Assessment of Family Empowerment in the Care of Patients with Sickle Cell disease in Siwa Oasis

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Abstract

Background: *Sickle-cell disease is a broad term that refers to a variety of diseases. The majority of those affected have chronic anemia, with a hemoglobin level of roughly 8 g/dl. The major issues emerge from red blood cells' tendency to become sickle-shaped and obstruct capillaries when oxygen tension is low, using patterns such as family-centered empowerment can be effectively promoting individual self-care behaviors. Family empowerment improves knowledge and attitudes, leading to improved performance and quality of care, improved self-care, accelerated patient recovery, and reduced complications of disease.* ***Objective:*** *This study aimed to assess the Family empowerment in the care of patients with sickle cell disease in Siwa Oasis.* ***Settings:*** *The study was conducted at the outpatient clinic provides a lot of services for patient with sickle cell disease such as (lab investigation , blood trance fusion and control pain crisis) at Siwa General Hospital which is the only hospital at siwa oasis which serve about 30000 citizens* ***Subjects:*** *the data was collected from (112) caregivers in caring with patients suffering from Sickle cell disease treated in the previously mentioned setting.* ***Tools:*** *two tools were used, family structured interview including; Socio-demographic Characteristics questionnaire, and Health profile, and Family empowerment scale (FES)* ***Results:*** *More than half of the studied families had "**high**" level of family empowerment . More than quarter of the studied families had "**moderate**" level of family empowerment .and the minority of them had "**low**" level of family empowerment .There were statistical significant differences between level of empowerment and their age, gender, level of education, and place of residence.* ***Conclusion****: The present study concluded that the level of empowerment affected by the level of education, availability of resources, severity of the disease, and the onset of the disease also the level to which extent this families have been empowered .* ***Recommendations:*** *Creating an integrated system to support people with sickle cell anemia by providing specialists, treatments and necessary examinations .*

Keywords: Family Empowerment, Sickle Cell disease, Siwa Oasis.

Introduction

Sickle-cell disease (also known as sickle-cell disorder or sickle-cell anemia) is a common hereditary ailment caused by a hemoglobin abnormality, which is caused by both parents inheriting mutant hemoglobin genes. Thalassemia and sickle-cell anemia are two of the most common haemoglobinopathies in the world. Haemoglobinopathies are caused by genes that affect about 5% of the world's population. Each year, around 300,000 babies are born with significant hemoglobin abnormalities, with over 200, 000 cases of sickle-cell anemia in Africa. The global meta-estimate for the birth prevalence of homozygous sickle cell disease was 112 per 100 000 live births with a birth prevalence in Africa of 1125 per 100 000 compared with 43.12 per 100 000 in Europe (Goldsmith et al., 2012; Wastnedge et al., 2018).

Siwa Oasis, near the Libyan border in

Egypt's Western Desert, has a population of about 23,000 people. Siwans is Egypt's most remote oasis community, with its own distinct Berber culture. Siwans are a closed, secretive people who usually marry from family members so they are liable to have genetic diseases, including hemolytic anemia and sickle cell haemoglobinopathy, which affects about 20% of the population. (Moez & Younan, 2016)

The affected children most commonly appear with painful swelling of the hands and/or feet between the ages of 6and18months (hand-foot syndrome) .In addition, survivors may experience frequent and unanticipated severe painful crises, as well as "acute chest syndrome" (pneumonia or pulmonary infarction), bone or joint necrosis, priapism, or renal failure. Simple protective measures, such as prophylactic penicillin injection in childhood, avoiding severe heat or cold and dehydration, and contacting a specialist center as soon as possible, can limit the frequency of problems in most people. If vulnerable infants are identified at birth, these safeguards are most successful. Some individuals require regular blood transfusions and iron chelation therapy due to their severe conditions (Piel et al., 2017).

