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### Abstract

**Background:** Haemoglobin disorders such as Sickle cell disease (SCD) have been acknowledged to be of great public health concern by the World Health Organization (WHO) in 2006. To reduce the tremendous public health and economic burden SCD exerts on many countries, the WHO is urging countries, especially those in Africa, to increase public awareness of the disease. Such awareness programmes among the young unmarried population will go a long way to prevent the birth of children with this painful genetic condition.

**Purpose:** This study therefore sought to assess the level of knowledge, attitude to people living with SCD, and perception of SCD among undergraduate students of the University of Cape Coast, Ghana.

**Methods:** A descriptive cross-sectional study was carried out. A total of 400 participants were selected using multistage sampling technique. Data was collected using a pretested, self-administered questionnaire and analyzed using SPSS software, version 25.

**Results:** Almost all the students (96.75%) were aware of SCD. School and the media were the main sources of information (50.65%, 32.3% respectively). The mean knowledge score was  $4.73 \pm 2.41$  (maximum score of 12) with 62%, 35.8% and 2.3% of participants having inadequate, moderate and adequate knowledge respectively. Majority of the participants (81.8%) had positive attitudes towards people living with SCD. Most respondents (78.5%) were likely to perform premarital genotype screening.

**Conclusion:** In general, there was inadequate knowledge on SCD despite the high level of awareness among participants.

**Recommendation:** Findings of the study highlights the need for continuous effective health education on sickle cell disease to students whose reproductive health choices will either increase or decrease the sickle cell disease burden in the very near future.

**Keywords:** *Sickle cell disease, University of Cape Coast, knowledge, Attitude and Perception.*

## INTRODUCTION

Sickle cell disease (SCD) is a hemoglobinopathy that causes chronic hemolytic anaemia. The disease is associated with mutations in the haemoglobin gene which result in defective haemoglobin. SCD remains one of the commonest genetic blood disorders among the African populace. Globally, approximately 400,000 children with SCD are born each year with almost 200,000 children with sickle cell anaemia in the Africa continent alone (World Health Assembly, 2006). About 25% of Africans are carriers of abnormal haemoglobin genes and an estimated 15000 (2%) of neonates are born with SCD annually in Ghana (Asare et al., 2018). The most common features of SCD are anaemia and pain—acute and chronic. Complications of SCD include pulmonary hypertension, chronic kidney disease, stroke, aseptic necrosis, and increased risk of infection. Common causes of death are acute chest syndrome, inter-current infections, pulmonary emboli, infarction of a vital organ, and chronic kidney disease (CKD). SCD is defined by the presence of abnormal haemoglobin- haemoglobin S, either in homozygous form (Hb SS), called Sickle Cell Anaemia or in combination with other abnormal haemoglobins such as sickle cell haemoglobin C disease (Hb SC), sickle cell haemoglobin D disease (Hb SD) and sickle cell  $\beta$ -thalassaemia (Hb S $\beta$ -Thal).

About 75-85% of children with sickle cell disease are all born in Africa with a high proportion of them (50% - 90%) dying before their fifth birth day (Piel et al., 2013). Since children are known to bear the brunt of this deadly condition (Wang et al., 2014), a key strategy in controlling this disease is preventing the birth of children with sickle cell disease. One such successful preventive strategy is pre-marital screening (WHO, 2016; Abubakar et al., 2019). Premarital genetic screening is defined as the screening of the prospective couples for a genetic disease, genetic predisposition to a disease, or a genotype that increases the risk of having a child with a genetic disease (Faremi, Olatubi, & Lawal, 2018).

The success of pre-marital screening in the prevention of sickle cell disease has been found to be influenced by the knowledge and attitudes of community members about sickle cell disease and how it is treated (Abioye-Kuteyi, Oyegbade, Bello, & Osakwe, 2009). Key target populations for any sickle cell prevention campaigns in the community are students especially those in tertiary institutions. This is because most are unmarried and may be contemplating on finding suitable marriage partners. Many studies (Odunvbun, Okolo, & Rahimy, 2008; Acharya, Lang, & Ross, 2009) have reported that more than half of couples enter marriage unaware of their sickling status. Among students, several studies have documented low levels of knowledge on sickle cell diseases (Olawaju et al., 2013; Owolabi et al., 2011). This study therefore sought to assess the knowledge, attitude, and perception toward Sickle Cell Disease among students at the University of Cape Coast, Ghana.

