

Challenges and Coping Skills of Mothers Caring For Children with Congenital Abnormalities in Two Selected Hospitals in OGUN State, Nigeria

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Abstract

Objectives

This study described participant's knowledge on congenital abnormalities and explored the challenges and coping skills of participants in caring for children with congenital abnormalities [CA] in Olabisi Onabanjo University Teaching Hospital (OOUTH) and Babcock University Teaching Hospital (BUTH) in Nigeria.

Method

The study adopted a qualitative research design that engaged data collection using interview method. A total of 5 participants were interviewed to explore the challenges that confronted them and their coping skills when caring for children with congenital abnormalities at the research sites.

Results

The result of the study show majority of the informants lacked knowledge about CA prior to giving birth to their children. Furthermore, result showed that the informants have been taking care of their children since they were born and they stated that it was not an easy task providing care for their children. The informants also revealed financial strain they encountered due to lack of support from their spouse and family members.

Conclusion

The study established that birth of a child with congenital abnormalities causes emotional and financial stress that are challenging to parents and caregivers and thus results in feelings of sadness and frustration. The difficulty encountered in the care of malformed child was attributed to poor knowledge of congenital anomalies. All diagnoses were made after birth and support groups for the affected mothers were not in existence. Nurses would play vital roles in health education to mothers and their families.

Key words: Congenital Abnormalities, Care, Challenges, Coping skills, Education.

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I. Introduction

Congenital anomalies (CA) also known as birth defects, congenital abnormalities, or malformations are the leading causes of morbidity in developed and developing countries of the world (Centers for Disease Control and Prevention, 2015). Congenital abnormalities, according to (WHO, 2016), can be described as structural or functional abnormalities that occur during intrauterine life and can be identified prenatally, at birth, or may be detected later in infancy. Research indicate that defects of prenatal origin result from defective embryogenesis or intrinsic abnormalities in the development process (Mathews, MacDorman, &Thoma, (2015). Congenital abnormalities (CA) causes significant physical dysfunction and can contribute to long term disabilities. Major congenital anomalies or defects that are present at birth have surgical, medical, or serious cosmetic significance (Hall, Graham, Cassidy &Opitz, 2009). These anomalies occur in about 3% of infants, according to data from the Metropolitan Atlanta Congenital Defects Program, a birth defects surveillance system administered by the

Centers for Disease Control and Prevention [CDC] (2015). A few examples of major congenital defects are cleft lip, gastroschisis, spina bi fida, and congenital heart defects, such as atrial and ventricular septal defects (p.57). It is argued that minor congenital anomalies are also present at birth but these are without medical, surgical, or serious cosmetic significance (Biesecker, et. al., 2009). Some examples include epicanthal folds, single transverse palmar crease, and fifth finger clinodactyly (CDC, 2008). Diminished function, as a result of this disease condition, has a significant adverse effect on the individual, families, health care system and the society at large. Caring for a child with disability affects the roles of both the father and the mother but the daily lives of the mothers are further depreciated because of their primary roles as care givers to their children (Wagathu, & Ongeso, 2018).

Parents are not usually prepared for the birth of a child with congenital abnormalities. This makes caring for such baby challenging. Coping skills of mothers caring for such children is very important (Lazar, 2016). Mothers caring for a child with congenital abnormality are confronted with several challenges ranging from increased parental stress, to coping and managing the stress with other responsibilities. Every woman who bears a child has a sacred responsibility to provide loving nurturance to the child so that the child can develop to his or her highest potential. Sabzevari, Nematollahi, Mirzaei & Ravari, (2016) describe mothers' roles as nurturing a child, caring for him or her, keeping the house clean and safe, teaching their children, praying with their children, playing with them, and ensuring that they are properly educated. A mother is a counsellor, a chef, a coordinator, and an income earner. But mothers of children with congenital abnormalities have increased parental responsibilities that may rob on caring for the other family members (Wagathu, & Ongeso, 2018)

It is no doubt that the challenges confronting mothers with abnormal babies are enormous. The coping skills and mechanisms employed by these mothers determine how they manage these challenges and maintain their emotional wellbeing. Wagathu and Ongeso, (2018) argue that mother's lack of knowledge on how to care for congenital abnormal babies affect how they cope with the challenges. Parenting becomes a hideous task and the impaired coping mechanisms make such mothers vulnerable to depression and eventually lifestyle diseases (Sabzevari, et al., 2016).

