

Mother's Knowledge and Practice regarding Care of Their Children with Sickle Cell Anemia

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ABSTRACT

Background: Sickle Cell Anemia is a hemoglobinopathy where an abnormal chain of hemoglobin is produced. It is an autosomal recessive hereditary anemia characterized by the presence of sickle-shaped red blood cells and by accelerated hemolysis due to the substitution of a single amino acid of the beta chain of hemoglobin. **The purpose of this study** was to assess mother's knowledge and practices regarding sickle cell anemia in their children. This study was a descriptive research design It was conducted at the Hematology Department in Specialized Pediatric Hospital at Benha City. **Sample** A convenient sample composed of 100 mothers accompanying their children with sickle cell anemia. **One instrument** was used to collect the required data. A structured interviewing questionnaire to assess mother's knowledge and practices regarding sickle cell anemia in their children. **The Results of this study revealed that** approximately two fifths of mothers had poor knowledge about sickle cell anemia, while the majority (90%) of mothers had satisfactory practices regarding their children with sickle cell anemia. **Conclusion:** there was a highly statistically significant relation between total knowledge score of mothers and their educational level and occupation) $P \leq 0.001$). There was a positive statistically significant correlation between total knowledge score and total practice score about sickle cell anemia. **Recommendation:** Periodical educational program should be conducted for mothers regarding sickle cell anemia to enhance their knowledge and practices to care for their children with sickle cell anemia.

Key words: Sickle Cell Anemia, Mothers knowledge and practice.

Introduction

Sickle cell anemia (SCA) is the most common genetic disease; it is an inherited disorder that the red blood cells become crescent-shaped because of a genetic defect. It is affecting the quality of life. It is characterized by mutation on the β -globin gene that result in producing abnormal hemoglobin S and is associated

with high morbidity and mortality. In sickle cell disease (SCD), the inter- and intra-individual variability has a major influence in disease manifestations. Disease manifestation may start as early as 6 months of life, which coincides with the switch of fetal haemoglobin to adult Haemoglobin (**Almutairi et al., 2017**) .

Recent global estimates suggest that more than 300 000 children are born annually with SCD about two-thirds of them in Africa. Accurate survival data for children with SCD are not available. However, studies from Benin and Nigeria suggest mortality rates of up to 50% and 90%, respectively. Major factors thought to contribute to high mortality rate among children with SCD in Africa are the cultural background, lack of medical education and limited health care facilities **(Daak et al., 2016)**.

The major manifestations of SCA include fatigue, severe pain, dactylitis (swelling and inflammation of the hands and/or feet), arthritis, and bacterial infections, splenic sequestration (sudden pooling of blood in the spleen and liver), lung congestion, injuries to the heart, leg ulcers, asepsis and bone infarction leading to the death of portions of bone **(Julie et al., 2014)**.

Episodes of severe pain in children with SCA often require hospitalization and limit their daily activities. The pain can last for hours to a week or more and is typically of a throbbing nature with a tendency to move around the body. Bones are often affected and abdominal pain with tenderness is common. The SCD has no cure, and so the aim of therapy is, first to prevent the sickling phenomenon, and second, to provide emergency medical treatment when sickle cell crises (SCC) occurs **(Joshua et al., 2014)**.

Mothers who have enough information about SCD could provide support for their children and adolescents with SCD. Many studies have shown that there is a connection between healthy

quality of life and parental educational level within families. Therefore, knowledge of the SCD disease is a key influential factor for providing social support for individuals with SCD. Medical knowledge about SCD helps parents to manage and reduce the severity of SCD **(Alrubh, 2016)**.

The role of the pediatric nurse is to educate the family and the affected children about the disease, how to help control it, to identify signs of infection and in general adopt lifestyle behaviors that don't aggravate the disease for example, the avoidance of high altitudes. Nursing intervention for acute pain related to tissue hypoxia includes elevating and supporting swollen joints and teaching the children techniques for easing pain such as relaxation, distraction and breathing exercises. When the pain has subsided, the role of the nurse is to implement measures to preserve function, for example, physical therapy, transcutaneous nerve stimulation and monitor the children for signs of infection and dehydration. The failure to manage symptoms effectively can cause dysfunction within the family and an increasing burden of care and despair **(Abd El-Gawad, 2017)**.