## Methods

**Study design:** This was an analytical cross-sectional study conducted in March 2021. The study made use of a semi-structured self-administered questionnaire.

**Setting:** The University of Cape Coast is a public university established in October 1962 and located in Cape Coast, the Central Region of Ghana.

**Population:** All regular undergraduate students 18 years and above were eligible for recruitment into the study. There were 14,815 regular undergraduate students for the 2020/2021 academic year (University of Cape Coast, 2020).

**Sampling:** The single population proportion formula by Leslie Fischer was used to determine the sample size. Prevalence estimates of sample size was assumed to be 50%. Using 95% confidence level and 5% margin of error, the minimum sample size was 384 participating students. In order to cater for possible data loss, the minimum sample size was increased by a 10% resulting in a final sample size of 422. Participants were selected using a multi-stage sampling technique. The study employed multistage sampling technique. Simple random sampling technique by ballot was used to select four out of eight traditional halls (1st stage), one hundred rooms from each of the four halls (2nd stage), and one student from each of the selected rooms in the chosen halls (3rd stage).

**Study Instrument:** a semi-structured self-administered questionnaire developed from existing literature (Boadu, & Addoah, 2018; Odunvbun, Okolo, & Rahimy, 2008; Acharya, Lang, & Ross, 2009) was used. Measures were taken to validate the questionnaire in the population. These included establishing face validity by asking experts to examine the contents. The questionnaire was then pre-tested using post graduate students at UCC. Cronbach Alpha of 0.78 was found after test for the internal consistency of the questionnaire was carried out. The questionnaire was arranged into the following five sections: Section I: socio-demographic data, entailed participants' age, gender, marital status, religion, program of study (college), and educational level. Section II: questions to ascertain respondent's knowledge of SCD which included general information of SCD, the inheritance pattern, diagnosis, major signs and symptoms, and prevention. Sections III and IV interrogated respectively participants' attitude and perception toward SCD. The final section (V), explored participants perceived benefits of, and, barriers to the performance of premarital genotype screening.

**Ethical consideration:** The Institutional Review Board of University of Cape Coast (UCCIRB) provided ethical clearance for the study. Areas of concern in ethical involvement with participants were mainly the issues of confidentiality, privacy and anonymity. These were addressed by training all members of the research team on how to follow standards of ethics in research. Also, no names, student identification numbers or any form of personal identification were used. A coding system was used to identify participants. The study was fully funded by investigators. None of the investigators have declared any conflict of interest regarding this study. Permission was sought from the management of the various halls of residences before data collection began. Informed consent was obtained from each participant before the administration of questionnaires.

**Data analysis:** data collected was entered into SPSS version 25. Descriptive statistics was used to summarize the data. One-way ANOVA was used to compare knowledge scores on SCD across the different levels of education and sex of participants. This was followed by Tukey's HSD (honest significant difference) test. Pearson's chi-square was used to examine the relationship between the dependent variable (participant's knowledge level on SCD) and independent variables such as, participants' demographic characteristics, attitude towards people living with SCD, susceptibility risk scores, and perceived benefits of pre-marital genotype screening. Independent variables with p value of  $< 0.25$  were entered into a logistic regression analysis to determine the independent

variables that adequately predict knowledge level of participants on SCD. Level of significance for all tests of association was put at  $p < 0.5$ .

## Results

Out of a total of 422 students invited to participate, 400 returned their filled questionnaire indicating a response rate of 94.70%. The participants were made up of 57.00% females (Table 1). About four-fifth (81.50%) of the participants were within the age range of 18-23 years and were mostly 1st and 2nd year students (33%, 28.25% respectively). Almost all the participants were single (95.50%) and Christians (92.00%). Close to half of the participants (40.25) belonged to the College of Humanities and Legal Studies. Almost all the participants (96.75%) were aware of the existence of SCD.

