Community Perception about Children with Hydrocephalus in Lagos State, Nigeria

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Abstract
This study which was anchored in Health Belief Model and Functionalism investigated the perceived cause of hydrocephalus and the influence of socio-demographic characteristics on such perception. Data were collected through questionnaire survey, Focus group discussions (FDGs), In-depth Interviews (IDIs) and Key Informant Interviews (KIIs). Results indicate that perception about the cause of the condition included that it is a kind of punishment for sin (50%), spiritual attacks (27.3%), genetic (13.7%) and infection (9%). Community perception was higher especially with respondents age 42-47 (OR=1.32), female (OR=1.47), tertiary education (OR=0.69), punishment for sin (OR=0.61), spiritual attacks (OR=0.26) and infection (OR=0.48) than genetic factor. Community belief that hydrocephalus does not require medical attention negatively affected seeking medical help early. Other limiting factors were fear of surgical complications, inability of mothers to take responsibility; poor family social supports system and stigmatisation. There is need for stakeholders and agencies to enlighten community members on hydrocephalus and provide social support for children with the condition.

Keywords: Community perception, poor family supports, hydrocephalus, Lagos, Nigeria

Background
Hydrocephalus is an abnormal accumulation of fluid called cerebrospinal fluid (CSF); a condition in which excess water builds up within the brain region, causing enlargement of the brain (Warf, 2016). This cerebrospinal fluid in brain can serve as a shock absorber and it can help the spinal cord to stand straight; it functions as one of the means of delivering nutrients to the brain, and aid in removing waste within the brain (Warf, 2016).

Hydrocephalus can affect cognitive and physical abilities, which can impact quality of life. Children may experience learning disabilities, physical disabilities, breathing and thinking problems. It is however clear that caring for
children who are living with hydrocephalus throughout sub-Saharan Africa is hindered by economic constraints, access to proper care and the required expertise to administer shunt on children with hydrocephalus (World Health Organisation, 2007). Shunt is a common surgery that is placed in the brain. It helps remove excess fluid and redirects it to another channel in the body (Hopkins, 2014). In the United States, the average patient has two to three operations for shunt failure during childhood, but in rural Africa, accessing emergency neurosurgical care is not (Warf, 2011).

Hydrocephalus is one of the least common birth defects, reported in 1 out of every 500 births each year (Bankole, 2015). In part of Asia and African countries, a large number of children die of this preventable and treatable condition (World Health Organisation, 2007). In Western societies, however, the incidence of hydrocephalus has reduced through the usage of both ‘primary prevention’ – with the use folic acid and dietary supplements in the first trimester of pregnancy. Secondary prevention like surgery, physiotherapy, massaging tools’ are largely associated with the majority of African countries.

In Nigeria, hydrocephalus often puts strain and stress on families regardless of their different socio economic status. The pressures exerted on caregivers may result in dumping of the children. Some have turned the children into instruments of begging, supposedly to raise fund for their health care. However, the effect of hydrocephalus can be prevented by early detection and surgical attachment of a shunt (Shokunbi, 2014).

The fact that hydrocephalus was not a lifestyle condition but a medical condition, some of this children in Ikeja and Ikorodu Lagos would have frequent episode of shunt treatment (Bankole, and Kanu, 2016). Despite considerable medical condition. This birth condition however can affect families regardless their socio-economic status (Fajemilo, 2016). Lagos state support group foundation encourages caregivers and improves the life of children living with hydrocephalus (Bankole, 2015).

Children living with hydrocephalus often undergo traumatic experiences such as multiple surgeries, frequent hospitalisation, stigmatization, lengthy rehabilitation and medical tests. A significant number of caregivers are not aware of the problem and treatments associated with hydrocephalus. Often time, such children are hidden, and perceived as evil. Many factors, such as cost of treatment; long distance and lack of health care facilities inhibit caregiver’s access to medical treatment which may further compound the conditions of affected children (Shannon, Simon, Reed, Franklin, Kirby, Kilgore, and Wellons 2011). The economic impact of ventriculoperitoneal shunt failure. J Neurosurg Pediatr. 2011 Dec; 8(6): 593–599. doi: 10.3171/2011.9.PEDS11192.

