Sickle cell disease in Nigerian children: A cross-sectional study on parental awareness and home management of pain

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Abstract

Pain, being the clinical trademark of Sickle Cell Disease (SCD), impacts negatively on clinical outcome in children. However, little is known regarding parental home pain management in children with SCD. We aimed to determine the parental awareness, use and perceived efficacy of pain relief techniques for children with SCD. This is a cross-sectional study involving 80 parents of children with SCD seen at General Hospital, Bwari, North-Central Nigeria. An interview-based, structured questionnaire was used to obtain information on socio-demographic characteristics, clinical history, parental awareness, use and perceived effectiveness of pain relief techniques. Data analysis was with SPSS version 20. Seventy-six (95.0%) respondents were aware of available pain relief technique(s) in SCD. Fifty-four (67.5%) respondents used pain relief techniques, 33 (61.1%) of whom used multiple pain relief techniques. The most commonly used drugs and Complementary and Alternative Medicine (CAM) were non-steroidal anti-inflammatory drugs (47.0%) and massage (36.0%) respectively. Thirty-three (61.1%) respondents perceived their selected techniques as effective. A higher proportion (27.3%) of the children with multiple hospitalizations used multiple pain relief techniques when compared with 4.8% who used drugs alone (p=0.038). However, there was no significant difference based on age, gender, maternal education, genotype, age at diagnosis, pain episodes, regularity of routine drugs and packed cell volume of the children and pain relief techniques used (p>0.05). This study found high parental awareness and utilization of home pain relief techniques for children with SCD. The use of multiple pain relief techniques was influenced by multiple hospitalizations of the children.

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Introduction

Sickle Cell Disease (SCD) is a genetic hematological disorder inherited as an autosomal recessive Mendelian trait and characterized by the presence of abnormal Haemoglobin (Haemoglobin S) in the Red Blood Cells (RBCs).[1,2] Whilst SCD encompasses all disorders with the phenomenon of red cell sickling, the most common and severe form, sickle cell anaemia, connotes homozygosity for Haemoglobin S (HbSS).[2,3] Globally, over 300,000 newborns are affected by this disorder annually, with about 76% occurring in Sub-Saharan Africa alone.[2,4,5] This percentage is projected to increase to 88% by the year 2050, thereby constituting a major public health concern.[5] Nigeria, being the most populous country in Africa, has the highest burden of children with SCD worldwide, with reported prevalence of 2-5% of population.[6–8] Furthermore, about 50-80% of affected children die of complications before five years of age due to limited resources available to provide the complex care required for them.[1–3]

Amongst other complications, persons living with SCD experience pain which has been found to be the most consistent and characteristic feature.[9–11] The spectrum of clinical expression is however heterogenous, varying in intensity, frequency, duration and affected sites.[3,9,12] Pain in SCD is classified as episodic (acute) or persisting (chronic).[9–13] Episodic pain occurs during vaso-occlusive events due to activation of nociceptive nerve endings in ischaemic bones or the mesenteric vessels of the abdomen.[9,10,12,13] On the other hand, persisting pain can result from tissue damage due to avascular necrosis or chronic leg ulcers, as well as subopti-

mal treatment of recurrent acute painful episodes.[9,12] While episodic pain is commoner in younger children, adolescents tend to experience more of persisting pain.[11,12] The attendant negative consequences associated with these painful episodes include decreased school attendance, social functioning, physical activity/mobility and negative psychosocial consequences.[10–12,14]

One of the core principles of management of pain in SCD include adequate analgesia with drugs such as paracetamol (acetaminophen), Non-Steroidal Anti-Inflammatory Drugs (NSAIDS) and opioids.[3,9,12,15] Recent guidelines on pain management have also recommended the use of non-pharmacologic methods including Complementary and Alternative Medicine (CAM).[15,16] Furthermore, it is recommended that mild to moderate painful episodes can be managed at home, while severe episodes require hospitalization and use of parenteral analgesia.[9,12,13] Even though a lot of pain episodes are initially managed at home, there is paucity of literature regarding caregiver home management of SCD-related pain in the paediatric age group. More attention is however focused on SCD pain management in hospital settings.[17,18] Furthermore, exploring the various caregiver pain management techniques and their perceived efficacy in Nigerian children with SCD would not be amiss as this may help in targeted counseling for integrated pain alleviation or otherwise, thereby ensuring improved quality of life.

