Evaluating and Addressing Challenges to Optimal Sickle Cell Disease Care: Health Literate Care Model

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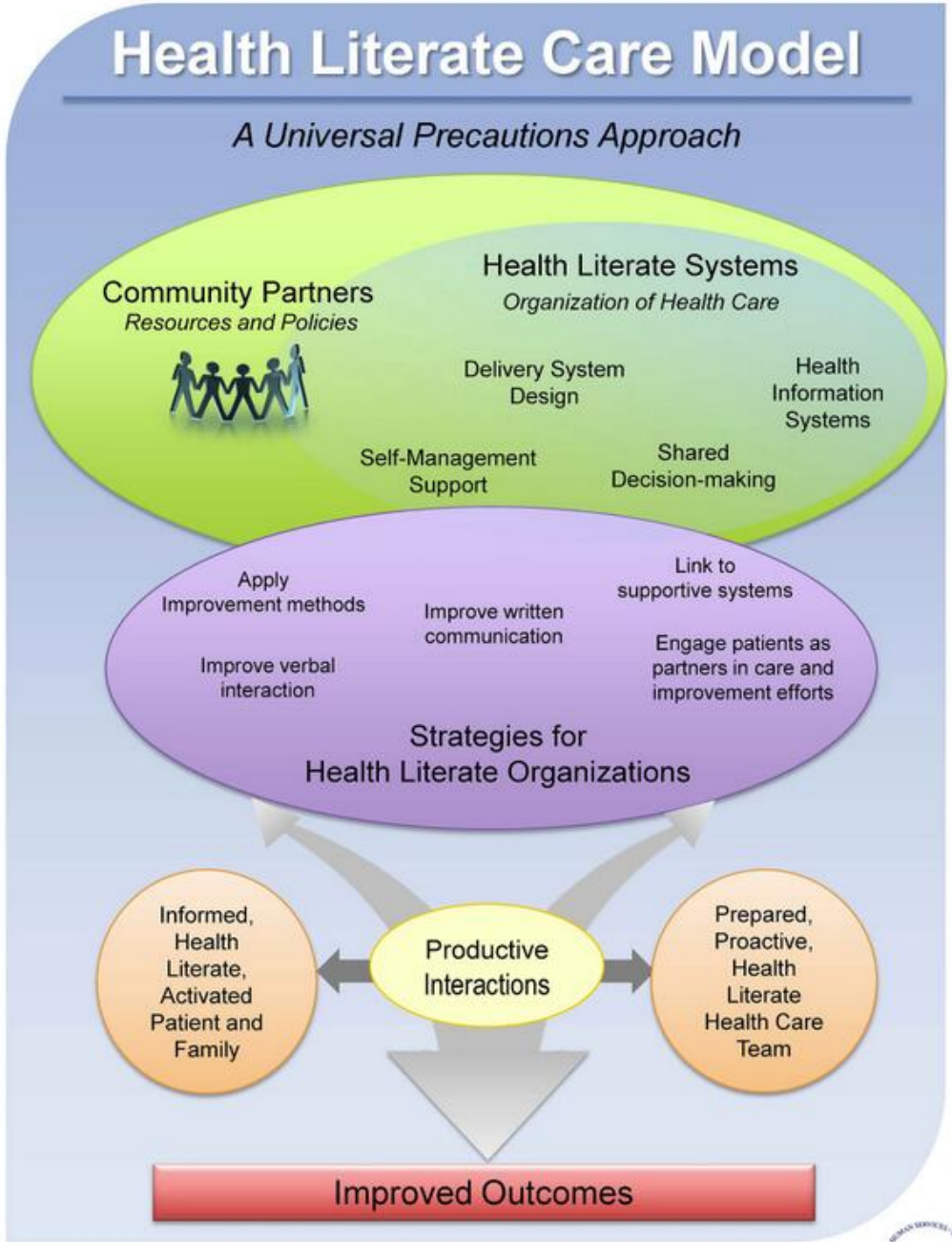
Objectives

- Review challenges to optimal SCD care within framework of the Health Literate Care Model
- Discuss strategies to overcome the barriers, emphasizing the partnership between clinicians, researchers, individuals with SCD and their families, and the community

Challenges to Optimal Sickle Cell Disease Care



See: Koh, H.; Brach, C.; Harris, L.M.; and Parchman, M.L. (2013) "A Proposed 'Health Literate Care Model' Would Constitute A Systems Approach to Improving Patients' Engagement in Care." *Health Affairs*. No. 2 (357-367).

Delivery System Design

- Lack of access to knowledgeable providers
- Bias, discrimination and stereotyping lower trust in healthcare system
  - Providers insensitive to SCD pain experiences and overly concerned about addiction, leading to failure to provide timely and adequate pain control when needed
  - In turn, negative health care experience may lead to postponement of seeking healthcare, self-discharge from the hospital and non-adherence

