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Knowledge and Perception of Pregnant Women on Control Measures for Sickle Cell Disorder (SCD) in South-western Nigeria

Olumide O. Adenmosun[1,2,7], Andrew L. Mbewe[2], Taiwo Oyelade[2], Stephen Nurse-Findlay[2], Gbolahan Obajimi[3], Alexander T. Owolabi[4], Taiwo Soyinka[5], Elizabeth O. Adenmosun[1,6]

[1]Florida Atlantic University, Boca-Raton, Florida, USA

[2]World Health Organization, Country Office, Abuja, Nigeria

[3]University College Hospital, Ibadan, Oyo State, Nigeria

[4]Obafemi Awolowo University Teaching Hospital, Ile-Ife, Osun State, Nigeria

[5]Neuropsychiatric Hospital, Aro, Abeokuta, Ogun State, Nigeria

[6]Obafemi Awolowo University, Ile-Ife, Osun State, Nigeria

[7]Bowen university, Iwo, Osun State, Nigeria

Corresponding Author:

Olumide O. Adenmosun

RM 337 – DAVIE WEST

Florida Atlantic University

3200 College Avenue

Davie FL 33314 USA

Abstract

Pregnant women and at-risk couples are key critical subjects in the crusade for the control of SCD. Thus there is need to examine their knowledge and perception about genetic counseling (GC), prenatal diagnosis (PND), pre-implantation genetic diagnosis (PGD) and bone marrow transplant (BMT) as control measures for SCD in Nigeria. 100 respondents were selected by convenience sampling from University College Hospital (UCH), Ibadan and Obafemi Awolowo University Teaching Hospital Complex (OAUTHC), Ilesha in Nigeria. 53% of respondents had adequate information on GC as a control measure for SCD while 80%, 87% and 91% of respondents did not have adequate knowledge on PND, PGD and BMT respectively. Majority (83%) of respondents would consider GC as a widely accepted control measure for SCD, 61% would go through with PND even when it involves termination of an ongoing sickle cell pregnancy. 56% would opt for PGD to select non-sickle-cell embryos for uterine transfer while 45% would choose to do BMT if it were available in Nigeria. Control measures for sickle cell

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disorder among pregnant women in Nigeria - with respect to knowledge and perception was hierarchically scaled as GC > PND > PGD > BMT.

Keywords: sickle cell disorder, genetic counseling, prenatal diagnosis, pre-implantation diagnosis, bone marrow transplant, pregnant women.

Introduction

Sickle Cell Disease (SCD) is the commonest genetic disorder in Sub-Saharan Africa. Nigeria carries the highest burden of sickle cell anemia cases with a prevalence rate of 1-3% for every hundred live births. It is a public health issue which also pertains to pre-conception and family health. The method of transmission is solely attributed to gene transfer from at-risk populations or heterozygotes – with peculiar hemoglobinopathies commonly identified as Hb-S and Hb-C among others (Modell and Darlison, 2008; Forget and Bunn, 2013).

1.1 Prevalence and health implications of SCD in Nigeria

Sickle cell anemia is responsible for about 10% of infant mortality in Nigeria (about 16% in other African Countries) and a need to employ more than a holistic management of the disease is necessary with the increasing population of at-risk persons (Odunvbun, Okolo and Rahimy, 2008; Piel *et al*., 2013). About 25% of the country's population are carriers of the sickle cell trait – which is averagely about 40-million people (Nnaji *et al*., 2013). Continued uncontrolled marriages among these populations may lead to an increased prevalence of sickle cell anemia and a subsequent increase in infant and child mortality in the near future. Studies have shown that women (especially those within the population groups at-risk) – being the carriers of the pregnancy, prefer to be provided with wider ranges of options on control measures for sickle cell births. A survey for example once showed that sixty-three per cent of mothers will rather opt for termination of a sickle cell pregnancy following a prenatal diagnosis (Nnaji *et al*., 2013; Durosinmi *et al*., 1995).