Significance of the study

Sickle cell anemia continues to be a global health problem that presents major challenges to our healthcare systems. The reviewed literature expresses a dire need for more public education and awareness on SCA. In comparison with other chronic diseases and blood disorders, sickle cell anemia remains one of the least understood and puzzling medical conditions by health care workers and the general public, as well as the least funded blood disorder. In addition, existing research on SCA focuses on the awareness of the disease among parents (Osbourne, 2012). In specialized pediatric hospital at benha city. Afterwords, the statistical records of hematology department in the yaer (2016) recorded nearly 408 admitted cases with sickle cell anemia. So this study, attempts to assess mother's knowledge and practice regarding care of their children with sickle cell anemia.

Methods

Purpose of the Study:

The purpose of this study was to assess mother's knowledge and practice regarding care of their children with sickle cell anemia.

Research Questions:-

Is there a relationship between knowledge of mothers and their practices to prevent sickle cell anemia complication?

Is there a relationship between personal characteristics of mothers and their knowledge about sickle cell anemia?

Research design:

A descriptive research design was used to carry out this study.

Setting:

This study was conducted at the Hematology Department in Specialized Pediatric Hospital at Benha City, This department was composed of two rooms ,each room contained four beds.

Sampling:

A convenient sample composed of 100 mothers and thier children with sickle cell anemia were recruited to the previously mentioned setting.

Instruments:

The instruments that were used for data collection included the following:

A structured interviewing questionnaire: It was designed by the researcher after reviewing related literature. It was written in an Arabic language and composed of 4 parts as follows:

- **Part (1):** Personal data of the studied mothers such as name, age, occupation, level of education,etc

-**Part (2):** Personal data of the studied children such as name, age, gender, level of education,etc.

-**Part (3):** Mother's knowledge about sickle cell anemia in children such as definition, causes, clinical manifestation, management and complications). It contains 14 question.

-Part (4): Mother's reported practice it was concerned with practices of mothers to prevent complications of sickle cell anemia and improve general health through asking questions (e.g. signs of anemia-chest pain-fever.....etc). It contain 20 question.

Scoring system for mothers knowledge:

Scoring system for each item:

Complete	2
Incomplete	1
Wrong	0

Total scoring system:

Good	75- ≤100%
Average	50- <75%
Poor	0- <50%

Scoring system for mothers reported practice:

Scoring system for each item:

Done	1
Not done	0

Total scoring system:

Satisfactory	>50%
Un satisfactory	≤50%

Pilot study:

A pilot study was carried out during April 2017 it involved 10mothers of the sample size to test validity of the study

tools, clarity of questions and availability of study sample. All participants in the pilot study were included in the sample, where no radical modification was carried out in the study tools as revealed from the pilot.

Validity of study tools:

The data collection tools were revised by a panel of three experts(assistant professor) in the field of pediatric nursing to test clarity, relevance, comprehensiveness, and applicability. Modifications of the study instrument were done according to the panel judgment in relation to clarity of sentences, appropriateness of content and sequence of items.

Ethical considerations:

The researcher informed all mothers about the aim, nature and expected outcomes of the research before their inclusion. The study subjects were informed that, the study is harmless and all the gathered data was used for research purpose only. An oral consent was obtained from each subject to participate in the study. Anonymity and confidentiality were secured and ensured that they have the right to withdrawal from the study.

Procedure:

1- An official approval was obtained from the director of Specialized Pediatric Hospital in Banha City . The purpose and the nature of the study were explained to the hospital's staff to obtain their cooperation to conduct the study.

2- The data was collected from mothers who attended in the previous mentioned setting through interview. Mothers were interviewed by the researcher. After the researcher introduced herself to the participants and explained the purpose of the study in order to obtain their acceptance to participate in the study using the previously mentioned tools and the study was conducted 2 day/week from 9.00 am to 12.00 pm (Saturday and Sunday). The time needed to fill in each questionnaire sheet ranged from 20-30 minutes. The actual field work was carried out on May (2017) up to the end of October (2017). The researcher asked questions in simple Arabic and recorded the response of mothers on the sheet.

Statistical analysis:

Collected data were organized, tabulated and analyzed using electronic computer and statistical analysis was done by using statistical package for social sciences (SPSS version 20). Frequencies and percentages were used for qualitative descriptive data, and chi-square coefficient χ^2 was used for associative relation tests, and Mean and standard deviation were used for quantitative data, Pearson correlation coefficient (r) was used for correlation analysis and degree of significance was identified.

