Community Health Workers Support Sickle Cell Health Maintenance

October 2017
Lewis Hsu, MD, PhD
Director, Pediatric Sickle Cell
UI Health Sickle Cell Center

Professor of Pediatrics
University of Illinois at Chicago
DISCLOSURE STATEMENTS

• Dr Hsu receives research contract funding for conduct of clinical trials of pharmaceutical agents from Astra Zeneca, Purdue Pharma, Pfizer, Sancilio, Emmaus, Global Blood Therapeutics, Incyte, and research funding from NIH and Center for Medicare & Medicaid Innovation.

• Consultant/ advisor on sickle cell for Pfizer.

• Consultant/ advisor on education and clinical care for Hilton Publishing, EmmiSolutions, DePaul University, Gerson-Lehman Group

• Volunteer Vice Chief Medical Officer for Sickle Cell Disease Association of America, medical advisor for Sickle Cell Disease Association of Illinois, Have a Heart for Sickle Cell Anemia. Member of SCORE, friend of Dr. Baba Inusa

• Hydroxyurea is not approved by FDA for children with sickle cell disease or for , but is endorsed by NHLBI 2014 guidelines
Social and cultural **alignment** of community health workers with the population they serve is an important aspect of CHW intervention. CHW improve patient-centered outcomes in underserved communities and other diseases.

Who.int

www.swctahaec.org
CHW can make Care Coordination happen!

My CHW cases come from Chicago, Atlanta, Philadelphia, and DC, but I hope to learn about UK, Jamaica, Nigeria, Brazil, India, …
Practice Barriers – Lack of access to comprehensive SCD care
- CHW makes early contact after newborn diagnosis
- CHW assist with identifying a provider
- CHW helps remote follow-up

Physician Barriers - Lack of resources allocated to SCD care
- CHW educates about disease management
- CHW tracks routine care

Patient Barriers – Socioeconomic, education, insurance, lack of adherence
- CHW identifies relevant community resources
- CHW facilitates access to community resources
- CHW reminds about appointments
- CHW assists with medication adherence
- CHW educates about disease management
- CHW provides social support

Sickle Cell Patient Council & Support Group

Community Health Worker

Clinic

UIC sickle consult

Care Coordinator in Hospital & Clinic

Hospital

Emergency Clinic

Hom e

Sickle Cell Champion In Emergency Dept

Chronic Disease Self-Mgt Workshop with Sickle Cell Disease Assoc of Illinois
Care Coordination: A Community Health Worker has core skills like listening, and knows the community well.
Care Coordination: CHW has core skills & knowledge. Training & experience adds Health skills, knowledge, and access to team.
NEWBORN SCREEN – EARLY CONTACT
• Pediatric sickle clinic cannot get a newly diagnosed baby to come for follow-up appointment or start prophylactic penicillin. Can the CHW persuade the family to come in? If not, the next step is filing a report of child neglect.

New mother says, “My baby looks fine! I don’t believe the test! I have seen adults with SCD and they are thin, they have yellow eyes, and they have pain. My baby is not showing any of those signs. I don’t want an appointment in the sickle cell clinic! Stop calling me.”

→Sympathize & leave her alone? Call child protective services? Other options?

University of Illinois Hospital & Health Sciences System

Changing medicine. For good.
EDUCATE ON MEDICATION ADHERENCE
19yo with sickle cell disease SS says “Can you help me? I want my prescriptions by mail or by phone for the next 6 months. Our car broke down and we don’t have money for repair. I cannot get to medical appointments for awhile.”

How will a Community Health Worker respond? (more than one correct answer)
(a) Sure! Let’s practice talking to your doctors with this request
(b) I know a good car mechanic
(c) It depends on your medications, what are they?
(d) What about public transit? Or medical transportation van?
EDUCATE ABOUT DISEASE MANAGEMENT
3yo with sickle cell disease SS is ready for day care. The day care center wants to postpone enrollment until she no longer has this disease, because other kids could catch sickle cell.
A 13yo with sickle cell disease SS says “I just watched the Winter Olympics. I want to be a pro snowboarder and race down really high mountains in the giant slalom.

