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Caregiver's Knowledge and Practices Regarding Care of their Children with Sickle Cell Disease

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Abstract

Background: Sickle cell disease is one of the most common monogenetic disorders worldwide and it is a group of genetic red blood cell disorders, inherited as an autosomal recessive condition characterized by the presence of an abnormal hemoglobin S. **Aim:** The current study aimed to assess the caregiver's knowledge and practices regarding care of their children with sickle cell disease. **Design:** A descriptive research design was used in this study. **Setting:** This study was conducted at inpatient department and outpatient clinic department in the Egyptian children's Hospital affiliated to General Authority of Health Insurance. **Sample:** A purposive sample of 50 caregivers and their accompanying children with sickle cell disease. **Tool:** The study consisted of two tools to assess: **I:** Structured Interview Questionnaire Sheet to assess caregiver's knowledge regarding sickle cell disease **II:** Observational checklists to assess caregiver's reported practices regarding care of their children. **Results:** Nearly two thirds of studied children were males and less than half of the studied children had hemoglobin ss sickle cell disease less than two thirds of the studied caregivers had unsatisfactory knowledge regarding sickle cell disease. more than half of the studied caregivers had incompetent practices regarding care of their children with sickle cell disease. **Conclusion**: The present study concluded that the studied caregivers had deficit level of knowledge and poor of level of reported practices, and also there were a statistical significant positive correlation between the studied caregivers' knowledge and their total reported practices regarding care of children with sickle cell disease. **Recommendations:** A periodical educational program for caregivers to improve knowledge and practices regarding care of their children sickle cell disease.

Key words: Children, Caregivers, Knowledge, Practice, Sickle cell disease.

Introduction

Sickle Cell Disease (SCD) is one of the most common monogenetic disorders worldwide affecting 1 in 365 births among African Americans in the United States, an estimated 230,000 births annually in Sub-Saharan Africa and more than 55,000 births annually in the Eastern Mediterranean and India [1].

Sickle cell disease is a group of genetic red blood cell disorders, inherited as an autosomal recessive condition characterized by the presence of an abnormal hemoglobin S leading to polymerization of hemoglobin in the deoxygenated state causing changes and distortion in the shape of red blood cells and reduction of the flexibility of the hemoglobin [2].

Sickle cell disease primarily affects the development of red blood cells, resulting in the formation of hemoglobin S **(Hb S)**, an abnormal type of hemoglobin which causes red blood cells to become sickle-shaped and inflexible. These abnormal cells clump together in the arteries; blocking blood flow to various organs and causing various complications include acute and chronic pain, severe anemia, infection and stroke [3].

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Clinical manifestations of SCD start around the sixth month of a child's life and include painful crises, jaundice, chronic anemia, priapism and increased risk for Cerebro-Vascular Accidents **(CVA)**, gallstones and recurrent infections, especially of the respiratory tract. The presence of physical symptoms mainly relates to painful reactions, which interfere with the daily life of children with SCD [4].

Management of sickle cell disease is usually aimed at avoiding pain episodes, relieving symptoms and preventing complications. Treatments might include medicines and blood transfusions. For some children, a stem cell transplant might cure the disease. Treatment will depend on the child's symptoms, age and general health. Early diagnosis and preventing further problems is important in treating this disease [5].

Caregivers of children with sickle cell disease play a vital role in daily disease management, several studies suggest that many caregivers lack adequate knowledge of the disease. This limited knowledge can affect the quality of home care and delay critical decisions during acute episodes. Without proper awareness, caregivers may misinterpret symptoms or fail to recognize early warning signs of serious complications, which in turn affects children patients outcomes and increases dependence on emergency care services [6].

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.Therefore, Nursing care is essential for pain management of children with SCD; it includes health education and prevention of subsequent sickle cell crisis. As well as, educating the family and SCD children about signs of infection and lifestyle behaviors that limited aggravate the disease. Pediatric nurses have significant roles to medication administration, monitor the children signs of infection and dehydration [7].

Significance of the Study

Sickle cell disease is the most prevalent severe inherited hemoglobin disorder globally, with an estimated annual birth of 300 000–400 000 affected children world-wide and leads to debilitating pain episodes, disability and early mortality. As the vast majority of children with SCD are Black/African Americans [8] . In Egypt, sickle hemoglobin carrier rates vary from 9% to 22% with a heterogeneous distribution [9].

Sickle cell disease is a chronic disease, requires a comprehensive and lifelong management. This requires participation of both health care providers and parents of children affected by SCD. Due to the importance of this lifelong health follow-up of those children; it is strongly emphasized that their relatives be properly oriented about this disease, the necessary care as well as about the early identification of signs of risk for complications, with a view to preventing its aggravation and importance of regular follow-up [10]. So, from the researcher point of view, it is important to shed light on assessesssment the caregiver's knowledge and practices regarding care of their children with sickle cell disease.

Aim of the Study

This study aimed to assess caregiver's knowledge and practices regarding care of their children with sickle cell disease.

Research Queations:

1. What is caregiver's knowledge and practices regarding care of their children with sickle cell disease?

2. Is there correlation between caregiver's knowledge and reported practices regarding care of their children with sickle cell disease?

Subject and Methods:

1)The technical Design:

A) Research Design

A descriptive design was used to conduct this study.

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Research Setting

The study was conducted at inpatient department and outpatient clinic department in the Egyptian children's Hospital affiliated to General Authority of Health Insurance.

Subjects

A purposive sample was consisted of caregivers (50) and their accompanying children with sickle cell disease who attained in the previously mentioned setting under the following:

Inclusion criteria:

1- Children from both genders
2- Children in the age group from 2 to 12 years
3- Children free from any chronic diseases and illiterate caregiver excluded from the study.