Sickle-cell disease management entails continuous monitoring of the patient from birth or, in the case of an adult, once the diagnosis of Sickle-cell disease has been made. The major goal of management is to avoid complications and treat disorders on a symptom-by-symptom basis. Following up on a patient's health entails taking precautions to avoid or at the very least make it easier to diagnose particular disease problems (Gesteira et al., 2020).

According to the evidence, involving the family members as a one of Health-care strategies can improve self-efficacy, knowledge of the disease condition, and self-care skills in individuals with chronic conditions. Some research confirms that using family-centered education and using patterns such as family-centered empowerment can be effectively promoting individual self-care behaviors. Family empowerment improves knowledge and attitudes, leading to improved performance and quality of care, improved self-care, accelerated patient recovery, and reduced complications of disease (Arda Sürücü et al., 2018).

In fact, family empowerment is a community based intervention used by nurses to assist families in caring for and providing support to family members with chronic diseases that are seen as the most important element for successful treatment. Nurses as health-care providers must not only examine the characteristics of respondents from the knowledge, attitudes, and health-care skills but also examine the family and cultural characteristics that can influence the health assessments. Nursing interventions are not only given to sick individuals but also families who care for them (Golubović et al., 2021).

Aims of the Study

This study aims to:

- Assess the Family empowerment in the Care of Patients with Sickle Cell disease in Siwa Oasis.

Research Questions

- What is the empowerment level of the family in the care of Patients with Sickle Cell disease in Siwa Oasis?

Materials and Method

Materials

Design:

A descriptive study design will be used to accomplish this study.

Settings:

This study was conducted at the outpatient clinic provides a lot of services for patient with sickle cell disease such as (lab investigation , blood trance fusion and control pain crisis) at Siwa General Hospital which is the only hospital at siwa oasis which serve about 30000 citizens , Siwa oasis is near the Libyan border in Egypt's Western Desert it is one from the eight directorates of Matrouh governorate in Egypt.

Subjects:

One hundred and twelve caregivers in caring with patients suffering from Sickle cell disease treated in the previously mentioned setting were included in the study after fulfilling the following inclusion criteria : The family members (the responsible person) who actively caring for the patients diagnosed with sickle cell disease , the patients almost diagnosed with sickle cell disease after 6 months of birth

Tools: two tools were used for data collection:

Tool 1: Family Structured Interview Schedule:

It was developed by the researcher after reviewing relevant recent literature to collect the required data from the families with patients suffering from Sickle cell disease. It included the following parts.

Part 1 :- Demographic & Socio-Economic Characteristics of the Patients and their Families. This part includes the following;

-Demographic characteristics of patients & family members in caring with them such as age, sex, residency area, marital status...etc.

-Socio- & Economic characteristics of the patients and their families.

It was adopted from Fahmy and El-Sherbini socio-economic scale 1983, which was modified by (El-Gilany et al., 2012). It was used to identify the patients and their families' socioeconomic level. This scale included questions such as educational level, occupation, family income, family size, crowding index … etc.,

The socio-economic level was estimated and scored as follows :-

Socio-economic level	Percentile
Very low	0-21
Low	22-42
Moderate	43-63
High	64-84

Part 2: The Patient's and the Family Member Health Profile:-

This part was used to collect data about the patients and their family member as well including; the past & present medical history, family health history, current complaints, presence of disability, current medications, schedule of follow up.

Tool 2: The adapted Family Empowerment Scale (FES):

The researcher used the adapted Family Empowerment Scale to assess the family level of empowerment in the care of patients with sickle cell disease, this scale was originally developed by(Koren et al., 1992) and revised by the behavioral and developmental services: (Dempsey & Keen, 2008) and then was adapted and used by Abd El-Gawad, 2017 after its translation in to Arabic language (Abd El-Gawad, 2017). In this scale the Family member will be asked to indicates how each statement applies to him or her on a 3 points likert scale ranging from (1) Not true at all to, Somewhat true (2) and Very true (3).

This scale consists of 34 –items, and was grouped into 3 subscales represent empowerment level specific to three different areas or contexts.