• My family never lets me go skiing or snowboarding. Winter is a tough season for me and cold triggers my sickle pain. I get tired before other kids do, but I will work to get in better shape.

• Can you get me a referral to physical therapy and sports trainers?”

(note SS can be severe, racing might not be compatible with rest breaks)
NAVIGATE THE HEALTH SYSTEM
An 18yo and 19yo both have SCD-SS and frequent admits for pain. They often talk and text each other. Some nurses state that they arrange to get admitted and discharged together. These staff question their pain and nickname them “the sickle cell party club.”

- You are asked to talk to these young ladies about how to manage their frequent admissions, and how others perceive them.
REMIND ABOUT APPOINTMENTS
20yo who had stroke has many appointments every month (transfusion, hematology, neurology, and other specialists). She comes by medical shuttle vans, requested 3 days in advance. She recently moved out of her mother’s home.

• **Now she misses at least one appointment each month.**

• Sometimes the van is late. Sometimes she forgot.

• Sometimes she woke up late.

• Sometimes appointments are too close together.
This 20yo young lady with stroke has many appointments but which have highest priority?

How will you help her to determine and focus on the highest-priority appointments?

(There might be more than one correct answer)

(a) Her choices determine the priorities
(b) Every appt must be equally important
(c) Ask the nurses
(d) Ask the doctors
(e) Ask the pharmacists
(f) Ask the social workers
16yo is proud! He found an after-school job. He sells Christmas trees from a parking lot in Chicago. He suffers more sickle cell pains because of the cold exposure, but he has avoided the ED because he has enough pain meds to take around-the-clock.
542 SCD patients age 15-44 years received treatment at participating institutions in year of observation, but only 247 (46%) received regular ambulatory care (at least two outpatient visits).
VALUE OF REGULAR COMPREHENSIVE CARE

**Care coordination**
- Prescriptions
- Forms for school or work

**Screening**
- TCD for SS and S beta-zero thal
- Retinopathy
- Avascular Necrosis
- Microalbuminuria
- Pulmonary hypertension
- Education / transition readiness

**Support**

**Research**
SCHOOL ISSUES

504 Plan – ADA accommodation for health condition

- Avoid dehydration
  - Ready access to water
  - Frequent urination
- Avoid exhaustion
  - Rest breaks in gym
  - Exercise at own pace
- Allow for pain, avoid triggers
  - Extra time for class change
  - Reduce stairs or more time
  - Extra set of books
  - Pain meds at school
  - Bus transportation

IEP Individualized Ed Program

- Extra time when ill
- Neurocognitive testing
- Work ahead of the class

Others

- Bullying
- Absences
- Jaundice
- Delayed puberty
- Realistic career / vocation
The school nurse said my child’s immunizations are up to date, but ... the sickle cell center says that there are other shots missing!
Figure 1. Recommended immunization schedule for persons aged 0 through 18 years – United States, 2016.

(For those who fall behind or start late, see the catch-up schedule [Figure 2]).

These recommendations must be read with the footnotes that follow. For those who fall behind or start late, provide catch-up vaccination at the earliest opportunity as indicated by the green bars in Figure 1. To determine minimum intervals between doses, see the catch-up schedule (Figure 2). School entry and adolescent vaccine age groups are shaded.

