Coping pattern and its relationship with mothers' knowledge and practices toward their children with sickle cell anemia

1 Omaima Mohamed Esmat2, Ferial Fouad Melika3, Rahma Mohammed Mohammed
1,2Assistant Professor of Community Health Nursing Ain shams university
3, lecturer at Community Health Nursing Damietta university.

Abstract

Introduction: Sickle cell anemia is a genetic blood disorder where the human body produces abnormally shaped red blood cells, often in the shape of a sickle crescent shaped. **Aim:** This study aimed at assessing mothers' coping patterns toward their children with sickle cell anemia. **Setting:** this study was conducted at the outpatient clinic of hematology and day care hematological pediatric department in the Ain shams university Hospitals **sample:**130 mothers having children with sickle cell anemia were included in this study. **Tools of data collection:** Two different tools were used, **First tool:** An interviewing questionnaire about socio demographic characteristics of mothers and their children, knowledge, practices, coping pattern of mothers toward their children with sickle cell anemia, **Second tool:** Medical record of child with sickle cell anemia. **Results:**59,2%. of mothers having children with sickle cell anemia, had poor level of knowledge while, 4,6% of them had good knowledge about sickle cell anemia.67,7% of the total mothers had inadequate practices regarding their children with sickle cell anemia. While 32.3% of them had adequate practices regarding their children with sickle cell anemia. 68,5% of mothers coping pattern adaptive. Compared to 31,5% of them were maladaptive. **Conclusion:** There was a statistical significant relation between the mothers' coping pattern and mothers' total knowledge and practices about sickle cell anemia, **Recommendation:** Improving mothers knowledge about health needs and problems of their children with sickle cell anemia, enhancing mother's knowledge and practices level toward care of their children with sickle cell anemia, improving mothers coping pattern and accepting responsibility of care for their children.

***Keywords**: Coping pattern, Mothers, Children, Sickle cell anemia, Nursing*

Introduction

Although the disease state of anemia is characterized by a decrease in red blood cell count and a corresponding decrease in hemoglobin concentration, its complexity is related to a number of possible pathophysiological causes, including genetic, environmental, and irregular epidemiological surveillance. It is a global public health issue that impacts health, socio-economic status, and preferred futures for those most directly impacted. Despite the potential for intervention and treatment, anemia has remained a major cause of mortality and morbidities regionally and globally **(Mulumba and Wilson, 2015).**

Hemolytic anemia caused by homozygosity or inheritance of the sickle hemoglobin gene is known as sickle cell anemia. It is distinguished by sickle hemoglobin's propensity to polymerize and distort red blood cells into sickles or crescent shapes, which leads to chronic hemolysis, progressive organ damage, and a distinctive vaso-occlusive phenomenon **(Kliegman et al., 2016).**

The hemoglobin diseases are the most common clinically significant single gene illness in the world, In Egypt, sickle cell anemia is widely encountered in the oases where the carrier rates vary from 9 to 22% **(El Safy, 2016).**

Hemoglobin S is a distinct type of hemoglobin produced by children with sickle cell anemia. Hemoglobin S-containing red blood cells live shorter lives than healthy ones. They become stiff and deformed, and they have a hard time getting through tiny blood arteries. Sickle-shaped cells obstruct blood vessels, making it challenging for blood to circulate smoothly to every portion of the

body. Tissue damage is a serious effect of sickle cell anemia as blood tissues do not receive normal flow of blood (in turn oxygen) causing damage **(Kliegman et al., 2016).**

Additional complications include cholelithiasis, stroke, enuresis, priapism, delayed puberty, proliferative retinopathy, avascular necrosis of the hip or shoulder, and leg ulcers. The ultimate objective of a community health nurse is to improve the child's chances of making a smooth transition to adulthood and to empower families to manage the child's complicated chronic disease **(Kaushansky et al., 2016)**

