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Parental Attitude to Children with Sickle Cell Disease in Selected Health Facilities in Irepodun Local Government, Kwara State, Nigeria

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ABSTRACT The study investigated parental attitude towards children with sickle cell disease in selected health facilities in Irepodun Local Government, Kwara State, Nigeria. 80 participants were purposively selected for the study. A self-reporting questionnaire was used to collect the needed information from the parents of children with sickle cell disease. Simple percentage and Chi-square were used to analyze the data. Findings from the study showed that about 87% of the participants regretted having such children and gave reasons such as lack of enlightenment programme on sickle cell anemia, no genetic counseling, ill-disposition to pre-marital genotypic screening, inadequate medical facilities for adequate test for genotype in rural areas, gross misrepresentation and wrong perception of sickle cell disease, lack of knowledge of people on sickle cell disease and nonchalant attitude to the result of screening due to love and interest in one's partners. It is therefore recommended that adequate mobilization of educative programmes on importance of pre-marital genetic counseling should be done, facilities should be provided for genotype screening freely for the members of the society, it should be made compulsory for all intending couples and where incompatibility exists, they should not be allowed to marry. The government should legislate in this area by not allowing marriages between non-compatible individuals and should provide free health service for sickle cell patients while their drugs should be made available in the clinics/hospitals.

INTRODUCTION

Sickle cell disorder (SCD) is one of the commonest but preventable inherited diseases. It is a disease that affects the red blood cells and is a lifelong ailment which has been with man since the existence of man. Sickle cell affects all races of the world, it affects the people of tropical Africa, Mediterranean Sea, Middle East and South India. It has contributed significantly to the high childhood mortality rate.

Nigeria has an estimated population of 150 million with annual growth rate of 3.2%. The current figure of individuals in Nigeria with this disorder is not known since the majority born in rural community do not survive childhood and for lack of proper statistics. However, an estimate of about 2.3% of the Nigerian population suffer from sickle cell disorder and about 25% of Nigerians are healthy carriers of the abnormal hemoglobin gene.

Anie et al. (2010) were of the view that SCD is a global health problem with psychosocial implications and that Nigeria has the largest population of people with SCD with about 150,000 births annually, although over 300,000 babies are born worldwide with SCD, mostly in low and middle income countries with the majority of these births in Africa.

Sickle cell disease was first found prevalent in the African American populations in 1910 (Durham 1991). Sickle cell anemia is a type of sickle cell disease in which there is a single point mutation on the β-globin gene.

Sickle cell anemia (SCA) and Hemoglobin SC disease (HbSC) are the two most frequent types of sickle cell disease (SCD) in Cuba and as both are hereditary diseases with an autosomal recessive pattern of inheritance. SCA is caused by a structural variant of the major adult hemoglobin called S or Sickle hemoglobin (HbS), while HbSC is caused by the presence of two variants, one of them is sickle hemoglobin and another is hemoglobin C (HbC) this variants result from HbS and HbC allelic genes in beta globin locus in chromosome 11p 15.5. HbS allele differs from the normal allele A, in a single amino acid; at position 6 a valine replace a glutamic acid residue. In HbC allele, at the same locus lysine replace glutamic acid residue also at position 6. Affected individuals with SCA are homozygous SS, because they inherit one HbS allele from each

parent; while affected individuals with HbSC are heterozygous SC, because they inherit one HbSC allele from a parent and one HbC allele from another one. These genes are quite common among African ancestry (Ruiz et al. 2007).

In Western and Central Africa where as many as 1-2% of children have sickle cell anemia or HbSC disease, sickle cell anemia is a public health and individual dilemma. Apart from the attendant high morbidity, sickle cell disease also inflicts economic psychological and physical strains on the patients' parents and their relations. Sickle cell disease arise from the inheritance of two abnormal hemoglobin genes one from each parent i.e. HbS. Hemoglobin is liquid part of the red blood cells which carries genes.

