NIGERIAN JOURNAL OF PAEDIATRICS

VOLUME 53 | NUMBER 2 | APRIL - JUNE 2026

https://www.njpaediatrics.com

PRINT: ISSN 0302-4660

ONLINE: ISSN 2814-2985

OFFICIAL JOURNAL OF THE PAEDIATRIC ASSOCIATION OF NIGERIA

ORIGINAL RESEARCH

Nigerian Journal of Paediatrics 2026 (June); Volume 53(2):168-179.
https://dx.doi.org/10.63270/njp.v53i2.2000061.

Disclosure of Sickle Cell Disease Diagnosis to Children and Adolescents Aged 5-18 Years at the University of Benin Teaching Hospital, Benin-City, Nigeria

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Abstract

Background: Disclosure of sickle cell disease diagnosis to affected children and adolescents remains a sensitive and complex issue in the care of the disease in sub- Saharan Africa.

Objectives: To assess the level of awareness, disclosure practices, perceived benefits and barriers to disclosure of SCD diagnosis among children with SCD and their parents attending a tertiary health facility in Benin City, Nigeria.

Methods: This was a descriptive, cross-sectional study of 146 children and adolescents with SCD aged 5-18 years and their parents. The data were collected using structured interviewer-administered questionnaires and analysed using descriptive and inferential statistics.

Results: A total of 146 child- parent pairs were studied. The mean age of the participants was 10.9±3.6 years with a male-to-female ratio of 1:1. Less than half (45.2%) of the participants had been informed of their SCD diagnosis, with a mean age at disclosure of 9.4±2.8 years. Mothers were the primary sources of disclosure. The most common reason for disclosure was to improve medication adherence. Non-disclosure was mainly attributed to the perception that the child was too young and the fear of stigma. Although most parents believed disclosure was right, over half felt it was not beneficial before the age of 15 years. Most parents and children reported minimal impact of SCD on daily and school activities, although school absenteeism was common.

Conclusion: Non-disclosure of SCD diagnosis to affected children and adolescents was common in the population studied, and disclosure tends to occur at a later age.

Keywords: Adolescence, Counselling, Haemoglobinopathy, Stigma, Treatment adherence.

Introduction

Sickle cell disease (SCD) is the most common genetic blood disorder globally, affecting approximately 20-25 million people, with the highest prevalence in sub-Saharan Africa.[1] Nigeria alone accounts for an estimated 150,000 newborns with SCD annually, making it the country with the greatest burden worldwide.[2] SCD results from a mutation in the beta globin gene leading to abnormal haemoglobin S, which polymerises under low oxygen tension, causing sickling of red cells. These abnormal cells cause vaso-occlusive crises, chronic anaemia, recurrent infections, multiple organ damage and early mortality.

Disclosure of an illness to an affected patient is the act of providing accurate, honest and complete information regarding their diagnosis, prognosis and treatment options.[3] Disclosure has been extensively studied in conditions like HIV, diabetes, and cancer, and its reported benefits include better treatment adherence,[4] psychological resilience and coping, as well as reduced stigma through open family communication.[5] In high-income countries,

disclosure of SCD diagnosis is usually structured, involving parents, physicians, nurses, and supported by counsellors and social workers who provide continuous counselling and psychosocial support. This structured approach ensures that children receive age-appropriate information that evolves as they mature.[6] In contrast, studies in low and middle-income settings, including Nigeria, suggest that disclosure is often *ad-hoc*, delayed and parent-driven with little guidance from healthcare professionals.

Children living with SCD face significant physical, psychological and social challenges. Disclosure of the child's SCD status is a critical but often overlooked aspect of care. Early and appropriate disclosure enables children to understand their condition, participate in treatment decisions, improve adherence, reduce anxiety and prepare for life-long self-management.[4] However, disclosure is complex. Parents and caregivers may delay informing children due to fear of psychological harm, stigma or lack of guidance from healthcare providers.[6] Some children discover their diagnosis accidentally, leading to confusion, mistrust, rebellion and poor coping. In Nigeria, cultural beliefs and limited psychosocial support contribute to delayed or non-disclosure of SCD.

