بسم الله الرحمن الرحيم

Shandi University

Faculty of Post Graduate And Scientific Research

Department Of Nursing Sciences

Research Title

Mother Awareness Regarding Care Of Child With Sickle Cells Anemia In Jafar ibn auf Hospital Khartoum-Sudan

A Thesis Submitted For Requirement Master Of Science Degree In Pediatric Nursing At The University Of Shandi

Submitted By

Mashaier Mohammedkhair Salih Ali

Bsc kassala university 2015

Supervisor:

Dr: Mariam Mohammed Elnajeeb

Assistance Professor pediatric nursing department- shundi university

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Table of contents

Table of contents

List of tables

List of figure

Appendices

List of abbreviation

HBB	hemoglobin beta gene
IEC	information, education and communication
NIH	national institute of health
SCA	sickle cell anemia
SCC	sickle cell crises
SCT	sickle cell trait
VOC	vaso occlusive crises
WHO	world health organization
GP	general practitioner
RBC	red blood cell

Dedication

This study is dedicated to my family and my husband for their support and encouragement during study.

Abstract:

Sickle cell disease (SCD) is one of the most common inherited disorders of haemoglobin in africa and it is expected that sickle cell trait varies in frequency in different areas in sudan.

Sickle cell criese is most couses of admissioin in jafar ubni uufhospiral, although there is no available cure for sickle cell anemia in sudan ,but the crises can be preventable most of the time .the main objective of the study aimed to examined the mother knowledge and awareness regarding care of child with sickle cells anemia .

This Is A Descriptive Cross-Sectional Hospital Based Study In jafar ubni uuf Hospital, Khartoum Locality, Khartoum State, Sudan from march to april (2018). Simple random sampling method without replacement was used and data was collected using interview schedule from 100 respondents who were mother with children with sickle cell anemia at hematology clinic/ward in jafar ubni uuf hospital. Data was collected ,sorted , coded and entered in SPSS spreadsheet and analyze using SPSS version 21.0.frequncy table ,pie charts and cross tabulation were used for easy understanding .

The study revealed that 8% of the respondents had a good knowledge of SCD, while the majority 50% had fair knowledge of SCD,and42% of the respondents had poor knowledge regarding care if child with SCD.

The study revealed 51% of respondents had fair knowledge of SCC ,while 37% had poor knowledge and 12% of the respondents had good knowledge. The study revealed that there is relationship between the level of education and the

knowledge of SCD the more educated mother have positive practice toward prevention of sickle cell crises.

The study recommended That for Ministry of health Should Ensure That Knowledge Of Sickle Cell Disease And Prevention Of Crises Booklets Are Available And Put Where Mother Will Be Able To Access Them.

ملخص الدراسه

مرض الأنيميا المنجليه هو من اكثر امرض الدم المتوارث جينيا في افريقيا,وايضا منتشر في اماكن متفرقه في السودان ’كما تتعتبر ايضا مضاعفات الانيميا المنجليه من اكثر الحالات الي تتسبب في دخول الطفل المستشفي بالرغم من عدم توفر علاج ناجع للانيميا المنجليه في السودان الا انه يمكن تفادي المضاعفات الناجمه من المرض .

الهدف الاساسي من هذه الدراسه فحص او دراسه معرفه الام وادراكها لرعايه طفلها المصاب بالانيميا المنجليه .

هذه الدراسه وصفيه مقطعيه-مقرها مستشفي جعفر بن عوف التخصصي محليه الخرطوم –ولايه الخرطوم-السودان من مارس الي ابريل2018

تم جمع البيانات عن طرق استبيان بطريقه عشوابيه بسيطه من 100 أم لها طفل مصاب بأنيميا منجليه في مستشفي جعفر بن عوف وحللت البيانات باستخدهم برنامج التحليل الاحصائى(SPSS)

اظهرت الدراسه ان 8% من الأمهات لهن معرفه جيده عن المرض و50%من الأمهات معرفتهن متعادله بينما 42% معرفتهن ضعيفه .

كما اوضحت الدراسه 51% من الامهات معرفتهن متعادله عن مضاعفات الانيميا المنجليه و37% من الامهات معرفتهن ضعيفه بينما12% من الامهات معرفتهن جيده.

كما اظهرت الدراسه ان هناك علاقه بين مستوي تعليم الأم ومعرفتها عن مرض الأنيميا المنجليه.

كما اوصت الدراسه وزاره الصحه بتوفير كتيبات عن مرض الانيميا المنجليه وكيفيه الوقايه من مضاعفاته في المستشفيات واماكن تواجد الامهات ذوي الاطفال المصابين بالانيميا المنجليه وتسهيل فرصه الحصول عليه.

Chapter one

1- Introduction:-

1-1Background

Sickle cell disease (SCD) is one of the most common inherited disorders of haemoglobin in africa and it is expected that sickle cell trait varies in frequency in different areas in sudan. An extensive literature search was carried out accessing the us national library of medicine, the who eastern mediterranean region resources, the catalogue for transmission genetics in arabs and papers and documents published in Sudan that included data on the prevalence of sickle cell anemia and trait. Rates of SCA and trait varied in different areas in Sudan with the highest rates reported from western and eastern sudan where one in every 123 children born in messeryia tribe in western sudan is at risk of having SCD.[1]

Sickle cell disease is an inherited hemolytic anemia that results from homozygous or compound heterozygous inheritance of the sickle haemoglobingene.[2]

sickle haemoglobinopathies have different genotypes. The archetypal sickle cell disease is the haemoglobin disease, otherwise called sickle cell anemia. Other sickle cell disease phenotypes include the compound heterozygous states such as haemoglobinsc disease and haemoglobin s-thalassemia syndromes. [2,3] Haemopoietic stem cell transplantation (HSCT) is the only potentially curative therapy for sickle cell disease.. [3,4].This study aimed to examined the mother knowledge and awareness regarding care of child with SCD in Jafar Ubni uuf hospital khartoum-sudan, among a cross-section study .

The method of this study was an analytic, cross-sectional study among 100 mother different nationality(my groups members) in Jafar ibn auf hospital,kartoum city, Sudan.

1-2-Justification:

Sickle cell disease (SCDS) is a genetic blood disorder affecting red blood cells, with high morbidity and mortality rates. The united nations has recognized SCD as a global public health concern, and the world health organization (WHO) recommends that 50% of member states will have established SCD control programs by 2020 . [7,8]

Because The disease process in SCA causes complications in multiple body organs. Some of the most common morbidities associatedwith SCD include chronic pain and intermittent painful episodes, musculoskeletal problems, stroke, pulmonary hypertension, andsepticemia.So it's imperative to assess mother awareness regarding care of their child with sickle cell anemia.

1-3 Objectives:-

1-3-1 General objective:

This studies aimed to assess the mother knowledge and awareness regarding care of child with sickle cells anemia in jafar ubniuuf hospital khartoum city-sudan

1-3-2 Specific adjectives:

1-To identify mothers knowledge about sickle cells anemia.

2-To assess mothers awareness about care of child with SCA.

3-To assess mothers knowledge about complication of the SCD (crisis).

4- Cross tabulation between the different values of the studies.

Chapter two

2-Literature review:-

2-1 definition:

Sickle-Cell Anemia (Also Known As Sickle-Cell Disorder Or Sickle-Cell Disease) Is A Common Genetic Condition Due To A Hemoglobin Disorder Inheritance Of Mutant Hemoglobin Genes From Both Parents. [8]

Sickle-Cell Disease (**SCD**) Is Group Of Blood Disorders Typically Inherited From A Person's Parents.[9] The Most Common Type Is Known As **Sickle-Cell Anemia** (**SCA**).[9] It Results In An Abnormality In The Oxygen-Carrying Protein Hemoglobin (Hemoglobin S) Found In Red Blood Cells. [9] This Leads To A Rigid, Sickle-Like Shape Under Certain Circumstances. [9]

Sickle Cell Disease (SCD) Is One Of The Most Common Inherited Disorders Of Hemoglobin In Africa And It Is Expected That Sickle Cell Trait Varies In Frequency In Different Areas In Sudan. [10]

Sickle Cell Disease Is An Inherited Hemolytic Anemia That Results From Homozygous Or Compound Heterozygous Inheritance Of The Sickle Haemoglobingene. [11]

Sickle Cell Disease (SCD) Denotes All Genotypes That Contain At Least One Sickle Gene In Which Hemoglobin-S (Hbs) Makes Up At Least Half Of The Hemoglobin Present . [12]

The Aim Of This Study To Assess The Level Of Knowledge And awareness Of Mother Regarding Care Of Child With Sickle Cells Anemia In jafar ubni uuf Hospital .

The Reviewed Literature Was Form Books, Published Article From Journals And Unpublished Articles. This Reviewed Literature Was Discussed According To Dependent And Independent Variables Which Were Knowledge And Practice Mother Towards Care Of Child With Sickle Cells Disease.

Sickle Cells Disease (SCD) Has Recently Been Recognized As Major Public Health Problem By World Health Organization. According To WHO Report (2006). SCD Is Considered As One Of The Most Prevalent Hematology’s Disease World Wide With About300 000 Children Born With Disease Every Year. It Is Found Many Part Of The World With The High Frequency Of The

Disease Among People Ancestry In Malaria Stricken Area. The Tropical Region Particularly Sub-Saharan, African ,Indian , Jamaica And The Middle East. The Geographic Distribution Of The Sickle Cells Trait Is Very Similar To That Of Malaria The Sickle Cells Trait Has Particular Protective Effect Against Malaria And This May Explain Why Sickle Cells Has Been Maintained At Such High Prevalence Level In Tropical Africa. Those Who Inherit The Gene From Both Parents Do Not Have This Protection. In Addition They Suffer From Sever Effect Of SCD And May Die Before Reach Reproductive Age. Despite The Fact That 70% Of Suffers Live In Africa Expenditure On The Related Care And The Reach On The Continent Is Negligible And The Most Advances And Understanding And Management Of This Condition Has Been Based On Research Conducted In The North. (8)

With Regarding Motility, Evidence From Studies Conduction The North, Show That The Highest Of SCD Related Motility Occur In Children Aged Between 6month To 3years The Common Cause Of Death Acute Chest Syndrom,AcutSpleenic Sequestration And Pneumococcal Septicemia. (8) .This Indicate Mother And Communities Need Education About Care Of Child With SCD To Prevent Those Complication.