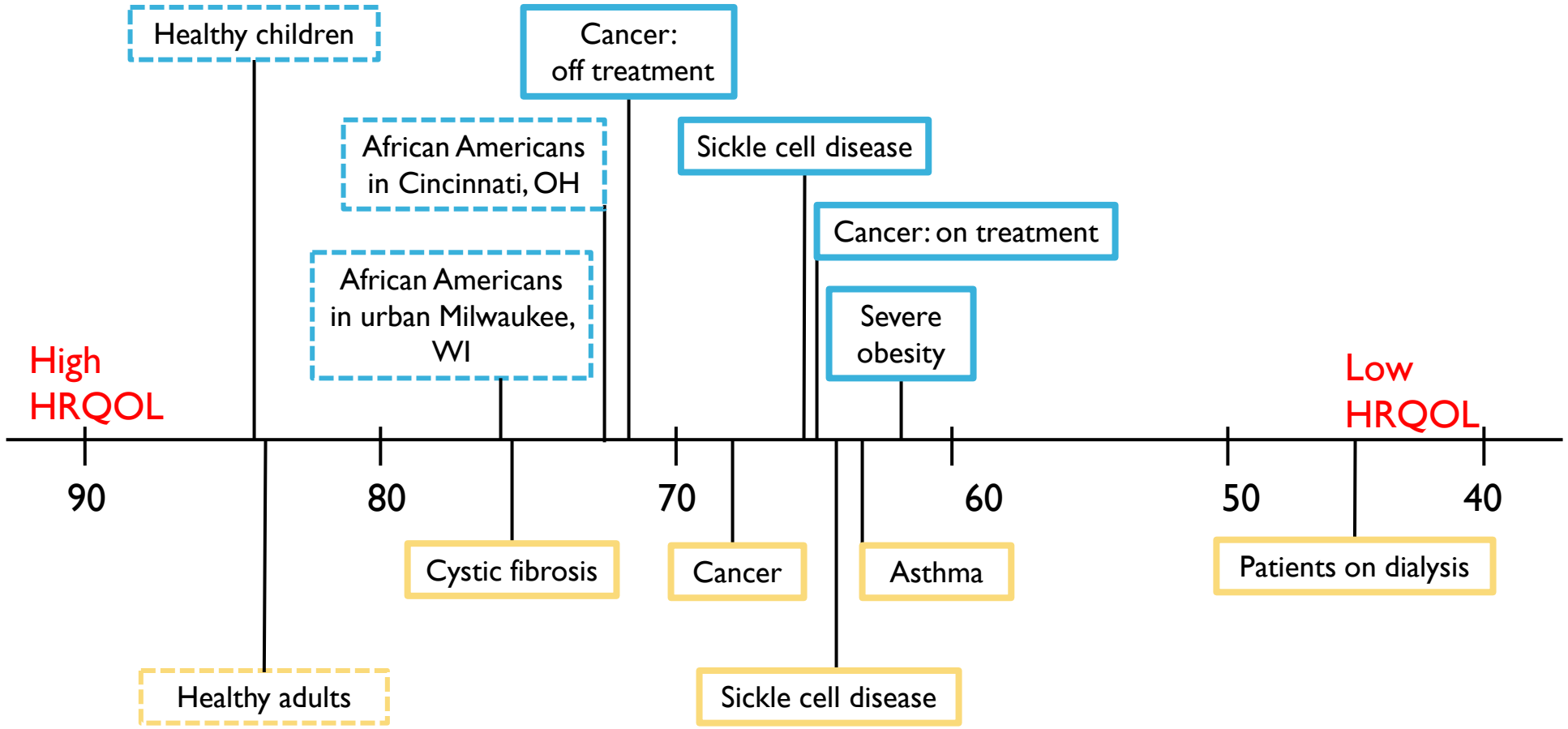
Haywood et al *J Gen Intern Med* 2014;29:1657-62
Jenerette et al *Pain Manag Nurs* 2014; 15:324–30
Haywood et al *J Hosp Med* 2010; 5:289–94
Sobota et al *Am J Hematol* 2011; 86:512-5
Haywood et al *JNMA* 2009:101;1022-33
Yawn et al *JAMA* 2014; 312:1033–48

Self-Management Support: Burden of Sickle Cell Disease

- Negative thinking and behavioral coping associated with increased pain intensity and healthcare utilization when in pain
- Greater healthcare utilization and use of opioids associated with lower mood and greater activity limitations
- Cerebrovascular disease, particularly ischemic brain injury or stroke is one of the most disabling complications of SCD
  - Language and verbal problems, visual/motor deficits, attention and executive functioning

Anie *British J Haematol* 2005:129;723–29
Vichinsky et al *JAMA* 2010;303:1823-31
Sanger et al *J Clin Exp Neuropsychol* 2016;38:661-71

Relative Burden of SCD

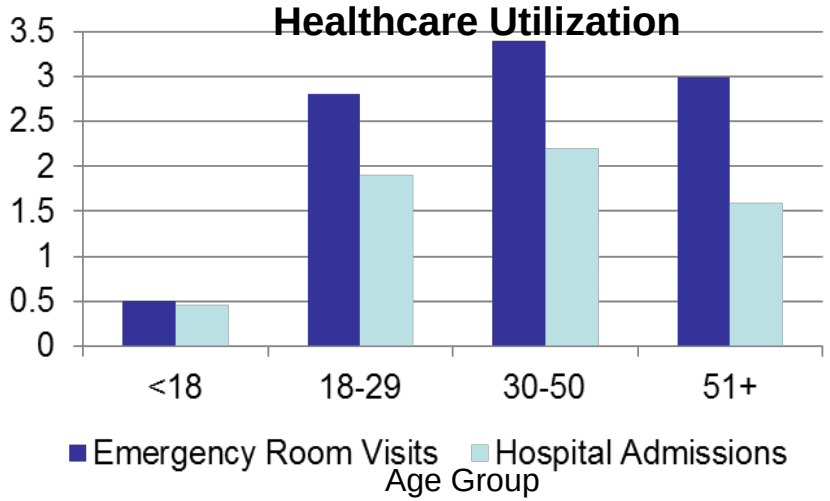


Healthy pediatric population
Healthy adult population
Children with illness
Adults with illness

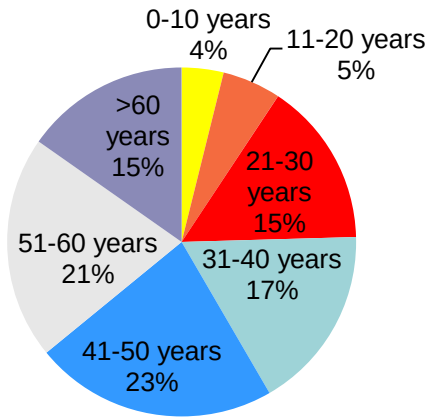
Adapted from: Panepinto J *Hematology* 2012;1:284-89

Self-Management Support: Age Related Disparities

- Pain episodes most frequent between 19 – 39 years of age
- In population based studies, adults with SCD 18 – 30 years have highest inpatient and ED utilization and 30 day rates of re-admission
- Dallas Newborn Cohort - 940 patients, 8857 patient years of follow-up - 7 new deaths occurred since 2002 – all in over 18 year age group and within 2 years of transfer



