IOSR Journal of Nursing and Health Science (IOSR-JNHS)
e-ISSN: 2320–1959.p- ISSN: 2320–1940 Volume 9, Issue 3 Ser. VI (May - June 2020), PP 21-30
www.iosrjournals.org

Effect of an Educational Program for Parents of Children with Sickle Cell Anemia

Nadia Ahmed El- Adham [1*], Doaa Abd-Elgawad Said[2] &Hanem Awad Mekhamier[3]

1. Lecturer of Community Health Nursing, Faculty of nursing, Fayoum University, Egypt
2. Lecturer of Pediatric Health Nursing, Faculty of nursing, Mansoura University, Egypt
3. Lecturer of Community Health Nursing, Faculty of nursing, Fayoum University, Egypt
**Corresponding author: Nadia Ahmed El- Adham*

Abstract: *Sickle cell anemia remains a huge public health problem in underdeveloped and developing nations. It represents a chain of inherited blood issues that affect the haemoglobin inside the red blood cells. This study aimed to assess the effect of an educational program for parents' of children with sickle cell anemia. A-Quasi-experimental research design using one group (pre, immediately post, and 3 months later) was used for this study. Setting: The study was conducted at the hematology Out-Patient clinics in Mansoura and Fayoum University children hospitals, Egypt. Subject: A convenience sample of 100 parents having children with sickle cell anemia have been attending the previously mentioned setting from May to October 2019 had been covered. Tools: One tool used to collect data: A structured interviewing questionnaire sheet comprised of three main parts to assess; parents, child socio-demographic characteristics, parents' knowledge about sickle cell anemia and reported practice regarding care of sickle cell children. Results: There was a statistically significant difference regarding parents' knowledge and their reported practice about sickle cell anemia immediately post and three after months of implementation of the program compared with before program. There was a positive highly statistically significant correlation between total knowledge and total practice with p =0.001. Conclusion: This study concluded that there was a significant improvement in parents' knowledge and reported practice regarding sickle cell anemia. Recommendations: Encourage the use of an educational booklet for parents having children with sickle cell anemia.*

Keywords: *Educational program, Out-patient, parents' knowledge, practice, sickle cell anemia.*

Date of Submission: 21-05-2020 Date of Acceptance: 08-06-2020

I. Introduction

Sickle-cell anemia (SCA) is one of the world's most common genetic diseases. It contributes a critical burden that is not abundantly addressed estimated that 200,000 children will be born worldwide with SCA annually. Children born in high-resource countries with significant hemoglobinopathies (including SCD) are more likely to survive and have lower mortality rates than those born in less-resourced countries.SCA is an autosomal recessive inherited disorder, characterized by the presence of Hbs, a product of structural changes that occur in the β chain of hemoglobin, in which the glutamic acid is replaced by valine at the 6th position (Hassan and Mohammad, 2018). [1]

Globally, the most affected group by SCA among children is those between six months to five years of age. This is the age at the first sickle cell crisis usually appears which results in the start of consequences of SCA early. The higher life expectancies for SCA children in high-resource countries could be due to early diagnosis, improved access to treatment, caregiver education, and better management of diseases (Yadav and Vagha, 2018).[2]

Different factors influence the high mortality rates in sub-Saharan Africa, including scarce resources leading to inadequate access to treatment and a lack of robust SCA management programs. In most poor - resource countries, programs which have been successful in reducing mortality among SCA patients such as new-born screening and prophylactic penicillin administration are not available (Mulumbaa, and Wilsonb, 2015).[3]

Complications of SCA include different acute and chronic squeal that have mostly a high fatality rate. Acute complications implicate a vasocclusive crisis, splenic sequestration crisis, hemolytic crisis, and on the other hand, SCA can affect student achievement and ability. The recurrent complications and rehospitalization are interfering with the caregiver's time, thereby affecting the caregiver's work and finances. Due to the complications of this disease, patients with SCA have high rates of health care use and public health insurance (Yawn et al., 2014).[4]

Despite the gaps identified by WHO in the modalities for controlling SCA by the affected countries, such as limited control programs that have no national coverage for systematic screening of citizens for SCA and the lack of facilities to manage children with the disorder (WHO, 2015).[5]Therefore, an important approach for controlling the disease is preventive; and this depends upon education, the detection of carriers, genetic counseling, and prenatal screening for fetal genotype done in couples who are both carriers and new-born screening for sickle cell genotype. However, there is a palpable lack of knowledge and awareness about the condition which has promoted the growth of misconceptions, misinformation, inadequate care, anger, and stigmatization with-prevalence (Amoran et al, 2016). [6]

Education is critical in addressing the growing burden of public health problems in developing nations. Goal 3 of the Sustainable Developmental Goals highlights the functionality of education as a requisite to achieving healthy lives and well-being across the life course (Maurice, 2015). [7]Establishing a viable link between education and health is essential to setting policy priorities. Training empowers people to make educated choices and control the individual's behavior, behaviors, or tendency toward a particular action (Allensworth et al, 2017). [8]