1.2 SCD control measures and practices in Nigeria

The widely accepted primary preventive measure for SCD is genetic counseling for at-risk populations. It informs and also enable them to know their genotypic status before considering marriage (Durosinmi *et al*., 1995; Adeyemi and Adekanle, 2007). Secondary control measures involve genetic diagnosis – which includes pre-implantation and pre-natal diagnosis. Perceptions on pre-natal diagnosis gradually being introduced in Africa have been associated with issues on ethics concerning the termination of an ongoing sickle cell pregnancy (Durosinmi *et al*., 1995).

Views on other secondary control measures such as Pre-implantation Genetic Diagnosis (following In-Vitro Fertilization) – to select non-sickle cell embryos before uterine transfer – have not been visited yet in Nigeria. The fate of embryos diagnosed with sickle cell genes, ethical justifications on donation of diseased embryos for research, and discarding of unwanted sickle cell embryos – are some of the issues of concern that shape the perception of at-risk populations (Strode and Soni, 2001). Other than the holistic management of SCD; perceptions on the introduction, costs, availability, benefits and risks of Bone Marrow Transplant as the current

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curative measure in the management of chronic sickle cell anemia cases, are also yet to be evaluated from at-risk populations and pregnant women – who tend to be the progenitors of sickle cell births (Serjeant, 1996).

1.3 Comparison of Sickle Cell Trait (SCT) incidence among African-Americans

A study by Ojodu et al (2014) on the incidence of sickle cell traits (SCT) among African Americans shows an incidence rate of 73.1 per 1,000 newborns across the USA – with states like Mississippi having as high as 34.1 per 1,000 screened newborns. Though the occurrence of SCT varies significantly among states that participated in the study, data collected showed that every state and racial or ethnic population including Hispanics had persons with the sickle cell trait. Given the possibilities of being at risk of birthing a child with full sickle cell disease (homozygote), primary care providers and genetic counselors begin to educate the families of newborns with the SCT about future reproductive considerations and potential health implications – over a period of time, as an extensive medical services program.

1.4 Assessment objectives

To ensure the proper integration of preventive and curative control measures for sickle cell disorder in Nigeria, an explorative public health survey on the current knowledge base and perceptions of at-risk populations on existing options need to be conducted. This will enable the introduction of health policies that may further ensure the provision and access of preferred and acceptable control measures for sickle cell disorder in Nigeria.

2. Methods

Study employed a descriptive survey tool to examine the perception of respondents on genetic counseling (GC), prenatal diagnosis (PND), preimplantation genetic diagnosis (PGD) and bone marrow transplant (BMT) as control measures for sickle cell anemia in Nigeria. Research setting was delimited to ante-natal clinics of two teaching hospitals in south-western Nigeria – University College Hospital (UCH), Ibadan, Oyo State and Obafemi Awolowo University Teaching Hospital Complex (OAUTHC), Ilesha, Osun State. The target population only included pregnant women seeking ante-natal care from these hospitals. Convenience sampling technique was used to randomly select one hundred (100) respondents at ante-natal clinics for the preliminary study (48 at UCH and 52 at OAUTH). A structured questionnaire was used after obtaining a verbal informed consent from the respondents. Group counseling was conducted for the respondents before joining the study and questionnaires were administered with a chaperone (doctor) in attendance. Descriptive and statistical analyses were done using EPI-Info and SPSS.

3. Results

Table 1: Socio-demographic data

Age group (Years)	N (%)
21 – 30	56 (56)
31- 40	44(44)

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Marital status	
Never married	1(1)
Married	99(99)
No of Pregnancies	
1	32(32)
2	17(17)
3	28(28)
Above 4	23(23)
Educational status	
Non-literate	2(2)
Primary school completed	6(6)
Secondary school completed	19(19)
Tertiary school completed	73(73)
Others	NIL
Religion	
Christianity	84(84)
Islam	16(16)
Others	NIL
Occupational Category	
Professionals	34(34)
Technicians and associate professionals	2(2)
Service and sales workers	43(43)
Elementary occupation	20(20)
Armed forces occupation	1(1)

Table 1 shows that 56% of the respondents are 21-30 years of age, 99% are married and 32% have had at least one pregnancy. 98% of respondents are literates having attended primary school to secondary or tertiary level.