Tools of Data Collection

two tools were used for data collection

Tool (I): Structured Interview Questionnaire Sheet (pre/post): It consisted of two main parts:

Part (1):- It was comprised the following:

a- **Characteristics of the studied caregivers** (age, sex, occupation, educational level, marital status, place of residence, type of family and family size).
b- **Characteristics of the studied children (**age, gender, number of sibling, birth order and educational level).
c- **The history of the child illness** (child′ diagnosis, onset of diagnosis, disease discovery, medication and compliance with treatment) and family history of the disease, consanguinity relationship between the father and the mother, family member suffering from the disease and number of affected sibling with disease).

Part (2): Caregiver′s knowledge regarding sickle cell disease that consisted of the following; It concerned with caregivers' knowledge:

Blood and its function (5) questions, sickle cell disease (18), nutrition (4) questions, medicine (5) questions, preventing infection and avoiding injuries (3) questions, caring for a child during a crisis (2) questions, follow up of the child after discharge (4) questions.

Scoring system: The answers of caregivers were checked using a model key answer. The score of each question when don't know answer or incorrect answer = (0) grade, incomplete answer= (1) grade and correct answer= (2) grades. The total score of caregivers′ knowledge was 82 grades (100%), total knowledge level of caregivers was classified into either satisfactory (≥ 60%) and unsatisfactory (< 60%).

Tool (II): Observational Checklist

It was adopted from [11] to assess the reported practices of caregivers as regards, hand washing (14 steps), measure of temperature (9 steps), cold compresses (7 steps), warm compresses (7 steps), oral medications (10 steps), deep breathing exercises (6 steps), pain assessment (FLACC scale) for children aged 2 to 7 years (10 steps) and pain assessment (Wing-Baker "FACES") for children aged 3 to more than 5 (8 steps).

Scoring system: As regards the scoring system for caregivers' reported practices, (2) grades were given to the caregivers for each step done correctly and (1) grade for each step done incorrectly and zero for not done. Accordingly, the caregivers' total reported practices were categorized into either inadequate (<60%) and adequate (≥ 60%).

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Tools Validity

The content validity of the tools reviewed by 3 experts in the field of pediatric nursing and community health nursing to test the content validity. The tools were examined for content coverage, clarity, relevance and applicability. Minor modifications of the tools were done according to the experts' comments on clarity of sentences, appropriateness of content and sequence of items.

Reliability of the Tools:

Reliability of the tools were tested by using Cronbach's Alpha for testing internal consistency of the tools was performed. The results were 0.82 for structured interview questionnaire, 0.85 for observational checklists.

II. Operational Design:

This phase includes a preparatory phase and a pilot study.

Preparatory Phase:

Review of the available past, current, national and international related literature and theoretical knowledge of various aspects of the study was done using books, articles, Websites, periodicals and magazines to get acquainted with various aspects of the research problem and develop the tools for data collection.

Pilot Study:

Pilot study was conducted on 10% of the study subjects which constitute 5 caregivers based on sample criteria. It was conducted to evaluate the clarity and applicability of the study tools. According to the obtained results from the pilot study, some modifications were done in the form of rephrasing and rearrangements of some items. The involved caregivers were excluded later from the main study sample.

Fieldwork

The actual field work was carried out for data collection over 6 months started from February 2024 till the end of July 2024 through interviewing every caregiver and their accompanying children at the inpatient and outpatient clinics.

Ethical Considerations:

Prior study conduction, ethical approval was obtained from the Scientific Research Ethical Committee of the Faculty of Nursing Helwan University. The purpose of the study was simply explained to the caregivers who agree to participate in the study prior to data collection. The researcher was assured maintaining anonymity confidentiality of the subject data. Caregivers were informed that they will be allowed choosing to participate or not in the study and they have the right to withdraw from the study at any time without giving any reasons.

III- Administrative Design

An official permission to carry out the study was obtained through an issued letter from the Dean of the Faculty of Nursing, Helwan University to the medical and nursing directors of the previously mentioned setting. The letter included the title, aim and the expected outcomes of the study to obtain their approval to conduct the study.

Statistical Analysis:

Data were organized, arranged, coded, entered and analyzed by using statistical package of social science (IBM SPSS Statistics for Windows, Version 20.0). The quantitative data were presented as mean and standard deviation. The qualitative data were presented as number and percentage. The P-value to detect the relations between the variables of the study.

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Results:

Table (1): Number and percentage distribution of the studied caregivers according to their characteristics (n=50).

Characteristics	No	%
Caregivers:		
Mother	42	**84.0**
Sister	5	10.0
Grandma	3	6.0
Age in years:		
18-<28	5	10.0
28-<38	27	**54.0**
38-≤48	18	36.0
X±SD	35.60±6.76	
Gender of caregivers:		
Male	0	0.0
Female	50	**100.0**
Educational level:		
Read and write	6	12.0
Primary school	6	12.0
Preparatory school	5	10.0
Secondary school	28	**56.0**
Highly educated	5	10.0
Marital status:		
Married	40	**80.0**
Divorced	5	10.0
Widow	5	10.0
Place of residence:		
Urban	18	36.0
Rural	32	**64.0**
Type of family:		
Nuclear family	18	36.0
Extended family	32	**64.0**
Family size:		
1< 4	14	28.0
4< 7	23	**46.0**
7≤ 10	13	26.0

Table (1) indicates that, the majority (84%) of caregivers were mothers, more than half (54%) of studied caregivers were in the age group from 28 < 38 years old, with mean and standard deviation values of age were 35.60±6.76 years. Regarding gender of caregivers, all of them (100%) were females and more than half (56%) of the studied of caregivers were graduated from secondary schools while few of them (10%) were graduated from preparatory and highly education. Majority of them (80%) were married and less than half of them (46%) had 4-7 family members.

