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Effect of Self Care Management Program on Pain and Fatigue in Sickle Cell Children

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Abstract: **Sickle cell disease is an autosomal recessive disease that causes considerable morbidity and mortality. The aim of the study is to evaluate the effect of self-care management program on pain and fatigue in sickle cell children. Research design: A quasi-experimental design was used to complete this study. Settings: The study was conducted at the hematology department at Benha Specialized Pediatric Hospital and Benha University Hospital at Benha City. Sample: A purposive sample of 100 children with sickle cell anemia was included from the above mentioned settings. Fulfilled the following criteria aged from 9-18 years. Tools: Five tools were used to collect the study data*: *Tool I: A structured interviewing questionnaire format. It was developed by the researchers and includes three parts to collect data: Part 1: Personal characteristics of mothers. Part 2: Personal characteristics and illness history data of the studied children. Part 3: Children' knowledge regarding sickle cell anemia Tool II: Pediatric pain coping strategies scale. Tool III: Pain assessment scale (Numeric Rating Scale). Tool IV: Assessment of Fatigue scale in Pediatric patient aged 7-18 for Parents. Tool V: Children self-care practices to avoid pain and fatigue. Results*: *Overall the results have a highly statistically significant differences (P<0.001) pre and post program implementation regarding pain and fatigue scales. Conclusion: The results suggest the effectiveness of self-care management program on the reduction of pain and fatigue in sickle cell children. Therefore, self-care management programs are advisable in order to empower children and assist their management of health-related problems. Recommendations: The study recommended the importance of educational program for children and families regarding self-care management.**

Keywords: **Self Care Management, Pain, Fatigue & Sickle Cell Children.**

1. INTRODUCTION

Sickle cell disease (SCD) is the most common genetic disease characterized by recurrent painful vaso-occlusive crises **(Wallen, 2014).** Sickle cell disease is a group of disorders that affects hemoglobin (the molecule in red blood cells that delivers oxygen to cells throughout the body). Children with this disorder have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle, or crescent, shape **(Collins et al., 2019).**

The major manifestations of SCD include fatigue, severe pain, dactylitis (swelling and inflammation of the hands and/or feet), arthritis, and bacterial infections, splenic sequestration (sudden pooling of blood in the spleen and liver), lung congestion, injuries to the heart, leg ulcers, asepsis and bone infarction leading to the death of portions of bone **(Julie et al., 2014).** The most frequent symptom associated with SCD is pain. Although, pain is the cardinal feature of SCD and it is characteristically unpredictable, episodic in nature, described as one of the most excruciating forms of pain that affects human beings. Pain occurs due to stimulation of nociceptive nerve fibers caused by micro vascular occlusion. The microcirculation is obstructed by S shaped RBCs, thereby restricting the flow of blood to the organ and this result in ischemia, oedema, pain, necrosis, and organ damage **(Inusa et al., 2019).**

Episodes of severe pain in children with SCD often require hospitalization and limit their daily activities. The pain can last for hours to a week or more and is typically of a throbbing nature with a tendency to move around the body. Bones are

often affected and abdominal pain with tenderness is common. SCD has no cure and so the aim of therapy is, first to prevent the sickling phenomenon and second to provide emergency medical treatment when sickle cell crises (SCC) occurs **(Joshua et al., 2014).** Furthermore, the most frequent complications are acute vaso-occlusive events resulting in severe pain episodes. The episodes (also known as pain crises) are predominantly managed within the home environment but require hospitalization when there are complications or when the pain becomes too great **(Curtis et al., 2019).**

Fatigue is an increasingly important symptom of this disease in the literature. The extent of fatigue in SCD is still unknown and causal mechanisms are not well understood. On the other hand, several symptoms of SCD such as the chronic hemolytic anemia, inflammation, and pain suggest that children's with SCD are at risk for experiencing acute and chronic fatigue, so that researchers of cancer-related fatigue have demonstrated that a systematic approach to the investigation of this symptom is necessary for understanding this phenomenon in SCD **(Ameringer et al., 2014).**

Self-care is the control of one's own care for the purposes of health, the person being able to decide how and what action needed to be taken and by whom, in order to sustain his/her care/treatment, and it is the activity that individuals are being involved in, finding effective ways to deal with their identified problems and enable them to achieve their goals **(Al-Azri et al., 2016).** Self-care becomes an integral part of an effective and efficient health care system, and self-management includes the strategies which individuals utilize to enhance control and maximize well-being. Children may engage in self-care activities, such as napping, sleeping longer, distracting themselves, or conserving energy by simplifying their activities **(Anie et al., 2016).**

Self- care management is the ability of child with a chronic disease, to participate in a daily, self-motivated, collaborative (conducted with family, social, and health care provider support) process to manage symptoms This process involves the domains of focusing on illness needs, activating resources, and living with a chronic illness. In chronic conditions, child's ability to perform behaviors that will alleviate the pain experience is instrumental in adapting to pain long-term **(Shruti Shukla et al., 2017).**