Studies from Nigeria and other African countries revealed that disclosure of chronic illnesses like Human Immunodeficiency Virus (HIV) to affected children often occurs late (usually after 10 years) and in many cases, some children remain uninformed into adolescence.[7-9] For SCD, outside of the high-income countries where structured age-related disclosure practices are carried out, disclosure practices for SCD in the middle and low-income countries are not known and have only been alluded to as being poor in some African and Asian studies.[10-12] In the University of Benin Teaching Hospital, Benin-City, Nigeria, little is known about the prevalence, timing and effects of SCD diagnosis disclosure. Addressing this knowledge gap is vital in improving holistic SCD management. Therefore, this study aimed to investigate SCD diagnosis disclosure patterns and the associated factors in Nigerian children and adolescents. It is hoped that the findings may be useful in guiding parents, clinicians and policy makers on structured disclosure processes tailored to Nigerian settings.

Methods

The study was a hospital-based, descriptive, cross-sectional study. It was conducted in the Paediatric Sickle Cell Outpatient Clinic of the University of Benin Teaching Hospital, Nigeria.

Study population

All children with SCD attending the clinic between July and September 2025 were consecutively recruited. A total of 146 parent/child pairs were enrolled on the study.

Ethical considerations

Ethical approval was obtained from the Ethics Committee of the University of Benin Teaching Hospital, Benin-City, Nigeria (with approval number NHREC -UBTH-HREC/24/12/2022B). Informed consent was obtained from the parents, and assent from children aged seven years and above.

Methods

This study was conducted by the researchers (OME and ELC) and two research assistants (one trainee-physician and one medical intern) who were trained in the methodology of the study, particularly with the administration of the questionnaires. The children and adolescents and their parents/caregivers were given clear and adequate information in English and/or Bini Languages and were allowed to make an informed decision.

Data collection

The questionnaires were administered privately in a separate room to ensure confidentiality.

The children were interviewed separately from their parents.

Data analysis

The data were entered into the Microsoft Excel® Spreadsheet. IBM Statistical Package for Social Sciences (SPSS) version 26.0 was used to analyse the data. Continuous variables (age of the children, age at disclosure) were summarised using the mean and standard deviation, while categorical variables (disclosure status to the child, school authorities and extended families) were expressed as percentages and frequencies. Associations between diagnosis disclosure and parental socioeconomic status and diagnosis disclosure to school authorities were assessed using the Chi-Square test. A p-value of <0.05 was considered statistically significant.

Results

Socio-demographic characteristics

The mean age of the children was 10.94±3.55 years. Fifty-seven (39%) of the children were aged 10-13 years. The proportions of males and females were similar (50.7% and 49.4%, respectively), with a male-to-female ratio of 1:1. The majority of the subjects were in primary and junior secondary schools (65.7%). Most of the caregivers were aged 31-50 years (41.8%), and they were largely female, while 44.5% belonged to the middle socio-economic class. Also, 76.6% of the caregivers/parents were legally married, as shown in Table I.

Duration of attendance of the sickle cell disease clinic

Eighty-two (56.2%) of the subjects had been attending the clinic for 1-5 years, while only 15.7% had attended for <1 year. The others had attended for >5 years.

Disclosure of SCD to subjects

The majority of subjects (54.8%) who participated in this study were unaware of their SCD status.

Age at disclosure of SCD to the subjects

The mean age at disclosure was 9.41±2.79 years. Most of the disclosures occurred between the ages of 5 and 10 years (54.5%), followed by 10-15 years (40.9%), as shown in Table IIa.

Child's preference for disclosure of the SCD

A greater proportion (72.7%) of the children were informed about their illness by their mother. The majority (58.2%) actually preferred that their mother should be the one to disclose the diagnosis to them. However, only 16.7% preferred that their doctor disclose the diagnosis to them. More than half (57.6%) of the children who had been informed about their illness reported that they would have preferred to be told when they were younger (Table IIb).