The observation difference and associations were considered as:

Highly significant (HS) ($P < 0.001$), significant (S) , ($P < 0.05$) and not significant (NS) ($P > 0.05$)

Results:

Table (1): Distribution of the studied mothers according to their personal characteristics (N= 100): This table shows that, 44 % of mothers aged 30 - <35 Years and their mean age was 31.5 ± 4.02 years ,

the majority 94% of them were married while 30% of them had secondary education. 84 % of them were not working and 78% of them had from 4-6 family members. Regarding their residence it was observed that 70% of mothers were living in rural areas while 30% of them were living in urban areas.

Table (2): distribution of the studied children according to their personal characteristics. This table shows that around two thirds(62%) of children were male, while 36.0% of them aged 5<9 Years and their mean age was 7.3 ± 4.17 years, nearly half (46%) of them had primary school education while(46%) of them ranked as 2nd among his siblings. All children had hospitalized before and the majority(98%) of them had hospitalized because of a reason related to the disease.

Table (3): Relationship between personal characteristics and total score of mother's knowledge. This table shows that, there was highly statistically significant relation between total knowledge score of mothers and their level of education and job, While there was significant relation between total knowledge score of mothers and their current social status, residence and numbers of family members .

Table (4): Relationship between total score of mothers reported practice and their personal characteristics. This table shows that, there were a highly statistically significant relation between total practice score of mothers and their level of education, while there was significant relation between total practice score of mothers and their job and their age. However there were no significant relation between total practice score of mothers and

their current marital status, number of family members and residence.

Table (5): Correlation between mothers' knowledge regarding sickle cell anemia and their practices (No=100). This table shows that, there was a highly significant correlation between total knowledge of mothers and their total practice.

Figure (1): Distribution of mother's total knowledge score about sickle cell anemia (NO= 100). This figure reveals that, 42% of

Table (1):-percentage distribution of the studied mother's according to their personal characteristics (N= 100).

the mothers had poor knowledge.

While 24% had good knowledge. And 34% had average knowledge about sickle cell anemia.

Figure (2): Distribution of mothers' total practical knowledge score about sickle cell anemia (NO= 100). This figure reveals that, the majority of the mothers (90%) had Satisfactory practice. While 10% of them had Unsatisfactory practice regarding their children with sickle cell anemia.

Personal characteristics of studied Mother's	No.	%
Age in years		
▪ <20	0	0.0
▪ 20 - <25	4	4.0
▪ 25 - < 30	32	32.0
▪ 30 - <35	44	44.0
▪ -35 yrs and more	20	20.0
Mean ± SD	31.5± 4.02	
Current marital status		
▪ Married	94	94.0
▪ widow	2	2.0
▪ Divorced	4	4.0
Education		
▪ Do not read or write	10	10.0
▪ Read and write	6	6.0
▪ Primary education	10	10.0
▪ Preparatory education	20	20.0
▪ Secondary education	30	30.0
▪ University education or more	24	24.0
Job		
▪ Working	16	16.0
▪ Not Working	84	84.0
Number of family members		
▪ 3	12	12.0
▪ 4-6	78	78.0
▪ > 6	10	10.0
Residence		
▪ Urban	30	30.0
▪ Rural	70	70.0

Table (2):-Percentage distribution of the studied children according to their personal characteristics (N= 100).

children characteristics	No.	%
Gender		
▪ Male	62	62.0
▪ Female	38	38.0
Age of the Child in years		
▪ day - <5	34	34.0
▪ 5 - <9	36	36.0
▪ 9 - < 13	18	18.0
▪ 13≥18	12	12.0
Mean ± SD 7.3± 4.17		
Educational stage		
▪ Before the age of Nursery	16	16.0
▪ Age of Nursery	24	24.0
▪ Primary school	46	46.0
▪ preparatory school	4	4.0
▪ Secondary school	10	10.0
Birth order		
▪ 1st	30	30.0
▪ 2nd	46	46.0
▪ 3rd and more	24	24.0
Reason in case of yes		
▪ reason related to the disease	98	98.0
▪ reason was not related to the disease	2	2.0
Reason related to the disease		
▪ To receive the treatment of the disease	62	62.0
▪ To treat the disease complications	36	36.0
▪ Another	2	2.0

Table (3): Associative relation between personal characteristics and total score of mother's knowledge