Therefore, babies born with Hydrocephalus in Western countries are likely to have surgery within 24 hours to repel infection from reaching the brain. In Nigeria, the detection rate is very low due to insufficient ultrasound facilities. Study reveals that, delay in detection of this condition may lead to other health
Community perception about children with hydrocephalus

Complications such as ocular disorder that may result in blindness in affected children (Maduka and Ezepre, 2010).

The challenge related to long distance to the few available healthcare facilities and infrequent hospital visits among pregnant women can result in infections among children including hydrocephalus (Adewusi and Nwokocha, 2018; Nwokocha and Obioma, 2016). Furthermore, Children with hydrocephalus are often socially isolated in the society, and this may limit caregivers’ access to health care. Therefore, caregivers tend to face difficulties in getting financial and social support for these children.

Theoretical/Conceptual Framework

The functionalist theory and Health Belief Model were employed as theoretical framework for the study. These perspectives explain therapeutic choices and care for children living with hydrocephalic condition among caregivers in Lagos State, Nigeria. Functionalism emphasizes interdependence of parts of a system for the stability of the entire super structure or the whole-system (Ritzer, 2008). In the present analogy, societies that perceive the essence of the contributions that individuals could make in the sustainability of the community are mostly support those that require some assistance to function optimally. Children with hydrocephalus perceived in that light would likely be supported as a member of such society with the effect that the burden of affected children and their Significant Others are ameliorated both in the short term and long run.

Therefore, efforts of the caregivers at socializing children living with hydrocephalus, providing unconditional love, inculcating in them self-esteem, imparting skills, psychological support and emotional security among others are critical for institutionalizing inclusiveness necessary to achieve cooperation and interdependence.

The Health Belief Model (HBM) seeks understand why some community dwellers do not take precautionary measures to prevent illness, as and when necessary (Rosenstock, 1974; Janz & Becker, 1984). The model is commonly employed in health behavioural research to offer useful guidance towards prevention of health conditions that find expression in perceptions that determine an actor’s attitude that drive health seeking behaviour (Rosenstock, 1974). The model explains preventive health related behaviour and the associated risks by focusing on how an actor views the condition in terms of their vulnerability, severity when the disease occurs, benefits, barriers, self-efficacy and cues to action.

The two basic premises of the model are that caregivers’ attitude and knowledge differ in how they perceive the personal benefits and risks of seeking healthcare for their children living with hydrocephalus. Tinuola (2006) argues that the health belief model should be a useful guide for families on preventive measures against disease conditions that require seeking healthcare.
from available facilities. Indeed, knowledge and perception of vulnerability to hydrocephalus will determine the actions that pregnant women would likely take for its prevention in their foetus. In addition, for families whose children were already living with hydrocephalus, their perception of severity of the condition and the benefits of a particular action will largely determine the health seeking behaviour to be adopted.

Methods
The fieldwork for the study began with investigation meant to find out different community perception about hydrocephalus in Lagos, Nigeria that make up considerate meaning of what hydrocephalus is all about. The study adopted a cross-sectional descriptive research design. Data collection was done through qualitative and quantitative methods. The study was conducted in selected locations in Lagos State. The choice of the state was purposive being the only state in Nigeria where a support group for children living with hydrocephalus condition exists.

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Community perception about children with hydrocephalus

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The primary data were collected using semi-structured questionnaire, key informant interview guide, IDI Guide, focus group discussion guide and case records for children living with hydrocephalus. A semi-structured questionnaire was administered on 422 respondents. Ikorodu and Ikeja Local Government Areas (LGAs) were purposively selected due to the existence of support groups for CWH. The LGAs were clustered into 32 communities, while six communities were randomly selected. Cochran’s (1977) sample size determination formula was used to systematically administer questionnaire on respondents in Oregun, Opebi, Ogba, Araro, Ejina and Ojubode.