-Family context include 12 items such as (I know what to do when problems arise with my patient)

-Service System context include 12 items such as (I feel that I have a right to approve all services my patient receives)

- Community/Political context include 10 items such as (I know how to get agency administrators or legislators to listen to me..).

The scoring System

To obtain a score for each area (subscale), sum the item responses and score in the same following direction.

Scoring of Family context or Services System Subscale. Each subscale "Family and services" consists of 12 statements with total score of 36.

Low empowerment ranged between 12 – 20 points, moderate empowerment ranged between 20– 28 points, higher empowerment ranged between 28 – 36 points

Scoring of Community/Political Subscale. Community/Political subscale consists of 10 statements with total score of 30.

Low empowerment ranged between 10 - 17 points, moderate empowerment ranged between 17 - 22 points, higher empowerment ranged between 23 – 30 points

Scoring of total empowerment scale .

Low empowerment ranged between 34 - 57 points, moderate empowerment ranged between 57 - 78 points, higher empowerment ranged between 78 – 102 points.

Method:

Approval from the Research Ethics Committee of the Faculty of Nursing and Administration of the Faculty of Nursing at Alexandria University was obtained before conducting the study. The participants' names were removed from each tool and all answered tools were analyzed by numerical coding numbers.

Official letter from the Faculty of Nursing was directed to the Directorate of Health in Matrouh governorate to inform them about the study objectives and to take their permission to conduct the study at the selected setting.

The family structured interview schedule tool (tool 1) was developed by the researcher after reviewing the recent literature.

The developed tool was tested for its content validity by five experts in community health nursing field. The validity of the tool was ≥ 0.80 %. Based on their comments, necessary modifications were done.

Reliability of the study tools was tested using Cronbach's alpha coefficient. The tools verified reliability were α = 0.928, 0.957, 0.882, and 0.964, for Family dimension, the services provided to patients with sickle cell anemia dimension, The involvement in the community diminution, and total the scale of family empowerment, respectively, also the practices of family caregivers total were α = (0.880) and (0.817) for the family members' knowledge.

Pilot study was utilized to ensure the clarity and applicability of the tool and identify obstacles and problems that may be encountered during data collection. It was carried out on 10% of the study subject 12 participants. They were randomly chosen and did not include in the study sample. Test re-test reliability was performed after three weeks using the same participants. will not be included in the study sample in order to assure the clarity, applicability and comprehension of the tool and identify obstacles and problems that may be encountered during data collection. Accordingly, the necessary modification will be done.

The researcher explained to the participants the purpose of this study and answered the participants' queries for any clarification. Each participant was interviewed individually to collect data for the study.

Data collection of the study covered a period from 20/5/2022 to 1/12/2022

Data analysis: Data were analyzed using SPSS version 18. Descriptive statistics like frequency, percentage, mean and standard deviation summarized study variables. Chi – square, independent t- test and Z tests were used to compare the study variables. The Pearson correlation and logistic regression were used to examine the relation and influence between the independent and dependent variables.

Ethical Considerations:-

Written informed consent was obtained from every participant included in the study after explanation of the aim of the study and assured them that collected data would be used only for the study purpose.

A witness consent was obtained from illiterate participant after explanation of the study purpose

Confidentiality of data and anonymity of subject were ensured.

The study subjects' privacy were maintained.

The study participants were assured that their participation were completely voluntary and they have the right to withdraw at any time from the study.

Results.

(Table-1) shows the social-demographic characteristics of the studied patients. It was found that 69.6% were less than 10 years old, while about quarter of them (25.0%) were 10 to 20 years old and about (5.4%) More than 30 years with a main age of 8.69±6.10years.

It is clear from the same table that More than half of the studied patients gender (57.1%) were females In addition, about (42.9%) were males The majority of the number of siblings of the studied patients (94.6%) were 5 or less and about (40.2%) were the first in ranking among him siblings

(Table-2) shows the socio-demographic characteristics of the care giver at the studied families . It was found that (5.4%) were less than 30 years old, while about (36.6%) of them were 30-40 years old also about (42.0%) of them were 41-50 years and about (16.1%) More than 50 years old with a main age of 42.48±8.99 years.