Table 2: Medical history

Relevant Medical History	N (%)
Genotype	
Hb-AA	51(51)
Hb-AS	26(26)

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Hb-AC	6(6)
Hb-SC	3(3)
Hb-SS	0(0)
Unknown	14(14)
Family history of sickle cell	
Close relative	12(12)
Distant relative	4(4)
Neighbor	2(2)
None	82(82)

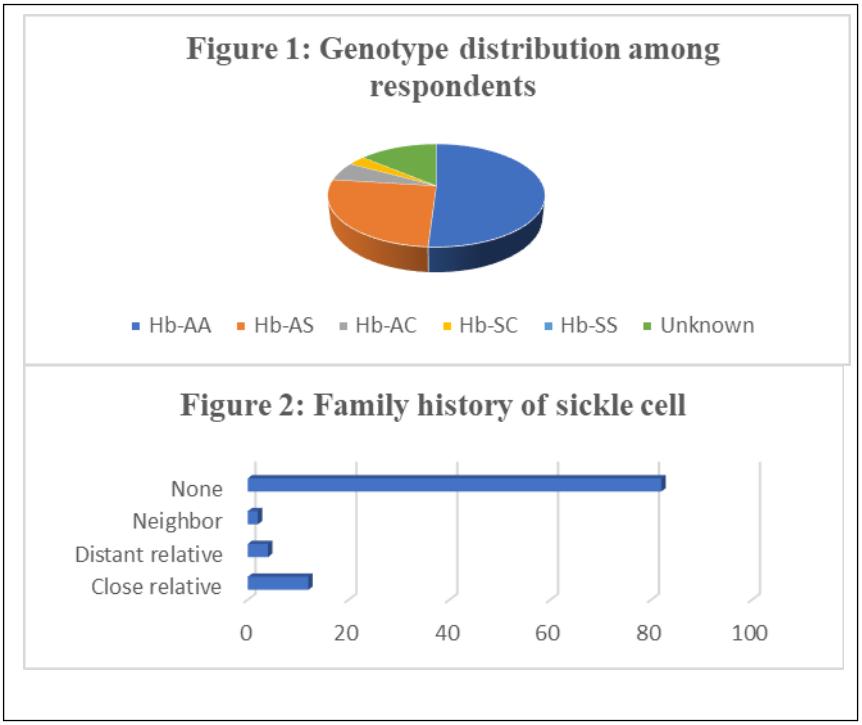

Table 2 and Figure 1 show that 86% of respondents have the prior knowledge of their genotype and 14% may have got pregnant without knowing their genotypic status. Figure 2 shows that 82% of the pregnant women had no family history of sickle cell disorder.

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Table 3: Knowledge of respondents' on the transmission of sickle cell disorder

Respondents view on how sickle cell is transmitted	N (%)
Act of God	4(4)
Both parent	74(74)
Father to child	1(1)
Mother to child	2(2)
Unknown	19(19)

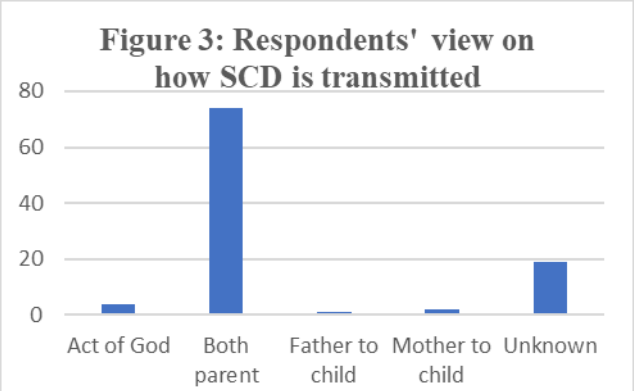

Table 3 and Figure 3 show that 74% of respondents identified both parents as sources of transmission for sickle cell disorder while 19% do not know how it is being transmitted, 4% of the respondents think sickle cell disorder is an act of God.