Mothers characteristics	total knowledge score						Chi-square (X2)	P-value
	Poor		Average		Good			
	No.	%	No.	%	No.	%		
Age/years								
▪ 20 - <25	3	7.1	1	2.9	0	0.0		
▪ 25 - < 30	16	38.1	5	14.7	11	45.8		
▪ 30 - <35	17	40.5	19	55.9	8	33.3		
▪ 35 and more	6	14.3	9	26.5	5	20.8		
Current social status								
▪ Married	42	100.0	28	82.4	24	100.0	13.706`	0.008*
▪ widow	0	0.0	2	5.9	0	0.0		
Education								
▪ Do not read or write	6	14.3	4	11.8%	0	0.0%	64.465	0.000**
▪ Read and write	5	11.9	1	2.9	0	0.0		
▪ Primary education	8	19.0	2	5.9	0	0.0		
▪ Preparatory education	15	35.7	5	14.7	0	0.0		
▪ Secondary education	7	16.7	15	44.1	8	33.3		
▪ University education or more	1	2.4	7	20.6	16	66.7		
Job								
▪ Working	1	2.4	2	5.9	13	54.2	30.166	0.000**
▪ Not Working	41	97.6	32	94.1	11	45.8		
Number of family members								
▪ 3	2	4.8	6	17.6	4	16.7	9.519	0.049*
▪ 4-6	34	81.0	24	70.6	20	83.3		
▪ > 6	6	14.3	4	11.8	0	0.0		
Residence								
▪ urban	15	35.7%	5	14.7%	10	41.7%	6.429	0.040*
▪ Rural	27	64.3%	29	85.3%	14	58.3%		

**Highly significant $P \leq 0.001$ *Significant $P \leq 0.05$

Table (4):): Associative relation between total score of mothers reported practice and their personal characteristics (N=100).

Mothers characteristics	total practices score				Chi-square	
	Unsatisfactory		Satisfactory			
	No.	%	No.	%	X2	P-value
Age/years						
▪ 20 - <25	2	20.0	2	2.2		
▪ 25 - < 30	4	40.0	28	31.1		
▪ 30 - <35	4	40.0	40	44.4		
▪ 35 and more	0	0.0	20	22.2		
Current social status						
▪ Married	10	100.0	84	93.3	1.306	0.520
▪ widow	0	0.0	2	2.2		
▪ Divorced	0	0.0	4	4.4		
Education						
▪ Do not read or write	2	20.0	8	8.9	20.907	0.001**
▪ Read and write	2	20.0	4	4.4		
▪ Primary education	4	40.0	6	6.7		
▪ Preparatory education	2	20.0	18	20.0		
▪ Secondary education	0	0.0	30	33.3		
▪ University education or more	0	0.0	24	26.7		
Job						
▪ Working	0	0.0	16	17.8%	3.693	0.05*
▪ Not Working	10	100.0	74	82.2%		
Number of family members						
▪ 3 members	0	0.0	12	13.3	5.275	0.072
▪ 4-6 members	10	100.0	68	75.6		
▪ > 6 members	0	0.0	10	11.1		
Residence						
▪ urban	4	40.0	26	28.9	0.505	0.477
▪ Rural	6	60.0	64	71.1		

**Highly significant $P \leq 0.001$

*Significant $P \leq 0.05$

Table (5):Correlation between mothers' knowledge regarding sickle cell anemia and their reported practices. (N=100)

Correlation	r	P-value
▪ Mothers' total knowledge	0.624	<0.001**
▪ Mothers' total reported practices		