Quantitative data were elicited on socio-demographic characteristics and community perception about Children with Hydrocephalus (CwH). Twelve Key Informant Interviews were conducted among health care practitioners; sixteen In-depth Interviews were conducted among caregivers of CwH; and four Focus Group Discussions were conducted among heads of support groups. Qualitative information was elicited on the gender dimensions in patterns of treatment, factors influencing caregivers’ therapeutic choices, consequences of hydrocephalus on affected children and families, and factors affecting coping strategies for CWH. Quantitative data were analysed using descriptive and logistic regression at $p \leq 0.05$, while qualitative data were content-analysed.

Ethical principles were followed throughout fieldwork. Anonymity of respondents were ensured to the extent that none of the responses could be traced to any of the research subjects. We also ensured that participation was based on voluntary and informed consent and that the participants reserved the right to withdraw from the study at any time they felt uncomfortable. Also, the instruments and their administration emphasized no-harm to research subjects. In addition, ethical approval was granted by the University of Ibadan Ethical Review Board number.

Results and Discussion
This chapter presents results analysis of the data gathered during the field work with a view to investigating community perception on hydrocephalus in Lagos State, Nigeria. The data are presented in frequency distribution tables, charts and multivariate regression analysis. Appropriate, quantitative and qualitative results were jointly discussed. The findings are presented based on the
objectives of the study. Necessary interpretations are being drawn from some of the findings in the light of the theoretical framework for the study.

The observed similarities and differences between the present study and the existing literature are determined using appropriate sociological explanation. The analysis is based on these five objectives of the study: people’s perception about children with hydrocephalus condition; gender dimensions in patterns of treatment for hydrocephalic condition; factors influencing caregivers’ therapeutic choices and care for children with hydrocephalic condition; consequences of hydrocephalic condition on affected children and their families; and mechanisms towards coping with hydrocephalic children. The demographic summaries are presented according to locations and characteristics.

4.1 Socio-demographic characteristics of the respondents
The result indicated that the highest percentage (24.2%) of the respondents were between the ages of 30 and 48, followed by some (17.5%) who were between the ages of 42 and 47, few (15.4%) were less than 30 years old. The sex distribution of the respondents showed that the percentage of females (64.2%) were more that of the male respondents (35.8%). The frequency distribution of the respondents according to their marital status showed that single parents had the highest percentage (57.8%), followed by widows/widowers (19.2%), then the married and those who had been separated had 10.5% and 7.8% respectively while very few were divorced (4.7%). The frequency distribution according to the respondents’ educational qualifications indicated that the respondents with Secondary education had the highest percentage (44.1%), followed by respondents with primary education (39.0%).

Table 1: Percentage distribution of respondents according to socio-demographic characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Categories</th>
<th>Frequency (n=422)</th>
<th>Per cent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 30</td>
<td>65</td>
<td>15.4</td>
<td></td>
</tr>
<tr>
<td>years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-35 years</td>
<td>102</td>
<td>24.2</td>
<td></td>
</tr>
<tr>
<td>36-41 years</td>
<td>91</td>
<td>21.6</td>
<td></td>
</tr>
<tr>
<td>42-47 years</td>
<td>74</td>
<td>17.5</td>
<td></td>
</tr>
<tr>
<td>48+</td>
<td>90</td>
<td>21.3</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>422</td>
<td>100</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single parent</td>
<td>81</td>
<td>19.2</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>244</td>
<td>57.8</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>33</td>
<td>7.8</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>44</td>
<td>10.5</td>
<td></td>
</tr>
<tr>
<td>Widowed/widower</td>
<td>20</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>422</td>
<td></td>
</tr>
</tbody>
</table>
Respondents with Post-secondary education had 10.0%, while respondents who had no formal education (6.9%). The frequency distribution of respondents according to their occupations revealed that while many of the respondents (40.5%) were artisan workers, some of the respondents (17.5%) were civil servants. Also, few of the respondents were farmers (4.1%) and traders (37.9). Larger proportion 271(64.2%) of the respondents were female
while the proportion of male were 151(35.8%) This depicts that female are more aware of hydrocephalus than their male counterparts because female are mothers and mother to be and child caregivers in the family. This indicated that female has more social responsibility in the caring and child socialization in the society. It also depicts that female have social bond with children than male. Information on the ethnic group of respondents revealed Yoruba to have larger proportion compare to other ethnic group, and this is expected, as a result of the location where the research was carried out. Southwest of Nigeria is dominated by the Yoruba followed the Igbo and the minority Hausa. Other ethnic groups represented in the study include Edo, Fulani and Itsekiri.

