

Caregivers' knowledge, attitude, and perception toward pneumococcal infection prophylaxis in pediatric sickle cell disease patients in Kumasi, Ghana

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Abstract

Background and Aims: Pneumococcal infection prophylaxis (PIP) is necessary for children with sickle cell disease (SCD) due to the enhanced risk of pneumococcal infections and associated mortalities. PIP measures include periodic administration of pneumococcal conjugate vaccine (PCV), twice-daily administration of phenoxymethylpenicillin tablets, and nonpharmacological measures. This work assessed the attitude, knowledge, and perception of parents of SCD children on PIP, how parents obtain phenoxymethylpenicillin, and their preference for PIP.

Methods: This prospective cross-sectional study involved 200 parents of SCD children between 2 and 12 years old seeking medical care at the SCD clinic of the Komfo Anokye Teaching Hospital, Ghana. Infants involved had hemoglobin SS, SC, or S- β thal. A survey questionnaire (written) was administered to gather and interpret the data using Statistical Package for Social Sciences version 25 software.

Results: Out of 200 respondents in this study, 12% knew vaccination could prevent pneumococcal disease, but only 4% had heard about PCV, 96% had heard about phenoxymethylpenicillin tablets, and 40% knew it could prevent it. Although phenoxymethylpenicillin is reimbursed on national insurance, 87% obtained the tablets from outside the hospital with cash, whereas 12% obtained the tablets from the hospital either on insurance or with cash. About 38% mentioned that they had discontinued treatment with tablets due to intentional withdrawal, lack of funds, noncompliant children, and running out of medicine. All but 2% of respondents said they would prefer vaccines to tablets.

Conclusion: There is a significant shortfall in knowledge, attitude, and perception of parents of SCD children concerning PIP, which warrants education and awareness creation on PIP in sickle cell clinics to ensure optimum clinical and health outcomes and reduce morbidity and mortality related to such infections.

KEYWORDS

children, parents, pneumococcal infection, prophylaxis, sickle cell disease, vaccine

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1 | INTRODUCTION

Sickle cell disease (SCD) is a haemoglobinopathy distinguished by two anomalous hemoglobins, of which at least one is hemoglobin S (Hb S).¹ There are many variants: hemoglobin SS (HbSS), hemoglobin SC (HbSC), hemoglobin S-Beta thalassemia (HbS β Thal), and other rare forms such as hemoglobin SE (HbSE), hemoglobin SD (HbSD), and hemoglobin SO-Arab (HbSO-Arab).² Generally, homozygous HbSS is the severest form of the disease.^{1,2}

Globally, there is an estimated heterozygous SCD of 42 per 1000 births, with the highest occurrence in Africa (161 per 1000 births) and the lowest occurrence in Europe (8 per 1000 births).³ Thus, Africa has the highest burden of SCD globally. Over 200,000 babies are estimated to be born with SCD in Africa annually,⁴ with 80% occurring within the sub-Sahara.⁵ A neonatal SCD screening study in Ghana revealed that approximately 2% of newborns in Ghana have SCD, with about 55% having HbSS.⁶

Mortality from SCD is a challenge and is attributable partially to infections secondary to high susceptibility from splenic dysfunction.⁷ The predominant infection suffered by SCD patients is caused by *Streptococcus pneumoniae*. An estimated 10%–20% of mortalities in infants below 5 years in developing countries are caused by pneumococcal infections.⁸ Available data in Ghana indicate that invasive pneumococcal disease is more prevalent among children under 5 years, and mortality is as high as 47%.^{9,10} To minimize the incidence of pneumococcal infections in SCD individuals, vaccination and antibiotics are administered as prophylaxis in conjunction with other disease prevention and control measures^{11,12} (American Academy of Pediatrics).¹³ Vaccines for *S. pneumoniae* include a 23-valent polysaccharide vaccine, pneumococcal conjugate vaccine (PCV) 10, and PCV 13.¹⁴