Materials and Methods

Study design

This was a descriptive, cross-sectional, hospital-based study of parents/caregivers of children with Sickle Cell Disease aged one to fifteen years and seen at the General Hospital, Bwari. Subjects were recruited over a period of four months (June to September, 2019). All parents/caregivers of eligible children were briefed about the purpose of the study, after which written consents were obtained. Ethical approval was obtained from the Health Research Ethics Committee (HREC) of the Federal Capital Territory Administration (FCTA).

Study location

The study was conducted at the General Hospital, Bwari, one of the fourteen public secondary health facilities located in the Federal Capital Territory (FCT), North-Central, Nigeria. The hospital is situated in Bwari town within Bwari Area Council of the FCT, with an estimated population of 365,007.[19] Bwari General Hospital offers Paediatric Emergency, in-patient and out-patient services, with an average monthly visits of 1,500 patients. The Paediatric Department of the hospital also offers specialist clinic services including the SCD clinic which is run once weekly for children with SCD aged fifteen years and below, and has an average monthly attendance of 35 patients. Every medical consultation involves history taking, physical examination, routine Packed Cell Volume (PCV) estimation with or without other investigations deemed necessary, and refill of routine drugs.

Study procedures

Eighty parents/caregivers of children with SCD aged one to fifteen years presenting to the Paediatric SCD and/or out-patient clinic and the emergency unit of the hospital for medical consultation were recruited. Caregivers were defined as those under whose care the index child has been for at least one year. Parents/caregivers who are skilled health workers (doctors, nurses and pharmacists), and those whose children required urgent referral or those who did not consent to participation in the study, were excluded from the study.

Data was obtained by the researchers from the respondents using an interviewer-administered, structured questionnaire. The questionnaire comprised of five domains namely: socio-demographic characteristics (viz: children's age and sex, maternal education, number of children in the family) and the Socio-Economic Status (SES) assessed using the father's occupation and the maternal educational attainment as proposed by Olusanya *et al.*[20] This method stratifies the SES into upper (classes I and II), middle (Class III) and lower (Classes IV and V); SCD history of the child [viz: genotype, age at diagnosis, frequency of hospital admissions/year, frequency of pain episodes/month, regularity of use of routine drugs, and Packed Cell Volume (PCV) obtained from the present medical consultation]; parental awareness regarding pain in SCD; parental home management of pain; and perceived effectiveness of current home pain management. For data quality assurance, the structured questionnaire was pretested and appropriate modifications were made prior commencement of the study.

The minimum sample size required for this study was determined using the formula for single population proportion[21] as follows:

$$n = \frac{Z^2 \times P\,(1-P)}{d^2}$$

where n is the minimum sample size required for the study; d is 5% margin of error= 0.05; Z is value of standard normal distribution (Z=1.96) with confidence interval of 95%; and P= prevalence of SCD (5%).[8]

Therefore,

$$n = \frac{(1.96)^2 \times 0.05\,(1-0.05)}{(0.05)^2} = 73$$

This gave the minimum sample size, n= 73. Allowing for 10% attrition rate, the final sample size became 80. The study participants were recruited consecutively until the desired sample size was achieved.

Data analysis

Data was analyzed using the Statistical Package for Social Sciences (SPSS) version 20.0 software (IBM Corp., Armonk, NY, USA). Measures of central tendency for quantitative variables, as well as frequencies and proportions for qualitative variables were obtained. The Chi-square test was used to measure association between dependent and independent variables. Binary logistic regression was used to determine socio-demographic and other predictors of multiple pain relief techniques, which is measured as the combination of conventional drugs and CAM use in this study. Variables at 95% of confidence interval and the p value of <0.05 were considered significant.

Results

Sample Demographics and SCD History

A total of 80 respondents were investigated. The respondents ranged in age from 18 to 64 years. Sixty-eight (85.0%) of the respondents were mothers, while 39 (48.8%) belonged to the middle social class. Fifty-nine (73.7%) of the children were aged

above five years, with mean age of 7.8 ± 3.5 years. Reflecting the distribution found in the general population, 76 (95.0%) of the children had genotype SS. Fifty-six (70.0%) were diagnosed by two years of age. However, a total of 12 (15.0%) and 19 (23.8%) had greater than two admissions/year and three or more pain episodes/ month respectively. Additional information about the sample population is as illustrated in Table 1.