Age at Death for People with SCD 2004-2008



Brousseau et al *JAMA.* 2010;303:1288-94
Quinn et al *Blood* 2010;*115*:3447-52
Paulukonis et al *Pediatr Blood Cancer* 2014;6:2271-6
Yusuf et al *Am J Prev Med* 2010:38;S

Self-Management Support: Youth in Transition

- 70 youth (17 ± 3 years) showed low readiness for transition
  - Limited knowledge, prior thought, interest
  - High anticipated difficulty
- 19 youth/young adults with SCD (20 ± 2.5 years) and 8 healthcare providers identified barriers to self-management:
  - Belief that their health would not suffer
  - Lack of tailored self-management support and mechanism to visualize self-management progress
  - Limited opportunities for peer interaction around self-management

Crosby et al *Pediatr Blood Cancer* 2016 Aug 30. doi: 10.1002/pbc.26177
McPherson et al. *Pediatr Blood Cancer* 2009;52:838–41

Self-Management Support: Youth in Transition

- Other barriers
  - Lack of financial independence and decision-making experience
- For youth already transitioned, barriers included
  - Perceived negative attitudes of adult staff
  - Lack of SCD specific knowledge for patients and staff
  - Competing priorities interfering with transition preparation
  - Issues in employment, insurance

Jordan et al *J Pediatr Hematol Oncol* 2013;35:165-9
Sobota et al *J Hematol Res.* 2015;2:17-24
Bemrich-Stolz et al *Int J Hematol Ther* 2015;1

Self-Management Support: Adults with SCD

- For 103 adults (18 – 30 years) with SCD, the quality and availability of social supports was associated with perceived self-care ability and self-care actions

Jenerette, Brewer *J Natl Med Assoc* 2010;102:1050-55
Matthie et al *Pain Manag Nurs* 2015; 16: 257–66

Self-Management Support: Children with SCD

- Importance of health beliefs
  - 163 caregivers of children with SCD completed measures of health beliefs, trust and adherence with a fever management protocol
  - Although trust in providers was high, as was the belief in importance of prompt fever evaluation, 45% of caregivers surveyed reported that they did not always adhere to the guidelines
  - The most adherent caregivers demonstrated greater belief in perceived susceptibility to fever/infection and benefits of prompt evaluation

Schultz et al *Pediatr Blood Cancer* 2015 Nov;62(11):1968-73

Shared Decision Making

- Under-utilization of evidence based therapies
- Hydroxyurea as exemplar
  - Providers – concerns about patient adherence, lack of knowledge, concerns about side effects
  - Families – concerns about side effects, increased laboratory monitoring, obtaining laboratory refills
  - Systems – poor access to care/lower quality of care, lack of a medical home, limited access to comprehensive sickle cell centers, lack of care coordination, and poor transition from pediatric to adult care

Brandow, Panepinto *Expert Rev Hematol* 2010:3;255-260

Shared Decision Making

- Assessed perceptions of hydroxyurea among SCD stakeholders using social media – 145 original messages and 2618 affiliated comments
- Perceptions that hydroxyurea masks SCD symptoms (e.g. artificially improving blood counts)
- Concerns about increased difficulty with accessing acute care when needed
- Concerns about hydroxyurea as a “cancer drug”

Walker et al https://ash.confex.com/ash/2016/webprogram/Paper96538.html

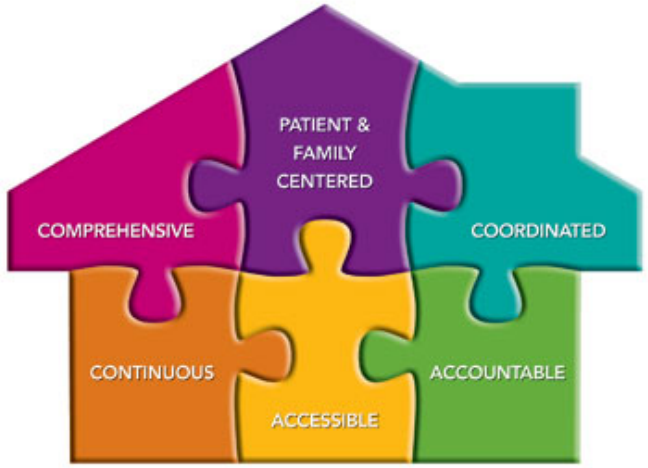
Shared Decision Making - Transplant

- Patient/family barriers
  - Fears of transplant related mortality, morbidity; risk of long-term complications (GVHD/infertility)
  - Comfort with chronic transfusion regimens
  - Gaps in knowledge about natural history/progressive organ damage
  - Mistrust of healthcare professionals
- Health care provider barriers
  - Provider reluctance to recommend HSCT
  - Gaps in knowledge about role of HSCT

van Besien et al *Bone Marrow Transplant*. 2001;28:545-9.
Benjamin *Ethn Health* 2011;16:447-63

Health Information Systems

- Care coordination – core element of the medical home
  - Only 11% of children with SCD in one study (16/150) qualified as having access to all four elements of PCMH (regular provider, comprehensive care, family-centered care, coordinated care)
  - Communication between medical and non-medical providers often rated as problematic
  - Patients/families often describe inability to contact providers, extended wait times, inconvenient clinic hours



Rattler et al *Am J Prev Med* 2016;51:S55-61
Jacob et al *J Adv Nurs* 2016;72:1417-29
Raphael et al *Pediatr Blood Cancer* 2013; 60: 275-80

Community Partners - Disparities

- Cystic fibrosis affects primarily Caucasians, and occurs in only a third of the numbers affected by SCD, but received 3.5 times more NIH and 400 times more private funding compared with SCD
- No drugs were approved between 2010 and 2013 for the treatment of SCD compared with five for CF
- Disparities in healthcare, particularly pain management, well documented

Strouse et al *Blood* 2013 122:1739
Gibson *www.themartincenter.org* 2013
Evensen et al *Medicine* 2016; 95: e4528 e4528.