The nurse's role is pivotal to the comprehensive care of individuals with sickle cell disease it focuses on delivering continuous information about the disease, maintaining a comprehensive health management program, acute disease identification, and control, and organizing and incorporating subspecialty treatment on time. Therefore, the nurse plays a vital role in the developmental and emotional anticipatory counseling and in encouraging the patient and family to speak for themselves (Pandarakutty et al, 2019). [9]

Up to our knowledge, there are no recent studies conducted at hematology Outpatient clinics in Mansoura and Fayoum University children hospitals in Egypt. That directed on providing an educational program for raising parents' knowledge and improving the practice of children's care.

1.1. Significance of the study:

Approximate 250,000 children are born with sickle cell disease (SCD) worldwide each year and 75 percent -85 percent of affected children are born in Africa; where mortality rates vary from 50 percent to 80 percent for those under 5 years. The highest prevalence of SCT in Africa occurs between 15 ° N and 20 ° S latitudes where the incidence ranges from 10 to 40 percent of the population. It is also estimated that, in sub-Saharan Africa, 240,000 children are born with SCD annually. Studies in Africa, however, have shown a substantial decline in child mortality rates from 2 to 16 months due to SCT (Stephen et al, 2018).[10] Nearly 9 to 22% of the populations are carriers of the sickle cell trait In Egypt. SCA is one of the most genetic disorders where limited researches were done about it. The burden of disease (SCA) has not been abundantly addressed yet (Zahran et al, 2016). [11]

1.2. Aim of the study:

This study aimed to assess the effect of an educational program for parents of children with sickle cell anemia. This aim can be achieved through:-

1. Assessing the parents' knowledge and reported practice about sickle cell anemia.
2. Designing and implementing an educational program based on parent's knowledge and practices about sickle cell anemia.
3. Evaluating the effect of implementing an educational program on parents' knowledge and practices about sickle cell anemia.

1.3. Research Hypotheses:

Implementing the educational program about sickle cell anemia will improve parents' knowledge and self-reported practices.

II. Subjects And Methods

2.1. Research Design:

A quasi-experimental research design was used to conduct this study- One group (pre, immediately post, and three months later).

2.2. Setting:

This study was conducted at the hematology Out-patient Clinics in Mansoura and Fayoum University Children hospital, Egypt. This place provides complete care and follow up for all cases with SCA and provides needs for parents who have sickle cell anemia children.

2.3. Subjects:

Convenience samples composed of 100 parents who have children with sickle cell anemia were attending the previously mentioned setting from May to October 2019.

2.4. Tools of data collection:

One tool was used for collecting data based on literature review and experts' opinions. A structured interviewing questionnaire sheet comprised of four main parts to assess the followings:

Part I: Socio-demographic characteristics of parents: This part includes 7 closed-ended questions such as age, sex, educational level, marital status, income, and residence.

Part II: Characteristics of sickle cell children: Child age, gender, birth order, academic year, academic achievements.

Part III: Parents knowledge about sickle cell anemia: This sheet was used to assess the parents' knowledge regarding sickle cell anemia including definition, symptoms and predisposing factors, complications, and protective measures of the disease. In addition to causative factors of pain crisis and the recommended types of food for sickle children. The questions were classified into (14) categories, in (62) questions.

Knowledge Scoring System:

All knowledge variables were weighted according to the items included in each question. Each knowledge question was given one mark for the correct answer. The total knowledge score was categorized into three levels. Poor level = scores less than 50% of total scores (<31 points). Fair level = scores 50% to < 65% of total scores (31 to less than 40.5 points) and good level = scores more than 65% of total scores (more than 40.5 points).

Part IV: Parents self-reported practice about the management of their sickle cell children. This sheet was divided into six divisions which composed of (40) questions based on the parameters of the sickle cell anemia standards and guidelines for clinical care (Dick, 2010). [12]

Scoring System: The practice sheet's scores were categorized into satisfactory practice that equals ≥65% of the total score (≥26 points), and unsatisfactory practice that less than 65% (<26 points) of the total score.

Data Collection Procedure:

1. Ethical considerations:

Official permission was obtained from the chairmen of Mansoura and Fayoum University Children Hospitals after being duly informed of the goal of the study. Ethical approval was sought and obtained from the Faculty of Nursing Research Ethics Committee (FNREC), Mansoura University, and Fayoum University before the commencement of the study. Oral and written informed consent was obtained from each participant before being assessed. Participants were assured of strict confidentiality. They were also informed about their right to withdraw from the study at any-time without giving any reason.

