

Awareness, Perception and Attitude of Parents Towards their Children with Sickle Cell Disease in Paediatric Department Tertiary Hospitals, Rivers State

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Abstract

Sickle cell disease (SCD) occurs due to a genetic mutation, a replacement of the nitrogen base thymine with adenine, which results in the substitution of glutamic acid with valine at the sixth position of the B chain on the short arm of chromosome. This study tried to investigate the awareness, perception and attitude of parents towards their children with sickle cell disease in Paediatric Department Tertiary Hospitals, Rivers State. A descriptive research design was adopted, with a population comprising of parents who have children with Sickle cell disease that came for check-up or were admitted were used. The instrument for data collection was a questionnaire which was distributed after using convenient sampling technique to select 313 respondents. Data was analyzed using the Microsoft excel and Statistical package for social sciences (SPSS) version 25.0. Findings showed that all of the respondents 313(100%) have heard of Sickle Cell Disease. They had good perception towards the disease but their attitude was poor because 192(61.3%) of the respondents find it difficult to accept the responsibility of caring for the child. It was concluded that all intending would be couples should do a pre-marital screening test to exclude SCD. It is recommended that, health care workers should continue to create awareness on the dangers of sickle cell disease, SCD should be added in the curriculum and parents should assist their children to live a health promotive and preventive life style.

Keywords: Awareness, Perception, Attitude, Parents

Introduction

Sickle cell disease (SCD) occurs due to a genetic mutation, a replacement of the nitrogen base thymine with adenine, which results in the substitution of glutamic acid with valine at the sixth position of the B chain on the short arm of chromosome (World Health Organization (WHO), 2016). This change leads to formation of structurally abnormal hemoglobin, called hemoglobin S (HbS), and, consequently, deformation and stiffening of the red cell membrane. Sickle cell Disease

is the most common monogenic blood disorder worldwide. It is associated with progressive organ damage coupled with episodes of acute illness from the sticky and stiff red blood cells which clog the tiny blood vessels. This often results into, various conditions not limited to organ and tissue damage, anaemia, increased risk of the infection and painful episodes (centers for disease control and protection 2016). According to Bunn (2017), SCD is a blood disorder in which the sickling allele for haemoglobin is inherited in the homozygous state or with another abnormal gene haemoglobin structure or production. Sickie red blood cells (RBCs) are unable to pass through capillary beds and are destroyed within 10-17 days in comparison to the normal 120-day life span of non-sickle RBCs, leading to chronic anaemia. Also, chronic haemolysis can lead to jaundice, formation of pigment gall stones and pulmonary hypertension, which is a major risk factor for death in SCD patients (Gladwin, et. al., 2018), Similarly, the obstruction of blood flow in small vessels by sickle cells can also lead to serious complications of ischemia or necrosis in all of the major organs, dactylitis and hypersplenism (Sergeant, 2017). Ohene-Frempong. et. al., (2018) found that approximately 11% of SCD patients experience a stroke by the age of 30. In addition, SCD may also affect the respiratory system resulting in acute chest syndrome and chronic sickle lung disease. These are leading causes of death and hospitalization for all ages of SCD (Schnog, 2017).

Awareness is the state wherein a subject is aware of some information when that information is directly available to bring to bear in the direction of wide range of behavioral actions. It is associated with consciousness in the sense that those concept denotes a fundamental experience such as feeling or intuition that accompanies the experience of phenomena (Wyalt et al., 2018). Attitude is a way of feeling or acting toward a person, thing or situation. It can be positive or negative evaluation of people, objects, events, activities and ideas. Perception in humans is the process whereby sensory stimulation is translated into organized experience. That experience or precept is the joint product of the stimulation and of the process itself.

Worldwide, there are about 300,000 babies born with SCD-every year, and the majority in low-income countries will pass away before their fifth birthday. More than 66% of the 120-million people affected worldwide by sickle cell disease live in Africa. Approximately 1000 children are born with the disease every day in Africa, making it the most prevalent genetically acquired disease in the region. Nigeria has a population of about 112 million with an annual growth rate of 3.2%. About 25% of adults throughout the country have sickle cell trait, as, while the Hb C trait is largely confined to the Yoruba people of Southwestern Nigeria in when it occurs in about 6%. Of a total of 5.4 million expected live births in 2013, about 90,000 will have SCD and 1.1 million the trait, (Ashley-Koch 2019).

Worldwide, the burden of sickle cell disease has not been adequately addressed; it affects millions throughout the world, It contribute to an equivalent of 5% of under-five death in the African continent and more than 9% of such death are in West Africa (Afolayan et al 2017). Ango et al (2019) states that Nigeria alone account for 20% of the sickle cell cases worldwide and about 2.3% of her population suffer from sickle cell disease with 25% being carriers. Patient with sickle cell disease lack accessible formal, social support structure to aid them cope better with the psychosocial burden of sickle cell disease. In addition, this has coupled with stigmatization and discrimination of people living with sickle cell disease causing isolation from family and society.

