

Empowering Mothers to Overcome Sickle Cell Crisis in Their Children through Engagement and Education

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Abstract Background: Sickle cell anemia is a common disease in Saudi Arabia. It causes major crises to children who suffering from it. Empowerment refers to measures designed, to increase autonomy and self-determination through professional support and engagement and empowerment. Mothers education and engagement are critical components of high-quality and early care of children suffering from sickle cell crises (SCC). **Aims:** To empower mothers to manage SCC events experienced by their children. To educate the mothers and engage them in caring for their children and to evaluate the effect of engagement and education on mother's knowledge and performance regarding SCC. **Study design:** A quasi-experimental design was used. Individualized interview and small group teaching with pre and post evaluation was applied. **Setting:** The study was conducted in Pediatric Hematological Department at Maternity and Children Hospital, at Makkah Al-Mukararma. **Subjects:** A purposive sample composed of 40 mothers recruited according to certain inclusion and exclusion criteria. **Tools:** Two tools were used to collect data including, **First:** Interview Questionnaire sheet was used to collect mothers' socio-demographic characteristics. **Second:** empowerment scale, that consisted of 34 items within three construct areas family, services system and community. **Results:** Nearly two thirds of the mothers had poor knowledge regarding SCA pretest compared to one fifth of them posttest. Statistical significant differences regarding was found ($P= 0.00$). Improved mothers' performance was recognized post-test, most of the mothers, always give immunization, and enough oxygen. Three quarters of the mothers offer plenty of fluids to their children. **Conclusion:** Mothers knowledge and performance were improved after education and engagement. Mothers empowerment was very true "post-test" and there was statistical significant difference pre and posttest. There were significant positive correlations between mothers' age and their education, total knowledge, and total performance. **Recommendations:** Empowering and engaging mothers in caring for their children with SCA. Developing educational program for mothers about SCA and SCC.

Keywords: *mothers' empowerment, sickle cell crisis, engagement and education*

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1. Introduction

Empowerment refers to measures designed, to increase autonomy and self-determination in people. It enables individuals to have the ability to act on their own authority, take personal responsibility for their actions and interests thus being able to act autonomously and with self-determination. It can be fostered by appropriate professional interactions and developed by individuals themselves to overcome their lack of influence, sense of powerlessness, and recognize and use their own resources and opportunities. [1] As a concept, it is characterized by moving away from a deficit-oriented towards strength-oriented perception and is increasingly present in educational provision, management disciplines, and the growing cultural promotion of a self-help ethos. [2]

Empowerment comprises three components, namely an interactional element involving an individual's relationship

to their social environment, a behavioral element in which individual's exercise control over their environment and an intrapersonal element involving an individual's beliefs about their perceived capability and self- efficacy. Each component has been identified in studies of maternal empowerment and correlated with the quality of their provision of child care. [3] Research has shown that, the ability to be confident and persistent in the provision of child care in stressful situations is a consequence of empowerment. [4]

The healthy social, emotional, cognitive, and physical development of young children has been shown to be connected with maternal engagement in early care and education as typed by a positive and fulfilling state of mind. [5,6,7] In general, engagement with the health care providers/professionals which are allied to a set of organizational policies designed to ensure a partnership between these parties. [8] The goal of pediatric nurse professional is to engage children and their families "mothers" with a range of interventions that are

appropriate to their clinical context. A consistent application of this strategy is expected to contribute to successful health outcomes, and reduce unnecessary health care costs. [9]

Sickle cell Anemia (SCA) is an inherited autosomal recessive disease inherited from both parents. These children experience higher levels of morbidity and mortality, and a higher incidence of autosomal recessive disorders among their offspring. Sickle cell disease (SCD) reduces the ability of hemoglobin to transport oxygen from the lungs to the bodily tissues by causing some of red blood cells to change from an approximately spherical shape to a rigid crescent shape. These abnormal cells then tend to block blood vessels leading to reduced efficacy of oxygen transmission around the body, pain and damage to organs. [10]

Sickle cell disease is a common disease present throughout Saudi Arabia, with provincial rates of occurrence of a proximately 0.170 (Qatif) , 0.103 (Gizan), 0.025 (Makkah) and 0.081 (Alula). In Khober, the disease was detected in 108 of 45.682 children and adolescent [10,11].

Consanguinity marriages in Saudi Arabia for social reasons and /or to retain property within families are thought to explain more than 50% of occurrences, particularly marriages between first cousins (40% to 50%). Offspring from consanguinity marriage tend to have higher morbidity, higher mortality and a higher incidence of autosomal recessive disorders. [12,13]

The major manifestations of SCA. include fatigue, severe pain, dactylitis (swelling and inflammation of the hands and/or feet), arthritis, and bacterial infections, splenic sequestration (sudden pooling of blood in the spleen and liver), lung congestion, injuries to the heart, leg ulcers, a sepsis and bone infarction leading to the death of portions of bone [14,15].

Episodes of severe pain in children with SCA often require hospitalization and limit their daily activities. Pain 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 [16,17]. 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 SCC occurs [18].

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. [18,19] Nursing intervention for acute pain related to tissue hypoxia includes elevating and supporting swollen joints and teaching the patients techniques for easing pain such as relaxation, distraction and breathing exercises. When the pain has subsided, the role of the nurse is to implement measures to preserve function, for example, physical therapy, transcutaneous nerve stimulation and monitor the patients for signs of infection. And dehydration. [20,21] The failure to manage symptoms effectively can cause dysfunction within the family and an increasing burden of care and despair. [22,23]

Caring for a child with SCD imposes practical and psychological demands on parents especially mothers.