The interplay between an individual's internal resources and external environmental pressures is known as coping. It involves efforts to lessen the perceived disparity between personal resources and situational expectations. **(Markofa and Nikitskya, 2017).**

For women and their children with sickle cell anemia, the community health nurse offers appropriate multidisciplinary treatment, including teaching mothers about prophylactic measures and vaccinations, such as pneumococcal vaccines. It is essential to educate people about the necessity of receiving immediate medical attention in order to manage acute chest syndrome, aplastic crisis, acute splenic sequestration, and feverish illness.. Education about splenic sequestration includes the need to seek medical attention immediately if the child is pale and listless and guidance on using abdominal palpation to measure the size of the spleen. It is important to review how to identify and treat dactylitis and other painful conditions**. (Elhosany, 2011).**

Enabling mothers to effectively manage their child's complicated chronic condition and improving the child's chances of making a smooth transition to adulthood are the ultimate goals of community health nurses**. (Kaushansky et al., 2016).**

Significance of the study

Sickle cell anemia is an inherited hematological condition that can be fatal. Significant morbidity and early mortality result from sporadic and recurrent problems caused by an abnormal sickle-shaped erythrocyte. Children with sickle cell anemia suffer from a variety of physical conditions, including hemolytic anemia, acute Vaso occlusion that causes excruciating pain, embolisms in different parts of the body, and ultimately death. As a result, they need frequent hospital care for long-term blood transfusion therapy and the management of acute complications.. Psychological health challenges, such as sleep disturbances, negative body satisfaction, fatigue, anxiety, depression **(Almutairi, 2015).**

Aim of the Study

Study aims at assessing mothers coping patterns toward their children with sickle cell Anemia through.

- Assessing health status of children with sickle cell anemia.
- Assessing mother's Knowledge about sickle cell Anemia.
- Determining mother practices toward care of their children with sickle cell Anemia.
- Assessing mother's coping patterns toward their children with sickle cell Anemia.

Research question:

- Is there a relation between the mother's knowledge about sickle cell anemia& their coping pattern?
- Is there a relation between the mother's practices to ward care of

their children with sickle cell Anemia & their coping pattern?

- Are there relation between mother's knowledge and practices toward care of their children with sickle cell anemia?
- Are there relations between mothers knowledge/ practices toward care of their children with sickle cell anemia and health needs/problems of children with sickle cell anemia?

Subjects and Methods

Research design

A descriptive analytical study was utilized to estimate the mothers' coping pattern toward their children with sickle cell anemia.

I. Technical design.

Setting

The study was conducted at outpatient clinic of hematology and day care hematological pediatric department in the Ain shams university Hospitals this hospital is the most crowding ones in Egypt where serve big numbers of hematological diseases and patients coming from all over the country.it is considered from the most special hospital in Egypt provide care for hematological diseases.

Sampling

The sample size was calculated by using Raosoft sample size calculator by a known total population of 273 subjects. The confidence interval was set at 95% with a margin of error accepted adjusted to 5% and power of the test adjusted to 80%. The sample was found in 130 subjects. In children of the last past three years from 2014 to 2015 according to the following inclusion criteria set for sample selection as follows;

Inclusion criteria

The children and their mothers were selected according to the following criteria;

-The children aged between 1-6 years

-The Children Diagnosed with sickle cell anemia for at least one year.

Exclusion criteria

Diagnosed with another chronic disease.

Tool of data collection

It was developed by the investigator, based on reviewing related literature, magazines and experts, opinions written in Arabic language to assess mothers coping with children with sickle cell anemia. The data was collected using the following two tools:

1.First tool; an interview questionnaire (Appendix 1) which includes the following parts.

Part (I): this part included: Questions to assess demographic characteristics of the sample study of children with sickle cell anemia and their mothers. This part included close ended questions (Q1-Q1` a2); such as age, gender, childbirth order for children, age of the mothers, educational level, job, monthly income, and family residence.