**Table 1: Demographic Characteristics of Participants**

| Variable                             | Frequency | Percent (%) |
|--------------------------------------|-----------|-------------|
| <b>Sex</b>                           |           |             |
| Male                                 | 172       | 43          |
| Female                               | 228       | 57          |
| <b>Age (years)</b>                   |           |             |
| 18-23                                | 326       | 81.5        |
| 24-29                                | 62        | 15.5        |
| 30-34                                | 8         | 2           |
| ≥ 35                                 | 4         | 1           |
| <b>Religion</b>                      |           |             |
| Christians                           | 368       | 92          |
| Moslem                               | 25        | 6.25        |
| Traditionalist                       | 3         | 0.75        |
| Other                                | 4         | 1           |
| <b>Marital status</b>                |           |             |
| Single                               | 382       | 95.5        |
| Married                              | 17        | 4.25        |
| Separated                            | 1         | 0.25        |
| <b>Programme of study (Colleges)</b> |           |             |
| Humanities and Legal studies         | 161       | 40.25       |
| Education Studies                    | 80        | 20          |
| Agriculture and Natural Science      | 66        | 16.5        |
| Health and Allied Science            | 93        | 23.25       |
| <b>Academic Level</b>                |           |             |
| 100                                  | 132       | 33          |
| 200                                  | 113       | 28.25       |
| 300                                  | 72        | 18          |
| 400                                  | 72        | 18          |
| 500                                  | 8         | 2           |
| 600                                  | 3         | 0.25        |

### Sources of information on SCD

School was the most frequent source of information, 196 (50.65%); followed by health professional or community meetings 126 (32.56%), and multimedia (radio and television), 125 (32.30%). Other sources of information included the internet 105 (27.13%), friends and family 93 (24.55%). Similarly, the findings of the study showed that the majority of the participants (77.00%) had received some form of education (scientific facts) on SCD in the past, primarily from classroom lectures 176 (57.14%) and the internet 91 (29.55%). However, close to half of them (41.56%) could not remember when the learning took place.

### Knowledge of SCD

Table 2 shows the general Knowledge about SCD as conveyed by the participants whilst Table 3 shows the knowledge of participants regarding the inheritance pattern of SCD.

**Table 2: Knowledge of SCD**

| Statement   | Frequency | %    |
|---|-----------|------|
| <b>How does a person get SCD (Causes of SCD)?</b>             |           |      |
| Acquired  | 21        | 5.3  |
| Inherited   | 280       | 70   |
| Don't know  | 99        | 24.8 |
| <b>What are the Signs &amp; symptoms of SCD?</b>              |           |      |
| Frequent illness  | 258       | 64.5 |
| Yellow eyes   | 76        | 19   |
| Pain  | 81        | 20.3 |
| Don't know  | 95        | 23.8 |
| <b>How is SCD diagnosed?</b>                                  |           |      |
| Blood test  | 250       | 62.5 |
| Urine test  | 18        | 4.5  |
| Don't know  | 132       | 33   |
| <b>What medication is given to people with SCD?</b>           |           |      |
| Herbal Medicine   | 10        | 2.5  |
| Conventional Medicine   | 189       | 47.3 |
| Prayers   | 4         | 1    |
| Don't know  | 197       | 49.3 |
| <b>SCD can be cured</b>                                       |           |      |
| Yes   | 60        | 15   |
| No  | 226       | 56.5 |
| Don't know  | 114       | 28.5 |
| <b>SCD can be prevented through?</b>                          |           |      |
| Genetic counselling   | 115       | 28.8 |
| Testing before marriage                                       | 71        | 17.8 |
| Don't know  | 214       | 53.5 |
| <b>Which of the following genotype is ideal for a couple?</b> |           |      |
| AS + AA   | 40        | 10   |
| AA + AA   | 171       | 42.8 |
| AS + AS   | 36        | 9    |
| Don't know  | 153       | 38.3 |

**Table 3: Knowledge of SCD Inheritance**

| Statement   | None of the children | All of the children | Half of the children | Quarter of the children | Don't know        |
|---|----------------------|---------------------|----------------------|-------------------------|-------------------|
|   | Frequency (%)        |                     |                      |                         |                   |
| <i>Chance of getting a healthy baby when both parents have SCD</i>                      | <b>139 (34.8%)</b>   | <b>88 (22%)</b>     | <b>48 (12%)</b>      | <b>35 (8.8%)</b>        | <b>90 (22.5%)</b> |
| <i>Chance of each child carrying SCD when both parents have sickle cell trait (SCT)</i> | <b>16 (4%)</b>       | <b>139 (34.8%)</b>  | <b>117 (29.3%)</b>   | <b>41 (10.3%)</b>       | <b>87 (21.8%)</b> |
| <i>Chance of each child carrying SCD when one of the parents have SCT</i>               | <b>48 (12%)</b>      | <b>21 (5.3%)</b>    | <b>134 (33.5%)</b>   | <b>97 (24.3%)</b>       | <b>100 (25%)</b>  |