These has raised the following questions; Is it that parents are not aware of sickle cell disease? Or do they perceive that such cannot be detected and treated in the hospital?

The researcher during her clinical experience in Tertiary Hospitals, Rivers State was opportune to interact with few parents who brought their sickle cell children for check-up. Through the interaction, the parents poured out their heart about the burdens they had gone through as a result of their sickle cell children which includes; Financial burden, stress of visiting the hospital each time the crisis surface irrespective of the distance, Family crisis and lack of knowledge on how to handle the situation. It was on this note that the researcher decided to carry out a study on Awareness, Perception and Attitude of Parents towards their children with sickle cell disease. The study provided answers to the following research questions:

1. What is the parental level of awareness on children with SCD in Paediatric Department, Tertiary Hospitals?
2. What perception do parents have on SCD in Paediatric Department, Tertiary Hospitals?
3. What is the attitude of parents towards their children with sickle cell disease in Paediatric Department, Tertiary Hospitals?
4. What are the factors that will improve parental care towards their children with sickle cell disease in Paediatric Department, Tertiary Hospitals?

Methodology

The study adopted a descriptive cross-sectional research design. The target population comprised of parents who had children with Sickle cell disease that were in the hospital within the period of one month. These include those met both in the ward and in the clinics for check-up. A sample size of 313 was selected using the convenient sampling technique. Data was collected using a self-structured questionnaire with a reliability index of 0.65. The information gotten was entered into Statistical Product and Service Solution (SPSS) version 23.0. It was coded, cleaned and analyzed with both SPSS and Microsoft excel. The descriptive Statistical analysis was presented in frequency distribution tables, percentages, charts, mean and standard deviation.

Ethical Consideration: A letter of introduction and permission to carry out the study was written and duly signed by the Coordinator of the School of Post Basic Nursing Studies. It was presented to the Head of Nursing Services (HNS), UPTH and BMH explaining the purpose of the research and requesting the permission to carry out the research in the facility.

Results

The results of the study are shown below:

Table 1: Socio-Demographic Characteristic of Respondents (n = 313)

<i>Variables</i>	<i>(f)</i>	<i>(%)</i>
Marital Status		
Single	77	24.6
Married	108	34.5
Divorced	90	28.8
Widow	38	12.1
Total	313	100
Gender		
Male	84	26.8

Female	229	73.2
Total	313	100
Age		
18 – 25yrs	68	21.7
26 – 32yrs	82	26.2
33 – 39yrs	73	23.3
40 and above	90	28.8
Total	313	100
Educational Qualification		
Primary Level	NIL	0.0
Secondary Level	7	2.2
Tertiary Level	306	97.8
Total	313	100
Occupation		
Trading	81	25.9
Farming	9	2.9
Civil Servant	127	40.6
Other Businesses	96	30.7
Total	313	100
Religion		
Christian	299	95.5
Islam	7	2.2
Pagan	7	2.2
Others	NIL	0.0
Total	313	100

Table 1 is showing the socio-demographic data of the respondents. The result showed that most of the respondents 108(34.5%) are married, and many 90(28.8%) are divorced and 77(24.6%) single. They are mostly 229(73.2%) of the female gender and they are fairly distributed within the age ranges. Most of the respondents 306(97.8) are educated and got up to tertiary level in education. They are mostly 127(40.6%) civil servants, but very few 9(2.9) are farmers. They are majorly 299(95.5%) of the Christian religion.

Table 2: Showing Parental Level of Awareness on Children with SCD.

S/n	Item	SA	A	D	SD	Mean	Std Dev
7	Have you heard of Sickle Cell Disease?	157(50.2%)	156(49.8%)	0(0.0%)	0(0.0%)	3.50	.50
8	Children with SCD does not fall ill often.	0(0.0%)	28(8.9%)	102(32.6%)	183(58.5%)	3.49	.65
9	Can be passed by parents through blood.	35(11.2%)	257(82.1%)	7(2.2%)	14(4.5%)	3.00	.56

10	Cannot be prevented if screened before having children.	14(4.5%)	7(2.2%)	96(30.7%)	196(62.6%)	3.51	.75
11	Early screening & treatment prolongs life.	206(65.8%)	107(34.2%)	0(0.0%)	0(0.0%)	3.65	.47
Grand Mean						3.43	0.58

Criterion mean = 2.50. Decision: <2.50 is poor, ≥2.50 is good

The table above illustrates Parental Level of Awareness on Children with SCD in Pediatric Department. The overall result shows that they have good level of awareness as the grand mean is 3.43 ± 0.58 . The result shows that all of the respondents 157(50.2%) SA and 156(49.8%) have heard of Sickle Cell Disease. Majority 183(58.5%) strongly disagreed to the fact that children with SCD do not fall ill often. Most of them opined that 206(65.8%) early screening & treatment cannot prolong life of children with SCD. None of them disagreed 0(0.0%) to the fact that early screening & treatment prolongs life.