2-2 Knowledge of Prevalence Of Sickle-Cell Anemia:

About 5% Of The World's Population Carries Genes Responsible For Haemoglobinopathies. Each Year About 300 000 Infants Are Born With Major Hemoglobin Disorders Including More Than 200 000 Cases Of Sickle-Cell Anemia In Africa. Globally, There Are More Carriers Healthy People Who Have Inherited Only One Mutant Gene from One Parent Of Thalassaemia Than Of Sickle-Cell Anemia, But The High Frequency Of The Sickle-Cell Gene In Certain Areas Leads To A High Rate Of Affected Newborns. Sickle-Cell Anemia Is Particularly Common Among People Whose Ancestors Come From Sub-Saharan Africa, India, Saudi Arabia And Mediterranean Countries. Migration Raised The Frequency Of The Gene In The American Continent. In Some Areas Of Sub-Saharan Africa, Up To 2% Of All Children Are Born With The Condition. In Broad Terms, The Prevalence Of The Sickle-Cell Trait (Healthy Carriers Who Have Inherited The Mutant Gene From Only One Parent) Ranges Between 10% And 40% Across Equatorial Africa And Decreases To Between 1% And 2% On The North African Coast And <1% In South Africa. This Distribution Reflects The Fact That Sickle-Cell Trait Confers A Survival Advantage Against Malaria And That Selection Pressure Due To Malaria Has Resulted

In High Frequencies Of The Mutant Gene Especially In Areas Of High Malarial Transmission. In West African Countries Such As Ghana And Nigeria, The Frequency Of The Trait Is 15% To 30% Whereas In Uganda It Shows Marked Tribal Variations, Reaching 45% Among The Baamba Tribe In The West Of The Country. The Sickle-Cell Gene Has Become Common In Africa Because The Sickle-Cell Trait Confers Some Resistance To Falciparum Malaria During A Critical Period Of Early Childhood, Favoring Survival Of The Host And Subsequent Transmission Of The Abnormal Hemoglobin Gene. Although A Single Abnormal Gene May Protect Against Malaria, Inheritance Of Two Abnormal Genes Leads To Sickle-Cell Anemia And Confers No Such Protection, And Malaria Is A Major Cause Of Ill-Health And Death In Children With Sickle-Cell Anemia. There Is Increasing Evidence That Malaria Not Only Influences Outcome But Also Changes The Manifestations Of Sickle-Cell Anemia In Africa. [8]

2-3 Prevalence Of SCA In Sudan:

Sickle Cell Disease (SCD) Is One Of The Most Common Inherited Disorders Of Hemoglobin In Africa And It Is Expected That Sickle Cell Trait Varies In Frequency In Different Areas In Sudan. An Extensive Literature Search Was Carried Out Accessing The Us National Library Of Medicine, The Who Eastern Mediterranean Region Resources, The Catalogue For Transmission Genetics In Arabs And Papers And Documents Published In Sudan That Included Data On The Prevalence Of Sickle Cell Anemia And Trait. Rates Of SCA And Trait Varied In Different Areas In Sudan With The Highest Rates Reported From Western And Eastern Sudan Where One In Every 123 Children Born In Messeryia Tribe In Western Sudan Is At Risk Of Having SCD. High Consanguinity Rates And Malaria Endemicity Are Strong Related Factors With Sickle Cell Gene In Sudan. This Review Will Present What Is Known About The Rates Of Sickle Cell Gene In Different Ethnic Groups In Sudan. [13]

2-4 Signs And Symptoms:

Sickle-Cell Anemia. Sickle-Cells In Human Blood: Both Normal Red Blood Cells And Sickle-Shaped Cells Are Present. Normal Blood Cells Next To A Sickle-Blood Cell, Colored Scanning Electron Microscope Image signs Of Sickle Cell Disease Usually Begin In Early Childhood. The Severity Of Symptoms Can Vary From Person To Person. [14]Sickle-Cell Disease May Lead To Various Acute And Chronic Complications, Several Of Which Have A High Mortality Rate. [15]

2-4-1 Sickle-Cell Crisis:-

The Terms "Sickle-Cell Crisis" Or "Sickling Crisis" May Be Used To Describe Several Independent Acute Conditions Occurring In Patients With SCD. SCD Results In Anemia And Crises That Could Be Of Many Types Including The Vaso-Occlusive Crisis, A plastic Crisis, Sequestration Crisis, Hemolytic Crisis, And Others. Most Episodes Of Sickle-Cell Crises Last Between Five And Seven Days.[16] "Although Infection, Dehydration, And Acidosis (All Of Which Favor Sickling) Can Act As Triggers, In Most Instances, No Predisposing Cause Is Identified. [17]

2-4-2 Vaso-Occlusive Crisis:-

The Vaso-Occlusive Crisis Is Caused By Sickle-Shaped Red Blood Cells That Obstruct Capillaries And Restrict Blood Flow To An Organ Resulting In Ischaemia, Pain, Necrosis, And Often Organ Damage. The Frequency, Severity, And Duration Of These Crises Vary Considerably. Painful Crises Are Treated With Hydration, Analgesics, And Blood Transfusion; Pain Management Requires Opioid Administration At Regular Intervals Until The Crisis Has Settled. For Milder Crises, A Subgroup Of Patients Manage On Nonsteroidal Anti-Inflammatory Drugs (Nsaids) Such As Diclofenac Or Naproxen. For More Severe Crises, Most Patients Require Inpatient Management For Intravenous Opioids; Patient-Controlled Analgesia Devices Are Commonly Used In This Setting. Vaso-Occlusive Crisis Involving Organs Such As The Penis . [18] Or Lungs Are Considered An Emergency And Treated With Red-Blood Cell Transfusions. Incentive Spirometry, A Technique To Encourage Deep Breathing To Minimise The Development Of Atelectasis, Is Recommended .[19]

2-4-3 Splenic Sequestration Crisis:-

Because Of Its Narrow Vessels And Function In Clearing Defective Red Blood Cells, The Spleen Is Frequently Affected. [20] It Is Usually Infarcted Before The End Of Childhood In Individuals Suffering From Sickle-Cell Anemia. This Spleen Damage Increases The Risk Of Infection From Encapsulated Organisms. [21,22]

Preventive Antibiotics And Vaccinations Are Recommended For Those Lacking Proper Spleen Function.Splenic Sequestration Crises Are Acute, Painful Enlargements Of The Spleen, Caused By Intrasplenic Trapping Of Red Cells And Resulting In A Precipitous Fall In Haemoglobin Levels With The Potential For Hypovolemic Shock. Sequestration Crises Are Considered An Emergency. If Not Treated, Patients May Die Within 1–2 Hours Due To Circulatory Failure. Management Is Supportive, Sometimes With Blood Transfusion. These Crises Are Transient, They Continue For 3–4 Hours And May Last For One Day. [23]

2-4-4 Acute Chest Syndrome:-

Acute Chest Syndrome (Acs) Is Defined By At Least Two Of The Following Signs Or Symptoms: Chest Pain, Fever, Pulmonary Infiltrate Or Focal Abnormality, Respiratory Symptoms, Or Hypoxemia.[24]It Is The Second-Most Common Complication And It Accounts For About 25% Of Deaths In Patients With Scd, Majority Of Cases Present With Vaso-Occlusive Crises Then They Develop Acs . [25,26] Nevertheless, About 80% Of Patients Have Vaso-Occlusive Crises During ACS.

2-4-5 Aplastic Crisis:-

Aplastic Crises Are Acute Worsenings Of The Patient's Baseline Anemia, Producing Pale Appearance, Fast Heart Rate, And Fatigue. This Crisis Is Normally Triggered By Parvovirus B19, Which Directly Affects Production Of Red Blood Cells By Invading The Red Cell Precursors And Multiplying In And Destroying The Parvovirus Infection Almost Completely Prevents Red Blood Cell Production For Two To Three Days . [27] In Normal Individuals, This Is Of Little Consequence, But The Shortened Red Cell Life Of Scd Patients Results In An Abrupt, Life-Threatening Situation. Reticulocyte Counts Drop Dramatically During The Disease (Causing Reticulocytopenia), And The Rapid Turnover Of Red Cells Leads To The Drop In Haemoglobin. This Crisis Takes 4 Days To One Week To Disappear. Most Patients Can Be Managed Supportively; Some Need Blood Transfusion . [28]

2-4-6 Haemolytic Crisis:-

Haemolytic Crises Are Acute Accelerated Drops In Haemoglobin Level. The Red Blood Cells Break Down At A Faster Rate. This Is Particularly Common In Patients With Coexistent g6pd Deficiency .[29] Management Is Supportive, Sometimes With Blood Transfusions .[19]

2-4-7 Other:-

One Of The Earliest Clinical Manifestations Is Dactylitis, Presenting As Early As Six Months Of Age, And May Occur In Children With Sickle-Cell Trait.[30] The Crisis Can Last Up To A Month .[31] Another Recognised Type Of Sickle Crisis, Acute Chest Syndrome, Is Characterized By Fever, Chest Pain, Difficulty Breathing, And Pulmonary Infiltrate On A Chest X-Ray. Given That Pneumonia And Sickling In The Lung Can Both Produce These Symptoms, The Patient Is Treated For Both Conditions .[32]It Can Be Triggered By Painful Crisis, Respiratory Infection, Bone-Marrow Embolisation, Or Possibly By Atelectasis, Opiate Administration, Or Surgery, Hematopoietic Ulcers May Also Occur.[33]

2-5 Pathophysiologies:-

Scanning Electron Micrograph Showing A Mixture Of Red Blood Cells, Some With Round Normal Morphology, Some With Mild Sickling Showing Elongation And BendingThe Loss Of Red Blood Cell Elasticity Is Central To The Path physiology Of Sickle-Cell Disease. Normal Red Blood Cells Are Quite Elastic, Which Allows The Cells To Deform To Pass Through Capillaries. In Sickle-Cell Disease, Low Oxygen Tension Promotes Red Blood Cell Sickling And Repeated Episodes Of Sickling Damage The Cell Membrane And Decrease The Cell's Elasticity. These Cells Fail To Return To Normal Shape When Normal Oxygen Tension Is Restored. As A Consequence, These Rigid Blood Cells Are Unable To Deform As They Pass Through Narrow Capillaries, Leading To Vessel Occlusion And Ischaemia .[34]

The Actual Anaemia Of The Illness Is Caused By Haemolysis, The Destruction Of The Red Cells, Because Of Their Shape. Although The Bone Marrow Attempts To Compensate By

Creating New Red Cells, It Does Not Match The Rate Of Destructio] . [34] Healthy Red Blood Cells Typically Function For 90–120 Days, But Sickled Cells Only Last 10–20 Days . [35]

2-6 Diagnosis:-

In Hbs, The Complete Blood Count Reveals Haemoglobin Levels In The Range Of 6–8 G/Dl With A High Reticulocyte Count (As The Bone Marrow Compensates For The Destruction Of Sickled Cells By Producing More Red Blood Cells). In Other Forms Of Sickle-Cell Disease, Hb Levels Tend To Be Higher. A Blood Film May Show Features Of Hyposplenism (Target Cells And Howell-Jolly Bodies).