Self-care management; is a collaboration between the child, family, and care providers. Moreover, self-care management for children improves health outcomes in chronic illness not only by improving adherence to the treatment plan but also by building the child's capacity to navigate challenges and solve problems. Support for self-management is a critical need among children and adolescents with chronic conditions **(Lozano & Houtrow, 2018).**

Nurses should be focused on the ability of children's to perform self-care, and practices of activities that initiate and perform on their own behalf in maintaining life, health and well-being. Care given to children with SCD during their painful experience requires skills from the nurses to identify evaluate and control the pain, always considering the age and the subjectivity of each child when facing their behavioral reactions, for an integral and humanized care. **(Magalhães, 2018).**

1.1. Significant of the study:

Sickle cell disease (SCD) is an autosomal recessive disorder characterized by production of abnormal hemoglobin S and is associated with high morbidity and mortality. Worldwide, 257,000 sicklier out of 330,000 children born with a major hemoglobinopathy **(Alkot et al., 2018).** This disease is predominantly present in individuals of African origin but also affects children of Middle Eastern, Indian, and Mediterranean descent. It is estimated that 1 in 13 children of African descent suffers from the sickle cell trait. Sickle cell disease affects 1 in 365 individuals of African descent; in America, about 100,000 individuals are currently suffering from this disease **(Mangla et al., 2019).**

Although many children with SCD lead normal lives, but there are complications associated with this disease. Approximately one third of children with SCD report acute or chronic pain almost daily and the majority of these children report experiencing pain for more than half of the day. Additional complications include silent strokes, acute chest syndrome, hand–foot syndrome, leg ulcers and infections. Despite these complications, most children with SCD are well most days. They negotiate their lives positively and actively seek to achieve a sense of normalcy, resenting any attention that frames them as different. Children with SCD require specific attention to maintain their health and prevent complications of their disease **(Haridasa et al., 2018).**

1.2. Aim of the Study

The study aimed to evaluate the effect of self-care management program on pain and fatigue in sickle cell children, through:

1. Assessing children knowledge regarding sickle cell anemia.
2. Assessing children self-care practices to avoid pain and fatigue.
3. Measuring the degree of pain and fatigue using pain and fatigue scales for children with sickle cell anemia.
4. Designing and implementing self-care management program for children with sickle cell anemia to decrease pain and fatigue.
5. Evaluate the effect of self-care management program for children with sickle cell anemia to decrease pain and fatigue.

1.3. Research Hypothesis

1- Self-care management program will improve the children's knowledge regarding sickle cell anemia and improve their self-care practices to avoid pain and fatigue.

2- Self-care management program for sickle cell children will decrease their pain and fatigue.

2. SUBJECT AND METHODS

2.1. Technical Design

2.1.1. Research Design

A quasi-experimental design was used to complete this study

2.1.2 Settings

The study was conducted at the hematology department at Benha Specialized Pediatric Hospital affiliated to the ministry of health and population, it is found in the fourth floor and consisted of one room contain (4) beds and Benha University Hospital, it is found in the medicine ward in fourth floor and consisted of two units each unit contain three rooms each rooms contain (6) beds.

2.1.3. Sample

A purposive sample of children diagnosed with sickle cell anemia (n=100) were included from the previously mentioned settings who were newly and old diagnosed with sickle cell anemia.

The inclusion criteria

-Children aged from 9-18 years.

-Children free from any other chronic disease, handicapping condition and cognitive problems.

2.1.4. Tools of data collection: Five tools were used to collect the study data*:*

Tool I: A structured interviewing questionnaire format: It was designed by the researchers after reviewing of the related literatures, it was written in an Arabic language. It comprised three main parts which are:

Part 1: Personal characteristics of the studied mothers: Such as age, marital status, educational level, job and residence.

Part 2: **Personal characteristics and illness history data of the studied children** including: age, gender, educational level, birth order, consanguinity relation between the father and the mother, presence of family members relatives suffering from sickle cell anemia, previous hospitalization, causes of past hospitalization, investigation have been performed to diagnose the child condition, routine tests done, routine tests carried out and number of blood transfusion per week.

Part 3: Children' knowledge regarding sickle cell anemia: Such as component of blood, the main place for the manufacture of blood and blood products, the function of red blood cells, definition of sickle cell anemia, causes, signs and symptoms of sickle cell anemia, the main treatment and complications, prevention and methods of prevention of disease, complication of blood transfusion and treatment of complication of blood transfusion. The total questions were (12 questions).

Scoring system for knowledge: Children' knowledge were evaluated upon completion of the interview questionnaire and accordingly, the correct answer was given (1) score and (0) for incorrect or don't know answers. The total knowledge were categorized as score of 75% and more was considered good, a score between 50% to less than 75% was considered average, while a score below 50% was considered poor.