Health education can empower mothers about how to minimize or prevent situations that can precipitate SCC., for example, keeping children warm, maintaining adequate hydration, by avoidance of stressful situations, and excessive physical activities. [24,25] Empowerment of mothers can be achieved through engagement and education. [26] By this route mothers can be helped to assert control over their children's wellbeing while maintaining their own independence. [27]

1.1. Significance of the Study

Children suffering from SCC require more frequent hospital care. The highest prevalence of SCD in Saudi Arabia is in the Eastern province. [28] Sickle cell diagnosis raises concerns about the affected child's life span. With appropriate clinical management supported by nurses' involvement in learning and education about their children' disease, 95 % of children will live beyond the age of 18. Encouragement emphasizes the importance of good care and creates a positive attitude toward life that can be achieved, in spite of the chronic illness. Empowerment is a necessary component in maintaining health and overcoming illnesses and diseases. It should become an integral component of health care. When mothers gain a better awareness of their children's health issues and take a proactive role in managing their health problems, through education and engaging, high costs of health care will be reduced. [29] Empowerment through engaging and education gives the mothers a sense of power and accountability in children's care, increase their satisfaction, and confidence that may lead to high quality children's care.

1.2. Aim of the Study

The aims of this study were to:

1. Empower mothers to overcome Sickle Cell Crises manage SCC events experienced by their children.
2. Educate the mothers and engage them in caring of their children suffering from Sickle Cell Crises.
3. Evaluate the effect of engagement and education on mother's knowledge and performance regarding their children with sickle cell crisis.

1.3. Hypothesis

1. Empowering mothers have a profound impact on the management of children with SCC.
2. Education and engaging have a positive effect on mothers' knowledge and performance regarding SCC.

2. Subjects and Methods

A. Research Design: It was a quasi-Experimental study design.

B. Research settings: The study was conducted in Pediatric Hematological Department at Maternity and Children Hospital, at Makkah Al-Mukararma.

C. Research Subjects: A purposive sample composed of 40 mothers of children suffering from SCC coming to

the previously mentioned setting, under the following inclusive and exclusive criteria:

- **Inclusive Criteria:** Mothers of school age Children ages from (6-12 years).
- **Exclusive Criteria:** Mothers of children with SCA associated with other disease (ex. thalassemia ...)

D. Tools of Data Collection:

Two tools were designed by the researcher to collect the necessary data which include:

1. Interviewing Questionnaire: It was designed by the researcher to collect socio-demographic characteristics and mothers' knowledge regarding SCA and SCC. It was consisted of two parts:

- **First part: Mothers' socio demographic questionnaire:** Used to assess mothers socio-demographic characteristics including their age, marital status, employment, educational level, etc.
- **Second part: Interview mothers' knowledge questionnaire sheets:** This part was used as a pre and post education test for all mothers. It includes two sections:
 - **First:** mothers knowledge regarding SCA. and SSC, including definition, signs and symptoms, causes of crisis, risk factors, medical treatment, health education, and health prevention for SSC in children.
 - **Second:** mothers knowledge regarding actions taken to overcome SCC., including giving immunization, plenty of fluids, enough oxygenetc.

Scoring system: Total number of questions was 20 equal (100%).

- Good knowledge was considered at > 70%.
- Average knowledge ranged between 50 - >70%.
- Poor knowledge was reported for < 50%.

2. The second tool was family empowerment scale:

The scale was originally performed by Koren, DeChillo, & Friesen (1992) and revised by the behavioral and developmental services: children's quality improvement, (2008). [30,31] It was Five point likert scale and was summarized in the current research, into three points Likert scale to be easy to use by the mothers, Not at all true (1), somewhat true (2) and very true (3) for ease applicability. The researcher adapted the scale, translated it into Arabic language and summarized it. The tool was consisted of 34 items within three construct areas family (12 statements), service system (12 statements) and community/political area (10 statements). The tool was tested for validity and reliability pre conduction the study.

2.1. Scoring System

A score of each area, is the sum of the item responses. The higher score indicates relatively more empowerment in each area. To obtain a score for each area, sum the item responses and scored in the same direction, higher. [22]

2.1.1. Scoring of Family or Services System Subscale

Each subscale "Family and services" consisted of 12 statements with total score of 36

- Low empowerment ranged between 1 – 17
- Moderate empowerment ranged between 18 – 26

- Higher empowerment ranged between 27 – 36

2.1.2. Scoring of Community/Political Subscale

Community subscale consisted of 10 statements with total score of 30

- Low empowerment ranged between 1 – 14
- Moderate empowerment ranged between 15 – 22
- Higher empowerment ranged between 23 – 30.

2.2. Validity and Reliability

Literature review using available textbooks, journals, articles, and magazines was used to gather enough information from the national and international references, related to the research problem. The tools of data collection were adapted, translated, modified by the researcher and tested for validity by 5 experts in the field of Pediatric nursing. Test of reliability was also done using chronpach alpha it was 0.712 for the questionnaire and 0.750 for empowerment scale.

2.3. Pilot Study

It was carried out on 10% of the study subjects to test the clarity, validity and reliability of the study tools. The subjects involved in the pilot study was excluded from the study and the necessary modifications were done according to the pilot study "as mentioned before in the second tool".

2.4. Procedures of the Study

Official permission was obtained from the directors of the study setting. Oral consent was obtained from the mothers before their inclusion in the study. Data collection from the beginning of December to the end of April 2015, for five months. The data was collected throughout three phases of assessment.