Sickling Of The Red Blood Cells, On A Blood Film, Can Be Induced By The Addition Of Sodium Metabisulfite. The Presence Of Sickle Haemoglobin Can Also Be Demonstrated With The "Sickle Solubility Test". A Mixture Of Haemoglobin S (Hb S) In A Reducing Solution (Such As Sodium Dithionite) Gives A Turbid Appearance, Whereas Normal Hb Gives A Clear Solution. [36]

Abnormal Haemoglobin Forms Can Be Detected On Haemoglobin Electrophoresis, A Form Of Gel Electrophoresis On Which The Various Types Of Haemoglobin Move At Varying Speeds. Sickle-Cell Haemoglobin (Hgbs) And Haemoglobin C With Sickling (Hgbsc)—The Two Most Common Forms—Can Be Identified From There. The Diagnosis Can Be Confirmed With High-Performance Liquid Chromatography. Genetic Testing Is Rarely Performed, As Other Investigations Are Highly Specific For Hbs And Hbc . [36]

An Acute Sickle-Cell Crisis Is Often Precipitated By Infection. Therefore, A Urinalysis To Detect An Occult Urinary Tract Infection, And Chest X-Ray To Look For Occult Pneumonia Should Be Routinely Performed . [37]

People Who Are Known Carriers Of The Disease Often Undergo Genetic Counseling Before They Have A Child. A Test To See If An Unborn Child Has The Disease Takes Either A Blood Sample From The Fetus Or A Sample Of Amniotic Fluid. Since Taking A Blood Sample From A Fetus Has Greater Risks, The Latter Test Is Usually Used. Neonatal Screening Provides Not Only A Method Of Early Detection For Individuals With Sickle-Cell Disease, But Also Allows For Identification Of The Groups Of People That Carry The Sickle Cell Trait. [38]

2-7 Management:-

Further Information: Pain Management In Children

Treatment Involves A Number Of Measures.

1-L-Glutamine Use by The Age Of 5 As It Decreases Complications . [39]

2-Folic Acid And Penicillin. [39]

3- Dietary Supplementation Of Folic Acid Had Been Previously Recommended By The Who 2016 Cochrane Review Of Its Use Found "The Effect Of Supplementation On Anaemia And Any Symptoms Of Anaemia Remains Unclear" Due To A Lack Of Medical Evidence . [40]

4-Vaso-Occlusive Crisis

Most People With Sickle-Cell Disease Have Intensely Painful Episodes Called Vaso-Occlusive Crises. However, The Frequency, Severity, And Duration Of These Crises Vary Tremendously. Painful Crises Are Treated Symptomatically With Pain Medications; Pain Management Requires Opioid Administration At Regular Intervals Until The Crisis Has Settled. For Milder Crises, A Subgroup Of Patients Manage On Nsaids (Such As Diclofenac Or Naproxen). For More Severe Crises, Most Patients Require Inpatient Management For Intravenous Opioids; Patient-Controlled Analgesia (Pca) Devices Are Commonly Used In This Setting. Diphenhydramine Is Also An Effective Agent That Doctors Frequently Prescribe To Help Control Itching Associated With The Use Of Opioids. [40]

5-Acute Chest Crisis

Management Is Similar To Vaso-Occlusive Crisis, With The Addition Of Antibiotics (Usually A Quinolone Or Macrolide, Since Cell Wall-Deficient ["Atypical"] Bacteria Are Thought To Contribute To The Syndrome). [41] Oxygen Supplementation For Hypoxia, And Close Observation. Should The Pulmonary Infiltrate Worsen Or The Oxygen Requirements Increase, Simple Blood Transfusion Or Exchange Transfusion Is Indicated. The Latter Involves The Exchange Of A Significant Portion Of The Person's Red Cell Mass For Normal Red Cells, Which Decreases The Percent Of Haemoglobin S In The Patient's Blood. The Patient With Suspected Acute Chest Syndrome Should Be Admitted To The Hospital . [24]

6-Hydroxyurea

The First Approved Drug For The Causative Treatment Of Sickle-Cell Anemia, Hydroxyurea, Was Shown To Decrease The Number And Severity Of Attacks In A Study In 1995] . [42] And Shown To Possibly Increase Survival Time In A Study In 2003 . [43] This Is Achieved, In Part, By Reactivating Fetal Haemoglobin Production In Place Of The Haemoglobin S That Causes Sickle-Cell Anemia. Hydroxyurea Had Previously Been Used As A Chemotherapy Agent, And There Is Some Concern That Long-Term Use May Be Harmful, But This Risk Has Been Shown To Be Either Absent Or Very Small And It Is Likely That The Benefits Outweigh The Risks. [44]

7-Blood Transfusion

Blood Transfusions Are Often Used In The Management Of Sickle-Cell Disease In Acute Cases And To Prevent Complications By Decreasing The Number Of Red Blood Cells (Rbc) That Can Sickle By Adding Normal Red Blood Cells . [45]

8-Bone Marrow Transplant

Bone Marrow Transplants Have Proven Effective In Children. Bone Marrow Transplants Are The Only Known Cure For Scd . [64]However, Bone Marrow Transplants Are Difficult To Obtain Because Of The Specific Hla Typing Necessary. Ideally, A Close Relative (Allogeneic) Would Donate The Bone Marrow Necessary For Transplantation. . [45]

9-Avascular Necrosis

When Treating Avascular Necrosis Of The Bone In People With Sickle Cell Disease, The Aim Of Treatment Is To Reduce Or Stop The Pain And Maintain Joint Mobility.[Current Treatment Options Are To Rest The Joint, Physical Therapy, Pain Relief Medicine, Joint Replacement Surgery, Or Bone Grafting.High Quality Randomized Controlled Trials Are Needed To Assess The Most Effective Treatment Option And Determine If A Combination Of Physical Therapy And Surgery Are More Effective Than Physical Therapy Alone. [46]

10-Psychological Therapies

Psychological Therapies Such As Patient Education, Cognitive Therapy, Behavioral Therapy And Psychodynamic Psychotherapy, That Aim To Complement Current Medical Treatments, Require Further Research To Determine Their Effectiveness. [20]

2-8 Prognosis:-

About 90% Of People Survive To Age 20, And Close To 50% Survive Beyond The Fifth Decade. [47] In 2001, According To One Study Performed In Jamaica, The Estimated Mean Survival For People With Sickle-Cell Was 53 Years Old For Men And 58 Years Old For Women With Homozygous Scd . [48] The Specific Life Expectancy In Much Of The Developing World Is Unknown . [49]

2-9 Complications:-

Sickle-Cell Anemia Can Lead To Various Complications, Including:

Increased Risk Of Severe Bacterial Infections Due To Loss Of Functioning Spleen Tissue (And Comparable To The Risk Of Infections After Having The Spleen Removed Surgically). These Infections Are Typically Caused By Encapsulated Organisms Such As *Streptococcus Pneumoniae* And *HaemophilusInfluenzae*. Daily Penicillin Prophylaxis Is The Most Commonly Used Treatment During Childhood, With Some Haematologists Continuing Treatment Indefinitely. Patients Benefit Today From Routine Vaccination For *S. Pneumoniae* . [50]

Stroke, Which Can Result From A Progressive Narrowing Of Blood Vessels, Prevents Oxygen From Reaching The Brain. Cerebral Infarction Occurs In Children And Cerebral Hemorrhage In adults. Silent Causes No Immediate Symptoms, But Is Associated With Damage To The Brain. Silent Stroke Is Probably Five Times As Common As Symptomatic Stroke. About 10–15% Of Children With Scd Suffer Strokes, With Silent Strokes Predominating In The Younger Patients. [51,52]

Cholelithiasis (Gallstones) And Cholecystitis May Result From Excessive Bilirubin Production And Precipitation Due To Prolonged Haemolysis.

Avascular Necrosis (Aseptic Bone Necrosis) Of The Hip And Other Major Joints May Occur As A Result Of Ischemia. [46]

Decreased Immune Reactions Due To Hyposplenism (Malfunctioning Of The Spleen) . [53]

Priapism And Infarction Of The Penis. [54]

Osteomyelitis (Bacterial Bone Infection) . [55]

Acute Papillary Necrosis In The Kidneys

Leg Ulcers. [56]

In Eyes, Background Retinopathy, Proliferative Retinopathy, Vitreous Hemorrhages, And Retinal Detachments Can Result In Blindness. Regular Annual Eye Checks Are Recommended.

During Pregnancy, Intrauterine Growth Retardation, Spontaneous Abortion, And Pre-Eclampsia . [57]

Chronic Pain: Even In The Absence Of Acute Vaso-Occlusive Pain, Many Patients Have Unreported Chronic Pain. [58]

Pulmonary Hypertension (Increased Pressure On The Pulmonary Artery) Can Lead To Strain On The Right Ventricle And A Risk Of Heart Failure; Typical Symptoms Are Shortness Of Breath, Decreased Exercise Tolerance, And Episodes Of Syncope. 21% Of Children And 30% Of Adults Have Evidence Of Pulmonary Hypertension When Tested; This Is Associated With Reduced Walking Distance And Increased Mortality. [59]

Chronic Kidney Failure Due To Sickle-Cell Nephropathy Manifests Itself With Hypertension, Protein Loss In The Urine, Loss Of Red Blood Cells In Urine And Worsened Anemia. If It Progresses To End-Stage Renal Failure, It Carries A Poor Prognosis. [60]

2-10 Preventing Complications:-

Complications From Sickle Cell Disease Can Include Gallstones, Lung Crises (Acute Chest Syndrome), Pulmonary Hypertension, Stroke, Leg Ulcers That Don't Heal, And Eye Damage.

Blood Transfusions Are Commonly Used To Treat Worsening Anemia And Sickle Cell Complications. Most Patients With Sickle Cell Disease Have At Least Occasional Blood Transfusions. Patients With Severe Complications–Such As Stroke And Acute Chest Syndrome–May Require Months Or Years Of Regular Transfusions Every Three To Four Weeks To Prevent Ongoing Damage.

Hydroxyurea Treatment May Be Helpful In Reducing Crises And The Need For Transfusions. (61)

People With Sickle Cell Disease Should Have Regular Checkups To Detect Eye Damage. And A Simple Ultrasound Test Of The Head Can Identify Children At High Risk For Strokes. (61)

Daily Doses Of Penicillin. Treatment May Begin As Early As 2 Months Of Age And Continue Until The Child Is At Least 5 Years Old.

All Routine Vaccinations (Including A Yearly Flu Shot), Plus Vaccination(S) Against Streptococcus Pneumonia.