Disclosure to immediate and extended family, friends, and school authority

Sixty-one per cent of the parents reported that their child's school authority was aware of the diagnosis. Likewise, 63.7% of the parents reported that the child's older siblings were not aware of the diagnosis. The majority (84.9%) of the parents reported that they had told their relations about the child's illness. Such relations included the parents' mother, the mother-in-law, the parents' father, and the father-in-law (in that order of decreasing frequencies). The greater proportion (63.6%) of the 22 parents whose relations did not know about the illness gave reasons for keeping the diagnosis to the immediate family only (Table IIc).

Association between disclosure to the child and disclosure to school authorities

Of the 80 caregivers who did not disclose the diagnosis to their child, 44 (55%) disclosed it to the school authorities. Of the 66 parents who disclosed the illness to their child, 68.2% also disclosed it to the school authorities. The difference in disclosure rate was not statistically significant ($\chi^2 = 2.640$, P = 0.126) as shown in Table III.

Table Ia: Socio-demographic characteristics of children and parents

Variable	Frequency (n = 146)	Percentage (%)
Age		
5 - 9 years	53	36.3
10 - 13 years	57	39.0
14 - 18 years	36	24.7
Sex of child		
Male	74	50.7
Female	72	49.3
Child's Level of Education		
Nursery	13	8.9
Primary	58	39.7
Junior secondary	38	26.0
Senior secondary	26	17.8
Finished secondary	5	3.4
Undergraduate	3	2.1
Stopped before senior secondary	3	2.1
Age of caregiver		
Up to 30 years	8	5.5
31 - 40 years	54	37.0
41 - 50 years	61	41.8
>50 years	23	15.8
Sex of caregiver		
Male	16	11.0
Female	130	89.0
Social class		
Upper class	28	19.2
Middle class	65	44.5
Lower class	53	36.3
Level of marriage		
Not married	14	9.6
Customary	20	13.7
Legally married	112	76.7

Association between disclosure to the child and parents' socio-economic status

A greater proportion (22; 78.6%) of the parents who disclosed SCD status to their children were in the upper socio-economic class ($\chi^2 = 16.626$, $p<0.001$) as shown in Table IV.

Reasons for diagnosis disclosure and non-disclosure to the children

The majority (81.8%) of the parents who disclosed the diagnosis to their children did so to improve compliance with medications Table

V. Out of the 80 parents who reported non-disclosure, a majority (86.3%) believed that the child was too young to understand such information, while approximately 11% were afraid that their child will reveal the information to other people. Thirty-four (42.5%) of the 80 parents who were yet to disclose the diagnosis to their child intended to do so when the child attains the age of 10 – 12 years; while 26.2% and 25% intended to inform the child at 13 – 15 years and 16 – 19 years of age, respectively. Most (75%) of the mothers preferred to do the disclosure (Table V).

Table IIa: Age at disclosure of SCD to the subjects

Variable	Frequency (n =66)	Percentage (%)
Age at disclosure		
<5 years	2	3.0
5 - 10 years	36	54.6
10 - 15 years	27	40.9
>15 years	1	1.5

Table IIb: Child's experience and preferences for disclosure of the disease

Variable	Frequency (n = 66)	Percentage (%)
Who told you about the illness?		
Mother	48	72.7
Father	2	3.0
Siblings	2	3.0
Other relatives	2	3.0
Doctor	10	15.3
Other	2	3.0
Who would you have preferred to tell you about your disease ?		
Mother only	39	58.2
Father only	1	1.5
Both of my parents	11	16.7
My doctor	11	16.7
Nurses	1	1.5
Other relatives	3	4.5
When would you have preferred to be told about your disease?		
When younger	38	57.6
When older	14	21.2
I'm not sure	14	21.2

Parents' beliefs on disclosure of SCD diagnosis to their child

The majority (91.8%) of the parents believed that telling their child about his/her illness was right. Likewise, 89.7% of them believed that

their child needed to know about his/her illness. More than half (58.2%) of these parents believed that disclosure was not beneficial to children under 15 years of age, while a majority (88.4%) did not believe that non-disclosure until adulthood was necessary. Likewise, a majority (89.7%) believed that only the parents should disclose the diagnosis to the child (Table VI).