2. Validity and reliability of the study tools:

The validity of the developed tools was tested for content validity by submitting the tools to a jury of five experts in the field of Pediatric Nursing and Community Health Nursing. Based on the gathered data, the required modifications were implemented, some questions were paraphrased, and others were omitted. Internal consistency reliability of the tool (Cronbach's α=0.61), whereby alpha Cronbach's coefficient test of knowledge assessment sheet was emerged as very high (Cronbach's α=0.95), in addition to, self-reported practice sheet was (Cronbach's α = 0. 85).

3. Pilot study:

A pilot study was conducted on 10% of the study sample (n= 10) who were excluded from the study to test the clarity, feasibility, viability, and applicability of the tools, as well as to assess the time required to fulfill the tools and modifications were done accordingly. Data collection was conducted six months and beginning from May to the end of October 2019.

4. Program construction

The program was conducted in four consecutive phases.

Assessment phase:

This phase was started by interviewing the parents at the hematology Outpatient Clinic of Mansoura and Fayoum University children hospital. The researcher started by introducing herself to parents and explains the aim of the study. It was designed for determining the participants' Scio-demographic data, their sickle cell children's characteristics, and then every participant was subjected to the following: 1)-assessing their knowledge about SCA. Responses to items of the interviewing questionnaire were filled by the researchers where every participant was interviewed from 1-2 times for 20-30 minutes in each session using (tool 1- part III). 2) - assessing self-reported practice regarding the management of the SCA disease symptoms, preventions of further complications using (tool 1- part IV).

Planning and implementing phase:

The researchers designed the educational program based on the actual assessment of the parent's needs to achieve the following objectives: improve parents' knowledge and practice regarding sickle cell anemia. This program consisted of two sessions. The first one focused on raising the parents' knowledge of SCA meaning, symptoms, predisposing factors and, complications, causative factors, and protective measures of the pain crisis. The second session illustrated the procedure of dealing with major SCA symptoms. In addition to, daily management regimen of SCA children, each session duration ranged from 30-40 minutes. Different teaching methods were used including lectures, small group discussions. The teaching aids used were brochures and posters. A booklet distributed to all studied parents after implementing the program sessions as a reference to achieve its objective.

Evaluation phase:

The effect of the educational program was evaluated immediately and three months after the implementation using (Tool 1 – part III and Part IV).

III. Statistical Analysis

Data was sorted, coded, organized, categorized, and then transferred into specially designed formats. Analysis performed using SPSS (Stands for Statistical Product and Service Solutions) version 20. The standard methods of descriptive statistics were used to describe the data (i.e. Frequencies and percentages for categorical variables and mean and standard deviation for continuous variables). T- test and correlation tests were used to analyze the collected data. A statistical test with a p value<0.05 was considered statistically significant.

IV. Results

Table 1 showed that; the mean age of mothers was 35.12±6.4 years; about 46% had a university education and 88% housewives. Regarding marital status, 90% of parents were married and 64% of them were living in rural areas. Also, this table shows that the mean age of fathers was 42.12 ±8.97 years; about 42% had a university education. In addition, more than two- thirds (66 %) of them had free work compared to 34% were working governmental entities. Furthermore, all parents didn't perform the premarital blood tests.

Table 2 clarified that; more than two-thirds (66%) of sickle cell children were male with a mean age of 8.24 ± 3.62 years. Also, 44% were ranked as the first child and 64% of them were studying during the primary stage. Regarding academic achievement (68%) of them had poor level. The majority of children (82%) didn't suffer from school problems because of his diseases. Also, 64% of sickle cell children didn't oblige to leave school, while more than half (58%) of them receive special health services from the school.

Table 3 demonstrated that all parents (100%) had a poor level of knowledge pre-program implementation with a mean score (5.02±4.16), while they had a good level of knowledge immediately post and 3 months after program application with a mean score (24.48±2.39 and23.52±2.64) respectively

Table 4& Figure 1 demonstrated that all studied parents (100%) had unsatisfactory total practice score level pre-program implementation with a mean score (9.46±5.77),while they had improved and satisfactory total practice score immediately post and follow up 3monthes after program implementation with a mean score (34.60±1.37 and 33.26±2.02, respectively p<0.001).

Figure 2 this figure shows that there was a positive correlation between knowledge and practice with p =.001 which means that as the knowledge level increases their practice level increased as well.

Table.5. this table showed that positive correlations between practice with an age of mother and father and occupation of father p =.001** but present negative correlation between mother and father education and mother occupation. A positive correlation between knowledge and education of mother and father with p=.001**, also a negative correlation between age of mother and father, and father occupation, also no relation between knowledge and mother occupation .p=.05.

Table (1): Distribution of socio-demographic characteristics of the studied parents (n=100).