Table 4: Knowledge and perception of respondents on control measures for sickle cell disorder

Knowledge of respondents on control measures	None (%)	Inadequate (%)	Adequate (%)	Perception (%)

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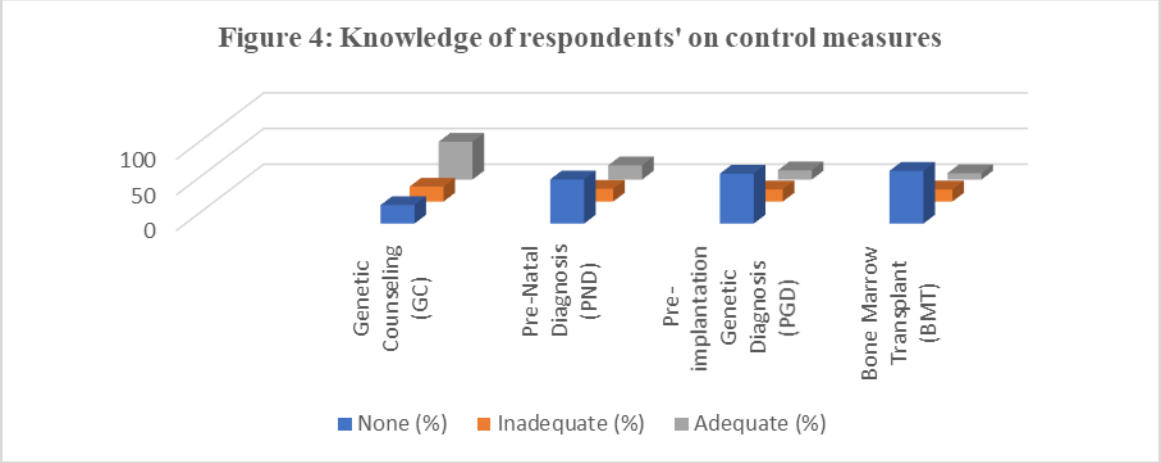
				(Yes)	(No)
Genetic Counseling (GC)	26	21	53	83	17
Pre-Natal Diagnosis (PND)	62	18	20	61	39
Pre-implantation Genetic Diagnosis (PGD)	70	17	13	56	44
Bone Marrow Transplant (BMT)	74	17	9	45	55

**Perception (Yes) (No) relates to whether or not respondents will approve of the control measure.*



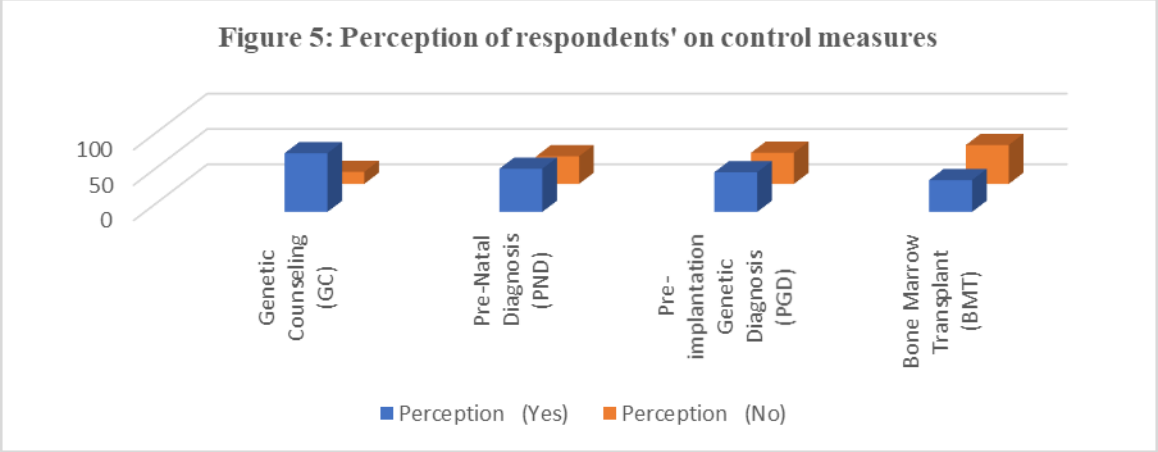


Table 4, Figure 4 and Figure 5 show that 53% of respondents have adequate knowledge on genetic counseling (GC), while 80%, 87% and 91% of respondents do not have adequate

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knowledge on prenatal diagnosis (PND), pre-implantation genetic diagnosis (PGD) and bone marrow transplant (BMT) respectively. Genetic counseling is perceived to be the most widely accepted control measure for sickle cell births by 83% of the respondents while 17% do not perceive it is the most acceptable control measure; 61% perceived prenatal diagnosis as a considerable alternative to controlling sickle cell births even if it involves terminating an ongoing pregnancy, while 39% believe it is not. 56% would go for pre-implantation genetic diagnosis (PGD) and 45% would consider bone marrow transplant if both procedures were readily available.