- **First Phase (Assessment phase):** was done prior to conducting education to the mothers. Mothers' demographic data was obtained at this phase through individualized interview. Knowledge and performance regarding SSA and SSC was also done at this phase (a pretest) using the first tool "part 1&2". Mothers' empowerment was assessed at this phase using the second. Time spent in conducting this phase was ranged between 20-30 minutes.
- **Second Phase (implementation phase):** was done to implement educational guidelines. It was applied for mothers through 4 sessions one session / week which lasted between 20- 30 minutes. **In the first session** the researcher discussed the definition of SCA, causes and precipitated factors of SCC, **second session** include clinical manifestations of SCA / SCC and complications of SCC. **The third session** include management of SCC and health teaching for the mothers about how to prevent SCC. **The fourth session** includes summary and revision of the main items of the educational guidelines.

The researcher use different methods of teaching such as lecture, and small group discussion. Different media was also used for example, illustrative pictures, and videos.

Guidance booklet was designed by the researcher and given to the mothers to illustrate essential information about SSC prevention. It was designed in a suitable manner as a guidance for mothers.

- **The third phase (Evaluation phase) include posttest:** the researcher evaluated the effect of education on mothers knowledge, and actions taken to overcome SCC one week after education. Empowerment was also tested at this phase using the second tool.

2.5. Ethical Considerations

Permission was obtained and the aims of the study were explained to the participants accordingly. Mothers' participation was voluntary and all information were coded and confidentiality was considered. The mothers were informed that they have the right to withdraw from the study at any point.

2.6. Statistical Analysis

The collected data were revised, tabulated and analyzed by using the SPSS package Version (15). Descriptive statistics using numbers and percentage, appropriate statistical tests as, simple frequency, mean and SD, Chi- square (χ^2), P-Value, and correlations were used to estimate the statistical significant differences.

3. Results

Figure 1 & Figure 2 shows distribution of the mothers according to socio-demographic characteristics. It was regarded that, half of the mothers (50%) aged from 35 - < 45 years and 37% of them, their age ranged between 25 - < 35 years with a mean age of 21.66 ± 2.54 (Figure 1). As seen in Figure 2, 42% of the mothers were illiterate, 15% of them had intermediate or secondary level of education and 10% of the them had university education.

Regarding to Figure 3, medical reports clarified that, 26% of the children diagnosed as SCA had suffering from

vaso-occlusive crises, and 24% had a plastic crises. Splenic sequestration crises was reported in 45% of the children compared to 5% for acute chest syndrome.

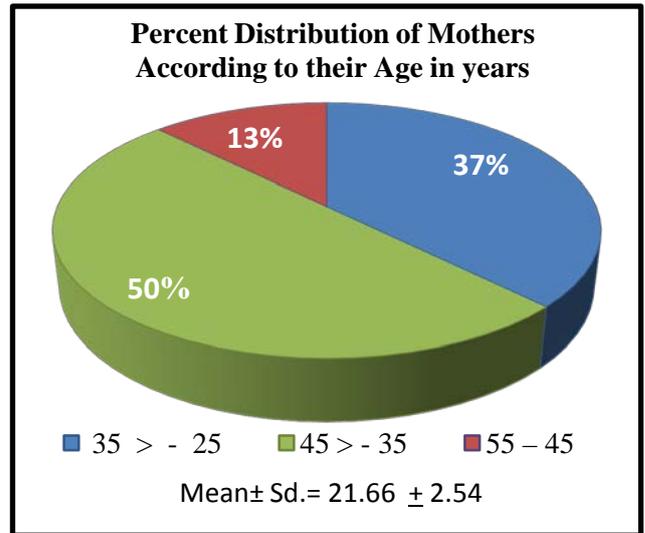


Figure 1.

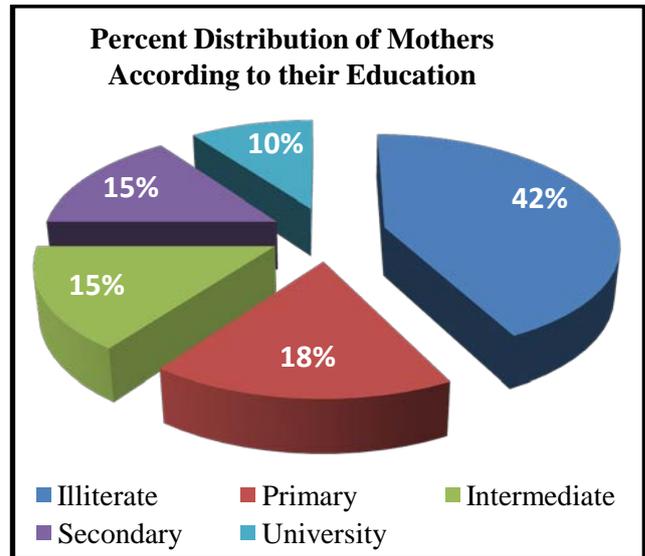


Figure 2.