Demographic characteristics	Mother		Father	
	No.	%	No.	%
Responsibility for child care	88	88.0	12	12.0
Age				
$\bar{X}$± SD	35.12±6.04		42.12 ± 8.97	
Level of education				
knows writing &primary	14	14.0	8	8.0
Primary/Preparatory	4	4.0	14	14.0
Secondary	36	36.0	36	36.0

University	46	46.0	42	42.0
Occupation				
Housewife	88	88.0	0	0
Working	12	12.0	0	0
Governmental work	0	0.0	34	34.0
Free work	0	0.0	66	66.0
Marital status of parents				
Marriage	90		90.0	
Divorce	6		6.0	
Widow	4		4.0	
Family type of parents				
Nuclear	62		62	
Extended	38		38	
Income of parents				
Enough and saving	12		12	
Enough	46		46	
Not enough	42		42	
Residence of parents				
Urban	36		36.0	
Rural	64		64.0	
Number of a family member				
3-5	82		82.0	
> 5	18		18.0	
$\bar{X}$± SD	**4.64 ± 1.13**			
Did you perform the Premarital Blood Test				
No	100		100.0	
Did your husband perform Premarital Blood Test				
No	100		100.0	

Frequencies, $\bar{X}$: mean, SD: standard deviation

Table (2): Distribution of the studied children characteristics (n=100).

Children characteristics		**N=100**	
		No.	**%**
Child age	<5ys	20	20.0
	5-<10 ys	32	32.0
	10-<15ys	44	44.0
	≥ 15 ys	4	4.0
Age in Years	**$\bar{X}$± SD = 8.24 ± 3.62**		
Gender	Male	66	66.0
	Female	34	34.0
Birth Order	First	44	44.0
	Second	42	42.0
	Third	14	14.0
Number of children	**X ± SD = 2.00 ± 1.02**		
Academic year	Not attended school	20	20
	Primary	64	64
	Preparatory	16	16
Academic achievements	Poor	68	68
	Average	32	32
Did your child suffer from school problems because of his diseases?	Yes	18	18.0
	No	82	82.0
Did your child be obliged to leave school?	Yes	36	36.0
	No	64	64.0
Did your child receive special health services from school?	Yes	58	58.0
	No	42	42.0

$\bar{X}$: Mean, SD: standard deviation

Table (3): Distribution of the studied parents according to their general knowledge categories about sickle cell anaemia (n=100).

Items of General Knowledge	Total number of parents =100							
	Pre program		Immediate Post		Follow up / 3 months		Test of significance	
	No.	%	No.	%	No.	%	F	P
Total knowledge score								
Poor (less than 14 marks)	100	100.0	0	0.0	0	0.0	1200.72	0.001**
Fair (14-19 marks)	0	0.0	0	0.0	0	0.0		
Good (20 marks)	0	0.0	100	100.0	100	100.0		
Total score (0-28) $\bar{X}$± SD	5.02±4.16		24.48±2.39		23.52±2.64			

(*) Statistically significant at p ≤ 0.05, F: repeated measure ANOVA, $\bar{X}$: mean, SD: standard deviation

Table (4): Distribution of the studied parents according to their reported total practice score about sickle cell anaemia through phases of educational program (n=100).

Items of practices	Pre program		Immediate post		Follow up / 3 months		Test of significance	
	No.	%	No.	%	No.	%	F	P
Total practices score								
• Satisfactory	0	0	100	100.0	100	100.0	1540.75	<0.001**
• Unsatisfactory	100	100.0	0	0	0	0		
Total score (0-35) B ± SD	9.46±5.77		34.60±1.37		33.26±2.02			

Fig. (1): Distribution of the studied parents according to their total practice about sickle cell anaemia (n=100).

