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Assessment of genetic counseling in self-care management by caregivers and parents of children with sickle cell disorder in Lagos state

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ABSTRACT

This study was conducted among parents and care-givers of children diagnosed with sickle cell disorder in selected health facilities-Maccy Sickle Cell Clinic, Gbagada Sickle Cell Clinic and National Sickle Cell Centre, Lagos; to assess the impact of genetic counselling on their preventive sickling crises measures and adherence level as diverse reports have predicted genetic counselling and public education about SCD as a vital factor that mediates the improvement of prospects for SCD management in low income countries. A total number of 104 parents or/and caregivers of children with sickle cell disorder in centres affiliated with Sickle Cell Foundation were interviewed through designed questionnaires. The mean age of the respondents studied was 38.6.Using Epi-info,statistical analysis showed an insignificant association between respondents' level of formal education and adherence to selfmanagement measures as $\chi^2 = 0.2$, P = 0.624 and Fishers P = 0. 616. Also, frequency of genetic counselling visits was unrelated to adherence as only 23.4% of respondents that have attended genetic counselling for four times and more, use a thermometre to measure their child's temperature while 76.6% from the same group do not. Hence, no statistical association was found as $\chi^2=0.4$, P=0.505 and Fishers' P=0.609. There is therefore, the need for incorporating improved psychosocial and behavioural interventions into existing social management protocol of sickle cell disorder to engender adoption and adherence of sickling crises prevention measures by caregivers and parents for improved health outcomes in sickle cell patients and across other domains of sickle cell disorder management.

Keywords: Sickle Cell Disorder (SCD), Genetic counselling, SCD management, SCD Perception, sickling crises prevention, Self-care measures, adherence, educational level, sickle cell trait, adoption.

INTRODUCTION

Sickle Cell Disorder (SCD) is an inheritable disorder which affects the red blood cells in man[1,2]. The disorder is caused by the inheritance of two defective hemoglobin genes one from each parent i.e. Hb^S which infers that there is a one in four, or 25% chance of a baby having sickle cell disorder with each pregnancy when both partners have the sickle cell trait. [3].

An estimate of about 2.3% of the Nigerian population was reported by [4] as sufferers of SCD while [5,6] stated that about 25% of Nigerians are healthy carriers of the abnormal hemoglobin gene. In view of this, the adoption of medical services in developed countries; such as neonatal screening, diagnostic testing and comprehensive care, have been proffered as measures that could significantly reduce ill health and death from SCD in infancy and early childhood [7, 8,9,10].

However, genetic education and counselling about the disorder has been indicated in several these reports to mediate the success of medical services for SCD management. This is achieved through genetic counsellors who ensures that person(s) affected with sickle cell disorder, their parents, or healthy carriers of sickle cell trait are provided with the necessary information on SCD to assist them in understanding the inheritance pattern, the manifestations, complications and self-management measures to prevent sickling crises [11-13].

Holistic Management of Persons with SCD

The implementation of a holistic approach that involves a multidisciplinary team of well trained professionals, and a well-defined social support system is therefore essential to meet the physical, emotional, psychological as well as the financial needs of people affected by SCD[14,15]. Also, the incorporation of genetic counselling into medical services has been deemed necessary to tackle its attendant psychosocial issues and lead to a better management of outcome in children with SCD.

Thus, social services and psychological support activities is an important component which determines comprehensive health maintenance outcome in sickle cell patients [16-18], because social workers are vital in solving numerous social and family problems[19]. This amongst other factors led to the establishment of Sickle Cell Foundation, Nigeria in partnership with MTN (multi-national telecommunication industry) under the chairmanship of Professor Olu Akinyanju in 1994; with the aim of proper care and control of SCD in Nigeria through health management facilities/clinics.

This foundation has helped in executing early intervention for accurate diagnosis and preventable problems with pain medications, antibiotics, nutrition, folic acid supplementation in a bid to reduce many of the major complications of SCD as recommended in previous studies [4,10,18].

The following are some of the tenets highlighted for the implementation of improved management services for people affected by SCD through a model national control programme which operates based on the following medical and non-medical practices [4,7,13]:

- a) Prevention and education (pre-natal diagnosis, counselling on family planning options).
- (b) Early detection and treatment.
- (c) Research and community education.