About two-thirds (70.00%) of participants know that SCD is an inherited disease. Two hundred and fifty-eight (64.50%), 76 (19.00%) and 81 (20.30%) know that frequent illness, yellowing of eyes and pain respectively are symptoms of SCD. Two hundred and fifty (62.50%) know that SCD can be diagnosed with blood test; 189 (47.30%) know that the disease is treated with conventional medicine; whilst 186 (46.60%) know that SCD can be prevented through genetic counselling or premarital genotype screening. Only 60 (15.00%) participants know that SCD can be cured. Close to half (42.80%) of the participants know AA + AA as the ideal genotype for a couple while majority answered incorrectly the questions on inheritance (Table 3). Only 139 (34.80%) answered correctly that there was no chance of producing healthy babies when both parents have SCD, 41 (10.30%) know there is a quarter chance two parents with sickle cell trait (SCT) will produce a child with SCD, and 48 (12.00%) know that none of the children will carry SCD when only one parent has the trait (SCT).

The total knowledge score was 12, with a minimum score of 0. Knowledge levels were grouped as inadequate (score <6), moderate (score 6-9) and adequate (score >9). The mean knowledge score was  $4.73 \pm 2.41$  indicating inadequate general knowledge of the participants. Of the 400 participants, approximately 62%, 35.8% and 2.3% respectively had inadequate, moderate and adequate knowledge of SCD. Male students had higher scores ( $M=4.98$ ,  $SD=2.54$ ) than female students ( $M=4.54$ ,  $SD=2.29$ ),  $t(398) = 1.80$ ,  $p=0.07$

A one-way ANOVA was performed to compare the effects of levels of education on knowledge scores. It revealed that there was a statistically significant difference in mean knowledge scores between at least two groups ( $F(5, 394) = [11.034]$ ,  $p < 0.001$ ). Tukey's HSD Test for multiple comparisons found that the mean value of knowledge score was significantly different between level 400 and all the other levels ( $p < 0.01$ , 95% C.I. = [-3.19, -1.28]).

When a one-way ANOVA was also performed to compare the effects of programme of study on knowledge scores, it revealed that there was a statistically significant difference in mean

knowledge score between at least two programmes of study ( $F(3, 396) = [27.00]$ ,  $p < 0.001$ ). Tukey's HSD Test for multiple comparisons found that the mean value of knowledge score was significantly different between College of Health and Allied Health Sciences and all other colleges ( $p < 0.01$ , 95% C.I. = [-3.19, -1.71]).

To compare the effects of age-group on knowledge scores, a one-way ANOVA was computed that revealed a statistically significant difference in mean knowledge score between at least two age groups ( $F(3, 396) = [3.68]$ ,  $p < 0.012$ ). Pearson's correlation coefficient was computed to assess the linear relationship between knowledge and attitude, susceptibility and benefit scores. Regarding attitude, knowledge scores of participants was found to be weakly positively correlated with Attitude scores ( $r = 0.25$ ,  $p < 0.001$ ). Thus, higher level of knowledge is associated with positive attitude toward SCD patients.

Knowledge of participants was found to be moderately positively correlated with Susceptibility score ( $r = 0.32$ ,  $p < 0.001$ ). Higher susceptibility score was desired as it implies good perception of individual risk of reproducing a child with SCD. Similarly, Knowledge of participants was found to be moderately positively correlated with Benefits score ( $r = 0.38$ ,  $p < 0.001$ ). Higher Benefits score was desired as it reflects good perception towards premarital genotype screening.

#### ***Attitude to people living with SCD***

The total Attitude score was 7. Attitude was categorized as negative (score  $< 4$ ) and positive (score  $\geq 4$ ). The mean attitude score was  $5.53 \pm 2.06$  indicating positive general attitude of the participants. Three hundred and twenty-seven participants (81.80%) demonstrated positive attitude toward people living with SCD.