Table IIc: Disclosure to immediate and extended family, friends, and school authority

Variable	Frequency (n = 146)	Percentage (%)
Does the schoolteacher/authority know about his/her illness?		
Yes	89	61.0
No	57	39.0
Does his/her older sibling know about his/her illness?		
Yes	53	36.3
No	93	63.7
Have you told his/her relations about his/her illness?		
Yes	124	84.9
No	22	15.1
If yes, who knows? *		
Mother	66	30.8
Mother-in-law	52	24.3
Father	50	23.4
Father-in-law	46	21.5
If your relations/parents do not know, why?	**n = 22**	
It may affect our marriage	3	13.6
We think only the immediate family should know	14	63.6
To avoid stigmatization	3	13.6
Not necessary	2	9.1

Table III: Association between disclosure to the child and disclosure to the school authority

Variable		Disclosure to the school authority		χ^2	p-value
		Not Disclosed	Disclosed		
Disclosure to the child	Not Disclosed	36 (45.0%)	44 (55.0%)	2.64	0.126
	Disclosed	21 (31.8%)	45 (68.2%)		

Table IV: Association between disclosure to child and parents' socio-economic status

Variable		Disclosure to the child		χ^2	p-value
		Not Disclosed	Disclosed		
Socio-economic status	Upper class	6 (21.4%)	22 (78.6%)	16.626	**< 0.001***
	Middle class	38 (58.5%)	27(41.5%)		
	Lower class	36 (67.9%)	17 (32.1%)		

Table V: Reasons for disclosure and non-disclosure by the parents to the subjects

Variable	Frequency (n = 146)	Percentage (%)
Why was your child informed about his/her illness?		
To make him/her comply with taking meds	54	81.8
Someone found out, and I confirmed by telling him	1	1.5
My child found out and asked me	3	4.5
The child kept troubling me about what was responsible	8	12.1
Why have you not told your child about his/her illness?	**(n = 80)**	
My child is too young	69	86.3
I don't want my child to blame me	1	1.3
I fear that he will be depressed	1	1.3
I'm afraid that my child may tell other people	9	11.3
At what age do you intend to tell the child?		
10 - 12 years	34	42.5
13 - 15 years	21	26.3
16 - 19 years	20	25
I don't have any specific age in mind	5	6.3
Who would you prefer to tell the child?		
Father only	3	3.8
Mother only	60	75
Both parents	14	17.5
Doctor/nurse	3	3.8

Challenges experienced by parents and children with SCD

More than half (53.4%) of the parents reported that their child often asked questions about medication intake, whereas 76.7% reported no challenges with giving their child medications. Likewise, a majority (77.4%) reported that the disease rarely affects the child's daily activities, while 74.0% also reported that the disease rarely affects the child's school activities (Table VII).

Discussion

More than half of the children studied had attended the clinic for up to five years, indicating sustained engagement with health services. However, the frequency of non-disclosure of SCD diagnosis to affected children was high (54.8%). The authors largely believed there has been very sparse previous documentation of delayed disclosure or non-disclosure of SCD diagnosis. Evidence alluding to delayed disclosure and non-disclosure was obtained from regional studies in sub-Saharan Africa, [10.11] and an Asian study.[12] None of those studies gave prevalence rates, but consistently reported that delayed disclosure and non-disclosure were common in low and middle-income countries but high in high-income countries where newborn screening was routinely practised and a structured counselling existed. Caregivers often delay disclosure of diagnosis due to concerns about the child's emotional maturity and ability to understand the illness.[13-15]

