

Domestic and Activities of Daily Living Challenges on Parents of Children with Neurologic Deficit in Zaria, Northern Nigeria: A Hospital based study

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Abstract: The study was aimed at identifying the burden of care on parents of children with neurological deficits. Design: A descriptive cross-sectional study. Setting: Paediatric Neurology Outpatient Clinic, Ahmadu Bello University Teaching Hospital Shika-Zaria, Kaduna State, Northern Nigerian. Methodology: A non-probability, availability sampling method was used to enrol 60 parents who participated in the study. Data were collected through an interviewer administered close-ended questionnaire and in-depth interview of 9 parents out of the 60 who participated in the study. Results: Sixty-one children were involved in the study. Cerebral palsy (50.8%) and seizure disorders (39.4%) were the commonest deficits found. The mean age of 5years, male (55.7%) and females were 44.3%. The burden of care of affected children was mainly shouldered by mothers; feeding, bathing, carrying, drug administration etc. No governmental or nongovernmental assistance programmes were identified. Conclusions: Meeting the physical needs/activities of daily living of children with neurological deficits places a high burden on the shoulders of their parents. Lack of or in accessible rehabilitation and education facilities contributes immensely to the burden. Multi-sectoral (health personnel, educationist and physiotherapist) approach in management is required with great support from government and non-government organisations. Parents should be educated on the importance of supervised antenatal care, deliveries and postnatal care, including routine childhood immunizations.

Keywords: Activities of daily living, domestic care, neurological deficit children, parental care

INTRODUCTION

Most children enjoy healthy childhood with little need for specialized health care services. However, some children experience difficulties in early childhood and may require long term special care. Caring and meeting the needs of children can be very demanding but no doubt a desired status by most. Although care giving is a normal function and desired expectation of every parent, challenges and misgivings occur when a child experiences functional limitation and long term dependence because disability in a child affects not only the child but the entire family (Raina *et al.*, 2005; Centre for Child Development, 2007).

Neurological disorders are major causes of functional disability in children (Bajraszewski *et al.*, 2008) and they can result from congenital and hereditary causes; head injuries; trauma to spinal cord; exposure to toxic chemicals; and various forms of viral, bacterial, parasitic and fungal meningo-encephalities (Batul, 2011; Raiford, 2013). Cerebral palsy, epilepsies and epilepsy syndromes, hydrocephalus, microcephaly, attention deficit, hyperactivity and autism, are common neurological disorders in children, which are associated with delays in developmental milestones, muscle rigidity and inco-ordination, impairment of speech,

hearing and vision. These disorders ultimately lead to learning disability and prolonged dependency (Idro *et al.*, 2010); thus posing enormous burden and physical challenges to parents, particularly with regard to day to day care of affected children. Because the challenges and the burden of care on these parents are difficult to quantify, we designed this study to investigate parental involvement in caring for the affected child and available facilities in-place for them, with the hope that our findings may provide some clues to appropriate preventive and palliative measures.

METHODS AND MATERIALS

Setting: Sixty parents of children with neurological deficits attending the Paediatric Neurology Outpatient Clinic of Ahmadu Bello University Teaching Hospital (ABUTH) Shika Zaria, were selected via non-probability, availability sampling. ABUTH Shika Zaria is a 700- bed capacity tertiary health institution located in Kaduna State, North western Nigeria. It has many specialized outpatient clinics that receive referrals from a population of more than 15 million people spread across 10 states in northern Nigeria, the Federal Capital, Abuja and adjoining states in southern Nigeria. The

paediatric neurology clinic is one of the specialist clinics.

Instrument and data collection: All the parents (51 mothers, 9 fathers) were interviewed using a 42- item semi-structured questionnaire comprising five sections:

- Socio demographic characteristics of parents
- Socio demographic characteristics of the affected children
- Possible predisposing factors and/or causes of neurological dysfunction (s)
- Socio-economic challenges
- Burden of care

The questionnaire was written in English (the official language in Nigeria), but was translated to Hausa (the language of communication in North western Nigeria) by a bilingual expert and then back translated to English by another bilingual expert who was blind to the first translation. Both Hausa and English versions were then pre-tested on 10 parents who were literate and fluent in Hausa language, but semi-literate in English language; in order to remove and correct any ambiguity in the questionnaire, simulate investigator-subject interaction and avoid inter-researcher errors. There after each of the 60 parents was interviewed either in Hausa or English language depending on their proficiency and choice. Some of them who consented were interviewed in depth.