Part (II): Questions to assess health history for children with sickle cell anemia. This part included closed ended question about health history for children with sickle cell anemia as reported by their mothers (Q1-Q7); such as onset of the disease, its way of detection, follow up and if other family member suffered from the disease.

bedside during sleep, carpets and rails firmly grounded to prevent accidents, tap water and the sanitary drainage inside the house good, careful monitoring during play and put a card showing his illness in the school bag.

Part (V): Questions to assess mother's knowledge about sickle cell anemia this part included closed ended question which divided into the following parts (Appendix 2).

(a) Mothers' knowledge about sickle cell anemia; this part included 5 closed ended questions (Q1-Q4) such as meaning of SCA, causes, sign and symptoms, complication, source of knowledge about SCA.

(b) mothers' knowledge about the care of the child with Sickle cell anemia; this part included 4 closed ended questions (Q5-Q9) such as the treatment method for SCA, the role of the mothers for children to protect them from complication, the importance of blood transfusion for children with SCA and the complication of blood transfusion on the child.

Scoring system of knowledge

The score ranged from zero to two, the level of poor knowledge = "(0)" grade, average knowledge = "(1)" grade & good knowledge = "(2)" grade. The total score for all items related to knowledge 9 graded and was categorized into three levels as following, the level of poor knowledge <50%, average knowledge (50%-75%), good knowledge >75%.

Part (VI): Questions to assess mother practices toward health care for their children with sickle cell anemia this part includes closed ended questions which are divided in to the following parts.

(a) Nutritional care and Medication Administration practices of mothers for their children with sickle cell anemia; this part included 5 closed ended questions (Q1-Q5) Such as the role of mothers in maintaining proper nutrition for child, the drinks that are not taken for your child, the exercise appropriate for those child, the mother's role toward child exercise and Medication taken only by the doctor order.

(b) This part included 3 closed ended questions (Q6-Q8) to assess mother's practices toward Care of Fever and Prevention of Infectious diseases such as the mothers doing

when the child is feverish, measuring the child temperature and Protection the child from infectious diseases.

This part included 2 closed ended questions (Q9-Q10) to assess mother's practices toward Care of signs and symptoms of sickle cell anemia and its complications such as the emergence checkup and the mother's role in preventing possible complications of the disease.

Scoring system of practices

Scoring systems ranged from zero to one, in ad equate practices level take "(0)' grade, and adequate practices level take ‘(1) grade. The total score for all items related to practices 10 grades and was categorized into two levels as followings less than 60% in adequate practice and more than 60% adequate practice.

Part VII: Questions to assess mothers coping pattern toward their children with sickle cell anemia this part included 43 questions adapted by **Elyazed (2011)** and adopted by the investigator to assess the coping pattern.

The coping pattern scale consists of three items such as active coping patterns, seeking support patterns and avoidance coping patterns. Every item consists of some points Active coping contains about 12items seeking support coping contains about 9 items and avoidance coping contains about 22 items.

Scoring system of mothers coping

Scoring ranged from (0-2) with the Likert rating scale to indicate the degree of use (never, sometimes & always). Whereby ‘0" represent never used at all, "1" sometimes used & "2" signifies always used. This scoring for questions from Q1-Q20 but the questions from Q21-Q43 the rating scale was reversed to’0"represent always used, '1" sometimes used, and "2"

represent never used at all. The total scores were summed up each of the items and the total divided by the number of the items, giving a mean score for the most part, those scores were converted into a percent score to be categorized into two levels as more than 50% adaptive level of coping and less 50% maladaptive level coping.

Scoring system of mothers coping

Scoring ranged from (0-2) with rating scale to indicate the degree of use (never, sometimes & always). Whereby "0" represent never used at all, "1" sometimes used & "3" signifies always used. This scoring for questions from Q1-Q20 but the questions from Q21-Q41the rating scale was reversed to"0"represent always used, '1" sometimes used, and "2" represent never used at all. the total scores were summed up each of the items and the total divided by the number of the items, giving a mean score for the most part, those scores were converted into a percent score to be categorized into two level as more than 50% adaptive level of coping and less 50% maladaptive level coping.

