cancer in north eastern Nigeria. *Niger J Clin Pract.* 9:139-141.
- Elzawawy AM, Elbahaie AM, Dawood SM, Elbahaie HM, Badran A. (2008). Delay in seeking medical advice and late presentation of Female Breast Cancer Patients in Most of the World. Could We Make Changes? The Experience of 23 Years in Port Said, Egypt. *Breast Care (Basel)* 3:37-41.
- Fahmy FE, Lancer JM, Ahmed A. (2007). Late presentation of congenital tracheoesophageal fistula. *Eur Arch Otorhinolaryngol* 2007; 264:81-84. Ingarfield SL, Jacobs IG, Jelinek GA, Mountain D: Patient delay and use of ambulance by patients with chest pain. *Emerg Med Australas.* 17:218-223.
- Heinsbergen I, Rotteveel J, Roeleveld N, Grotenhuis A. (2002). Outcome in shunted hydrocephalic children. *Eur J Paediatr Neurol.* 6: 99-107.
- Idowu OE, Apemiye RA. (2009). Delay in presentation and diagnosis of adult primary intracranial neoplasms in a tropical teaching hospital: A pilot study. *International Journal of Surgery.* 7:396–398.
- Kidanto HL, Kilewo CD, Moshiro C. (2002). Cancer of the cervix: knowledge and attitudes of female patients admitted at Muhimbili National Hospital, Dar es Salaam. *East Afr Med J.* 79:467-475.
- Mehrotra S, Jarrett WS. (2002). Improving basic health service delivery in low-income countries: 'voice' to the poor. *Social Science and Medicine.* 54:1685-1690
- Mezue WC, Eze CB. (1992). Social circumstances affecting the initial management of children with myelomeningocele in Nigeria. *Dev Med Child Neurol* 1992;34:338-41
- Paul S. (2002). Accountability in public services: exit, voice and control. *World Development.* 1047-1059.
- Reich RM. (2002). Reshaping the state from above, from within, from below: implications for public health. *Social Science and Medicine.* 54:1669-1675.
- Stagno V, Navarrete EA, Mirone G, Esposito F. (2013). Management of hydrocephalus around the world. *World Neurosurg.* 79: S23.e17–S23.e20
- Tarcan T, Onol FF, Ilker Y, Alpay H, Simsek F, Ozek M. (2006). The timing of primary neurosurgical repair significantly affects neurogenic bladder

prognosis in children with myelomeningocele. *J Urol.* 176: 1161-5

Warf BC. (2010). Pediatric hydrocephalus in East Africa: prevalence, causes, treatments, and strategies for the future. *World Neurosurg.* 73: 296–300

Warf BC. (2013): Educate one to save a few. Educate a few to save many. *World Neurosurg.* 79: S15.e15–S15.e18

Warf BC. (2015). “Who is my neighbor?” Global neurosurgery in a non-zero-sum world. *World Neurosurg.* 84: 1547–1549

Weil AG, Fallah A, Bhatia S, Ragheb J. (2015). Pediatric neurosurgery in the developing world: the Haiti experience. *J Craniofac Surg.* 26: 1061–1065.