Adults Who Have Sickle Cell Disease Should Also Receive Flu Shots Every Year And Get Vaccinated Against Pneumococcal Infections. Both Adults And Children Are At Risk For A Variety Of Infections, Such As Pneumonia And Bone Infections. They Should Be Examined Whenever They Experience Fevers, Since Early Diagnosis And Treatment Result In Better Outcomes . (61)

2-11 Types:-

What Are The Types Of Sickle Cell Disease?

Hemoglobin Is The Protein In Red Blood Cells That Carries Oxygen. It Normally Has Two Alpha Chains And Two Beta Chains. The Four Main Types Of Sickle Cell Anemia Are Caused By Different Mutations In These Genes.

1-Hemoglobin Ss Disease:-

Hemoglobin Ss Disease Is The Most Common Type Of Sickle Cell Disease. It Occurs When You Inherit Copies Of The Hemoglobin S Gene From Both Parents. This Forms Hemoglobin Known As Hb Ss. As The Most Severe Form Of Scd, Individuals With This Form Also Experience The Worst Symptoms At A Higher Rate. (62)

2-Hemoglobin Sc Disease:-

Hemoglobin Sc Disease Is The Second Most Common Type Of Sickle Cell Disease. It Occurs When You Inherit The Hb C Gene From One Parent And The Hb S Gene From The Other. Individuals With HbSchavesimilar Symptoms To Individuals With Hb Ss. However, The Anemia Is Less Sever.(62)

3-Hemoglobin Sb+ (Beta) Thalassemia:-

Hemoglobin Sb+ (Beta) Thalassemia Affects Beta Globin Gene Production. The Size Of The Red Blood Cell Is Reduced Because Less Beta Protein Is Made. If Inherited With The Hb S Gene, You Will Have Hemoglobin S Beta Thalassemia. Symptoms Are Not As Severe. (62)

4-Hemoglobin Sb 0 (Beta-Zero) Thalassemia:-

Sickle Beta-Zero Thalassemia Is The Fourth Type Of Sickle Cell Disease. It Also Involves The Beta Globin Gene. It Has Similar Symptoms To HbSs Anemia. However, Sometimes The Symptoms Of Beta Zero Thalassemia Are More Severe. It Is Associated With A Poorer Prognosis.

Hemoglobin Sd, Hemoglobin Se, And Hemoglobin So

These Types Of Sickle Cell Disease Are More Rare And Usually Don’t Have Severe Symptoms . (62)

2-12 Sickle Cell Trait:-

People Who Only Inherit A Mutated Gene (Hemoglobin S) From One Parent Are Said To Have Sickle Cell Trait. They May Have No Symptoms Or Reduced Symptoms. (62)

2-13 Risk Factors:-

Who Is At Risk For Sickle Cell Anemia?

Children Are Only At Risk For Sickle Cell Disease If Both Parents Carry Sickle Cell Trait. A Blood Test Called A Hemoglobin Electrophoresis Can Also Determine Which Type You Might Carry.

People From Regions That Have Endemic Malaria Are More Likely To Be Carriers. This Includes People From:

Africa

India

The Mediterranean

Saudi Arabia . [62]

2-14 Information, Education, And Communication On Care Of Child With Sickle Cells Disease:-

Symptoms And Associated Problems

As Blood Circulates To All Parts The Body, Sickling Can Occur Anywhere Resulting In A Range Of Complications. Symptoms Usually Start After The Age Of Four To Six Months And Can Include All Or Some Of The Following:-

1-Pain:

Because Of The Sickle Cell Shaped Blood Cells, They Sometimes Get Stuck In The Small Veins And Prevent Normal Blood Flow. These Blockages Cause Pain In The Arms, Legs, Back And Stomach. Sometimes This Pain Is Quite Severe. Sickle Cell Disorders Can Also Cause Swelling Of The Hands And Feet, With Stiff Painful Joints And Extreme Tiredness. Episodes Of Severe Pain Are Known As "Crises". Sickle Pain Can Happen At Home And At School – In Fact Anywhere – So It Is Important For Families And Sufferers, As Well As Carers And Teachers, To Know The Best Ways Of Coping.[63]

How Severe Will The Effects Be?

The Problems Of Sickle Cell Disorder Are Very Variable – Some People Are Mildly Affected And Largely Free From Pain, While Others Have Frequent And Severe Pains; Most Children Go Through Good And Bad Patches. Doctors Cannot Predict Who Will Be Severely Affected.

How Much Pain Is Usually Experienced, And What Kind Is It?

Although Everyone Is Different, Pain Is A Common Event In All Children, Whether Or Not They Have Sickle – On Average Some Degree Of Pain Is Experienced On At Least A Quarter Of All Days. But, In Children With Sickle Cell, Pain

Happens More Often (On An Average Of One Third Of All Days);

Lasts Longer (Generally All Day, Even If Not Continuously All Day);

Is Associated With Great Tiredness About Half The Time;

Causes Them To Spend Significant Time In Bed – On Average The Time Spent Wholly Or Partly In Bed Adds Up To About A Week Of Every School Term . [63]

Which Parts Of The Body Are Painful?

Most Commonly, Children And Adolescents Report Sickle Pain In Hands, Arms, Legs And Lower Back, With Pain In The Joints Being Less Usual. Headaches And Pains In The Chest And Abdomen (Tummy Aches) Are As Frequent In Non-Sickle As In Sickle Children. [63]

Boys May Get Priapism, Which Is A Painful, Stiff Penis, Often Noticed As Pain In The Groin. They May Be Too Embarrassed To Mention This, But It Is Important To Get Medical Attention Because Severe Sickling Is In The Penis Can Lead To Impotence (Poor Erection Of The Penis). [63]

When Do Children With Sickle Cell Disorder Suffer Pain?

Infections, Thirst And Dehydration Caused By Not Drinking Enough Even If Thirst Is Not Felt, Over-Exertion, Over-Excitement, Cold Weather And Cold Drinks And Swimming Have All Been Reported By Sickle Children To Cause (Trigger) Pain. Bangs, Bumps, Bruises And Strains (Trauma, In Technical Language) Have Also Been Reported To Do So. Stress Triggers Pain In Adults, But Does Not Seem To Do So In Children.[63]

Can You Tell If Pain Is Coming?

Children And Families Can Often Tell When A Severe Sickle Pain Is Coming On By Thirst, Or The Eyes Turning Yellow (Jaundice), Or By The Sufferer Being More Irritable Or Tired Than Usual. These Features May Not Be Present, But One Or More May Predict Crisis. (63)

Living With The Pain:-

There Are No Easily Detectable Signs Of Sickle Pain, So Children Known To Have Sickle Cell Disorder Who Say They Are In Pain Must Be Trusted; If They Can Rely On The Adults Around Them To Take Them Seriously, Each Person Should Find Out What The Limitations Are That Sickle Imposes On Their Life, And What Triggers Pain For Them. The Causes Differ From Person To Person, And It Is Important To Be Your Own Detective About Your Body, Or Your Child's. Every Time A Pain Is Felt Ask Yourself What May Have Caused It; It Is Not Always Obvious, But If Enough Detective Work Is Done Over A Long Enough Period, You Can Often Make The Link. For Instance, One Parent Noticed His Child Was Especially Likely To Be Affected If She Drank A Very Cold Drink From The Fridge, So Her Drinks Are Not Kept In The Fridge Now And She Is Helped To Avoid Pain.(63)

2-Infections:-

Someone With Sickle Cell Disorders Is At Risk Of Developing Severe Infections, And Is Strongly Advised To Take Penicillin Twice A Day Every Day.

Penicillin Is Taken As A Prophylactic, That Is To Prevent A Particular Infection. (63)

3-Anemia:-

Children With Sickle Cell Disorder Tend To Be Anemic. Most Of The Time They Feel Quite Well, But If The Anemia Gets Worse They May Feel Tired And Unwell. Folic Acid Is A Vitamin, Found In Fruit And Vegetables, Which Everyone Needs To Help Make Blood. People With Sickle Cell Disorder Especially Need It To Prevent Them Becoming Run Down. (63)

4-Jaundice:-

People With Sickle Cell Anemia Frequently Have A Mild Jaundice (Yellowing In The Whites Of The Eyes). This Is Not A Cause For Concern Unless It Becomes Noticeably Worse . [63]

2-15 What To Do If Someone Has A Sickle Cell Crisis?

Someone Having A Crisis Will Suddenly Become Unwell Or Complain Of Severe Abdominal Or Chest Pain, Headache, Stiffness Of The Neck Or Drowsiness.

Someone Having A Sickle Cell Crisis Needs Urgent Hospital Treatment.

There Are Several Practical Steps You Should Take To Help Reduce The Frequency And Severity Of Sickle Cell Crises.

Make Sure The Child Does Not Become Dehydrated.

This Means Encourage Them To Drink Much More Than Normal And More Often. The Child Will To Go To The Toilet More Often Than Usual Because Of This Extra Fluid Intake. This Problem May Also Cause Bed-Wetting Until The Child Reaches His Or Her Teens. Never Restrict The Amount The Child Drinks Because Of This. Discuss The Problem With The Child's Doctor, Social Worker Or A Sickle Cell Counselor.[63]

Pain Can Be Eased By Simple Measures

1-Warmth, (Probably By Increasing The Blood Flow), By Massaging And Rubbing And By Heat From Hot Water Bottles And Deep Heat Creams.

Bandaging To Support The Painful Region.[63]

2-Resting The Body:-

Getting The Sufferer To Relax, By Deep Breathing Exercises And Distracting The Attention, And By Other Psychological Methods.

Pain Can Be Also Be Relieved By Pain-Killing Medicines (Analgesics), Which Can Be Used At Home.

The Gentlest Analgesic To Try Is Paracetamol, Given Three Times A Day (62.5 Mgm Under 12 Months, 125 Mgm 1-4 Years, 250 Mgm 4-10 Years, 500 Mgm 10-14 Years, And 1 Gm 15 Years Upwards).

The Next Gentlest Is Codeine Phosphate, Given Four Times A Day, At 1-2 Mgm For Every Kilogram Of Body Weight Of The Sufferer.

A Stronger Analgesic Is A Non-Steroidal Anti-Inflammatory Agent, Such As Diclofenac, Which Is Given Three Times A Day, At A Dose Of 1 Mgm For Every Kilogram Of Body Weight Of The Sufferer.

