World Journal of Advanced Research and Reviews
eISSN: 2581-9615 CODEN (USA): WJARAI
Cross Ref DOI: 10.30574/wjarr
Journal homepage: https://wjarr.com/

(RESEARCH ARTICLE)

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Awareness and acceptability of child adoption as a reproduction alternative among parents at risk of having another child with sickle cell disease in Enugu, Nigeria

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World Journal of Advanced Research and Reviews, 2026, 29(01), 1149-1157

Publication history: Received on 06 December 2025; revised on 14 January 2026; accepted on 17 January 2026

Article DOI: https://doi.org/10.30574/wjarr.2026.29.1.0100

Abstract

Background: Sickle cell disease is a group of inherited blood disorders that are life-long and associated with lots of morbidities and mortality. Child adoption is one of the reproduction alternatives for reducing the risk for having children with SCD. Awareness and acceptability of child adoption for this indication have not been assessed in our environment.

Objective: To assess the awareness and acceptability of child adoption as reproduction alternative for reducing the risk for having children with SCD among couples with SCD children.

Materials and Methods: Seventy-three biological parents of children with SCD were interviewed with semi-structured questionnaire following consent at the Paediatric Haematology outpatient clinic of ESUT Teaching hospital Parklane, Enugu. Convenient sampling method was used. Data obtained was entered into SPSS version 26 and later exported to SPSS version 29 with which it was analyzed.

Results: Only 2 (2.7%) of the respondents were aware of child adoption as reproduction alternative for reducing the risk for having a child with SCD among at risk couples. Even, after education it was only acceptable to 15 respondents (20.5%). Fifty-four respondents (74%) gave desire for biological children as reason for non-acceptance.

Conclusion: Awareness and acceptability of child adoption as reproduction alternative was very low among the respondents. To change these trends, elaborate campaigns and legislative interventions targeted at changing people's attitude about adoption are needed.

Keywords: Sickle cell disease; Prevention; Child adoption; Awareness; Acceptability

1. Introduction

Sickle cell disease (SCD) refers to a group of inherited blood disorders that are life-long and they affect many people globally [1]. It is an autosomal recessive genetic disorder of red blood cell which is transferable from parent carriers to their offspring [2]. The greatest of the global burden of sickle cell anemia (SCA) is in sub-Saharan Africa with Nigeria reported as the country with the highest burden of SCD [3,4] contributing up to 33% of newborn babies delivered with SCD annually [5]. Also, of about 50 million people estimated to be living with SCD globally Nigeria has been reported to be home to 4 – 6 million of them [2]. Life expectancy of an individual born with SCD in sub-Saharan Africa is very poor with 50%-90% of children born with SCD in low- and low-middle-income countries of sub-Saharan Africa reported to die before their fifth birthday [6].

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Parents go through a lot of challenges in the process of raising a child with SCD. The challenges are so enormous that some parents of children living with SCD have been reported to decide against further child bearing even when they want more children for fear of giving birth to more children with SCD [7]. In our environment, so much premium is placed on having children such that procreation is regarded as the primary function of marriage, thus having children is a source of personal satisfaction and social status [8]. For couples who have had children with SCD and in need of more children they are faced with a serious dilemma. Such couples will most likely prefer any alternative option for having children that will spare them of the challenges associated with having more children with SCD. In our setting where abortion law is restrictive [9,10], such couples are limited to three alternative options for having children free of SCD namely invitro fertilization with pre-implantation genetic testing, invitro fertilization with donor gamete and child adoption [7]. The challenge with the first two of the three options is that both involves invitro fertilization which is an assisted reproductive technology procedure. Unfortunately, and in line with current reality in our environment, a previous study had revealed that assisted reproductive technology procedures are expensive and cannot be afforded by many people [8]. With as many as 4 out of every 10 Nigerians reported to live below the National poverty line [11] majority of the parents of children with SCD who are also carrying the financial burden of caring for children with SCD are most unlikely to afford the bills for assisted reproductive technology. For such parents, child adoption would appear as the most viable option to have children free from SCD.