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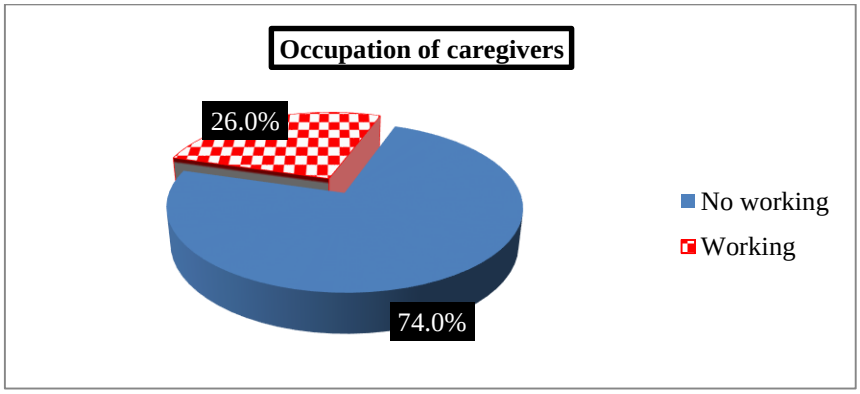

Figure (1): Percentage distribution of the studied caregivers according to their occupation (n=50).

Fig (1) shows that about three quarters (74%) of the studied caregivers were housewives and more than one quarter (26%) of them were working.

Table (2): Number and percentage distribution of the studied children according to their characteristics (n=50).

Characteristics of studied children	No	%
Age (years):		
1 < 3	9	18.0
3 < 6	13	26.0
6 ≤12	28	**56.0**
X±SD	6.57±1.25	
Gender:		
Male	32	**64.0**
Female	18	36.0
Number of sibling:		
None	5	10.0
1-2	13	26.0
3-4	17	**34.0**
5-6	15	30.0
Children's school enrollment condition:		
Pre nursery	10	20.0
Nursery	17	34.0
Primary	23	**46.0**

Table (2) reveals that more than half (56%) of studied children were in the age group from 6 ≤ 12 years old, with mean and standard deviation values of age were 6.57±1.25 years. Regarding the gender, nearly two thirds (64%) of studied children were males, more than one third (34%) of them had three or four siblings. According to children's school enrollment condition, less than half (46%) of them were enrolled in primary school.

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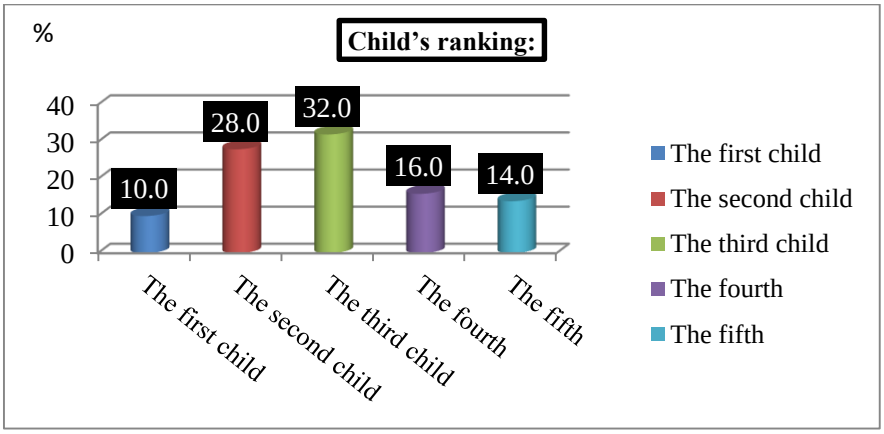

Figure (2): Percentage distribution of the studied children according to their child's ranking (n=50).

Fig (2) states that nearly one third (32%) of the studied children were ranked the third child in their family and few of them (10%) were ranked the first child in their family.

Table (3): Number and percentage distribution of the studied children according to their history of illness (n=50).

History of illness	No	%
Type of sickle cell disease:		
Hemoglobin SS	23	**46.0**
Hemoglobin SC	8	16.0
Hemoglobin SB thalassemia	11	22.0
I don't know	8	16.0
The child age at diagnosis:		
>6 (m)	7	14.0
6 (m) > year	12	24.0
One year and more	19	**38.0**
.Can't remember	12	24.0
Disease discovered:		
By Chance	17	34.0
Symptom of the disease	20	**40.0**
Periodic examination	5	10.0
Complication of disease	8	16.0
Treatment of the child:		
Medical treatment	8	16.0
Blood transfusion	5	10.0
Medical treatment and blood transfusion	25	**50.0**
Oxygen therapy	6	12.0
Splenectomy	6	12.0
Bone marrow transplant	0	0.0
Comply with treatment regularly:		
Yes	36	**72.0**
Not always	10	20.0
No	4	8.0

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Table (3) clarifies that less than half (46%) of the studied children had hemoglobin ss sickle cell disease, while more than one third (38%) of them were diagnosed as sickle cell disease after one year of life and more. Regarding method of the disease discovered, more than one third (40%) of them discovered the disease by its symptoms. Moreover, half (50%) of them were treated with medical treatment and blood transfusion and more than two thirds (72%) of them were complied with the treatment.

Table (4): Number and percentage distribution of the studied children according to their family history of disease (n=50).

