



COUPLE'S ROLES AND DECISION-MAKING IN THE MANAGEMENT OF CHILDREN WITH SPINA BIFIDA IN IBADAN METROPOLIS

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Abstract

Spina bifida is characterised by the abnormal accumulation of cerebrospinal fluid within the spine, however, it presents multifaceted challenges to the families, physical, cognitive, and social development of the affected children. Despite a growing body of research highlighting the potential of children with disabilities, including those with spina bifida, there exists a gap in understanding the specific social implications of decision-making among couples for this demographic, particularly within the Nigerian context. This study aims to bridge this gap by providing a comprehensive examination of the social dynamics associated with decision-making among couples with children living with Spina bifida. Specifically, the study investigates how decision-making influences the social development and social order among families of children with spina bifida in Nigeria. A qualitative research design was employed. Data were collected through in-depth interviews (IDIs) with 35 couples with children diagnosed with spina bifida in Ibadan metropolis. Findings revealed poor differences in decision-making among couples, the belief that the spina bifida condition does not require medical attention hence, affected couples seeking medical help are in a dilemma. The age of the respondents was 32.9 ± 9.13 years. Seventy percent of the respondents were females, 26.9% had no formal education and 57.8% were married. Respondents perceived spina bifida as punishment for sin (40.0%), spiritual attack (20.3%), genetic (29.7) and infection (10.0%). Loss of memory and blindness were identified as consequences of spina bifida on the affected children while emotional separation and social separation from family members were identified as consequences on families. Family denial and unfriendly relationship from neighbours were experienced by couples. The study concludes that there is a need for stakeholders' agencies to enlighten community dwellers and couples on spina bifida as a common condition and provision for social support to maintain social order for families and children living with spina bifida in Nigeria.

Keywords: Couples, decision making, poor family social support system, children, spina bifida, Ibadan metropolis

Introduction

The collapse state of health condition in Nigeria today reveals a condition that cannot give assurance of a reforming process of human feelings. Nevertheless, Nigeria is signatory to millennium development goals (MDGs) declaration but till date she has not made any significant milestone in actualizing the human development goals in which Goal 5 stated out to improve maternal health. Women have become element of the so called house wife material (Lagos State Ministry of Health, 2015). The stressor, lack of social inclusion and awareness on women caring for children with spinal bifidals has become problematic for nursing mothers and career women in academics (Alatise, 2006). As a result, medical, emotional and coping mechanisms remain unabated. Although the global occurrence of spina bifida are most visible in sub- Sahara Africa compare to Asia and western societies.

Research has revealed that more children have died of this preventable condition in this region of the continent due to lack of knowledge (Bakare, 2021). Studies however indicates that most spouses in sub- Sahara Africa, including Nigerians now attach cultural beliefs to the condition other than having knowledge on the coping mechanism (Bankole, 2018). In some communities in Ibadan Nigeria, knowledge about spina bifida is still unsatisfactory and disappointing low, and as such many pregnant women still engage in behaviours that promote risk of giving birth to children with spina bifida such as taking up fight with partners and neighbours, absents from antenatal care, not taking folic acid regularly, taking traditional herbs without measurements and not taking precaution on nutritional diets, among others.

However, Spinal bifida is relatively common birth defect among infant in which an area of the spinal column does not form properly, leaving a section of the spinal cord and spinal nerves exposed through an opening in the back. (Warf, 2017). 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, 2017). If an injury or illness then alters the circulation of this cerebrospinal fluid, the spine becomes enlarged.

Gender segregation in role taken has crashed numerous family. Men play minority role in caring for childcare, and this has contributed to neglect of men seeing women as household instrument. This alone has affected the cognitive reasoning and social life pattern (Bakare, 2021). Men's perceptions affects women's attitude and up keeping of their child living with spina bifida. Children living with spina bifida condition often undergo traumatic experiences such as multiple surgeries, frequent hospitalization, stigmatization, lengthy rehabilitation and medical tests. A significant number of women are not aware of the problem and treatments associated with spina bifida. For the most part, such children are hidden, and perceived as evil (Fajemilo, 2020).

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 their condition. Therefore, babies born with spina bifida are likely to have surgery within 24 hours to repel infection from reaching the spine, while, in Nigeria; the detection rate and educational knowledge of women are

very low due to insufficient ultrasound facilities at primary health care center (Bakare, 2020). . Study reveals that, delay in detection of this condition may lead to other health complications such as paralysis that may result to blindness in affected children (Shokunbi, 2014).