The second tool: medical analysis record (Appendix 8)

This tool included child physical examination and laboratory investigation such as complete blood count and hemoglobin level.

(a) Physical measurements assess children's growth such as weight and height measurements and are composed of two levels normal and abnormal.

Height; measurement of the standing height was done by using non stretchable tape, for measurement the child stands erect without shoes with weight equally distributed equally distributed on both feet and heels together and touching the vertical board ,while arms are hang freely at the side of the trunk ,with palm facing the

thigh looking straight ahead height is recorded to the nearest 0,5cm,and also using measurement table Amarke was used done at the head and heals .then, the child was removed and distance measured with centimeter tape.

Weight: weight was measured by a bath room scale. The child was in minimal clothing and without shoes. Standing with weight evenly distributed on both feet. Weight is recorded to the nearest 0,1 Kg. and also using calibrated pediatric scales were used. Clothes were removed except under pants, including diapers. The investigator's hand was kept close to but not touching the child to prevent accidents from falling.

Scoring system of growth.

The investigator assessed the growth of children by measurement weight and height using scale and then following the growth percentile charts which are simplified graphic representation of growth was used for follow up of growth and early detection of deviation from normal growth (e.g growth retardation) it was developed by **(WHO, 2016).** Using it the investigator was able to determine child has normal growth & those who had abnormal one. normal growth ranged from 3rd-97th percentile and abnormal is 3rd or 97th percentile.

(b) An observational checklist to assess child physical examinations; this part included 39 items about procedure to assess child physical examinations

Scoring system of physical examinations.

A scoring system for each item of physical examinations items present was scored '1" grade and not present scored "zero" grade.

(c) physical examination of child growth and development using Denver developmental screening test **(Berman, 2012);** this tool included child level of growth and

development as Denver development screening scale such as: weight /Kg, height /Cm.

II. Operational design.

Preparatory phase

A review of literature was done regarding current and past available literature, covering the various aspects of the problem, using textbooks, articles, magazines and internet search. This was necessary for the investigator to get acquainted with, and oriented about aspects of the research problems, as well as to assist in development of data collection tools.

Ethical consideration: All ethical considerations were considered for ensuring the mother's privacy and confidentiality of the data collected during the study. The purpose and the nature of the study were explained for the participation after being informed that each study subject is free to withdrawal at any time through the study. All selected study sample agreed to participate in the study, and they were assured that the study would posed on risks or hazards on their social, psychological or physical health.

Pilot study

A pilot study was conducted at the beginning of the study. On 10 cases (10% of the total sample) to investigate the feasibility of data collection tools, their content, validity, clarity and simplicity. It took about one month from the beginning of January 2017 to the end of January 2017. Subjects included in the pilot study were included in the actual study sample.

Field work

The actual process of data collection was carried out in the period from the beginning of January 2017 until the end of June 2017.two days weekly about 4 hours daily (Sundays, Wednesdays) to collect the total sample. The investigator

interviewed herself with the hospital administrator and the other health teamwork that will help her in data collection to save the time and to also gain the trust of mothers. The investigator explained the aim of the study to all of them and then distributed the questionnaire sheet after explaining the way to fill it out. The interviewing tools took about a maximum of 30 minutes for every mother and the physical assessment tool took about 15 minutes for each child. The observational checklist took about 15 minutes.

III. Administrative design.

Formal letter from the dean of the faculty of nursing, Ain shams university to the directors of outpatient clinics of hematological disease of pediatric hospital of Ain Shams University, requesting their approval for conducting this study from these outpatient clinics.

IV. Statistical design

Data was analyzed using the statistical package for social science (SPSS) version 19. Qualitative data was presented as number and percentage. Relations between different qualitative variables were tested using chi-square test (x^2). Probability (p-value) 0.05 was considered significant and 001 was considered highly significant.