Majority, 347 (86.80%) disagreed that people with SCD should be isolated from others; 338 (84.50%) disagreed that people with SCD should not be enrolled in school with others; 271 (67.80%) agreed to have person with SCD as their roommate; 309 (77.30%) agreed to have person with SCD as their study mate; 322 (80.50%) agreed to have person with SCD as a friend; 321 (80.30%) agreed to invite person with SCD to their birthday party; whilst 300 (75.00%) agreed to eat with a person living with SCD.

#### ***Perceived seriousness of and susceptibility to SCD; perceived benefits of and barriers to premarital genotype screening***

In determining participants' perceived seriousness of SCD, 22.50% agreed that the thought of SCD scares them while 75.50% agreed that SCD is a strain to family financial status. Most of the participants (81.30%) agreed that the thought of SCD can reduce life span while 76.30% agreed that it can disrupt the academic pursuit of a child. Many participants (51.30%) agreed that it is better not to have a child with SCD as it stigmatizes the child and family while 70.30% agreed that SCD can destabilize a family. With regards to participants' perceived susceptibility to SCD, 69.30% of the participants agreed that their child could be prone to SCD because they are carriers of the SCD trait while 68.5% agreed that their child could be prone because their partner is a carrier of the trait. Also, 31% participants agreed that their child could be prone to SCD because someone in their family has SCD trait.

Results of participants' perceived benefits of premarital genotype screening showed that majority (73.3%) agreed that genotype screening for intending couples will prevent unnecessary worry



about giving birth to a child with SCD while 81.3% agreed that premarital genotype screening will help them to find out if they want to marry a person with genotype “SS”. Participants however indicated some barriers to premarital genotype screening. About a third of the participants (37.50%) agreed that premarital genotype screening can increase their worries about SCD while 20.30% agreed that it can make them prone to blood borne diseases like infections. Also, 25.80% of the participants agreed that premarital genotype screening is painful while 39.50% agreed that premarital genotype screening is costly.

### ***Likelihood of performing Premarital Genotype Screening***

Almost all the participants (95.00%) said they will go for premarital genotype screening when they are engaged to their partner while 77.50% said if they and their partners are carriers of the trait they will not go ahead to marry. Also, most participants (75.30%) said they cannot cope with the consequences of having a child with SCD.

## **DISCUSSION**

The majority of the students who participated in this study were between the ages of 18 and 23 years and almost all the participants were unmarried which made them suitable for the study.

### ***Knowledge on Sickle Cell Disease***

Knowledge assessment in the questionnaire ranged from the etiology of SCD, signs and symptoms, diagnosis, the pattern of inheritance, management and prevention. Students in level 400 had higher knowledge scores compared to those in the lower levels. Also, students from the College of Health and Allied Sciences had higher scores relative to the knowledge scores of participants of the other colleges. These findings are not surprising as it is expected that as a student ascends the academic ladder his or her knowledge on various topics including SCD will increase. Also, students reading health and allied science courses are expected to have been exposed to SCD literature compared to other students. This study’s findings were similar to that of Ugwu (2016) where medical students had significantly more adequate knowledge on SCD compared to students from other faculties.

Most of the students knew that SCD can be inherited as previously reported among Saudi Arabian respondents in the study of Alghamdi et al. (2018) and Ugandan participants in a study conducted by Tusuubira et al. (2018). More than half of the students knew frequent illness as a symptom while only 20.3% knew bone pain and 19% knew yellow eyes as symptoms of SCD. This was also consistent with the findings of Djan and Mensah (2020) in their study among Senior High School students in the Brong Ahafo Region of Ghana. In their study, frequent illness was the most common symptom known by most of the respondents (76.3%); only 27.5% knew bone pain and 21.6% knew joint pain as a symptom of SCD. Another finding from this study that corroborated with the result of Djan and Mensah (2020) was regarding the diagnosis of SCD as more than half of the participants knew that SCD is diagnosed by a blood test. This finding was contrary to the report of Faremi et al. (2018) where very few (4.1%) of the participants knew that SCD can be detected in the blood through genetic screening. Also, this study revealed that, close to half of the participants noted that conventional medicine was the ideal treatment for SCD, this is similar to the report of Tusuubira et al. (2018). In a study by Alghamdi et al. (2018), all the respondents stated that there is currently no cure for SCD. However, in this study, 15% of the participants stated that SCD can be cured. Future studies can investigate the knowledge and acceptance of hematopoietic stem cell transplantation among the different populations that have a high incidence

of SCD. Hematopoietic stem cell transplantation remains the only curative treatment for SCD. According to Bhatia and Sheth (2015), the first successful hematopoietic stem cell transplantation was performed in 1984, and to date, approximately 1,200 transplants have been reported.