Community Partners – Social Determinants of Health

- SDoH – social, economic and physical conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks
- Patterns of social engagement and sense of security and well-being affected by where people live
- Resources that enhance quality of life have significant influence on population health outcomes

IOM *Primary care and public health* 2012

Social Determinants of Health

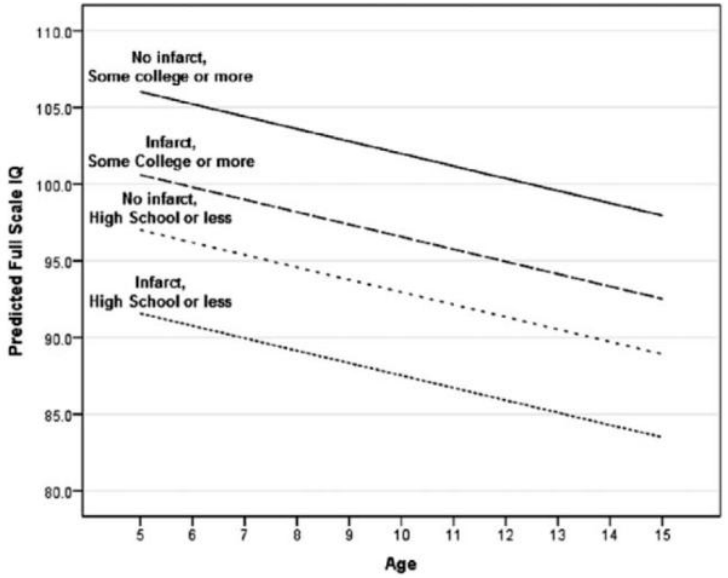
- In SCD, poverty associated with
  - High prevalence of poor psychological adjustment
  - Academic underachievement
  - Unemployment
  - Increased utilization for acute events

- Exposure to neighborhood stress also contributes to diminished HRQoL
- Risks associated with poverty and illness are cumulative

Laurence et al *J Natl Med Assoc. 2006; 98:365-9*
Yarboi et al *Child Neuropsychol* 2015 Nov
Barbarin, Christian *J Black Psychol* 1999;25:277-93
Palermo et al *J Pain* 2008;9:833-40

Predictors of Neurocognitive Challenges

- 150 children 5 – 15 years screened for silent cerebral infarcts and completed assessments of cognitive functioning



- Among 536 students 5 – 15 years, household income associated with grade retention while presence of SCI was not
- For adults, cognitive impairment contributed to the risk of unemployment

King et al *Am J Hematol* 2014;89:162-7
King et al *Am J Hematol* 2014; 89: E188–92
Sanger et al *J Clin Exp Neuropsychol* 2016;38:661-71

Assessing Barriers to SCD Care

Assessment of SDoH

- Brief, validated measures to assess patient/family context in the domains of
  - Financial resource strain
  - Stress
  - Depression
  - Social Isolation
- Also attend to
  - Neighborhood
  - Head of household education/health literacy
- Make connections with community resources, identify need for more resources

Adler, Stead *N Engl J Med* 2015:372;698-01

Patient Reported Outcomes

- NIH has sponsored the development of precise, flexible and comprehensive measurement systems

  http://www.healthmeasures.net/
- Shared, unifying terminology and metrics for PRO measurement to improve:
  - Patient-centered research, clinical trials reporting, population monitoring, global health
- Clinical relevance
  - Measure changes in PROs, compare the PROs of patients with different conditions, monitor patients who receive different treatments, design interventions

Alonso et al *Health and Quality of Life Outcomes* 2013;11:210
Fayers P, Hays RD *Assessing quality of life in clinical trials* 2005

Primary HealthMeasures	Secondary HealthMeasures
Adults with SCD	
ASCQ-Me Measures	**ASCQ-Me Measures**
Pain Impact	Emotional Functioning
Pain Episodes	Social Functioning
Stiffness Impact	Sleep Impact
PROMIS Measures	**PROMIS Measures**
Pain Interference	Cognitive Functioning
Fatigue	Physical Function
	10 item Global Health Scale
Measures available in computer adaptive or fixed forms	

Quality of Care

ASCQ-Me
Adult Sickle Cell Quality of Life Measurement Information System

- Developed and pilot tested SCD quality of care questions consistent with Consumer Assessments of Healthcare Providers and Systems surveys
- N =556 at 7 U.S. sites, 63% aged 18 to 34 years; 64% female; 64% SCD-SS
- Identified factors: Access, Provider Interaction, and ED Care composites
- Compared to general adult CAHPS scores, adults with SCD had worse care, adjusted for age, education, and general health

Evensen et al *Medicine* 2016; 95: e4528

Primary HealthMeasures - Pediatric SCD

PROMIS Measures
Physical Functioning Mobility
Physical Functioning Upper Extremity
Pain Interference
Fatigue
Depressive Symptoms
Anxiety
Peer Relationships
Anger

Dampier et al *Pediatr Blood Cancer* 2016;63:1031 - 37
Dampier et al *Pediatr Blood Cancer* 2016;63:1038 – 45

ED-SCANS and PNA-SCD

Emergency Department Sickle Cell Assessment of Needs Survey

- Research-based
- Quality improvement (QI) framework
- Seven key decisions
- Supported by algorithm
- Suggesting best practices

http://sickleemergency.duke.edu/emergency-department-sickle-cell-assessment-needs-and-strengths-ed-scans

Psychosocial Needs Assessment in SCD

- Guided by ED-SCANS
- Decision 4 (high risk, high user) and 7 (referrals, particularly for psychosocial needs)
- Guided by Chronic Care model
- Based on responses from patients with SCD seen in the ED

Tanabe et al *Adv Emerg Nurs J* 2013; 35: 143–53

Health Related Stigma

- Devaluation, judgment or social disqualification based on a health-related condition
- “Diagnosis profiling”
  - Frequent flier
  - Sickler, sickler personality
- 11 item **Measure of Sickle Cell Stigma** loaded on the factors *Social Exclusion, Internalized Stigma*, and *Expected Discrimination* and was associated with patient-reported perceptions of disease severity and utilization
- **SCD Health Related Stigma Scale** also reliable, valid tool