Genes are responsible for all inherited characteristics of humans and the main function of hemoglobin is to carry oxygen and food to other parts of the body. In Africa, children with sickle cell disease are usually first diagnosed following an acute disease and not by screening hence regrettably, diagnosis are often delayed. An overwhelming majority of parents having children with sickle cell disease in Africa live and die without tests needed to establish the correct diagnosis. Most infants with sickle cell disease are unlikely to have been diagnosed before or even during episodes of acute illness. Most of all children in rural Africa have no access to modern healthcare facilities and where traditional system is practiced, there is no chance that an infant with sickle cell disease will be diagnosed correctly.

The association of hemoglobin S with cases of renal medullary carcinoma, early stage of renal failure in autosomal dominant polycystic kidney disease and surrogate endpoint for pulmonary embolism are not necessarily the result of hemoglobin S polymerization, while buttressing his argument, he maintained that complications from sickle cell trait are important because about three million people in the USA have this genotype, about 40 to 50 times the number with sickle cell disease. Nagel and Fleming (1992) reported that a number of studies have shown association of sickle cell trait with prematurity and lower birth weight of babies. They added that complications attributed by some to sickle cell trait includes proliferation retinopathy, worsening of diabetic retinopathy, stroke, myocardial infection, leg ulcers, vascular necrosis, arthritis of the joints and increased frequency of the bends from driving although there is no convincing evidence that sickle cell trait increases the incidence of these problems.

Lesi (1982) identified some types of sickle cell crises as hemolytic crisis, aplastic crisis and vaso-occlusive crisis and factors contributing to the crisis are infections caused by Diplococcus pneumonia, haemophilus, influenza, Escherichia coli, Salmonella, malaria, exercises, cold weather etc.

The trauma experienced from sickle cell disease cannot be over emphasized. Katibi (2008) stated that patients with sickle cell disease may have recurrent illness and be hospitalized due to various complications of the disease. The cost implication and mental agony of the parents in particular are of significant note. He further identified physical deformities of the patients such as frontal bossing, protruding abdomen, thin extremities and gnathopathy. Other impacts are: absenteeism from school due to frequent illness, difficulty in getting marital partner, damaging effect of the stigma of being a sickler on his/her psyche, reduced chances of getting pregnant for females, fear of frequent illness during pregnancy (females), increased abortion rate, anxiety on the possible genotype of the baby in – utero, needs for ante-natal diagnosis and its attendant risks, need for therapeutic abortion in case of an unfavorable genotype attendant risk, persistent state of anxiety and tension because the individual can get ill at any time and psychosocial trauma of the knowledge of imminent death. More importantly, the victims may be unable to realize/ actualize his dreams in life and there is denial of some rights and privileges such as work, freedoms, marriage and sex. Katibi stated further that cost of daily maintenance of sickle cell patient is colossal in terms of drugs, nutrition, prevention of crisis, hospitalization and that the affected individuals or families suffer a burden of anxiety, frequent illness, excess mortality rates, ignorance and lack of appropriate health services and research.

Family as a social system theory was used as theoretical basis for the study. According to the most acceptable and common view, the family has been defined as a group of persons united by ties of marriage, blood or adoption constituting a single household. This shows that family implies that usually this small kin-group is a single economic unit, all members share a common culture and authority may be vested in one or many persons of the household. Family is

generally seen as a functional and a socio-cultural unit of the society. It involves the recognition of just those who are closely related to oneself through constant physical continuity, physical cooperation, emotional bonds and blood ties. The sex and hunger drives of a man, his economic compulsions and cultural traditions within which he is bound have provided theoretical justification for the recognition of the existence of family. The birth of off-springs cements and integrates his family life (NOUN 2004).

Noll et al. (1998) asserted that families who have children with sickle cell disease (SCD) endure numerous potentially stressful experiences and daily hassles related to the biological complications of SCD. These ordeals can cause difficulties with finances, work, transportation and changes to daily routines. Mothers of children with SCD are at risk for excessive anxiety, depressed mood, guilt, social isolation and personal health problems.

Psychosocial issues for people with SCD and their families mainly result from the impact of pain and symptoms on their daily lives and society's attitudes to SCD and those affected. In Africa, cultural factors are particularly relevant to these problems because of beliefs and traditional practices. In Nigeria, beliefs are usually influenced by cultural and religious values, which influence health behaviours such as coping strategies.