Tool II: Pediatric pain coping strategies scale: This tool was developed by **(Varni et al., 1995).** It consisted of five subscales named: **Cognitive-Instruction**; included (7 items), **Problem-Solving**; included (7 items), **Distraction;** included (9 items), **Seeks Social Support**; included (5 items) and **Cata strophizing/Helplessness**; included (5 items).

Scoring system for the pediatric pain coping strategies were classified as: Always (3), Sometimes (2) and Never (1). Higher scores on all subscales indicate more adaptive coping with pain.

Tool III: Pain assessment scale (Numeric Rating Scale): It was adopted from **Bijur, (2003)** to assess pain for children with sickle cell anemia included four dimensions named :No pain (0), mild pain (1-3)**,** moderate pain (4-6) and severe pain (7-10). Ranged from no pain to severe feeling with pain and the total score ranged from 0-10 (maximum score).

Tool IV: Assessment of fatigue scale: It was adopted by **Ozlem et al., (2014),** for the assessment of fatigue in pediatric patient aged 7-18 for parents. It consists of totally 27 items and 3 lower dimensions named**: Dimension of general problems;** included (18 items) aimed at determining the fatigue of pediatric patients, **Dimension of sleep problems;** included (6 items) aimed at determining the sleep problems of pediatric patients caused by fatigue and **Dimension of treatment problems** included (3 items) aimed at determining the effect of treatment received by pediatric patients upon fatigue.

Scoring system for the pediatric pain coping strategies were classified as: Always (3), Sometimes (2) and Never (1).

Tool V: Self-care practices: It was adopted by (**Matthie, 2015**) and refers to child's perceived ability to participate in general activities aimed to improve health status and quality of life as well as actual performance of those activities, it is contributes to children pain and fatigue management and thus pain crisis prevention and included (6) steps (go to sleep early, drink 8 glasses of water or more daily, skin care, put a plan of daily living activities, get a balanced diet and mouth care).

Scoring system for children self-care practices as reported the children sickle cell anemia practices was calculated for each item as follows: done practices was scored (1) and not done was scored (0).

2. 2. Operational Design:

2.2.1. Preparatory Phase: A review of the past and currently available literatures related to the research problem using books, evidence-based articles, periodicals, and magazines were done to be acquainted with all aspects of the study problem and also in order to develop relevant tools for data collection and designing the content self-care management program for pain and fatigue in sickle cell children. This period extended from the beginning of January 2019 to the end of February 2019.

2.2.2. Tool validity and reliability: Tools validity was tested through a jury of three experts in pediatric nursing field to test the tool clarity, relevance, comprehensiveness, simplicity and applicability. Modifications of the tools were done according to the expert's judgment on the clarity of sentences, appropriateness of content and sequence of items. The experts agreed on the content, according to their review and minor modifications were done in the contents. Internal consistency reliability of all items of the tools was assessed using Chronbach's Alpha test. It was 0.83for the structured interviewing schedule, and 0.86 for pediatric pain coping strategies.

2.2.3 Ethical Considerations and human rights: A permission to carry out the study was obtained from the hospitals managers and the supervisor of hematology units in the previously mentioned study settings through submission of an official letter issued from the Dean of Faculty of Nursing, Benha University. All participants were assured that participation in the study was voluntary; each child and his parent was informed about the purpose, procedure, benefits and nature of the study and each child had the right to withdraw from the study at any time without any rationale, then oral consent obtained from them. Confidentiality and anonymity of each subject was assured through coding of all data and all information has taken was protected.

2.2.4. Pilot Study: The pilot study was carried out on 10 children and their mothers representing 10.0% of the study subject over a period of one month (March, 2019). The purpose was to ascertain the feasibility of the study, the clarity and applicability of the tools. It also helped to estimate the time needed for filling out the forms. Based on the results of the pilot, the necessary modifications on the study tools were done and pilot study subjects were included in the study sample.

2.2.5. Field Work

The field work was performed from the beginning of from April 2019 to the end of September 2019 to collect data. The researchers were available four days per week (Saturday and Sunday) at Benha Specialized Pediatric Hospital, (Monday and Tuesday) at Benha University Hospital in the morning shift from 10.00 a.m. to 1.00 p.m. Explanation of the purpose of the research was done to the sickle cell children and their mothers in order to gain their cooperation. The current study was carried out through the following phases:-

Assessment phase:

At the beginning, the researchers introduce themselves to the children and their mothers. Explained the aim of the study and their approval has taken to participate in the study prior data collection. Each child and his mother were interviewed individually for 15 minutes to fill out the structured interviewing questionnaire sheet (**Tool 1**). The researchers clarified and answered any related questions. Then, discuss with each child regarding pain coping strategies scale **(Tool II)**. Then, the researchers ask each child to explain how they would describe pain in their own words. **(Tool III)**. The researchers were discussing with each mother regarding the assessment of fatigue in her child and how her child feel in the past week **(Tool IV)**. Finally discuss with each child self-care practices to avoid pain and fatigue **(Tool V)**. The average time for completion of all tools was around 60-75 minutes for each child, divided as (10-15 minutes) for each tool, ensuring complete privacy and total confidentiality. The children were given pens for their participation in the study. This phase took about two months.

