Integrated Sickle Cell Care Models: Outpatient Community Based Clinics

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A first in Seattle: SCD care moves to a Community based Clinic - 1982

Dr. Blanche Lavizzo (1925-1984), first medical director, Odessa Brown Clinic

Dr. M.A. Bender at Odessa Brown Children’s Clinic Seattle Children’s Hospital.
Patients and Families preferred:

- Medical Office Care
- NOT Hospital with all of the negative memories and associations
- Ownership
- Effective preventative care in medical home
- Community based support
- Cost Effective
A Legacy of Excellence in Sickle Cell Disease Research—Extending Life Expectation

- 1916: National Sickle Cell Act
- 1940: Penicillin
- 1995: Hydroxyurea
- 2016: Transfusion

https://www.nhlbi.nih.gov/health/health-topics/topics/sca/research
Impact of **Absent** System of Integrated Multidisciplinary Care

95% of children with SCD live to 21yr of age currently.

Figure 1. Components of SCD-related costs by age. SCD, sickle cell disease; ED, emergency department; Rx, prescription drugs.

Impact of **Absent** System of Integrated Multidisciplinary Care

- **Transfusion**
- **Penicillin**
- **National Sickle Cell Act**
- **Hydroxyurea**

**Life Expectancy (Years)**

**UK/USA**

**USA**

**So Cal**

**Present**
Shift in support for Teaching Hospitals

1992

Corporate Takeover of Teaching Hospitals

Maxwell Gregg Bloche
Georgetown University Law Center, bloche@law.georgetown.edu
Now Training Hospitals avoid chronic complex disease patients...

...Negative Impact on workforce and Loss of Integrated Care Delivery
Without Multidisciplinary Team Clinics
Increased Utilization of "Unnecessary Care"

• In 2004, the cost of hospitalization and ER visits for SCD was estimated at $488 million/year paid primarily (79%) by Medicaid and Medicare.

• Currently, it is estimated by Johns Hopkins researchers to be close to $1 billion for pain related complications alone.
“Our healthcare system abandons adult sickle cell patients” - Washington Post – 3/21/2016
<table>
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<tr>
<th>State</th>
<th>Total Population 2015 Census (estimates)</th>
<th>% Black/African American</th>
<th>% Hispanic</th>
<th>Estimated Sickle Cell Disease Population</th>
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<sup>a</sup>census.gov 2015; <sup>b</sup>Brousseau et al, 2010; <sup>c</sup>Paulukonis et al 2015
Center for Inherited Blood Disorders
Community based Subspecialty Clinic
Coalition of Clinics in Orange County

- 60% of Californians live in the lower third of the state
- Multi-racial, Diverse Ethnicities and Economic barriers.
- Interpreters needed: 46% Hispanic and 10% Asian patients at CIBD.
- Integrated Healthcare Team with MDs, RN, genetics counselors, nutrition, health psychology, transition
51% of Californian adults with SCD live in L.A.

SCD mortality higher in L.A. than rest of the country

Last Comprehensive Care Adult Center at large university closes and only 5 hematologists identified in Los Angeles County for over 3000 Sickle Cell patients

Powars Medicine 2005
CBO Capacity: Data for GIS Mapping

Los Angeles Residents with Sickle Cell Disease

age 15-45 years old
Zip code of Residence, 2015.

Data sources: Sickle Cell Disease Foundation of California, and Center for Inherited Blood Disorders.

Map created by UCLA CTSI as part of PRISM-SCD: Promoting Implementation Science Methodologies for Sickle Cell Disease RFA-HL-16-010
Building Adult SCD Clinic

L.A. County tries new approach to serving health needs of area's Sickle Cell Patients

Los Angeles Times 10/8/2016

Dr. Susan Claster, left, and Dr. Bernadette Manalo, right, talk to patient Philadelphia Philpot at the MLK Jr. Outpatient Center's new sickle cell clinic. (Marcus Yam / Los Angeles Times)
Life Expectancy in Sickle Cell Disease

• Simply gathering Registry information on care delivery in the few, isolated SCD centers of excellence
• Does not address the needs of the majority of SCD patients without a medical home or subspecialty center where optimal care is delivered,
• Importantly, for most patients there is no system or network, through which they can get access to innovations in treatment or gene therapy.
Impact of **Network** of Integrated Multidisciplinary Care Centers

**Access** to New Therapy
- Agents Decrease Sickling
- Research/ Clinical Trials
- Small molecules
- Gene Editing
- Gene Therapy/Transfer

Quality of Life improved
Decrease HC cost...

**Cure!**
New models of *Sustainability* needed for SCD Comprehensive Care Clinics

- **Workforce**: Loan Repayment for Providers including MD, RN, SW, genetic counselors, and health psychology
- **Bundled payments** to cover increased time and needed services by *all* providers in clinic
- **Decreased utilization** of hospital and ER demonstrated
- It will take working together to *raise awareness* of the needs of this vulnerable patient population and
- Focus effectively on helping our current healthcare system to understand the *benefit of extending not only life expectancy, but also the quality of life* for all patients with SCD.
Thanks to our PARTNERS