Bennett (2007) was of the view that a child affected by SCD is often a shock for the parents no matter how well prepared the parents may have felt. The initial hurdle of accepting the diagnosis is often quite difficult and parents may experience the initial emotion of denial. Other common emotions include anger, fear and even grief.

Sometimes there is an overwhelming sense of frustration, the blame of self and also of partners and feelings of inadequacies are not uncommon but for the majority of parents, these are transient emotions but others never come to terms with the fact that their offspring is affected by SCD.

Environmental and social factors are major influences on the parents' ability to cope and these have far reaching implications affecting the child in all aspects of his or her development. Parents with little or no support, living in unsuitable accommodation would perhaps find it more difficult to cope with an affected child more so than those parents who are well supported and are not experiencing hardship (Shepherd and Stuart 2001; Kiddy and Thurtle 2002).

Whitehead et al. (2010) opined that most of the crises faced by the parents of children with SCD could have been prevented or better managed if their parents had knowledge of newborn screening but review of the literature shows that most parents are unaware of newborn screening unless their infant has had an abnormal result.

Parents who are aware of the screening are not knowledgeable about the process of reporting screening result or the conditions for which newborns are screened. In fact, many parents also confuse genetic screening with testing for jaundice, infections or drug exposure.

Parents are unaware of and unable to consider the implications of testing which can increase their distress if the result is abnormal.

In this study, the children with sickle cell disease are products of the parents' genes who are biological members of the fathers and mothers. Interestingly, his/her present state he/she picked it from them and whatever he/she becomes is the handiwork of the parents as family is said to be the cradle of the future society. When a family properly understands this especially parents, they will be able to show a positive and warm attitude towards their children with sickle cell disease. Definitely, if the parents show a positive attitude, other members of the family (siblings) will not show a negative attitude towards their kins with sickle cell disease, but would show a loving, caring and passionate attitude since all have the same bond.

METHOD

The research design adopted was a descriptive method to investigate the parental attitude towards children with sickle cell disease in selected health facilities in Irepodun Local Government Area of Kwara State, Nigeria.

Population

All the parents of children confirmed with diagnosis of sickle cell disease qualified for the study as participants in Irepodun Local Government Area of Kwara State.

Sample and Sampling Procedure

80 participants were selected from identified health facilities in Irepodun Local Government.

For better representation, four government and one private hospitals were chosen for the study. Four hospitals were either owned by federal, state and local government authorities and the fifth one owned by a private individual. The participants were selected by convenience in the various hospitals and by volunteerism as: General Hospital, Oro: 20, General Hospital, Omu-Aran: 20, Comprehensive Health Centre, Esie: 20, Local Government Health Centre, Ajase-Ipo: 10 and Adeyemo Private Hospital: 10 (20+20+20+ 10+10=80 participants). 65 females and 15 males were selected for the study with the age range between 20 and 60 respectively.

Instrumentation

Self-reporting questionnaire was constructed to gather the required data for the study. The questionnaire was divided into two units. Unit A dealt with personal data of the participants while Unit B was on related questions on sickle cell disease and attitudes of parents toward their children with sickle cell disease. Unit A had seven items while Unit B had 46 items with Yes/No responses.

The questionnaire was given to senior researchers in the Faculty of Nursing, Niger Delta University for their inputs, the corrections and suggestions were effected which improved the quality of the instrument to meet the content and face validity.

A pilot study was conducted on two participants each from the five selected health facilities that were used for the final study, the outcome was collated and where necessary corrections were made on the items and the test-retest coefficient was 0.78.

Ethical Consideration

The researchers visited all the selected health facilities for the study, discussed with the Officers-in-charge on the aims and objectives of the study, the procedure and feedback was assured which would contribute immensely to the management of their patients and hospitals. At the end of each meeting with the hospital management, informed consent was given. Luckily, each hospital runs a sickle cell disease clinic day which made the contacts easier for the researchers. The participants were met on the day of clinics for their children by the researchers and hospital heads so that they could be explained to the objectives of the study, given assurance of confidentiality of information offered and assurance of feedback at the end of the study, all these assurances made the participants give their informed consent with ease and hence, they volunteered themselves for the study.