Parental awareness and knowledge of pain relief techniques

The Venn diagram (Figure 1) shows that 39 (48.8%) of the respondents knew the techniques of medications and CAM for pain relief, while 35 (43.7%) knew medications as the only means of pain relief. Respondents who knew only CAM as pain relief techniques were two (2.5%), while 4 (5.0%) had no idea of type of pain relief used during pain episodes. Figure 2 illustrates the respondents' knowledge of CAM as pain relief techniques. Massage was the commonest form of CAM for pain relief known to the respondents' (40.0%), followed by prayers (32.6%), while only one respondent (1.1%) knew relaxation as CAM for pain relief.

Table 1. Demographic characteristics and SCD history of the study population.

Variables	Frequency (N = 80)	Percentage (%)
Children's age (years)		
≤ 5	21	26.3
6-10	43	53.7
11-15	16	20.0
Children's gender		
M	49	61.2
F	31	38.8
Socioeconomic status		
Lower (IV & V)	13	16.2
Middle (III)	39	48.8
Upper (I & II)	28	35.0
Respondents' relationship to child		
Mother	68	85.0
Father	9	11.2
Others	3	3.8
Genotype		
SS	76	95.0
Others	4	5.0
Age at diagnosis (years)		
≤ 2	56	70.0
> 2	24	30.0
Hospital admissions/year		
≤ 2	68	85.0
> 2	12	15.0
Pain episodes/month		
<3 Episodes	61	76.2
≥3 Episodes	19	23.8
Regularity of routine drugs		
Yes	62	77.5
No	18	22.5
Latest PCV		
Mild anemia (32-30%)	2	2.5
Moderate anemia (29-21%)	51	63.7
Severe anemia (< 21%)	27	33.8

Parental practice and perceived effectiveness of pain management

Fifty-four of the 80 respondents (67.5%) reported use of home pain relief for their child's pain episodes over the past six months. Among the 54 parents, 33 (61.1%) used multiple pain relief techniques (drugs and CAM). Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) were the commonest group of drugs used (47.0%), while Massage was the commonest CAM used by the respondents (50.0%). Thirty-three (61.1%) of the 54 respondents who practiced home pain management believed that the techniques were effective (Table 2). Table 3 shows the relationship between perceived effectiveness of home pain management and the technique used. A higher proportion of parents who used drugs alone for home pain

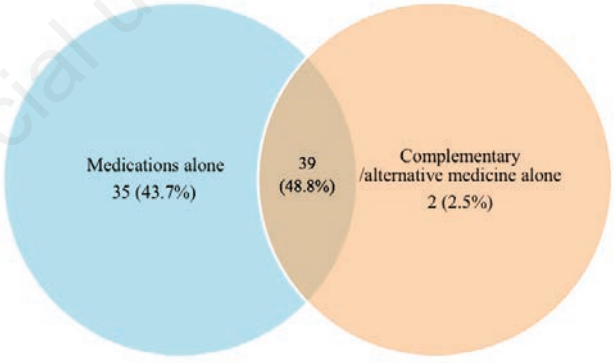

Figure 1. Respondents' knowledge of pain relief techniques in SCD.

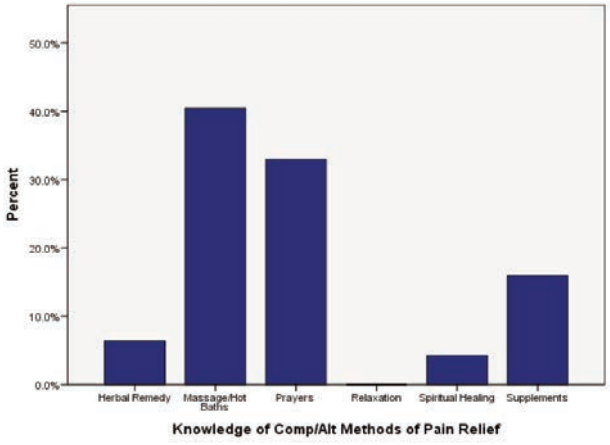

Figure 2. Knowledge of complementary/alternative methods of pain relief.

management (66.7%) had good perception of effectiveness of home pain management than those who used drugs and other methods (57.6%), but the difference in proportions was not statistically significant (p=0.504).

Pain relief techniques and selected parameters

Table 4 shows that index children aged five years and below had a higher proportion (27.3%) and slightly higher odds of using multiple pain relief techniques (drugs and CAM) for home pain management when compared with children above five years of age. However, the difference was not statistically significant (p=0.777). Similarly, the maternal education, gender, genotype, age at diagnosis, number of pain episodes per month, regularity of routine drugs, as well as the latest PCV of the index children did not significantly influence the use of multiple pain relief techniques (p>0.05).