If These Are Not Effective, Then Admission To Hospital Of Pain-Killing Treatment With Morphine Should Be Arranged. (63)

3-Make Sure The Child Is Always Warm And Dry. (63)

4-Make Sure The Child Does Not Become Over Tired. (63)

Encourage Him Or Her To Rest Whenever He Or She Feels Tired.(63)

5-Make Sure The Child Is Fully Immunized Against Infectious Illnesses.(63)

6-Ensure That He Or She Also Takes Any Vitamins (Folic Acid) And Antibiotics (Penicillin) Prescribed By The Doctor. (63)

7-Make Sure The Child Visits The Gp And Hospital Clinic Regularly.

There Will Be A Blood Test And Physical Examination, And The Opportunity To Ask Questions And To Discuss The Condition.(63)

8-Remember To Ensure The Child Takes Any Prescribed Medication At The Right Time And Dosage, And Hospital / Clinic Appointments Are Always Kept.(63)

9-Make Sure The Child Is Adequately Prepared For Travel.

If He Or She Is Going On A Planned Journey Ask For Advice On Precautions To Take Before Or During The Flight – For Instance: Increased Fluids, Pain Killers Or Oxygen May Be Recommended (Airline Cabin Staff Must Be Aware Of The Special Needs). This Must Be

Brought To The Attention Of The Airline As Early As Possible Prior To Departure, So They Can Make Suitable Arrangements). More Information Is Available On Our Travel Page.[63]

10-Ensure Anti – Malaria Protection Is Given When Visiting Countries In The Malarial Zone. . [63]

11-Ssupport The Child.

Like Any Other Chronic Illness Sickle Cell Disorder Is Sometimes Difficult To Come To Terms With. The Child May Some Times Feel Unable To Cope With The Inconvenient And Painful Effect Of The Condition.

You Can Help By Being Aware Of His Or Her Feelings And By Making Allowances When Necessary. When Pain Stops Normal Life, And Particularly When The Child Has To Go To Bed Because Of It, Have A Good Supply Of Books, Games And Videos.

12-You Also Need To Arrange Your Family Life So Someone Can Care For Your Child When He Or She Has To Go To Bed, Or Cannot Go Out, Or To School, Because Of The Pain. [63]

13-Use The Support Agencies

Social Services, Advice Centers And Sickle Cell Groups Can All Be Contacted For Support. As Well As Receiving Help And Advice, Sharing Experiences And Meeting Others With Sickle Cell Disorder Can Be Beneficial To The Care And The Child Alike.

14-Make Sure That You, The Child And The Whole Family Are Well Informed About Sickle Cell Disorders.

15-New Doctors And Your Dentist Must Be Told Before Any Treatment Is Prescribed .[63]

2-16 Note:-

People Who Only Have Sickle Cell Trait Do Not Suffer Any Of The Symptoms Of Sickle Cell Anemia, Sickle Cell Trait Is Not An Illness And People With Trait Are Perfectly Healthy. However, They Require Extra Oxygen During Anaestheticand Operations, And Are Advised Against Participating In Some Sports, Such As Scuba Diving Or Climbing Very High Mountains, Where The Oxygen Supply May Become Reduced. (64)

How You Can Help With The Education Of Children With Sickle Cell.

Sickle Cell Disorders Do Not Affect A Person's Intelligence. Children With Sickle Cell Disorders Can Almost Always Attend School And Participate Fully In Normal Activities. (64)

Talk To The Child's Teachers, Play Group Leaders And Child minders. If A Child Has A Sickle Cell Disorder, Discuss The Condition With The Adults He Or She Spends Time With And Pass On Information Leaflets, Including The Sickle Cell Society's Leaflet A Guide For Teachers And Others Caring For Children, To Make Sure That They Understand The Condition And How It Might Affect The Child.

The Class Teacher And The Head Teacher Should Know Of The Diagnosis And Understand The Limitations Sickle Can Impose On A Child – The Need For Frequent Drinks And Easy Access To Lavatories, The Triggering Of Pain By Over-Exertion Or Cold. The School Should Have A Quiet Place Where A Child Can Rest, And Simple Analgesics, Such As Paracetamol, Should Be Available. The Teacher May Need A Letter Of Permission From The Child To Be Sent Home With Only Mild Sickle Cell Pain, And Good Communication Between Parents And Staff Can Prevent This Happening. (64)

Remember, To Do This Every Time There Is A Change Of Teacher. Stress How Important It Is That Everyone Who Has Contact With The Child Should Understand The Condition. This Includes All Teachers And Support Staff Who Will Need To Know The Effect Of Cold And Wet Weather. Although Sickle Cell Disorder Has No Effect On The Intelligence, The Child May Find It Difficult To Concentrate When In Pain Or May Get Easily Tired And Lethargic If Badly Anemic. (64)

The Child With Sickle Cell Disorder May Have To Miss Lessons Or Take Days Off School When Attending Clinics Or During A Crisis. These Interruptions May Cause The Child To Fall Behind With School Work. If This Is The Case You Can Help By Ensuring That The Teachers Understand Why He Or She Is Behind And By Helping Him Or Her To Keep Up With Lessons. (64)

Ensure That The Child Always Has Some Work Which Can Be Done At Home If He Or She Is Away From School For Any Period At All.

For Longer Stays Away From School, Home Or Hospital Tuition May By Necessary, And You Can Help By Keeping In Touch With The Child's School.

Encourage The Child To Consider Appropriate Careers At An Early Age So That He Or She Can Give Particular Attention To Keeping Up With The Subjects Which Will Be Most Relevant. (64)

Try To Raise The Awareness Of Sickle Cell Disorders In The Child's School. Encourage Teachers To Use The Disorder In Their Teaching – Tell Them About The Sickle Cell Society Leaflet Guidelines For The Inclusion Of Sickle Cell Disorder In Teaching As Well As The Teaching Resources Page On This Web Site.

Remember That You Can Work With Doctors And Teachers To Help The Child With A Sickle Cell Disorder To Lead A Full And Normal Life. (63)

Where To Get Further Help, Advice And Information:-

1-School Health Service. Ex; The School Nurse Or Medical Officer. (63)

2-The Child's General Practitioner (Gp).(63)

3-The Child's Hospital Doctor. Ex; The Paediatrician Or Haematologist.(63)

4-Local Health Promotion Unit. (63)

5-Your Local Sickle Cell Centre Or Support Group.[63]

2-17 Home Care For Children With Sickle Cell Disease:-

Sickle Cell Disease Is An Inherited Disorder In Which Red Blood Cells Become C-Shaped. This Causes Impaired Blood Flow, Pain, And Other Health Problems. Symptoms Usually Show Up By About 5 Months Of Age.

Although A Child Who Has Sickle Cell Disease Should Be Under A Healthcare Provider's Care, Parents Can Do Many Things At Home To Reduce Symptoms And Maintain The Child's Health. (64)

1-Take Steps To Prevent Infections:-

Contagious Diseases Like The Flu Can Be Dangerous For Children With Sickle Cell Disease. They, As Well As Their Caregivers And Family Members, Should Wash Their Hands Several Times A Day With Soap And Water To Reduce The Spread Of The Flu Virus And Other Germs. Children With Sickle Cell Disease Are Also Vulnerable To Illness From A Bacterium Called Salmonella. To Avoid Salmonella, They Should Avoid Eating Raw Or Undercooked Meats And Eggs. They Can Carry The Bacterium. Make Sure Your Child's Immunizations Are Up To Date.(64)

2-Take Fevers Seriously:-

If Your Child Has A Fever Of 101°F (38.3°C), Contact Your Child's Healthcare Provider For Advice. Resist The Temptation To Simply Treat Your Child At Home With Fever-Reducing Medicines. The Fever Could Be A Sign Of A More Serious Complication. If Your Child Has No Fever But Does Not Look Well To You, Trust Your Instinct. Call Your Healthcare Provider Right Away Or Bring Your Child To The Emergency Room. (64)

3-Be Aware Of Your Child's Surroundings:-

Extremely Hot Or Cold Temperatures May Trigger A Sickle Cell Crisis. This Is A Sudden Episode Of Pain Throughout The Body. To Keep Your Child's Body Temperature At The Best Level, Always Make Sure He Or She Wears A Coat During Cold Weather And Spends As Much Time As Possible In Air-Conditioned Areas On Hot Days. Staying Well-Hydrated In Hot Weather May Reduce The Risk Of A Sickle Cell Crisis. (64)

4-Learn How To Manage Pain:-

Children With Sickle Cell Disease Will Sometimes Experience Pain Episodes. Talk With Your Child's Healthcare Provider About The Best Ways To Handle These Episodes At Home. It May Be Appropriate To Give Your Child Pain-Relieving Medicines Like Ibuprofen For Mild Episodes Or Stronger Pain Relievers For More Severe Flare-Ups. Heating Pads, Warm Baths, And Massage May Also Be Soothing. (64)

5-Maintain Healthy Habits:-

Make Sure To Introduce Healthy Practices Into Your Child's Daily Life. Drinking Plenty Of Fluids To Help Prevent Dehydration And Eating A Balanced Diet Are Important. Children With Sickle Cell Disease Should Also Participate In Physical Activity And Stay Active. Rest Breaks Are Advised, Though, To Avoid Working Too Hard Or Becoming Overly Tired. (64)

6-Reach Out To Support Groups:-

Children With Sickle Cell Disease, Particularly Teenagers, May Have A Hard Time Coping With Their Condition Because Of Delayed Puberty. They May Also Feel Anxious About Having Sudden Pain Episodes. Support Groups For Children With Sickle Cell Disease Can Be Helpful In Learning Ways To Cope With These Situations. Also, These Support Groups Can Be Helpful For Simply Sharing Their Worries With Peers Who Have Similar Concerns And Feelings. Ask Your Child's Healthcare Provider Or Your Local Hospital For Advice On Finding A Group In Your Area. (64)

2-18 Conclusions:-

The Benefit Of Care Of Child With Sickle Cells Disease Go For Beyond Reduce The Frequent Of Admission To Hospital Literature Review Has Show The Information, Education, And Communication Is Key To Acquiring Knowledge On Prevention Measure For Sickle Cells Crises Literature Review Established That If Mother Have Inadequate Knowledge Of Sickle Cells Disease, The Precipitating Factor To Crises And Preventive Measure, This Will Effect Their Practice. It Is For This Reason That The Investigator Desired To Determine The Practice

And Knowledge Of Mother/Caretaker With Child With Sickle Cells Disease Towards The Prevention Of Crises.It Evident That Increase The Mother Knowledge And Attitude Regarding Care Of Child With Sickle Cells Anemia Would Potentially Effect Their Practices Toward Crises Prevention Thus Reducing The Suffering Of Children During Crises.

Chapter three

3- Research Methodology:-

3-1 Research Design:-

This Is A Descriptive Cross-Sectional Hospital Based Study. This Study Used A Descriptive Approach To Assess Of Mother Knowledge And Attitude Regarding Care Of Child With Sickle Cells Anemia In jafar ibn auf Hospital, Khartoum Locality, Khartoum State, Sudan (2018).

