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Knowledge attitude and practices of parents with children suffering from sickle cell disease towards factors that precipitate sickle cell crises,at arthur davidson children's hospital in Ndola Zambia

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ABSTRACT

Introduction: Sickle cell disease is an autosomal recessive disease that causes considerable morbidity and mortality. The general objective of the study was to define the knowledge attitude and practice of parents with children that have sickle cell disease towards factors that precipitate sickle cell crises ,while the specific objectives were to determine the knowledge of factors that precipitate sickle cell crises among parents with children suffering from sickle cell disease, to assess the attitude of parents towards reducing the sickle cell crises, to describe the practices that parents do in order to reduce the frequency of hospitalization. **Methodology:** A cross-sectional quantitative study was conducted on parents with children that had sickle cell disease who went for monthly review at Arthur Davidson Children's hospital in Ndola Zambia. The self-administered structured questionnaire was used for data collection .Data was analyzed using descriptive and inferential statistics on SPSS version 20**Results:**A total of 216(100%) parents were enrolled into the studyof which 173(80.1%) were female and 43(19.9%)male. Most respondents were aged between 27- 37 and were all from Ndola. About half of the respondents had average knowledge 53.9 %.**Conclusion:**The study reviewed that respondents had average knowledge about sickle cell and factors that precipitate crises, 91. 2% of the respondents had a positive attitude towards the disease and they practiced good methods that have the potential of reducing the crises.

Key words: Attitude, Sickle cell Crises, Knowledge, Practice, Sickle cell disease.

Introduction

Sickle Cell Disease (SCD) afflicts millions of people throughout the World and is one of the most prevalent and costly genetic disorder[1].It is an autosomal recessive genetically transmitted hemoglobinopathy that causes considerable morbidity and mortality[2].The disease is widely distributed in African and American negroes but it is also seen in Arabian peninsula, Indian subcontinent and parts of Europe[3].

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Historically the disease dates as far as 1910 when James B.Herick noticed peculiar elongated and sickle-shaped red blood cells in a case of severe anemia[4], Linus Pauling on the other hand demonstrated electrophorecally an abnormal hemoglobin S(HBS) which is an abnormal variant of hemoglobin A(HbA) in 1949.[5]So a sickle cell patient is one who inherited two abnormal genes that code for hemoglobin S instead of hemoglobin A and this possess serious health problems on the patient as they tend to have frequent attacks called crises as the red blood cells sickle when the body is subjected to conditions like infections, dehydration, physical exercise, extreme temperatures and other forms of stress. Clinically there are four crises that are known, Aplastic, Hemolytic, Sequestration and Vaso-occlusive that make the presentation of sickle cell very complex, very common to sickle cell is a type of anemia called hemolytic anemia which is usually chronic and also comes with a

variety of consequences [6].Zambia is one of the countries whose population has been affected by sickle cell disease and it being a developing nation resources to support the increased incidence of the disease are not readily available thereby increasing the need for innovative ways of preventing complications that may arise secondary to the disease. One of the ways in which the complications can be prevented is by finding out how knowledgeable caregivers of sicklers are with regards to factors that precipitate sickle cell crises which is a form of secondary prevention of the disease. A study was conducted at Arthur Davidson's children hospital to determine the knowledge attitude and practices of parents with children suffering from sickle cells disease towards factors that precipitate sickle crises.

Methodology

Study design, population and site

This was a cross-sectional study that was conducted from 1st January to 7thJune 2017 at Arthur Davidson children's hospital which in the city of Ndola. This was after obtaining ethical approval from the Tropical Disease and Research Centre (TDRC) and local administration. Included in the study where parents of children that had sickle cell disease regardless of the age and consented to take part in the study.

Data collection

A pre-tested, structured and self-administered questionnaire was used to collect the data. It was prepared in English. Background information of the parents regarding age, gender, level of education, Ethnicity, place of work, Residence was collected. Details of Knowledge on sickle cell such as family history of the disease, sickle cell trait, number of sick children and precipitants of crises were obtained. Information about the attitude and practices was also collected the questions assessed the willingness of parents to take their children to the hospital when attacked by a crisis. Data was collected by distributing the pretested, structured questionnaire to each respondent after obtaining both oral and written consent from each respondent. Explanation on the objective of the study, relevance of the study and how to fill the questionnaire to the study subjects was given before they filled the questionnaire.

Data Analysis

The data errors related to inconsistency were checked and corrected during data cleaning. Data was entered and analyzed using SPSS version 20.0 windows.

Results

The sample size of the research was 218, two questionnaires were invalid, and this brought the sample size to 216, of which 43(19.9%) were male and 173(80.1%) female participated.

Table 1:Sample demographic characteristics of respondents n=216

VARIABLE	Male%(n)	Female%(n)	Total%(n)
AGE			
<18	0.0%(0)	100%(1)	100%(1)
18-27	4.8%(3)	95.2%(59)	100%(62)
28-37	20.6%(20)	79.4%(77)	100%(97)
38-47	38.5%(20)	61.5%(32)	100%(52)
48-57	0%(0)	100%(4)	100%(4)
MARITALSTATUS			
Married	20.0%(42)	80%(168)	100%(210)
Not Married	16.7%(1)	83.3%(5)	100%(6)
PLACE OF WORK			
Formal	42.9%(6)	51.7%(8)	100%(14)
Informal	18.0%(36)	82.0%(164)	100%(200)
LEVEL OF EDUCATION			
Grade 7	8.9%(5)	91.1%(51)	100%(56)
Grade 9	22.5%(25)	77.5%(86)	100%(111)
Grade 12	25%(9)	75%(27)	100%(36)
Tertiary	30.8%(4)	69.2%(9)	100%(13)
ETHNICITY			
Zambian(Negroid)	19.9%(43)	80.1%(173)	100%(216)
Not Zambian			