Literature Review and concepts

Children living with spina bifida, often undergo traumatic experiences such as multiple surgeries, frequent hospitalization, stigmatization, lengthy rehabilitation and medical tests. A significant number of married couples are not aware of the problem and treatments associated with spinal bifida (Fajemilo, 2020). 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. Therefore, babies born with spina bifida in Western countries are likely to have surgery within 24 hours to repel infection from reaching the brain and spine. 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 complications such as ocular disorder that may result to blindness in affected children (Bankole, 2018). Globally, children, especially among European, American, part of Asia and African countries, die of this preventable and treatable condition (World Health Organisations, 2007; National Institutes of Health, 2017). In Western society, with the incidence of live births spina bifida 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' associated to majority of African countries. Spina bifida is one of the most common birth defects, each year one out of every 500 births results in spina bifida (National spina bifida foundation 2018).

Couples face long distance challenges coupled with few available health care facilities and infrequent hospital visits can result in infection among children. Furthermore, Children with spina bifida condition are often socially isolated in the society, and this may limit caregivers' access to health care. Therefore, some women tend to face difficulties in getting financial and social support for these children. Hence, medical cost for spina bifida is over 3Million Naira (\$6,000) per shunt in Nigeria (Modupe, 2014), to corroborate with this assertion, the National cost of surgery and lifelong burden of this birth defect has affected families enormously (Shokunbi, 2014). This in turn may be a major barrier to accessing health services by caregivers. Sometimes it is influenced by taboos, religious beliefs, stigmatization and pervasive negative attitude from the society, all of which influence the health seeking behaviours of the caregivers, thereby leading to concealment of the children's health condition and leading to societal isolation. The consequences of all these sometimes may result in blindness, cognitive problem and physical disabilities, which can affect the child's quality of life.

The approaches used in investigating spina bifida condition in Nigeria, are most time systematically clinical. The social dimensions on how gender differences affected the care for children living with spina bifida is practically neglected. However, most studies on spina bifida in

Nigeria have focused on medical and surgical treatment with little emphasis on the social dimension and gender coping mechanisms. The focus of this study is to find out the spousal defies and coping mechanisms on children with spina bifida condition in Lagos State, Nigeria. This will be carried out using these specific objectives; i.) Examine community perception about children with spina bifida; ii.) Examine the gender dimensions in patterns of treatment for spina bifida in the study area and Investigate coping strategies adopted by couples.

Theoretical Framework

The Health Belief Model (HBM) is a social psychological model that attempts to explain and predict health behavior (Tinuola,. Obisesan, Adeyemo, and Fakokunde,2006) The model was developed by three scholars within which the social psychological environment, they are; Godfrey Hochbaum, Stephen Kegels and Irwin Rosenstock (1974) .The predictive ability of the model is based on focusing on the attitudes and beliefs of the individua, (Jgede,2002). The HBM is base on the understanding that individuals will tend to take a health related actions or decisions (i.e intake of folic acid) if the person feels convinced thier child neative health condition(spina bifida) can be prevented; has a positive expectations that by taking a recomended action (drugs prescribed by medical doctors) will make the child more healthy. (Rosenstock, Strecher and Becker, 1988). A pregnant woman will feel comfortable using the folic acid with confedence

Key Variables in HBM as applicable to this study

Perceived Susceptibility: Explains the extent to which the couples feels vulnerable to certain disease conditions that are associated with hard drug intake. When a woman is pregnant at the early stage, the woman feels, there is a tendency to begin to relate to early stage sickness due to her pregnant condition

Perceived Severity: The instance the individual begins to connect a particular aerly morning sickness due to her pregnant condition , the severity becomes the contention. There is a tendency for younger-old educated couples to seek for professional advice of drugs and food to consume which will be related to doctor’s advice. Certain habits and activities may begin to stop or reduce at this point for many uneducated couples. There is an attempt to want to manage health better than before by the educated couples.

Perceived Benefits: The instance of a pregnant woman begins to make lifestyle and health related decisions and changes, it is in view of maintaining optimal health. On the other hand, if the couples decide to cooperate to take the child with spina bifida for checkup in this case, Most educated couples are aware of the physical, social, financial and mental limitations that accustom to having a child with spina bifida, it is an area of ‘negative stage’ which married couples are highly likely to want to avoid.