Procedure for Data Collection

On the clinic days of each selected health facility, the researchers met the participants, re-explained the purpose of the study and assured them of confidentiality of privileged information and a feedback after the study as told to them in the last meeting. Then the researchers requested for volunteers in relation to the required number per health facility. The volunteers were enthusiastic to be part of the study and they assured of their maximum cooperation to help the study and themselves also. The questionnaires were distributed to them individually, they were given 40 minutes to complete after which the instruments were retrieved, various questions they had were responded to, to the best of knowledge of the researchers. It was quite an eventful moment at each study centre.

Hypotheses

Five hypotheses were used for the study, tested at the significance level of 0.5.

1. There will be no significant relationship between the sex of the participants and their attitude towards children with sickle cell disease.
2. Religion would not make significant difference in the attitude of parents towards their children with sickle cell disease.
3. There will be no significant relationship between knowledge about the cause(s) of sickle cell disease of the participants and their attitude towards their children with sickle cell disease.
4. Knowledge of the impact of sickle cell disease will not make significant difference in the attitude of parents with children with sickle cell disease.
5. There will be no significant relationship between the knowledge of the participants on the prevention of sickle cell disease and their attitude towards children with sickle cell disease.

RESULTS

The data were collated and simple percentage used while Chi-square was used in the testing of the hypotheses at significant level of 0.5.

Table 1 showed the personal data of the 80 participants as: distribution was 25% were from General Hospital, Omu-Aran; 25% from General Hospital, Oro; 25% from Comprehensive Health Centre, Esie; 12.5% from Local Government Health Centre and 12.5% from Adeyemo hospital i.e. private hospital. The age distribution showed that 43.75% were between 35 and 44 years, 25% were between 25 and 34 years of age, 12.50% were between 45 and 54 years, 12.50% were above 54 years, and 6.25% were below the age of 25 years. Gender distribution showed that 81.25% were females and 18.75% were males.

Distribution of marital status showed that 37.50% were divorced, 25% were widowed, 18.75% were married, 12.50% were separated and 6.25% were single (single parents). The age of marriage distribution showed that 43.75% were between 11 and 15 years, 12.50% below 2 years and 2.5 years respectively and 6.25% were between 16 and 20 years and also above 20 years while the frequency in hospital showed that 50% come to hospitals every month, 25% every 3-4 months, 18.75% every 1-2 months and 6.25% 5-6 months.

Hypothesis 1: There will be no significant relationship between the sex of the participants and their attitudes towards children with sickle cell disease.

The calculated value (31.61) was greater than the table value (12.3) indicating a significant relationship between the sex of the participants and their attitude towards children with sickle cell disease (Table 2).

Hypothesis 2: Religion would not make significant difference in the attitude of parents towards their children with sickle cell disease.

The calculated value was 16.62 which was higher than the table value of 12.3 this showed that religion had significant difference in the attitude of parents whose children have sickle cell disease (Table 3).

Hypothesis 3: There will be no significant relationship between the participants' knowledge about the causes of sickle cell disease and their attitudes toward children with sickle cell disease.

Table 1: Personal data of the participants

Variables	*f*	*%*
Name of Hospital		
General Hospital, Oro	20	25.0
General Hospital, Omu-Aran	20	25.0
Comprehensive Health Centre, Esie	20	25.0
Local Government Health Centre, Ajase-Ipo	10	12.5
Adeyemo Hospital (Private), Omu-Aran	10	12.5
Age		
20 -25 years	5	6.25
25- 34	15	18.75
35- 44	30	37.5
44 -54	20	25.0
54-60	10	12.5
Sex		
Male	15	18.75
Female	65	81.25
Marital Status		
Single	10	12.5
Married	10	12.5
Divorced	35	43.75
Widowed	15	18.75
Separated	5	6.25
Age of Marriage	5	6.25
Below 2 years		
2 -5 years	70	85.0
6 – 10 years	4	2.0
11 – 15 years	6	3.0
16 – 20 years	2	1.0
Above 20 years	18	9.0
Frequency in Hospital		
Every month	40	50.0
1 – 2 months	15	18.75
3 – 4 months	20	25.0
5 – 6 months	5	6.25

