



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

Train-the-Trainer Workshop

Abuja, Nigeria

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Recruiting Sickle Cell Patients....

Pediatric sickle cell unit UATH



Background: The Sickle cell unit of UATH

- Over 15years
- Suffered a major set back with death of the unit head
- Unit started thriving again in 2016 with a new consultant

Vision: To provide qualitative and accessible care aimed at reduction of disease burden for children with SCD and their families such that all may live a longer and happier life.

Slogan: THAT ALL MAY LIVE A LONGER AND HAPPIER LIFE.

Mission: Establish a comprehensive care for patients and their families

Challenges:

- Poor turn out of patients and families
- Very low health literacy level
- High prevalence of stroke/ No TCD screening
- Frequent hospitalizations
- High prevalence of depression among adolescents and mothers
- Absence of neonatal screening
- Absence of a structured Health Education
- Absence of HydroxyUrea therapy



Source of Patient Recruitment

- No New Born Screening Program
- Patients come from :
 - Referrals to clinics
 - Emergency room
 - Word of mouth
 - Parent support Group
 - Community screening (Prof Nnodu's team)



Patient statistics

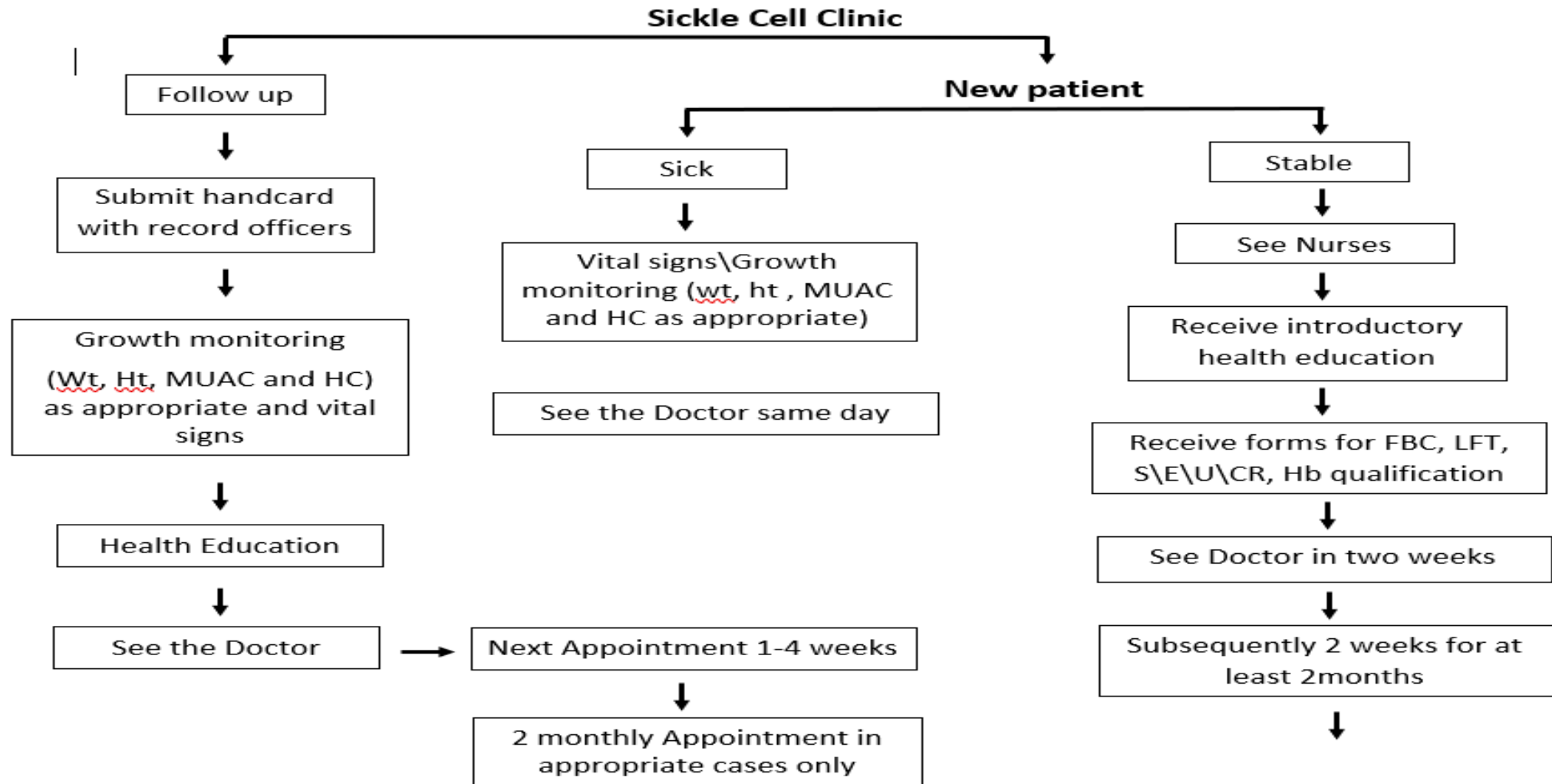
	2016	2018	2019 (end of august)
Patient Enrolment	135	518	684
Clinic Attendance	773	2736	2370
Under 3	-	136	177(26%)
Transition Clinic	-	111	148(22%)
On Hydroxyurea	-	111	127 (19%)
Received extra immunization	-	178	280 (41%)
New patients monthly average (clinic)	-	24	18
New patients monthly Average (emergency)	-		06