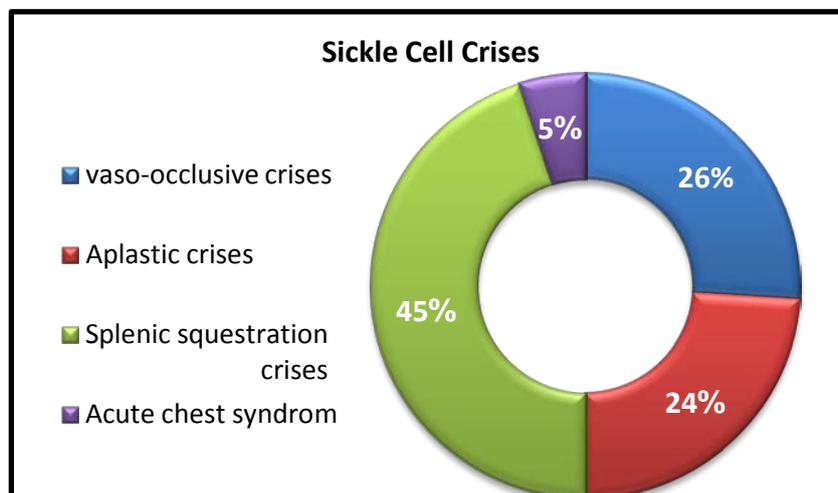


Figure 3. Percent Distribution of children According to Types of Sickle Cell Crises

Mothers knowledge regarding sickle cell crises were illustrated in Table 1. It was clear that, 65% of the mothers had poor knowledge regarding the definition of SCA pretest compared to 20.4% of them posttest. Poor knowledge regarding causes and complication of sickle cell anemia was found in 47.5% and 57.5% of the mothers respectively pretest, while the percentage was decreased posttest, it was 16.2% for causes and 25.7% for complications. Statistical significant differences regarding definition, causes and complications pre and posttest were found (P= .000). Few percentage of the mothers (7.5%) reported good knowledge regarding treatment and prevention of SCC pretest compared to 39.7% and 37.3% respectively posttest, and statistical significance was found for treatment (P=.013) and (P=.000) for prevention. Poor total knowledge regarding SCA was reported by more than half of the mothers (55%) pretest compared to 13.5% of them posttest and there was statistical significant differences regarding mothers' total knowledge (P=.000).

Mothers knowledge regarding precipitating factors was illustrated in Table 2. It was found that, the majority of the mothers had poor knowledge pretest. The percentage was 37.5% for fever, 55% for infection and cold, 60% for dehydration, 32.5% for pain and nutritional deficiency. It was evident that, mothers knowledge was improved posttest. Good knowledge regarding precipitating factors was reported by the majority of the mothers, 55% for fever, 40% for pain, 70% cold, 60% dehydration and

57.5% for nutritional deficiency. There were statistical significant differences regarding the predisposing factors pre and posttest (P = ≤ .005).

Table 3 shows, mothers performance to overcome SCC. It was evident that, pretest 50% of mothers always give their children immunization, while the majority of them (82.5% and 62.5%) never gave children enough oxygen and didn't offer their children plenty of fluids respectively. Nearly three quarters of the mothers, (70% and 77.5%) didn't avoid physical activity or emotional stress to their children respectively pretest. Improved mothers' knowledge was recognized post-test. Most of mothers, (62.5%) always give immunization, enough oxygen, and follow up visit to their children. Seventy five percent of the mothers offer plenty of fluids to their children and 55% avoid emotional stress. There were statistical significant differences regarding all mothers actions pre and post-test (P = ≤ .005).

Table 4 shows mothers' empowerment in caring for their children. It was evident that, family empowerment subscale was very true for 15% of the mothers pretest compared to 50% of them post-test and there was statistical significant difference (P=.001). Very true was reported by 20% and 15% of the mothers regarding services system and community /political subcategories of empowerment respectively pre-test. While, it was 65% for services system and 55% for community /political subcategories of empowerment post-test and there were statistical significant differences (P=.000).

Table 1. Percent Distribution of the Mothers According to their Knowledge Regarding Sickle Cell Anemia Pre and Post instructions

Statements	Pre test			Post test			χ^2	p-value
	Poor	Average	Good	Poor	Average	Good		
	%	%	%	%	%	%		
Definition of Sickle cell Anemia	65	22.5	12.5	20.4	38.6	41	34.35	.000*
Causes of Sickle cell Anemia	47.5	12.5	40	16.2	41.2	42.6	59.79	.000*
Signs & symptoms of Sickle cell Anemia	7.5	7.5	85	1.6	2.5	95.9	78.31	.000*
Complications of Sickle cell Anemia	57.5	35	7.5	25.7	33.5	40.8	18.15	.001*
Treatment of SCA	60	32.5	7.5	28.8	31.5	39.7	8.678	.013**
Preventions of crises	70	22.5	7.5	18.4	44.3	37.3	50.95	.000*
Total knowledge	55	22.5	22.5	13.5	44.1	42.4	90.6	.000*

*Significant at .001 level.

**Significant at .05 level.

Table 2. Distribution of the Mothers According to their knowledge regarding precipitating factors of Sickle Cell Crises Pre and Post instructions (no.= 40)

Statements	Pre test			Post test			χ^2	p-value
	Poor	Average	Good	Poor	Average	Good		
	%	%	%	%	%	%		
Fever	37.5	55	7.5	7.5	37.5	55	22.85	.001*
Anemia	27.5	52.5	20	10	42.5	47.5	15.90	.031*
Pain	32.5	30	37.5	5	55	40	15.71	.047*
Infection	55	35	10	12.5	62.5	25	31.85	.000*
Cold	55	32.5	12.5	5	25	70	18.56	.004*
Dehydration	60	27.5	12.5	7.5	32.5	60	18.56	.004*
Nutrition deficiency	32.5	50	17.5	12.5	30	57.5	21.51	.002*

*Significant at .05 level.