Table 2: Relationship of sex and attitude of the participants toward children with sickle cell disease

Variable	*Response*				
	Yes	*%*	*No*	*%*	*Total*
Sex					
Male	5	6.25	10	12.50	18.75
Female	60	75.00	5	6.25	81.25
Total	65	81.25	15	18.75	100.00

χ^2 cal = 31.61 χ^2 tab = 12.3, df = 1
= χ^2 (1, N = 80) = 31.61 , P < .05.

Table 3: Summary of χ^2 of the religion of the participants

Variable	*Response*				
	Yes	*%*	*No*	*%*	*Total*
Participants' Knowledge					
Male	12	15.0	3	3.75	18.75
Female	60	75.0	5	6.25	81.25
Total	72	90.0	90	10.00	100.00

χ^2 cal = 15.60, χ^2 tab = 12.3, df = 1
= χ^2 (1, N = 80) = 15.60, P<.05.

The table 4 showed that calculated value of 15.60 higher than table value of 12.3 showing that there was a significant relationship between knowledge about the cause(s) of sickle cell disease and the attitude of parents towards their children with sickle cell disease.

Hypothesis 4: Knowledge of the impact of sickle cell disease will not make significant difference in the attitude of parents with children with sickle cell disease.

Calculated value of 19.41 was higher that table value of 12.3 hence knowledge of impact of sickle cell disease made significant difference in the attitude of parents with children with sickle cell disease (Table 5).

Hypothesis 5: There was no significant relationship between the knowledge of the participants on the prevention of sickle cell disease and their attitude towards children with sickle cell disease.

The table 6 showed that calculated value of 14.44 higher than table value of 12.4 so there was a significant relationship between knowledge of the participants as par prevention of sickle cell disease and attitude towards their children with sickle cell disease.

Table 4: Participants' knowledge about causes of sickle cell disease and attitudes towards children

Variable	*Response*				
	Yes	*%*	*No*	*%*	*Total*
Participants' Knowledge					
Male	12	15	3	3.75	18.75
Female	60	75	5	6.25	81.25
Total	72	90	90	10	100.00

χ^2 cal = 15.60, χ^2 tab = 12.3, df = 1
= χ^2 (1, N = 80) = 15.60, P<.05.

Table 5: Knowledge of the impact of sickle cell disease and attitudes towards children

Variable	*Response*				
	Yes	*%*	*No*	*%*	*Total*
Knowledge of the Impact of Sickle Cell Disease					
Male	8	10	7	8.75	18.75
Female	55	68.75	10	12.5	81.25
Total	63	78.75	17	11.25	100.00

χ^2 cal = 19.41, χ^2 tab = 12.3, df = 1
= χ^2 (1, N = 80) = 19.41, P<.05.

Table 6: Participants' knowledge about the prevention of sickle cell disease and attitudes toward children

Variable	*Response*				
	Yes	*%*	*No*	*%*	*Total*
Knowledge of the Participants on the Prevention of Sickle Cell Disease					
Male	15	18.75	0	0	18.75
Female	58	72.5	7	8.75	81.25
Total	73	91.25	7	8.75	100.00

χ^2 cal = 14.44, χ^2 tab = 12.3, df = 1
= χ^2 (1, N = 80) = 14.44, P<.05.

DISCUSSION

The findings showed that sex correlates with the attitude of the parents to the children with sickle cell disease although most of the participants were females because they interacted with the health facilities since mostly mothers stay with their children in the hospitals or accompany them to the hospitals, most mothers are more caring than fathers regardless of the diagnoses of their children even the prognoses. It showed majority of the respondents ended up with their marriages in divorce, separation, even death of spouses which may be due to their attitudes towards sickle cell disease. Females are better enduring individuals than males especially in difficult situations as they will not ignore or neglect their children even in case of sickle cell disease that does not have a cure.