Information about Perception on hydrocephalus
Figure 4.2 shows percentage distribution of respondents implies that (13.7%) of the respondents noted that hydrocephalus condition could be inherited, 27.3% of the respondents claimed that it was caused by spiritual attack and punishment for sin, 50.0% of the sample stated that hydrocephalus could occur through Infection while 8.1%. However, Warf (2016: 5) disagreed to the view that hydrocephalus is a spiritual attack and punishment of sin. Fajemilo (2014) argued that latest presentation of hydrocephalus is not strange when such condition is usually attributed to being possessed by evil spirit and witchcraft. In relation to this assertion, relatives and caregivers often seek solution from elsewhere such as spiritual homes, native doctors and traditional healers before going to the hospital (Bankole, 2015).
Table 4:3 Displays data on respondents perceived causes of hydrocephalus. Majority claims that hydrocephalus can be caused by complication during birth. This contrasts people’s opinion on hereditary perceived causes. Explaining the factors that gave rise to hydrocephalus, according to scholars, they argued that hydrocephalus can occur due to what pregnant woman consume or inhale. This process begins from the foetus. During the developmental period the embryo is most susceptible because it is the time when the major body parts (arms, legs, hands, feet, livers, genitalia, heart, eyes and brain) begin to develop (Muo & Jiang, 2015).

![Figure 1: Percentage distribution of respondents by information about Perception on hydrocephalus](image-url)
As shown in figure 4.2, Hydrocephalus is perceived to be caused by several factors. Hydrocephalus can occur in children based on the following; alcoholism, lack of social support, accident, self-medication, hereditary, complication during birth, drug abuse, smoking and so on. Virtually everything a woman consume or inhale while pregnant will be passed through to the brain (Bankole, 2015).

**Alcoholism**  
Another infection that can affect the baby during pregnancy is alcohol intake. Alcohol intake by pregnant women increases the risks of giving birth to a hydrocephalus child. This is also responsible for defects and below average intelligence. In human being, alcohol intake can be associated with structural and functional injury to the brain, as well as cognitive damage with deficit in the functioning of the brain (Harper, 2007). However, a child with hydrocephalus defects could develop attitudinal change in behaviour, heart defect, malformed limbs, a curve spine, a small or big head, unusual facial characteristics, small body size, and low birth weight. Hydrocephalus can also
lead to mental retardation in a new born baby. Taking alcohol during pregnancy is one of the leading causes of hydrocephalus. Research revealed that there is no known safe amount of alcohol consumption that is healthy for a pregnant woman (Claire, 2015). Alcohol consumption and some certain drugs, if used during pregnancy, significantly make the brain susceptible to problems (Steven, Shelov and Roger, 2015).

A health worker who is also a caregiver stated below that alcohol can be one of the causes of hydrocephalus:

Virtually everything you consume or inhale while pregnant affects the unborn baby. The process begins as soon as a woman conceives. In fact the embryo is most vulnerable during the first two months, when the major body parts like the legs, arms, hand feet, liver heart, genitalia, eyes, and brain are just starting to form. Chemical substances such as those in cigarettes, alcohol, illegal drugs and certain medications can interfere with the developmental process and some can even cause congenital abnormalities that will result to hydrocephalus. It is more common in Yoruba land to use alcohol in place of drugs. They belief that alcohol works faster than drugs during child birth. [KII Female /48 years Ikorodu General Hospital Ejina]

It can be deduced from the above that in some parts of Yoruba land, it is generally believed that intake of alcohol will make the baby look healthy and clean the infant body immediately after birth. Among the Ilaje people in Lagos mainland, a variety of herbs are taken together with alcohol, which is popularly called ‘shepe’ or ‘Ogogoro’ known as local gin. Also, among the caregivers in Ejina Ikorodu Local Government area, pregnant women are asked by traditional birth attendants to take at least a bottle cover of local gin (5ml) after meal in the morning to keep the baby healthy. Most of these traditional birth attendants believe that alcohol works faster than any other drugs. Steven, Shelov and Roger (2015) refuted this assertion by stressing that some medications taken during pregnancy can cause harm to the fetus. Thus, head injuries are the primary cause of hydrocephalus because most head injuries are caused by accidents, intake of alcohol, congenital malformation, and infection. However, literature affirm that alcohol is identified as a substance used to ease child-birth pains (Shokunbi, 2014).