It was observed that (96.4%) of the care giver at the studied families were males and about only (3.6%) of them females and (100.0%) of the care giver were married ,the relationship of the care givers with the patients was like that about (95.5%) of them were fathers , (2.7%) of them were mothers and (1.8%) of them were Husband, the majority of the places of residence of the studied families were 82.1% rural.

The table show that only (7.1%) of them have College or higher institute studies , (3.6%) of them have Intermediate Institute studies , near half of them (42.9%) have General secondary education or its equivalent , and the rest was between preparatory or primary education, literacy, or uneducated.

The same table shows the frequency and percentage of social and economic level of the families It turns out that about (37.50%) of this families have low social and economic level , (58.93%) of this families have moderate social and economic level with a very weak percentage of these families have a high social and economic level (3.57%).

(Table-3) shows that the majority of onset of the disease starts more at the age of six months or more after birth (71.42%) .

It was obvious from the table that about 102 from 112 patient have been hospitalized ,and the reasons were related to the disease , 44 out of 112 patients had a current complaint, including Cholesterol disorder(9.09%) , gallstones and an enlarged spleen (4.55%), Kidney failure (4.55%) , Hemoglobin deficiency (11.36%) and the major complain was Pain(70.45%).

It clear from the same table that 41 from 112 patient have an complications related to the disease , Severe pain (29.27%) , Clot (12.20%) , Pus in the bones (4.88%) , Osteoporosis (12.20%) , Enlarged spleen (41.46%). And 84 from 112 patient did not monitoring the health status constantly because Cost, Distance , have no time, Lack of medical service, and Only when necessary, The Current treatment for this patients based on Antimetabolites (Hydra) , antibiotic , analgesics ,and diet supplement (folic acid , L.Carnatine) with some deferments between cases

(Table-4) The services provided to the patients with sickle cell disease in siwa ,as it clear all studied families (100%) say that the provided services was (Diagnosis , lab analysis, blood transfusion, treatment) , but only (8.93%) of them see this services very satisfied , the majority of them (66.07%) say that the services was satisfied, and quarter of them (25.00%) were not satisfied with this services .

the most common problems in caring for patients with sickle cell anemia in Siwa Oasis were (Distance, lack of specialists, difficulty in transporting) (98.21%) of studied families said that .and majority of them(70.91%) suggested to solve these problems that (Providing blood bags, laboratories and raising awareness before marriage), (29.09%) of them suggested that (Providing specialists).

As it clear from this table (71.43%) of the studied families say that there are support group for patients with sickle cell disease in siwa which called (Italian Association and Patient Support Fund) ,(28.57%) of them say that there is no support group for patients with sickle cell disease in siwa.

(graph-1) shows the extent to which this families have empowered to take care of them patients and it is based on three levels (family , the services provided to patients with sickle cell anemia, and the involvement in the community), on the level of the family it turns out that majority of this families (76.79%) have high level of empowerment , About the services provided to patients with sickle cell anemia more than half of this family(57.14%) of them have high level of empowerment, and about the involvement in the community (44.64%) of them have high level of empowerment , and the total of this scale shows that more than half of this families (62.50%) have high level of empowerment , third of them (30.36%) have

moderate level of empowerment and (7.14%) of them have low level of empowerment.

It is clear from**(Table-5)** of the Correlation between the variables and each other that there is a statistically significant relationship between the variables and each other, where the calculated value of (r) ranged between (0.278, 0.664) and this value is greater than the tabular value of (r) at the level of (0.05) (0.01).

It is clear from the **(Table -6)** relationship between empowerment scale and socio demographic data of caregivers, the existence of a relationship was as follows :-

Age (years):- total of the scale of family empowerment (F=3.464) p (o.o5)

Gender:- there isn't relation between gender and total of family empowerment.

level of education:- total of the scale of family empowerment (F=4.787) p (o.o5)

Place of residence, total of the scale of family empowerment (T=2.574) p (o.o5).

