



**MANAGEMENT OF CHILDHOOD HYDROCEPHALUS IN OUR CENTRE: PARENTS' KNOWLEDGE, EXPERIENCES AND EXPECTATIONS**

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**ABSTRACT**

**BACKGROUND** Childhood hydrocephalus is a surgical condition and ventriculo-peritoneal shunting is the mainstay of treatment. The shunt is prone to malfunction and this complication is challenging to parents and health professionals. Adequate knowledge on the diagnosis and treatment of childhood hydrocephalus by the parents is essential for optimum care and follow up.

The aim of this study was to assess parents' knowledge, experiences and expectations of their child with hydrocephalus.

**METHODA** cross-sectional based interview study was carried on One-hundred and forty parents who are living with child that has hydrocephalus. The interviews were done in the Neurosurgery Outpatient Clinic of our hospital using question guide proforma and the responses were recorded for analysis.

**RESULTS** Parents demonstrated appreciable knowledge on the diagnosis of hydrocephalus, its treatment and likely complications that may arise in their child. Though they are not certain about optimum neurocognitive, physical and psychosocial development of the child in the future but experiences gather over time as they live with child have prepared them for challenges ahead.

**CONCLUSION** Lving with child with hydrocephalus is a life-long commitment for parents or other care givers. It is stressful but over time, parents have adapted with the challenges and stress. Also have blended these challenges and stress with their routine daily activities.

**KEYWORDS :** Childhood, Hydrocephalus, Parents', experiences

**INTRODUCTION**

Childhood hydrocephalus is a surgical disease. It can be defined as excessive accumulation of cerebrospinal fluid in the ventricular system within the brain. Most of the children with hydrocephalus are managed with ventriculo-peritoneal (VP) shunt, which divert the excessive cerebrospinal fluid to peritoneum, among other compartments.<sup>1</sup> With present-day standard of care, most patients with hydrocephalus will survive; however, some deaths still occur and complications from treatment among long-term survivors are frequent and often severe.<sup>2, 3</sup> The VP shunt failure rate is 40-50% within the first year of placement.<sup>4</sup> Avoidance of permanent neurological impairments and shunt's related death will require early identification and treatment of shunt malfunction.<sup>5</sup>

Adequate knowledge on the diagnosis and treatment of childhood hydrocephalus by the parents is required for optimum care and follow up. Prompt recognition of symptoms of shunt malfunctions by the parents in their child is the key to early presentation and treatment, though these symptoms may be unreliable and sometimes resemble common prevalent childhood illness.<sup>6</sup> Most parents are faced with dilemma of taking decision on the non-specific symptoms, whether to stay at home or see a health professional for treatment. Optimum assessment of children with possible shunt malfunction requires an informed parents and expert health professional.<sup>6, 7</sup> The decision taken by the parents on the choice of when to present and where to present, on the suspicion of shunt malfunction of their children is anchored on the amount of knowledge they have on hydrocephalus, treatment and its complications. Also the experiences they gather over the period of living with a child with hydrocephalus will also influence their decision.

This work is aimed to evaluate how much parents who have child with hydrocephalus know about childhood hydrocephalus; its treatment, complications and outcomes.

**METHODOLOGY**

A cross-sectional interview based survey was carried out. A semi-

structure interview using question guide (Table 1) on the parents of children with hydrocephalus. A total number of 140 parents were interviewed. Informed consent was obtained and the data were obtained between August 2016 and July 2017 in Regional Centre for Neurosurgery, Usmanu Danfodiyo University Teaching Hospital Sokoto. Nigeria.

**Table 1: Question guide**

<b>Knowledge on hydrocephalus</b>
Have you heard of the condition before your child was diagnosed with hydrocephalus?
What do you think can cause the hydrocephalus?
What do you know about the treatments for hydrocephalus?
How can you explain your child's hydrocephalus to family or friends?
<b>Making decisions about illness symptoms</b>
What sort of symptoms did your child have the last time he/she was sick?
Did you worry that the illness may be related to the shunt?
What particular symptoms are you looking for if it is shunt problem?
<b>Experiences of living with a child with hydrocephalus</b>
How did you feel at the time your child was diagnosed with hydrocephalus?
How do you feel hydrocephalus has affected, if at all, aspects of your child's life?
Do you think your child's hydrocephalus has affected the rest of the family and how?
What worries, if any, do you have about your child having a shunt?
Do you think with this shunt, your child will not have any problem related with hydrocephalus again?
In your day to day life, do you make any extra considerations because your child has a shunt?