Phenoxymethyl penicillin (penicillin V) prophylaxis is recommended in children <5 years and in older infants with a prior case of pneumococcal infection or surgical asplenia.¹⁵ For children <5 years with SCD, 125 mg of oral prophylactic antibiotics is taken twice daily, and for children \geq 5, the dose is 250 mg taken twice daily. In addition, newborns screened for SCD and those who test positive are also prescribed penicillin V prophylaxis.^{11,15}

Whether to vaccinate or not or administer antibiotic prophylaxis, especially penicillin V, to a child rests with the parents or caregivers. Their knowledge, attitude, and perception toward pneumococcal vaccination and penicillin V prophylaxis can be complex.^{16,17} However, these parents and caregivers of SCD patients are best positioned to ensure that children under 5 years undergo their scheduled vaccination and antibiotics, especially penicillin V prophylaxis. A study done in Singapore reported that parents lack knowledge of PCV, which may affect vaccine intake. Also, their attitude could be positively influenced if they adequately understand the disease, vaccination, and prophylaxis.¹⁸ Another similar study in Indonesia also reported a lack of knowledge of PCV and the disease, which influenced the uptake of PCV.¹⁹ Findings from a study done in India among mothers of children under 5 years suggest that many parents or caregivers without formal education and with low

Key points

- Agents often used are oral phenoxymethylpenicillin and pneumococcal vaccines.
- There is a significant deficit in parents' knowledge, attitude, and perception of pneumococcal infection prophylaxis (PIP).
- Education on PIP in sickle cell clinics is necessary to improve children's clinical and health outcomes with sickle cell disease.

socioeconomic status who were educated by their health service personnel on pneumococcal infections and PCV were aware of PCV.²⁰ Based on the above, this can be concluded that knowledge is essential for vaccine and antibiotic prophylaxis intake. In contrast, other research in India, Nepal, and Uganda discovered that knowledge is more significant than other determinants for antibiotic prophylaxis and PCV intake.^{21,22}

According to literature reviews, studies on PCV and antibiotic prophylaxis among parents and caregivers of SCD patients have yet to be thoroughly examined in Ghana, which warrants more research. Therefore, the present study sought to document caregivers' knowledge, attitude, and practice of PCV and penicillin V prophylaxis among children living with SCD.

2 | METHODS

2.1 | Study type

This cross-sectional quantitative study was designed to generate data from parents and guardians of pediatric SCD patients accessing care at a tertiary hospital's pediatric sickle cell specialist clinic.

2.2 | Study site and population

This work was carried out at the Komfo Anokye Teaching Hospital (KATH), which has 15 directorates: 13 clinical and two nonclinical. This 1200-bed tertiary health facility in Kumasi, Ghana, is a referral center for 13/16 regions within Ghana, and the Child Health Directorate of the Ministry of Health conducts one of the country's largest specialist outpatient pediatric sickle cell clinics.²³ By 2–3 months, babies diagnosed with SCD are enlisted at the clinic and put on therapy, which includes phenoxymethylpenicillin taken twice daily, PCV scheduled immunization, and once daily folic acid. Children up to 3 years are expected to visit every 2 months, and those above 3 years are scheduled for visits every 3 months. In addition, clinic attendees must undergo routine health evaluations such as complete blood counts with reticulocyte count and kidney and liver function tests.²⁴ The caregivers of the clinic attendees comprised the study

population for this study. These parents or carers are from diverse backgrounds as the clinic, although in the city's center, receives referrals from other suburbs and regions in the country.