Perceived Barriers: The course of having a child with spina bifida . At this stage the couples will have to reschedule some certain activities or roles and relationships; these mark the onset of barriers. Due to the child's condition, work and income diminishes, some low income couples make be lacking financial aid to only stipends they receive as salary/welfare their jobs or support from relatives, and they are limited in a lot of ways. Social mobility at that point may take a downward spiraling, physical activities reduce, social networks will dwindle and the couples become confined. By reason of these conditions, social, economic, physical and locational barriers are set around the couples. All these conditions have effect on the child with spina bifida and transitional stage for both the couple and the child.

Cues to Action: In the light of the availability of information and the possible role of significant others around couple and the child.., various actions are taken to maximize the health of child with spina bifida. Access to information will influence the feeding and transitional stage for the child living with spina bifida.

Self-Efficacy: Having acquired information and knowledge about personal health and care, the couples at this point begins to make health related decisions/judgments that they believe is in the best interest of their wellbeing. At this point, emphasis is on self-reliance, based on residual knowledge or acquired information which will guide restriction from certain foods, activities and other health related behaviours. It is a feeling of self-efficacy that is capable of making a child with spina bifida wanting to buy some sort of food, buy some sort of drugs without prescription or to seek some form of care outside of the formal health care system.

Conceptual Clarifications

Spina bifida: Spina bifida is what is known as a neural tube defect. It occurs during development prior to birth. It's when the spinal cord, brain, or meninges (their protective covering) does not completely develop. It can be anywhere along the spine and usually can be seen in an opening in the baby's back at birth. It may also appear as a sack of fluid that has grown outside the body on the spine. This sack may or may not include the spinal cord inside.

Shunt: This is a common surgery for the treatment of spina bifida (water on the brain). It involves insertion of a device that diverts fluid from the brain into the abdominal cavity where it is safely absorbed into the blood stream. Shunt may be inserted in children and adults.

Therapeutic choice: The decision made by parents, about the type of curative and preventive modes of treatment and care. It is the steps one take to get treatment for an ailment. It also involves seeking different therapies like consulting the Neuropsychologist, Therapist, Phoenix instructor, Pediatrics consultant, House help, baby sitter consultant, Faith based clinic, traditional-medical consultants and so on.

Coping Mechanism: In this this study, the coping mechanisms of caregivers lie on the advice and efficacy of advice received from members of the community members.

Spousal defies: Souses may experience suffering and in some occasions, even feelings of personal guilt for the sufferings, real and imagined, of the affected child. Occasional disputes, and family breakups, emotional violence can occur

Methodology

The study basically employed an observational studies that compared and analyzed the social dimensions on how couple differences affected the care for children living with spina bifida at a single point in time. On the other hand, this design was used to measure the children living with spinal bifida and couples health outcomes, understand determinant of their features and their health outcomes. Inferences were based on the data collected. The study population consisted of the couples with children below 2 years of age ($\leq 24months$) who are currently with the condition of spina bifida. Therefore, couples with children living with spina bifida fall in the above category were studied. Other participants comprise of health officers including clinical officers/nurses, and health practitioner (Doctors, Matrons, Social workers and couples with children with spina bifida) located in the selected local government area. The study made use of the principle of social randomly selected inclusion; for this reason, the study was fair-minded in nature. Every individual within the population of the study who satisfied the criteria for the study had a chance of being selected. The sample size of the study was determined by using the Cochran formula thus: $n = \frac{n_0}{1 + ((n_0 - 1)/N)}$. Where: n = Sample Size; N = Population; e = accepted margin error (0.05) with 422 as the sample size. P is the (estimated) proportion of the population which has the attribute in question,

This study adopted a multi-stage sampling technique. By the first stage, Local Government Area was using the raffle method. The second stage, involves the section of couples whose children lived with spina bifida, health centers (hospitals) where they treat and care for children with spina bifida were purposively selected. The selection of the health care centers was guided by two major pre-conditions such as: (1) The health centers should have attendants who have children with spina bifida who are from diverse background;(2) The number of couples who have children with spina bifida must be sufficient and large to allow good random selection of participants. The study used questionnaire having information on demographic questions such as age group, religions, and marital status; (1) The perception of couples with children living with spina bifida.; (2) health workers/ relatives attitude/perception towards children with spina bifida, (3) Types of defects of children with spina bifida in the study area and (4) coping mechanisms of couples living with children with spina bifida in the study area and Questionnaires and interviews were administered and distributed to collect both quantitative and qualitative data from the study area. Data collected for this study were analyzed with SPSS Version 25 using descriptive statistical methods. Descriptive methods such as means and percentages were employed to describe couples defies and coping mechanism information. Cross-tabulation, chi-square analyses and other statistics were used to determine significance differences and relationships between variables. To explore these issues, a phenomenological qualitative research design was also employed. Data were collected through semi-structured interviews with 35 significant others (Doctors, Matrons, Social workers and couples) of children diagnosed with hydrocephalus in Oyo State, Nigeria. Purposive sampling ensured diversity in perspectives and backgrounds. Thematic analysis was utilized to identify recurring patterns, themes, and insights from the interview data.