Table 3. Percent Distribution of the Mothers According to their Actions to overcome SC crises of their Children Pretest and Posttest (no. = 40)

Statements	Pre test			Post test			χ^2	p-value
	Always	Sometimes	Never	Always	Sometimes	Never		
	%	%	%	%	%	%		
Give Immunization	50	25	25	62.5	25	12.5	5.00	.082
Give enough Oxygen	5	12.5	82.5	62.5	20	17.5	14.45	.001*
offer plenty of fluids	12.5	25	62.5	75	17.5	7.5	9.05	.011*
Follow up visit	25	50	25	62.5	37.5	-	6.65	.036*
Avoid physical activity	5	25	70	30	35	35	24.05	.000*
Avoid emotional stress	12.5	10	77.5	37.5	42.5	20	40.55	.000*
Avoid infection	27.5	30	42.5	55	40	5	7.85	.020
Avoid sun	7.5	17.5	75	35	45	20	24.55	.000*

*Significant at .05 level.

Table 4. Percent Distribution of the Mothers' according to Empowerment Pre and Posttest (no. = 40)

Family empowerment Sub Scales	Pre test			Post test			χ^2	P- Value
	Not at all true	Some what true	Very true	Not at all true	Some what true	Very true		
	%	%	%	%	%	%		
Family	65	20	15	15	35	50	52.67	.001*
Services system	55	25	20	25	10	65	41.2	.000*
Community	60	25	15	20	25	55	76.7	.000*

*Significant at .001 level.

Table 5. Correlation Matrix between Mothers demographic data, total knowledge, total performance and total empowerment

Items		Mothers' age	Mothers' education	Total knowledge "SCA"	Total knowledge "SCC"	Total Actions	Total empowerment
Mothers' age	r	-	-	-	-	-	-
	P	-	-	-	-	-	-
Mothers' education	r	.174	-	-	-	-	-
	P	.000*	-	-	-	-	-
Total knowledge "SCA"	r	.172	.174	-	-	-	-
	P	.000*	.000*	-	-	-	-
Total knowledge "SCC"	r	.229	.118	.206	-	-	-
	P	.000*	.012**	.000**	-	-	-
Total performance	r	.089	.319	.740	.091	-	-
	P	.05**	.000*	.001*	.054	-	-
Total empowerment	r	.021	.278	.034	.181	-.291-	-
	P	.540	.000**	.474	.000**	.000**	-

* Correlation is significant at the 0.001 level.

** Correlation is significant at the 0.05 level.

As regards, [Table 5](#) shows a correlation matrix between mothers demographic data, total knowledge, total performance and total empowerment. It was regarded that, there were significant positive correlations between mothers' age, mothers' education, total knowledge, and total performance. These correlations mean with increase mothers' age there both knowledge and performance increase. Significant positive correlations were also found between mothers' education and total knowledge, total performance and total empowerment. These results reflect that, mothers' education increased the level of knowledge, improve performance and enhance empowerment. Significant correlations between mothers' total empowerment, total knowledge, and total

performance were also found. This was explained as empowerment of mothers to care for their children improve their total knowledge and performance regarding SCC.

4. Discussion

Empowerment enables individuals to act on their own authority, and take personal responsibility for their actions. This can be achieved through engagement and education. Pediatric nurse helps mothers to develop themselves to overcome their lack of influence, sense of powerlessness, and use their own resources and opportunities to care for

their children.⁽¹⁾ Sickle cell disease is common in Saudi Arabia, consanguinity marriages are thought to explain more than 50% of SCA occurrences. [12,13] The aims of the current study were, to empower mothers to overcome SCC, and manage events experienced by their children. Educate the mothers and engaging them in child care and evaluate mother's knowledge and actions taken to care for their children. Mothers engagement and education in the current study helped them to assert control over their children's health, improve their knowledge and actions regarding SCA in general & SCC specifically. Mothers engagement and education help them to maintain autonomy, independence, and self-determination.

In the current study, half of the mothers aged from 35 - < 45 years and more than one thirds of them aged from 25 - < 35 years with a mean age of 21.66 ± 2.54 . These results are congruent with the study Hilda H.(2012) [32] who reported that, nearly one third of her study sample was between 30-40 years. Another study about parental Influence on SCC by Olorunfemi E., et al., (2016) [33] also, is in agreement with the current study, the majority of young adults in their study were between age 25-39 years.

Less than half of the mothers in the present study were low education, while less than one fifth of them had intermediate or secondary level of education and a minority had university education. These results are in accordance with the results of Almutairi F. et al., (2017) [34] who assess mother's knowledge regarding children with SCD. They reported that nearly one fifth of the mothers had high school, and, slightly more than one third of them were illiterate. Another study by Olorunfemi E., et al., (2016) [33] contradict with the results of the current study. They reported that, nearly one fifth of the participants had primary or tertiary education, and nearly two thirds had secondary education. This discrepancy may be due the different nature of societies and variation of educational and cultural level.

Sickle cell crises in the current study revealed that, nearly one quarter of the children suffering from vaso-occlusive crises "VOC" or a plastic crises and less than half of the children had splenic sequestration crises compared to a minority of children who suffered from acute chest syndrome (Figure). These results are in agreement with the study of Finkelstein Y et al., (2007) [35] who reported that, most of the children in their study presented to the emergency department for painful VOC and developed acute chest syndrome. Another studies conducted by Buchanan ID, et al., (2005) [36] and, Lewing 2011 [37] are also, consistent with the current results, they found that most of the children aged in their study suffering from VOC. They reported that, the incidence of Vaso occlusive crises and acute chest syndrome in patients presenting to hospital with a painful sickle cell episode were less than one third of the children suffering from SCC.

