ARISE

African Research And Innovative Initiative For Sickle Cell Education

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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)

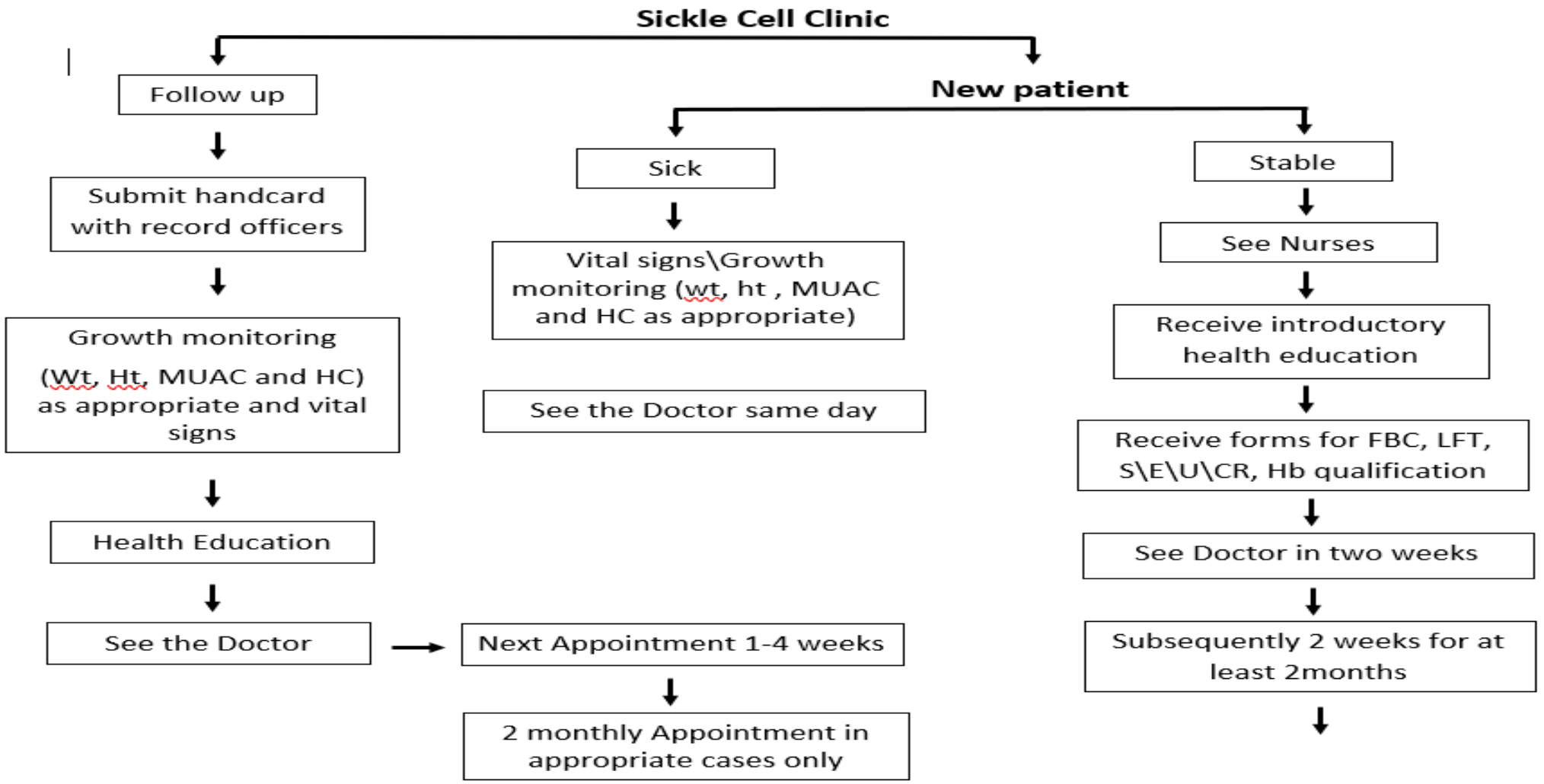
Patient statistics

	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 ……

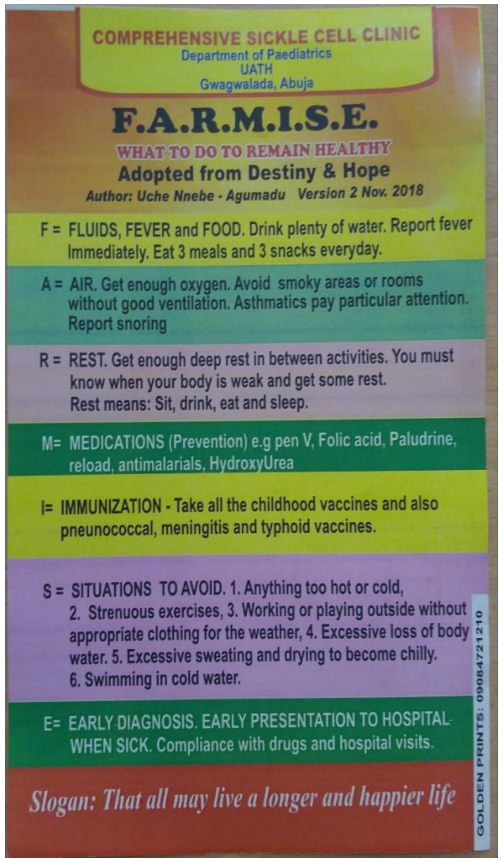
- Tell parents about the parent support group
- Give relevant H/E flyers
- Do FBC + Hb electrophoresis or quantification, LFT and SEUCr
- Schedule visit in 2 weeks
- Pt is contacted if appointment is missed without reason