3-2 Research Sitting:-

The Study Is Conducted at hematology clinic/ward of jafar ibn auf hospitalWhich Is Large Referral Hospital In Sudan..

3-3 Study area:-

Jafar ibn auf hospital was established 2014, which lies in khartoum locality. It has the largest number of patients from Khartoum state and occasionally from other states. Jafar ibn auf Hospital has intensive care unit with a maximum of 10 beds. Departments of jafar ibn auf Hospital: -

Medicine (endocrine, nephrology, neurology, cardiology, GIT and chest)

,Dialysis, Intensive care units for pediatric, Nursery unit, Endoscopy unit, Blood bank, Laboratory, Out patient's clinic, X-ray department, Infection control ,Ambulance department – Management, Nursing department, Engineering Examination center, General Communications, Diet Therapy,General health.-Kitchen, Health insurance, A counting department, and quality department.

3-4 Study Population:-

The Study Population Include All Mother/Caretaker To Children (Children Below 16 Years) With Sickle Cells Disease. the main study was conducted at the hematology ward and clinic on mother who were bringing their children for review at the time of study. mother where able to gave their information on their knowledge and attitude regarding care of child with sickle cells anemia because they were the primary caregivers for children with sickle cells disease.

3-5 Sample Selection:-

The Participation Of This Study Were Selected Using The Simple Random Sampling Method.

3-6 Inclusion Criteria:-

Participants Who Were Included In The Study Were All Mother Have Children Bellow 14 Years With Sickle Cells Disease Who Were Attending To jafar ibn auf Hospital At That Time.

3-7 Exclusion Criteria:-

Mother Who Not Have Children With Sickle Cells Disease And Not attending to jafar ibn auf Hospital.

3-8 Sample Size:-

100 mother with children with sickle cells anemia were sampling from hematology ward and clinic.

3-9 Data Collocation Technique and tool:-

Data collected by questionnaire field by researcher which consist of four part

divided into sections .section A contained question on biodemographic data, section B had question on section-economic status of respondents, section C had question of mother knowledge about SCD, section D mother attitude and practices toward prevention of sickle cell crises.

3-10Data analysis:

By using the statistical package for social sciences (SPSS) version 21.0

3-11 Ethical Consideration:

The Researcher got Permission From shandi university, ministry of health research department and the Hospital Of The Study(jafar ibn auf) With Official Letter From The Faculty Of Applied Medical Sciences To Directors Of The Hospital, With The Agreement Of The Target Population, Every Individual Observed Once. Verbal Consent From Interviewed Persons Was Also Obtained After Explaining The Study And Its Objectives To Them. Confidentiality Was Given Consideration And The Information Is Used For The Research Purpose Only .The Respondent Were Told That They Had The Right To Participate Or Withdraw From The Study at any time With No Penalty.

3-12 Scoring:

For assessing Knowledge about Sickle Cells Anemia and Knowledge about Sickle Cells Anemia complication each correct answer carried one mark while wrong answer carried 0 mark. Total score for two knowledge domains ranged between 0-4. For question contain four correct answers 0.25 mark assigned for each answer and for question contain three correct answers 0.33 marks

assigned for each correct answer. The score in two domains were not normally distributed then expressed by median and categorized into Poor(<median), Fair(Median) and Good (>median).

Chapter four

4- Results

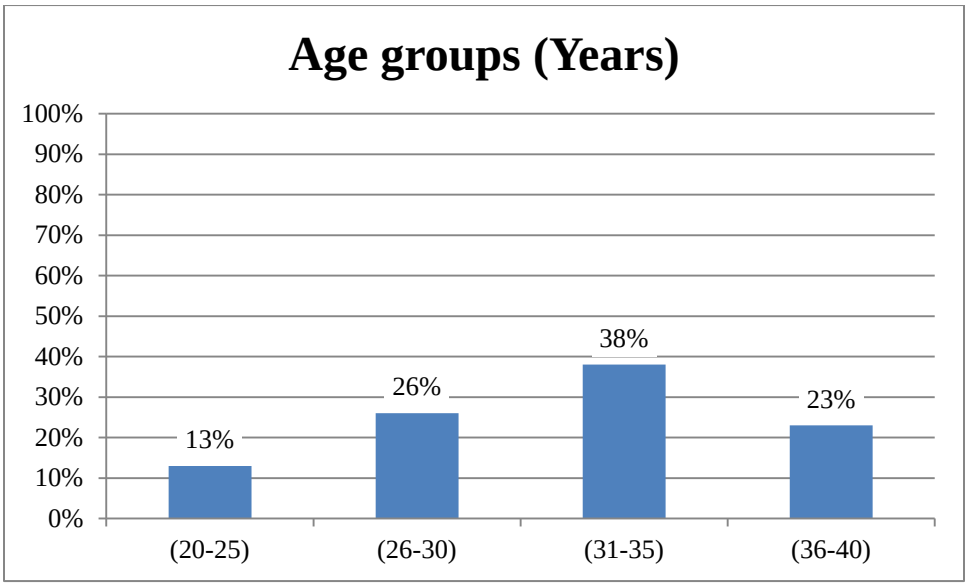

Figure4.1 age groups this figure showed 38% of mother age (31-35) years,26% of mother age (26-30)years,23% of mother(36-40)years and 13% of mother age(20-25)years

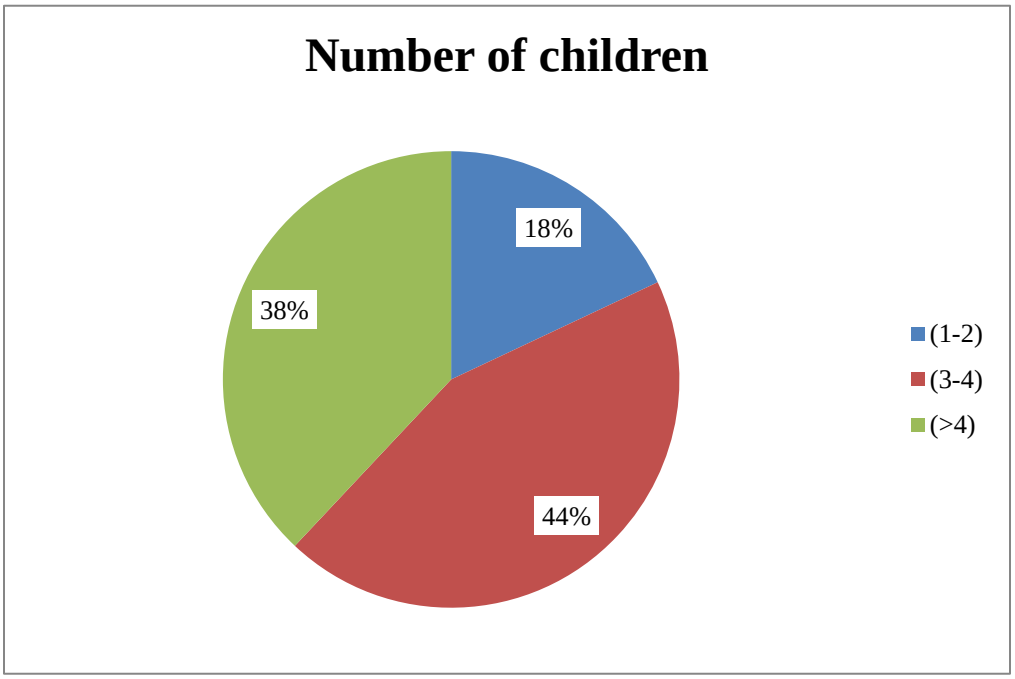

Figure 4.2 number of children

This figure showed number of children .44% of mother have (3-4)child,38% have>4 child,18% of have (1-2) child.

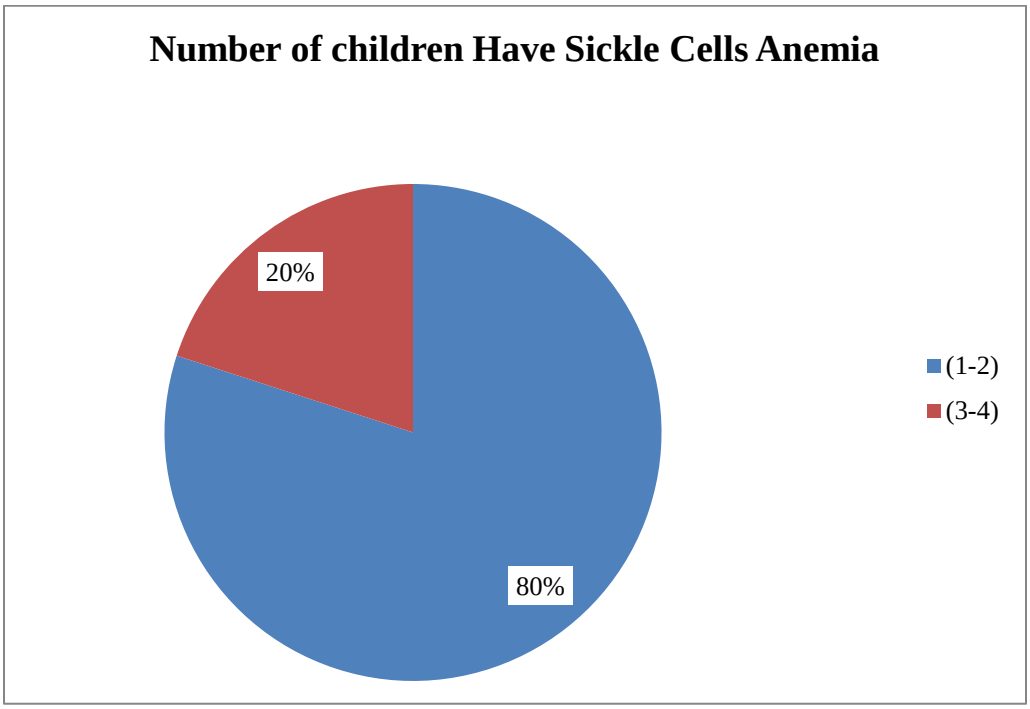

Figure 4.3 number of children have sickle cell anemia

This figure showed number of children with SCA 20% of mother have (1-2) child with SCA and 80% of mother have (3-4) child with SCA

Table 4.1 education level

Education Level	Number	Percent
Primary School	13	13%
Secondary School	41	41%
University	46	46%
Total	100	100%

Table 4.1 showed 46% of mother studiesuniversity,41% secondary school, and 13% of mother primary school

Table 4.2 occupation

Occupation	Number	Percent
Employed	28	28%
Unemployed	72	72%
Total	100	100%

This table showed mother employment 72% of mother employed while 28% of mother unemployed