Data analysis: The data obtained were analyzed using descriptive statistics expressed as continuous variables, standard deviations, percentages and proportions. Chi-

Square test was used to define relationships between variables; Level of significance was set at 5%, within 95% confidence interval.

The information from the indepth interviews was translated and/or transcribed, and analysed thematically to complement the quantitative data.

Ethical clearance: Permission was obtained from the Ethical Committee of the hospital. Respondents' participation was voluntary after adequate information on the reasons for the study. No name or other form of identification was required and information acquired was treated confidential and strictly for the purpose of the study.

RESULTS

The socio demographic characteristics of respondents: Table 1 shows that 51 (85.0%) of the parents were mothers while 9 (15.0%) were fathers. All the parents were married, except one who was a widow. Majority were Muslims (51, 85%) and Hausa/Fulani (43, 71.7%), respectively. Many respondents, 22 (36.7%) have tertiary form of education, while 15 (25%) had no form of western education. Majority of respondents, 27 (45.0%) are self employed while 15 (25.0%) are full housewives. Many, 27 (45.0%) of respondents could not ascertain how much income they get in a month, however, 12 (20.0%) earn less than N10, 000.00 per month. Mean income was N57, 666.00. Socio economic level in this study appears low, women need to be learned, empowered and more job opportunities be created to meet increasing demands of the family.

Table 1: Socio demographic characteristics of parents of affected children

Variables	Mother 51 (85%)	Father 9 (15%)	Total N = 60 (100.0%)
Marital status			
Married	50 (83.3%)	9 (15%)	59 (98.3)
Widow	1 (1.7%)	0 (0.0)	1 (1.7)
Tribe			
Hausa/Fulani	38 (63.3)	05 (8.3)	43 (71.6)
Northern/ southern minorities	09 (15)	03 (5.0)	12 (20.0)
Igbo	02 (3.3)	01(1.7)	3 (5.0)
Yoruba	02 (3.3)	00 (0.0)	2 (3.3)
Religion			
Islam	46 (76.7)	05 (8.3)	51(85)
Christianity	05 (8.3)	04 (6.7)	9 (15.0)
Educational attainment			
None	13 (21.7)	2 (3.3)	15 (25.0)
Primary	5 (8.3)	0 (0.0)	5 (8.3)
Secondary	15 (25.0)	3 (5.0)	18 (28.0)
Tertiary	18 (30.0)	4 (6.7)	22 (36.7)
Occupation			
None or full housewife	15 (25.0)	0 (0.0)	15 (25.0)
Self employed	22 (36.7)	5 (8.3)	27 (45.0)
Government employed	14 (23.3)	4 (6.7)	18 (30.0)
Income per 30 days (Naira)			
None/I don't know	25 (41.7)	2 (3.3)	27 (45.0)
< 10, 000.00	12 (20.0)	0 (0.0)	12 (20.0)
11, 000.00-20, 000.00	2 (3.3)	0 (0.0)	2 (3.3)
21, 000.00-30,000.00	2 (3.3)	0 (0.0)	2 (3.3)
31, 000.00-40,000.00	0 (0.0)	2 (3.3)	2 (3.3)
41, 000.00 and above	10 (16.7)	5 (8.3)	15 (25.0)

Table 2: Distribution of age of affected children and their neurological dysfunctions by sex

Variables	Males 34 (55.7 %)	Females 27 (44.3%)	Total 61 (100.0%)
Age of child (years)			
1.0 – 2.0	8(13.1)	8(13.1)	16 (26.2)
2.1- 4.0	11(18.0)	7(11.5)	18 (29.5)
4.1- 6.0	3(4.9)	5(8.2)	8 (13.1)
≥ 6.1	12 (19.7)	7 (11.5)	19 (31.1)
Mean ± SD $X^2 = 1.911$, df = 3, sig. Level = 0.05, cv = 7.815	5.3 years	4.8 years	5 years
Type of neurologic deficit			
Cerebral palsy	15 (24.6)	16 (26.2)	31 (50.8)
Seizures	15 (24.6)	9 (14.8)	24 (39.4)
ADHD	2 (3.3)	2 (3.3)	4 (6.6)
Microencephaly	2 (3.2)	0 (0.0)	2 (3.2)

