COMMITTEE ON ADDRESSING SICKLE CELL DISEASE: A STRATEGIC PLAN AND BLUEPRINT FOR ACTION

TRUMAN MEDICAL CENTER
COMPREHENSIVE SICKLE CELL DISEASE CENTER
PROGRAM DESCRIPTION FOR ORGANIZING AND MANAGING CARE

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CERTIFIED SICKLE CELL COUNSELOR/EDUCATOR
SICKLE CELL PROGRAM MANAGER
TRUMAN MEDICAL CENTER
KANSAS CITY, MO
2008 INTRODUCTION TO SICKLE CELL


National Heart, Lung, and Blood Institute’s Evidence-Based Management of Sickle Cell Disease, 2004

Thirty plus years of nursing, 20 + as family nurse practitioner

General patient centered, bio-psychosocial chronic disease management approach to care.

Patients/families living with sickle cell
FIRST LESSON: BELIEVE THEIR PAIN
“TEN REDEFINED” BY HERZ NAZAIRE
BE CAREFUL WITH STAMPING?

Use with Caution (avoid):

- “Sickler”
- May contribute to perpetuating stigma

Consider:

- sickle “warrior”
- sickle “defier”
- Or simply, person who has sickle cell disease
2008: HU STATS

25 out of 110 patients on HU

All uniform dose of 1000 mg a day

No lab or HGB electrophoresis monitoring

No dose escalation
<table>
<thead>
<tr>
<th>Encounter Type</th>
<th>Description</th>
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<tbody>
<tr>
<td>Total weekly average visits</td>
<td>10 visits</td>
</tr>
<tr>
<td>Clinic follow up</td>
<td>5 visits every 2 months with physician</td>
</tr>
<tr>
<td>Weekday hospital</td>
<td>5 visits for urgent care for crisis</td>
</tr>
<tr>
<td>RBC exchange for stroke prophylaxis</td>
<td>1 RBC exchange for stroke prophylaxis</td>
</tr>
<tr>
<td>No inpatient consultations</td>
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2008: AHM

- Maybe annual flu vaccine
- Maybe a single PNC 23
- No Prevnar 13
- No Meningococcal vaccine
- No annual urine microablumin/cr
- Maybe dilated eye exam
- No consult with hematology
2008: OPIOID MANAGEMENT

- Rx pick up every Thursday (no assessment required)
- Clinic evaluation every 2-3 months.
- No structured opioid abuse risk assessment
- Generous/liberal escalations as needed
- Resultant high dosing – accepted standard at the time
Community
- Resources and Policies
- Self-Management Support

Health Systems
- Organization of Health Care
  - Delivery System Design
  - Decision Support
  - Clinical Information Systems

Services
- Patient-Centered
- Timely and Efficient
- Evidence-Based & Safe
- Coordinated

Productive Interactions
- Informed, Empowered Patient and Family
- Prepared, Proactive Practice Team

Improved Outcomes
MASLOW’S HIERARCHY OF NEEDS
FOCUS GROUP OUTCOME

got hydrea?
Take as directed.

It could change your life.

TMC Sickle Cell Clinic

Donna McGarr, RN, ARNP, FNP-BC
Comprehensive Sickle Cell Resource Center
(512) 580-4290

TMC
An Evening of Fun and Education in Celebration of Sickle Cell

Earn tickets
Fitness Challenge – 2 tickets
Wellness Experience – 4 tickets
Yes, you can dance! – 6 tickets
Game Master (limited activity) –
  Participant 1 ticket
  Winner 2 tickets

How you can spend your tickets:
Raffle Prize Drawings:
Your Inner Child - 1 ticket
Day at the Spa – 2 tickets
Movie Night – 3 tickets
Cake Walk – 2 tickets

The Well Cell Festival

Program

5:00 – 6:00 pm - Meet, greet, games, earn raffle tickets

6:00 – 6:30 pm - Dance Experience with Mr. Danny Diallo-Hinds

6:30 – 8:00 pm - Taco Bar

7:00 – 7:30 pm Cake Walk

7:30 - 7:45 pm Open Mic

7:45 – 8:00 pm
  Raffle Prize Drawing

Closing Remarks
THE TMC SICKLE CELL TEAM

Primary Care Medical Home Model

30 collective years with sickle cell disease management

Partner with Heartland/Southwest Sickle Cell Disease Network
EXTERNAL PARTNERS

- Heartland/Southwest Sickle Cell Disease Network

- Sickle cell provider partners (primary care, hematologists) in MO, IA, KS, NE, OK, TX, AR, LA.