Child adoption is the legal act of permanently placing a child with a parent or parents other than the biological ones [12]. In Nigeria, adoption process is regulated by the Nigerian Child Right Act of 2003 [13]. Reasons for child adoption in our environment as reported in previous studies include childlessness, male child syndrome, family expansion, gender selection, and helping a child in need, desire to replace a dead child, to acquire company for an only child, to stabilize a marriage, to legitimate an illegitimate child, to sustain a particular line of descent, to rescue a child in an irreversible situation of abandonment and to relieve parents who are unable to take care of their child [8,12,13]. In other words, desire for children free from genetic diseases such as SCD by at risk couples appeared not to have been considered as reason for child adoption in previous studies in our region. However, reports from study done elsewhere recognized genetic abnormality in the biological child of a couple as a reason for adoption [14]. To the best of our knowledge, there is no study in our environment that has assessed the awareness and acceptability of child adoption as reproduction alternative to reduce the risk of having children with SCD among at-risk couples. In the light of the enormous challenges faced by parents in raising a child with SCD, the genetic nature of its transmission from parents to their offspring and the life-long nature of SCD, as well as morbidity and mortality associated with it, child adoption is a valid reproduction alternative for parents at risk of giving birth to children with SCD. This study was carried out to determine the awareness and acceptability of child adoption as a reproduction alternative for having children free from SCD among parents of children with SCD accessing care at the Paediatric haematology outpatient clinic of ESUT Teaching hospital Parklane Enugu, Enugu state Nigeria.

2. Materials and Methods

This study was part of a bigger study on the alternative reproduction options for reducing the risk for having children with sickle cell disease among parents of children with sickle cell disease that accessed care at Paediatric Haematology Outpatient Clinic of ESUT Teaching Hospital, Parklane Enugu during the study period. The study was a cross-sectional study and spanned from September 2022 to July 2024. ESUT Teaching hospital is located in the center of Enugu metropolis. It serves as a referral center for most states in the South East Nigeria. The department of Paediatrics is one of the four major departments of the hospital and Paediatric haematology clinic is one of the outpatient clinics in the department of Paediatrics. The Paediatric haematology clinic takes care of patients up to 18years of age and runs from 8:00 a.m. to 4:00 p.m. every Monday. The clinic is managed by a consultant paediatric haematologist, resident doctors, nurses, and other allied health workers. Paediatric Haematology outpatient clinic is a fairly busy clinic; other paediatric cases other than haematology cases are also managed in the clinic.

The target population for this study was biological parents of sickle cell disease children who received care at the outpatient clinic over the study period hence only biological parents of sickle cell children were included in the study. Convenient sampling method was used to select study participants. Written informed consent was obtained from all the respondents and they were reassured of the confidentiality of the information provided. Data was obtained using an interviewer-administered semi-structured questionnaire after obtaining consent. Information obtained included sociodemographic variables of the respondents, as well as their awareness and willingness to accept child adoption as a means to reduce the risk of having children with SCD. The questionnaire was pretested and all ambiguity removed.

As a protocol, after administering the initial part of the questionnaire comprising of biodata and assessment of awareness of child adoption as reproduction alternative for reducing the risk for having children with SCD, each respondent was adequately counselled and educated on child adoption as a means for prevention of sickle cell disease

before assessing the acceptability of child adoption to them as reproduction alternative for reducing the risk for having children with SCD. Ethical clearance for the study was obtained from the ethics committee of ESUT Teaching Hospital Parklane, Enugu.

Data collected were entered into SPSS version 26 and later exported to SPSS version 29 with which it was analyzed. Data cleaning was performed to ensure completeness and accuracy prior to analysis. Categorical variables, including awareness and acceptability of child adoption were summarized using frequencies and percentages.

Associations between categorical variables were examined using Fisher's exact test with statistical significance set at $p < 0.5$.

3. Results

A total of 73 respondents were interviewed. A little less than half of the respondents 35(47.9%) were below 40 years of age while majority 38(52.1%) were above the age of forty. Majority of the respondents were females 65(89%), of the Igbo extraction 72(98.6%), and lived in the urban area 62(84.9%).

All the respondents were Christians. Of these, 45(61.6%) were Catholics, 18(24.7%) were Pentecostals, 8(11%) were Anglicans, while 2(2.7%) belonged to other Christian denominations. The rest of the respondents' characteristics are as shown on **Table 1** below.