The above result is corroborated with participants’ views from the qualitative aspect of the study. Hence, a 37- year’s old female respondent noted:

I and my husband have an agreement to seek solution to our child’s ailment through a friend who advises us to meet with a traditional herb seller called ‘Elewe omo’. This herb seller gave
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us ginger, Shea nut oil, cloves, aloe Vera, cats claw, moriga and so on I noticed that out of what the herb seller gave us, the traditional moriga medicine work more effective anytime my child drinks the blended liquid. Moriga helps to boost my child’s energy. IDI Female Caregiver 6 /37 years Ikorodu Ejina

In discussing the perception of community members on hydrocephalus, in corroboration of Oyewole and Adeloye (2005), parents express that there are difficulties associated with hydrocephalus. Further to this, as discovered by Banninka and Hove (2012), perceived hydrocephalus as stressor for parents who have children affected by hydrocephalus.

Steven and Roger (2015: 536-537g) on the other hand stated that hydrocephalus is caused by congenital abnormalities during the foetus’ development before birth. Certain medications can affect the developmental process which can cause congenital abnormalities. Smoking for instance, among elders can distort their thinking ability; In addition, pregnant women are not exempted because it can decrease baby’s weight (Warf, 2016). To corroborate this finding, Wright (2011) perceived hydrocephalus as stressor for parents who have children affected by it.

Bankole (2015) argues that hydrocephalus is a lifelong condition that has no cure, but it can only be managed with a shunting device. The above finding indicates that not all community members really have the knowledge or have the exact understanding of hydrocephalus. However, literature revealed that ‘hydrocephalus can occur in children and adults. Bankole, (2015) added that adults can develop hydrocephalus due to failure of cerebrospinal fluid or a blockage in the brain.

More than 90% of the children’s parents in the study conducted by Bannink and Hove (2012) actually showed no evidence of any knowledge of the preventive measures for the CNS birth defects. Therefore, referral for appropriate treatment appeared to be a big challenge for most parents, as knowledge is limited and health workers may equally be ignorant. This on the other hand contradicts the perception of the community members. Some of the community members believe that hydrocephalus is an inherited disease from the parents of the child or family.

**Multivariate Analysis**
Table 2 reveals results of the multilevel analyses involving logistic regression. The multivariate technique helps in the simultaneous assessment of association between perception and information about hydrocephalus and other selected set of factors. It also assists to examine the association between information about hydrocephalus and each specific independent variable in the model net effect of other variables. The strength of association between the independent variables and perception is measured using the odds ratio. Odds ratio significantly greater than one indicate that respondents with the attribute(s) are likely to have hydrocephalus knowledge or information about hydrocephalus.
than their reference category, while a relatively odds ratio significantly less than one indicates that respondents with the attributes are not likely to have hydrocephalus knowledge than their reference category.

The results in table 4.2 indicate that the odds of information about hydrocephalus among caregivers vary significantly by age, education, gender and perceived causes of hydrocephalus.

Caregivers who are within age range less than 30 years are 67.8% less likely to perceive hydrocephalus positively, while those who are between 36 to 41 years are 1.3 times more likely to perceive hydrocephalus positively than others within age range of 30 to 35 years while caregivers within the range of 42 to 47 years are 1.225 likely had information about hydrocephalus than caregivers within the age range of 30 to 35 years and also caregivers within the range of 48 years are 0.748 are likely to source for information about hydrocephalus compare to caregivers within the age range of 30 to 35 years. In other words, this result reflects the fact that the higher the age of the respondents the higher or the more likely the caregivers perceive hydrocephalus in children positively due to caregivers’ experience. Furthermore, this means that age is significantly associated with community perception about hydrocephalus in children.