The instrument for the study included survey, key informant Interview (KII) and in- depth Interview (IDI) and case studies .The two Local Government Area (Ibadan North and South were purposively selected). Different research instruments were simultaneously used in different Local Government Area.

Existing data on reported number of spina bifida children cases, deaths due to spina bifida, major shunts done for 2 years,4 years and above of children covering the period .Data were collected as secondary data from the Hospital records with the view of determining the prevalence rate of spina bifida illness among children within the age of 0 to 6 and above. Couples coping mechanisms were examined and their decisions relating to the children long-term condition were explored.

A total of 422 respondents were sampled in the survey, using questionnaire schedule that was designed in open and close ended and pre-coded form. A semi- structured was used for the study to test for the people's perception and couples coping mechanisms were investigated. The designing of the questionnaire followed information generated from a pilot survey. Quantitative research data collection was used to obtain primary information from respondents. The questions were in relation to the study objectives. . The data were tracked on field serially to ensure that all or most of the research instruments are retrieved. Tracking of the research instruments during its computer imputation was also embarked upon. The data was sorted, coded and entered serially and cleaned. The retrieved research instruments were kept safe under lock. The recorded interviews and discussions were transcribed to a Pidgin language and also translated into English language though it was depending on the language used in conducting the interview. Labeling of data into computer files for the KIIs, CS and IDIs was based on respondents ID code and name of the communities. This was done to ensured easy identification and usage of the instruments.

Ethical Considerations

Ethical consideration was done to deal with the integrity of the investigators, the protection of the target population and communities where the study was conducted. Approval was sought from the Social Science Research Ethical Review Board. Generally, the following ethical issues were observed: confidentiality, beneficence, voluntariness and non-malfeasance to participant.

Result and Discussion

This chapter presents results analysis of the data gathered during the field work with a view to investigating perception and coping strategies for fibroid among Celibate women in the Catholic Ecclesiastical Province of Ibadan. The data are presented in frequency distribution tables, charts and cross-tabulations, using bivariate and multivariate regression analysis. Where 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 hydrocephalic condition; gender dimensions in patterns of treatment for hydrocephalic condition; factors influencing caregivers' therapeutic choices and care for children with spina bifida condition; consequences of spina bifida 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 than 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%), and then

Table 4.1: Percentage distribution of respondents according to socio-demographic characteristics

| Characteristics | Categories | Frequency (n=422) | Per cent (%) |
|--------------------|---------------------|----------------------|-----------------|
| Age Group | Less than 30 years | 65 | 15.4 |
| | 30-35 years | 102 | 24.2 |
| | 36- 41 years | 91 | 21.6 |
| | 42- 47 years | 74 | 17.5 |
| | 48 + | 90 | 21.3 |
| | Total | | 422 |
| Marital Status | Single Parent | 81 | 19.2 |
| | Married | 244 | 57.8 |
| | Divorced | 33 | 7.8 |
| | Separated | 44 | 10.5 |
| | Widowed/widower | 20 | 4.7 |
| | Total | | 422 |
| Gender | Male | 151 | 35.8 |
| | Female | 271 | 64.2 |
| | Total | 422 | 100 |
| w Education | No formal education | 29 | 6.9 |
| | Primary | 165 | 39.0 |
| | Secondary | 186 | 44.1 |
| | Post-secondary | 42 | 10.0 |
| | Total | 422 | 100 |
| Occupation | Artisan | 171 | 40.5 |
| | Civil Servant | 74 | 17.5 |
| | Farming | 17 | 4.1 |
| | Trading | 160 | 37.9 |
| | Total | 422 | 100 |
| Monthly Income (N) | Less than 10 000 | 37 | 8.8 |
| | 10,000 - 19,999 | 54 | 12.8 |
| | 20,000 – 29,999 | 114 | 27.0 |
| | 30000 – 39999 | 144 | 34.2 |
| | 40,000 – 49999 | 41 | 9.7 |
| | 50000 + | 31 | 7.4 |
| | Total | 422 | 100 |
| Religion | Christianity | 153 | 36.2 |
| | Islam | 245 | 58.1 |
| | Traditional | 24 | 5.7 |
| | Total | 422 | 100 |
| Ethnicity | Yoruba | 162 | 16.1 |
| | Hausa/Fulani | 68 | 38.4 |
| | Igbo | 173 | 41.0 |
| | Others | 19 | 4.5 |
| | Total | 422 | 100 |