Table 3: Showing Perception of parents towards sickle cell disease.

S/N	Item	SA	A	D	SD	Mean	Std Dev
12	Sickle Cell Disease is curse.	7(2.2%)	0(0.0%)	200(63.9%)	106(33.9%)	3.29	.58
13	SCD is caused by witches & wizards	14(4.5%)	0(0.0%)	105(33.5%)	194(62.0%)	3.53	.72
14	It is a curable disease.	0(0.0%)	0(0.0%)	190(60.7%)	123(39.3%)	3.39	.48
15	My family is stigmatized for it.	35(11.2%)	119(38.0%)	150(47.9%)	9(2.9%)	2.42	.72
16	Family relatives must not know.	7(2.2%)	56(17.9%)	0(0.0%)	250(79.9%)	2.77	.82
17	SCD is as a result of sin of parents.	7(2.2%)	0(0.0%)	56(17.9%)	250(79.9%)	3.75	.56
Grand Mean						3.19	0.64

Criterion mean = 2.50. Decision: <2.50 is poor, ≥2.50 is good

Table 3 above is a table illustrating the perception of parents towards sickle cell disease. The result shows that most of the respondents 200(63.9%) did not agree that Sickle Cell disease is a curse. They believe 194(62.0%) it is not caused by witches and wizards. Most 250(79.9%) of the respondents did not agree that family members should not know about the illness, and they disagreed 250(79.9%) to the fact that Sickle Cell Disease is as a result of sin of parents. On the contrary, none of the respondents 0(0.0%) agreed that Sickle Cell Disease is a curable disease. Therefore, the overall result showed that the parents have a good perception about Sickle Cell Disease as the criterion mean is 3.19 ± 0.64 .

Table 4: Showing the attitude of parents towards their children with Sickle Cell Disease.

S/n	Item	SA	A	D	SD	Mean	Std Dev
18	Difficult to accept responsibility of care.	31(9.9%)	192(61.3%)	90(28.8%)	0(0.0%)	2.18	.59
19	Feel depressed about child's condition.	85(27.2%)	143(45.7%)	85(27.2%)	0(0.0%)	2.00	.73
20	Occasionally feel child should be kept in a hospital.	56(17.9%)	128(40.9%)	129(41.2%)	0(0.0%)	2.23	.73
21	Feel the child is a burden on my family's income.	7(2.2%)	76(24.3%)	164(52.4%)	66(21.1%)	2.92	.73
22	I am glad caring for him/her.	98(31.3%)	180(57.5%)	28(8.9%)	7(2.2%)	1.82	.67
Grand Mean						2.23	0.69

Criterion mean = 2.50. Decision: <2.50 is poor, ≥2.50 is good

The above table which is a table 4.4 showing the attitude of parents towards their children with Sickle Cell Disease. The overall result shows that the parents do not have good attitude toward their children with Sickle Cell Disease as the grand mean is below the criterion mean. It shows that most parents 192(61.3%) find it difficult to accept the responsibility of caring for the child. Most of them 143(45.7%) said that they feel depressed about child's condition, only 27.2% of the respondents said that they don't feel depressed. Of the 213 respondents, almost same number agreed 128(40.9%) and disagreed 129(41.2%) that child should be kept in a hospital for care always. Most of them 180(57.5%) agreed that they are glad caring for them.

Table 5: Showing factors that will improve parental care towards their children with SCD

S/n	Item	SA	A	D	SD	Mean	Std Dev
23	Enough income will enhance child's care	218(69.6%)	95(30.4%)	0(0.0%)	0(0.0%)	3.69	.46
24	Free medical services will enhance care.	204(65.2%)	109(34.8%)	0(0.0%)	0(0.0%)	3.65	.47
25	Understanding disease process improves care	181(57.8%)	132(42.2%)	0(0.0%)	0(0.0%)	3.57	.49

26	Parents' unwillingness to accept condition improve care.	0(0.0%)	0(0.0%)	167(53.4%)	146(46.6%)	1.53	.49
27	Parents tight schedule will enhance care.	0(0.0%)	0(0.0%)	148(47.3%)	165(52.7%)	1.47	.50
Grand Mean						2.78	0.48

Criterion mean = 2.50. Decision: <2.50 is poor, ≥2.50 is good

Table 5 describes the factors that will improve parental care towards their children with SCD. The result shows that all the respondents strongly agree 218(69.6%) and agree 95(30.4%) that enough income will enhance care. No respondent objected to this. All equally agreed 109(34.8%) and strongly agreed 204(65.2%) that free medical service will improve care, this is equally with no objection. The whole respondents disagreed to the fact that parents' unwillingness to accept condition improve care. Also, tight schedule of parents will not improve care.