Caregivers who attained no formal education are 0.266 times less likely to perceive hydrocephalus positively than their other counterparts who attained secondary education, also caregivers who attained primary education are 0.472 times less likely to perceive hydrocephalus positively than their other counterparts who attained secondary education and caregivers who attained post-secondary education are 0.693 times less likely to perceive hydrocephalus positively than their other counterparts who attained secondary education. This indicates that the higher the level of education the higher the level of sources of information gotten about children living with hydrocephalus.
Table 2: Logistic Regression showing Association between perception and information about Hydrocephalus among caregivers

<table>
<thead>
<tr>
<th>Socio demographic Characteristics</th>
<th>Odds ratio (OR)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 30 years (RC)</td>
<td>0.678*</td>
</tr>
<tr>
<td>30 - 35 years</td>
<td>1</td>
</tr>
<tr>
<td>36 - 41 years</td>
<td>1.324**</td>
</tr>
<tr>
<td>42 - 47 years</td>
<td>1.225**</td>
</tr>
<tr>
<td>48 years and above</td>
<td>0.748*</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>0.266*</td>
</tr>
<tr>
<td>Primary</td>
<td>0.472**</td>
</tr>
<tr>
<td>Secondary (RC)</td>
<td>1</td>
</tr>
<tr>
<td>Post Secondary</td>
<td>0.693**</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male (RC)</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>1.469**</td>
</tr>
<tr>
<td><strong>Perceived causes</strong></td>
<td></td>
</tr>
<tr>
<td>Inherited (RC)</td>
<td>1</td>
</tr>
<tr>
<td>Punishment of sin</td>
<td>0.614**</td>
</tr>
<tr>
<td>Spiritual attack</td>
<td>0.258*</td>
</tr>
<tr>
<td>Infection</td>
<td>0.480*</td>
</tr>
<tr>
<td>Model chi- square</td>
<td>126.46</td>
</tr>
<tr>
<td>Nagelkerke R square</td>
<td>0.660</td>
</tr>
<tr>
<td>-2Loglikelihood</td>
<td>178.437</td>
</tr>
</tbody>
</table>

Significant at p<0.05*, p<0.01**, p<0.001***, RC - reference category

Caregivers who are female are 1.469 times less likely to perceive hydrocephalus positively than their other counterparts who are male. This reflects that in Nigeria culture though men sometimes reactions in both negative and positive way, there are families with supportive fathers. Also, the values placed on these children before birth are likely to change because of the condition of the infant. However, mothers were sometimes, placed in difficult situations due to the abandonment of the child (Shokunbi, 2014). In various cases the mother was blamed for giving birth to a child with disability and was abandoned by her husband and/or mistreated by her in-laws (Bannin and Hove, 2012). These characteristics will on the other hand aid the female to seek for more information on how to care for children living with hydrocephalus.
Perception about Hydrocephalus

Caregivers who perceived hydrocephalus as punishment for sin were 0.614 less likely to perceive hydrocephalus positively than their other caregivers who perceived hydrocephalus as inherited, while those who perceived it as spiritual attack are 0.258 less likely to perceive hydrocephalus positively than their other counterparts. Although, peoples religious belief were attached to hydrocephalus, stating that is a spiritual problem. This indicates that, irrespective of caregivers religious background, some caregivers due to experience attach hydrocephalus to be a spiritual problem.

Hydrocephalus affects one out of every 500 to 1000 children born in Africa. It has caused a wide variety of medical problems, and the circumstances surrounding each child’s condition were unique. A number of experienced medical professionals and caregivers of children with hydrocephalus perception can help in understanding the treatment pattern and coping strategies. Hydrocephalus is an abnormal accumulation of fluid- called cerebrospinal fluid or CSF within cavities called ventricles inside the brain (Bankole, 2015). Hydrocephalus is commonly treated by a surgical procedure, performed by a neurosurgeon, in which a tube called shunt is placed into the child’s brain or body. Most often, hydrocephalus is caused by neonatal infection in East Africa (Oyewole, 2005).