Congenital abnormalities are major causes of infant and childhood chronic illnesses, disability and mortality (WHO, 2016). Research indicate it is likely that more than 192,000 of the 2.6 million annual stillbirths, may be as a result of an underlying congenital disorder (Lawn, Blencowe, Waiswa, Amouzou, Mathers, Hogan et al., 2016). Literature show that 94% of the birth defects, which is about (8.46 million infants) occur in the developing countries of the world to which Nigeria belongs (Animasahun, Adekunle, & Kusimo, 2018; Ekanem, Bode-Thomas, Wilson, Orogade, Otaigbe, Ujunwa et al., 2018). The birth of a congenital malformed child is life changing and devastating to the family because it requires long term care. Fost (cited in Emordi & Osifo, 2017, P.1) states that, the expectation of every parent is to hold in their arms a 'bundle of joy' in form of a healthy new-born after a period of pregnancy and birth of the infant. On the contrary, the birth of a congenital malformed child puts additional stress on mothers and the family as a whole (Okuyama, et al., 2017). As is the norm in some cultures, mothers have the major responsibility of caring for children, so with the child being sick they are confronted with additional responsibilities that is capable of weighing her down psychologically, socially, emotionally, and impacts on the economy of the family as well (Tusano, 2015).

A newborn baby is considered the beginning of hopes and dreams, and becoming a parent is one of life's greatest joys but, the birth of a congenital deformed child challenges those dreams (Ghimire, 2017). Range of emotions experienced by these mothers after the diagnosis of malformed child include shock, denial, sadness, and anger which is similar to losing a child (Emordi & Osifo, 2017). These mothers confronted with increased parental stress, may be forced to quit their careers in order to care for their child (Pate, 2009). Huge financial responsibilities, for multiple and complex surgical procedures, are often required to care for congenital abnormal children and this is a mountainous challenge for parents in developing countries of the world with scarce resources (Emordi & Osifo, 2017). The fear of having another baby with similar disease condition, may make mothers to be afraid of having other children (Okuyama, et al., 2017).

Existing cultural and societal beliefs on congenital abnormality breeds negative attitude towards mothers with a malformed child and this could also be a threat to their marriages. Mothers of children with congenital abnormalities are often stigmatized and isolated from the family and friends, causing unavailability of support system (Ghimire, 2017; Okuyama, et al., 2017). The child is also locked indoors to avoid shame. In the presence of these challenges, mothers are often left on their own to care for their children with congenital abnormality. The lack of coping skills for these mothers attempt to make matters worse especially in societies where there are no government support system in place to cater for parents and children with challenging health conditions. These further compromises their health status and leaves them vulnerable to abuse in the society (Lazar, 2016). This study therefore explored the knowledge of participants about congenital abnormalities and coping skills with the challenges they encounter while caring for their malformed children.

II. Methodology

The study adopted an exploratory – descriptive qualitative research design for data collection using interview. This allows for deeper understanding of the thinking behind the respondents' answers. Gray, Grove and Southerland (2015) argued that the presence of an interviewer, unlike quantitative survey design, gives respondents additional comfort while answering the questions and consequently ensures correct interpretation of the questions. The aim of the interview was to explore the challenges of mothers with congenital abnormal babies and to ascertain the coping skills that these mothers employed while caring for children with congenital abnormalities at Olabisi Onabanjo University Teaching Hospital OOUTH, Shagamu, and at Babcock University Teaching Hospital (BUTH), Ilishan-Remo, Ogun State.

The sample size was not calculated because all participants who met the inclusion criteria were approached and requested to participate after providing them adequate clarification of the process and purpose of the study. The number of children admitted with congenital abnormalities in the hospitals were ascertained which provided a clue to the number of participants to approach for the interview.

Target Population: The population of this study are mothers of children admitted in the study centers for the period of six month as shown in table 1 below. The total population is forty-five. However, all were not used for the purpose of this study.