2.3 | Sample size

A minimal sample size of 197 was obtained and used for this study using the sample size determination formula at an $\alpha = 0.05$ confidence limit and a desired precision of 5%.²⁵

2.4 | Sampling and patient recruitment

The study was carried out from May to July 2022. Consecutive sampling was used to recruit participants on clinic days until the required total was obtained. The clinic's attendees are children determined to have a hemoglobin SS (HbSS), hemoglobin SC (HbSC), or Hemoglobin S-Beta thalassemia (HbS β Thal). The statuses described above were determined via DNA tests or electrophoresis with family studies. The child should be between 2 and 12 years to be included in the study. Their carers must be their biological parents or any individual they live with who sees to their daily care (feeding, administering medicines, and general upkeep). Participants were approached individually during the Outpatient Department clinic days of the Sickle Cell Disease Unit. Trained medical research assistants within the public health department of the hospital identified participants based on inclusion and exclusion criteria. They presented and verbally explained all the information and documents to the participants before enrolling in the study after the consent, and in cases where participants could not personally write their responses, their responses were recorded for them based on their feedback.

2.5 | Data collection tool

A structured questionnaire using the planned behavior theory and the health belief model was adapted to suit the research aim.^{26,27} The tool (written questionnaire) consisted of 27 questions: sociodemographic of participants (five questions), knowledge of phenoxymethylpenicillin, pneumococcal vaccine, and pneumococcal disease (eight questions), attitude toward infection prevention (five questions), adherence to phenoxymethylpenicillin (two questions), preference for the vaccine (one question), perception of pneumococcal disease and its prophylaxis (five questions), and how phenoxymethylpenicillin is obtained (one question). In addition, participants who had questions concerning pneumococcal disease and its prophylaxis were addressed after completing the survey.²⁸

2.6 | Data management and statistical analysis

Participants were anonymized by being given a unique identifier. Completed questionnaires were crosschecked before entry into a

predesigned Microsoft Excel[®] database. The data entered was appropriately coded and stored on a password-protected computer. A questionnaire was considered valid for analysis if 80% of the questions were answered. Descriptive statistics such as frequencies, mean, and standard deviations were obtained from the data. The association between the sociodemographic of respondents and their KAP on pneumococcal infection and its prophylaxis was investigated using the χ^2 test. Data obtained were interpreted with Statistical Package for Social Sciences (SPSS) version 25 at a p -value of 5% to determine statistical significance.

3 | RESULTS

3.1 | Sociodemographic characteristics

Out of the 200 respondents, 171 were females, and 29 were males, with the middle age of their children being 7 years. Half of the respondents were between the ages of 31–40 years. About half (109) of respondents had secondary education as their highest level of education. A majority (62%) earned less than GH¢ 1000, and 38% made between GH ¢1001 (\$81) and GH ¢3000 (\$244). The summary of the sociodemographics of the respondents is detailed in Table 1.

3.2 | Knowledge of respondents on pneumococcal disease and its prophylaxis

The respondents' knowledge of pneumococcal disease and its prophylaxis is shown in Table 2. Most of the respondents have heard about pneumococcal disease (58%), the risk of babies acquiring pneumococcal disease (55%), and the risk of SCD patients contracting pneumococcal disease (55.5%). The percentage of females who knew about pneumococcal disease was higher than males (56%:48%). Only 12% of respondents knew vaccination could prevent pneumococcal disease, and 4% had heard about PCV. Almost all respondents (96%) had heard about penicillin V tablets; all male respondents (100%) had heard about penicillin V tablets. However, less than half of the respondents (40.5%) knew penicillin V could prevent pneumococcal disease.

3.3 | Attitude and perception of pneumococcal disease prophylaxis

The attitude and perception of respondents toward pneumococcal disease and its prophylaxis are shown in Table 3. A few respondents (5%) perceived that PCV does more harm than good, whereas about a quarter (26%) agreed that PCV is effective. Over three-quarters (83%) of the respondents agreed that oral phenoxymethylpenicillin is effective, and one-fifth (20%) believed there are too many phenoxymethylpenicillin tablets for their child to be taking. Most respondents disagree with the statement that their children do not need any vaccine or tablet as they are strong enough to cope with the disease, contrary to a few (4.5%).

TABLE 1 Sociodemographics of respondents.