Bediako et al *J Health Psychol* 2016; 21: 808-820
Jenerette et al *Issues Mental Health Nurs* 2012;33:363–69

Addressing Barriers to SCD Care

Reducing Stigma

- Young adults with SCD 18 – 35 years (n = 90) were randomized to care-seeking intervention (CSI) or attention control
- Participants in CSI were able to utilize communication skills to decrease health related stigma, compared with control group

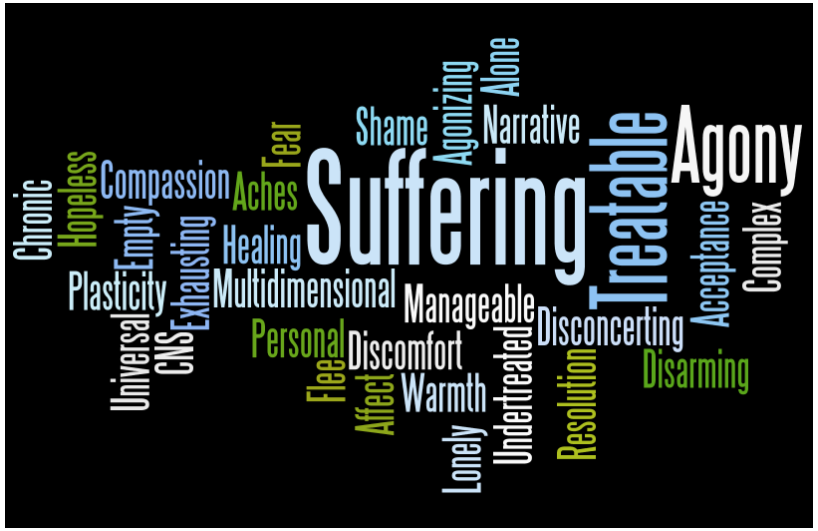
Jenerette et al West J Nurs Res 2014;36:599-619

Addressing Adequacy of Pain Management

- It is possible to directly impact negative provider attitudes
  - Both a 2.5 day high-intensity educational and experiential intervention using videos about the SCD patient experience and a 90 minute in-service were associated with improvement of attitudes of pediatric providers toward patients with SCD
  - Emergency department providers' (n = 96) attitudes improved after viewing an 8 minute online video designed to address misconceptions and stereotypes

Haywood et al *Hospital Pediatrics* 2015:5;377-84
Puri et al *J Pain Symptom Manage* 2016;51:628-32

Addressing Adequacy of Pain Management



- Many types of interventions can be effective to improve provision of appropriate pain management
  - Clinical protocols
  - Audit and feedback to providers
  - Circumvention of emergency department with direct admit or day hospital utilization

Haywood et al *J Natl Med Assoc* 2009:101; 1022 – 33
Treadwell et al *J Clin Outcomes Manag* 2014:21:62-70
sicklecell.nichq.org

Self-Efficacy

- Belief in one's ability to succeed in specific situations or accomplish tasks
- 9 item Sickle Cell Self-Efficacy Scale has been evaluated in a number of studies to date
- In our multi-site study (n = 125), youth with SCD and higher self-efficacy expressed better readiness for transition to adult care/adult life; higher self-efficacy was associated with decreased reports of stress

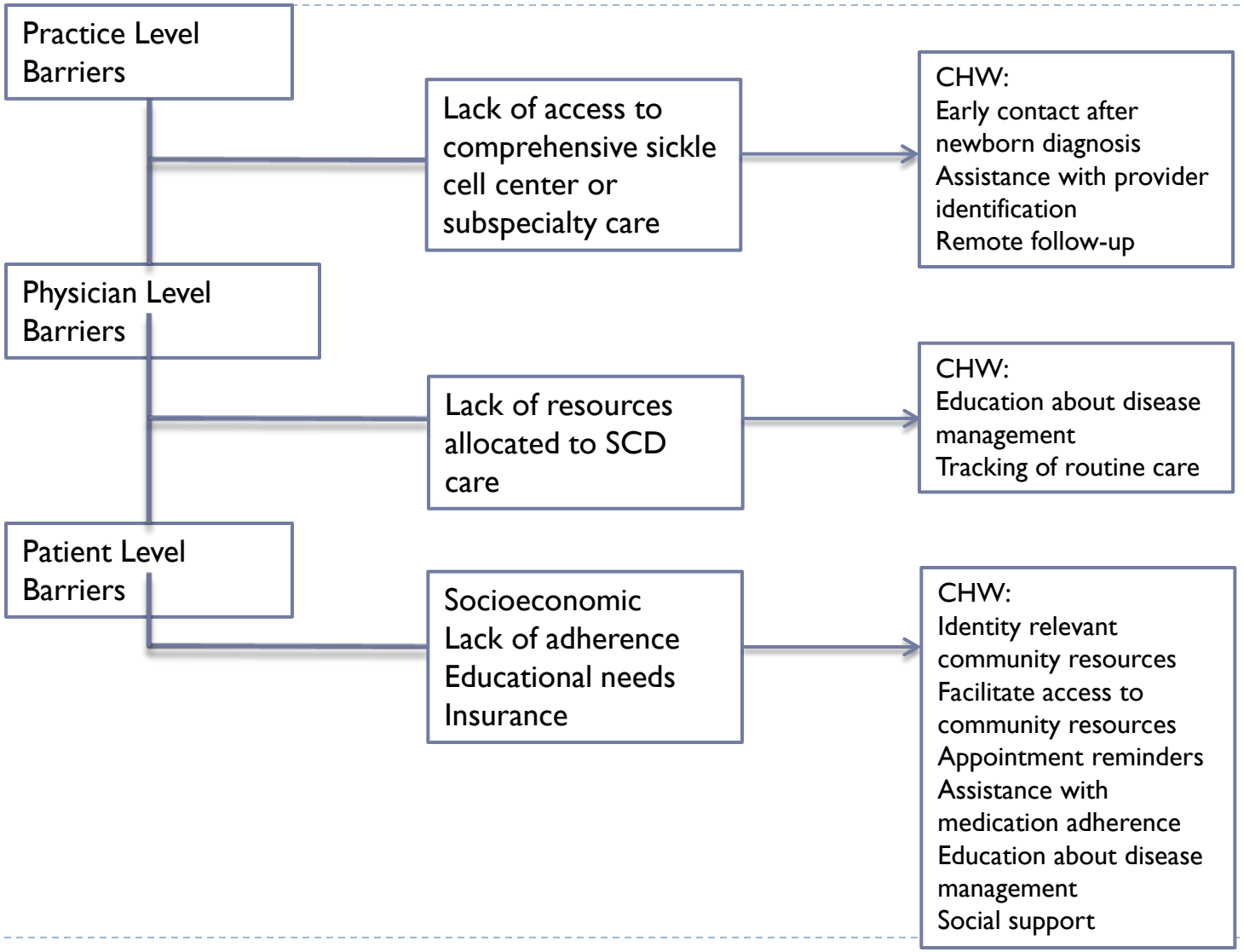
Edwards et al *Behav Research Therapy* 2000:32;951-63
Treadwell et al *Int J Adol Health* 2015