Table 4.3 monthly income

Monthly income	Number	Percent
Low	3	3%
Medium	93	93%
High	4	4%
Total	100	100%

This table showed monthlyincome of mother 93% of mother medium monthly income while 4% high income and 3% low in come

Table 4.4 definition of SCD

What Is SCD ?	Number	Percent
It Is Inherited Hemolytic Anemia	29	29%
Is A Common Genetic Condition Due To A Hemoglobin Disorder Inheritance Of Mutant Hemoglobin Genes From Both Parents	83	83%
Is Group Of Blood Disorders	84	84%
n=100		

This table showed mother definition of SCA 84% saidIs Group Of Blood Disorders,83% saidIs A Common Genetic Condition Due To A Hemoglobin Disorder Inheritance Of Mutant Hemoglobin Genes From Both Parents and 29% of mother It Is Inherited Hemolytic Anemia

Table 4.5 cause of SCA

The Cause Of SCA Is?	Number	Percent
Infectious	8	8%
It May Result From Child Immune	40	40%
Hereditary	89	89%
n=100		

This table showedcause of SCA 89% of mother said hereditary ,while 40% of mother said it may result from child immune and 8% said infections

Table 4.6 symptoms of SCD

Symptoms Of SCA?	Number	Percent
Chest Pain, Spleen Enlargement	36	36%
Hypertensive And Tachycardia	61	61%
Joint Pain ,Fatigue , Necrosis	79	79%
Fever ,Pale, Dehydration	92	92%
n=100		

This table showed symptoms of SCD 92% saidFever ,Pale, Dehydration,79% of mother saidJoint Pain ,Fatigue , Necrosis,61% said Hypertensive And Tachycardia and 36% of mother saidChest Pain, Spleen Enlargement

Table 4.7 symptoms that appear in your child

What Is Symptoms That Appear In Your Child ?	Number	Percent
By Your Knowledge Of SCD Symptoms And Appear That On Your Child	6	6%
Sudden Discover By SCC Appear On Your Child	40	40%
Unable The Child To Doing Exercise That Demanding More Oxygen	43	43%
Your Child Complain From Fatigue ,Joint Pain, And Wight Loss	48	48%
n=100		

This table showed symptoms that appear in child with SCA 48% of mother saidYour Child Complain From Fatigue ,Joint Pain, And Wight Loss,43% said Unable The Child To Doing

Exercise That Demanding More Oxygen,40%Sudden Discover By SCC Appear On Your Child and 6%By Your Knowledge Of SCD Symptoms And Appear That On Your Child

Table 4.8 mother action when SCA symptoms appear on their child

What Is Your Action When SCA Symptoms Appear On Your Child?	Number	Percent
Direct Go To Doctors	97	97%
Give The Child Traditional Therapy	18	18%
n=100		

This table showedmother action when SCA symptoms appear on their child 79% of mother go direct to docror,18% of mother give the child traditional therapy

Table 4.9 the type of treatment that given to child after disease is discover

What Type Of Treatment Was Given To Child After The Disease Is Discover?	Number	Percent
Blood Transfusion	59	59%
Antibiotic	88	88%
Folic Acid Tablets	91	91%
n=100		

This table showedthe type of treatment that given to child after disease is discover 91% siadFolic Acid Tablets,88%saidAntibioticand 59% of mother saidBlood Transfusion

Table 4.10 type of nutrition Gavin To Your Child After Disease Discover ?

What Type Of Nutrition Did You Given To Your Child After Disease Discover ?	Number	Percent
White Meat Only	19	19%
Red Meat Only	37	37%
Vegetable And Fruit	76	76%
Nutritional Food That Content Of Folic Acid Source	88	88%
n=100		

This table showed type of nutrition Gavin To Your Child After Disease Discover 88% saidNutritional Food That Content Of Folic Acid Source, 76% saidVegetable And Fruit, 37% saidRed Meat Only,19% saidWhite Meat Only

Table 4.11 the specific treatment of SCA

How Can Treat The SCA Totally?	Number	Percent
By Specific Antibiotic	12	12%
Bone Marrow Transplant	38	38%
Continues Blood Transfusion To Child	65	65%

Totally Change Of Child Blood	74	74%
n=100		

This table showedthe poor knowledge of mother about specific treatment of SCA 74% saidTotally Change Of Child Blood,65% saidContinues Blood Transfusion To Child,38% saidBone Marrow Transplant and 12% of mother saidBy Specific Antibiotic

Table 4.12 the crises that can affect sicklier child

What The Crisis That Can Affect The Child With SCA?	Number	Percent
Hypertension And Stroke	24	24%
Cholecystits And Liver cirrhosis	36	36%
Chronic Pain And Infusion	69	69%
Inflammation And Bone Pain	74	74%
n=100		

This table showedthe crises that can affect sicklier child 74% of mother saidInflammation And Bone Pain,69% saidChronic Pain And Infusion,36%Cholecystits And Liver cirrhosisand 24% saidHypertension And Stroke

Table 4.13 treatment of the crises

How To Treat SCC?	Number	Percent
Blood Transfusion	48	48%
Nutrient Vegetable That Content Of Folic Acid	75	75%
Regular To Take Folic Acid	84	84%
Regular Follow-Up	89	89%

n=100

This table showedtreatment of the crises 89% of mother saidRegular Follow-Up,84% saidRegular To Take Folic Acid ,75%Nutrient Vegetable That Content Of Folic Acid and48% said Blood Transfusion

Table 4.14 the predispoising factor to SCC

What Are Predispoiding Factor To SCC?	Number	Percent
Doing Activities Demanding More Oxygen	37	37%
Infection And Exposures To Cold	56	56%
Dehydration	66	66%
Fever	66	66%
n=100		

This table showedthe predispoising factor to SCC 66% of mother said fever and dehydration,56% said infection and exposures to cold, and 37% said Doing Activities Demanding More Oxygen

Table 4.15 the prevention of SCC

How Do You Prevent SCC?	Number	Percent
Take The Child To Traditional Healer	30	30%
Restrict The Child From Doing Exercise Demanding More Oxygen And Dress The Child Warm Cloth	53	53%
Give The Child Plenty Of Fluid	84	84%
Feed The Child Nutrition Food And Folic Acid	91	91%
n=100		

This table showedthe good knowledge of mother about prevention of SCC 91% of motherFeed The Child Nutrition Food And Folic Acid,84% of motherGive The Child Plenty Of Fluid ,53%Restrict The Child From Doing Exercise Demanding More Oxygen And Dress The Child Warm Cloth and30%Take The Child To Traditional Healer

Table 4.16 source of mother information

What Is Source Of Your Information On Sickle Cell Crises Prevention ?	Number	Percent
Internet	23	23%
Television And Radio	30	30%
Nurse	82	82%
Doctor	92	92%
n=100		

This table showed the good roles of doctor and nurse to inform the mother about SCD.92% of mother said doctor,82%said nurse,30% said television and radio and 23% of mother said internet

Table 4.17 knowledge about SCA

Knowledge about Sickle Cells Anemia	Number	Percent
Poor	42	42%
Fair	50	50%
Good	8	8%
Total	100	100%

This table showed mother knowledge about SCA 8% of mother has good knowledge, 50% have fair knowledge and 42% have poor knowledge

Table 4.18 cross tabulation between each variable of study about Knowledge Sickle Cells Anemia

Cross tabulation		Knowledge about Sickle Cells Anemia			Fisher's exact test P value
		Poor	Fair	Good	
Age groups (Years)	(20-25)	6	7	0	0.607*
		6.00%	7.00%	0.00%	
	(26-30)	9	16	1	
		9.00%	16.00%	1.00%	
	(31-35)	15	18	5	
		15.00%	18.00%	5.00%	
	(36-40)	12	9	2	
		12.00%	9.00%	2.00%	
Number of children	(1-2)	6	12	0	0.194*

		6.00%	12.00%	0.00%	
		16	22	6	
	(3-4)	16.00%	22.00%	6.00%	
		20	16	2	
	(>4)	20.00%	16.00%	2.00%	
		35	41	4	
	(1-2)	35.00%	41.00%	4.00%	
Number of children Have Sickle		7	9	4	
Cells Anemia	(3-4)	7.00%	9.00%	4.00%	0.100*
	Primary	10	3	0	
	School	10.00%	3.00%	0.00%	
	Secondary	25	16	0	
	School	25.00%	16.00%	0.00%	
		7	31	8	
Education Level	University	7.00%	31.00%	8.00%	0.000001**
		7	16	5	
	Employed	7.00%	16.00%	5.00%	
		35	34	3	
Occupation	Unemployed	35.00%	34.00%	3.00%	0.023**
		2	1	0	
	Low	2.00%	1.00%	0.00%	
		39	46	8	
	Medium	39.00%	46.00%	8.00%	
		1	3	0	
Monthly income	High	1.00%	3.00%	0.00%	0.779*
n=100					

- **.P value <0.05 that's considered as statistically significant.
- *.P value >0.05 that's considered as statistically insignificant.

This table showed mother who studies university and have occupation have good knowledge about SCA more than mother unemployed and uncompleted studies.

Table 4.19Knowledge about Sickle Cells Anemia complication

Knowledge about Sickle Cells Anemia complication	Number	Percent
Poor	37	37%
Fair	51	51%
Good	12	12%
Total	100	100%

This table showedKnowledge about Sickle Cells Anemia complication12% of mother have good knowledge,51% have fair knowledge, and 37% have poor knowledge

Table 4.20 shows cross tabulation between each variable of study about Knowledge of Sickle Cells Anemia complication

Cross tabulation		Knowledge about Sickle Cells Anemia complication			Fisher's exact test P value
		Poor	Fair	Good	
Age groups (Years)	(20-25)	8	14	4	0.607*
		8.00%	14.00%	4.00%	
	(26-30)	14	19	5	

		14.00%	19.00%	5.00%	
		7	14	2	
	(31-35)	7.00%	14.00%	2.00%	
		10	7	1	
	(36-40)	10.00%	7.00%	1.00%	
		14	22	8	
	(1-2)	14.00%	22.00%	8.00%	
		13	22	3	
	(3-4)	13.00%	22.00%	3.00%	
		31	39	10	
Number of children	(>4)	31.00%	39.00%	10.00%	0.300*
		6	12	2	
	(1-2)	6.00%	12.00%	2.00%	
Number of children Have		8	5	0	
Sickle Cells Anemia	(3-4)	8.00%	5.00%	0.00%	0.730*
	Primary	14	25	2	
	School	14.00%	25.00%	2.00%	
	Secondary	15	21	10	
	School	15.00%	21.00%	10.00%	
		14	9	5	
Education Level	University	14.00%	9.00%	5.00%	0.041**
		23	42	7	
	Employed	23.00%	42.00%	7.00%	
		3	0	0	
Occupation	Unemployed	3.00%	0.00%	0.00%	0.064*
		31	50	12	
	Low	31.00%	50.00%	12.00%	
		3	1	0	
	Medium	3.00%	1.00%	0.00%	
Monthly income	High	19	21	2	0.103*

		19.00%	21.00%	2.00%	
Knowledge about Sickle Cells Anemia	Poor	19	21	2	0.231*
		19.00%	21.00%	2.00%	
	Fair	16	26	8	
		16.00%	26.00%	8.00%	
	Good	2	4	2	
		2.00%	4.00%	2.00%	
n=100					

- **.P value <0.05 that's considered as statistically significant.
- *.P value >0.05 that's considered as statistically insignificant.