Genetic Counselling

Genetic counselling is a clear communication process whereby the functional understanding and genetic mechanism by which a particular inherited disorder is transmitted, developed and prevented[20]. It also presents the client with an array of choices that could be made in a bid to clear bias and misconceptions about the disorder.

Also, patients or relatives are advised of the options open to them in management and family planning, medical, psychological, social issues related to the condition in order to prevent the disorder [21].

Genetic counselling/education for parents/caregivers of children for management of children with SCD are focused on the following:

• Nutritional Counselling

Several biomedical researchers have suggested a strong link between diet and better health outcomes as this can be achieved when nutritional requirements are adapted and controlled for individuals considering their acquired genetic characteristics [22].

Mothers are encouraged to breastfeed their infants, give their child/wards with SCD fluids and balanced die regularly in order to boost their immunity [23]. Genetic counselling enables follow-up of parents and caregivers on adherence to balanced diet regimen and nutrient-based food for their child/ward with SCD which is essential so as to avoid frequent hospitalizations and crises incidence.

• Recognition Of Early Signs Of Illness And Home Care

During parent education sessions, information is provided on general measures of health care and the need for regular clinic visits. Also, training and monitoring skills are taught to help them with special investigations

[23,24]. Physical assessment skills such as palpation of the spleen, avoidance of vaso-occlusive complication measures and treatment of pain is also essential to promote the achievement of a notable decline in frequency of SCD children hospitalizations, resulting from early detection and improved medical management [13].

However, it is important that educational sessions and materials match the literacy level of the parent/ caregiver[25] as appropriate education is necessary to erase religious/cultural bias and untruths about the genetic disorder which will also result in a positive attitude for better health utilisation and management[26,27].

Also, adequate education about the disorder help to increase their awareness which ultimately reduces stigma and depression in parents who are mostly faced with the burden financially and physically due to multiple hospitalizations of their child/children with SCD[27,28].

Psychological researchers have also suggested that outcome in children with SCD is strongly linked to compliance to prescribed drugs and home care. In view of this, a Health Belief Model is used by genetic counsellors to reinforce the benefit of compliance to routine nutritional guide, health care and prescribed drug administration to parents and caregivers of children with SCD [28,29].

However, it is important to note that counselling goals are entirely based on the principle of self-determination and the counsellors' success is not determined by a decline in the incidence of SCD but the extent to which informed self-interest decisions are made [13].

Also, the feat of achieving a qualitative genetic counselling in the management of SCD is directly related to combined effect of accurate diagnosis, treatment, primary health care, and social support services etc [30].

A study by [20,31]opined that there are a number of factors which range from formal educational level, socio economic status, culture, location etc and could be attributed as factors that modify the adherence level of caregivers. These factors could significantly predict or modify health outcomes [23].

Therefore, addressing the social issues that many of the African American families face is important to the success of these interventions i.e no amount of education may modify behaviour until other pressing issues such as poverty and housing needs for families are addressed[26].

Non adherence in primary health care have been traced to the following factors: cost of medications, side effects/fear of side effects, failure to keep track of medications/complexity, location of health centre etc [23,25]. There is also an indication that parents of children with SCD in facility-based clinics (where drugs and diagnosis is at no cost or reduced rate) are motivated to attend their clinic appointments promptly as the Sickle Cell Foundation operations has helped in reducing their financial burden by providing free drugs, consultation and counselling sessions on their clinic days(as reported by the respondents during the course of interview for this study).

They also admitted that the subsidy, and much more the enlightenment on SCD; has influenced their lives positively and a factor that explains the tremendous success recorded in their increased SCD knowledge and health care management of their children.

MATERIALS AND METHODS

The study population was parents and caregivers of children with SCD in selected healthcare facilities –Maccy Sickle Cell Clinic, Gbagada Sickle Cell Clinic, National Sickle Cell foundation. The centre is focused on Sickle Cell Disorder healthcare and management .A total of 104 parents/caregivers of children with SCD in these centres were interviewed.