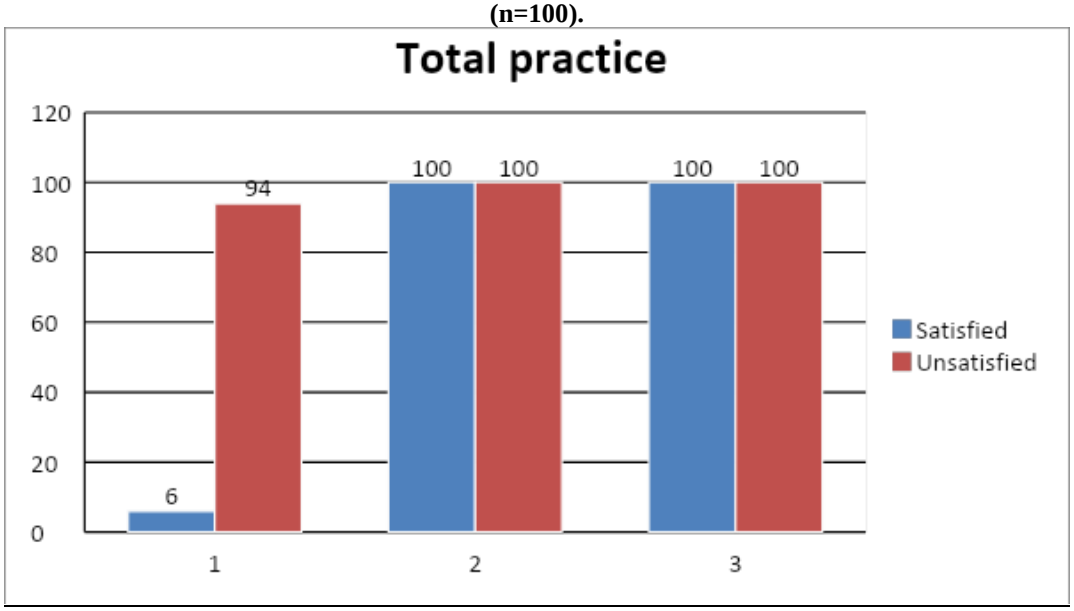

Fig. (2): Correlation between knowledge and practice of the studied parents according to sickle cell anaemia (n=100).

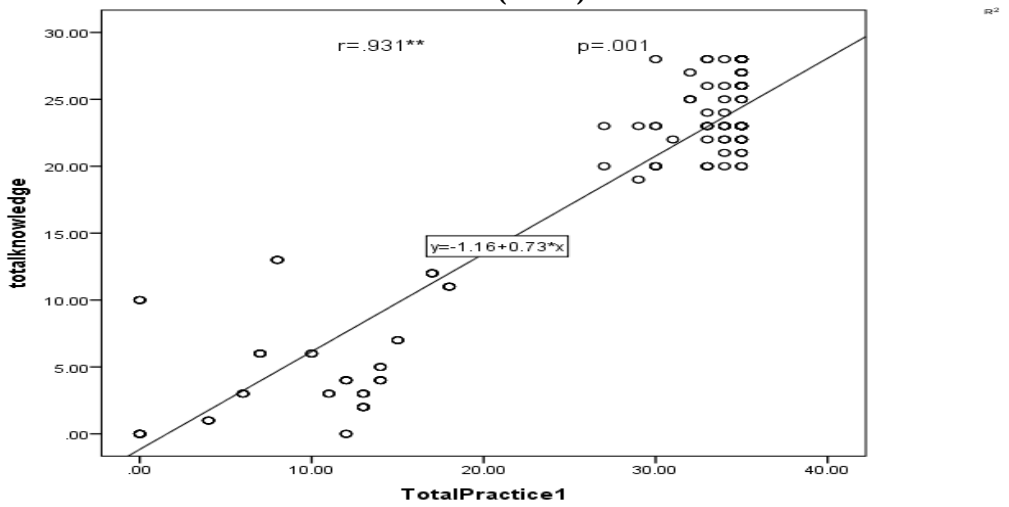

Table (5): Correlation matrix between demographic data, knowledge, and practice of the studied parents according to sickle cell anemia (n=100).

Correlations matrix

		Total Practice	Total knowledge	Mother Education	Mother Age	Mother Occupation	Father Age	Father Education	Father Occupation
Total Practice	Pearson Correlation	1	.931**	-.279**	.423**	-.353**	.454**	-.386**	.324**
	Sig. (2-tailed)		.000	.005	.000	.000	.000	.000	.001
Total knowledge	Pearson Correlation	.931**	1	.355**	-.031	.132	-.072	.425**	-.292**
	Sig. (2-tailed)	.000		.000	.760	.190	.474	.000	.003
Mother Education	Pearson Correlation	-.279**	.355**	1	-.237*	.311**	-.506**	.741**	-.481**
	Sig. (2-tailed)	.005	.000		.018	.002	.000	.000	.000
Mother Age	Pearson Correlation	.423**	-.031	-.237*	1	.110	.620**	-.410**	-.057
	Sig. (2-tailed)	.000	.760	.018		.276	.000	.000	.576
Mother Occupation	Pearson Correlation	-.353**	.132	.311**	.110	1	-.154	.349**	-.514**
	Sig. (2-tailed)	.000	.190	.002	.276		.127	.000	.000
Father Age	Pearson Correlation	.454**	-.072	-.506**	.620**	-.154	1	-.739**	.269**
	Sig. (2-tailed)	.000	.474	.000	.000	.127		.000	.007
Father Education	Pearson Correlation	-.386**	.425**	.741**	-.410**	.349**	-.739**	1	-.452**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000		.000
Father Occupation	Pearson Correlation	.324**	-.292**	-.481**	-.057	-.514**	.269**	-.452**	1
	Sig. (2-	.001	.003	.000	.576	.000	.007	.000	

	tailed)								
**. Correlation is significant at the 0.01 level (2-tailed).									
*. Correlation is significant at the 0.05 level (2-tailed).									