$X^2 = 4.084$, df = 4, sig. level = 0.05, cv = 9.488

Table 3: Position of the affected children among other siblings of the family

Position of child in the family	Frequency	Percentages (%)
1 st	18	30.0
2 nd	09	15.0
3 rd	08	13.3
4 th	08	13.3
5 th and above	17	28.3
Total	60	100.0

Missing data- 1

Table 4: Domestic Burden of care on the parents

Care challenges	Mother (%)	Father (%)	Combined (%)
Taking child to hospital/ give drugs	78 (76.4)	04 (3.9)	20 (19.6)
Paying medical bills	2 (3.8)	38 (73.1)	11 (21.1)
Carrying other domestic chores	170 (88.1)	03 (1.5)	20 (10.4)
Monitoring/ playing/ training/carrying child	91 (70.0)	05 (3.8)	34 (26.2)

Socio demographic characteristics of affected children: As indicated in Table 2, of the 61 affected children, 34 (55.7%) were males. The ages of the children range from one to above six years, with a mean age of 5 years (with a mean age of 4.8 for females and 5.3 years for males). The common deficits seen were cerebral palsy, seizure disorders and attention-deficit hyperactivity disorder. Male children, in the study (24.6%) each suffer both cerebral palsy and seizure disorders.

As shown in Table 3, more (30.0%; n = 18) of the affected children are first children (first born) in their respective families; many others (28.3%) are 5th or more.

Challenges of domestic responsibilities and activities of daily living: The burden of caring for the child with neurological defects by both parents in terms of the needs of the child was also analyzed based on some of the child's demand. This was based on what the mothers and fathers singly handle and then both parties jointly perform. It appears that mothers are more involved in the caring task. This included domestics (feeding, bathing etc) (88.1%) and taking child to

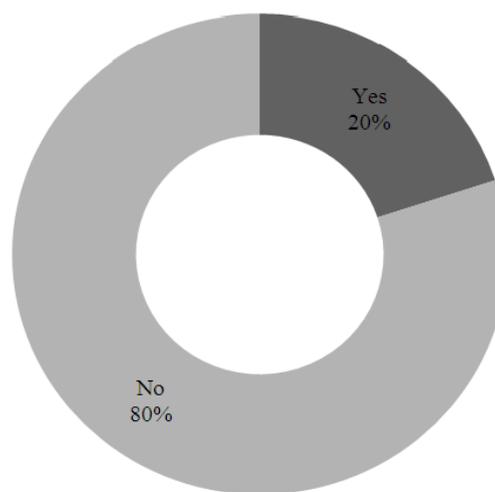


Fig. 1: Access to special school

hospital/giving of drugs (76.4%) among others. Fathers (38; 73.1%) were significantly responsible for the payment of the child's medical bills, as shown in Table 4.

Complementing these findings by narratives from parents, a father said:

"I don't stay at home I have to look for money, His mother takes care of him"

Most mothers ascertained caring task. Some said:

"I do everything he needs sometimes my other children help me."

Another said: "my neighbour helps me, He likes to stay with her",

while yet another said: "It's not easy, but God is helping us."

The mothers too attest to the fact that most fathers are more proactive in the payment of medical bills.

On the whether there is any institution within respondents' vicinity where children can be cared if the parents so desired, only 20% of the parents were aware of the availability of such special education opportunities (Fig. 1), but none of the children was reported to be in any of these schools.

DISCUSSION OF FINDINGS

Socio-demographic Characteristics of parents of affected children:

The socio-demographic characteristics of respondents, shows that 98.3% of the respondents are married, 85% Muslims and 71.7% make up of Hausa/Fulani tribe in this study. These findings can be attributed to the fact that the area of study (ABUTH, Shika-Zaria) is located in Northern Nigeria, a predominantly Muslim, Hausa-Fulani settlement with high regards for culture. Among the practice of the Muslim faithful is not allowing a woman to work outside the home. While the Hausa/Fulani culture appears to shift responsibilities and needs of a first child to the grand- parents. What the Hausa-Fulani's call "*kunyan dan fari*" i.e., (shy of the first child). This practice may necessitate failure of the child's mother to speak out even if she notices a problem associated with or in her child. A good number of them (n = 22; 36.7%) had tertiary education, implying an improvement in western education, although with a need for more awareness and enlightenment to boost parental knowledge of where and how to manage their children with neurologic deficits and early identification of other complications that may arise. The occupational profile as identified in this study has shown a need for more employment, as findings shows low socio-economic status hence a need for women empowerment with active supports by government and family counselling. Many (25%) of the mothers are housewives, 43.1% are self employed and only 27.5% are government employed. Most fathers in the study were either self or government employed with poor family income. Many 45% could not tell or don't know how much they make in a month. For those who could ascertain their income, it appeared low. Most mothers, (20%) earn less than N10, 000.00 per month and few (mothers 16.7%; fathers 8.3%) could make above N41, 000.00 per month. This represents a low income, coupled with the fact that polygamous is an acceptable practise in the study area.

Socio demographic characteristics of affected children:

Many (55.7%) of the affected children are males, with a mean age of 5.3 years. The males appears to suffer both (24.6%) cerebral palsy and seizure disorder than other form of neurological deficits in this study. 44.3% make up the females in this study, with a mean age of 4.8 years and most (26.2%) suffer from cerebral palsy. Irrespective of gender, the affected children are mostly the 1st child in the family.

These findings are in line with Ogunlesi *et al.* (2008) who found a 50.3% prevalence of cerebral palsy in paediatric neurology clinic in south-western Nigeria. This study also revealed males were more affected (55.7%) compared to females (44.3%). In this study, males are seen to suffer cerebral palsy and seizure

disorder equally (24.6%) while females suffer more of cerebral palsy (26.2%) and less seizure disorders (14.8%). These findings slightly tilt away from other study, with findings by Frank-Briggs and Alikor (2011) indicating male child more affected than females in south-south Nigeria. In this study, it was found that many (26.2%) of affected children were either the 1st or 2nd child in the family. Although no previous study was seen related to this, it might suggest poor child-bearing and rearing abilities. Such families might also lose hope or the dreams expected from a 1st child in the family and even subsequent ones. Some parents had more than a child affected, hence, increasing the challenges.

Domestic Burden of Care on activities of daily living:

Various caring tasks (activities of daily living) needed by the affected child were identified in this study to compare responsiveness by the parents, to assess who is more proactive in carrying them out. Findings were typical of an African culture. Most husbands are more pro-active in footing hospital bills. While mothers are found saddled with meeting the physical needs/activities of daily living (administration of drugs, assisting with toileting, feeding, lifting and carrying among others (Table 4). This finding is in line with Guyard *et al.* (2011) and Raina *et al.* (2005) that mothers and father do not experience this situation in the same way probably due to the role played by each one in the family. Mothers take day to day responsibility for the care of their children with handicaps (Marcento and Meyers, 1991). Ausserhofer *et al.* (2009) opined that parents are exposed to a variety of burden and find relief with their own family. Child health matters most for maternal employment. Hours spend in meeting Activities of Daily Living (ADL) of disabled children is unfavourable to maternal work. Certain limitations in children's activities are found to have significant effects on wives. However, husbands buffer the impact of disabilities on wives (Powers, 2001).

CONCLUSION

The burden of caring for children with neurological deficits cannot be overemphasised. Effective management during ante-natal, delivery, prompt resuscitation of asphyxiated babies and quick identification and management of jaundice are major preventive measures. In addition, physical challenges have been identified to affect parents and other members of the family. Burden of meeting the physical needs and virtually all activities of the daily living needs to be carried out by the parents or care givers. Mothers in particular shoulder a greater aspect in meeting the (physiologic) self care needs of the affected child. None availability of educational and rehabilitative facilities was an added burden.

RECOMMENDATIONS

Based on the above findings, all hands must be on deck in addressing the perceived causes and burden of care challenges facing parenting of neurological deficit children. The health team needs quick identification of high risk, continuous campaign on immunization, identification and provision of vaccines during outbreaks of diseases cannot be overemphasized. Parents need to be made aware of the availability of special schools and rehabilitating centre alongside formation of support group by Government and non-governmental organization is a desirable need.

ACKNOWLEDGMENT

The authors thank the Management of Ahmadu Bello University Teaching hospital, Zaria and the staff of the Paediatric Outpatient Department. We also thank the parents for their time and cooperation.

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