Family history of disease	No	%
Consanguinity between parents:		
Yes	37	**74.0**
No	13	26.0
There is a family member or relative suffering from this disease:		
Yes	41	**82.0**
No	9	18.0
If yes, consanguinity with the child: (n=41)		
Father/mother	7	17.0
Brother/sister	13	**31.7**
Uncle	4	9.8
Aunt	2	4.9
Grandfather/ Grandmother	7	17.0
Uncle's children	4	9.8
Aunt 's children	4	9.8
Number of affected sibling with the disease:		
None	32	**64.0**
One	13	26.0
Two	5	10.0

Table (4) illustrates that, nearly three quarters (74%) of the studied children were having consanguinity between parents, also the majority (82%) of them were having family member or relative suffering from the disease and about one third (31.7%) of them had brothers/ sisters suffering from the disease. According to number of affected sibling with disease, nearly two thirds (64%) of them were not having siblings with disease while more than one fifth of them had one sibling affected with SCD.

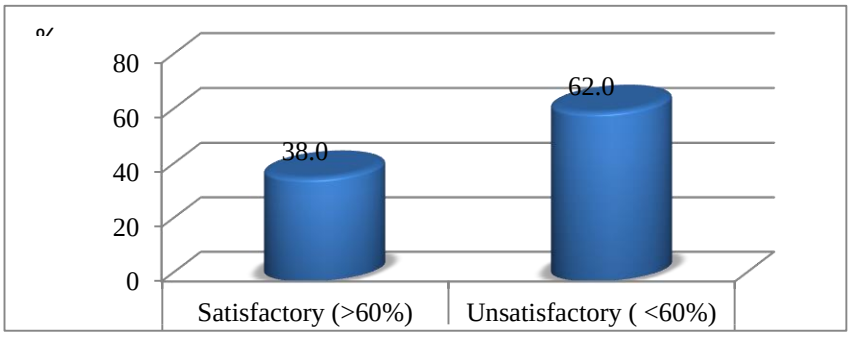

Figure (3): Percentage distribution of the studied caregivers according to level of knowledge regarding sickle cell disease (n=50).

Fig (3) shows that less than two thirds (62%) of the studied caregivers had unsatisfactory level of knowledge regarding sickle cell disease.

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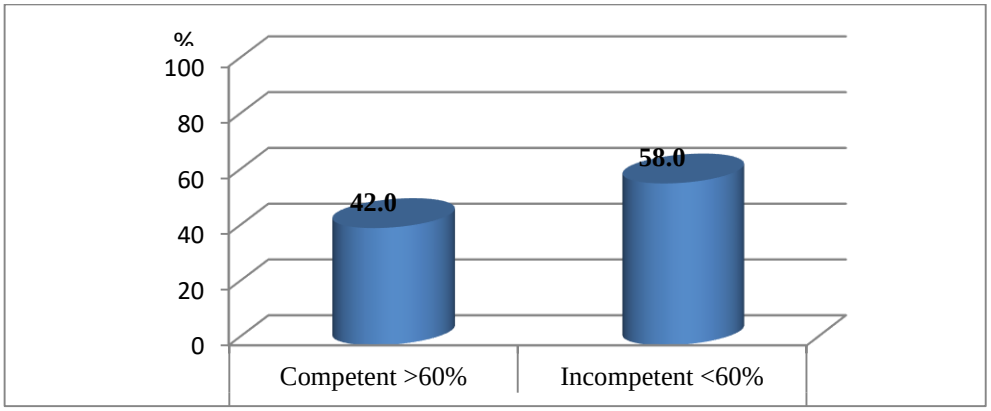

Figure (4): Percentage distribution of the studied caregivers according to their level of reported practices (n=50).

Fig (4): illustrates that more than half (58.0.%) of the studied caregivers had incompetent level of reported practices regarding care of their children with sickle cell disease.

Table (5): Relation between the studied caregivers' characteristics and their level of knowledge regarding sickle cell disease (n=50).

`Characteristics	Level of knowledge				Chi-square test	
	Satisfactory *(n=19)*		Unsatisfactory *(n=31)*			
	No	%	No	%	x2	p-value
Family caregivers:						
Mother	16	84.2	26	83.9	0.036	0.982
Sister	2	10.5	3	9.7		
Grandma/Grandpa	1	5.3	2	6.5		
Age in years						
18-<28	1	5.3	4	12.9	**7.684**	**0.042***
28-<38	8	42.1	19	61.3		
38-≤48	10	52.6	8	25.8		
Occupation of caregivers:						
No working	9	47.4	10	32.3	**8.015**	**0.032***
Working	10	52.6	21	67.7		
Educational level						
Read and write	3	15.8	3	9.7	**9.158**	**0.022***
Primary school	3	15.8	3	9.7		
Preparatory school	2	10.5	3	9.7		
Secondary school	9	47.4	19	61.3		
Highly educated	2	10.5	3	9.7		
Marital status						
Married	15	78.9	25	80.6	0.021	0.989
Divorced	2	10.5	3	9.7		
Widow	2	10.5	3	9.7		
Place of residence						

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Urban	9	47.4	9	29.0	0.590	0.442
Rural	10	52.6	22	71.0		
Type of family						
Nuclear family	8	42.1	10	32.3	0.160	0.688
Extended family	11	57.9	21	67.7		
Family size						
1-2	6	31.6	8	25.8	1.066	0.586
3-4	7	36.8	16	51.6		
5-6	6	31.6	7	22.6		

***Significant at p ≤0.05 **Highly significant at p ≤ 0.001 Not significant at p>0.05**

Table (5) shows that there were a statistically significant difference between caregivers' characteristics namely; age, educational level and occupation and their level of knowledge respectively, while there were no statistical significant difference between caregivers' knowledge and their marital status, place of residence, type of family and family size.

Table (6): Relation between the studied caregivers' characteristics and their level of reported practices related to care of their children with sickle cell disease (n=50).

