County Level Surveillance of Sickle Cell Disease Population, Healthcare Utilization, and Fragmentation to Support Improvements in Access to Care

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Sickle Cell Data Collection

Sickle Cell Care Coordination Initiative

UCSF Benioff Children's Hospitals

UC DAVIS HEALTH

BACKGROUND AND OBJECTIVES

- In California, there are an inadequate number of facilities, specialists and primary care physicians with training and resources to care for adolescents and adults with sickle cell disease (SCD).
- CDC has implemented the Sickle Cell Data Collection (SCDC) project in California and Georgia to establish true population based surveillance systems.
- SCDC data allow investigation of healthcare utilization and outcomes for over 80% of these states' SCD patients in all settings, including those not seen by SCD specialists.
- Researchers at University of California San Francisco Benioff Children's Hospital Oakland (BCHO) collaborated with SCDC to obtain aggregated data about SCD patient populations, care fragmentation, and inpatient and emergency department utilization (ED) in five Northern California counties.
- BCHO's goal was to obtain NIH/NHLBI grant funding to support outreach to adolescent and adult patients (ages 15-45 years) seen in hospital settings but not by SCD specialists. Now awarded, this grant supports targeted outreach to ED facilities with a high number of patients with SCD.
- Outreach based on these findings will broaden the network of collaborating providers in the region, and improve access to care.

METHODS

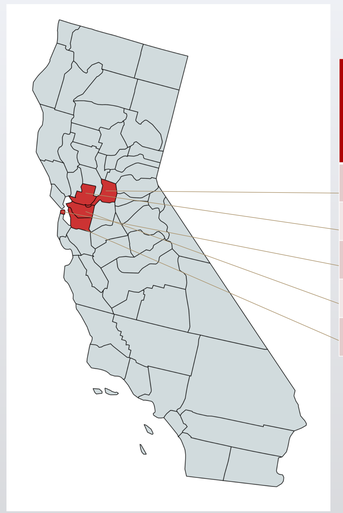
- Hospital admission, ED and Medicaid claims data for the years 2004 through 2015 were obtained for those with SCD ICD codes.
- Social security number + date of birth was used to link across data sources.
- Inclusion criteria:
  - Three or more SCD coded healthcare encounters within any five year period AND
  - Healthcare utilization or residence within one of the five target counties during 2013-2015 AND
  - Age 15-45 years during 2013-2015.

RESULTS

- 1,024 persons met the inclusion criteria (Table 1).
  - 82% of these were older than 21 at close of study period.
  - Adolescents had a mean of 2.0 ED visits and 1.8 inpatient admissions over the three year study period;
  - Adults had a mean of 6.0 ED visits and 2.4 inpatient admissions over the three year study period.

RESULTS

Figure 1: Five County Region of Sickle Cell Disease Surveillance – Distribution by Patient Residence



County	Hospitals (Inpatient and/or Emergency) in County	Hospitals with 25 or more SCD encounters/year	Resident SCD patients
Sacramento	10 (incl UC Davis Med Ctr)	6	311
Solano	4	3	72
San Francisco	8	4	78
Contra Costa	6	5	159
Alameda	8 (incl BCHO)	5	232

Table 1: Healthcare Utilization in Five Counties among Patients with SCD 15-45 years of age, 2013-2015

	All Persons with SCD Living or Receiving Care in 5 County Region			Persons with ED or Inpatient Encounters		
	Persons	Mean ED Util (# encounters over 3 years, not admitted)	Mean Inpatient Util (# stays over 3 years)	Persons	Low/Med Care Fragmentation (row %)	High Care Fragmentation (row %)
Teens (15-20 years)						
Male	89	1.9	1.5	53	41 (77)	12 (23)
Female	98	2.1	2.0	54	48 (89)	6 (11)
Adults (21-45 years)						
Male	323	5.2	2.6	220	148 (67)	72 (33)
Female	514	6.5	2.3	323	181 (56)	142 (44)
Total	**1,024**	**5.3**	**2.3**	**650**	**418 (100)**	**232 (100)**

Table 2: Care Fragmentation among 650 Patients with SCD, 15-45 years of age, 2013-2015

# of ED and Inpt Encounters	Number of Facilities						
	1	2	3	4	5	6 or more	Total (col %)
1	93	-	-	-	-	-	**93 (14)**
2	59	29	-	-	-	-	**88 (13)**
3	32	27	3	-	-	-	**62 (10)**
4	23	14	10	2	-	-	**49 (7)**
5	16	9	11	0	0	-	**36 (6)**
6 or more	114	73	53	37	21	24	**322 (50)**
Total (row %)	**337 (52)**	**152 (23)**	**77 (12)**	**39 (6)**	**21 (3)**	**24 (4)**	**650 (100)**

RESULTS

- 70% (n=543) of adults (21 years and older) and 44% (n=107) of adolescents (15-20 years) had inpatient/ED utilization (Table 1).
  - 12% lived outside the five target county area.
  - 18% of adolescents and 39% of adults had high levels of care fragmentation (<90% of hospital/ED encounters at same facility).
- 23 EDs and 5 inpatient facilities within the five target counties had 25 or more SCD encounters per year but no connection to a SCD care facility (Table 3).

CONCLUSIONS

- Even in a metro region with quality SCD care centers, 18% of adolescents and 39% of adults had high levels of care fragmentation.
- There is opportunity for outreach to the 23 EDs and 5 inpatient centers not associated with a quality care center for SCD but with more than 25 SCD encounters per year.
- State surveillance of SCD supports increased networking and collaboration among SCD care providers, and may ultimately facilitate bringing additional patients into high quality care networks.
- Surveillance efforts can also allow us to evaluate the effectiveness of our outreach and training efforts

ABOUT THE SICKLE CELL DISEASE IMPLEMENTATION CONSORTIUM

- NHLBI committed to funding research into the implementation of evidence-based therapies in heart, lung and blood disorders and established the Center for Translational Research and Implementation Science (CTRIS) in 2014.
- CTRIS is also concerned with disparities in the delivery of health care and these two major themes converge in SCD, where youth and adults experience high mortality, severe pain, progressive decline in functional status and poorly understood barriers to care.
- The SCDIC, comprised of 8 sites around the U.S. and funded in 2016, is working to address these disparities and to enhance the delivery of evidence-based therapies for SCD.

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