The planning phase

The self-care management program was designed by the researchers after an extensive review of related literatures and the needs identified in the assessment phase. An Arabic booklet concerning sickle cell disease was prepared based on their knowledge and self-care practices need after the pre-test.

Implementing phase

The self-care management program was implemented in about two months. They were asked to feel free to ask any question. The total number of the subjects was 100 children; they were divided into 10 groups, each group contains 10 children to acquire the related information, and the researcher continued to reinforce the gained information, answered any raised questions and gave feedback. A schedule for sessions was developed, and each participant selected the suitable time.

The program content included knowledge related to component of blood and its functions, definition of sickle cell disease ,causes, signs and symptoms, complication of disease, pain and fatigue such as meaning of fatigue, signs and symptoms, causes, precaution to avoid fatigue, factors aggravating fatigue and factors relieving fatigue. Self-care practices to improve health and decrease pain and fatigue level.

The program includes three sessions regarding self-care management to decrease pain and fatigue. Each session takes from 20-30 minutes. The sessions were presented to each group separately. At the beginning of each session, the researchers started by a summary about what was given through the previous session and objectives of the new one, taking into consideration using simple and clear language to suit the children. Different teaching strategies were used for implementation of the program such as; lectures, small group discussion, brain storming, role play, demonstration and re-demonstration. Suitable teaching aids as booklet, colored posters. Children were motivated to cooperate and participate actively in different stages of the study. At the end of each session, 10-15 minutes were allowed for discussion to correct any misunderstanding. Also they were informed about the time of next session. At the end of the program implemented, an Arabic booklet of the program was given to each children participated in the study as a reference. This phase took about two months.

Evaluating phase:

After the completion of the program contents; children' knowledge and their self-care practices were evaluated immediately after implementing the program, the post tests were administered by using same pretest tools. Additionally, the researchers evaluated the pain and fatigue level for children to assess the effect of program implementation on their self-care management. This phase took about two months.

2.2.6. Statistical design

The collected data were categorized, analyzed and tabulated using the SPSS (Statistical Package for the Social Science Software) computer program Version 21. Numerical data were expressed as the mean and standard deviation. Qualitative data were expressed as frequency and percentage. A comparison between qualitative variables carried out by using a parametric Chi-square test. A statistically significant difference was considered at p-value < 0.05, a highly statistically significant difference was considered at p-value < 0.001 and no statistically significant difference was considered at p-value > 0.05.

3. RESULTS

Table (1): Reveals distribution of the studied mothers according to their personal characteristics. It was found that, the mean age of mothers was 34.36 ± 4.05 years, more than one third of them (36.0%) were having preparatory school education, the less than two thirds of them (64.0%) were not working and more than two thirds of them (68.0%) were living in rural residence.

Table (2): Shows distribution of the studied children according to their personal characteristics. It was found that, the mean age of the children was 12.90, 3.15 years, more than half of them (55.0%) were males, more than half of them (53.0%) were in preparatory school and more than half of them (59.0%) were ranked as the first child in the family.

Table (3): Reveals that the illness history of the children with sickle cell anemia and indicated that, all of them (100.0%) had previous hospitalization, tests have been performed to diagnose their condition and perform routine tests. Also, more than two fifth of them (44.0%) taken blood transfusion once time / 3weeks.

Table (4): Elaborates children' knowledge regarding sickle cell anemia pre and post program implementation. It was found that the children' knowledge were improved after implementing the program, the highest increasing was observed at signs and symptoms of sickle cell anemia (19.0%) before the program and reach 95.0% after the program and the lowest at complications of sickle cell anemia (23.0%) before the program to reach (65.0%) after the program, there was a highly statistical significant difference (P<0.001) pre and post program implementation.

Table (5): Reveals the frequency distribution of studied children regarding to pediatric pain coping strategies scale. It is found that, there was a highly statistical significant difference (P<0.001) pre and post program implementation

Table (6): Reveals distribution of the studied children regarding pain assessment scale pre and post program implementation. It was found that the pain level decreased in the studied children post program implementation. Also, there was a highly statistical significant difference (P<0.001) regarding pain scale pre and post program implementation.

Table (7): Shows distribution of studied parents regarding assessment of fatigue scale in pediatric patient aged 7-18 for Parents. It was found that, less than two thirds (61.0%) of the studied children always feel tired in the evening pre program to reach more than two thirds (67.0%) never tiered post the program. More than half (55.0%) always sleep too much pre-program compared with less than two thirds (63.0%) never sleep too much post program. Also, there was a highly statistical significant difference (P<0.001) pre and post program implementation regarding feeling fatigue.