The current study revealed that, more than two thirds of the mothers had poor knowledge regarding the definition of SCA (pretest) compared two fifth of them who had average to good knowledge respectively (posttest Table 1). These results are in agreement with the study of Jaffer E.D. et al., (2009) who studied patients' knowledge and attitude toward the preventive measures of SCC. They reported

that, slightly less than three quarters of the respondents were able to define SCC correctly while, one quarter was defined it wrongly [38].

Poor knowledge regarding causes and complications of SCA was found in nearly half of the mothers pretest, while, less than half of them had good knowledge about causes and complications posttest. Good knowledge regarding treatment of SCA and prevention of SCC were reported by two fifth of the mothers posttest compared to a minority of them pretest. The majority of mothers had good knowledge regarding signs and symptoms pre and posttest. These results are in agreement with the study of Olorunfemi E., et al., (2016) [33] who reported that, two fifth of the participants had adequate knowledge of SCD, three quarters on prevention of crisis and nearly two thirds on predisposing factors to sickle cell crisis.

The findings of the current study revealed poor to moderate knowledge regarding causes of SCC pretest. This improved to good knowledge posttest assessment. The highest percentage was reported for cold, dehydration, nutritional deficiency and fever while, the least percentage of the mothers mentioned that, most of the known predisposing factors was infection (Table 2). These results are consistent with the study of Hussain R.et al., (2011) [39] who mentioned that nearly one third of the respondents reported cold and dehydration as predisposing factors while the minority of them reported fever and activities as predisposing factors. [32] Another studies done by Jaffer et al., (2009) [38] support the findings of the current study. They established that knowledge of cold, fever, exhaustion, vomiting and diarrhea were the leading predisposing factors to SC crises.

Pretest half of the mothers overcome SC crises for their children by giving immunization but less than one fifth of them were giving plenty of fluids. Nearly three quarters of the mothers never discouraged physical activity or attempted to avoid emotional stress to their children. The actions carried out by the mothers were improved after engagement and education. Post-test, three quarters of the mothers offering plenty of, followed by immunization, giving enough oxygen, and two thirds of them planning for follow up visit. The least prevented measures reported by one third of the mothers were avoidance of physical activity and emotional stress. This can be explained by the growth nature of children in this age who likes playing and can't be controlled for a long time (Table 3).

The results of the current study to some extent, in agreement with the study of Hussain R.et al., (2011) [39] who reported that, the commonest preventive measures was giving plenty of fluid as stated by less than half of the participants, followed by giving prescribed drug and keeping the child warm. In their study, the least methods used was giving nutritious food. A studies conducted by Bethesda MD., (2002) [40] & Wethers DL. (2000) [41], are contradict with the current study, they reported that, the parents of children with SCD, had good baseline knowledge related to preventing dehydration; avoiding exposure to severe cold or heat; preventing infections; maintaining nutrition, and getting early medical follow-up for symptoms such as fever; and implementing pain evaluation and management. This contradiction may be due to the differences in the demographic data, lack of education regarding SCD and lack of mothers' awareness.

Mothers' empowerment in caring for their children revealed that, half of the mothers become "very true" empowerment post-test. "Very true" was reported by nearly two thirds of the mothers regarding services system and community/political subcategories of empowerment post-test compared to nearly one fifth of the mothers pretest (Table 4). These results are in agreement with the study of Mahat G (2007) [42], who reported that, empowerment, support groups, and advocacy organization may provide effective ways to improve information and awareness-related activities. He reported that, empowerment should be an important component of effective public health strategies through direct education, counseling, provision of information material, and referral to other.

The findings of the present study revealed significant positive correlations between mothers' age, education, and total knowledge (Table 5). This may be explained as with higher education there were increase in the level of knowledge, improvement in actions and inverse level of empowerment. The current study also, reported statistical significant positive correlations between mothers' total empowerment, total knowledge, and total actions. This was explained as empowerment of mothers to care for children improve their total knowledge and performance regarding SCC.

The previous results are supported by the research conducted by Fahad F., et al., (2017) [42] who reported that, older parents and caretakers had adequate knowledge on prevention of crises compared to younger parents. Another study done by Arrayed and Hajeri (2009) [43] on public awareness of SCD in Bahrain was in agreement with the findings of the current study. They reported that, the majority of older age participants gave more correct answers about SCD. This may be explained as older age mothers are more experienced and knowledgeable about SCD and prevention of crises while younger ones were lack in experience.

In the current study, significant positive correlations were found between mothers' educational level total actions and total empowerment. These can be explained by increased education empowering mothers to be more knowledgeable and act effectively. These findings are supported by Fahad F., et al., (2017) [44] who demonstrated a relationship between the level of knowledge and crises prevention practices. They reported that the majority of the respondents who had adequate knowledge also had positive practices.

5. Conclusion

Sickle cell disease is a common disease in Saudi Arabia, with a high prevalence in the Eastern and Southern regions. Mothers' empowerment to engage in their children's care has been positively related to overall quality of performance and children's care. The current study concluded that, although there were evidences in the literature supporting the findings of the current study, mothers who participated in the present study didn't have the baseline data about SCD before education (pretest). Mothers knowledge and actions regarding SCD and SCC were improved after education and engagement (posttest). There were statistical significant differences regarding

knowledge of predisposing factors ($P = \leq .005$). improvement in mothers empowerment was "very true" after education and there was statistical significant difference pre and posttest. After education, the current research revealed significant positive correlations between mothers' age, their education, total knowledge, and total performance. Significant correlations were also found between mothers' total empowerment, total knowledge, and total performance.