Characteristics	Pre-Intervention (n=50)				Chi-square test	
	Level of practice					
	Competent *(n=21)*		Incompetent *(n=29)*			
	No	%	No	%	x2	p-value
Family caregivers:						
Mother	18	85.7	24	82.8	0.113	0.944
Sister	2	9.5	3	10.3		
Grandma/Grandpa	1	4.8	2	6.9		
Age in years						
18-<28	2	9.5	3	10.3	**10.146**	**0.001****
28-<38	12	57.1	15	51.7		
38-≤48	7	33.3	11	37.9		
Occupation of caregivers:						
No working	15	71.4	22	75.9	0.000	0.979
Working	6	28.6	7	24.1		
Educational level						
Read and write	3	14.3	3	10.3	**18.443**	**0.001****
Primary school	3	14.3	3	10.3		
Preparatory school	2	9.5	3	10.3		
Secondary school	10	47.6	18	62.1		
Highly educated	3	14.3	2	6.9		
Marital status						
Married	17	81.0	23	79.3	0.021	0.989
Divorced	2	9.5	3	10.3		
Widow	2	9.5	3	10.3		

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Place of residence						
Urban	8	38.1	10	34.5	**15.251**	**0.001****
Rural	13	61.9	19	65.5		
Type of family						
Nuclear family	8	38.1	10	34.5	0.001	0.971
Extended family	13	61.9	19	65.5		
Family size						
1-2	7	33.3	7	24.1	0.952	0.621
3-4	8	38.1	15	51.7		
5-6	6	28.6	7	24.1		

***Significant at p ≤0.05 **Highly significant at p ≤ 0.001 Not significant at p>0.05**

Table (6) clarifies that there were highly statistical significant difference between caregivers' characteristics namely; age, educational level and place of residence and their level of reported practices respectively, while there were no statistical significant difference between caregivers' practices and their occupation and marital status, type of family and family size.

Table (7): Correlation between the studied caregivers' level of knowledge and reported practices regarding care of their children with sickle cell disease (n=50).

Level of reported practice		**level of knowledge**			
		Satisfactory (19)		**Unsatisfactory (31)**	
		N	**%**	**N**	**%**
Competent (21)		14	28	7	14
Incompetent (29)		8	16	21	42
	R=	R= 0.712			
	P- value	**P= < 0.001**			

***Significant at p ≤0.05 **Highly significant at p ≤ 0.001 Not significant at p>0.05**

Table (7) shows that there were statistical significant positive correlation between their level of knowledge, reported practices regarding care of their children with sickle cell disease.

Discussion

The result of the present study (table 1) revealed that the majority of caregivers of children with sickle cell diseases were mothers. This result was supported by **Esomonu and Afolabi** [12] in Nigeria who conducted a published study entitled "Sickle cell disease: As assessment of awareness, knowledge and perception among parents of children attending a suburban health facility in north central Nigeria" and reported that, 84% of parents were mothers.

Also this finding was in conformity with **Madani et al.** [13] in western Saudi Arabia who carried out a published study entitled "Quality of life among caregivers of sickle cell disease patients: a cross sectional study" and found that, (79.4%) of caregivers were mothers. From the researcher point of view, this result might be due to mothers assume the large part of child's care duties and home care than fathers.

Concerning the age of caregivers the current study (table 1) represented that more than half of studied caregivers were in the age group from 28 < 38 years old, with mean and standard deviation values of age were 35.60±6.76 years. This result goes in line with **Namugerwa et al.** [14] in Eastern Uganda, who conducted a published study entitled "Knowledge and attitude towards sickle cell anemia among care givers of paediatric sickle cell patients at a tertiary hospital in Eastern Uganda: a cross sectional study" and revealed that 44.09% of caregivers were in the age group of 31 years to 40 years.

As well, this result was matched with **Baker et al.** [15] in India, who carried out a published study entitled "Burdens on caregivers of children ages one to sixteen years living with sickle cell disease

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attending a specialized clinic in urban" and found that, (85%) of caregivers were aged between 20 and 49 years old.

Considering gender of caregivers, the present study (table1), showed that all caregivers were females. This finding was congruent with study conducted by **Esomonu and Afolabi,** [12] in Nigeria who reported that, (83.7%) of parents were females. This result was in the same context with **Campbell et al.** [16] in the United States, who carried out a published study entitled "The burden of sickle cell disease on children and their caregivers: caregiver reports of children's health-related quality of life and school experiences, caregiver burden and their association with frequency of vaso-occlusive crises" and represented that, the majority (77.84%) of caregivers were females.

This study disagreed with **Mumun et al.** [17] in Ghana, who studied "Burden experienced by informal caregivers of children with sickle cell disease (SCD): a qualitative exploratory study at Tamale Teaching Hospital, Ghana" and revealed that, majority of caregivers were males. From the researcher points of view, this result may be due to the majority of family care providers of children with sickle cell diseases were mothers.

Regarding to the studied caregivers educational level, the present study illustrated that more than half of the studied caregivers of children with sickle cell diseases were graduated from secondary schools while few of them were graduated from preparatory and highly education. These results were in harmony with **Al Nagshabandi and Abdulmutalib** [18] in Egypt, who conducted a published study entitled "self-care management and self-efficacy among adult patients with sickle cell disease" and revealed that, (48%) of all adult patients were a secondary school, while (38%) were bachelor degree.

In addition, these results were in the same context with **Abed El Fatah et al.** [19] in Egypt, who conducted a published study entitled "Mothers' knowledge and practices for their children with sickle cell anemia at New Valley Governorate Hospitals" and observed that, nearly two thirds of mothers (64.4%) were graduated from the secondary schools, while one quarter of them were highly educated and only (4.4%) of them received primary education. Although, this result disagreed with **Abd Elaziz and Mohamed** [20] who revealed that more than one third (36%) of the studied mothers were having preparatory school education.