Characteristic	Overall (N = 200)	Female (N = 171)	Male (N = 29)	p Value ^a
Age in years of child, median (IQR)	7.0 (4.8–9.0)	7.0 (4.5–9.0)	7.0 (5.0–9.0)	0.862
Caregiver's age in years, n (%) (year)				<0.001
21–30	22 (11%)	20 (12%)	2 (6.9%)	
31–40	100 (50%)	94 (55%)	6 (21%)	
≥41	78 (39%)	57 (33%)	21 (72%)	
Caregiver's educational level completed, n (%)				0.009
Primary	58 (29%)	56 (33%)	2 (6.9%)	
Secondary	109 (55%)	89 (52%)	20 (69%)	
Postsecondary	33 (16%)	26 (15%)	7 (24%)	
Caregiver's income level, n (%)				0.004
<GH¢ 1000	124 (62%)	113 (66%)	11 (38%)	
GH¢ 1001 to GH¢ 3000	76 (38%)	58 (34%)	18 (62%)	

^aWilcoxon rank sum test; Fisher's exact test; Pearson's χ^2 test.

TABLE 2 Knowledge of respondents on pneumococcal disease and its prophylaxis.

Characteristic	Overall (N = 200)	Female (N = 171)	Male (N = 29)	p Value ^a
Heard about pneumococcal disease, n (%)	117 (58%)	103 (60%)	14 (48%)	0.227
Babies are at risk of pneumococcal disease, n (%)	109 (55%)	95 (56%)	14 (48%)	0.560
SCD patients are at risk of pneumococcal disease, n (%)	111 (55.5%)	97 (56.7%)	14 (48%)	0.538
Vaccination can prevent pneumococcal disease, n (%)	24 (12%)	19 (11.1%)	5 (17%)	0.324
Heard about penicillin V tablets, n (%)	192 (96%)	163 (95%)	29 (100%)	0.606
Penicillin V can prevent pneumococcal disease, n (%)	81 (40.5%)	71 (41.5%)	10 (34%)	0.362
Heard about pneumococcal vaccine, n (%)	8 (4.0%)	6 (3.5%)	2 (6.9%)	0.327
Know how long penicillin V will be given, n (%)	53 (26.5%)	43 (25%)	10 (34%)	0.292

Abbreviation: SCD, sickle cell disease.

^aPearson's χ^2 test; Fisher's exact test.

Regarding measures taken to prevent a child from getting infections, 88% of them routinely administered phenoxymethylpenicillin tablets, 84% observed good basic personal hygiene, and 74% reduced exposure to known crisis triggers. Other measures adopted by respondents include a healthy diet (25%) and administering homemade herbal preparation (6%).

To obtain oral phenoxymethylpenicillin, 87% of the respondents bought these tablets from outside pharmacies with cash, 9% from

hospital pharmacies on NHIS, and 3.2% from hospital pharmacies with cash.

About one-third (38%) of the respondents had discontinued phenoxymethylpenicillin at any time in the past 6 months due to the child being uncooperative (15%), forgetfulness of guardian to administer medication (35%), running out of medicine (10%), guardian unavailable (5.9%) and lack of funds to obtain drug (5.9%), intentional withdrawal (12%), and unwell child (2.9%). Almost all respondents

TABLE 3 Attitude and perception of respondents toward pneumococcal disease and its prophylaxis.