V. Discussion

Sickle cell anemia is still a critical public health affair in underdeveloped and developing countries. Globally, it is categorized as one of the most prevalent genetic diseases. It is one of the school-age diseases that mostly affect children in different life aspects. Consequently, the goal of effective SCA management is to allow children to function with minimal constraints and enjoy a good quality of life throughout their lives Hockenberry and Wilson (2018). The present study was aimed to assess the effect of an educational program for parents of children with sickle cell anemia.

The results of this study revealed that the majority of the participants were mothers as primary caregivers. This finding was in accordance with Igboanugo, and Martin (2011) a study was done in Niger Delta University, who indicated that most of the participants were mothers because they interacted with the health facilities since most mothers stay with their children in the hospitals or accompany them to the health facilities. Also, they are more caring than fathers regardless of their children's diagnosis, or even their prognosis according to Asomugha et. al, (2011).

According to the socio-demographic characteristics of the studied parents, the present study findings revealed that the mean age of mothers was 35.12±6.07 years, while the mean age of fathers was 42.12 ± 9.02 years. Regarding marital status the majority of studied parents were married and two- fifth of them had secondary education, respectively; the majority of mothers were housewives while, more than two-thirds of fathers had free work and about two-thirds of them were living in rural areas. This findings were in agreement with Fowora (2016), who conducted a study on" adherence to self-care management of sickle cell disease among caregivers" and found that the mean age of caregivers was 34.95 and Ninety-one percent of caregivers were married and most of them had medium to a high level of education. Additionally, Karadag et al., (2018), who found that, the parents aged, were 36-45 years old, 82% were married. A study by Mahmoud et al., (2017) supported this finding; as 44 % of mothers aged 30 -<35 years with a mean age was 31.5 □ 4.02years, the majority were married, 84 % were not working, and 70% were living in rural areas.

Regarding characteristics of sickle cell children, the present study finding revealed that the mean age was 8.24 ± 3.6 years, more than two-thirds were males and nearly two-fifths were ranked as the first child in birth order also, more than half were studying during the primary stage of education. This finding was in agreement with Mahmoud et al., (2017), who reported that the mean age of children was 7.3 □ 4.17 years and the majority of them were males and in the primary stage of education. In the present study more than two-thirds of children have a poor level of academic achievement also, the majority of them didn't suffer from school problems because of his diseases and more than half didn't oblige to leave school, and receive special health services from the school. Daniel et al., (2015) were in the same line as they mentioned that the study findings indicated poor academic achievements among (68%) of the studied SCA children. Also, according to Cynthia and King (2015) children with SCA are in jeopardy of miserable health-related quality of life (HRQL), especially in school functioning. Moreover, the present study findings are harmonious with Hockenberry and Wilson (2018), who indicated that SCA is one of the school-age diseases that mostly affect children's school attainment and achievements.

Concerning the total knowledge score of studied parents regarding SCA pre, immediate post, and follow-up three months post-program implementation as shown in (Table 3). The present study findings revealed that the all studied parents had a poor level of knowledge with a mean score (5.02±4.16) pre-program implementation, while they had a good score level of knowledge immediately post and 3 months after program implementation with a mean score (24.48±2.39 and 23.52±2.64) respectively, with significant improvement. This result indicates that the educational program was successful in improving the parents' knowledge. This finding was in agreement with Adewoyin et al, (2015) reported that about 95% of the study participants had heard about SCD, suggesting a good level of awareness. Also, this study results supported Vasava et al, (2010) who reported that there was an increase in the knowledge of all parents about sickle cell disease. About eighty-six percent of the parents understood the in-depth idea of the disease. The response to the questions about sickle cell anemia improved considerably. The parents used proper and precise words for describing the signs and symptoms of crises. The answers to the questions which were open type were complete and elaborative. This finding is in accordance with Siddiqui et al. (2012), who found that substantial knowledge gaps about sickle cells in surveyed people of reproductive age from the Dominican and African American communities in Northern Manhattan, despite the high prevalence of SCD in both groups. On the other hand, this finding was incongruent with Daak et al., (2016), who found that half of the sample had poor knowledge about sickle cell anemia.

Regarding the total reported practice score of the studied parents about SCA pre-program, immediate post, and follow-up three- month program implementation, (Table 4 &Figure 1). The present study results revealed that all studied parents had a satisfactory score of reported practice immediately post and 3 months after program application with a mean score (34.60±1.37 and 33.26±2.02) respectively, and improved significantly at ($P < 0.001$). This finding was in agreement with Mahmoud et al., (2017), who found that, the majority of the mothers (90%) had a satisfactory total practice score. While10% of them had unsatisfactory practice regarding their children with sickle cell anemia. The finding is also consistent with the results of a study by Hilda, (2012), entitled "knowledge and practice of parents and caregiver 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.