Discussion of Findings

This study aimed to ascertain the awareness, perception and attitude of parents towards their children with Sickle Cell Disease in Paediatric Department in Tertiary Hospitals, Rivers State. The result of the findings showed that the parents had a high level of awareness of Sickle Cell Disease as the grand mean is 3.43 ± 0.58 . This is expected because they are already in the hospital with the case. This study was supported by the study Shapino et al., (2017) conducted on knowledge, perception and practices towards sickle cell disease; a community survey among adults in Lubaga division, Kampata Uganda. They reported that, 91.2% of the respondents had heard of sickle cell disease. Ugwu (2016) buttressed the same point with this study with the exposition made by their study that all the participants (100%) were aware of the existence of sickle cell disease. It was equally reaffirmed by Olarewaju et al., (2013) that majority of the respondents 133 (97.4%) were aware of sickle cell disease. Adeseye et al., (2020) also confirmed through the result of their study that (74.1%) of the respondents had good knowledge of SCD. The study is at variance with the study of Adewoyin et al., (2015) which claimed that only 17.8% had good knowledge of sickle cell disease. Also in disagreement with this study is the study of Boadu, et al., (2018) on knowledge, beliefs and attitude towards sickle cell disease among university student in Ghana campus. They opined that 45.1%, 47.8% and 7.1% respectively had poor, moderate and excellent knowledge of sickle cell disease.

The study findings showed that the parents of children who have sickle cell disease is good as the criterion mean is 3.19 ± 0.64 . The respondents 200(63.9%) did not agree that Sickle Cell disease is a curse. They believe 194(62.0%) it is not caused by witches and wizards and they disagreed 250 (79.9%) to the fact that Sickle Cell Disease is as a result of sin of parents. This study was at disparity with the study conducted by Abubakar, et al., (2016) on perceptions about Sickle Cell Disease and its prevention among undergraduates of tertiary institutions in Kano State Nigeria. They reported that, there is deficiency in the perceptions about SCD. Also, Olatunya, et al., (2020) said that the perception and practice of early sickle cell disease diagnosis is suboptimal.

On the attitude, the overall result shows that the parents do not have good attitude toward their children with Sickle Cell Disease as the grand mean is below the criterion mean 2.23 ± 0.69 . Most parents 192(61.3%) find it difficult to accept the responsibility of caring for the child and many 143(45.7%) said that they feel depressed about child's condition. This study was in disparity with that of Olubiya et al (2016) who said that 94.4% had positive attitude towards actions that will enhance wellbeing in Sickle Cell Disease. Ugwu (2016) on sickle cell disease; awareness, knowledge and attitude among undergraduate student of a Nigeria tertiary educational institution in Ebonyi State University, Abakaliki, Ebonyi, Nigeria stated that, majority of the participants have positive attitude to people living with SCD as 93.6% agreed that people with SCD should not be isolated from others.

The study identified factors that improve parental care towards their children with SCD. Those factors include but not limited to: enough income 218(69.6%); free medical services 204(65.2%); understanding disease process 181(57.8%), among others. In comparison with the study of Adeseye et al., (2020) vast majority (91.2%) of the respondents has lost financial income due to time spent caring for the child, 77.3% reported that the child's illness disturbed activities at home, almost all (96.8%) reported an atmosphere of tension in the home due to child's illness, 80.6% reported episode of depression and feeling sorrowful, 34% felt angry with self or child and 14.3% felt stigmatized because of child's illness.

Conclusion

Sickle cell disease is a burden to the patient, family, hospital and society at large but it can be prevented through pre-marital screening. Parents should therefore ensure that their children embark on this screening before marriage to avoid the menace since permanent treatment is not easily assured. Every misconception relating to Sickle cell disease and its management should be thoroughly cleared.

Recommendations

The following recommendations were made based on the findings of the study:

To Health Care Workers

- They should ensure that intending couples should go for pre-marital screening before tying the knot.
- They should continue to create awareness on the dangers of sickle cell disease.

To Schools

- SCD should be added in the curriculum for both secondary and tertiary schools to avoid future mistakes.
- There should be routine check in schools on student genotypes.

To parents

- Embrace the situation with positive attitude. This will help ease the stress and tension.
- Assist children to live a health promotive and preventive life style

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