Hydrocephalus is relatively common in Nigeria today. The condition also could be termed hydrodynamic disorder of CSF. Acute hydrocephalus can occur over days, sub-acute hydrocephalus occurs over weeks, and chronic hydrocephalus occurs over months or years. Hydrocephalus was reported to be a lifelong condition with long-term medical condition which could lead to complications. There is need for parents to be alert. The changes that signal a possible complication require understanding because a complication left undiagnosed and untreated can cause severe brain damage, or threaten the life of a child living with hydrocephalus.

This section deals with the subjective opinion of the caregivers and professionals. The brain and the spinal cord are reported to be working together from the central nervous system. These vital structures are surrounded and protected by the bones of the skull and vertebral column. In infants, the skull which is actually composed of unconnected bones is an area where the bones meet and grow. In one of the interview sessions, a caregiver commented thus:

Wel… l, it was a real crisis for me to have a child living with hydrocephalus. It was a grieving process. I understood that it was a time of trial but I just developed a strong heart to move on in caring for my baby. Caring for my child was difficult, even after shunt the first shunt treatment it was looking as if, we have not done anything. Many people from my community kept asking when is my ‘Boy’ going to walk. Sometimes they asked question
like, is he paralyzed? I hear different stories day by day of where and how to get treatment, some will subjectively say that is ‘Ise-esunii’ (It is subject to the work of the Devil). [Caregiver 1/ Lagos/ Ikeja zone]

It can be deduced that the community already had an understanding and explanation regarding what hydrocephalus is all about. Nevertheless, some of the community members cannot easily identify hydrocephalus. Most of the community members described hydrocephalus to be ‘Oka-Ori’. The consultant neurosurgeon said once the cerebrospinal fluid is not flowing and the brain retains its fluid, it would lead to a massive head size (Bankole, 2015). It appears that the community’s conception about hydrocephalus is appropriate because it is similar to the explanation given by some of the therapists and bone setters. It is therefore reasonable to say that the perception of hydrocephalus goes beyond just the physical appearance with head structure and symbols.

In similar manner respondents from support group during the (FDG) session at Ojubode Ikorodu explained that:

Hydrocephalus is a chronic medical condition, meaning it is a lifelong condition that has no cure. In most cases, hydrocephalus children are identified with the shunt mark on their head. Thus, There are early signs of hydrocephalus in infants living with hydrocephalus include: Bulging fontanel, or soft spot on the surface of the skull, a rapid increase in head circumference, eyes that are fixed downward, seizures, extreme fussiness, vomiting, excessive sleepiness, poor feeding, low muscle tone and strength. [Caregiver 5/ Ojubode/ Ikorodu]

Indeed, it was reported that in the developed countries, the incidence of hydrocephalus ranges from 3 to 5 cases per thousand live births. But little is known about the discourse regarding the frequency of hydrocephalus in African (Fajemilo, 2014). It was found that hydrocephalus, a serious problem in sub-Saharan Africa, is still unknown to the majority of Africans (Steven and Roger, 2015). The estimated incidence of hydrocephalus is one out of every 1,000 births (Shokunbi, 2015). Hydrocephalus is the most common neurosurgical problem encountered in the pediatric population in Lagos (Bankole, 2015). Hydrocephalus is the excessive accumulation of cerebrospinal fluid (CSF) within the cranial vault due to excessive production or inadequate absorption (Warf, 2016). Oyewole (2005) confirmed that hydrocephalus can be present if there is excessive intake of iron supplement in human body.
Conclusion
This study has revealed that community perception and understanding of hydrocephalus are largely incorrect. Hydrocephalus is neither infectious nor contagious contrary to the notion held by a number of respondents. Thus, the challenge is not only caregivers’ lack of access to healthcare facilities to manage hydrocephalus among children but also lack of awareness, which undermines appropriate health seeking behaviour as and when necessary. There is need to therefore increase the people’s level of awareness about the condition as the surest way of ensuring that children with hydrocephalus are given the proper medical and psychological attention necessary to overcome the condition.

References

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