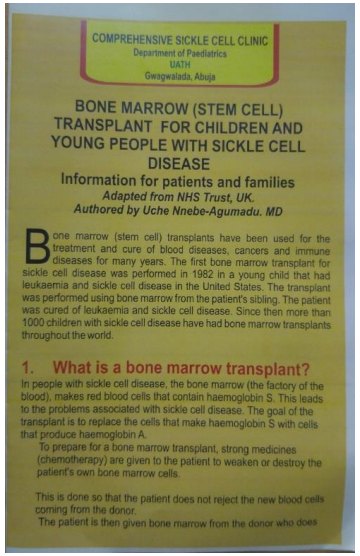
Adolescents(from 13yrs): receive introductory message as above

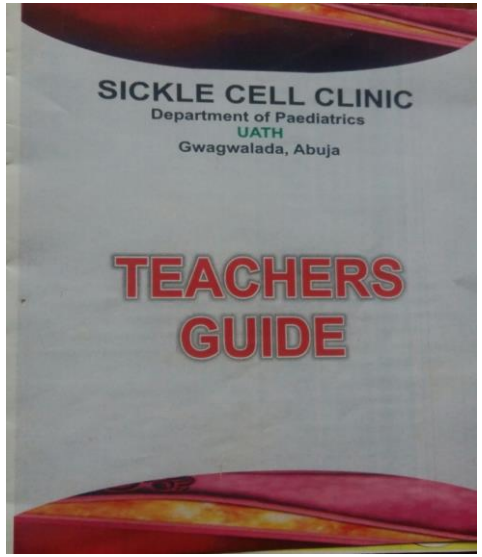
In addition:

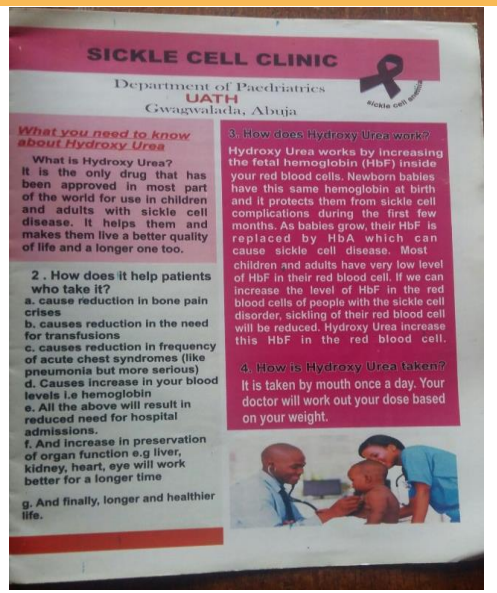
- Give preliminary information about Transition clinic
- Give “Transition clinic flyers” and “what you need to know about SCD” to take home

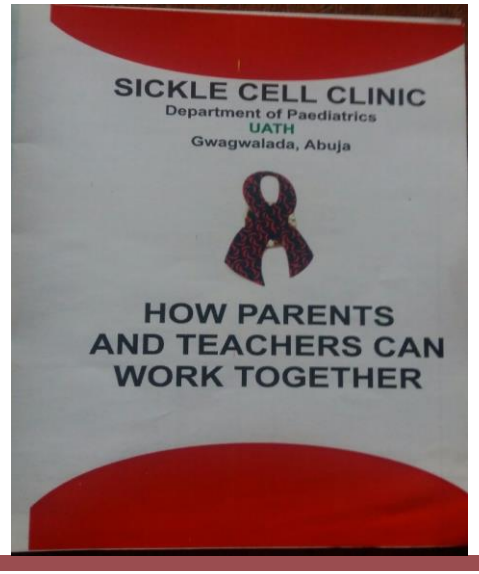
Some Health Education Flyers

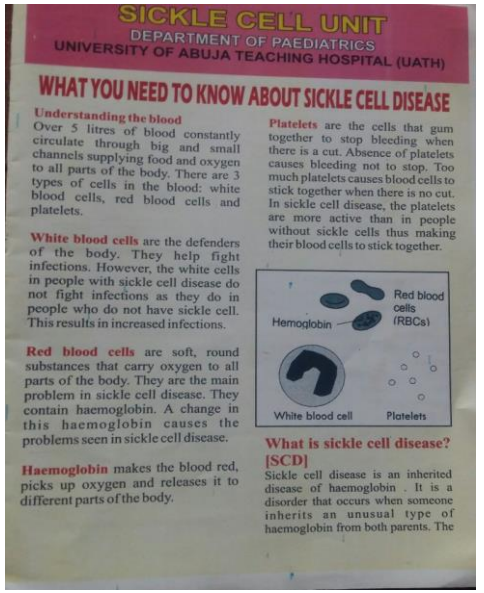


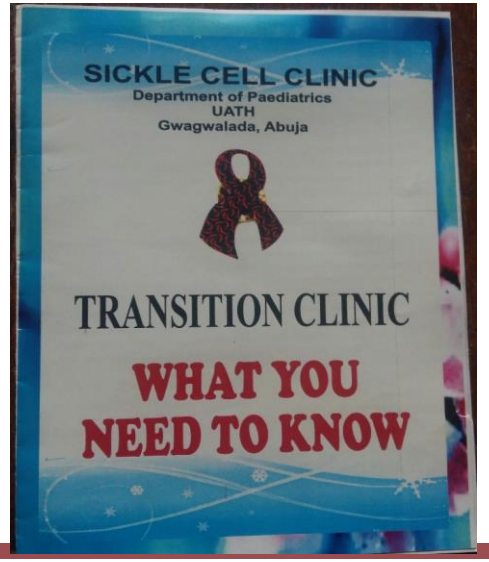












First visit: meeting the doctors

- 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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