Type of Research Design

The research design adopted was a descriptive study to assess the impact and relationship of genetic counselling with caregivers' adherence to preventive sickling crises measures via questionnaire method.

Population

All the parents of children confirmed with diagnosis of SCD (104) were respondents for the study and questionnaire administration was on the clinic days at National Sickle Cell Centre Idi-Araba, Gbagada General Hospital, and Maccy Children Hospital, Lagos State(the two (2) sickle cell clinics affiliated with National Sickle Cell Foundation). These two centres with the sickle cell clinic, formed the study population (a total of 104 participants-98 females and 6 males).

Instrumentation

The method of data collection was through the use of self-reporting/administered questionnaire containing closed-ended questionswhich was given to senior researchers at the centre for improved quality and validity of the instrument. The corrections and suggestions were effected to meet the content and face validity criterion.

Ethical Considerations

Confidentiality: Respondents were assured of strict confidence and that no direct or indirect reference to their persons will be made throughout the study and even after the study. They were not required to write their names.

All these were ensured throughout the study. As a facility-based evaluative study, approval and endorsement was given by the management of the Sickle Cell Foundation.

Informed Consent: The respondents were formally informed about the reason for the study and their consent were sought and obtained before their participation in the study.

Research Hypotheses

- 1) There is no significant relationship between frequency of genetic counselling visits and adherence to preventive self-care measures.
- 2) There is no significant relationship between the parental/caregivers' level of formal education and adherence to preventive self-care measures.

RESULTS

The data was analyzed using Epi-info 2009 statistical software .Key variables include: Educational level of parents/care givers, adherence to preventive self-care measures, access to genetic counselling, access to subsidy on drugs and health.

Table 1shows 84.4% of the respondents have easy access to genetic counseling while 15.4% of respondents do not have easy access (based on respondents' accessibility to SCD healthcare centres).

Table 1: Frequency distribution of respondents' access to Genetic Counselling					
Variable: I have easy access to the healthcare centre &people that educate me on SCD Frequency Percentage					
A.	Yes	88	84.6%		
B.	No	16	15.4%		
Total		104	100%		

Table 2: Frequency distribution of respondents' access to subsidy on drugs/health ca				
Variable: I have access to free drugs	Frequency	Percentage		
A. Yes	85	81.7%		
B. No	19	18.3%		
Total	104	100%		

Table 3: Distribution of respondents' perception of impact of genetic counselling					
Variable: Genetic counselling has helped me in caring for my child with SCD Frequency Percenta					
A.	Yes	96	92.3%		
B.	No	1	1.0%		
C.	I don't know	7	6.7%		
Total		104	100%		

Table 4: Association between the frequency of genetic counselling and adherence to preventive self-care measure						
Frequency of genetic counselling visits	Variable: I use a thermometer to monitor my child's temperature	Variable: I use a thermometer to monitor my child's temperature	Total			
	A. Yes	B. No				
Once-thrice 8(8.7) Four times and more 11(12.0) Total 19(20.7)		37(40.2)	45(100%)			
		36(39.1)	47(100%)			
		73(79.3)	92(100%)			
$\chi^2 = 0.4$. P = 0.505 and Fishers p= 0.609						

Frequency of genetic counselling visits	Variable: I can palpate my child's spleen &I do it regularly	Variable: I can palpate my child's spleen &I do it regularly	Total	
	A. Yes	B. No		
Once-thrice 13(14.1)		32(34.8)	45(100%)	
Four times and more	18(19.6)	29(31.5)	47(100%)	
Total 31(33.7)		61(66.3)	92(100%)	

Table 6: Association between level of education and adherence to preventive self-care measures						
Level of education	Variable: I use a thermometre to	Variable: I use a thermometre	Total			
	monitor my child's temperature at home	to monitor my child's temperature at home				
	A. Yes	B. No				
Secondary and below	14(13.6)	56(54.4)	70(100)			
Tertiary and College	8(7.8)	25(24.2)	33(100)			
Total 22(21.4)		81(78.6)	103(100)			
χ^2 =0.2,P=0.624 and Fishers p=0.616						

Table 2shows 81.7% of the respondents have access to free drugs while 18.3% of them do not.

