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## Perception of pain among adolescences with sickle cell disease in Benin city, Edo state, Nigeria

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### ABSTRACT

Sickle cell disease (SCD) is a genetically transmitted disorder of red blood cells which is characterized by severe haemolysis and recurrent vaso-occlusive episodes. This study aimed at determining the perception of pain, frequency, and period in which pain occur most among adolescents with sickle cell disease attending Sickle Cell Centre in Benin-city, Edo State. A descriptive design of self-designed 32-item questionnaire containing three sections was distributed to adolescents attending out-patient clinic and those admitted within the period of study. A sample size of 80 was drawn from the total population using a purposive sampling technique. Data obtained was analyzed using descriptive and inferential statistics with *p*-value set at 0.05 to test generated hypotheses. The result make known that the highest number of respondent were between the ages of 16-19years. High number reported to be the first or fourth position in their family. 13.8% accounted for highest level of perception, 63.8% accounted for medium and 22.5% accounted for lowest level of perception of pain (crisis). 47.5% agreed they can stay for weeks/months without pain. 62.8% have pain which last over 24hours, and 92.5% reported that they experience pain most during raining season. From the study no significant association was found between level of perception of pain and age despite the fact their perception towards pain increases with age. But there was significant association between perception of pain and duration of pain. Therefore, health care provider should provide comprehensive information and provide opportunity for question which will promote perception and management of pain. Program should be organized to encourage adolescents and their parent on how to prevent pain and to reduce sickle cell crisis to promote health.

**Key words:** perception, pain, adolescent, sickle cell disease,

### INTRODUCTION

Sickle cell haemoglobinopathy shares the common feature of an abnormal globin chain which leads to sickling of erythrocytes and obstruction of microcirculation (Jaussen, Garduer, Kirchhof, and Ryan, 2007). Sickle cell disease is one of the most important haemoglobinopathies (Schnog, Duits, Muskiet, Cate, Rojer, and Brandjes, 2004) which was first described in a Grenadian dental student in Chicago in 1910 (Serjeant, 2005). Sickle cell disease is one of the commonest hereditary diseases in the world. SCD have been acknowledged to have a global impact by the World Health Organization (WHO). SCD comprises a group of inherited red blood cell conditions that result from the synthesis of variant or mutant haemoglobin. Over 300,000 babies are born worldwide with SCD mostly in low

and middle income countries, with the majority of these births in Africa. SCD originates in tropical regions as a result of its advantage against malaria. It is predominant among people from African, Asian, Arabian and Mediterranean countries; nonetheless it is a global health problem because of population migration. Sickle cell disease affects millions of people throughout the world and it is particularly common in people of sub-Saharan Africa origin (Creary, Williamson, and Kulkarni, 2007). In general about 25% of people of African origin carry the sickle cell gene but only about 2-3% suffers from sickle cell disease. However in some parts of Africa sickle cell disease is still often lethal in childhood. In Nigeria the prevalence of HbSS is 1-3% and it poses a severe burden on the affected individuals and their families. Sickle cell disease commonly manifests itself as a painful crisis affecting joints and limbs. Factors such as infection, dehydration, exhaustion and a change in temperature may precipitate this crisis. There is a wide variation in the severity of pain, from mild transient attacks to severe pain of longer duration with some patients requiring hospitalization. Even though life expectancy is on the rise for sickle cell disease patients, it is still shorter than that of the general population (Schnog et al, 2004). Pain in sickle cell disease (SCD) presents unique challenges for patients, families, and health care professionals. Pain is the most frequent problem experienced by people with SCD. It has profound effects upon comfort and function in work, school, play and social relationships (Shapiro, 2005). The frequency and severity of painful episodes are highly variable among patients. Some patients have pain daily but others only occasionally. Painful episodes may start in the first year of life and continue thereafter. The episodes last from hours to weeks followed by a return to baseline. Onset and resolution can be sudden or gradual. Dehydration, infection, stress, fatigue, menses, and cold (including air conditioning and swimming in cold water) can precipitate painful episodes (Serjeant et al, 2005). However, the majority of painful episodes have no clear precipitant. Patients experience a wide variety of symptoms spanning acute and chronic pain and assessment and management must be suitable for both. Because pain and SCD itself are lifelong problems that have profound effects upon the quality of life, understanding of individual development and adopting a biopsychosocial approach is crucial (Shapiro, 2004). The experience of pain varies with each developmental phase and painful episodes are often termed "crises." Some people avoid the use of crises so that the major goal of treatment will take the sense of catastrophe out of the crisis. However, replacing a word does not change perceptions. The same is true for the strength, resilience, and vulnerability of each patient, as reflected in coping skills, mood, social life, and function. Therefore this disorder is to be taken into consideration for proper prevention and managements to reduce the effect the disease condition produce.