Discussion

Sickle cell disease is an autosomal recessive disorder characterized by chronic hemolytic anemia and vaso-occlusive events. It affects approximately 1 in 600 African Americans and is the most common genetic disease in the United States. The disease is caused by an alteration in the structure of hemoglobin, resulting in the production of hemoglobin S (HbS). Clinical manifestations of sickle cell disease are variable and can affect multiple systems, leading to lower life expectancy.(Lobitz et al., 2021) Complications include organ damage, such as cerebrovascular disease and cognitive impairment, as well as damage to the brain, kidneys, lungs, bones, and cardiovascular system. (Proske et al., 2021) Management of pregnant women with sickle cell disease requires a multidisciplinary team approach involving various specialists . Hydroxycarbamide has been shown to reduce morbidity and mortality in patients with sickle cell disease, and new drugs and treatment approaches, such as gene therapy, are currently being tested .

Empowerment is considered as the capacity and ability of an individual to plan and implement transformative actions with a gender perspective, as well as to have control over their lives and resources. (Kinkingninhoun Medagbe et al., 2023) It involves the development of knowledge, skills, attitudes, and the ability to aspire to a different life (Eger et al., 2018) .

The current study showed that about quarter of the studied care givers obtained their information about sickle cell anima either from Publications such as books, posters and brochure the remaining three-quarters receive information from caregivers and their relatives, these could be explained through the result of the present study that nearly half of the mothers and fathers did not obtain a certificate higher than preparatory school and secondary school, these findings were in agreement with a study conducted by (Aboagye et al., 2019; de Sousa Santos et al., 2021) they found that healthcare professionals play a crucial role in providing correct information about the disease and its management.

The findings of the present study indicated that almost majority of families who had patient with sickle cell anima use folk medicine and self-treatment, This finding could be explained in the light of the cultures and beliefs of the oasis , these findings were in agreement with a study conducted by (Tavares et al., 2017) he found that The use of folk medicine can provide a source of succor for individuals in developing countries who rely heavily on traditional medicine due to cultural alignment and affordability issues , On the other hand, the current findings contradicted the finding of (Abat et al., 2017) he found that the active principles in these plants are mostly unidentified, and there is limited scientific data supporting the folkloric claims of these plants.

The current study showed the social and economic level of the families. It was noticed that about One third of the studied families have low social and economic level , These could be explained through the fact that Siwa is an oasis that relies heavily on agriculture and that the education rate is weak, these findings were in agreement with a study conducted by (Quansah, 2022) Insufficient food production, low incomes, and extreme poverty are also common problems in developing countries, which perpetuate malnutrition and poverty

conditions, Furthermore, demographic risk factors such as low maternal age, single motherhood, low parental education, Finally, school-related factors such as school time schedule, resources, school climate, guidance and counselling, and school-parents' relationship can significantly contribute to the academic achievements .

The major treatment for the studied patient was (Hydra, antibiotic ,analgesics ,and folic acid) , These findings were in agreement with a study conducted by (Steinberg, 2020) The most commonly used treatments for sickle cell disease (SCD) include hydroxyurea, erythrocyte transfusion, and hematopoietic stem cell transplantation.

The current study findings illustrated that the major current complaint of studied patients was pain, this could be explained by the fact that pain attacks are the most frequent occurrence for patients with sickle cell anemia, and that the climate of Siwa helps these attacks to occur. these findings were in agreement with a study conducted by (Colombatti et al., 2022) Pain crises in sickle cell disease (SCD) patients can be caused by various factors. The pathophysiology of pain in SCD is complex and involves oxidative stress, vaso-occlusion, ischemia-reperfusion injury, and inflammation .