Table 1: Average number of children with congenital abnormalities admitted in the study centers within six months (December 2018- May 2019).

MONTHS	OOUTH	BUTH
December 2018	2	3
January 2019	2	1
February 2019	8	3
March 2019	4	7
April 2019	2	1
May 2019	4	8
Total	22	23

Source: Olabisi Onabanjo Teaching Hospital (OOUTH) and Babcock University Teaching Hospital (BUTH) Field work, 2019.

Purposive sampling technique was used to recruit participants for this study by making use of participants who were accessible and ready to engage in this study. There are no specific numbers because this depends on data saturation. A semi-structured in-depth interview guide was developed, reviewed, and corrected to be used as a guide to obtain data from participants on knowledge about congenital abnormalities in children, challenges of care and their coping with care. In order to execute the study, an introductory letter was obtained from the School of Nursing Sciences, Babcock University while ethical approval was obtained from the Babcock University Health Research Ethics Committee (BUHREC) and from the ethical committees of BUTH and OOUTH. Prior to the commencement of the interview, the purpose of the research was explained to the participants. The interview was explained for clarity and to promote good understanding. The participants were also informed that participation is voluntary. Consent was obtained from the participants for interviewing and for audio recording of the interview in order not to miss any valuable information. Finally, the interview was conducted involving consented participants in a separate room at the clinic of the hospital with one participant being interviewed at a time to provide privacy.

The audio recorded information during the interview was first transcribed verbatim in an exercise book prepared for this research. Then the socio-demographical data were analyzed using the Statistical Package Social Science Version 23 (SPSS 23) and descriptive analysis (frequencies and percentages) was performed. Data obtained from the interview were organized and analyzed using content analysis. This was a qualitative study using an exploratory descriptive approach.

Aims:

1. To describe participants knowledge on congenital abnormalities
2. To explore the challenges that underlies the experience of taking care of congenital abnormal children
3. To explore the coping skills of the participants when caring for their children with congenital abnormalities in OOUTH and BUTH?

Population and sampling

Participants were recruited from Olabisi Onabanjo University Teaching Hospital OOUTH, Shagamu, and Babcock University Teaching Hospital (BUTH), Ilishan-Remo, Ogun State.

A purposive sample was used to ensure that the sample chosen was able to provide the information needed for the topic using the following inclusion criteria.

Inclusion criteria

- 18 years of age and over,
- A mother caring for her congenital abnormal child
- Willing to participate in the study.
- Understands and speaks simple English language.

Participant's recruitment:

Nurses attending to the mothers with CA children reviewed their notes to evaluate inclusion and exclusion criteria. Mothers who met the inclusion criteria were approached and invited to participate in the interview. Informed consent was obtained from those who accepted to participate and were consequently scheduled for interview. During the interview, confidentiality and anonymity were ensured.

Interview guide:

Part 1: Knowledge of congenital abnormalities

1. Tell me what you know about congenital abnormalities.
2. What information did you receive during antenatal care about congenital abnormalities?

Part 2: Challenges of caring for a child with congenital abnormalities

1. What are the challenges that confronted you when caring for your child with congenital abnormalities?

Part 3: Coping with care

1. What coping skills do you employ when caring for a child with congenital abnormalities?
2. Could you describe the support you received that helped you cope with caring for your child?

Data collection

Data were obtained by semi-structured interview using pre-prepared interview guide of aspects of the participant's knowledge, challenges and coping with care of congenital abnormal child. Interview were conducted by researcher number two. The researchers do not work in the sites where the participants were recruited and did not have direct clinical relationship with the participants. The interviews took place in an office used for counselling in the hospital. Participants were encouraged to talk freely in their words. The interviews were audio recorded and the duration was between 30-45 minutes.