Table 1 Socio-demographic characteristics of the respondents

Respondent Characteristics	Variables	Frequency (n = 73)	Percentages (%)
Age	<40 years	35	47.9
	>40 years	38	52.1
Sex	Male	8	11
	Female	65	89
Residence	Rural	11	15.1
	Urban	62	84.9
Tribe	Igbo	72	98.6
	Others	1	1.4
Christian Denominations	Catholics	45	61.6
	Anglicans	8	11
	Pentecostals	18	24.7
	Others	2	2.7
Educational Status	Primary	6	8.2
	Secondary	36	49.3
	Post-Secondary Education	31	42.5
Employment Status	Unemployed	7	9.6
	Self-employed	51	69.9
	Government/Private Sector employed	15	20.5
Marital Status	Married	64	87.7
	Never Married	1	1.4
	Separated/Widow/Widower	8	11.0
Duration of Marriage	< 10 years	26	35.6

	≥ 10 years	46	63
	Not applicable	1	1.4
Number of Children	< 2	8	11
	≥ 2	65	89

Table 2 Impact of SCD on respondents' families

Respondent Characteristics	Variables	Frequency (n = 73)	Percentage (%)
Number of children with SCD	1	60	82.2
	2	12	16.4
	3	1	1.4
Child died of SCD	Yes	17	23.3
	No	56	76.7

Majority of the respondents 60(82.2%) had one child living with SCD. However, 12(16.4%) had 2 children with SCD while one respondent had 3 children with SCD. As many as 17(23.3%) had lost at least one child to SCD.

Table 3 Awareness and acceptability of child adoption as a reproduction alternative to reduce the risk for having children with SCD

	Yes	Percentage	No	Percentage
Awareness of child adoption as reproduction alternative	2	2.7	71	97.3
Acceptability of child adoption as reproduction alternative	15	20.5	58	79.5

Only 2(2.7) of the respondents were aware of child adoption as a reproduction alternative to reduce the risk for having children with SCD. Also, child adoption as a reproduction alternative to reduce the risk for having children with SCD was acceptable to only 15(20.5%) respondents.

As shown on Table 4 and Table 5 below none of the respondents' characteristics was significantly associated with awareness of and acceptance of child adoption as reproduction alternative respectively.

Table 4 Relationship between awareness of child adoption as reproduction alternative to reduce the risk for having children with SCD and respondents' characteristics

Respondent Characteristics	Variables	Aware of Child adoption		Unaware of Child adoption		P – value
		Frequency	Percentage (%)	Frequency	Percentage (%)	
Age	< 40 years	1	1.4	34	46.6	1.000
	≥ 40 years	1	1.4	37	50.7	
Sex	Male	0	0	8	11	1.000
	Female	2	2.7	63	86.3	
Residence	Rural	0	0	11	15.1	1.000
	Urban	2	2.7	60	82.2	
Tribe	Igbo	2	2.7	70	95.9	1.000

	Others	0	0	1	1.4	
Christian Denominations	Catholics	1	1.4	44	60.3	0.065
	Anglicans	0	0	8	11	
	Pentecostals	0	0	18	24.7	
	Others	1	1.4	1	1.4	
Educational Status	Primary	0	0	6	8.2	1.000
	Secondary	1	1.4	35	47.9	
	Post- Secondary Education	1	1.4	30	41.1	
Employment Status	Unemployed	0	0	7	9.6	0.515
	Self-employed	1	1.4	50	68.5	
	Government/ Private sector employed	1	1.4	14	19.2	
Marital Status	Married	2	2.7	62	84.9	1.000
	Never married	0	0	1	1.4	
	Separated/ Widow/ Widower	0	0	8	11	
Duration of Marriage	< 10 years	2	2.7	24	32.9	0.151
	≥ 10 years	0	0	46	63	
	Not applicable	0	0	1	1.4	
Number of Children	< 2	1	1.4	7	9.6	0.209
	≥ 2	1	1.4	64	87.7	
Children with SCD	1	2	2.7	58	79.5	1.000
	2	0	0	12	16.4	
	3	0	0	1	1.4	
Child died of SCD	Yes	0	0	17	23.3	1000
	No	2	2.7	54	74	

Table 5 Relationship between acceptance or rejection of adoption as reproduction alternative to reduce the risk for having children with SCD and respondents' characteristics

Respondent Characteristics	**Variables**	**Accept Child adoption**		**Do not accept Child adoption**		**P – value**
		Frequency	**Percentage (%)**	**Frequency**	**Percentage (%)**	
Age	< 40 years	5	6.8	30	41.1	0.254
	≥ 40 years	10	13.7	28	38.4	
Sex	Male	3	4.1	5	6.8	0.348