- Supported by HRSA Grant with objective to increase PCP knowledge sickle cell care and meet certain benchmarks of care

- Lead PI: Allison King, MD Washington University St. Louis

- TMC Site PI: Donna McCurry, APRN, FNP-BC

- Every 3rd Friday 11AM-12PM CST.

- To Register: easowt@wustl.edu
EXTERNAL PARTNERS

HEARTLAND/SOUTHWEST SICKLE CELL DISEASE NETWORK

- Sickle cell provider partners (primary care, hematologists) in MO, IA, KS, NE, OK, TX, AR, LA.
- Supported by HRSA Grant with objective to increase PCP knowledge sickle cell care and meet certain benchmarks of care
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- **Sickle Cell Disease TeleECHO Clinic** Every 3rd Friday 11AM-12PM CST.

To Register: easowt@wustl.edu
SICKLE CELL DISEASE
TELEECHO CLINIC.

Heartland/Southwest Sickle Cell Disease Network

Serving patients and providers in MO, IA, KS, NE, OK, TX, AR, LA.

Every 3rd Friday 11AM-12PM CST. To Register: easowt@wustl.edu
SICKLE CELL EDUCATION
KIBULI NURSING SCHOOL
KAMPALA, UGANDA

Donna McCurry
Mandela Washington Reciprocal Exchange Program
American Awardee
Sharif Tusuubira
YALI Fellow
Mandela Washington Fellow
2018
GOT HYDREA?

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TMC Sickle Cell Clinic
SICKLE CELL HYDREA SUPER STARS
SICKLE CELL CRISIS ED PROTOCOL

- Opioid of choice started at highest dose tolerated
  - Q30 minutes x 3 doses with reassessments
- Benadryl 25 mg po
- Phenergan 25 mg or Zofran 4 mg ODT
- Ketorolac 30 mg IV or 60 mg IM (kidneys healthy?)
- IVF with N.S. or 0.45% NS
- If pain not controlled, admit to hospital
- Continue home pain regimen
- Continue parenteral opiate every 2-4 hours
- Consider PCA

American Pain Society/National Heart Lung and Blood Institute
Evidence-Based Management of Sickle Cell Disease, 2014
WHAT TO DO WITH THE MVPS?

MULTIPLE VISIT PATIENTS

➢ Believe their pain

➢ Sometimes hard to believe the treatment

➢ Keeping patients engaged if opioids have to be stopped

➢ “Fire the molecule, not the patient”
RECOMMENDED ACUTE PAIN PROTOCOL:
For ED:

Morphine 5 mg IV 1-3 doses at Q30 min in ED; follow by oxycodone 10 mg po x 1
No NSAID
Acetaminophen 325 mg po x 1
Benadryl 25 mg po
Consider sub-dissociative dose ketamine infusion
Hydrate orally unless there are concerns for dehydration

For Inpatient:

Continue morphine 5 mg Q3H as tolerated
oxycodone 10 mg one po Q6H
acetaminophen 325 mg Q4H scheduled
hydration as noted above
discharge with oxycodone 10 mg one po Q6H #10 with instructions to taper off at home.

NOTE: SICKLE CELL IS NOT PROVIDING ANY LONG TERM OPIOIDS AT THIS TIME
DISEASE SELF MANAGEMENT EDUCATION
BENCHMARKS OF CARE

TOTAL WEEKLY AVERAGE 40 VISITS
25 /WEEK HEALTH MAINTENANCE CLINIC FOLLOW UP
EVERY 2 MONTH VISIT WITH PHYSICIAN
3/DAY SICKLE CELL CRISIS MANAGEMENT
5 MONTHLY RBC EXCHANGE FOR STROKE PROPHYLAXIS
3 INPATIENT CONSULTATIONS/DAY

3 /YEAR PED TO ADULT TRANSITION
~38 /45 SS, SBT ON HU WORKING TOWARD MDT
MONTHLY SUPPORT GROUP
ANNUAL CONSULTATION WITH HEMATOLOGIST
NHLBI GUIDELINES
PERFORMANCE IMPROVEMENT

- Making sense of central sensitization, chronic pain syndrome in sickle cell
- Getting better at breaking the news when its time to stop opioids without breaking the patient relationship.
- Facilitating ego strong, self directed, high functioning sickle cell individuals
- Turning challenges of frequent ED visits to shared patient/provider victories.
SUMMARY

Specialty and primary care

- based on principles of chronic disease management

Multi-discipline network

- multi-organizational
- regional,
- national,
- international
STAY COMPASSIONATE

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REMEMBER YOUR WHY

THANK YOU!