Table (8): Demonstrates distribution of studied children regarding self-care practices to avoid pain and fatigue pre and post program. It was found that there were positive changes of children with sickle cell anemia regarding self-care practices post program than pre-program especially for mouth care from 12.0% pre-program to 83.0% post program, getting rest during activities and balanced diet from 19.0, 20.0% pre-program to 85.0, 86.0% post program. Also, there was a highly statistical significant difference (P<0.001) pre and post program implementation.

Table (9): Shows distribution of the studied children total knowledge regarding sickle cell anemia pre and post program implementation. It was found that nearly two thirds of studied children (65.0%) had poor level of knowledge regarding sickle cell anemia preprogram implementation. While three quarters of them (75.0%) had good level of knowledge post program implementation. In addition, there was a highly statistically significant difference (P<0.001) in children's total knowledge regarding sickle cell anemia pre and post program implementation.

Table (1): Distribution of the studied mothers according to their personal characteristics (n=100).

Items	No	%
Age in years		
25 - <30	22	22.0
30 - <35	39	39.0
35 - <40	38	38.0
40- ≤45	1	1.0
Mean± SD 34.36 ± 4.05		
Marital status		
Married	89	89.0
Widower	11	11.0
Divorced	0	0.0
Educational Level		
Illiterate	19	19.0
Read and Write	0	0.0
Primary	15	15.0
Preparatory	36	36.0
Secondary	19	19.0
University	11	11.0
Job		
Working	36	36.0
Not working	64	**64.0**
Residence		
Urban	32	32.0
Rural	68	**68.0**

Table (2): Distribution of the studied children according to their personal characteristics (n=100).

Items	No	%
Age in years		
9- >12	20	20.0
12- >14	15	15.0
14- >16	41	41.0
16- ≤18	24	24.0
Mean±SD 12.90±3.15		
Gender		
Male	55	55.0
Female	45	45.0
Educational Level		
Primary	18	18.0
Preparatory	53	53.0
Secondary	29	29.0
Birth order of the child in the family		
First	59	59.0
Second	36	36.0

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Third	5	5.0
Consanguinity relation between the father and the mother		
yes	45	45.0
No	55	55.0
Presence of family members relatives suffering from sickle cell anemia		
No	58	58.0
Yes	42	42.0
The relation in case of yes(58)		
Uncles / uncles	40	69.0
Others	18	31.0

Table (3): Distribution of the studied children according to their illness history (n=100).

Items	No	%
Previous hospitalization		
Yes	100	100.0
No	0	0.0
If the answer is yes, why?		
Cause related to the disease	94	94.0
Cause not related to the disease	6	6.0
If the cause is related to the disease, what is it?(94)		
to receive treatment of the disease	94	94.0
to treat the complications of the disease	0	0.0
Investigation have been performed to diagnose the child condition		
Complete blood image	100	100.0
Electrophysiological test of hemoglobin	100	100.0
Routine tests done.		
Complete blood image		
Hemoglobin ratio	100	100.0
Percentage of iron	100	100.0
Functions of liver and kidney	100	100.0
	100	100.0
Number of blood transfusion / weeks.		
Once / 2	24	24.0
Once / 3	44	44.0
Once / 4	32	32.0

Table (4): Distribution of the studied children according to their knowledge regarding sickle cell anemia pre and post program implementation (n=100).

Items	Pre program				Post program				X^2	P-value
	Correct		Incorrect		Correct		Incorrect			
	No	%	No	%	No	%	No	%		
Component of blood	21	21.0	79	79.0	81	81.0	19	19.0	38.44	<0.001**
The main place for the manufacture of blood and blood products	12	12.0	88	88.0	79	79.0	21	21.0	57.76	<0.001**
The function of red blood cells	17	17.0	83	83.0	76	76.0	24	24.0	43.56	<0.001**
Definition of sickle cell anemia	15	15.0	85	85.0	82	82.0	18	18.0	49.00	<0.001**
Causes of sickle cell anemia	15	15.0	85	85.0	86	86.0	14	14.0	51.84	<0.001**
Signs and symptoms of sickle cell anemia	19	19.0	81	81.0	95	95.0	5	5.0	81.00	<0.001**
The main treatment of sickle cell anemia	45	45.0	55	55.0	94	94.0	6	6.0	96.04	<0.001**

Complication of blood transfusion	17	17.0	83	83.0	77	77.0	23	23.0	43.56	<0.001**
Treatment of complication of blood transfusion	24	24.0	76	76.0	80	80.0	20	20.0	27.04	<0.001**
Complications of sickle cell anemia	23	23.0	77	77.0	65	65.0	35	35.0	29.16	<0.001**
Prevention Complications of disease	23	23.0	77	77.0	80	80.0	20	20.0	36.00	<0.001**
Methods of prevention of disease	16	16.0	84	84.0	79	79.0	21	21.0	46.42	<0.001**

****A highly statistical significant at P value <0.001**

Table (5): Distribution of the studied children regarding pediatric pain coping strategies scale pre and post program implementation, (n=100).