Concerning of the marital status, the current study (table1) clarified that majority of the studied caregivers were married. This result was in harmony with **Okoko et al.** [21] in Congo who carried out a published study entitled "Knowledge, attitudes and practices of parents in the vaso - occlusive crises of the sick children in Brazzaville" and found that, (67.1%) of parents were married. This result was on the same line with the study conducted by **Abubakar et al.** [22] in Nigeria, who studied "Clinical status of sickle cell anemia and the impact on the caregivers finances at a tertiary hospital, North-West Nigeria" and found that, (85.7%) of the caregivers were married. This result was disparity with **Adewoyin et al.** [23] in Nigeria, who carried out a published study entitled "knowledge, attitude and control practices of sickle cell disease among youth corps members in Benin City" and found that, most (74.9%) of respondents (74.9%) were single. From the researcher's point of view, the difference may due to culture, traditions and attitude differences between countries and individuals.

Considering the place of residence, the present study (table 1) showed that nearly two thirds of caregivers lived in rural areas. This result was in agreement with **Awd et al.** [24] in Egypt who observed that, (70%) of mothers were living in rural areas while 30% of them were living in urban areas. Although this study disagreed with **Mostafa et al.** [25] in Egypt who carried out a published study entitled "Evaluation of pulmonary function in Egyptian children with sickle cell disease: a single center study" and represented that, (80%) of the study population lived urban cities. From the researcher points of view, this may be due to the absence of near hospitals in rural areas for pediatric hematology intervention lead to children's referral to far hospitals in urban areas.

Conerning type of family the current study revealed that, nearly two thirds of the studied caregivers belonged to extended family while more than one third of them belonged to nuclear family. These results agreed with **Romeeh et al.** [26] in Egypt, entitled "Mothers' awareness about poisoning prevention among their children under five years old" and showed that, more than half of the studied mothers lived in extended families. These result disagreed with **Elsayed et al.** [7] in Egypt, entitled "Assessment of mothers care toward

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their children having phenylketonuria" and revealed that (59.6%) of the studied mothers were belonged to nuclear family.

In relation to family size, the present study (table 1) indicated that less than half of caregivers had 4-7 family members. This result supported with **Fouda et al.** [27] in Egypt, entitled "Effect of self-learning guidelines on quality of life and self –care reported practice of adolescents with sickle cell anemia" and showed that, less than two thirds (62%) of the studied sample numbers of their family are three members. Also, this result comes in line with **Awd et al.** [24] who showed that, (78%) of the studied mothers had from 4-6 family members.

As regard the studied caregivers occupational status, the current study (figure 1) clarified that about three quarters of the studied caregivers were housewives and more than one quarter of them were working. This result was similar to **Awd et al.** [24] in Egypt who conducted a published study entitled "Mother's knowledge and practice regarding care of their children with sickle cell anemia" and found that, (84 %) of studied mothers were not working while 16.0% of them were working. As well, this result was matched with **Abd Elaziz and Mohamed** [20] in Egypt, who studied "Effect of self-care management program on pain and fatigue in sickle cell children" and reported that, less than two thirds of the studied mothers (64.0%) were not working. Meanwhile this finding was contradictory to **Baker et al.** [15] in India, who reported majority (76%) of caregivers were employed. From the researcher points of view, these results due to that most of the Egyptian mothers preferred to stay at home to provide care for their husbands and children especially if they had chronic ill child.

Concerning the age of studied children, the present study (table 2) indicated that more than half of studied children were in the age group from 6 ≤ 12 years old, with mean and standard deviation values of age were 6.57±1.25 years. These results agreed with **Kazal et al.** [28] in Africa, who conducted a published study entitled "Factors associated with growth retardation in children suffering from sickle cell anemia; first report from central Africa" and revealed that, (32.5%) of the studied children were aged from 5-9 years with the mean age at 8.4 ± 4.9 years of age.

Moreover, these results were matched with **Abdo et al.** [29] in Jordan who conducted a published study entitled "Management of sickle cell disease pain among adolescent and pediatric patients disease pain among adolescent and pediatric patients" and showed that, (56.7%) of pediatric patients aged from 1-11 years. From the researcher point of view, this may be due to the children in this age group are enjoy with play and move more, this exposes them to pain attack that require them to be hospitalized.

Regarding the gender, the present study (table 2) displayed that nearly two thirds of children were males, this finding was in conformity with **Apprey et al.** [30] in Ghana, who conducted a published study entitled " Nutritional status of children with sickle cell disease A study at the Komfo Anokye Teaching Hospital of Ghana" and showed that, majority of the participants (57 %) were males. Furthermore, this result was reinforced by **Essawy et al.** [31] in Egypt, who carried out a published study entitled "quality of life of children with sickle cell anemia" and found that, nearly three quarters of children (73%) were males.

This finding was dissimilar to the result of **Adeyemo et al.** [32] in Nigeria who studied "Knowledge, attitude and control practices of sickle cell diseases among senior secondary students in Osun State, Nigeria" and stated that, (55%) of the students were females. From the researcher point of view sickle cell disease is not an X-linked disease. Although, no particular gender predilection has been shown in most series in addition, this could be attributes to that Egyptian families are paying attention and seeking medical advice for both boys and girls offspring's.

In relation to number of sibling, the current study (table 2) described more than one third of the studied children with sickle cell disease had three or four siblings. This finding was in conformity with **Namugerwa et al.** [14] in Eastern Uganda, who demonstrated that 70.43% of caregivers had a total number 5 children or less. In addition, the result of this study disagreed with the finding of **Elsayed et al.** [7] who found that, (36.2%) of the studied children had one sibling.