Results: -

Table (1) shows that 55,4% of the total sample of children having sickle cell anemia were male aged 1 to2 years with Mean- Std. Deviation = 2.99± 1.559. Regarding the childbirth order 56.9% of them were second birth order. This table also shows that 72.3% of children didn't attend school

Table (2) displays that, 51,6% of the total mothers aged 30- <40 years and 33,1%of them were

highly educated compared to 35,4%were illiterate while, 88,5% of them were housewife, regarding children family residence 60% of them were living in rural areas and 40% of them living in urban areas. The family monthly income, 59,2% of the total sample income, did not enough. Regarding parental consanguinity, 83,8% of them had parental consanguinity.

Figure (1) illustrates that 59.2% of total mothers having children with sickle cell anemia had poor level of knowledge, 36.2%of mothers had average level of knowledge while 4.6% of mothers had good knowledge about sickle cell anemia disease and heath care for their children with sickle cell anemia.

Figure (2) illustrates that 67.7% of the total study sample had inadequate practices regarding their children with sickle cell anemia. while 32.3% of them had adequate practices regarding their children with sickle cell anemia.

Figure (3) this figure illustrates that68,68,5% of mothers coping were adaptive. Compared to31,5% of them were maladaptive with their children having sickle cell anemia.

Table (3) shows that there was a statistical significant relation between the mothers' coping pattern and mothers' total knowledge about sickle cell anemia. Where X2=6.054 respectively at P value‹0.05.

Table (4) shows that there was a statistical significant relation between the mothers coping pattern and the mothers' total practices toward care of their children with sickle cell anemia. Where X2= 7.431 respectively at P value‹0.05.

Part I: - Demographic characteristics for children with sickle cell anemia and their mothers.

Table (1): Distribution of study sample of children with sickle cell anemia according to their demographic characteristics (n=130).

Items		No	%
Age	1: < 2	34	26.2
	2:< 3	25	19.2
	3:< 4	10	7.7
	4: < 5	32	24.6
	5: < 6	29	22.3
Minimum= 1year, Maximum= 6 year, Mean- Std. Deviation = 2.99± 1.559			
Gender	Male	72	55.4
	Female	58	44.6
Child birth order	First	36	27.7
	Second	74	56.9
	Third	15	11.5
	Fourth	5	3.8
Educational level	Nursery	20	15.4
	Primary	16	12.3
	Did not attend school	94	72.3

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Table (2): Distribution of study samples of mothers according to their socio-demographic characteristics (n=130).

Items		No	%
Mothers' age	< 20 years	5	3.8
	20- <30 years	52	40.0
	30- <40 years	67	51.6
	40 +	6	4.6
Minimum = 19 Maximum = 42, Mean_= 31.02 Std. Deviation = ± 5.794			
Mothers' educational level	Illiterate/ Read / write	46	35.4
	Primary education	5	3.8
	Preparatory education	15	11.5
	Secondary education	21	16.2
	Highly education	43	33.1
Mothers job	House wife	115	88.5
	Employee	15	11.5
Residence	Rural	78	60.0
	Urban	52	40.0
House type	House owner	83	63.8
	House rent	47	36.2
Family income	Enough	53	40.8
	Not enough	77	59.2
There is a parental consanguinity	Yes	109	83.8
	No	21	16.2
Degree of parental consanguinity	First	**N= (109)**	
		62	56.9
	Second	31	28.4
	Third	16	14.7