Table VI: Parents' beliefs on disclosure of SCD to their child

Variable	Frequency (n = 146)	Percentage (%)
Do you believe telling your child about his/her illness is right?		
Yes	134	91.8
No	12	8.2
Do you believe your child must know about his/her illness?		
Yes	131	89.7
No	15	10.3
Do you believe disclosure is not beneficial to children under 15 years?		
Yes	85	58.2
No	61	41.8
Do you believe non-disclosure until adulthood is necessary?		
Yes	17	11.6
No	129	88.4
Who do you believe should be the one to tell your child?		
Only the parents	137	93.8
Healthcare providers	6	4.1

Table VII: Challenges experienced by parents and children with SCD

Variable	Frequency (n = 146)	Percentage (%)
Does your child often ask questions about medication intake?		
Yes	68	46.6
No	78	53.4
Do you have any problems giving him/her medications?		
Yes	34	23.3
No	112	76.7
Does the disease affect his daily activities?		
Rarely	113	77.4
Sometimes	20	13.7
Frequently	13	8.9
Does the disease affect his school activities?		
Rarely	108	74
Sometimes	23	15.8
Frequently	15	10.3

When the diagnosis disclosure was done, it happened at a later age. The later age of disclosure of SCD is similar to that reported for disclosure of HIV diagnosis from Nigerian and Ghanaian studies, where parents tended to postpone disclosure until they believed the child was cognitively mature enough to understand the diagnosis.[7,9,16] This suggests that

disclosure practices are influenced more by perceived cognitive readiness than by clinical guidelines, which remain poorly defined in many low-resource settings.

Mothers were the primary sources of diagnosis disclosure in the present study. Mothers are the primary caregivers in most households and often, the day-to-day caregivers of children with chronic ill health. They are responsible for medical management, clinic attendance and emotional support and are thus, the most likely persons to disclose the diagnosis behind their child's illness. [17-19] Both children and parents expressed a preference for maternal disclosure, reinforcing the central role of mothers in SCD care within the sociocultural context of Nigeria. The limited roles of healthcare workers in disclosure, as observed in this study, mirror findings from other studies, where disclosure is often viewed as a family responsibility rather than a clinical one.[4,6,20,21] This highlights a gap in structured provider-led disclosure support. Most children expressed a preference for their mother as the source of diagnosis disclosure and wished they had been informed at a younger age. This supports existing evidence that age-appropriate early disclosure may reduce anxiety, enhance trust and improve self-management behaviours in children with SCD.[5]

This study showed that diagnosis disclosure positively influenced medication adherence in a substantial proportion of children. This is consistent with findings in earlier studies that the knowledge of diagnosis improves treatment adherence, clinic attendance and self -care behaviours among adolescents with SCD.[19,20] Improved compliance following disclosure may be related to enhanced illness perception and a sense of responsibility for health outcomes by the caregivers.
The predominant reason for disclosure was to improve medication compliance, highlighting a pragmatic, behaviour-driven approach by parents. Similar motivations have been reported in Nigerian and Jamaican studies where parents' disclosure of diagnosis was primarily meant to enhance co-operation with treatment rather than to promote autonomy or psychosocial development. [7, 21]

The most common reason for non-disclosure in this study was the perception that the child was too young, followed by a fear that the child might disclose the information to other non-family members. These concerns were consistent with findings from Nigeria and Ghana, where stigma, fear of discrimination and cultural misconceptions about SCD strongly influenced secrecy surrounding the diagnosis.[22, 23] Fear of blame and parental guilt related to genetic transmission of the disease was not prominent in the present study. Planned disclosure was most targeted at ages 10-12 years, consistent with parental perceptions of developmental readiness rather than clinical guidelines.

Most parents had informed extended family members, particularly female relatives such as mothers and mothers-in-law, about their child's diagnosis. This reflects the communal nature of caregiving in African families and the reliance on extended family support for managing chronic illnesses.[24] However, disclosure to older siblings was relatively low, possibly due to fears of inadvertent disclosure or sibling anxiety. Disclosure to school authorities was recorded in 61% of cases, suggesting moderate awareness of the child's diagnosis within the educational system. Studies have shown that informing school personnel can reduce absenteeism, improve emergency responses and enhance academic support for children with SCD.[25] Nonetheless, concerns about stigma and discrimination may limit full disclosure in school settings.