According to children's school enrollment condition, the present study (table 2) revealed that less than half of the studied children were enrolled in primary school. Furthermore, this result was the same opinion with **Essawy et al.** [31] who discussed that, (79%) of the studied children were enrolled in primary schools. Also, the result of the current study was in accordance with the findings of **Abed**

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El Fatah et al. [19] who found that, more than half of the children are at the primary education (68.8%), while less than one quarter of them (11.1%) were at secondary and diploma schools. Contrariwise, this result was incongruent with **Abd Elaziz and Mohamed** [20] who showed that, more than half of the studied children (53.0%) were enrolled in preparatory school.

As regard the studied children ranking in their family, (figure 2) revealed that nearly one third of the studied children with sickle cell diseases were ranked the third child in their family and few of them were ranked the first child in their family. This result was discrepancy with **Mousa et al.** [33] in Egypt, who carried out a published study entitled "Factors causing sleep disturbances among school age children with sickle cell disease" and demonstrated that, half (50%) of children ranked as the first child in their family. As well as this finding was disagreed with **Fouda et al.** [27] who found that less than half (46%) of them were ranked as the first child in their family.

The current study **(table 3)** clarified that less than half of the studied children had hemoglobin SS sickle cell disease. This result was support with **Martin et al.** [34] in Washington, who studied "Clinical outcomes of children and adolescents with sickle cell disease and COVID-19 infection: A year in review at a metropolitan tertiary pediatric hospital" and showed that, (74%) of the studied children were having hemoglobin SS sickle cell disease. Also, this result was in unison with those of **Apprey et al.** [30] who revealed that, the most occurring type of SCD found among the study participants was the SS genotype (65%).

Although this study disagreed with **Nnodu et al.** [35] in Nigeria, who carried out a published study entitled "Child mortality from sickle cell disease in Nigeria: a model-estimated, population-level analysis of data from the 2018 Demographic and Health Survey "and found (77·2%) of children were having HbAA. From the researcher point of view, this may be hemoglobin SS is the most common and most severe kind of sickle cell disease.

Considering the child age at diagnosis, the current study (table 3) implied that more than one third of studied children were diagnosed as sickle cell disease after one year of life and more. This result was supported by with **Hussein et al.** [36] who conducted a study about "Determination of daily living activities of school age children with sickle cell anemia in Al Nasiriya City" and revealed that, (70%) of studied children were first diagnosed above one year of age.

Also, this result comes in line with **Iliyasu et al.** [37] in Northern Nigeria, who studied "A child with sickle cell disease can't live with just anyone; A mixed methods study of socio-behavioral influences and severity of sickle cell disease in northern Nigeria" and indicated that, the majority (71%) of children were diagnosed during infancy. Although, this result disagreed with **Elkholy et al.** [38] who conducted a study about "Application of precede-proceed planning model on quality of life among children with sickle cell anemia" and revealed that, more than one half of studied children were diagnosed at 6 months of age.

From the researcher point of view, this result due to signs and symptoms of the disease begin to appear after (6) months and the affected

infants do not develop symptoms in the first few months of life because the hemoglobin produced by the developing fetus (fetal hemoglobin) protects the red blood cells from sickling. This fetal hemoglobin is absent in the red blood cells that are produced after birth so that by 5 months of age, the sickling of the red blood cells is prominent and symptoms begin.

Regarding method of the disease discovered, the present study (table 3) explicated that more than one third of the studied children discovered sickle cell disease by its symptoms. This result supported by **Claeys et al.** [39] who conduct a study published entitled "Varied age of first presentation of sickle cell disease: case presentations and review" and revealed that, most children were discovered the disease after the age of one year, usually by presenting with symptoms.

Although, this finding was dissimilar to the result of **Alamun et al.** [40] in Bouake who carried out a published study entitled "Psychological experience of mothers of children with sickle cell disease followed at the pediatric department of bouake university teaching hospital" and demonstrates that, the disease was discovered incidentally in 62.5% of cases.

Regarding the studied children treatment, the current study (table 3) portrayed that half of the studied children with sickle cell diseases were treated with medical treatment and blood transfusion. This

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result was support with **Campbell et al.** [16] who revealed that the most frequently reported current treatments for SCD included folic acid (72.46%), antibiotics (68.26%), blood transfusions (50.90%), hydroxyurea (49.70%), and non-steroidal anti-inflammatory drugs (44.31%).

Also, this result supported with **Abolwafa et al.** [41] in Egypt, entitled "Effect of instructional based nursing intervention program on self-efficacy, depression and quality of life in children with sickle cell disease" and found that, (90%) of children with SCD receive blood transfusion. From the researcher point of view, this result may be due to blood transfusion remains an important therapeutic intervention in children with sickle cell disease

Regarding the studied children compliance with treatment, the present study (table 3) indicated that more than two thirds of them were complied with the treatment. This result supported with **Namugerwa et al.** [14] who found that more than half of the caregivers (69.89%) agreed that child had to take medication. In addition to this study agreed with **Elsoudy et al.** [42] in Egypt, who studied entitled "Compliance of children with thalassemia to their therapeutic regimen" and found that, (98.0%) of studied children were always in compliance with their therapeutic regimen.

In relation to consanguinity between parents, table (4) illustrated that nearly three quarters of the studied children were having consanguinity between their parents, also the majority of them were having family member or relative suffering from the disease and about one third of them had brothers/ sisters suffering from the disease. These results come in line with **Abolwafa et al.** [41] who demonstrated that, 87.5% of parents of children have sickle cell disease were having close consanguinity.

In additional to these results were confirmed with **Iliyasu et al.** [37] who revealed that, more than a third (40.3%) of the children had at least one sibling who also had SCD. Although these results were disagreed with **Abd Elaziz and Mohamed** [20] who revealed that, more than half of the studied mothers were no presences any one of family suffering from this disease. From the researcher point of views, the result due to consanguineous marriage is still high in Egypt .Couples with sickle cell trait will have each of their pregnancy having (25%) chance of giving birth to a child affected by sickle cell disease.