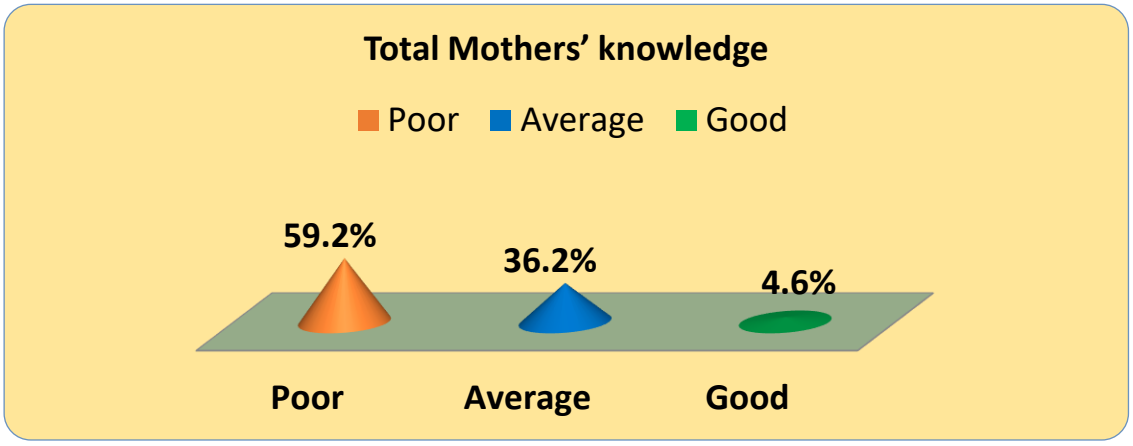

Figure (1): Distribution of the studied mothers' total knowledge about the sickle cell anemia disease and health care for their children with sickle cell anemia (n=130).

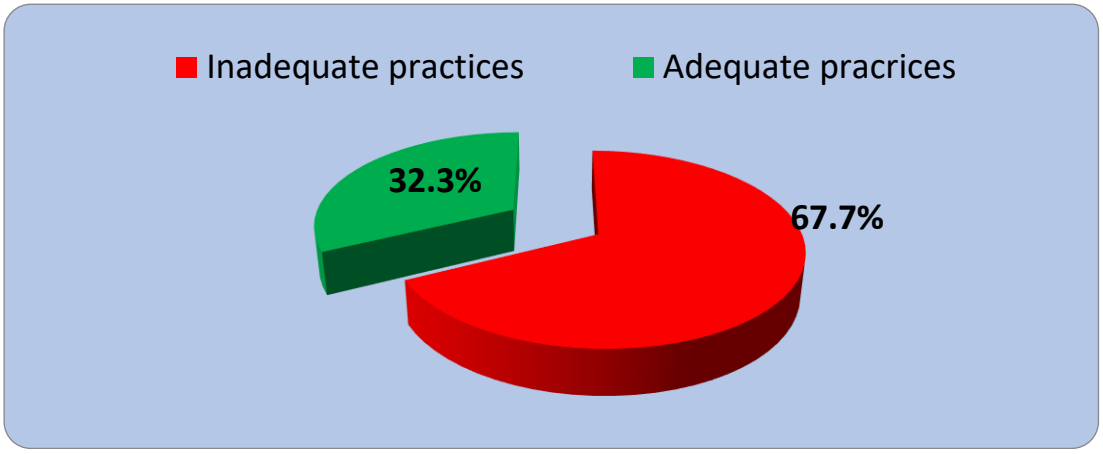

Figure (2): The distribution of the Total mothers' practices level with their children with sickle cell anemia (n=130).