The present study findings revealed that, a highly statistically significant positive correlation between the studied parents' total knowledge and total practice throughout the phases of educational program which means knowledge plays an important role in changing behavior leading to change of practices. The increase in total knowledge was associated with an increase in the total practice score (Figure 2). This finding was in agreement with Abd El-Gawad, (2017), who found that there were significant positive correlations 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 an association between total knowledge score and total practice score to prevent sickle cell anemia complication. Also, the present study finding agreed with Fahad et al., (2017), entitled "Assess mother's knowledge regarding their children with sickle cell disease" They reported that the majority of the respondents had adequate knowledge also had positive practices. A study performed by Al-Qattan et al, (2019) titled "Quantifying the Levels of Knowledge, Attitude, and Practice Associated with Sickle Cell Disease and Premarital Genetic Counselling in 350 Saudi Adults" was in the same line as reported that practice level is increased as the knowledge level increased. Also, the lack of knowledge regarding SCD caused an increase in disease incidence and a decrease in the quality of life among the disease sufferers.

Finally, the present study showed that there were positive correlations between practice with the age of mother and father and occupation of a father with p =.001** but there was a negative correlation between mother and father education and mother occupation. A Positive correlation was found between the knowledge and education of mother and father with p=.001**, also, there was a negative correlation between age of mother and father, and father occupation, also there was no relation between knowledge and mother occupation .p=.05. From the researchers' point of view, these results are accepted as the education level of parents increased their ability to gain knowledge and practice that enable them to manage their children's disease.

VI. Conclusion

Based on the findings of the current study, it is concluded that there was a significant improvement in parents' level of knowledge and practices regarding sickle cell anemia with calculated $P < 0.0001$.

VII. Recommendations

In light of the study findings, the following recommendations are suggested:

1. An educational campaign needs to be implemented for parents to improve their ability to care for children with sickle cell anemia.
2. Encourage those parents to use the educational booklet and programs about preventive measures of sickle cell crisis and prevent recurrent complications.
3. Establishment of designated training and genetic counseling centers on SCD with adequate resource staff for improving public health knowledge about SCD, especially among the trait carriers.
4. A similar study can be replicated using a large sample and among more number of areas so that findings can be generalized for a large population.

References

[1]. Abd El-Gawad,s.,(2017): "Empowering Mothers to Overcome Sickle Cell Crisis in Their Children through Engagement and Education." American Journal of Nursing Research, 5(5): 182-190. doi: 10.12691/ajnr-5-5-4.
[2]. Adewoyin A.S., Alagbe A.E., Adedokun B.O. , and Idubor N.T. (2015): Knowledge, Attitude And Control Practices Of Sickle Cell Disease Among Youth Corps Members In Benin City, Nigeria, Annals of Ibadan Postgraduate Medicine. Vol. 13 No. 2.
[3]. Allensworth D, Lawson E, Nicholson L,(2017): Schools & Health: Our Nation's Investment. 10thed. Philadelphia: Elsevier, 200- 9.
[4]. Al-Qattan H M, Amlih D F , Sirajuddin F S, Alhuzaimi D I , AlageelM S , Bin TuwaimR M , and Al Qahtani F H (2019): Quantifying the Levels of Knowledge, Attitude, and Practice Associated with Sickle Cell Disease and Premarital Genetic Counseling in 350 Saudi Adults. Advances in Hematology. Article ID 3961201, 7 pages https://doi.org/10.1155/2019/396120
[5]. Amoran O E, Ahmed A B and Alabi A D (2016): Parental Influence on Sickle Cell Crisis among Patients Attending Secondary Facilities in Abeokuta South Local Government Area, Ogun State, British Journal of Medicine & Medical Research 14(9): 1-10,
[6]. Arrayed S, A & Hajeri A., A. (2009). Public Awareness of SCD in Bahrain, Available at http://www.ned.nlm.nih .gov/sites/entrez?cmd=search&PubMede & term. Accessed on 25/01/2018.

[7]. Asomugha, A., Fawehinmi, H., & Ejele, O. (2011). Growth parameters among sickle cell disease patients in the Niger Delta Region of Nigeria. Tropical Journal of Medical Research, 12(2). doi: 10.4314/tjmr.v12i2.65398.

[8]. Cynthia R, King S. (2015). Quality Of Life: From Nursing and Patient Perspectives. 9thed. Philadelphia: Elsevier, 107- 9.

[9]. Daak, A. A., Elsamani, E., Ali, E. H., Mohamed, F. A., Abdel- Rahman, M. E., Elderdery, A. Y., & Fawzi, W., (2016): Sickle cell disease in western Sudan: genetic epidemiology and predictors of knowledge attitude and practices . Tropical Medicine & International Health, 21(5), 642-653.

[10]. Daniel, L. C., Li, Y., Smith, K., Tarazi, R., Robinson, M. R., Patterson, C. A., Barakat, L. P. (2015). Lessons Learned From a Randomized Controlled Trial of a Family-Based Intervention to Promote School Functioning for School-Age Children With Sickle Cell Disease. Journal of pediatric psychology, 40(10), 1085–1094. doi:10.1093/jpepsy/jsv063

[11]. Dick, M. (2010). Sickle cell disease in childhood (2nd Ed.). London: NHS Sickle Cell and Thalassaemia Screening Programme.