It was obvious from this study that the history of the sickle cell disease in the family was two thirty, as it is clear also that near to half of this families have a consanguinity between the parents, and about more than quarter of this families not keen to do a pre-marital examination for the rest of the family this leads to an increase in the number of patients with SCD and traits in Siwa oasis these findings were in agreement with a study conducted by (Ahmed et al., 2016; Moez & Younan, 2016) the high frequency of Hb S carriers in the closed Egyptian community (siwa), Additionally, poor quality of life and poor general health have been found to increase the rate of SCD-related emergency department visits, These findings suggest that the genetic predisposition to SCD in the Siwan population, along with factors such as poor quality of life and general health, contribute to the increased number of patients with SCD and traits in Siwa Oasis.

It was obvious that the extent to which this families have empowered to take care of them patients and it is based on three levels (family , the services provided to patients with sickle cell anemia, and the involvement in the community), on the level of the family it turns out that majority of this families have high level of empowerment , About the services provided to patients with sickle cell anemia more than half of this families have high level of empowerment and about the involvement in the community less than half of this families have high level of empowerment, These could be explained through that the nature of the remoteness of the place, the unavailability of services, and even the difficulty of providing them in the near future, the current findings contradicted the finding of (Gesteira et al., 2016; Meier, 2018) Despite these challenges, families play a crucial role in providing care for their children and advocating for their quality of life, Nurses and multi-professional teams can support families by providing guidance, support, and empowering them to seek comprehensive care.

The total of scale of empowerment shows that more than half of this families have high level of empowerment I think that the empowerment could be affected by different factors such as the age of onset of disease ,the attitude of the family , services provided and support groups additionally, The burden of care falls primarily on the family, who must acquire the necessary skills and abilities to care for their children with sickle cell disease Families of children with sickle cell anemia this results were in agree with the results of the study conducted by (Caprini & Motta, 2020; Gesteira et al., 2020) Families of children with sickle cell anemia face various challenges in being empowered in their care. These challenges include a lack of knowledge about the disease before diagnosis, limited support from spouses, fear of losing their children, and a lack of social aid and support, Additionally, families may struggle with managing the psychological impact of the disease, such as disease-related stress, coping with anxiety and depression, and maintaining family functioning.

Conclusion

According to the findings of the present study, it can be concluded that More than half of the studied families had "high" level of family empowerment . More than quarter of the studied families had "moderate" level of family empowerment .and the minority of them had "low" level of family empowerment .and the level of empowerment based on the level of knowledge and reported practices for this families so we found that. Less than half of the studied caregivers had "average" knowledge scores related to the sickle cell anemia . Half of the studied caregivers had "poor" knowledge scores related to the sickle cell anima. The majority of caregivers had "satisfactory" level of reported practices to deal with patients with sickle cell anemia .There were statistical significant differences between caregivers' total knowledge, reported practices and empowerment and their age, gender, level of education, and place of residence.

There were significant positive correlations between caregivers' sociodimographic status, total knowledge scores, and reported practices with total of empowerment score .

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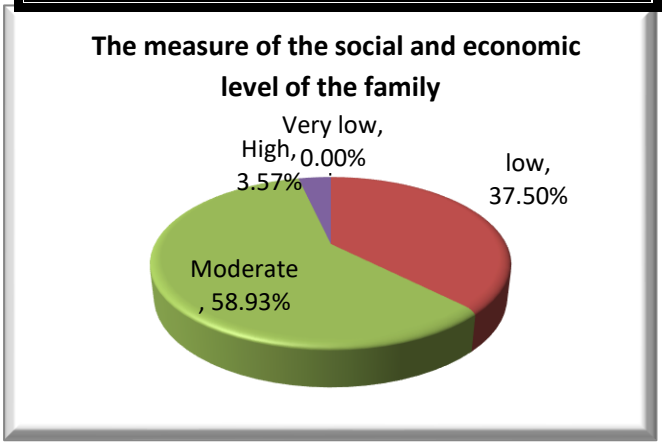
Recommendations

Based on the current study findings, the following recommendations are suggested:

- Health teaching sessions about healthy diet for patient with SCD.
- Health care providers in different health care settings should provide caregivers with updated simplified Arabic handouts, brochures, pamphlets, and booklets about SCD to improve caregivers' and their families' awareness.
- A hot-line telephone concerned with answering mothers' questions about weaning practices should be established and advertised through all mass media.
- Mass media should emphasize the physical, psychological, and social needs of patient with SCD and their families to raise society's awareness regarding this disease.
- Creating an integrated system to support people with sickle cell anemia by providing specialists, treatments and necessary examinations

(Table -1) Distribution of the study subjects according to their Sociodemographic data:

Sociodemographic data	Frequency (N=112)	Percent
Patient demographic characteristics		
Age (years)		
▪ Less than 10 years	78	69.6
▪ 10-20 years	28	25.0
▪ More than 30 years	6	5.4
▪ Min- Max	1.50-36.00	
▪ Mean ± SD	8.69±6.10	
Gender		
▪ Male	48	42.9
▪ Female	64	57.1
Number of siblings		
▪ 5 or less	106	94.6
▪ More than 5	6	5.4
Ranking among his siblings		
▪ First	45	40.2
▪ Second	13	11.6
▪ Middle	4	3.6
▪ before Last	26	23.2
▪ Last	24	21.4



(Table -2) Distribution of the care givers according to their Sociodemographic data

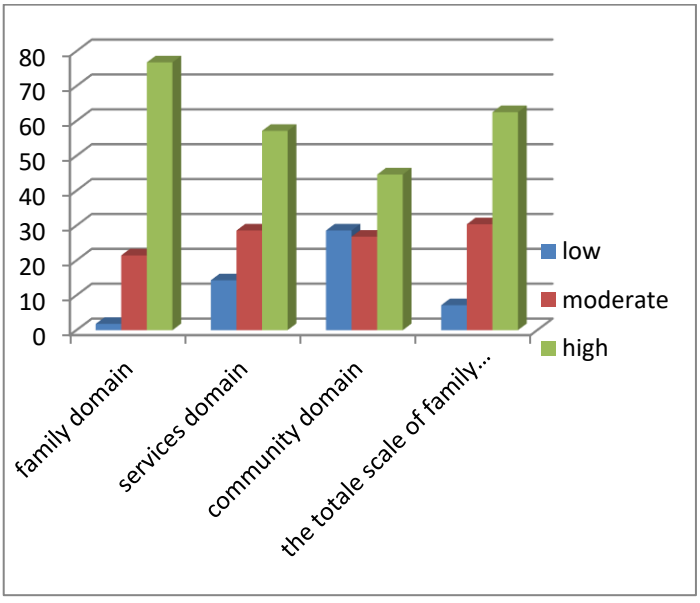
caregivers demographic characteristics	Frequency	Percent
Age (years)		
▪ Less than 30 years	6	5.4
▪ 30-40 years	41	36.6
▪ 41-50 years	47	42.0
▪ More than 50 years	18	16.1
Min- Max	27.00-64.00	
Mean ± SD	42.48±8.99	
Gender		
▪ Male	108	96.4
▪ Female	4	3.6
marital status		
▪ Married	112	100.0
Level of education		
▪ Un educated	6	5.4
▪ Reade and write	16	14.3
▪ Primary education	14	12.5
▪ preparatory education	12	10.7
▪ General secondary education or its equivalent	48	42.9
▪ Intermediate Institute	4	3.6
▪ College or higher institute	8	7.1
Place of residence		
▪ Urban	20	17.9
▪ Rural	92	82.1
the relationship with the patient		
▪ Father	106	95.5
▪ Mother	4	2.7
▪ Husband	2	1.8
measure of the social and economic level of the family		
▪ low	42	37.50
▪ Moderate	66	58.93
▪ High	4	3.57