#### **Purpose of study**

1. To determine the perception of pain among adolescent with SCD.
2. To determine the perception on causes of pain among adolescent with SCD.
3. To determine the frequency of pain (crisis) and period in which pain occur most among adolescents with SCD

#### **Hypotheses**

1. There is no significant association between age and perception of pain among adolescents with sickle cell diseases.
2. There is no significant association between perception and duration of pain among adolescents with sickle cell disease.
3. There is no significant association between period of occurrence of pain and perception of pain among adolescents with sickle cell disease.

### **MATERIALS AND METHODS**

A descriptive research design was used and the study was carried out in Sickle Cell Centre, Sir Gabriel Avenue, Benin City, Edo State in 2010. The hospital is a tertiary institution that renders preventive, promotive-, curative and rehabilitative health care services to clients with sickle cell disease. The target population comprised all adolescents with genotype HbSS and HbSC who received in and out-patient care in the Sickle Cell Centre within the period of study. Purposive sampling technique was used to select 80 adolescent with sickle cell crisis who were admitted or seen within the period of study. Instrument for data collection was self developed questionnaire consisting of three sections of 32-items question was used for data collection. Descriptive statistics in form of frequency and percentage were used to summarize the data obtained; as well as inferential statistic in form of chi-square was used for testing hypotheses generated at 5% level of significance. The purpose of the research and sections included in the questionnaire were explained clearly in a simple language to the respondents. Anonymity and confidentiality of individual subject was maintained. The parental or significant other consent as well as the respondents' consents was sought before including them in the study.

**RESULTS****Table 1: Demographic characteristics of respondents**

S/N	Characteristic	Group	Frequency	Percentage
1.	Age	8-11	22	7.5
		12-15	20	25.0
		16-19	38	47.5
2.	Sex	Male	32	40.0
		Female	48	60.0
3.	Occupation	Student	72	90.0
		Apprentice	8	10.0
	Religion	Christian	80	100.0
		Islam	0	0.0
	Education	Primary	8	10.0
		Secondary	54	67.5
		Tertiary	12	15.5
		No formal	6	7.5
	Position in the family	1 <sup>st</sup>	20	25.0
		2 <sup>nd</sup>	13	16.3
		3 <sup>rd</sup>	18	22.5
		4 <sup>th</sup>	19	23.8
		Others	10	12.5

Table 1 reported that respondents between the ages of 8-11years were 27.5%, 12-15years were 25.0% and 16-19years were 47.5%. Majority were females. All the respondents were Christian and 90.0% accounted for student while majority were in secondary school. Respondents were 25.0%, 16.3%, 22.5%, 23.8% and 12.5% with 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup>, and others position in the family respectively.

**Table 2 Respondents Perception On Causes Of Pain Crisis N=80**

S/N	QUESTIONS		FREQUENCY	PERCENT (%)
1	Does excess exposure to cold cause pain?	Yes	67	83.8
		No	13	16.3
2	Does excess heat cause pain?	Yes	16	20.0
		No	64	80.0
3	Is pain cause by stress?	Yes	67	83.8
		No	13	16.3
4	Is pain cause by prolong standing?	Yes	42	52.5
		No	38	47.5
5	Does pain occur after smoking?	Yes	26	32.5
		No	54	67.5
6	Does pain occur as a result of poor diet?	Yes	60	75.0
		No	20	25.0
7	Does pain occur due to lack of drug compliance?	Yes	55	68.8
		No	25	31.3
8	When do you have pain most?	Raining season	74	92.5
		Dry season	6	7.5

Table 2 indicated that majority 67(83.8%) of the respondents opined excess exposure to cold can lead to pain while 13(16.3%) said no. Also majority of the respondent indicated that excess exposure to heat does not cause pain. The highest number of respondents 67(83.8%) stated that pain can be caused by stress while 13(16.3%) stated otherwise. Most 42(52.5%) agreed that prolong standing can result in pain crisis while 38(47.5%) did not. Majority 54(67.5%) of the respondent don't know if smoking can result in pain while 26(32.5%) said yes. The highest number of respondents 60(75.0%) reported that poor diet can cause pain while 20 (25.0%) said no. 55(68.8%) indicated that pain occur due to lack of drug compliance while 25 (31.3%) said no. The highest number of respondents 74(92.5%) indicated that they have pain mostly in raining season.