[12]. Fahad F. A., Naif F. A., Albandari F. A., Almutairi M., (2017): Assess Mother's Knowledge Regarding Their Children with Sickle Cell Disease., International Journal of Healthcare Sciences, 4(2), (736-739).

[13]. Fowora M A (2016): Adherence to Self-Care Management of Sickle Cell Disease among Caregivers, Walden Dissertations and Doctoral Studies Walden Dissertations and Doctoral Studies Collection. https://pdfs.semanticscholar.org/be44/03f18d0229b672cf39fdbccda5470fdcf262.pdf .

[14]. Hassan, G.S., & Mohammad, A.A. (2018). Evaluation of the Most Common Complications of Sickle Cell Anemia and Management in Children: Simple Literature Review. The Egyptian Journal of Hospital Medicine, 72(2), 3951-3960. doi: 10.21608/ejhm.9076.

[15]. Hilda,H.,(2012): Knowledge and practice of parents and care giver towards prevention of sickle cell crises in children with sickle cell diseaseat the university teaching hospital(lusaka),master degree , Zambiauniversity,(1-85).

[16]. Hockenberry M.J &Wilson D. (2018). Wong's Nursing Care Of Infants And Children, CHAP 5 Pain Assessments and Management In Children 11thed. Philadelphia: Elsevier Co., 364.

[17]. Igboanugo G M, and Martin C H (2011): What pregnant women in a rural Niger Delta community's perception of conventional maternity service provision? An exploratory qualitative study, African Journal of Reproductive Health 15(3):59-72

[18]. Karadağ G, Güngörmüş Z, and Olçar Z (2018): Experiences and Problems Encountered by Families of Children with Sickle Cell Anemia, Journal of Caring Sciences, Tabriz University of Medical Sciences, 7(3): 125–129. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6163154/.

[19]. Mahmoud, R., Abdel-Sadik B.,and El-AAsar H., (2017). Mother's Knowledge and Practice regarding Care of Their Children with Sickle Cell Anemia. MenoufiaNursingJournal,November, Vol.2,No.2

[20]. Maurice, J. (2015). UN set to change the world with new development goals. The Lancet, 386(9), 1121-1124.

[21]. Mulumbaa L, and Wilsonb L, (2015): Sickle cell disease among children in Africa: An integrative literature review and global recommendations, International Journal of Africa Nursing Sciences, Volume 3, Pages 56-64

[22]. Pandarakutty S, Murali K, Arulappan J, and Thomas D S (2019): Effectiveness of Nurse-Led Intervention on Health-Related Quality of Life among Children with Sickle Cell Disease in Oman: A Pilot Study, Advances in Hematology,/|Article ID 6045214 | 9 pages | https://doi.org/10.1155/6045214

[23]. Siddiqui S, Schunk K, Batista M (2012): Awareness of sickle cell among people of reproductive age: Dominicans and African Americans in northern Manhattan. J Urban Health, 89:53-8.

[24]. Stephen N, Nden N, Gusen NJ, Kumzhi PR, Gaknung B, Auta DA, Bulndi LB, Mbursa C, Kumari VP, Nanvyat N. (2018): Prevalence of sickle cell disease among children attending plateau specialist hospital, Jos, Nigeria. Acta Med Int;5:20-3

[25]. Vasava B, Chudasama R, Godara N, Srivastava R. (2010): Prevalence of sickle cell disease in tribal adolescents of the South Gujarat region, India. Internet J Trop Med.;6(1):1-7.

[26]. World Health Organization (WHO): (2015). Sickle Cell Disease Prevention and Control. Retrieved fromhttp://www.afro.who.int/en/clusters-a-programmes/dpc/non-communicable-diseasesmanagementndm/programme-components/sickle-cell-disease.html.

[27]. Yadav P. & Vagha J. (2018).Impact of education on the knowledge and skills of parents of children with sickle cell disease. Int J Contemp Pediatr, 5, 209-13.

[28]. Yawn, B.P., Buchanan, G.R., Afenyi-Annan, A.N., Ballas, S.K., Hassell, K.L., et al. (2014). Management of sickle cell disease: summary of the evidence-based report by expert panel members. JAMA, 312, 1033–1048.

[29]. Zahran, A.M., Elsayh, K.I., Saad, K., Embaby, M., Ali, A.M.(2016). Regulatory B cells (CD19þ CD38hiCD24hi) in all immunized and in all immunized children with b-thalassemia major. Blood Cells Mol Dis, 57,91-96.

Nadia Ahmed El- Adham, et. al. "Effect of an Educational Program for Parents of Children with Sickle Cell Anemia." *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, 9(3), 2020, pp. 21-30.