6. Recommendations

1. Empower and engage mothers in caring for their children suffering from SCA.
2. Design and develop an educational program for mothers about SCA and SCC as a protocol inside the hospitals.
3. Engage children in educational sessions to empower them to care for themselves.

References

- [1] Adams, Robert. Empowerment, participation and social work. New York: Palgrave Macmillan, 2008, p.6.
- [2] Zimmerman, M.A. (2000). Empowerment Theory: Psychological, Organizational and Community Levels of Analysis. "Handbook of Community Psychology," 43-63.
- [3] Ebrahimi H., Malek A., Babapoor J., Abdorrahman N., & Empowerment of Mothers in Raising and Caring of Child with Autism Spectrum Disorder, 2013, International Research Journal of Applied and Basic Sciences, www.irjabs.com., Vol, 4 (10): 3109-3113.
- [4] Laschinger, H. K. S., Wilk, P., Cho, J., & Greco, P. (2009). Empowerment, engagement and perceived effectiveness in nursing work environments: Does experience matter? *Journal of Nursing Management*, 17, 636-646.
- [5] Baltimore, MD, McWayne, C., Hampton, V., Fantuzzo, J., Cohen, H.L., & Sekino, Y. (2004). A multivariate examination of parent involvement and the social and academic competencies of urban kindergarten children. Paul H. Brookes Publishing Co. *Psychology in the Schools*, 41(3), 363-377.
- [6] Bakker, A. B., LeBlanc, P. M., & Schaufel, W. B. (2005). Burnout contagion among intensive care nurses. *Journal of Advanced Nursing*, 51 (3), 276-287.
- [7] Laschinger, H. K. S., Wilk, P., Cho, J., & Greco, P. (2009). Empowerment, engagement and perceived effectiveness in nursing work environments: Does experience matter? *Journal of Nursing Management*, 17, 636-646.
- [8] Adapted from Maurer M, Dardess P, Carman, KL, et al. Guide to Patient and Family Engagement: Environmental Scan Report. (Prepared by American Institutes for Research under contract HHSA 290-200-600019). AHRQ Publication No. 12-0042-EF. Rockville, MD: Agency for Healthcare Research and Quality; May 2012.
- [9] Benjamin K. Chu, M.D., 2013, the AHA Committee on Research released Engaging Health Care Users: A Framework for Healthy Individuals and Communities (<http://www.aha.org/research/cor/engaging/index.shtml>).
- [10] Oni L, Dick M., Walters J., & Rees D., A parent's guide to managing sickle cell anemia, 3 rd edition Brent sickle cell & thalassemia center, London.
- [11] Mansour M., Mohammed I., Abdullah S., Alherbish A., Ahmed A., & Al-omar., The Prevalence of Sickle Cell Disease in Saudi children and adolescent, Saudi Med. Journal Volume, 2008; 29(10). 1481-1483.
- [12] Yawn BP, Buchanan GR, Annan AN, et al. (2014). Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members. *JAMA* 312: 1033-1048.
- [13] DeBaun MR (2014) The challenge of creating an evidence-based guideline for sickle cell disease. *JAMA* 312: 1004-1005.