Table 2. Parental home management of pain.

Variables	Frequency (N = 80)	Percentage (%)
Use of home pain relief over last 6 months		
Yes	54	67.5
No	26	32.5
If yes, kind of pain relief techniques used	**(N = 54)**	**(%)**
Drugs alone	21	38.9
Both Drugs and CAM	33	61.1
Drugs used for pain relief (multiple responses)		
NSAIDS (Ibuprofen, Diclofenac etc)	32	47.0
PCM	31	45.6
Opioids	1	1.5
Others	4	5.9
Selected CAM used for pain relief (multiple responses)		
Massage	27	50.0
Prayer	17	31.4
Spiritual healing	3	5.6
Herbal remedies	3	5.6
Supplements	3	5.6
Others	1	1.8
Perceived effectiveness of home pain management		
Effective (pain mostly resolves at home)	33	61.1
Not effective (mostly requires hospital admission)	21	38.9

However, a significantly higher proportion (27.3%) of the index children who were hospitalized more than twice a year managed their pain episodes with multiple pain relief techniques when compared with 4.8% who used drugs alone as pain relief techniques (p=0.038).

Discussion

This study aimed at evaluating parental awareness, knowledge and home pain management of Nigerian children with SCD. We further explored the relationship between the pain relief techniques employed and parents' perceived effectiveness, as well as its relationship with selected socio-demographic and other parameters. Expectedly, 95% of the respondents knew one form of pain relief technique or the other, which underscores the prominence of pain as a symptom of SCD. Being the commonest symptom experienced by sufferers, most parents/caregivers would employ any known measure to alleviate or halt the progression of pain so as to relieve discomfort and avoid hospitalization, which could be distressing to the child and family. Alongside medication use, about half of the respondents knew various forms of CAM as means of pain relief, lending further credence to an increasing recognition of CAM use in this part of the world which is consistent with global trends.[22]

Data analysis also indicates that about two out of three parents reported use of home pain relief techniques for their children's pain episodes over the past six months, majority of whom (61.1%) used a combination of orthodox drugs and CAM. In tandem with other studies that investigated paediatric SCD population,[23,24] our findings on CAM utilization are much lower than the reported prevalence from adult SCD population.[25–27] This may be due to children's inability to take decisions on their own health care, thereby relying on adults for choice of pain relief. Furthermore, a higher percentage of adults with SCD experience chronic, debilitating pain which may prompt them to seek alternative means of pain control.[9,11,26]

The use of Non-steroidal anti-inflammatory drugs (NSAIDs) as the medication for pain relief were in the majority (47.0%) in this study, which is not surprising, given its proven efficacy and recommendation for use in mild to moderate painful episodes.[3,12,15,16] On the other hand, it was found that massage was the most frequently used CAM among the respondents (50.0%). Although with prevalence rates of 14-67% reported by previous studies, massage was one of the leading CAM employed for pain relief in SCD.[26–28] On the contrary, prevalence rates of 2.0% and 4.0% reported in studies carried out in Lagos, South-west Nigeria indicate a low utilization of massage in that region, with predominance of biological products' as CAM.[25,29]

It is also noteworthy that, unlike studies from other parts of the world, none of the respondents in our study admitted to use of cer-

Table 3. Relationship between perceived effectiveness of home pain management and the technique used.

Perceived effectiveness of home	Technique used for home pain management (n = 54)		χ^2	p value
	Drug use alone n (%)	Drug use and CAM n (%)		
Pain management				
Effective	14 (66.7)	19 (57.6)	0.446	0.504
Not effective	7 (33.3)	14 (42.4)		

tain types of CAM such as acupuncture, hypnosis, homeopathy, biofeedback, and other cognitive strategies.[26–28] The reason adduced to this disparity include unfamiliarity to certain types of CAM, as culture, health beliefs and religious underpinnings may influence preference of type of CAM.[25] In addition, the lack of access to professional services for certain CAM such as acupuncture, as well as patients in the paediatric age group could be barriers in the utilization of some forms of CAM.