**RESULTS**

One-hundred and forty parents participated in the interview. Majority of them were females (86%) while most of the participants were younger than 30 years of age (85%). Forty-four percent of the participants had no formal education and Ninety-five percent earned below \$5 per day (Table 2).

**Table 2: Parents Demographic Data**

Variables	Total (n) = 140 /Percent
<b>Sex</b>	
Female	120 (86%)
Male	20 (14%)
<b>Age (years)</b>	
Below 20	71 (51%)
21- 30	48 (34%)
31- 40	14 (10%)
41- 50	6 (4.3%)
Above 51	1 (0.7%)
<b>Academic qualification</b>	
Higher institution	12 (8.6%)
Secondary	18 (12.9%)
Primary	48 (34.2%)
None	62 (44.3%)
<b>Average income/day</b>	
Below \$5	95 (68%)
\$5- 10	35 (25%)
Above \$10	10(7 %)

n=total number of participants, \$=US Dollar,)

Table 3 showed the mean age of the children with hydrocephalus which was 5.5 ± 4.6. Majority of the children with hydrocephalus were males (55.6%).

**Table 3: Children with hydrocephalus statistics**

Groups	Age groups/ Frequency (%)	Age at 1st presentati on (Month) (Mean ± SD)	Admission delay(Day) (Mean ± SD)	Hospital stay (Days) (Mean ± SD)	Sex/ Frequency (%)
All Patients	<12	5.5 ± 4.7	13.0 ± 4.4	12.9 ± 4.4	M
	114(80.3)				F
	12 – 24 28(19.7)				63(44.4)
Congenit al	<12	3.0 ± 3.2	42.3 ± 42.8	14.3 ± 4.7	M
	66(93)				F
	12 – 24 5(7)				26(36.6)
Post- infective	<12	8.0 ± 4.6	75.6 ± 98.8	11.5± 3.7	M
	48(67.6)				F
	12 – 24 23(32.6)				37(52.1)

M= male, F=Female

**DISCUSSION**

Knowledge about hydrocephalus, its treatment and shunt's complication by the parent was in depth, though nearly all the parents have never heard about the condition before. The knowledge on management of hydrocephalus was acquired during the diagnosis, treatment, evolving complications of the treatment and follow up. This form of knowledge acquisition has been reported in other study.<sup>8</sup>

Diagnosis of long term illness has been linked with so many uncertainties that are related with diagnosis and what it means,

complications of the illness, treatment options and it effectiveness, and long term consequence of the condition.<sup>9</sup> These uncertainties were seen in all the parents interviewed and this was a major concern to them living with a child that has hydrocephalus. The uncertainty has been identified as a major psychological stressor for patient and their family with a long term illness.<sup>10</sup> Parents' accounts of living with a child with hydrocephalus showed that through experience, they acquired confidence in their ability to recognize and respond to shunt malfunction. We also found out that as parents acquired more knowledge about the management of their child they wanted greater involvement in care decisions when seeking advice from health professionals. Parents were willing to acquire skills and more knowledge to manage the long term health condition of their child, this was aimed to optimize child's development and health and minimize physical, social and psychological impact of the condition on the child.<sup>11</sup>

All the participants during their daily routine have developed constant awareness and vigilance required for early detection of symptoms that may suggest shunt malfunction and this is in consonance with findings that over a long period of time, majority of the parents living with a child that has chronic illness embedded their child's need in the routine of their daily life.<sup>12</sup>

**CONCLUSION**

Participants demonstrated an appreciable knowledge on the diagnosis, treatment and treatment's complications of hydrocephalus.

Living with child with hydrocephalus is a life-long commitment for parents or other care givers. It is stressful but over time parents have adapted with the condition and blended it with the routine daily activities. Parents were prepared to prevent and ensure early treatment for shunt malfunction.

Uncertainties were profound in the minds of the parents about the child neurocognitive and psychosocial development but reassurances from health professionals and interaction with other affected parents were their motivation.

**Author Contributions**

DrOgunleye Olabisi: Research design, data collection and analysis, paper development and financing; Dr Ismail Nasiru: Research design and paper development, Dr Lassini Ali: Research design and paper development; Professor Shehu Bello: Research design and paper development.

**Conflict of interest: Nil**

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