Patient statistics: Community screening (18months)

Total number of patients	65 (30M, 35F)
Age range	4days to 12years
0-1year	29
1-4years	23
5-9 years	08
10-14 years	05
15-18years	0



Clinic flow chart



First visit: Nurses

- welcome patients with a message of Hope and support
- Give a simple overview of SCD
- Explain services that the clinic offers
- Emphasize need for regular and long term follow up
- Introduces health maintenance education using acronym:
F.A.R.M.I.S.E.
- Second phase of H/E comes with subsequent visits: recognizing acute complications of scd: sequestration, stroke, priapism
- Reiterates message of hope and gives unit phone number for 24 hr access to the matron and other unit members. Teaches slogan.



First visit: Nurses

- Tell parents about the parent support group
- Give relevant H/E flyers
- Do FBC + Hb electrophoresis or quantification, LFT and SEUCr
- Schedule visit in 2 weeks
- Pt is contacted if appointment is missed without reason

Adolescents(from 13yrs): receive introductory message as above

In addition:

- Give preliminary information about Transition clinic
- Give “Transition clinic flyers” and “what you need to know about SCD” to take home



Some Health Education Flyers

COMPREHENSIVE SICKLE CELL CLINIC
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F.A.R.M.I.S.E.
WHAT TO DO TO REMAIN HEALTHY
Adopted from Destiny & Hope
Author: Uche Nnebe - Agumadu Version 2 Nov. 2018

F = FLUIDS, FEVER and FOOD. Drink plenty of water. Report fever immediately. Eat 3 meals and 3 snacks everyday.

A = AIR. Get enough oxygen. Avoid smoky areas or rooms without good ventilation. Asthmatics pay particular attention. Report snoring

R = REST. Get enough deep rest in between activities. You must know when your body is weak and get some rest. Rest means: Sit, drink, eat and sleep.

M= MEDICATIONS (Prevention) e.g pen V, Folic acid, Paludrine, reload, antimalarials, HydroxyUrea

I= IMMUNIZATION - Take all the childhood vaccines and also pneumococcal, meningitis and typhoid vaccines.

S = SITUATIONS TO AVOID. 1. Anything too hot or cold, 2. Strenuous exercises, 3. Working or playing outside without appropriate clothing for the weather, 4. Excessive loss of body water, 5. Excessive sweating and drying to become chilly, 6. Swimming in cold water.

E= EARLY DIAGNOSIS. EARLY PRESENTATION TO HOSPITAL WHEN SICK. Compliance with drugs and hospital visits.

Slogan: That all may live a longer and happier life

GOLDEN PRINTS: 09084721210

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BONE MARROW (STEM CELL) TRANSPLANT FOR CHILDREN AND YOUNG PEOPLE WITH SICKLE CELL DISEASE
Information for patients and families
Adapted from NHS Trust, UK
Authored by Uche Nnebe-Agumadu, MD

Bone marrow (stem cell) transplants have been used for the treatment and cure of blood diseases, cancers and immune diseases for many years. The first bone marrow transplant for sickle cell disease was performed in 1992 in a young child that had leukaemia and sickle cell disease in the United States. The transplant was performed using bone marrow from the patient's sibling. The patient was cured of leukaemia and sickle cell disease. Since then more than 1000 children with sickle cell disease have had bone marrow transplants throughout the world.