Data analysis

Data collection and analysis ran concurrently to permit the exploration of the main themes and determine when data saturation is achieved. All interviews were audio recorded and transcribed verbatim to allow the researchers make sense of the informant's narratives. Analysis took the following sequence:

1. Transcribed data were arranged and rearranged
2. Data copiously read to gain a general understanding of the narratives.
3. Significant statements pertaining to knowledge of CA, challenges of CA for a child with CA and coping with care of a child with CA were extracted.
4. The extracted statements were sorted and formulated into themes and clusters of themes.
5. These themes were clustered and validated with the original data to identify experiences that were common to the participants. The first three steps were repeated for each participant so that overarching themes are generated. Any variant from the other theme were examined for relevance.
6. Findings were validated with the study participants to compare the descriptive results that were obtained with the original narratives.
7. On the final analysis, corrections from the participant's feedback were incorporated into the themes representing the participant's knowledge, challenges and coping skills as they care for their children with congenital abnormalities.

Assumption

The assumptions of the researchers were that participants' ability to cope with challenges associated with caring for children with CA is influenced by knowledge about CA.

III. Results

Seven participants who are mothers of children with congenital abnormalities accepted to participate in the study. However, data saturation was achieved after interviewing five participants. The table below shows the participants' demographic data.

Table 2: Participants' demographical data

Participants =5			
DEMOGRAPHIC	CATEGORY	FREQUENCY	PERCENTAGE (%)
AGE	20-25	1	20.0
	31-35	3	60.0
	36-40	1	20.0
MARITAL STATUS	MARRIED	5	100.0
ETHNICITY	YORUBA	3	60.0
	HAUSA	1	20.0
	IGBO	1	20.0
RELIGION	CHRISTIAN	4	80.0
	ISLAM	1	20.0
LEVEL OF EDUCATION	PRIMARY	2	40.0
	TERTIARY	3	60.0
NUMBER OF CHILDREN BY THE RESPONDENTS	One	1	20.0
	Two	1	20.0
	Three	1	20.0
	Five	2	40.0
AGES OF CHILDREN	1	1	20.0
	3	1	20.0
	10	1	20.0
	14	1	20.0
	15	1	20.0

Table 3. Themes in the results

S/N	Themes	Sub-themes
1	Having knowledge of Congenital abnormalities	Not having any knowledge of CA Discovering about CA.
2.	Challenge of care	Emotional stress Excess workload Lack of support
3.	Coping with Care	Dependence on God Support from family members Financial demands

The table above shows that three themes emerged from the analysis. These themes are: having knowledge of congenital abnormalities, Challenges of caring for Children with CA, and coping skills.

Theme 1: Having knowledge of congenital abnormalities

The knowledge and understanding of any situation is key to knowing how to face the challenges arising from it. Two distinct sub-themes were observed in this item. There were those who perceived they had no knowledge of CA before they gave birth to their children. Others were those who discovered that their children were born with congenital abnormalities and have to learn to care for them with trial and error approach.

Not having any knowledge of CA

Some of the participants who did not have any knowledge about CA before the birth of their child did not know what was wrong with their children. These participants felt that they should have been taught about CA during their antenatal period. The verbalized that they would seek investigation during pregnancy to rule out congenital abnormalities. They said they would seek adequate care if CA is identified during pregnancy:

...I did not know anything about this type of disease before I gave birth to my child. It was few weeks after I gave birth to her that I started noticing that something is not normal about her health.If I had known anything about this disease before her birth, I would have learned what to do to care for her adequately ... (Mother A)

Another participant whose child had Dawn Syndrome verbalized that she did not know about CA. The participant observed that her child was slow in meeting up her developmental milestone during infancy:

... I never heard about CA up until my child was born malformed three years ago. I discovered that she was slow at each developmental stage of life. My child also had a distinct facial appearance... (Mother B)

Similarly, another participant expressed not having any knowledge at all until she gave birth to her baby:

... I had no idea that such problems exist before I had this baby. That is why I have to take her to the hospital. Since then we have been coming here for medical attention ... (Mother E).

Discovering about CA

One of the participants stated that it took her about two years to discover that her child had a problem of anorectal malformation which she did not discover on time. During this time she discovered that faecal matter had been coming out of her vaginal orifice which she kept on washing when changing her napkin:

...I found out about Congenital Abnormalitywhen this my child was 2years old. She was born in *Ile-Alagbo* (traditional birth attendant) without Anus and when I gave birth to her, some said we should have a surgery while others said there was no need so I did not do anything till she was 2years old when she started having pains then I took her to the hospital... (Mother A).