Religion was another variable that influenced the attitude of these parents to their children with sickle cell disease. With highly religious parents, their attitudes would be obviously positive as they would show more of love, care, compassion and passion in whatever they do for these children, especially when in crisis, they will also accept their fate for having such children, see it as an act of God, as destiny, while the low religious parents will blame themselves for having married such a spouse who produced such children. They might have expression of regret which their children might see, they feel bored hence, so may end such marriages in divorce or separation, leaving the victims with either the fathers or mothers.

Anie et al. (2010) were of the opinion that cultural and religious values have significant impact on the attitudes of parents of children with sickle cell disease especially in Nigeria as these variables influence their health behavior in relation to coping strategies as most parents submit to their fate.

Knowledge about the causes, impacts and prevention is crucial to the management of sickle cell disease. In Nigeria, the majority are illiterate and poor, subjected to economic exploitation, deprivation and social ostracism which is reflected in their low quality of life. These underprivileged ones in the society face social stigma forcing them to occupy the lowest rung of the social ladder, leading to inability to meet the daily demands of their sickle cell afflicted children. Erinosho (2005) explained that the general belief among Nigerians is that illness can be caused by natural, preternatural and mystical factors. The preternatural explanation is related to the belief in witchcraft where the onset of illness is attributed to the evil machinations of an enemy and he concluded that in most Nigerian cultures, there is the belief that a sorcerer, wizard and other malevolent human beings can cause illnesses, including sickle cell disease. Where there is no sound knowledge about the causes, impacts and prevention of sickle cell disease, then the preternatural and mystical beliefs will be predominant and this will definitely affect their attitudes towards their children with sickle cell disease but where these parents have sound and scientific knowledge of causes, impacts and prevention of sickle cell disease, it is sure that this scientific knowledge would affect their attitude positively towards their children with sickle cell disease as their attitude will be caring, loving, compassionate, empathetic and warm despite the fact that the presence of the disease in the family is not a joyful occasion , the knowledge acquired will afford a better capacity of coping mechanism by the parents and other members of the family (Rowe 2002).

The level of understanding is reflected by the attitude of the parents i.e. how parents talk about the disease and behave towards the child, even those with full knowledge about the disease, the discovery of a sickler in the family is not a moment of joy rather a moment of sadness, sorrow, despair, regrets and apportioning blames on each other. To some it may be a moment of critical decision making like divorce or separation, abandonment or rejection while some may decide for some defense mechanisms which may be a temporary solution or may worsen the situation. No doubt, individual differences will come in at this moment of discovery as reactions may be unpredictable.

CONCLUSION

Many people are sufferers of sickle cell disease today which is a hidden problem. In Africa, children with sickle cell disease are usually first diagnosed following an acute illness and not by screening. Sickle cell anemia is a preventable health problem that is commonly occurring in couples who are not aware of their genotypes.

The high incidence of sickle cell disease in Africa makes it a public health problem but it is often not recognized as such because so many cases go undiagnosed before or even after death.

The clinical spectrum of sickle cell disease is not well described because only the few patients followed-up in urban, modern medical centers form the basis of what appears in medical literature while majority of cases are in rural areas. It is of note that malaria and its complications further worsen the morbidity and mortality of sickle cell disease.

RECOMMENDATIONS

From the study, the following recommendations were offered:

- Religious leaders should educate their youths on the importance of pre-marriage genotype screening and especially before marriages are conducted it should be a criterion.
- Sickle cell associations/clubs must be created at several locations and aided by government where parents and the affected can discuss freely and be rehabilitated, as this will serve as psychosocial support for both.
- A vigorous enlightenment campaign on sickle cell disease should be put in place through appropriate media like print and electronics.
- Medical treatment of sickle cell disease should be highly subsidized by the government if not entirely free to make it affordable and accessible for all.
- Counseling sessions should be run by psychologists and social workers for parents and children with sickle cell disease as this will reduce the disease burden on families and individuals.
- Government in collaboration with private individuals should run a rehabilitative centre for children or individuals with sickle cell disease, parents and spouses should be involved too.

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