Table 3 shows the respondents' perception of the impact of genetic counselling in the management of their children with SCD.

Table 4 shows that 23.4% of respondents that have attended genetic counselling for four times and more, use a thermometre to measure their child's temperature while 76.6% from the same group do not. 17.8% of the respondents that have attended for once-thrice use a thermometre to measure their child's temperature while 82.2% from this group do not use a thermometre to measure their child's temperature. No statistical association as $\chi^2 = 0.4$, P = 0.505 and Fishers p= 0.609

Table 5 shows that 38.2% out of the 47 respondents that have attended genetic counselling session for four times and more palpates their child's spleen and 29(61.7%) of them do not.Also,13(28.8%) of respondents that have attended genetic counseling about once-thrice palpates their child's spleen while 32(71.1%) from this group do not palpate their child's spleen. No statistical association as $\chi^2 = 0.9$, P = 0.340 and Fishers p value = 0.383

Table 6 shows that 24.2% of the respondents that have tertiary or college level of education use a thermometre to monitor their child's temperature while 75.8% from this group do not use a thermometre. 20% of respondents with secondary level of education and below use a thermometre to measure their child's temperature while 80% from this group do not use a thermometre to measure their child's temperature. No statistical association as χ^2 =0.2,P=0.624 and Fishers p=0.616

DISCUSSION

The mean age of the respondents (parents /caregivers of children with SCD) studied was 38.6years, with a Standard Deviation of 7.9.

Respondents' practice of preventive self-care measures is poor as parental or caregivers' frequency of genetic counselling visits was unrelated to their adherence and adoption of preventive self-care measures practices as 38.3% out of the respondents that have attended genetic counselling session for four times and more palpates their child's spleen and 61.7% of them do not.Also,28.8% of respondents that have attended genetic counselling about once-three times palpates their child's spleen while 71.1% from this group do not palpate their child's spleen.

Furthermore, another variable which was examined in relation to adherence to preventive care measures was found to be unrelated to the frequency of genetic counselling visits as only 23.4% of respondents that have attended genetic counselling for four times and more, use a thermometre to measure their child's temperature while 76.6% from the same group do not.17.8% of the respondents that have attended for once-thrice use a thermometre to measure their child's temperature while 82.2% from this group do not use a thermometre to measure their child's temperature and this result is in consonance with studies tested by [32] which showed no significant relationship between the two variables.

Perhaps, the major component of genetic counselling; which is education to impart accurate knowledge about the disorder do not always imply compliance level and adherence to preventive self-care measures as it is extensively based on the parents/caregivers' 'doing' that implies success and not their knowledge or willingness to comply. Also adherence isnot only about subsidy but a complex relationship between health behaviour, economical factors, drugs side effects and perception.

Also, statistical findings from this study shows that the level of formal education of respondents' and their adherence to preventive self-care measures is unrelated as 24.2% of the respondents that have tertiary or college level of education use a thermometre to monitor their child's temperature while 75.8% from this group do not use a thermometre.20.0% of respondents with secondary level of education and below use a thermometre to measure their child's temperature while 80.0% from this group do not use a thermometre to measure their child's temperature.

This finding is inconsistent with studies by [25,33]which reported a positive correlation between level of formal education and adherence. This is perhaps due to the fact that genetic counselling sessions are primarily delivered in caregivers lay language which is simple enough to enhance caregivers' knowledge of the disorder regardless of their formal educational level.

OUESTIONAIRE

The questionnaire was divided into five sections namely:

- Section A:this is designed to collect demographic data of the parents/caregivers such as occupation, level of education, religion, ethnicity etc
- Section B: This is designed to assess the knowledge of the parents and caregivers about the cause of SCD and its symptoms.
- Section C: This explores issues that pertains to perception and biases about SCD.
- Section D:This explores the genetic counselling aspect, its perceived effectiveness etc
- Section E: This is meant to collect data on the self management measures and adherence to health care lessons.

STUDY QUESTIONAIRE

I,IBITAYO ADEJOKE OLUKAYODE, a post graduate student of the Department of Cell Biology and Genetics, Faculty of Science, University of Lagos, Akoka; kindly request your consent as a respondent in the study. Confidentiality will be ensured as information provided will be used strictly for the purpose of this study.