Self-Management Support

- There are few well designed RCTs in SCD, but evidence with other chronic conditions supports that cognitive behavior therapy can improve self-management, particularly in relation to pain and HRQoL
- Individuals with SCD may benefit from self-care interventions that enhance social support, SCD self-efficacy, and access to education

Anie, Green *Cochrane Database of Systematic Reviews* 2015, 5
Matthie et al *Pain Manag Nurs* 2015; 16: 257–66

Community Health Worker Support



Hsu et al *Am J Prev Med* 2016;51:S87-98

Community Health Worker Core Roles

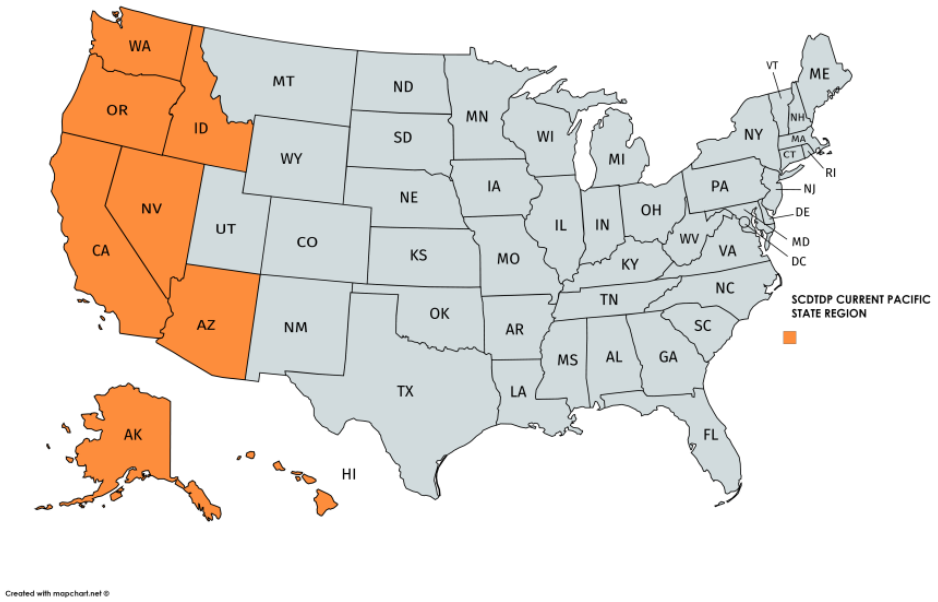
1. Cultural mediation
2. Informal counseling and social support
3. Culturally appropriate health education
4. Advocacy for individual and community needs
5. Assurance that people receive needed medical and social services for which they are entitled
6. Direct social and supportive services
7. Support for building individual and community capacity

Hsu et al *Am J Prev Med* 2016;51:S87-98

Community Partnerships

State of Sickle Cell Disease: 2016 Report
scdcoalition.org

Collective Impact



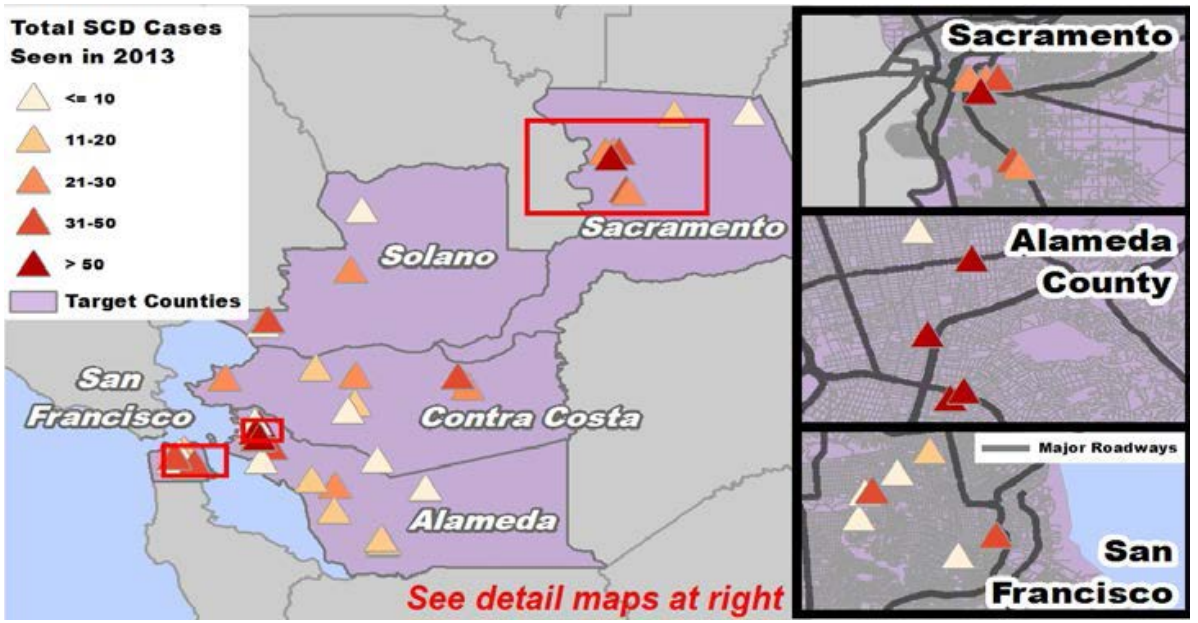
Sickle Cell Care Coordination Initiative