Source: Field Survey (2016)

min. age 20yrs, max. Age 60yrs mean age =38.9±9.13yrs

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 spina bifida 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.

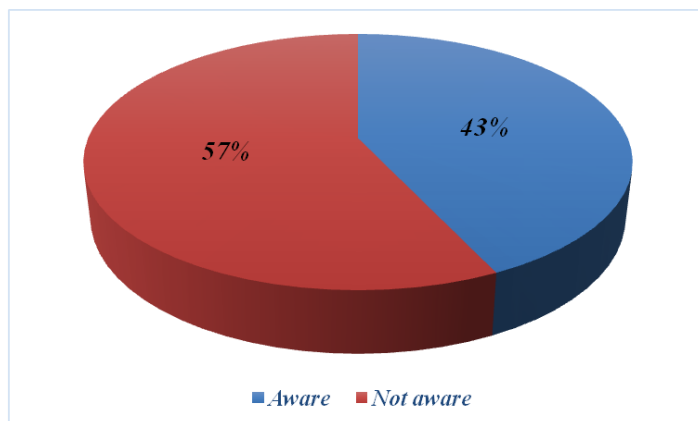


Figure1. Pie chart showing percentage distribution of respondents by description of spina bifida

Figure 4.1 shows that the 57% of the respondents are not aware of spina bifida, while about 43% of the respondents are aware of spina bifida condition. The above chart confirms that majority of the respondents are not aware of spina bifida. Information on mode of information about spina bifida reveals that respondents do not have adequate knowledge. Hence, the information above corroborates with a study conducted by scholars (Banninka, Stroekena, Idro and Hove, 2015) that there is no evidence of any knowledge of preventive measures for central nervous system birth defects and most workers are ignorant of the condition. The perception of majority shows that, people hide under the cover of spiritual attack. Indeed information about spina bifida is concealed and majority of respondents identified that they are not aware of the condition. This finding corroborates earlier findings that the media stand as a major mode accounting for the source of information. This assertion simply indicates influence of western media and technology which often promotes new role model is contrast to traditional values. However, opinion on spina bifida

brought about change in the use of foreign drugs. Observation however, reveals that even though, there is an advance level of technology, still the level of awareness is low

Factors Affecting Coping Strategies for Spina Bifida:

Many interventions teach caregivers everyday problem-solving strategies managing children with spina bifida. Strategies for coping with spina bifida were mentioned in detail along successful and transition strategies. The coping strategies involve the movement taken by caregivers from child-centred to adult oriented activities. It involve the process taken by caregivers that depends on early care, education, and coordination of effort by all involved persons, caregivers, relatives, and significant others. The importance of caring for spina bifida children involves understanding several strategies which include caregiver's self-development in many areas. Five major copying strategies were mentioned.

Strategies used from home to community living (Social support)

This objective reveals a functional role taken by caregivers; it also involved functional role taken by caregivers from the child home to community living. An active caregiver is not free of role conflict in coping with children with spina bifida. A child with spina bifida needs a functioning adults or caregiver who is able to satisfy the need of the child. The caregivers also have the role of making the child to know about the social environment culture and for him to cope. The posited question here is that, how do this children cope with the condition. A balance exists in the functioning of individual that allows the child to develop his or her cognitive reasoning. Aside this, it also empower the child to develop the ego to control and have defense mechanism.

It was discovered that children who received proper care from their caregiver, can make use of his or her energy to grow and developed the skill of interaction among members of the society. On the other hand dysfunction can make coping mechanism to form poor or unrealistic body image, poor self-identity, poor self-esteem, unbalance use of deference and an inability to cope. Changes occur trying to cope with children living with spina bifida; however theory of structural functionalism gave way to resolve the coping strategies problem by creating avenue for "sick role" which Lagos State hospitals, institutions and caregivers adopted in order to create therapeutic mechanism which made children to function and develop experience on the consequences of their own illness episode.