Table 5: Knowledge of respondents in relation to their occupation/profession – on the control measures for sickle cell disorder

Occupation	Adequate knowledge of respondents on control measures (%)			
	GC	PND	PGD	BMT
Elementary occupation	55	18	15	0
Professionals	68	31	17	18
Service and sales	42	12	9	7

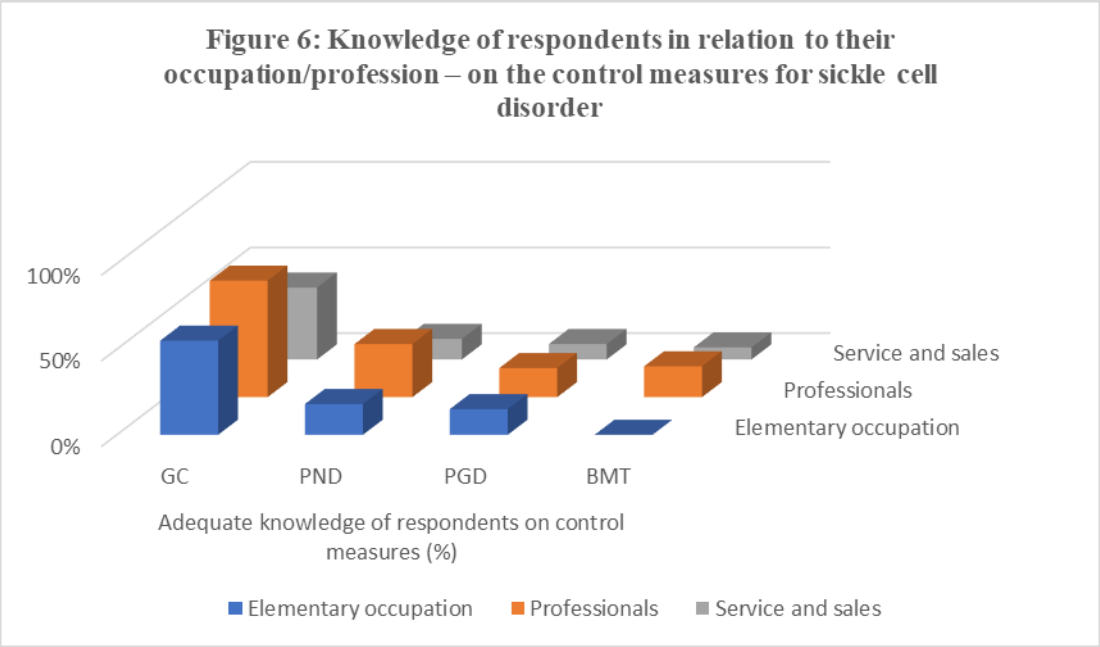

Table 5 and Figure 6 show that professionals have more adequate knowledge on all four control measures followed by those in the elementary occupation. 7% of service and sales respondents

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seem to have more knowledge on bone marrow transplant (BMT) than those in the elementary occupation.

Table 6: Perception of respondents in relation to their occupation on the control measures for sickle cell anemia

Occupation	Perception of respondents on control measures (%)			
	GC	PND	PGD	BMT
Elementary occupation	100	64	65	45
Professionals	86	74	66	50
Service and sales	72	49	47	42