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Birth</th>
<th>1 mo</th>
<th>2 mos</th>
<th>4 mos</th>
<th>6 mos</th>
<th>9 mos</th>
<th>12 mos</th>
<th>15 mos</th>
<th>18 mos</th>
<th>19-23 mos</th>
<th>2-3 yrs</th>
<th>4-6 yrs</th>
<th>7-10 yrs</th>
<th>11-12 yrs</th>
<th>13-15 yrs</th>
<th>16-18 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B (HepB)</td>
<td>1st</td>
<td>2nd</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rotavirus (RV) / RV1 (2-dose series); RV5 (3-dose series)</td>
<td>1st</td>
<td>2nd</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diphtheria, tetanus, &amp; acellular pertussis (DTaP)</td>
<td>1st</td>
<td>2nd</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemophilus influenza type b (Hib)</td>
<td>1st</td>
<td>2nd</td>
<td>3rd</td>
<td></td>
<td>4th</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumococcal conjugate (PCV13)</td>
<td>1st</td>
<td>2nd</td>
<td>3rd</td>
<td></td>
<td>4th</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inactivated poliovirus (IPV: &lt;18 yrs)</td>
<td>1st</td>
<td>2nd</td>
<td></td>
<td>3rd</td>
<td></td>
<td>4th</td>
<td>5th</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influenza (IV; LAIV)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td>5th</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measles, mumps, rubella (MMR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td></td>
<td></td>
<td></td>
<td>4th dose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varicella (VAR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meningococcal (Hib-MenCY) ≥ 6 weeks; MenACWY ≥ 9 mos; MenACWY-CRM ≥ 2 mos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tetanus, diphtheria, &amp; acellular pertussis (Tdap)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Human papillomavirus (HPV: females only; 4vHPV: males and females)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annual 1 or 2 doses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This schedule includes recommendations in effect as of January 1, 2016. Any dose not administered at the recommended age should be administered at a subsequent visit, when indicated and feasible. The use of a combination vaccine generally is preferred over separate injections of its equivalent component vaccines. Vaccination providers should consult the relevant Advisory Committee on Immunization Practices (ACIP) statement for detailed recommendations, available online at http://www.cdc.gov/vaccines/hcp/acip-recs/index.html. Clinically significant adverse events that follow vaccination should be reported to the Vaccine Adverse Event Reporting System (VAERS) online (http://www.vaers.hhs.gov) or by telephone (800-822-7967). Suspected cases of vaccine-preventable diseases should be reported to the state or local health department. Additional information, including precautions and contraindications for vaccination, is available from CDC online (http://www.cdc.gov/vaccines/recs/vacc-admin/contraindications.htm) or by telephone (800-CDC-INF0 (800-232-4636)).

This schedule is approved by the Advisory Committee on Immunization Practices (http://www.cdc.gov/vaccines/acip), the American Academy of Pediatrics (http://www.aap.org), the American Academy of Family Physicians (http://www.aafp.org), and the American College of Obstetricians and Gynecologists (http://www.acog.org).

NOTE: The above recommendations must be read along with the footnotes of this schedule.
FACILITATE ACCESS TO COMMUNITY RESOURCES
13yo with sickle cell disease SC says “I want to be a professional basketball player

• I know that I get tired before other kids do.
• I will work to get in better shape and I will be able to run longer.
• Can you get me a referral to physical therapy and sports trainers?”

(note SC can be less severe than SS, basketball allows rest breaks)
HELP COMMUNITY HEALTH WORKERS BE MORE EFFECTIVE

⇒ SPECIFY CLINICAL PRIORITIES
A CASE OF INFORMATION SILOS

The clinical team is happy to refer an 18 year old to the CHW. He is in the hospital and emergency department for sickle cell pain more days than he is at home, but never comes to appointments.

They give the CHW his name and phone number but no further discussion.

The CHW does not have access to clinic charts and history.
A CASE OF INFORMATION SILOS

The clinical team gave the CHW only a name and phone number
The CHW does not know the history

“Do you have any problems with getting to appointments?”
“No”
“OK. Do you need help with anything else?”
“I want an afterschool job and I want to join a support group”
CLINICAL FACULTY

- Victor Gordeuk, MD
- Michel Gowhari, DO
- Robert Molokie, MD
- Shivi Jain, MD
- Johara Hassan, MD
- Santosh Saraf, MD
- Angela Rivers, MD, PhD
- Lewis Hsu, MD, PhD