	Female	12	16.4	53	72.6	
Residence	Rural	1	1.4	10	13.7	0.441
	Urban	14	19.2	48	65.8	
Tribe	Igbo	15	20.5	57	78.1	1.000
	Others	0	0	1	1.4	
Christian Denominations	Catholics	8	11	37	50.7	0.577
	Anglicans	3	4.1	5	6.8	
	Pentecostals	4	5.5	14	19.2	
	Others	0	0	2	2.7	
Educational Status	Primary	1	1.4	5	6.8	0.063
	Secondary	4	5.5	32	43.8	
	Post- Secondary Education	10	13.7	21	28.8	
Employment Status	Unemployed	1	1.4	6	8.2	0.421
	Self-employed	9	12.3	42	57.5	
	Government/ Private sector employed	5	6.8	10	13.7	
Marital Status	Married	14	19.2	50	68.5	1.000
	Never married	0	0	1	1.4	
	Separated/ Widow/ Widower	1	1.4	7	9.6	
Duration of Marriage	< 10 years	3	4.1	23	31.5	0.386
	≥ 10 years	12	16.4	34	46.6	
	Not applicable	0	0	1	1.4	
Number of Children	< 2	0	0	8	11	0.193
	≥ 2	15	20.5	50	68.5	
Children with SCD	1	13	17.8	47	64.4	1.000
	2	2	2.7	10	13.7	
	3	0	0	1	1.4	
Child died of SCD	Yes	3	4.1	14	19.2	1.000
	No	12	16.4	44	60.3	

Table 6 Pattern of Reasons for acceptance of adoption as reproduction alternative for reducing the risk for having children with SCD

Reason	Yes		No		Not applicable	
	Frequency	Percent (%)	Frequency	Percent (%)	Frequency	Percent (%)
Cultural belief	1	1.4	14	19.2	58	79.5
Societal acceptance	2	2.7	13	17.8	58	79.5
Desire for biological child	0	0	15	20.5	58	79.5
Nature of the process	5	6.8	10	13.7	58	79.5
Cost	2	2.7	13	17.8	58	79.5
Religious belief	3	4.1	12	16.4	58	79.5

Table 7 Pattern of reasons for non-acceptance of child adoption as reproduction alternative for reducing the risk for having children with SCD

Reason	Yes		No		Not applicable	
	Frequency	Percent (%)	Frequency	Percent (%)	Frequency	Percent (%)
Cultural belief	10	13.7	48	65.8	15	20.5
Societal acceptance	14	19.2	44	60.3	15	20.5
Desire for biological child	54	74	4	5.5	15	20.5
Nature of the process	12	16.4	46	63.0	15	20.5
Cost	18	24.7	40	54.8	15	20.5
Religious belief	3	4.1	55	75.3	15	20.5

Findings in Table 6 above suggests that nature of the process 5(6.8%) was the commonest reason for acceptance of child adoption as a reproduction alternative for reducing the risk for having children with SCD among the few that accepted it.

On the other hand, findings in Table 7 suggests that desire for biological children 54(74%) was the main reason for non-acceptance of child adoption as a reproduction alternative for reducing the risk for having children with SCD among the respondents.

4. Discussion

Sickle cell disease is associated with significant morbidity and mortality among affected individuals across different age groups and even more among children with the disease. Our study revealed that up to 17 parents among the respondents had lost at least a child to SCD. SCD also places significant financial and emotional burden on the caregivers and families of affected individuals with significant impact on their quality of life [15,16]. The challenges associated with raising a child with SCD is so enormous that some parents of affected children had been reported to have decided against further child bearing for fear of giving birth to another child with SCD [7]. On the other hand, in our environment so much premium is placed on having children that it is commonly believed that the primary reason for marriage is to have children [8]. Such is the dilemma of parents of children with SCD who desire more children. It is against this background that this study assessed the awareness and acceptability of child adoption as a reproduction alternative for reducing the risk for having another child with SCD among parents of children with SCD that accessed care at Paediatric Haematology outpatient clinic of ESUT Teaching hospital Parklane Enugu, Nigeria within the study period.

Of the 73 respondents interviewed majority were females, above 40 years of age, of the Igbo tribe and urban dwellers. Majority of the respondents being females is similar to findings from the study done by Schultz and colleagues [7]. Also, that the majority of the respondents were Igbo is expected because the study was conducted in Enugu South East Nigeria

where the dominant ethnic group is the Igbo tribe. All the respondents were Christians and predominantly of Catholic denomination is also expected because the dominant religion in Enugu South East Nigeria is Christianity [17]. Again, 42.5% of the respondents had post-secondary education and this is less compared to 11 out 18 (61.1%) respondents in the study by Schultz and colleagues. Similarly, only 20.5% of the respondents in our study were employed by the government or the private sector and this is very much less than 12 out of 18 (66.7%) respondents as reported by Schultz and colleagues.