UCSF Benioff Children's Hospitals

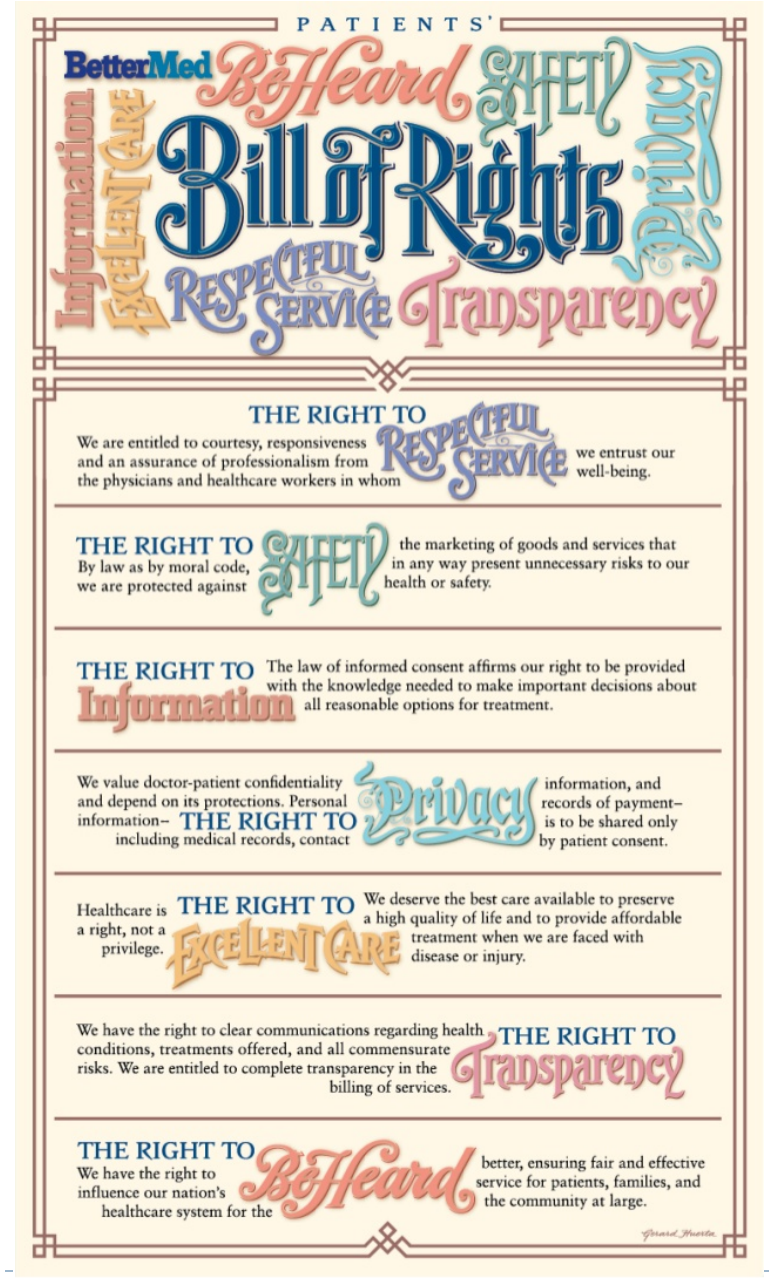
UCDAVIS HEALTH

PSCRC

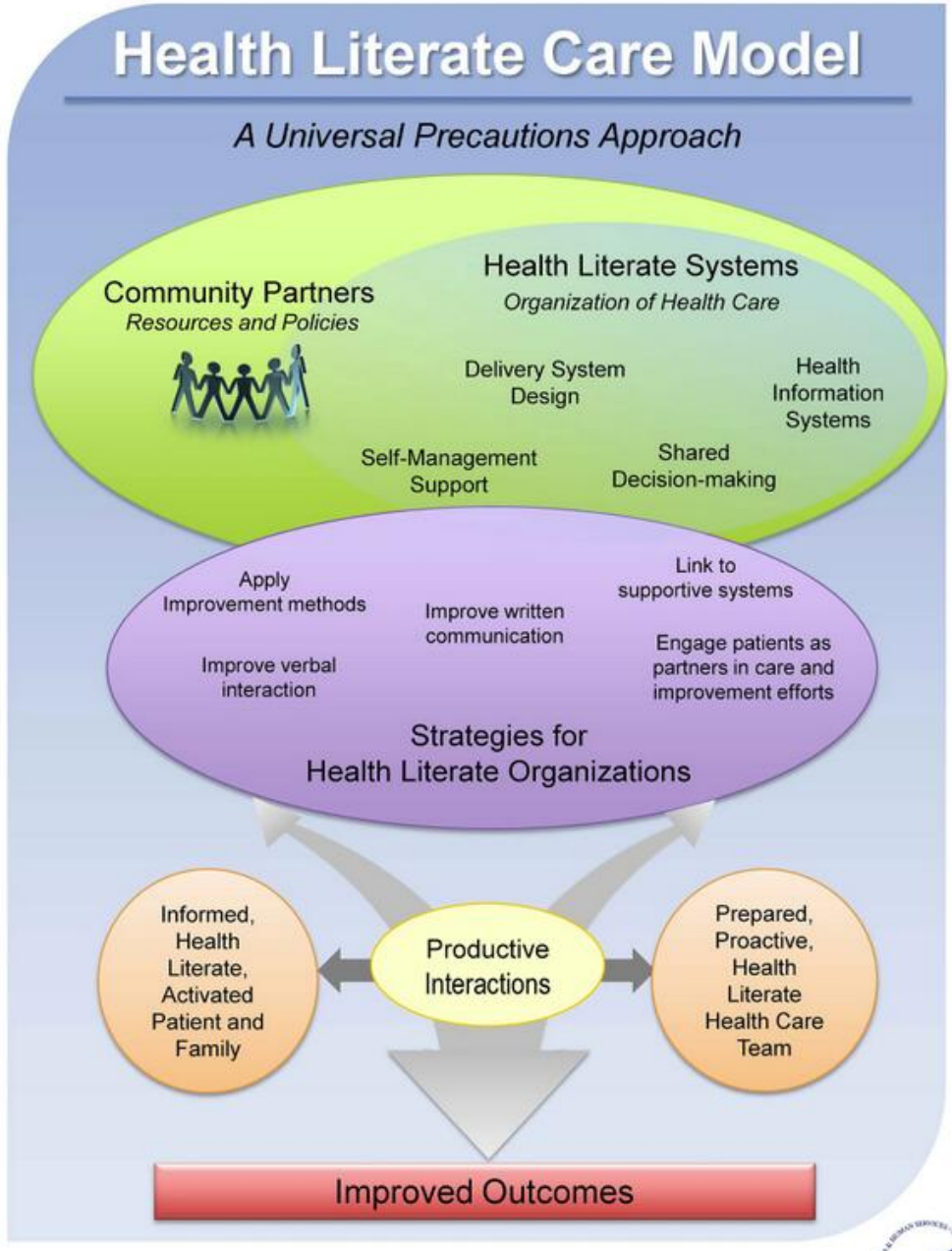
The Pacific Sickle Cell Research Collaborative works to ensure that people with sickle cell disease receive quality care, no matter where they live or seek care.