Characteristic	Overall (N = 200)	Female (N = 171)	Male (N = 29)	p Value ^a
PCV does more harm than good, n (%)	10 (5.0%)	10 (5.8%)	0 (0%)	0.363
PCV is effective, n (%)	53 (26%)	40 (23%)	13 (45%)	0.016
Oral Pen V is effective, n (%)	166 (83%)	141 (82%)	25 (86%)	0.792
Too many Pen V to take, n (%)	40 (20%)	37 (22%)	3 (10%)	0.160
The child does not need any vaccine or tablet, n (%)	9 (4.5%)	8 (4.7%)	1 (3.4%)	>0.999
Infection prevention: administer Pen V, n (%)	175 (88%)	149 (87%)	26 (90%)	>0.999
Infection prevention: avoid triggers, n (%)	147 (74%)	128 (75%)	19 (66%)	0.292
Infection prevention: personal hygiene, n (%)	168 (84%)	142 (83%)	26 (90%)	0.583
Infection prevention: herbal remedy, n (%)	12 (6.0%)	10 (5.8%)	2 (6.9%)	0.687
Infection prevention: avoid mosquitoes, n (%)	12 (6.0%)	11 (6.4%)	1 (3.4%)	>0.999
Infection prevention: healthy diet, n (%)	50 (25%)	45 (26%)	5 (17%)	0.297
Infection prevention: staying hydrated, n (%)	10 (5.0%)	10 (5.8%)	0 (0%)	0.363
Infection prevention: other means, n (%)	7 (3.5%)	7 (4.1%)	0 (0%)	0.596
How Pen V tablets are obtained, n (%)				0.005
From outside pharmacy with cash	164 (87%)	143 (90%)	21 (72%)	
From hospital pharmacy on NHIS	17 (9.0%)	13 (8.2%)	4 (14%)	
From the hospital with cash	6 (3.2%)	2 (1.3%)	4 (14%)	
From outside pharmacy on NHIS	1 (0.5%)	1 (0.6%)	0 (0%)	
Ever discontinued Pen V, n (%)	71 (38%)	65 (41%)	6 (21%)	0.039
Reason discontinued Pen V, n (%)				0.451
Forgot	24 (35%)	23 (37%)	1 (20%)	
Child uncooperative	10 (15%)	10 (16%)	0 (0%)	
Child unavailable	8 (12%)	7 (11%)	1 (20%)	
Intentional withdrawal	8 (12%)	6 (9.5%)	2 (40%)	
Run out of medicine	7 (10%)	6 (9.5%)	1 (20%)	
Guardian unavailable	4 (5.9%)	4 (6.3%)	0 (0%)	
Lack of funds	4 (5.9%)	4 (6.3%)	0 (0%)	
Child unwell	2 (2.9%)	2 (3.2%)	0 (0%)	
No reason	1 (1.5%)	1 (1.6%)	0 (0%)	
Would guardian prefer vaccine, n (%)	183 (98%)	156 (99%)	27 (93%)	0.064

Abbreviation: PCV, pneumococcal conjugate vaccine.

^aFisher's exact test; Pearson's χ^2 test.

(98%) would prefer periodic vaccine administration to daily administration of oral phenoxymethylpenicillin.

4 | DISCUSSION

In this study, we investigated the sociodemographic profiles of sickle cell patients and their caregivers and explored the pharmacoeconomic implications of pneumococcal vaccine and penicillin V among

SCD patients. The findings from our sociodemographics revealed that half of the respondents were between 31 and 40 years of age. Available statistics show that in Ghana, among women aged 25–49, the median age at which they have their first child is 21.5 years.²⁹ This observation explains why most of our respondents were between 31 and 40, as this study considers children between 2 and 12 years old.

Again, we observed that 80% (4/5) of our respondents were females. Having more female respondents than males is not

surprising, as the burden of care for children born with SCD falls majorly on mothers.³⁰ In Ghana, the mean childbearing age is 29.79 years, with the highest fertility rate between 25 and 29 years, explaining why about half of the respondents are between 31 and 40 years old and their children are between 2 and 2 years.³¹ Additionally, the gender roles and expectations within the Ghanaian culture could explain why more females report at SCD Clinics with their wards than men. This assertion is supported by reports of more females reporting various illnesses at health institutions than males.³²

Again, more than half, 61% (122/200), of the respondents had less than ₵1000.00 as their combined monthly household income. The international poverty line of \$1.90 a day is the threshold that determines whether an individual is poor and is established on the number of goods essential to sustain one adult.³³ Therefore, a combined household income of 1000.00 Ghana cedis monthly means about 33.33 Ghana cedis per day, assuming 30 days a month. The average dollar rate at the beginning of this study was USD 7.09786 to one (1) Ghana Cedi; the standard deviation between March 1, 2022 and March 31, 2022 is +9.59%. Therefore, the equivalent of 33.33 Ghana Cedis is 4.70 USD. Chaudry and Wime³⁴ argue that poverty is an essential indicator of societal and child well-being and that poverty and low income could affect cognitive, developmental, and educational outcomes.