A higher proportion of parents who did not disclose the illness to their child actually disclosed it to the school authorities. This suggests that parental decisions regarding diagnosis disclosure to children and school authorities may be influenced by different considerations. While disclosure to children is

driven by family dynamics and perceived maturity, disclosure to schools may be influenced by concerns about stigma, confidentiality and discrimination as previously reported by Dyson *et al.*[21]

Disclosure to the child was significantly associated with higher socio-economic status. Parents in the upper social class were more likely to disclose the diagnosis behind the illness to their child, possibly due to higher health literacy, better access to counselling and reduced stigma. This finding aligns with reports from Nigeria and the United States, where higher parental education and income levels predict earlier and more open disclosure of chronic illnesses to children. [7, 26]

Despite delayed disclosure practices, most parents in this study believed that disclosure was both right and mandatory, although many felt it was not beneficial before the age of 15 years. This suggests that caregivers recognise the ethical importance of disclosure but remain uncertain about its optimal timing. This paradox has been described in other studies, where parents intellectually support diagnosis disclosure but emotionally struggle with its timing. [4, 20, 21.] Improved medication adherence was the most frequently cited reason for disclosure in this study, and not curiosity, nor desire for understanding of the disease. This finding is strongly supported by existing literature, which demonstrates that children who are aware of their SCD diagnosis are more likely to adhere to medications, attend clinics regularly and engage in self-care behaviours. 20,21 The majority of children in this study reported better medication adherence following disclosure, further reinforcing this association.

Interestingly, most children and parents reported that SCD rarely affected daily or school activities. Similar findings have been reported in other Nigerian studies, particularly among children receiving regular follow-up care, suggesting adaptation to chronic illness and improved disease control.[8,15] However, school absenteeism remained common, with many children missing school multiple times due to illness and on days of clinic attendance. In this study, almost all the children missed school during clinic attendance. In Uganda, 88.8% missed at least one school day in the previous term and 33% missed >10% of school days (chronic absenteeism).[27] Schwartz *et al.* noted that their SCD participants missed 12% of the school year, and 35% missed at least one month of school sessions. Clinic attendance and painful crisis were the most significant causes of absenteeism in that study.[28]

Limitations

Being a hospital-based study conducted in a tertiary health facility, the findings may not be fully generalizable to children with SCD who do not regularly attend specialist clinics or who receive care in primary or secondary health facilities. The cross-sectional design limits the ability to establish causal relationships between disclosure and outcomes. Information on disclosure status, reasons for disclosure or non-disclosure was based on self-reporting by parents and children, which may be subject to recall bias and social desirability bias.

Conclusion

This study demonstrates that non-disclosure of sickle cell disease diagnosis to affected children and adolescents in Nigeria is common, and the disclosure was often delayed until late childhood and early adolescence. Mothers were the major persons who bore the responsibility of disclosing the diagnosis. Many caregivers remained uncertain about the appropriate timing for disclosure. The perception that children are too young to understand and the fear of stigma were the major barriers to disclosure.

It is recommended that there is a need for context-appropriate, age-based guidelines for disclosure of the diagnosis of SCD to children in Nigeria. Routine counselling sessions should be integrated into sickle cell disease clinics to educate parents on the benefits of early diagnosis disclosure, address misconceptions

and provide skills for effective communication with children with SCD.

Disclosure assessment should become part of routine clinic activities, with periodic evaluation of whether the child has been informed, their level of understanding and any emotional or behavioural responses.

Acknowledgements: The authors acknowledge the patients and caregivers who participated in the study and Dr Vitalis Ezeuko, who supported data analysis.
Authors' Contributions: OME conceived and designed the study. Both authors participated in data collection, analysis, interpretation and drafting of the manuscript. Both authors read and approved the final version of the manuscript.
Conflicts of Interest: None declared.
Financial support: The authors did not receive any financial support for this research or for the preparation of this manuscript. Conflict of interest:
Accepted for publication: 28th May 2026.

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