Patient Rights and Responsibilities



S.1052 Bipartisan Patient Protection Act congress.gov



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Health Literate Care Model

- Make health literacy a cultural value, modeled by leadership and integrated into all aspects of planning and operations
  - Assess practice, raise awareness, obtain feedback from patients
- Use strategies to support self-management
  - Teach-back method, action planning
- Staff members take on new roles to support Delivery System Design
  - Brown bag medication review

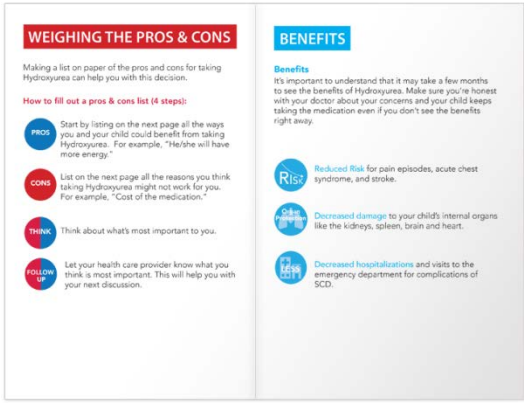
Koh et al *Health Aff (Millwood)* 2013:32;357-67

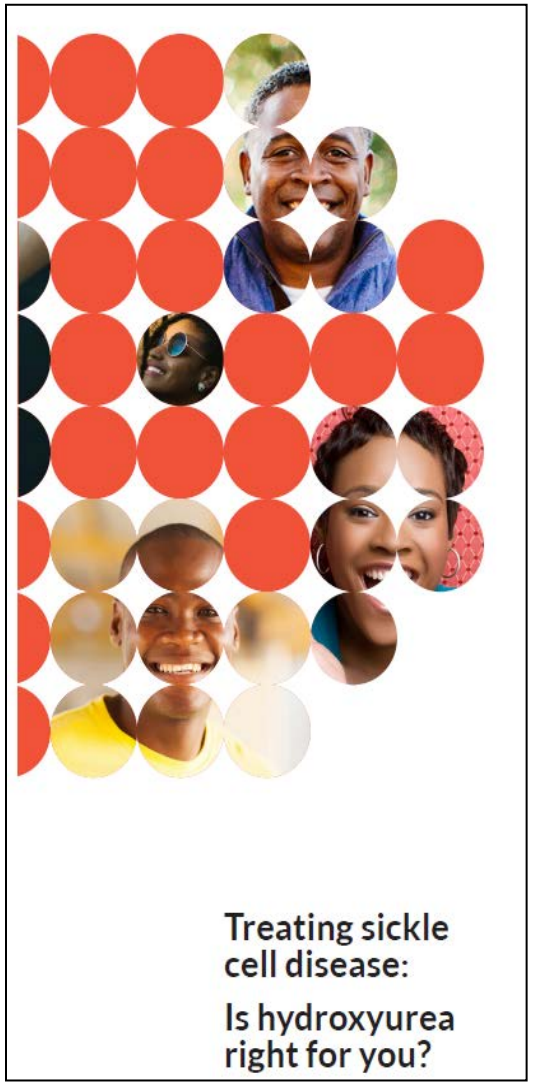
Health Literate Care Model

- Share evidence based guidelines with patients/families and promote shared decision making
  - Design easy to read material
  - Use health education materials effectively
- Re-design clinical information systems to facilitate personalized online patient education, care coordination and referrals
  - Includes user-friendly interface to enable patients to view their health related information

Koh et al *Health Aff (Millwood)* 2013:32;357-67

Hydroxyurea Education and Decision Making





Creary et al *BMC Res Notes* 2015 Aug 25;8:372.
Crosby et al *Pediatr Blood Cancer* 2015 62:184-85.

casicklecell.org
nichq.org

Health Literate Care Model

- Community partnerships broaden resources to address social determinants of health
  - Link patients to nonmedical support
  - Medication resources
  - Use health literacy resources in the community
- Establish goals and measures to monitor progress and continually improve strategies for health literacy and patient engagement
  - Measure patient experiences including perceptions of self-management support, delivery system design, decision support, clinical information systems and community partners

Koh et al *Health Aff (Millwood)* 2013:32;357-67
IOM *Primary care and public health* 2012

Future Directions/Priorities

- Measure HRQoL, SDoH consistently across settings for comparison and monitoring
- Need for high quality observational studies and randomized controlled trials of barriers to SCD care and interventions designed to overcome them

ASH Agenda for Hematology Research, 2012
www.hematology.org

Thank You!