The respondents' education level was another critical area in the sociodemographics that impacted knowledge and perception of pneumococcal disease prophylaxis. More than half of the respondents, 54.4% (109/200), had secondary school education. Education is vital since it will ensure that carers are well-informed on measures to adapt for children living with SCD. In addition, a secondary level education provides relevant and science-based reasons to individuals who would be able to apply standards in SCD children to live safely and healthily with the condition. These suggest that those with lower education may lack knowledge of pneumococcal disease prophylaxis.^{35,36} Rawlings³⁷ investigated the influence of education of parents on infant health in China. The study showed that the education level of the mother is crucial for the child's health. Still, additional educational years for mothers generally increase the height-to-age of the child and lower the probability of a child being stunted.³⁷ Similarly, another study found that maternal education is significantly associated with long-term health outcomes, whereas paternal education affects immunization decisions.³⁸ In addition, mothers are generally more involved in childcare, so their education level will impact the child's healthcare outcomes.

Parents must be educated on pneumococcal infections, prophylactic measures, and the need thereof. In assessing parents' knowledge of pneumococcal disease and its prophylaxis, results showed that 55%–58% (109–117, $n = 200$) of the respondents had heard about pneumococcal disease and babies and SCD patients being at risk of pneumococcal disease. In a similar study, 69% ($n = 74$) of mothers had poor knowledge, below 42%–45% of parents with poor knowledge of pneumococcal disease in this study.³⁹ On the use of prophylactic antibiotic therapies, it was determined that low educational levels of parents were the key risk component correlated to antimicrobial abuse.¹⁶

Moreover, we observed a statistically significant association between the level of parental knowledge and their level of education ($\chi^2 20.56, p = 0.001$). When parents were asked about pneumococcal disease if babies were at risk, and if sickle cell individuals were at risk, more than half of the parents answered correctly (58%, 71%, and 76%, respectively). However, when they were asked if vaccination could prevent pneumococcal diseases and if they had heard about the pneumococcal vaccine before, only a few parents answered correctly (15% and 4%, respectively). When it comes to pneumococcal vaccination as a measure of pneumococcal infection prophylaxis (PIP), the majority of respondents didn't know about it.

In assessing parents' perception, their perception of both pneumococcal vaccine and phenoxymethylpenicillin was evaluated. A majority (>70%) took a neutral stance when asked if PCV does more harm than good and if PCV is effective. This may be so because they need to learn more about the vaccine and cannot answer about its effectiveness. On the other hand, one-fifth of respondents disagreed that PCV does more harm than good, and this may be so because, generally, vaccines are one of the highly efficacious means of preventing diseases and saving lives.⁴⁰ In addition, vaccination is mandatory and required for school registration in some jurisdictions. Therefore, parents are compelled to oblige to all the necessary vaccines and have a positive perception and attitude toward vaccines/immunization.⁴¹

A great majority (83%) of respondents agreed that oral penicillin is effective, with a small minority (14%) remaining neutral and a few (3%) disagreeing. Penicillin prophylaxis is initiated as early as possible when a diagnosis of SCD is made as prophylaxis. Hence, a majority of respondents agree. Those remaining neutral may not have seen any benefit or harm after their children were initiated on oral penicillin. The few who disagree on the effectiveness of oral penicillin may have had crises with SCD or episode(s) of infection and hence may differ that oral penicillin is effective. We may have to investigate what parameters parents consider to measure the effectiveness or otherwise of therapy initiated in their wards.