- [14] Julie A., Sylvia T., Cristiane B., Timothy L., Bogdan D., Sandra Sherman-B., Christy B., and James W., PedsQLTM Multidimensional Fatigue Scale in Sickle Cell Disease: Feasibility, Reliability, and Validity., *Pediatric Blood Cancer* 2014; 61: 171-177.
- [15] Valavi E., Ansari M.J. & zandian K., How to Reach Rapis Diagnosis in Sickle cell disease? *Iran J Pediatr*, Mar (2010); 20(1): 69-74.
- [16] Asnani MR, Reid ME., Ali SB, Lipps G, & Williams-Green P., Quality of life in Patients with Sickle Cell Disease in Jamaica: Rural-Urban Differences, *Rural and Remote Health*. 2008; 8: 890: <http://www.rrh.org.au>.
- [17] Panepinto Julie A., Pajewski Nicholas M., Foerster Lisa M., Svapna Sabnis, Raymond G. Hoffmann: 2009: Impact of Family Income and Sickle Cell Disease on the Health-Related Quality of Life of Children. *Qual Life Res* (2009) 18:5-13. Pages from, 9412-8.
- [18] Joshua J, Vichinsky E., & DeBaun M., Overview of the Management and Prognosis of Sickle Cell Disease, Wolters Kluwer, Literature Review Current through: Dec 2014. Available at, <http://www.uptodate.com/contents/overview-of-the-management-and-prognosis-of-sickle-cell-disease>.
- [19] Akohoue SA, Shankar S, Milne GL, et al. Energy Expenditure, Inflammation, and Oxidative Stress in Steady-State Adolescents with Sickle Cell Anemia. *Pediatric Res* 2007; 61:233-8.
- [20] Xandra W., Janneke Hatzmann, Elske E., Johanna H. Marjolein Peters, Karin F., and Martha G. Quality of Life of Female Caregivers of Children with Sickle Cell Disease: a Survey, *Haematological* 2008; 93(4):588-593.
- [21] Palermo, T. M., Schwartz, L., Drotar, D., & McGowan, K. Parental report of Health Related Quality of Life in Children with Sickle Cell Disease, *J Behav Med*. 2002 Jun; 25(3): 269-83.
- [22] Michael RD, Vichinsky E., Behrman RE, Jenson HB, Stanton BF, Hemoglobinopathies In Kliegman , Nelson Textbook of pediatrics. 18th ed. New Delhi: Elsevier Publication; p. 2026. (2008).
- [23] Shanna Lea Gustafson. Knowledge and Health Beliefs of Sickle Cell Disease and Sickle Cell Trait: the Influence on Acceptance of Genetic Screening for Sickle Cell Trait., Master theses, University of Pittsburgh. (2006).
- [24] Hand L. Sickle Cell Treatment Guideline Released. *Medscape Medical News*. Available at <http://www.medscape.com/viewarticle/831603>. Accessed September 14, 2014.
- [25] Kumar S, Powars D, Allen J, & Haywood LJ. Anxiety, Self-concept, Personal and Social Adjustment in Children with Sickle Cell Anemia. *J Pediatr*, 2005; 88: 859-63.
- [26] Sickle Cell Disease Awareness and Education Strategy Development Workshop Report, National Heart, Lung, and Blood Institute. (2008). Sickle cell anemia. Diseases and Conditions. Retrieved from <http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA>.
- [27] Lessing S., Vichinsky E., Parents' handbook of sickle Cell Disease, Children's Hospital – Oakland, California Department of Public Health, Genetic Disease Screening Program; Revised 1998; Revised 2008.
- [28] Jastaniah W (2011). "Epidemiology of sickle cell disease in Saudi Arabia". *Annals of Saudi Medicine*. 31 (3): 289-93.
- [29] Jump up ^ Memish ZA, Saedi MY (2011). "Six-year outcome of the national premarital screening and genetic counseling program for sickle cell disease and β -thalassemia in Saudi Arabia". *Annals of Saudi Medicine*. 31 (3): 229-35.
- [30] Koren, DeChillo, & Friesen, Family Empowerment Scale, Regional Research Institute, Portland State University, Portland.
- [31] Family empowerment scale, Department of behavioral and developmental services: Children's quality improvement assessment data, 2008.
- [32] Hilda H. (2012). Knowledge and practices of parents and caretakers towards prevention of Sickle Cell Crises in Children with Sickle Cell Disease at the University Teaching Hospital (LUSAKA).
- [33] Olorunfemi E. A., Ahmed B. J., and Alabi A. D., (2016). Parental Influence on Sickle Cell Crisis among Patients Attending Secondary Facilities in Abeokuta South Local Government Area, Ogun State, *British Journal of Medicine & Medical Research* 14(9): 1-10, 2016.
- [34] Almutairi F., Almutairi N., Almutairi A., & Almutairi M., (2017). Assess Mother's Knowledge Regarding Their Children With Sickle Cell Disease, *International Journal of Healthcare Sciences*, Vol. 4, Issue 2, pp: (736-739), www.researchpublish.com.
- [35] Finkelstein Y, Schechter T, Garcia-Bourmissen F, et al. Is morphine exposure associated with acute chest syndrome in children with vaso-occlusive crisis of sickle cell disease? A 6-year case-crossover study. *Clinical Therapeutics*. 2007; 29: 2738-43.
- [36] Buchanan ID, Woodward M, Reed GW. Opioid selection during sickle cell pain crisis and its impact on the development of acute chest syndrome. *Pediatric Blood & Cancer*. 2005; 45: 716-24.
- [37] Lewing K, Britton K, Debaun M, et al. The impact of parenteral narcotic choice in the development of acute chest syndrome in sickle cell disease. *Journal of Pediatric Hematology/Oncology*. 2011; 33: 255-60.
- [38] Jaffer E.D. and Amrallah KF., Ali MK., Mohammed An., Hasan AR., & Humood MZ., (2009). Adult Sickle Cell Disease Patients' knowledge and Attitude toward the Preventive Measures of Sickle Cell Disease Crises. Available online <http://www.academicjournal.org/ijnm@2009AcademiaJournal>. Accessed on 8/7/2011.
- [39] Hussain R. Yusuf, MD., Michele A. & Lloyd-Puryear., Sickle Cell Disease The Need for a Public Health Agenda., *American Journal of Preventive Medicine*, 2011;41(6S4): S376-S383) Published by Elsevier Inc.
- [40] Bethesda MD., (2002). The management of sickle cell disease. 4th ed., National Heart, Lung, and Blood Institute, Division of Blood Diseases and Resources, NIH Publication No. 02-2117, 2002.
- [41] Wethers DL. Sickle cell disease in childhood: part I. laboratory diagnosis, pathophysiology, and health maintenance. *Am Fam Physician*, 2000; 62: 1013-20.
- [42] Mahat G, Scoloveno MA, Donnelly CB. Written educational materials for families of chronically ill children. *J Am Acad Nurse Pract* 2007; 19: 471-6.
- [43] Arrayed S, A & Hajeri A., A. (2009). Public Awareness of SCD in Bahrain, Available at <http://www.ned.nlm.nih.gov/sites/entrez?cmd=search&PubMed&term>. Accessed on 25/01/2012.
- [44] Fahad F. A., Naif F. A., Albandari F. A., Almutairi M., (2017), Assess Mother's Knowledge Regarding Their Children With Sickle Cell Disease., *International Journal of Healthcare Sciences*, Available at: www.researchpublish.com.