Items	Pre program			Post program			X^2	P-value
	Always	Some-times	Never	Always	Some-times	Never		
Cognitive-Instruction								
Tell myself to be brave	0.0	13.0	87.0	59.0	25.0	16.0	54.76	<0.001**
Imagine can make the pain or hurt disappear by myself	0.0	9.0	91.0	59.0	32.0	9.0	76.46	<0.001**
Pretend I don't have any pain or hurt	0.0	12.0	88.0	62.0	18.0	20.0	57.76	<0.001**
Tell myself that it will be all right	0.0	12.0	88.0	32.0	52.0	16.0	57.76	<0.001**
Know that I can do something to make the pain or hurt feel better	0.0	13.0	87.0	78.0	15.0	7.0	90.74	<0.001**
Know that I can ask for something that will make the pain or hurt Feel better	0.0	16.0	84.0	30.0	55.0	15.0	46.24	<0.001**
Pretend that the pain or hurt doesn't hurt as much as it really does	0.0	15.0	85.0	68.0	13.0	19.0	54.62	<0.001**
Problem-Solving								
Ask for medicine	0.0	14.0	86.0	67.0	16.0	17.0	51.84	<0.001**
Take deep breaths	0.0	15.0	85.0	76.0	15.0	9.0	82.46	<0.001**
Sit quiet	0.0	19.0	81.0	71.0	17.0	12.0	64.22	<0.001**
Ask to go to the doctor	0.0	100.0	0.0	72.0	13.0	15.0	67.34	<0.001**
Ask someone to explain to me why I hurt	0.0	12.0	88.0	72.0	14.0	14.0	67.28	<0.001**
Put ice or heat on the sore spots	0.0	15.0	85.0	77.0	12.0	11.0	85.82	<0.001**
Go to sleep until it feels better	0.0	99.0	1.0	72.0	19.0	9.0	96.04	<0.001**

****A highly statistical significant at P value <0.001**

Continue Table (5): Distribution of the studied children regarding pediatric pain coping strategies scale; pre and post program implementation, (n=100).

Items	Pre program			Post program			X^2	P-value
	Always	Some-times	Never	Always	Some-times	Never		
Distraction								
Think about going away on vacation or a trip	0.0	11.0	89.0	68.0	13.0	19.0	60.84	<0.001**
Watch TV	0.0	24.0	76.0	72.0	12.0	16.0	67.52	<0.001**
Play a game	0.0	19.0	81.0	72.0	14.0	14.0	67.28	<0.001**
Eat or drink something	10.0	70.0	20.0	76.0	14.0	10.0	96.04	<0.001**
Try not to think about the	0.0	17.0	83.0	64.0	20.0	16.0	43.56	<0.001**

pain or hurt or ignore the pain or hurt								
Think about happy things	0.0	17.0	83.0	69.0	19.0	12.0	57.98	<0.001**
Play with my pet	0.0	21.0	79.0	58.0	20.0	22.0	33.64	<0.001**
Read a book or color in a coloring book	0.0	0.0	100.0	69.0	18.0	13.0	57.62	<0.001**
Talk about what I did today	0.0	8.0	92.0	85.0	15.0	0.0	70.56	<0.001**
Seeks Social Support								
Ask for someone to understand how 1 hurt	0.0	0.0	100.0	31.0	57.0	12.0	96.04	<0.001**
Play with my friends	0.0	1.0	99.0	35.0	50.0	15.0	96.66	<0.001**
Have my mother, father or a friend sit with me	99.0	1.0	0.0	35.0	46.0	19.0	38.44	<0.001**
Tell my mother or father	99.0	1.0	0.0	74.0	17.0	9.0	75.38	<0.001**
Ask to stay by myself	0.0	19.0	81.0	42.0	45.0	13.0	56.44	<0.001**
Cata strophizing/Helplessness								
Cry or yell	1.0	99.0	0.0	29.0	56.0	15.0	96.04	<0.001**
Think it will just get worse	99.0	1.0	0.0	32.0	2.0	66.0	157.44	<0.001**
Wish for it to go away	99.0	1.0	0.0	88.0	12.0	0.0	153.75	<0.001**
Try to be brave and not say anything	0.0	15.0	85.0	60.0	15.0	25.0	83.50	<0.001**
Think that I can't do anything to stop the pain	0.0	13.0	87.0	32.0	54.0	14.0	78.07	<0.001**

****A highly statistical significant at P value <0.001**

Table (6): Distribution of the studied children regarding pain assessment scale pre and post program implementation (n=100).

Pain assessment scale (Numeric Rating Scale)	The studied children (n=100)				X^2	P-value
	Pre program		Post program			
	No	%	No	%		
No Pain**(0)**	0	0.0	21	21.0	36.30	<0.001**
Mild Pain**(1-3)**	23	23.0	48	48.0	30.00	<0.001**
Moderate Pain**(4-6)**	14	14.0	19	19.0	40.82	<0.001**
Severe Pain**(7-10)**	63	63.0	12	12.0	42.33	<0.001**

****A highly statistical significant at P value <0.001**

Table (7): Distribution of studied parents regarding Assessment of Fatigue scale in Pediatric patient aged 7-18 for Parents pre and post program implementation (n=100).