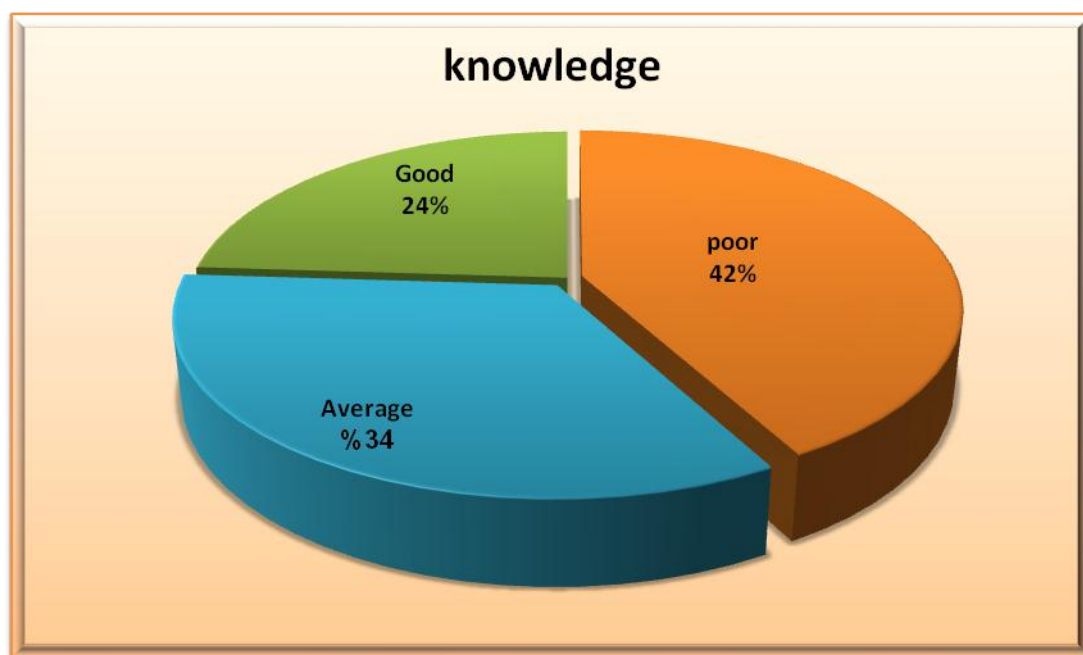


Fig (1): Percentage distribution of mother's total knowledge score about sickle cell anemia (N=100).

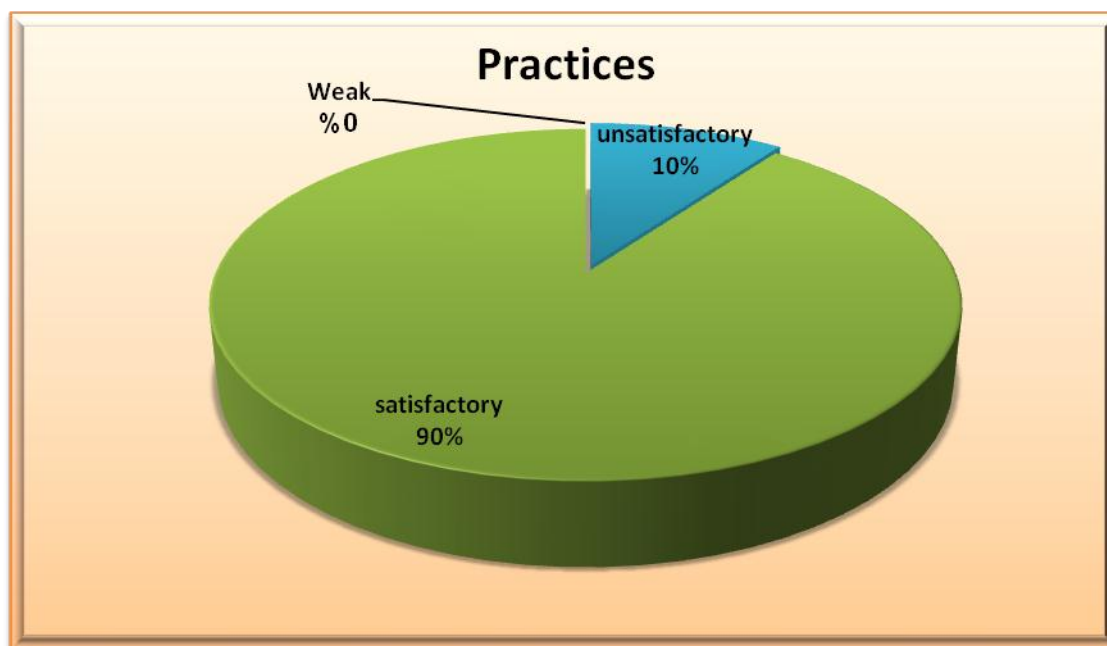


Fig (2): percentage distribution of mothers' total reported practice score about sickle cell anemia.

Discussion

As regards to the personal characteristics of the studied mothers. Findings of the current study revealed that regarding mothers age, about nearly half of mothers aged between 30<35 years . This finding was supported by the finding of a similar study by **Ezenwosu et al., (2015)**, entitled “Knowledge and awareness of personal sickle cell genotype among parents of children with sickle cell disease in southeast Nigeria” they reported that, the age of the studied

who found that nearly half of mothers aged between 30 -39 years.