1. What is a bone marrow transplant?
In people with sickle cell disease, the bone marrow (the factory of the blood), makes red blood cells that contain haemoglobin S. This leads to the problems associated with sickle cell disease. The goal of the transplant is to replace the cells that make haemoglobin S with cells that produce haemoglobin A.
To prepare for a bone marrow transplant, strong medicines (chemotherapy) are given to the patient to weaken or destroy the patient's own bone marrow cells.
This is done so that the patient does not reject the new blood cells coming from the donor.
The patient is then given bone marrow from the donor who does

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What you need to know about Hydroxy Urea

What is Hydroxy Urea?
It is the only drug that has been approved in most part of the world for use in children and adults with sickle cell disease. It helps them and makes them live a better quality of life and a longer one too.

2. How does it help patients who take it?
a. causes reduction in bone pain crises
b. causes reduction in the need for transfusions
c. causes reduction in frequency of acute chest syndromes (like pneumonia but more serious)
d. Causes increase in your blood levels i.e haemoglobin
e. All the above will result in reduced need for hospital admissions.
f. And increase in preservation of organ function e.g liver, kidney, heart, eye will work better for a longer time
g. And finally, longer and healthier life.

3. How does Hydroxy Urea work?
Hydroxy Urea works by increasing your red blood cells. Newborn babies have this same haemoglobin at birth and it protects them from sickle cell complications during the first few months. As babies grow, their HbF is replaced by HbA which can cause sickle cell disease. Most children and adults have very low level of HbF in their red blood cell. If we can increase the level of HbF in the red blood cells of people with the sickle cell disorder, sickling of their red blood cell will be reduced. Hydroxy Urea increase this HbF in the red blood cell.

4. How is Hydroxy Urea taken?
It is taken by mouth once a day. Your doctor will work out your dose based on your weight.



SICKLE CELL UNIT
DEPARTMENT OF PAEDIATRICS
UNIVERSITY OF ABUJA TEACHING HOSPITAL (UATH)

WHAT YOU NEED TO KNOW ABOUT SICKLE CELL DISEASE

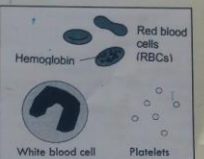
Understanding the blood
Over 5 litres of blood constantly circulate through big and small channels supplying food and oxygen to all parts of the body. There are 3 types of cells in the blood: white blood cells, red blood cells and platelets.

White blood cells are the defenders of the body. They help fight infections. However, the white cells in people with sickle cell disease do not fight infections as they do in people who do not have sickle cell. This results in increased infections.

Red blood cells are soft, round substances that carry oxygen to all parts of the body. They are the main problem in sickle cell disease. They contain haemoglobin. A change in this haemoglobin causes the problems seen in sickle cell disease.

Haemoglobin makes the blood red, picks up oxygen and releases it to different parts of the body.

Platelets are the cells that gum together to stop bleeding when there is a cut. Absence of platelets causes bleeding not to stop. Too much platelets causes blood cells to stick together when there is no cut. In sickle cell disease, the platelets are more active than in people without sickle cells thus making their blood cells to stick together.




What is sickle cell disease? [SCD]
Sickle cell disease is an inherited disease of haemoglobin. It is a disorder that occurs when someone inherits an unusual type of haemoglobin from both parents. The

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TEACHERS GUIDE

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HOW PARENTS AND TEACHERS CAN WORK TOGETHER

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TRANSITION CLINIC

WHAT YOU NEED TO KNOW





First visit: meeting the doctors

- Symptomatic patients are treated and H/E reserved for next visit
- Overview of SCD emphasizing:
 - Need for long-term follow-up
 - Need to understand and talk about scd and how it affects your child
 - Our dependence on them to take care of child until 13years
 - That we deal directly with the kids subsequently in transition clinic to prepare them for adult life.
 - Need for frequent follow-up visits in order to learn all aspects of health maintenance

Explain the 2 common symptoms of SCD: pain and anemia

We always end with a message of hope and reminding them of improved survival with adherence to our instructions and that we are together in this long journey



Meeting the doctors....

- Always give parents opportunity to ask questions

Adolescents: in addition to above, we emphasize:

- Need for personal involvement in care
- Career development and our readiness to help them achieve their dreams

Psychosocial counselling using acronym H.E.E.A.D.D.S.S. It captures the context of an adolescent's life.

With this introductory encounter, we ignite interest of the child and family on ensuring regular follow-up. They believe the future is indeed bright and our slogan lives on:

“THAT ALL MAY LIVE A LONGER AND HAPPIER LIFE”



THANK YOU





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This presentation reflects only the author(s)'s view and the EU Research Executive Agency (REA) is not responsible for any use that may be made of the information it contains.



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