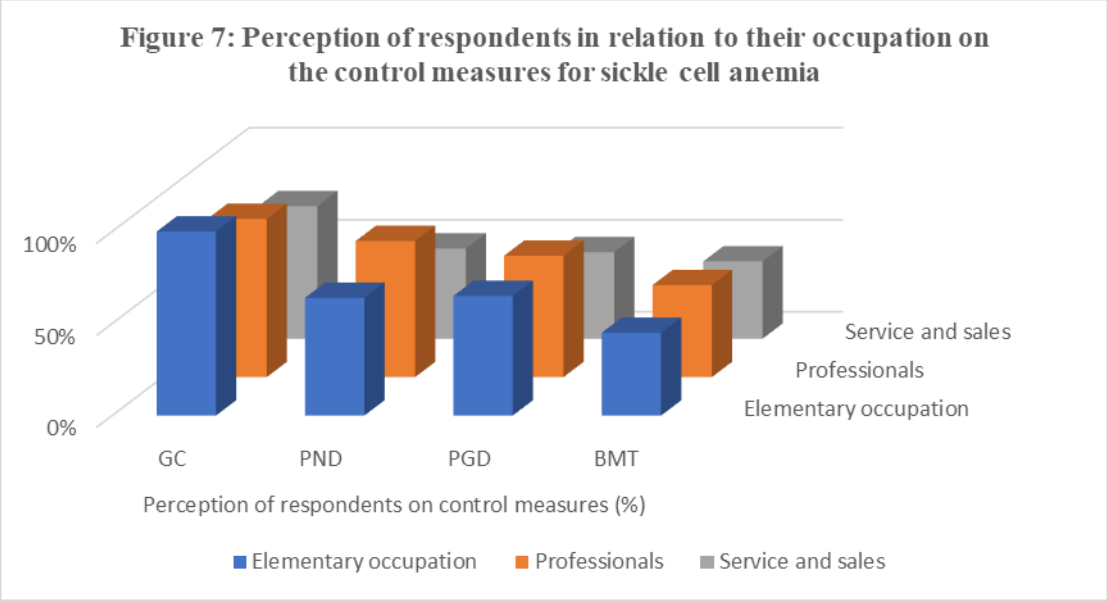

Table 6 and Figure 7 show that more professionals (74%) perceive prenatal diagnosis (PND) as an acceptable control measure for sickle cell births – even when it involves termination of an ongoing sickle cell pregnancy. All respondents with elementary occupation (100%), more than professionals (86%) – would support genetic counseling as a more acceptable control measure to prevent sickle cell disorder.

4. Discussion

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Majority of respondents were in their child bearing ages from 21 to 40 years of age with 56% of them being less than 30years of age and 68% have earlier had at least one pregnancy as shown in the social demographics data in table 1. This category of pregnant women may also be extensively targeted in the dissemination of information on control measures for sickle cell disease (Naik and Lanzkron, 2012).

Despite the literacy level (73% with tertiary education – from table 1) among respondents, very few (20%) still have adequate knowledge about prenatal diagnosis as an existing control measure for sickle cell births and just above 53% (table 4) of the pregnant women have adequate knowledge on genetic counseling to make proper decisions prior to getting married or getting pregnant. However when respondents were adequately informed (as they were actually enlightened during the assessment) about current control measures for sickle cell disorder; 83% approved of genetic counseling, 61% approved of pre-natal diagnosis, 56% approved of pre-implantation genetic diagnosis while 45% approved of bone marrow transplant. On why respondents would rather consider terminating an ongoing pregnancy following a confirmation of sickle cell disorder after pre-natal diagnosis; most asserted that the trauma of having a sickle cell baby would be too much to bear. This also agrees with the study conducted by Durosinmi *et al* (1995) where 63% of mothers will rather opt for termination of a sickle cell pregnancy following prenatal diagnosis.

Religion was not critically assessed in this study as a determining factor for the knowledge and perception of respondents, as 84% practiced Christianity while 16% practiced Islam (table 1) – although some other studies have shown it has a critical determinant role in the acceptability of the control measures (Durosinmi, Odebiyi and Akinola, 1997).

One important demographic variable that also influenced the knowledge base of the respondents was their occupation. More learned professionals had a better grasp of all existing control measures for sickle cell disease in Nigeria at present – including pre-implantation genetic diagnosis and bone marrow transplant where 17% and 18% showed adequate knowledge respectively (table 5). Other than genetic counseling and prenatal diagnosis which seem to be the more popular control measures for sickle cell disease in Nigeria as shown in previous studies (Durosinmi *et al*., 1995; Adeyemi and Adekanle, 2007); pre-implantation genetic diagnosis (PGD) and bone marrow transplant (BMT) are yet to be sufficiently embraced as considerable measures in Nigeria also for the control of sickle cell disease. PGD is a secondary selective control measure for sickle cell disease following IVF cycles (Xu *et al*., 1999) while bone marrow transplant – as a curative control measure for sickle cell anemia, is still scantily practiced in Nigeria (Kirby, 2012).