Table 2: Study participant's knowledge variable questions

VARIABLE	Answer	Gender		Total
		Female	Male	
Any family history of sickle cell disease	Yes	27.3% (59)	8.8% (19)	36.1% (78)
	No	52.8% (114)	11.1% (24)	63.9% (138)
Knowledge on family history of sickle cell trait	Yes	43.5% (94)	16.7% (36)	60.2% (130)
	No	36.6% (79)	3.2% (7)	39.8% (86)
Sickle cell patients	Yes	1.4% (3)	0% (0)	1.4% (3)
	No	78.7% (170)	19.9% (43)	98.6% (213)
How many of their children have sickle cell	One	57.9% (125)	16.2% (35)	74.1% (160)
	Two	17.6% (38)	3.2% (7)	20.8% (45)
	Three	4.6% (10)	0.5% (1)	5.1% (11)
Range of knowledge	Poor knowledge	16.7%(36)	2.3%(5)	19%(41)
	Average knowledge	44.9%(97)	9.3%(20)	54.2%(117)
	Good knowledge	18.5%(40)	8.3%(18)	26.9%(59)

Table 2 shows how much knowledge parents with children suffering from sickle cell have on sickle cell.Most respondents had average knowledge on sickle cell disease.

Table 3 : Study participants' attitude variable

Variable	Attitude	Gender		Total
		Female	Male	
Stay at home	Negative attitude	1.9%(4)	0.5%(10)	2.3%(5)
Call for help	Neutral	3.3%(7)	1.9%(4)	5.1%(11)
Rush to the hospital	Positive attitude	75.2%(161)	17.3%(37)	92.5%(198)

Table 3 shows the attitude that the respondents had when their child suffered an attack of sickle cell crises.Three quarters of the respondents had a positive attitude because they rushed to the hospital whenever their child(or children) fell sick.

Table 4 study participant' practices variable

Variable	Type of Practice	Gender		Total
		Female	Male	
Give herbal medication, give water, keep warm and apply wet cloth	Bad Practice	8.2%(17)	2.9%(6)	11.1%(23)
Give medication from the hospital, give water, keep warm, and take to the hospital	Good Practice	72.9%(151)	15.9%(33)	88.9%(184)

Table 4 shows that about four-fifths of the respondents practiced good methods that had a potential of reducing the frequency of hospitalization.

Discussion

The results of the current study were consistent with studies that say sickle cell patients and guardians mostly lack or have average knowledge about the disease. In 1997 it was found that sickle cell disease patients will be having little or moderate knowledge about their disease [6].in addition other studies reviewed that most people affected by sickle cell did not understand the basics about the disease [7.] All these findings show that theirs need to educate guardians of sickle cell disease patients about basic information on sickle cell.

The study reviewed that participants who had knowledge about their sickle cell disease status, more than one child with sickle cell and a family history of sickle cell had good knowledge about the disease. But this was a lesser frequency compared to that of the participants that had average knowledge.

This is similar to a study that was done by Acharya and colleagues in 2009 that reviewed that among parents with child identified with sickle cell disease or trait and parents known to have either trait or disease, the level of knowledge about sickle cell was good[8], furthermore; Treadwell and colleagues established that respondents who learnt information from friends and family were three times more likely to know their trait status[9], demonstrating potential benefit of family discussions about sickle cell. The current study reviewed that most respondents obtained information about sickle from the hospital and this included those that had a family background of the disease 74.2%

A study done by Gil in 1989 stated that acquisition of knowledge about a disease is important in behavior adaptation, especially if it is paired with the belief that one's behavior will have a positive impact on health[10]. The statement explains the importance of knowledge in affecting the attitude. But this is not the case in the current study because 92.5% of the respondents had a positive attitude towards reducing disease progression and there was no association between range of knowledge and attitude

A study that was done in Nigeria showed that more than half (51.4%) of the respondents had a positive attitude towards sickle cell disease and 48.6% of the respondents had negative attitude towards sickle cell disease [11], in contrast to these findings only 18% of the respondents showed negative attitude towards sickle cell disease in the study by Bazuaye and Olayemi [12]

Ghimire established a weaker correlation between knowledge and attitude among respondents compared to the study done by jeffal et al [12]The current study reviewed that respondents share similar beliefs about practices that reduce sickle cell crises, among them were giving medication from the hospital, giving 500ml room temperature water at least 4 times a day and taking the patient to the hospital whenever the child fell sick, this formed what was called 'good practice" in the current study and represented a frequency of 88.9%.However;this did not correlate with the number of times the respondents would visit the hospital other than the normal review dates. Perhaps other variables like social economic factors should be investigated to assess if they are related to frequency of hospitalization.

A limited number of studies have been conducted to examine the African knowledge Attitude and practices of parents with children that have sickle cell towards factors which precipitate the sickle cell crises. The few studies that have been done have consistently demonstrated a significant lack of awareness regarding differences between Trait and how trait status increases the chance of one having a child with disease [8, 9]

Conclusion

The study reviewed that respondents had average knowledge about sickle cell and factors that precipitate crises, 91. 2% of the respondents had a positive attitude towards the disease and they practiced good methods that have the potential to reduce the crises.

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