One participant whose child has a cyanotic heart defect indicated that she was not aware of what was happening to her child. She later discovered through trial and error of herbal treatment that the child was born with heart problem before taking her to the hospital:

... My child was not breathing well, and I used some herbal medication after which it became worse, before I brought her to hospital and an x-ray was done and the report show that my child has a problem in the middle of the heart... (Mother C).

Challenge of Care

Caring requires knowledge and skills about what to do in any situation of life. But when the individual providing care has no knowledge of what to do, such situations could pose serious challenges to the care giver and the care recipient.

Several challenges were faced by these mothers varying from physical, financial, social, psychological, and emotional as reported below:

Emotional stress

Some of the participants verbalized how traumatic their experiences had been seeing their child not functioning normally as other children. There is also the anxiety of leaving child alone or with other people because of not knowing what would happen.

... It is only God that can take control, the challenges are plenty and hard, the child passes stool through her vaginal hole and each time that happens I have to clean her up and wash her... (Mother A).

... The stress is too much, I have to be around him or keep him with someone either any of his elder siblings because he cannot do anything on his own and he always has seizures, so anything can happen at any time... (Mother B).

... It is frustrating taken care of a CA child; it denies me of my sleep. I have been in the hospital for 12days now, it is not fun staying here, also the mosquitoes, but I have to do anything for my child. Apart from the fact that I just gave birth, the stress of caring for this child is double... (Mother C).

Excess workload

Some of the participants in this study complained of too much workload as a result of additional demands of caring for their children with CA. This excess workload hinders them from socializing with other people in the community thus resulting to additional stress:

... Sometimes I wake up at mid night and would not be able to return back to sleep so as to take care of my child... (Mother A).

... It is frustrating, taken care of a CA child; it denies me of my sleep. I have been in the hospital for 12days now, it is not fun staying here, also the mosquitoes, but I have to do anything for my child. Apart from the fact that I just gave birth, the stress of caring for this child is double... (Mother C).

Lack of support

Other participants in this study narrated how they did not receive support from their spouses and other family members. This made the care of their child more difficult since they have to make every decision by themselves:

... My husband is not supportive, he left us alone and I have four other children to care for in addition to this child. I do not have time to go to my shop to look after my business... (Mother A).

...The family discriminated against me and did not give any support morally and financially. I have to do everything by myself... (Mother E)

Coping with care

Care giving responsibilities for a loved one can be stressful and may take toll on someone's emotional, psychological and spiritual health. Therefore, caregivers must learn to be resourceful in managing their wellbeing through positive coping mechanism in the difficult times associated with caring for congenital abnormal child. Most of the respondents linked their coping strategies to praying to God, talking with health care givers and support from spouse.

... It has been God who has been taken care of us. My husband is not supportive, he left us alone and I have four other children, there is no time to go to my shop. Also, health workers have been coming to my aid... (Mother A).

Dependence on God

Some participants expressed dependence on God's constant care for their coping. They also observed that regular prayer and trust in God was their vital source of coping hence they relied on Him.

... It is only God who has been helping us in this situation... (Mother C)

Mother D stated that the husband is very helpful; she also said that God is her source of coping. For mother E she prays when she gets tired as well as rest and asked questions from the health workers.

Support from family members

A few participants in this study indicated receiving support from family. Such support helped them to deal with care of their children with congenital abnormalities:

... My husband, my children and few of my relatives are very supportive. I also thank God for giving me an understanding family. At times when I am sad and crying, my daughter comes to console me, and I also pray a lot... (Mother B)

... I have a lovely, supportive husband. This is our first child, so we are doing everything together... (Mother C)

Financial demands

Money is an aspect of the family that cannot be neglected. However, the burden of care becomes heavier when there is a lack in this area. Perhaps no family can successfully operate in the management of their home without adequate finance to care for the daily needs of the family. For some participants it was evident that lack of finance affected their coping with the care of their children with congenital abnormalities:

... Coping with my child became difficult because of financial problems as my family did not offer any support. Rather I was discriminated against because of my child with CA... (Mother E)

... The money I have also spent is too much; still I have not been able to completely pay the bills... (Mother A)

Discussion of findings

Demographic Characteristics

The result from the socio demographics responses of the respondents show that majority 60.0% of the respondents are within the ages of 31-35, all the five respondents are married. A major chunk (60.0%) of the respondents are from Yoruba ethnic group of Nigeria, about 80.0% of the respondents are Christians, while about 20.0% of them are Muslims. About 60.0% of the respondents have up to tertiary level of education. The result also show that 40% of the respondents had five children, 20.0% had two children, 20.0% had one child, and 20.0% had three children.