According to number of affected sibling with disease, the current the study (table 4) explicated that nearly two thirds of the studied children with sickle cell disease were not having siblings with SCD while more than one fifth of them had one sibling affected with SCD. These results were reinforced by **Fadil and Efe** [43] in Turkey, who carried out study entitled "The effect of non-pharmacological pain management training given to parents of children with sickle cell disease on parents' knowledge in two different countries" and showed that, (59.6 %) of participants were not having sibling with sickle cell disease.

These results were disagreed with **Elsayed et al.** [7] who revealed that more than two thirds (64.6%) of family had only child. This result was in disparity with **Iliyasu et al.** [37] in Northern Nigeria who reported more than a third (40.3%) of the children had at least one sibling who also had SCD. Also, these results were disagreed with **Abd-Alrazzaq and Aziz** [44] in Baghdad, who entitled "Assessment of mothers' knowledge about their children with sickle cell anemia and non-pharmacological approaches to pain management in Basra center for hereditary blood diseases" and found that more of (80%) of the studied mothers are reported that they have patient inflicted with sickle cell anemia in family.

Figure (3) presented that less than two thirds of the studied caregivers had unsatisfactory level of knowledge regarding sickle cell disease. This result was consistent with **Awd et al.** [24] who revealed that approximately two fifths of mothers had poor knowledge about sickle cell anemia

As well as these results were matched with **Namugerwa et al.** [14] who found that 55.91% of the participants had poor knowledge about sickle cell disease. Although, this study disagreed with **Adigwe** [45] who studied "Knowledge and awareness of sickle cell disease: a cross sectional study amongst unmarried adults in Nigeria's capital city" and revealed that, majority of the participants (92.50%) were aware of sickle cell disease

Figure (4) illustrated that more than half of the studied caregivers had incompetent level of reported practices regarding care of their children with sickle cell disease. This result comes in line with **Amour and Jumanne** [46] who studied "Caregivers' level of knowledge and home- based practices for prevention of sickle cell disease related complications among children attending Mnazi mmoja hospital in Zanzibar" and

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reported that 52% of caregivers had inappropriate home based care practices for prevention of SCD complications.

This result disagreed with **Awd et al.** [24] who clarified that the majority (90%) of mothers had satisfactory practices regarding their children with sickle cell anemia. Also, this result was incongruent with **Abed El Fatah et al.** [19] who conduct apublished study entitled "Mothers' knowledge and practices for their children with sickle cell anemia at New Valley Governorate Hospitals" who found that half of mother's (51.1%) had satisfactory level of practice regarding sickle cell anemia

Table (5) demonstrated that there were a statistically significant difference between caregivers' characteristics namely; age, educational level and place of residence and their level of knowledge respectively, while there were no statistical significant difference between caregivers' knowledge and their occupation, marital status and family size. These result agreed with **Oluwole et al.** [47] who studied "Sickle cell disease: caregiver's awareness and phenotype distribution among children presenting to children emergency of a tertiary hospital in Lagos, Nigeria" and found that there was a statistically significant difference between the caregivers educational level and their awareness of SCD.

In additional to **Musonda** [48] who study "Knowledge, attitudes and practices of caregivers of children with sickle cell disease towards sickle cell disease at Kitwe teaching hospital, Kitwe Zambia" and showed that there was an association between the studied caregivers level of knowledge and demographic chareacteristics which included age, level of education, monthly income at p-value<0.05. These result agreed with **Al-Qattan et al.** [49] who conduct a published study entitled "Quantifying the levels of knowledge, attitude, and practice associated with sickle cell disease and premarital genetic counseling in 350 saudi adults" and demonstrated that association between the participants level of knowledge and age groups. The age group with best knowledge was 29–39 years, while The other study variables showed no significant associations.

Table (6) clarified that there were highly statistical significant difference between caregivers' characteristics namely; age, educational level and place of residence and their level of reported practices respectively, while there were no statistical significant difference between caregivers' practices and their occupation and marital status, type of family and family size. This result supported with **Ezaat et al.** [50] in Egypt, entitled "Effect of educational program on mothers' knowledge and practices regarding their children with splenomegaly" and indicated that, a high statistically significant difference was found between the mothers' practices and their ages, level of education and place of residence, with p-values of (0.000). This result disagreed with **Khresheh and Brair** [51] in Jordan, entitled "Knowledge and practices among mothers about care of their children with beta thalassemia major: a descriptive study" and found that, there was no significant association between socio- demographic characteristics of mothers and the overall care practices score of Desferal tablets administration ($\chi 2=15.0$,(P=0.81).

As regard correlation between caregivers' level of knowledge and their level of reported practices, the current study table (7) showed that there were statistical significant positive correlation between their level of knowledge and reported practices regarding care of their children with sickle cell disease. This result was supported with **Abed El Fatah et al.** [19] who revealed that**,** there was a statistical significant positive correlation between the level of mothers' knowledge and score of practices (r= 0.451 & P= 0.002). Also this result comes in line with **Musonda** [48] who found that there was significant association between caregivers'level of knowledge and practices at a p-value of <0.001.

Conculsion

Based upon the results of the present study concluded that the studied caregivers had deficit level of knowledge and poor level of reported practices, and also there were a statistical significant positive correlation between the studied caregivers' mean score of knowledge and reported practices regarding care of children with sickle cell disease.

Recommendations

Based on the study findings, the following recommendation was suggested:

A periodical educational program for caregivers to improve knowledge and practices regarding care of their children sickle cell disease.

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