Items	Pre program			Post program			X^2	P-value
	Always	Some-times	Never	Always	Some-times	Never		
Do you think your child how feel for the past week Dimension of General Problems								
He/She feels tired.	28.0	65.0	7.0	20.0	33.0	47.0	61.74	<0.001**
He/She feels tired even if eating.	0.0	19.0	81.0	0.0	6.0	94.0	115.94	<0.001**
He/She feels more tired in the morning.	12.0	11.0	77.0	0.0	1.0	99.0	96.82	<0.001**

He/She feels more tired in the afternoon.	13.0	23.0	64.0	0.0	33.0	67.0	54.82	<0.001**
He/She feels more tired in the evening.	61.0	24.0	15.0	12.0	21.0	67.0	106.94	<0.001**
He/She having trouble get out of bed during the day.	0.0	99.0	1.0	18.0	23.0	59.0	126.04	<0.001**
He/She wants to just lie down rest.	0.0	99.0	1.0	14.0	24.0	62.0	134.14	<0.001**
He/She needs to stop and rest while walking.	1.0	99.0	0.0	21.0	58.0	21.0	123.38	<0.001**
He/She needs help in doing his/her daily work	0.0	100.0	0.0	14.0	65.0	21.0	45.68	<0.001**
He/She feels powerless for do his/her favorite things(play games, spend time with his/her friends and etc.)	20.0	80.0	0.0	19.0	70.0	21.0	98.66	<0.001**
He/She is having trouble starting his/her day job.	54.0	20.0	26.0	20.0	50.0	30.0	33.96	<0.001**
He/She is having trouble finishing his/her daily business.	61.0	21.0	18.0	15.0	46.0	39.0	49.86	<0.001**
He/She needs to rest too much going on.	61.0	21.0	18.0	20.0	48.0	32.0	45.84	<0.001**
He/She doesn't want to do anything.	57.0	20.0	23.0	15.0	48.0	37.0	41.96	<0.001**
He/She feels too tired to deal with the external appearance.	62.0	22.0	16.0	20.0	45.0	35.0	44.66	<0.001**
He/She feels exhausted / sluggish.	66.0	20.0	14.0	25.0	46.0	29.0	43.46	<0.001**
He/She feels sick.	66.0	20.0	14.0	21.0	50.0	29.0	61.46	<0.001**
He/She has had to deal with fatigue during the day.	61.0	24.0	15.0	22.0	49.0	29.0	46.78	<0.001**

****A highly statistical significant at P value <0.001**

Continue Table (7): Distribution of studied parents regarding Assessment of Fatigue scale in Pediatric patient aged 7-18 for Parents pre and post program implementation (n=100).

Items	Pre program			Post program			X^2	P-value
	Always	Some-times	Never	Always	Some-times	Never		
Dimension of Sleep Problems								
He/She sleeps too much.	55.0	24.0	21.0	15.0	22.0	63.0	61.26	<0.001**
He/She wakes up at night consistently.	24.0	43.0	33.0	17.0	37.0	46.0	18.22	>0.05
He/She wakes up tired in the morning.	17.0	50.0	33.0	24.0	17.0	59.0	46.38	<0.001**
He/She needs to sleep during the day (nap).	79.0	1.0	20.0	17.0	34.0	49.0	114.26	<0.001**
He/She is having trouble keeping his/her eyes open.	18.0	64.0	18.0	20.0	19.0	61.0	76.46	<0.001**

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He/She having trouble falling asleep at night.	0.0	1.0	99.0	10.0	29.0	61.0	145.86	<0.001**
Dimension of Treatment problems								
He/She feels tired before treatment.	0.0	0.0	100.0	0.0	0.0	100.0	00.0	>0.05
He/She feels tired during treatment.	40.0	35.0	25.0	10.0	67.0	33.0	53.54	<0.001**
He/She feels tired after treatment.	100.0	0.0	0.0	17.0	63.0	21.0	39.98	<0.001**

****A highly statistical significant at P value <0.001; no statistical significant at P value >0.05**

Table (8): Distribution of studied children regarding children self-care practices to avoid pain and fatigue pre and post program implementation (n=100).

Children self-care practices	Pre-program				Post-program				X^2	P-value
	Yes		No		Yes		No			
	No	%	No	%	No	%	No	%		
Going to sleep early	26	26.0	74	74.0	81	81.0	19	19.0	61.56	<0.001**
Drinking 8 glasses of water or more	100	100.0	0	0.0	100	100.0	0	0.0	0.00	>0.05
Skin care	36	36.0	64	64.0	82	82.0	18	18.0	47.46	<0.001**
Put a plan of daily living activities	19	19.0	81	81.0	85	85.0	15	15.0	87.44	<0.001**
Getting balanced diet	20	20.0	80	80.0	86	86.0	14	14.0	87.88	<0.001**
Mouth care	12	12.0	78	78.0	83	83.0	17	17.0	74.56	<0.001**

****A highly statistical significant at P value <0.001; no statistical significant at P value >0.05**

Table (9): Distribution of the studied children total knowledge regarding sickle cell anemia pre and post program implementation (n=100).