Knowledge level of the mothers caring for their children with congenital abnormalities

Responses from mother A on what she understands by congenital abnormalities show that she did not know about CA till her child was 2years old. Mother B confirmed that she had never heard about CA till her child became 3 years. She stated that she discovered that her child was slow at each developmental stage of the baby's life. Similarly, mother C like the previous respondents stated that she was not aware of CA, she reported that the child was not breathing well, and they used some herbal medication after which it became worse, they took the child to the hospital and after x-ray the doctor told them that the child had cyanotic heart defect. Evidence from this study also show that mother D and mother E did not also have any knowledge of CA, till they gave birth to their children. Results from these respondents show that they did not have any idea of the concept of congenital abnormalities. These findings align with the findings of Wagathu and Ongeso (2018) who corroborated the lack of knowledge of mothers with congenital abnormal children. Their findings established importance of pre-natal care and knowledge about congenital diseases in neonates. Most of the mothers have never seen a birth defect and did not know the causes (Dellicour, 2013).

Challenges with mothers caring for children with congenital abnormalities

Most mothers in this study indicated that their challenges were many and complex. One mother reported that her child passes stool through her vaginal meatus which is uncomfortable for both mother and child as she must wake at midnight to take care of the child and thus deprived of sleep. Other challenges were financial and emotional trauma as they barely had enough to take care of themselves. Some mothers verbalized how taking care of their child with CA had affected their jobs and their families as they are confronted with

financial burdens, discrimination, and lack of support from families and the society. Braeuner and Media (2014) observe that financial burden is a colossal challenge of parenting children with disabilities. Tusano, (2015) observe that most families of children with special needs have greater financial need arising from the loss of employment of one of the spouses and this could be a source of stress.

Coping skills in caring for children with congenital abnormalities

Results of how mothers cope in caring for their children reveal some disparities. While a few received support from their families, others were abandoned. However, they received help from health workers who came with some aide. This is in line with some previous findings which show that most mothers cope well through family support and support groups as they take care of their children with congenital diseases (Bruce, 2014; Tusano. 2015, Bratt, 2015)

IV. Conclusion

The birth of a child with congenital abnormalities brings feelings of sadness and frustration to parents. A long hospital stay for these anomalous neonates is experienced due to slow interventions and lack of prompt management. However, the poor knowledge on what causes congenital anomalies increases these frustration and anxiety. All the diagnoses of congenital abnormality were made after birth. Support groups for the affected mothers would go a long way to boosting their confidence in support of their children with congenital abnormalities. Based on the findings we recommend the followings that:

1. Regular antenatal care be made compulsory for pregnant women. The major objective of antenatal care is to ensure optimal health outcomes for mother and child. Antenatal care provided by skilled health workers, such as nurses, midwives and obstetricians enables early detection of complications and prompt treatment of any congenital anomalies and thus reduce morbidity.
2. Continuous education and the sensitization of mothers on the knowledge of congenital abnormalities be made visible on prints and posters to enable mothers be aware of its complications and how to manage it if it occurs and not treat the child as evil spirit from the ancestors.
3. Encourage support groups for families affected. Instead of abandoning mother and child, husbands and other relatives should be encouraged to render moral, emotional and financial support to mother and child. Stigmatization should also be discouraged in all levels so that children with CA and their parents can live normal lives in the presence of health challenge.
4. Government should support NGOs that assists and support parents of congenital abnormal babies through financial and tax breaks and other services.
5. Emotional support groups should be created for these mothers to meet and share their challenges and coping strategies to improve their wellbeing while caring for their congenital anomalous children.

Conflict of interest

There is no conflict of interest

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