Thus, the intellectual and policy contribution of the study is that it bridges the knowledge gap that thus far existed in understanding the way different caregivers utilizes choices of care to determine certain competences in their children. Some of the findings from this study give better understanding of how caregivers made choices on the type of care given to their children. Furthermore, findings could become a channel to policy makers, practitioners and stakeholders (therapist and neurosurgeon) in planning in the direction of early prevention of hydrocephalic condition.

A caregiver said the following during interview (knowledge on coping mechanism) for children living with spina bifida:

I think parents especially we the mothers lack skills in coping with our children. Most mothers often complained to me about their infants but I often advise them that a baby cry is designed for the thriving of a baby and the development of the parent. Let's take for an example, we learn how to cope with this children when they over react because is normal. This is because they go through pains. We should also know that the flow of breast increases when baby cries. Though is not easy to cope with these children. [IDI Female / 40 years/ Ikeja/ FDG Caregiver 8/ Jan, 2017]

The researcher approach with the above assertion is to investigate not only the growth of the baby but also on wellbeing and the coping mechanism of the parents, it was discovered that most parent needs their child's growth, stimulation, mutual sensitivity. As caregivers care for these children through the first two years of development together, there is a natural mutual sensibility between the couples especially if the child develop fast (Shokunbi, 2014). The child and caregiver become sensitive to each other, this is in line with parent's ideas from head of support group, learning one step at a time and learning necessary intervention at home. Mutual shaping is one of the coping strategies used by caregivers in other to become mutual sensitive to mutual shaping of behaviour is well illustrated by the ways caregivers shape their babies language (Watch Tower Magazine, 2018). On the other hand, caregivers appear to undergo regression to the level of the child affected with spina bifida. The caregivers act, talk and think down at the baby's level. At this level the infant developed communication skills. The concept of mutual shaping is one of the coping strategies used by caregivers to get bond with their infants.

Traditional Birth Attendant also has this to say (knowledge on coping mechanism) for children living with spina bifida:

We used to help them within our own way because most of the caregivers are sober wanting to have relationship with us that can revive their child but what can we do? All we can do is to help them gain their strength. We do this by giving them Oori (shell butter) that they will use as a massaging tool that will the children strong to walk on their feet. I do counseling session with both pregnant mothers and parents with spina bifida children, also rendered help in order to make things easier by allowing them having free mind to speak to me.

[KII/Female Traditional Birth Attendant/54 years/Ikorodu/ /Adamo LGA)Jan, 2017]

Traditional therapeutics have been confirm in terms of creating and maintaining a good relationship with caregivers. Traditional healer's treatment remains viable efficacy for caregivers. Traditional Mode of treatment determines the perception and belief of the community .The notion of caregivers who beliefs in traditional healers contrast with the belief system of other community like Ikeja and Ikorodu

Conclusion

This study concludes that there is wrong perception of the community understanding of what spina bifida is all about. spina bifida is neither infectious nor contagious. Caregivers who live in Lagos lack health facilities. The practical expression in some observed practices such as high cost of treatment, delays in treatment, and follow up treatment is infrequent. Majority of the community perception is low on the awareness about what spina bifida is all about. spina bifida could either be congenital or acquired depending on the biological make-up of the individual carrier. Majority referred spina bifida to be inheritance, Punishment of sin and spiritual attack .The community perception on spina bifida was based on the ideology of religious beliefs that most children with spina bifida were given birth to with bulge bottom structure simply because of what the mother must have seen and consumed during pregnancy period.

The case of walking at midday and midnight were perceived by the mothers to cause spina bifida. On the other hand the wrapping of sharp objects such as pins, nails, stones, key son the dress or at the tip of the dress. Emotion and social development reported very low that infant spent much time trying to fix the right sound and signals to parent or caregivers around. There was no available creation centre for children living with spina bifida. The occupation of the caregivers does not encourage social support and care for the children. The government policy does not reveal vivid responsibilities for children living with spina bifida.

Recommendations

- Having regular screenings like ultra sound scan and prompt treatment for any illnesses or infections that could put one at risk of giving birth to child with spina bifida condition.
- Financial aid and necessary attention should be given to the caregivers, who have children with spina bifida especially when shunt (surgical treatment) needed to be carried out?
- Support for spouses and technological mechanism should be provided to ensure that every caregivers are knowledgeable about skills and equipment usage for children with spina bifida.

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