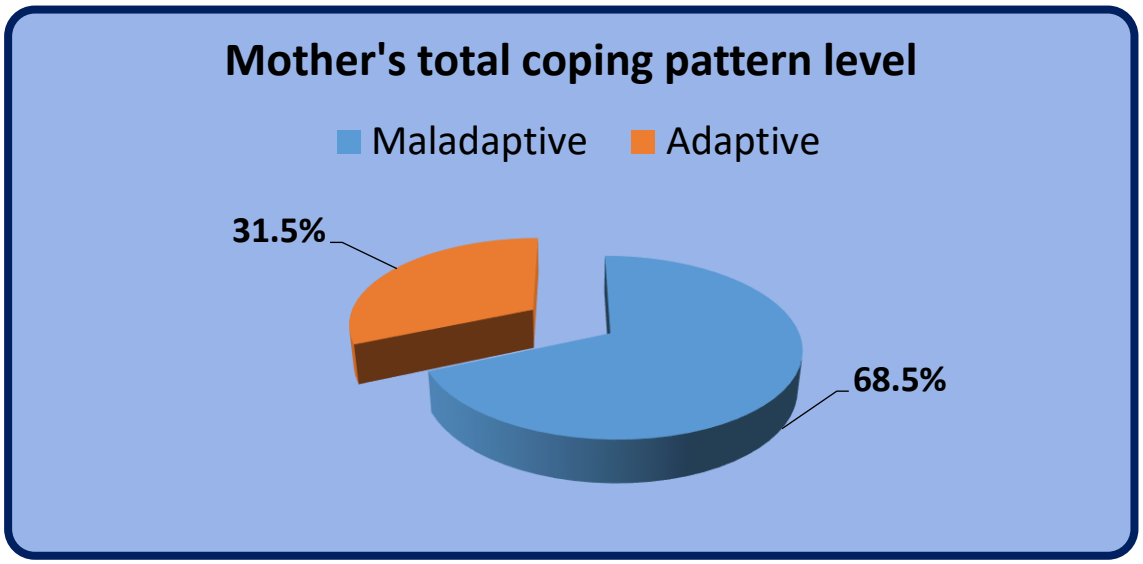

Figure (3): - The distribution of the mother's total coping pattern level toward their children with sickle cell anemia (n=130).

Table (3): The relation between the mother's knowledge about sickle cell anemia and their coping pattern (n=130).

Mothers' total knowledge	Mothers' coping pattern						Chi-Square X^2	P value
	Mal adaptive		Adaptive		Total			
	No	%	No	%	No	%		
Poor knowledge	56	43.1%	21	16.2%	77	59.2%	6.054	**0.048 S
Average knowledge	27	20.8%	20	15.4%	47	36.2%		
Good knowledge	6	4.6%	0	0.0%	6	4.6%		
Total	89	68.5%	41	31.5%	130	100.0%		

Table (4): The relation between the mother's practices toward care of their child with sickle cell anemia and their coping pattern (n=130).

Mothers' total Practices	Mothers' coping pattern						Chi-Square X^2	P value
	Mal adaptive		Adaptive		Total			
	No	%	No	%	No	%		
Inadequate practices	67	51.5%	21	16.2%	88	67.7%	7.431	**0.006 S
Adequate practices	22	16.9%	20	15.4%	42	32.3%		
Total	89	68.5%	41	31.5%	130	100.0%		

Discussion

Sickle cell anemia is a hereditary hematological condition that can be fatal. Worldwide, sickle cell anemia afflicted an estimated 5,788,700 newborns. Significant morbidity and early mortality result from recurrent, intermittent complications caused by abnormal sickle-shaped erythrocytes. There are several physical and mental health issues that children with sickle cell anemia face. Since parents are frequently the primary caregivers for their children with sickle cell anemia, all of those problems cause them to face several difficulties and expectations. All of those issues result in multiple challenges and demands on parents of children with sickle cell anemia, as those parents are often the primary caregivers **(Ware, 2017).**

According to the current study's findings, male children aged 1 to 5 made up more than half of the sample of children with sickle cell anemia. In terms of the birth order of the children, almost half were second in line. Additionally, it was discovered that over two-thirds of them did not go to school. **(table 1).** This result was supported by **Al Meida**, **(2012)** who conduct his

study **in Brazil** who revealed that the majority of children were male and presented at the age of six years or less. Also this result was in consistence with **Adegoke, (2012)** who achieved his study **in Nigeria** who emphasized that more than three quarter of the study sample did not attend nursery. In my out of view this result related to sickle cell anemia is a critical case which effect on general health status of children.