As regards to educational level of mothers, the present study findings showed that nearly one third of mothers had secondary education. This finding was in the same line with **Tunde-Ayinmode., (2011)**, entitled “Children with sickle cell disease who are experiencing psychosocial problems concurrently with their mothers: a Nigerian study” they found that quarter of mothers had secondary education. This finding was incongruent with **Almutairi**

et al., (2017), entitled “ Assess Mother's Knowledge Regarding Their Children With Sickle Cell Disease” they societies and variation of educational and cultural level.

The current study revealed that, more than three quarters of studied mothers not working. This finding was congruent with **Daak et al., (2016)**, entitled “Sickle cell disease in western Sudan: genetic epidemiology and predictors of knowledge attitude and practices” they found that three quarters of studied mothers were unemployed. On the other hand this finding was incongruent with **Kayle et al., (2017)**, entitled “Challenges in Shifting Management Responsibility From Parents to Adolescents With Sickle Cell Disease” who found that more than three quarters of studied mothers were employed.

The present study revealed that there was a highly statistically significant relation between total knowledge score of mothers and their educational level and job. This may be explained as with higher education there were increases in the level of knowledge. And there was significant relation between total knowledge score of mothers and their social status. This finding was in agreement with **Al-Suwaid et al., (2015)**,

found that nearly one third of mothers had bachelor education. This discrepancy may be due the different nature of entitled “Knowledge and misconceptions about sickle cell anemia and glucose-6-phosphate dehydrogenase deficiency among adult sickle cell anemia patients in al Qatif Area (eastern KSA) ” they reported that there was a statistical significant relation between total knowledge score and educational level, social status respectively job.

The current study showed that there was a highly statistically significant relation between total practice score of mothers and their educational level and there was significant relation between total practice score of mothers and their age respectively job. This may be explained as older age mothers are more experienced about SCD and prevention of crises while younger ones were lack in experience and increased education empowering mothers to act effectively.

These findings were in agreement with **Abd El-Gawad, (2017)**, entitled “Empowering Mothers to Overcome Sickle Cell Crisis in Their Children through Engagement and Education” They found that there was significant positive correlations were found between mothers' educational level respectively

age and total actions. Also, this study results supported by **Arrayed and Hajeri (2009)** on public awareness of SCD in Bahrain, they found that there was correlation between total knowledge score and total practice score to prevent sickle cell anemia complication. This might be due to knowledge play important role for changing behavior leading to change of practices. The increase in total knowledge was associated with an increase in the total practice score. This was in agreement **Fahad F., et al., (2017)**, entitled “Assess Mother’s Knowledge Regarding Their Children with Sickle Cell Disease” They demonstrated a relationship between the level of knowledge and crises prevention practices. They reported that the majority of the respondents who had adequate knowledge also had positive practices. Concerning the total knowledge score of mothers regarding sickle cell anemia, the result of current study revealed that approximality two fifth of mothers had poor knowledge about sickle cell anemia. This finding was in agreement with **Daak et al., (2016)**, who found that half of the sample had poor knowledge about sickle cell anemia .On the other hand this finding was in disagreement with **Amoran et al., (2016)**, entitled “Parental

association between age, level of education and practice.

The results of the present study showed that there was statistically significant Influence on Sickle Cell Crisis among Patients Attending Secondary Facilities in Abeokuta South Local Government Area, Ogun State” They found that slightly less than two fifth of the sample had adequate knowledge of sickle cell anemia.

Concerning to total practice score of the mothers regarding care of their children with sickle cell anemia, the result of present study showed that the majority of mothers had satisfactory practice. This finding was parallel with **Hilda, (2012)**, entitled “knowledge and practice of parents and care giver towards prevention of sickle cell crises in children with sickle cell disease at the university teaching hospital(lusaka) ” who found that The majority of respondents had a good practice toward prevention of sickle cell crises.

Conclusions:

Approximately two fifth of mothers had poor knowledge about sickle cell anemia, while the majority of mothers had satisfactory practice. There was a highly statistically significant

relation between total knowledge score of mothers and their educational and occupation. Moreover, There was a positive statistically significant correlation between total knowledge score and total practice score about sickle cell anemia.

Recommendations:

- Periodical educational training program for mothers should be designed hospital by using booklets and other audiovisual aids about care of their children with Sick Cell Anemia.
- Development of A guideline leaflet should be developed for mothers of children with Sick Cell Anemia is essential to upgrading their knowledge about care of children with Sick Cell Anemia.
- Reinforce the importance of Pre-marriage examination, minimizing the phenomenon of marriage of relatives and prenatal examination

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