On the categorization of occupation and its influence on the knowledge and perception of respondents on sickle cell control measures, people in the elementary occupation cadre such as technicians and associate professionals seem to rub-off on the knowledge of professionals which may be horizontally transferred from formal and informal routes. This however may justify why 100% of respondents in the elementary occupation cadre (table 6) seem to approve genetic counseling as the more preferred primary control measure, than the learned professionals would

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simply admit. The learned professionals are also more in support of other aggressive control measures such as PND, PGD and BMT.

From the preliminary assessment of relevant medical history of respondents, data shows that the actual risk groups are 49% (table 2) of the total respondents – including those with the sickle cell trait (AS or AC genotypes), the actual sickle cell genotypes (SS, SC) and those who do not know their genotypic status prior to getting pregnant. However, the study's recommendations also emphasized that respondents without the sickle cell genotypes be not excluded from being aware of the control measures for sickle cell disorder. In cases where such homozygous subjects with the normal hemoglobin genotypes (AA) get married to heterozygous subjects with the sickle cell traits (AS, AC and others), their offspring may then be categorized as part of the risk groups as well.

The current situational analysis of the basic knowledge base of respondents show that 74% of the pregnant women know that sickle cell disorder results from both parents whose genotypes are either heterozygous or homozygous for sickle cell; 19% do not know how sickle cell disorder is caused, while 4% actually think it is an act of God (table 3). Such misconceptions on SCD etiology seemed to be consistent with results from similar studies among subjects from neighboring African country – Benin (Zounon *et al*., 2012). This therefore suggests that most of the respondents in this study still have a basic understanding of the causes of sickle cell disorder. However beyond this is also a need to have adequate knowledge of the existing control measures – to help prevent future sickle cell births and conditions of sickle cell anemia from such at-risk groups.

4.1 Contrasting framework of SCD control measures between Nigerians and African-Americans

The practice of genetic counseling for SCD in Nigeria rarely focus on newborn screening. Prenatal screening or testing on the other hand is not also often practiced. Except for known cases where both couple have earlier been identified with sickle cell trait (SCT) and are prone to birthing a sickle cell baby – when assisted reproductive options are not considered, then prenatal screening or testing may be suggested. Such screenings are not also readily available and accessible, except at specialists or tertiary health institutions. Genetic counseling for SCD in Nigeria mainly involves blood genotype testing and educational awareness (Durosinmi *et al*., 1995) about genotypic matches or unions – that may potentially give rise to sickle cell births.

However, practices obtainable in the USA among Africa-Americans includes newborn screening and an extensive follow-up for confirmatory testing – for cases earlier identified with the sickle cell trait (SCT). Both prenatal testing and newborn screening are widely acceptable forms of genetic testing among African-Americans; but there are still significant personal, familial and societal barriers to education and awareness on the inheritance factors and probable risk of giving birth to a child with sickle cell disease (Long et al., 2011).

Conclusion

Knowledge and acceptance of sickle cell control measures among pregnant women was hierarchically scaled as GC > PND > PGD > BMT in south-western Nigeria. The knowledge of

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respondents about control measures for sickle cell disorder was not a determining factor in their perception or acceptance of the control measures. Therefore, we recommend that adequate information and provision of actual diagnostic and treatment services be made available for each of these control measure options – to enable at-risk populations make adequate choices and informed decisions in the prevention and control of sickle cell disorder.

Conflict of interest

The authors declare that there are no conflicts of interest.

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Authors' Contributions

OOA conceived the research project, designed the methodology, coordinated the survey and analyzed the results. ALM, TO and SN reviewed the methodology and proof-read the final manuscript. GO and ATO reviewed the methodology and coordinated the surveys at the hospitals. TS and EOA co-analyzed the results and proof-read the final manuscript.

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