Socio demographic characteristics for mothers

The results of the current study showed that over half of moms' ages were between 30 and 40. The majority of moms were housewives, and less than half were illiterate. In terms of family residency, almost 50% of them reside in rural areas. Additionally, over three-quarters of them were consanguineous with their parents. **(table 2).**

This finding was relevant with **Almutairei, (2017)** whose study, "Mothers' Knowledge Regarding Their Children with Sickle Cell Disease," conducted in Saudi Arabia, revealed that most mothers were in their thirties (20/50), one-third were illiterate, and over half were housewives. This could be because it makes it difficult for them to understand the actions that medical professionals recommend, whether it's regarding medical procedures or the laws that protect their children's rights.

Also this result was agreement with **(Al Meida, 2012), fedral university in Brazil** who mentioned that the majority of the mothers had attend elementary and middle schools. As well as this study in accordance with **(Zaini, 2016), Taif University** He stated that the high frequency and prevalence of sickle cell disease, which affects over 50% of people, has been connected to consanguineous marriages, with the rate of marriage between first cushions ranging from 40% to 50%. This may be because sickle cell

anemia has been associated with a high incidence and prevalence in consanguineous marriages.

Moreover a study conducted at Brazil by. **(Fernands and Sonati, 2015)** Nearly half of the mothers in this study lived in towns that were fairly far from the referral centers, and less than one-fifth of them reported difficulties getting to the centers to perform the recommended treatment. In addition, the need to travel for treatment puts the lives of the children at risk. They discovered that the distance to reference centers is a barrier to the implementation of a comprehensive care program for sickle cell anemia children. In my opinion, there is a lack of specialized hospitals and health facilities that deal with treating patients with hematological diseases in rural areas.

Additionally, there was a statistically significant correlation between the mother's coping strategy and their overall level of sickle cell anemia knowledge **(table 5).** This results were relevant with **Helmi,(2016)** who conducted her study at **Ain shams university hospital** showed that the mother's overall knowledge and how they adjusted to their children after being discharged from the hospital with congenital heart disease were statistically related.

The findings showed a statistically significant relationship between the mothers' coping style and their overall approach to childcare. **(table 6).** This results were agreed with **Helmi,(2016)** who conducted her study at **Ain shams university hospital** demonstrated that there was a statistical significant relation between the mother's total practices and their adjustment toward their children post congenital heart disease after hospital discharge sickle.

The findings showed that the mother's overall knowledge and habits regarding the care of their sickle cell anemia-affected children

were highly statistically significant**. (table 7).** This finding was in accordance with **(Almutairi, 2017) in Saudi Arabia**. They came to the conclusion that moms had a markedly lower level of understanding and expertise regarding the causes, signs, and crises of sickle cell disease.

Conclusion

The findings of the study indicated a statistically significant correlation between the mother's coping style and mothers' total knowledge and practices about sickle cell anemia, there was a highly statistical significant relation between the mothers' total knowledge and the mother's total practices toward care of their children with sickle cell anemia, and health needs of their children with sickle cell anemia.

Recommendations

Based on the current study findings the following recommendations were proposed.

- Providing mothers with basic knowledge about health needs for their children because sickle cell anemia is a critical health condition
- Providing mothers with basic knowledge about health problem of their children with sickle cell anemia associated with chronic pain, unpredictable painful crisis and cognitive dysfunction which effect on self-esteem, dissatisfaction with body image and social isolation especially during childhood.
- Encourage education programs on importance of pre-marital genetic counseling facilities screening program to control of genetic diseases.

- Encourage mothers to share their opinions and share medical staff to take decisions about child care.
- Improving mothers' understanding of sickle cell anemia's symptoms and signs, as well as how to treat its complications, as it is a potentially fatal illness.
- Improving the degree to which mothers take care of their children's infectious diseases by giving them the right vaccinations and nutritional support.
- Enhance mothers' ability to manage and take ownership of raising children with sickle cell anemia.

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