Level of knowledge	Program implementation phases				X^2	P-Value
	Pre program		Post program			
	No	%	No	%		
Good (75-≤100%)	10	10.0	75	**75.0**	126.50	<0.001**
Average (50-<75%)	25	25.0	15	15.0		
Poor (0-<50%)	65	65.0	10	10.0		

****A highly statistical significant at P value <0.001**

4. DISCUSSION

Sickle cell disease (SCD) is the most common genetic disorder of hemoglobin worldwide. The disease is characterized by painful crises due to obstruction of blood vessels; it affects around 100,000 people in the United States and is one of the most common genetic diseases in United States. Occlusive episodes cause complications characteristically associated with SCD such as pain, stroke, aplastic crisis, severe hemolytic anemia, acute chest syndrome and chronic damage to organs; however, pain in the abdomen, chest, lower back and joints are the most common problems reported by SC patients, which are considered the most common causes of referral to emergency departments **(Badawy et al., 2016).**

Regarding the personal characteristics of the studied mothers, the results of the current study showed that, more than one third of them have age between 30-35 years, and have preparatory school and nearly two thirds of them no working. This results were agree with **Hatzmann et al., (2008)**, in a study entitled "Hidden consequences of success in pediatrics: parental

health-related quality of life results from the care project" who reported that more than one third of them have age between 30-35years and have preparatory school and more than two thirds of them no working.

Regarding the personal characteristics of the studied children, the results of the current study showed that, more than two fifth of them have age 12-15 years and more than half of them were males. This result was similar to the result of a study by **Abd El-aal et al., (2015)** in a study entitled "Effect of self-care management program regarding fatigue among adolescents' cancer patients" who reported more than two fifth of the study sample have age 12-15 years and more than half of them were males. This result was similar to the result of a study by **Mohamed et al., (2014),** entitled "Behavioral impact of sickle cell disease in young children with repeated hospitalization", who reported more than half of the study sample were males.

Concerning presence of family members relatives suffering from sickle cell anemia, the current study revealed that, more than half of them were no presence any one of family suffering from this disease. This result agree with **Elise et al., (2017),** in a study entitled "Knowledge attitude and practices of parents with children suffering from sickle cell disease towards factors that precipitate sickle cell crises" who reported that more than half of children no having family history for sickle cell.

Concerning the total knowledge of the studied children regarding sickle cell anemia, the current study showed that, there was nearly two thirds of them had poor knowledge level at pre-program and three quarters had good knowledge level at post program. This findings similar with **Olatona et al., (2012),** in a study entitled "Effects of health education on knowledge and attitude of youth corps members to sickle cell disease and its screening in Lagos state" who found that, more than two thirds of the studied children had poor knowledge level at pre educational intervention and majority of them had good knowledge level at post educational intervention.

Regarding self-care practices of the studied children to deal with fatigue, the present study revealed that there were positive changes of the studied children with sickle cell anemia regarding fatigue post program than pre-program especially for going to sleep early from more than one quarter pre-program to majority of them post program and put a plan of daily activity from nearly of one fifth pre-program to the majority post program. Also, there was a highly statistically significance differences ($P<0.001$) pre and post program for all items. This findings similar with **Abd El aal et al., (2015)** who found in their study that there were positive changes of adolescent patients with cancer regarding fatigue post program than pre-program especially for going to sleep early from more than one quarter pre-program to most of them post program and put a plan of daily activity from nearly of one fifth pre-program to the majority post program post program. Overall the results have statistically significance differences pre and post program for all items. **Speller-Brown et al., (2019)** added that self-care management skills have been linked to improved health outcomes, decrease emergency room utilization and hospital admissions.

Concerning to level of pain ,the present study found that, the level of pain decreased for nearly half of studied children post program and there was a highly statistically significance differences ($P < 0.001$) pre and post program,this finding similar with **Fein et al., (2016),** in a study entitled "Intranasal fentanyl for initial treatment of vaso-occlusive crisis in sickle cell disease" who found in their study,that mean score for frequency and duration of pain decreased significantly after program intervention ($P < 0.001$).

5. CONCLUSIONS

The results suggest the effectiveness of self-management programs on the reduction of pain and fatigue in sickle cell children. Therefore, self-management programs are advisable in order to empower children and assist their management of health-related problems.

6. RECOMMENDATIONS

- The study recommended the importance of educational program for children and families regarding self-care management.

- Illustrated booklet should be distributed at all outpatient clinics for all children with sickle cell anemia and their families regarding disease.

- Physical, emotional, social and school aspects of the life should be considered of care and follow up of sickle cell children and their mothers.

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