**Table 3** Frequency distribution of perception of pain (crisis) n=80

S/n	Questions	Frequency	Percent (%)	
1	Pain crisis can be managed	Agree	35	43.8
		Strongly agree	28	35.0
		Disagree	10	12.5
		Strongly disagree	7	8.3
2	I can stay for weeks/months without pain crisis	Agree	38	47.5
		Strongly agree	30	37.5
		Disagree	10	12.5
		Strongly disagree	2	2.5
3	Vigorous exercise/stress increases pain	Agree	36	45.0
		Strongly agree	24	30.0
		Disagree	20	25.0
		Strongly disagree	0	0
4	Exposure to cold climate triggers pain crisis	Agree	48	60.0
		Strongly agree	20	25.0
		Disagree	9	11.3
		Strongly disagree	3	3.8
5	Pain crisis is like having a minor injury	Agree	19	23.8
		Strongly agree	16	20.0
		Disagree	26	32.5
		Strongly disagree	19	23.8
6	Pain is an emergency crisis in sickle cell disease	Agree	54	67.5
		Strongly agree	17	21.3
		Disagree	9	11.3
		Strongly disagree	0	0

Table 3 shows majority of the respondent 35(43.8%) agreed that pain can be managed while 7(8.3%) strongly disagreed. 38(47.5%) agree they can stay for weeks/months without pain crisis while 30(37.5%) strongly agree, 10(12.5%) disagree and 2(2.5%) strongly disagreed. Highest number of respondent 36(45.0%) agree that vigorous exercise/stress increases pain and 24(30.0%), 10(12.5%) and 0(0.0%) strongly agreed, disagreed and strongly disagree respectively. Majority of the respondent 48(60.0%) agreed that exposure to cold climate triggers pain crisis while 3(3.8%) strongly disagree. 19(23.8%) of respondent both agree and strongly disagreed to pain crisis is like having a minor injury while 16(20.0%) strongly agreed and 26(32.5%) disagreed. the highest number of respondent, 54(67.5%) agreed that pain is an emergency crisis in sickle cell disease. 17(21.3%) strongly agreed, and 9(11.3%) disagreed

#### TESTING OF HYPOTHESES

Hypothesis		Level of pain perception			X <sup>2</sup>	df	P-value	Remark
		Low	Middle	High				
Age	8-11years	5	15	2	5.314	4	0.257	No significant association
	12-15years	3	16	1				
	16-19years	10	20	8				
Duration of pain	30-1hr	9	11	0	16.461	6	0.011	Significant association
	2-4hrs	3	4	0				
	5-7hrs	0	3	0				
	Others	6	33	11				
Period of occurrence of pain	Raining season	15	48	11	3.264	2	0.195	No significant association
	Dry season	3	3	0				

There was no significant association between age and perception of pain among adolescents with sickle cell diseases under study with  $p>0.05$ . Also there was no significant association between period of occurrence of pain and perception of pain among adolescents with sickle cell disease with  $p>0.05$ . However there was significant association between duration of pain and perception of pain among adolescents with sickle cell disease under study with  $p<0.05$

#### DISCUSSION

Majority of the respondent are female between the ages of 16-19 years and most of them were secondary school student. Most of the respondents are either first or fourth position in the family. This study supports the fact relayed

on how there is high incidence of occurrence of sickle cell disease among the children who are fourth born of the family whose parent have a genotype AS. Most of the respondent perceived that malaria, stress, prolong standing, poor diet lack of drug compliance and dehydration triggers pain (crisis) and strongly agreed that stress and excess exposure to cold causes pain. This corroborates the report from Serjeant et al (2005) and Creary, et. al (2007), that dehydration, infection, stress, fatigue, menses, cold (including air conditioning and swimming in cold water), and malaria can precipitate painful episodes. However, Majority of the respondent don't know if smoking can result in pain crisis. Majority of the respondent reported that the duration of pain experienced is for over 24 hours in which the occurrence is common in raining season than in dry season.

The study also revealed that there was no significant association between age and perception of pain among adolescents with sickle cell diseases under study, despite the fact that there was increase perception with age. Also there was no significant association between period of occurrence of pain and perception of pain among adolescents with sickle cell disease with  $p>0.05$ . This implies that period of occurrence of pain does not influence pain perception. However; there was also significant association between duration of pain and perception of pain among adolescents with sickle cell disease under study with  $p<0.05$  and according to Serjeant et al, (2005) that the frequency and severity of painful episodes are highly variable among patients. Some patients have pain daily but others only occasionally. Painful episodes may start in the first year of life and continue thereafter. The episodes last from hours to weeks followed by a return to baseline. Onset and resolution can be sudden or gradual.

### CONCLUSION

From these finding, it is concluded that majority of the adolescent have average level of perception of pain. The health care team should be aware that some of adolescent have low threshold to pain. Hence, Health care providers have an important role to play in preventing, promoting, caring, counseling and health educating adolescents with sickle cell disease especially during pain crisis.

### RECOMMENDATIONS

Based on the findings discussed in this study, the following recommendations were made:

- The health care team should educate adolescents with sickle cell appropriately on prevention of pain with emphasis on the prevention without the use of drugs.
- A program should be organized or it should be included when giving a health talk to sickle cell patient and relatives on prevention of sickle cell crisis and encouragement should be given to them on the ways of promoting health status.
- Emphasis should be paid on quick management of pain before it becomes a chronic pain which can cause complication like organ dysfunction (kidney, brain) and ulceration of the leg.

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