This table showed mother who studies university have good mother more than who studies secondary and primary school.

Chapter five

5- Discussion:-

Chapter 5 presents discussion of finding collected from a sample of 100 respondents, the respondents were mother with children with SCD at jafar ibn auf hospital ,kharyoum-sudan.

The general objective of this study was to To Examined The Mother Knowledge and awareness Regarding Care Of Child With Sickle Cells Anemia at hematology clinic/ward of jafar ibn auf Hospital Khartoum City-Sudan.

The socio-demographic characteristic of this respondents which were relevant to this study were age, level education and family income, the other variable discussed are knowledge, information, prevention of complication of sickle cell disease.

5-1 Characteristic of the sample:

The sample include mother aged 20 years and above. the majority (38%) of the respondents was between 31-35 years,(26%) between26-30 years,(23%)between36-40 years,13% were between20-25 years(figure 4.1).

Majority(44%) of respondents had 3-4 child in household, while(38%) of respondents had more than 4 children, only(18%) of the respondents had 1-2 children (figure 4.2).allmost of 80% of respondents had children 1-2 with sickle cell anemia while only 20% of the respondents had3-4 child with sickle cell anemia (figure 4.3).

In terms of level of education, majority 46% of the respondent attained of university,41% attained of secondary school, while 13% attained primary school(table 4.1).

Majority 72% of respondents unemployment while28% employment (table 4.2).this could be attributed to majority of the respondents went up to university and those with only primary and secondary education they could not be employment.

In terms of monthly income for the family, majority 93% of the respondent medium,4% of respondents hight,while3% is low (table4.3)

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5-2 Discussion of variable:

Knowledge of SCD:

Knowledge is information that mother have about SCD.

Almost 84% of the respondents were able to define SCD correctly, while 83% is medium answer, the least know of respondents about 29% (table 4.4).

All most 89% of the respondents were able to know the causes of SCA , while 48% of the respondents they define it wrongly (table 4.5).

The finding showed that the commonest known symptoms of SCA by the respondents 92% fever, pale, dehydration.79% of the respondents followed by joint pain ,fatigue ,necrosis ,while 61% of respondents followed by hypertension ,tachycardia and 36% followed by chest pain and spleen enlargement(table 4.6).this was followed by another question which was asked to establish mother information about symptoms of SCD the findings showed that the commonest 48% of respondent followed by fatigue ,joint pain, Wight loss. while 43% of the respondent they said unable the child to doing exercise that demanding more oxgen.40% of the respondents followed by sudden discover by sickle cell crises appear on thier children, 6% of the respondents they known the symptoms of SCA (table 4.7).that reflect the lack of respondent knowledge about the SCA.

Majority 97% of the respondent go direct to doctors, while 18%of the respondents gave the child traditional therapy (table 4.8) that reflects the community is high educated.

The findings showed 91%of the respondents they given folic acid ,blood transfusion and antibiotic. while 88% of the respondents they gavin antibiotic and folic acid and59% only Gavin antibiotic, folic acid and blood transfusion(table 4.9).

Majority 88% of the respondent given the child nutrition content of folic acid source, vegetable and fruit, whit and red meat, while 76% of the respondents given the child vegetable and fruit, whit and red meat,37% given red meat and nutrition content of folic acid, fruit and vegetable and 19% of the respondents given whit meat only (table 4.10) that mean the community have a good knowledge about the nutrition of child with SCA.

The findings showed only38% of the respondents answer the treatment of SCA correctly, while the other respondents answer this question wrongly(table 4.11) that indicate the mother don't have enough information about the treatment of SCA.

Majority74% of the respondents the crises that affect their children inflammation and bone pain,while64% said inflammation ,bone pain, chronic pain and infucation,36% inflammation ,bone pain,choronic pain ,infection ,cholystitis and liver thorosis ,and only 24% their known all the crises of SCA.(table 4.12).that indicate the mother don't have suffusion knowledge about the crises.

89% OF the respondents said regular follow-up to treat the SCC ,84% said regular tack of folic acid and regular followup,75% said regular follow up and folic acid and nutrient vegetable that content of folic acid ,while 48% of the respondent said all the above pulse blood transfusion(table 4.13)

That mean the mother have a good knowledge of crises treatment.

The finding showed that the commonest known of predisposing factor is fever and dehydration 66%,56% followed by infection and exposure to cold ,were the least known predisposing factor doing activities demanding more oxygen 37%(table 4.14).

Crises of sickle cell disease can be prevented by employed preventive measures such as maintaining adequate nutrition to optimize the patients resistance to infection and resource for healing. in this study the commonest method known of the prevention feed the child nutrition food and folic acid 91%,the second common method plenty of fluid mentioned by 84%,and 53% restrict the child from doing exercise demanding more oxygen and dress the child warmth cloth, the last method tack the child to traditional healer 30%(table 4.15).

That reflect the mother have a good information about the prevention method of crises.

Regarding mother source of information majority 92% get information from doctor, nurse, internet ,television and radio while 82% from nurse, internet, television and radio30% television and radio, internet and23% only from internet (table 4.16) more information they given from doctor and nurse that probably because each time the mother took the child to clinic for review or when admitted to hospital ,hospital staff gave them information about SCD.

The study finding on level of education there is relationship between the level of education and the knowledge about SCA, mother who study university is knowledgeable more than who study primary and secondary school, that indicate the level of education of mother is helps to understand the information being given during clinic visit. Also there is statistical significant on occupation, the employed mother is more knowledgably than the unemployed mother.

5-3 Conclusion:

This study was conducted to determine mother knowledge and awareness of care regarding child with sickle cell anemia at hematology clinic/ward of the jafar ibn auf hospital

The study concluded that 8% of the respondents had a good knowledge of SCD, while the majority 50% had fair knowledge of SCD,and42% of the respondents had poor knowledge regarding care if child with SCD.

The study revealed that 80% of the respondents have (1-2) child with SCA and 20% had (3-4)child with SCA. the study further revealed 51% of respondents had fair knowledge of SCC ,while 37% had poor knowledge and 12% of the respondents had good knowledge. the study revealed that there is relationship between the level of education and the knowledge of SCD the more educated mother have positive practice toward prevention of sickle cell crises.

5-4 Recommendation:-

The Following Recommendation Are Based On The Findings Of This Study:

To Ministry Of Health:

-The Ministry Should Ensure That Knowledge Of Sickle Cells Anemia Booklets Are Made Available To Hospital For Mother To Be Reading In Order To Keep On Reminding Themselves On Prevention Of Sickle Cells Crises.

-Ministry Of Health Should Also Continue Funding Nursing Schools In Order To Train More Nurses And In Turn This Will Improve The Staffing Level In The Hospitals, This Will Enable The Staff To Spend More Time Reminding Mother Thought Health Education In Each Visit To Clinic On The Importance And Benefit Of Their Right Care To Their Children With SCA To Prevent Sickle Cells Crises.

To Jafar ibn auf Hospital Management:

- Jafar ibn auf Hospital Management Should Encourage Hospital Staff Need To Demonstrate The Actual Practice And Giving Information, Education And Communication On Sickle Cells Disease And Prevention Of Crises As This Would Be Of Help To Mother Because It Is Easy To Put Observe Behavior Into Practice.

  -There Also Need For Hospital Staff To Ensure That All Mother Are Given Information, Education And Communication On SCD And Prevention Of Crises On Each Visit To Hospital/Clinic As Information Given By Hospital Staff Is More Valid And Reliable Than Other Sources.

  - The Hospital Management Should Work In Collaboration With Sickle Cell Association In Khartoum In Order To Promote Behavior Change In Prevention Of Sickle Cell Crises.

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بسم الله الرحمن الرحيم

جامعـــــــة شنـــــــدي

كلية الدراسات العليا والبحث العلمي

مركز الخرطوم

النمرة : ج ش/ك د ع /م خا1/ 2018/2/19م

الى من يهمه الامر مستشفي جعفر بن عوف التخصصي

المحترمين

السلام عليكم ورحمة الله وبركاته

الموضوع : الطالبة/ مشاعر محمد خير صالح

بالإشارة إلى الموضوع أعلاه نفيدكم بأن الطالبة المذكور أعلاه من ضمن طلاب الكلية بالفصل الدراسي الرابع – ببرنامج ماجستير علوم التمريض، تخصص تمريض الأطفال، وهي بغرض توزيع استبانة لدراسة الحالة لبحث التخرج والذي عنوانه :

Motherknowledge and awareness regarding care of child with sickle cells anemia in jafar ubni owf Hospital - khartoum - sudan .

نرجو شاكرين تسهيل مهمته

ولكم فائق الشكر والتقدير،،،

الصادق أحمد عبدالقادر هباني

مسجل المركز

وزارة الصحة - ولاية الخرطوم
مستشفى د.جعفر بن عوف المرجعي للأطفال
مكتب إدارة التدريب – مكتب البحث

التاريخ 24/ 4/ 2018م

السيد / المدير الطبي (العيادة المحوله)

....المحترم....

السلام عليكم ورحمة الله تعالى وبركاته

الموضوع /إذن لإجراء بحث

بالاشاره للموضوع اعلاه نرجو من سيادتكم التكرم بمساعدة الطالبة من جامعة شندي في إجراء هذا البحث بعنـــــــــوان:-

Mother Knowledge AndAwarenessRegarding Care Of Child With Sickle Cells Anemia In Jafar Ibn Ouf Hospital Khartoum Sudan .

وذلك بعد ان وافقت لجنة اخلاقيات البحث بالمستشفى على هذا البحث بمساعده الباحثة وتسهيل مهمتها .

إسم الباحثة:-

مشاعر محمد

مستشفى د. جعفر بن عوف التخصصي لطب الأطفال
إدارة التدريب
د/ امانى حسن الخضر

مدير ادارة البحوث والتدريب

24.4.2018