Despite most participants being knowledgeable of the fact that SCD is inherited, only a few answered correctly the questions on SCD inheritance pattern. This is not different from the report of Boadu and Addoah (2018). In general, this study revealed a lack of comprehensive knowledge (poor understanding) of SCD as about two-thirds of the respondents had inadequate knowledge of SCD. Though 77% of the respondents in this study claimed to have received education on SCD, close to half of them could not recall when they received such knowledge (more than 5 years). This highlights the need for sensitization and continuous education on SCD, with a focus on enlightening the public on how SCD is inherited. Apart from health education, future study can investigate people's understanding of their chances of reproducing children affected with SCD based on the ("would-be") spouses' genotypes.

### ***Awareness of SCD***

Almost all the students were aware of SCD and the major source of information was found to be school, followed by the media (radio, television) and health professional or community meetings. This concurs with the earlier reports by other authors (Boadu & Addoah, 2018; Ameade et al., 2015). Also, from this study, the majority of the participants specifically maintained that they had previously received education (scientific facts) on SCD. Again, classroom lecture was found the commonest avenue for such education followed by the internet. This implies that schools and the media can be effective avenues for educating the public on SCD.

### ***Attitude towards People with SCD***

Most of the participants in this study demonstrated a positive attitude toward people affected with SCD. This general positive attitude is similar to the report of Boadu and Addoah (2018), and Ugwu (2016). Though the study found that more than half of the respondents had inadequate knowledge on SCD, the study found a positive weak correlation between knowledge and attitude. Thus, higher level of knowledge was associated with positive attitude toward SCD patients. This also agrees with a report by Abubakar et al. (2019).

### ***Perceived Seriousness and Susceptibility to SCD and Perceived Benefits and Barriers to pre-marital genotype screening (PMGS)***

This study revealed that most of the respondents have right perception of SCD. The participants have high perception of the serious consequences of SCD since three-fourth of them submitted that SCD could strain the financial status of a family, destabilize marriage, reduce the life span of affected child or disrupt their academic pursuit. They also have a high perception of their susceptibility to SCD (individual risk of reproducing SCD child), since most of them submitted that their child could be prone to SCT because they or their spouse has SCT. This is consistent with the report of Faremi et al. (2018). Regarding barriers to PMGS, 39.5% and 37.5% respectively submitted that PMGS is costly and it can increase their worries about SCD. Such response suggests a potential hindrance to performing PMGS despite good perceived PMGS benefit scores. Faremi et al. (2018) associated less misconception about PMGS with good understanding of the purpose of PMGS by respondents.

### **Likelihood of Performing PMGS**

Regarding the likelihood of performing PMGS, 78.5% are likely to undertake such test. It is very encouraging to note that these future parents are willing to perform the test that is known to be critical in the prevention of the birth of SCD children. This is however, contrary to the findings by Otovwe (2019) who reported that only few of his participants agreed to go for genotype screening test before marriage. Most participants (77.50%) in this study said if they and their partners are carriers of the trait, they will not go ahead to marry. This was not different from the findings of Daak et al. (2016) where more than half of the studied population reported that they would not get married to someone if he/she knew beforehand that they were both carriers of SCD, and that of Al-Farsi et al. (2014) where only 15.3% participants said they will marry even in the case of incompatible results of premarital testing.

### **Conclusion**

Generally, with respect to the specific objectives of this study, there was: inadequate knowledge (poor understanding) of SCD, positive attitude toward people affected with SCD and the right perception towards SCD. Majority of participants perceived SCD as serious and are susceptible to the condition. Many participants are likely to perform PMGS.

Based on the findings of this study, it is recommended that Ghana's Ministry of Health embark on continuous education on SCD with a focus on enlightening the public on how SCD is inherited using schools and the media as effective avenues for educating the public on SCD.

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