Only 2.7% of the respondents were aware of child adoption as a reproduction alternative for reducing the risk for having children free from SCD among at risk couples. Slightly higher awareness was found by Schultz and colleagues in Pennsylvania, United State of America who reported that 2 out of 18 (11.1%) parents of children with SCD they interviewed were aware of adoption as a reproduction alternative for reducing the risk for having children with SCD [7]. Better access to health information due to environmental factors may explain the slightly higher awareness. Generally, there is paucity of researches on this subject both globally and in our environments. Of all the respondents' characteristics assessed none was significantly associated with awareness of child adoption as a reproduction alternative for reducing the risk for having children with SCD among couples at risk. Further study with larger sample size may throw more light on the factors that influence awareness of child adoption as a reproduction alternative for reducing the risk of having children with SCD among at risk couples.

Only 20.5% of the respondents indicated willingness to accept child adoption as a reproduction alternative for reducing the risk of having children with SCD among at risk couples. Marginally higher acceptance was found by Schultz and colleagues who reported that 7 out of 18 parents of children with SCD interviewed (38.9%) indicated willingness to accept child adoption as a reproduction alternative for reducing the risk for having children with SCD [7]. Even though slightly higher than the finding from our study, acceptance of child adoption as reproduction alternative for reducing the risk for having children with SCD among at risk couples in both studies appears to be poor.

The commonest reason for acceptance among the few that indicated willingness to accept adoption as a reproduction alternative was the nature of the process (6.8%). Most likely this has to do with the fact child adoption is the only option among the three alternative reproduction options that do not involve invitro fertilization with its attendant cost implications. The other two reproduction alternatives include in vitro fertilization with preimplantation genetic diagnosis and in vitro fertilization with donor gamete. On the other hand, the dominant reason for non-acceptance among majority of the respondents that rejected child adoption as reproduction alternative was desire for biological children (74%). This is similar to the report by Omosun and colleagues following a related study done to assess the knowledge, attitude and practice of child adoption among women attending infertility clinic in Lagos state Nigeria [18]. They revealed that the major reason offered by the respondents for their unwillingness to accept child adoption was that they desired to have their own biological children. Among the Igbos there are lots of cultural bias against child adoption and adopted children. This is the major reason why almost every woman will do everything possible to have their own biological children. For example, an adopted child is hardly accepted as a traditional ruler in a traditional community [12]. Again, in traditional Igbo community adopted children may be denied a share in inheritance of communally owned properties such as land [12]. It is because of these reasons that child adoption is usually only considered after all hopes of achieving conception and delivery of biological children had faded. Schultz and colleagues also reported that some of the respondents in their study stated that in their culture adoption was not accepted hence they also had desire for biological children as reason for non-acceptance of child adoption as reproduction alternative for reducing the risk for having children with SCD [7]. More still, Gallo and colleagues following a qualitative study conducted to assess reproductive decisions in people with sickle cell disease or sickle cell trait found out that for the most part, participants believed that child adoption and foster care was usually not an option for young people because of their desire to have their own biological children [19]. None of the respondents' characteristics was found to be significantly associated with acceptance or otherwise of child adoption as a reproduction alternative for reducing the risk for having children with sickle cell disease among at risk couples. Further study with increased sample size may be required to reveal respondent characteristics that are significantly associated with acceptance of child adoption as a reproduction alternative for reducing the risk for having children with sickle cell disease.

5. Conclusion

Experience with raising SCD children has not led to an awareness about child adoption as reproduction alternative for reducing the risk for having children with SCD in such parents. Also, even with counselling and education acceptance of the option among the respondents was very low. There is need for increased campaign to improve awareness and acceptance of the alternative including campaign against cultural practices unfavorable towards adopted children. Government agencies including the legislative arm, media organizations, not for profit organizations, and religious

organizations should synergize to ensure improved acceptance of child adoption as reproduction alternative especially among couples at risk of giving birth to more children with SCD.

Compliance with ethical standards

Acknowledgments

The author hereby acknowledges and appreciates the guidance and encouragement from Prof. Samuel Ajogwu Robsam Ohayi and Prof. Uchenna Ekwochi in the course of this work.

Disclosure of conflict of interest

The author declares that there is no conflict of interest.

Statement of ethical approval

Ethical clearance for the study was obtained from the ethics committee of ESUT Teaching Hospital Parklane, Enugu Nigeria.

Statement of informed consent

The author declare that written informed consent was obtained from all the respondents.

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