Table -3 health profile of the subject:-

The health status of the patient	(N=112)	
	Frequency	Percent
The onset of the disease		
▪ Before 6 months after birth.	32	28.57
▪ 6 months or more after birth.	80	71.42
Previous hospitalization .		
▪ A reason related to the disease	112	100.00
▪ A reason not related to the disease	0	0.00
The current health complaints		
▪ Have no complaints	68	60,71
▪ Have complaints	44	39,28
The types complaints		
▪ Pain	35	79.54
▪ Hemoglobin deficiency	5	11.36
▪ Cholesterol disorder	4	9.09
The current health complications		
▪ Have no complications	71	63,39
▪ Have complications	41	36.60
The types complications		
▪ Enlarged spleen	20	48.78
▪ Clot	8	19.51
▪ Osteoporosis	6	14.63
▪ Kidney failure	5	12.19
▪ Pus in the bones	2	4.88
Current treatment		
▪ Antibiotic ,analgesics ,and, diet supplement (folic acid , L.Carnatine)	27	24.55
▪ Antimetabolites (Hydra) , antibiotic , analgesics ,and diet supplement (folic acid)	62	56.36%
▪ Antimetabolites (Hydra) , diet supplement (folic acid , L.Carnatine), antibiotic , and analgesics .	21	19.09%
Regular follow up		
▪ Doesn't follow up regularly	28	25,0
▪ follow up regularly	84	75,0
The reason for not following up regularly		
▪ Cost	26	30.95
▪ Distance and cost	12	14.29
▪ Have no time	8	9.52
▪ Lack of medical service	14	16.67
▪ Do it only when necessary	24	28.57

(Table -4): Distribution of the study subjects according to the services provided to the patients

the services provided to the patients with sickle cell disease in siwa .	(N=112)	
	Frequency	Percent
The services provided to patients with sickle cell anemia in Siwa		
▪ Diagnosis , lab analysis, blood transfusion, treatment	112	100.00%
The satisfaction about the services provided ?		
▪ Not satisfied	28	25.00%
▪ Satisfied	74	66.07%
▪ very satisfied	10	8.93%
The most common problems in caring for patients with sickle cell anemia		
▪ Distance, lack of specialists, difficulty in transporting	110	98.21%
▪ There isn't any problems.	2	1.79%
suggestions to solve these problems		
▪ Providing blood bags, laboratories ar raising awareness before marriage	78	70.91%
▪ Providing specialists	32	29.09%
support groups for anemia patients		
▪ Italian Association and Patient Suppo Fund	80	71.43%
▪ There isn't any support groups	32	28.57%



(Graph -1) Distribution of the study subjects according to the family empowerment levels.

Table (4- 5): Correlation between Variables.

		Socio economic level of the family
Total the scale of family empowerment	R	0.447**
	P	0.00

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

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

⋆ Pearson correlation test

Table (4-6): Relationship between each variables and the socio demographic data (n = 112)

Sociodemographic data	the scale of family empowerment
caregivers demographic characteristics	Mean ± SD.
▪ Age (years)	
▪ Less than 30 years	79.33±17.56
▪ 30-40 years	79.80±17.24
▪ 41-50 years	85.66±14.24
▪ More than 50 years	70.44±23.51
Test of sig.(p)	F=3.464(0.019)*
Gender	
▪ Male	80.91±18.12
▪ Female	76.00±0.00
Test of sig.(p)	T=0.539(0.591)
Level of education	
▪ Un educated	77.00±9.47
▪ Reade and write	80.00±15.52
▪ Primary educatio	65.71±17.83
▪ preparatory education	77.67±7.85

Sociodemographic data	the scale of family empowerment
caregivers demographic characteristics	Mean ± SD.
▪ General secondary education or its equivalent	82.75±19.45
▪ Intermediate Institu	69.00±0.00
▪ College or higher institute	101.00±0.00
Test of sig.(p)	F=4.787(0.000)*
Place of residence	
▪ Urban	89.80±13.79
▪ Rural	78.76±18.04
Test of sig.(p)	T=2.574(0.011)*

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