CONSENT FORM

Respondent consent form for semi-structured questionnaire survey

I,..... years old male/female have been fully made aware of the purpose and importance of this survey. I also fully understand and have confidence that the information I give will be used only for the purpose and hereby consent to participate in this study.

Signature:
SECTION A- DEMOGRAPHIC DATA
Tick ($$) the appropriate answer in the column
Occupation: Farming(), Civil servant(), Business(), Trader(), Employed(), Not employed()
Highest educational level obtained: Primary (), Secondary (), College (), Tertiary (), None ()
Religion: Christian (), Muslim (), others (pls specify)
Ethnicity: a) Hausa b) Igbo c) Yoruba d) Others (pls specify)
Have you attended a genetic counseling session before? Yes () $/ No$ ().

If yes, how many times? Once(),Twice(),Thrice(),Four(),Five times and more()

My child was diagnosed at:1-5yrs(),6-10yrs(),11-15yrs(),16-20yrs(),21-25yrs(),Others(pls specify)......

SECTION B

KNOWLEDGE ABOUT SICKLE CELL DISORDER

Tick ($\sqrt{ }$) the appropriate answer in the column

YES NO I DON'T KNOW

1)Sickle cell	disorder	ic a	disorder	affecting	the red	blood	celle
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- 2) SCD is passed from parents to their children.
- 3) Genotype test is a way to know if one carries the sickle cell disorder.
- 4) When both parent carry the sickle cell trait e.g. (AS) one or more of their children may have Sickle Cell Anemia
- 5) When one carries the sickle cell trait e.g.(AS) and the other doesn't(AA) ,one or more of their children may have Sickle cell disorder
- 6) Good nutrition and care for my child with Sickle cell anemia can help reduce crisis
- 7) Severe anemia, periodical pain and bacterial infection are ways a child with sickle cell anemia is affected.

SECTION C

PERCEPTION ABOUT SICKLE CELL DISORDER

YES NO I DON'T KNOW

- 8) Caring for my child with sickle cell is a waste of time and resources.
- 10) Children with SCD can live a normal life if properly taken care of.
- 9) I worry about what people think of my sickle cell child/ward.
- 10) Blood transfusion is against my cultural belief.
- 11) Sickle cell disorder is caused by spiritual attack from my enemies
- 12) I don't allow my child with Sickle cell anemia participate in exercises/activities at home and school because of stress.

SECTION D

ACCESS TO GENETIC EDUCATION AND COUNSELING

YES NO I DON'T KNOW

- 13) I have easy access to the healthcare centre and people that educate me on SCD
- 14)The counseling service has helped me to know how to care for my child living with Sickle Cell Anemia
- 15) I understand better when I am taught in my mother tongue than English language.
- 16) I can afford to come for Counseling service because it is affordable
- 17) Genetic counseling sessions are time consuming and boring

SECTION E:

MANAGEMENT MEASURES AND HEALTH CARE

YES NO I DON'T KNOW

- 18) I belong to a family support group/health facility on SCD.
- 19) I know when and how to use the routine drugs for my child.
- 20) I have prompt access to regular health check up for my child.
- 21) I give my child balanced food rich in nutrients.
- 22)I have access to free drugs.
- 23) Diagnosis is cheap and affordable.
- 24) I use a thermometer to monitor my child's temperature at home
- 25) I can palpate my child's spleen and I do it regularly.
- 26) I attend and keep my clinic appointments promptly as and when due.
- 27)I give my child with sickle cell anemia lots of fluids.

CONCLUSION

The incorporation of improved behavioural and psychosocial interventions into existing SCD social management services is an evident need for these caregivers and parents as this would engender their commitment to the course of preventive self-care management of their wards and children. Also, use of patient/caregiver reminder system e.g use of automated voice calls, reminder notes, stickers, action graphics to describe self-care skills to foster adoption and adherence is necessary as well. Educational materials (which matches the level of literacy of caregiver/patient) on vaccination, nutrition, medication, disease complications should be given to caregivers and parents of SCD children to enhance better understanding of the SCD sickling crises prevention and management.

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