The descriptive information from this study shows that 61.1% of the respondents adjudged their current home pain relief strategy as effective, indicating that most pain episodes reduce or resolve without resulting in hospital visits/admission. This compares well with previous reports evaluating patient-perceived benefits of pain relief, particularly with use of CAM in conjunction with conventional treatment of SCD.[25,28] However, this study found that the respondents' perception of effectiveness occurred irrespective of whether drugs were used alone, or in combination with CAM as relief for pain episodes. This finding also puts to question the additional benefits of some forms of CAM, particularly massage whose beneficial effects evaluated by previous studies were conflicting, probably due to application by patients and relatives who are mostly non-professionals.[30] Moreover, the long term efficacy of CAM cannot be reflected in our findings given the study period.

In this study, the use of multiple pain techniques for pain relief was not significantly influenced by socio-demographic characteristics such as age, gender, maternal education and genotype of the index children. This is in congruence with findings from previous studies which evaluated the influence of CAM utilization for pain in SCD.[25–27] Busari *et al.* reported that age, gender, genotype, level of education and a stable haemoglobin concentration >7g/dl did not significantly influence CAM use, although respondents who were Christians and of Yoruba ethnicity were more likely to use CAM.[25] In another study by Thompson *et al.*, there was no significant influence of age, marital status and genotype on CAM use, but noted that males and those with less than high school education were less likely to use CAM for relief of pain episodes.[27] On the other hand, Majumdar *et al.* documented a significant association of marital status with relaxation therapy, as well as age and level of education with use of prayer.[26]

Against the background of dearth of studies documenting the relationship between pain relief techniques and patient SCD history, this study observed that a significantly higher number of children who were admitted twice or more times a year used multiple pain relief techniques for home pain relief. This is in consonance with reports by Sibinga *et al.* in which CAM use was associated with SCD severity, particularly multiple hospitalization.[23] However, the use of single or multiple pain relief techniques were comparable irrespective of factors such as age at diagnosis, number of pain episodes per month, and regularity of routine drugs. In view of paucity of published studies, further studies will be needed to disprove, or otherwise, the influence of patient SCD history on the choice of use of pain relief techniques.

Table 4. Relationship between pain relief techniques and selected parameters.

Variables	Pain Relief Technique (n =54)		P-value on bivariate analysis	AOR (95% CI) on multivariate analysis
	Drugs alone n (%)	Drugs and CAM n (%)		
Age of child (years)				
≤ 5	5 (23.8)	9 (27.3)	0.777	1.663 (0.354-7.801)
>5	16 (76.2)	24 (72.7)		
Gender of child				
Male	7 (33.3)	14 (42.4)	0.504	2.391 (0.567-10.083)
Female	14 (66.7)	19 (57.6)		
Maternal education				
< High school (SSCE)	3 (14.3)	10 (30.3)	0.180	2.299 (0.383-13.802)
≥ High school (SSCE)	18 (85.7)	23 (69.7)		
Genotype				
SS	20 (95.2)	31 (93.9)	0.839	1.317 (0.066-26.342)
Others	1 (4.8)	2 (6.1)		
Age at diagnosis (years)				
≤ 2	15 (71.4)	23 (69.7)	0.892	0.433 (0.081-2.333)
> 2	6 (28.6)	10 (30.3)		
Hospital Admissions/year				
≤ 2	20 (95.2)	24 (72.7)	0.038	0.098 (0.008-1.238)
> 2	1 (4.8)	9 (27.3)		
Pain episodes/month				
<3 Episodes	17 (81.0)	20 (60.6)	0.117	0.498 (0.101-2.453)
≥3 Episodes	4 (19.0)	13 (39.4)		
Regularity of routine drugs				
Yes	17 (81.0)	29 (87.9)	0.485	0.428 (0.070-2.453)
No	4 (19.0)	4 (12.1)		
Latest PCV				
Mild-Moderate anemia	15 (71.4)	23 (69.7)	0.892	1.271 (0.295-5.470)
Severe anemia	6 (28.6)	10 (30.3)		

AOR: Adjusted Odds ratio, CI: Confidence Interval

One of the limitations of this study is that it was a single hospital-based study. A more elaborate community-based or multicenter study may be needed to improve generalization of the findings. Another limitation was that the use of home pain relief was assessed over six months, and as such, the long-term effectiveness of pain relief techniques utilized could not be ascertained.

Conclusions

This study shows that a substantial number of parents/caregivers employed home pain relief for their children's pain episodes, with majority using multiple pain techniques. A variety of pain relief techniques were used, with the most common drug and CAM being NSAIDs and massage therapy respectively. Most of the parents considered their current home pain management as effective, irrespective of whether single or multiple pain relief techniques were utilized. A higher number of the children with multiple yearly hospitalizations used multiple pain relief techniques.

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