Additionally, most parents (78%) disagreed that their child does not need any vaccine or tablet as they are strong enough to cope with the disease. This supports the fact that most parents agree that oral penicillin is effective. Over half (60%) of parents disagreed that their child must take too many phenoxymethylpenicillin tablets. The reason for this could be that they know phenoxymethylpenicillin is effective. Hence, the benefits they stand to gain when tablets are administered to children outweigh the number of tablets the children must take daily. However, 20% agree that their children must take too many phenoxymethylpenicillin tablets. This is important to note because it is likely to affect adherence to penicillin prophylaxis in this group.

Further investigations may be conducted to assess adherence, factors influencing it, and measures to improve it and create a positive perception/attitude through education. For example, a Sickle Cell Antibiotic Adherence Level Evaluation could be employed for a thorough investigation.⁴² This is necessary because in a chronic and critical condition such as SCD, even a low incidence of infections could lead to mortalities, "when a little is a lot."⁴³

As much as prophylactic treatments are recommended and instituted to prevent or reduce the incidence of pneumococcal diseases, caregivers and their wards' role in infection prevention and control is vital.⁴⁴ Aside from the targeted vaccination and penicillin prophylaxis, the CDC recommends hand washing, food safety, and staying away from reptiles in children with SCD. Hand washing is one of the best infection prevention and control methods, especially before making food and eating. Food safety measures include washing utensils before and after use in cooking, washing fruits and vegetables before eating, cooking meat until it is well done, and not eating raw or undercooked eggs or raw or unpasteurized milk or other dairy products.⁴⁵ From this study, parents' most predominant measure was routine administration of penicillin (90.2%), followed by good basic personal hygiene such as hand washing with soap under running water (86.6%). In addition, most respondents (73.2%) identified reducing exposure to known crisis triggers as a measure to prevent children from getting infections. However, this is not a measure of infection prevention. Drinking plenty of fluids, wearing warm clothing to prevent cold, and limiting strenuous activity, among others, cannot be considered measures to prevent infection. According to respondents, other measures adopted to avoid infection in children included healthy eating, including fruits and vegetables (20.5%), and a few (4.6%) admitted to administering homemade herbal preparations routinely. A double-blinded clinical trial is ongoing in Uganda to assess the effectiveness of zinc supplementation in infection prevention. Zinc deficiency leads to reduced immunity and increases the risk of infection in many people living with SCD; therefore, adding zinc to the treatment regime will likely decrease the risk of diseases.⁴⁶ If the hypothesis is confirmed with the "zinc study results," it will significantly add to the measures instituted to prevent infections.

Adequate knowledge of pneumococcal infections and the need for prophylaxis should motivate parents of children with SCD to adopt effective measures to prevent or reduce the risk of infections and adhere to prophylactic treatment. Therefore, another interest of this study was to assess whether patients had difficulty getting penicillin tablets and what the problems were, if any. Also, would they opt for an option instead of daily administration of penicillin if they could? These are factors that influence treatment adherence. Patient compliance with treatment protocols is often compromised by socioeconomic factors, the healthcare team, and disease therapies.⁴⁷ Data obtained can influence other studies and further be investigated to ensure the optimum treatment for PIP in SCD or extrapolate to other long-term therapies for chronic diseases. When respondents were asked how they obtained Phenoxymethylpenicillin tablets, about 87% got them from pharmacies outside the hospital with cash, and about 9% got them from the hospital pharmacy on insurance, thus Ghana National Health Insurance Scheme (NHIS) specifically. Few (3.2%) were obtained from the cash pharmacy of the hospital, and one respondent refilled their prescription from an outside pharmacy with their NHIS. Should we be concerned that most parents fill prescriptions for phenoxymethylpenicillin tablets from pharmacies outside the hospital with cash? Indeed, we should

be. This is because the cost of treatment can easily influence medication adherence.

Research by the National Pharmaceutical Council and Xcenda of the USA show that high "out-of-pocket" healthcare costs worsen medication adherence.⁴⁸ Therefore, hospital pharmacies should try to stock phenoxymethylpenicillin tablets at all times, as SCD patients rely heavily on them to prevent infections. Also, if patients do not have insurance or are inactive, they should be encouraged to activate it to obtain the medication on insurance easily. This will reduce the monthly expenditure and positively promote adherence. Parents were asked if their wards had discontinued Phenoxymethylpenicillin prophylaxis within the past 6 months and the reason for that. About 38% of respondents admitted to having discontinued, and the reasons included the child not complying with medicine administration, parent traveling, forgetfulness of parents, bitter taste of medicine, parents not knowing how the drug works, lack of funds to refill prescription, and child being too young to take medications every day. These genuine concerns raised by parents should be attended to increase the adherence rate and ensure optimum health outcomes.

Parents were again asked if the child could take one dose of a vaccine periodically instead of daily administration of phenoxymethylpenicillin tablets, would they be willing for their child to be vaccinated? About 98% of parents agreed they would be willing. Again, this shows a positive perception of vaccination. If further studies can be done to assess the effectiveness of PCV outside the recommended EPI by WHO schedule, the duration for which it is effective, and if it can be given periodically (yearly or more) in place of twice-daily administration of oral penicillin, the clinical outcomes and cost benefits to patients and the healthcare system will be tremendous.

5 | CONCLUSION

Measures taken by parents to prevent children from getting infections are as crucial as the prophylactic treatment children are prescribed by their clinicians. Therefore, there is a need for education and awareness creation on pneumococcal infection and its prophylaxis, including the use of the vaccine (PIP) in sickle cell clinics to ensure optimum clinical and health outcomes, as well as an overall reduction in morbidity and mortality related to pneumococci infections in SCD patients. Additionally, PIP is a long-term therapy, and its effectiveness is greatly affected by adherence to therapy; hence, measures should be implemented to enhance adherence to prophylactic treatments among SCD patients.

6 | LIMITATIONS

1. The obtained data is localized but may be comparable to other areas with tertiary hospitals and specialist clinics serving diverse backgrounds.

2. Direct participant interviewing may introduce bias from both participants and interviewers in interpreting responses.
3. There is a probability that participants' embarrassment toward the interviewer may affect the quality of their answers.
4. The number of participants used in the study was based on responses to the survey until the determined sample size was reached. Therefore, the level of education and income could not be unified.

AUTHOR CONTRIBUTIONS

Elom Doe: Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; software; visualization; writing—original draft. **Samuel B. Nguah:** Formal analysis; investigation; resources; supervision; validation; writing—original draft; writing—review and editing. **Kofi B. Mensah:** Conceptualization; methodology; supervision; visualization; writing—review and editing. **Kwame O. Buabeng:** Conceptualization; project administration; supervision; visualization; writing—review and editing.

ACKNOWLEDGMENTS

I want to acknowledge the Sickle Cell Pan-African Research Consortium, Kumasi, Ghana, for providing funding support to carry out this study as a fellow.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. However, most of the data generated is captured in this article.

ETHICS STATEMENT

The Committee on Human Research Publication and Ethics (CHRPE) of the Kwame Nkrumah University of Science and Technology (CHRPRE/AP/107/22) and the Research & Development Department of KATH Institutional Review Board (KATH-IRB) (KATH IRB/AP/018/22) gave ethical approval before the commencement of the study. Accordingly, the ethical approval for the study was granted on March 23, 2022, and May 4, 2022, respectively.

TRANSPARENCY STATEMENT

The lead author Elom Doe affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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How to cite this article: Doe E, Nguah SB, Mensah KB, Buabeng KO. Caregivers' knowledge, attitude, and perception toward pneumococcal infection prophylaxis in paediatric sickle cell disease patients in Kumasi, Ghana. *Health Sci Rep*. 2023;6:e1665. doi:10.1002/hsr2.1665