



# Fragmentation of Care for Young Adults with Sickle Cell Disease in California

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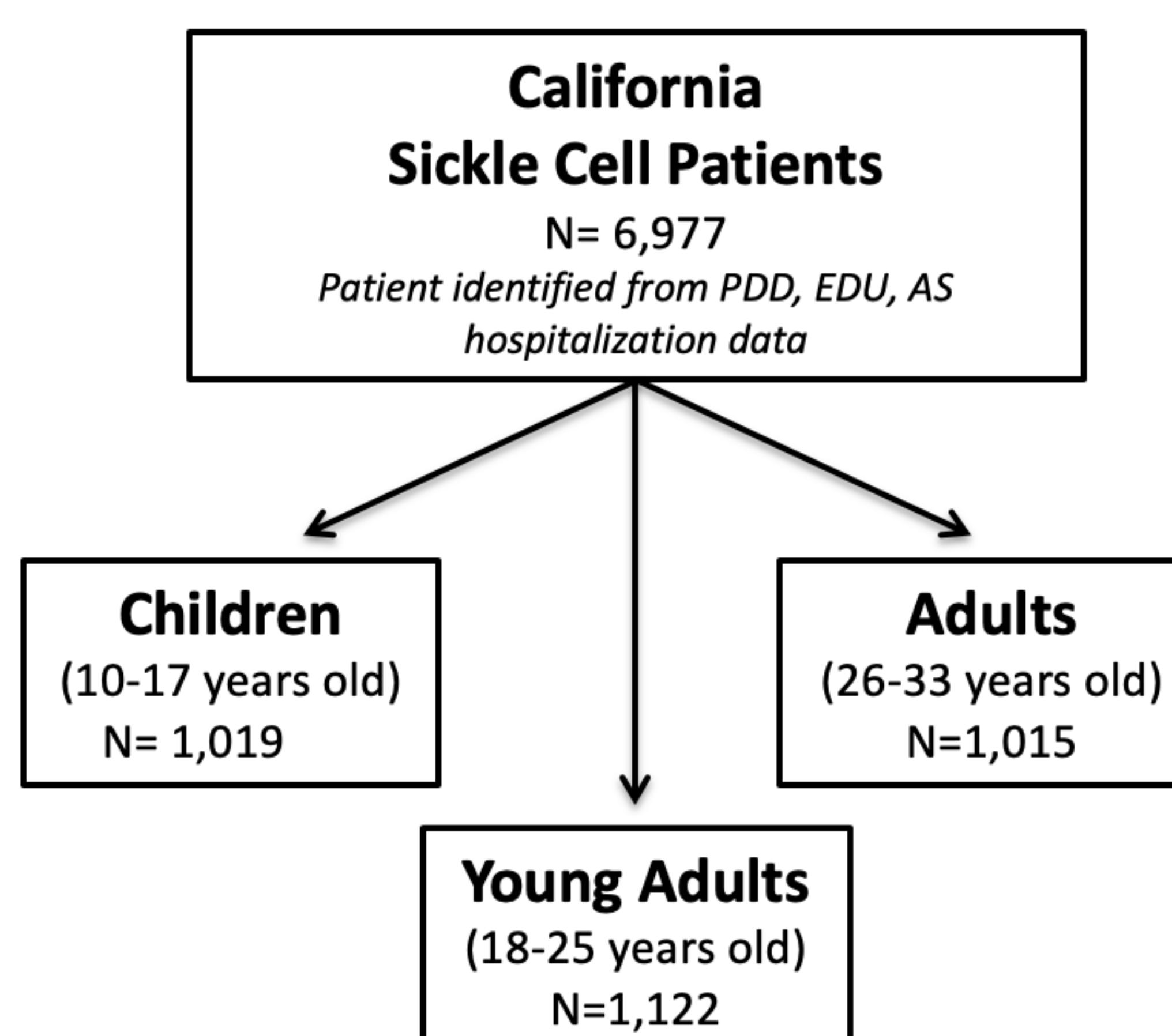
## Introduction

- Sickle Cell Disease (SCD) predominantly affects people of African ancestry and a multidisciplinary complex care model has been suggested to optimize care
- Young adults (YA) 18-25 years of age transition from pediatric to adult models of care and the effect of receiving care at multiple medical facilities (fragmentation) during this time on outcomes has not been well-described
- We sought to examine fragmentation of care for YA SCD patients and the potential effect of fragmentation on mortality.

## Methods

- California Patient Discharge, Emergency Department, and Ambulatory Surgery datasets were used to identify SCD patients from 1991-2016
- The number of inpatient admissions were categorized during their time patients spent in each age group as <10, 10-19, 20-29, and ≥30 inpatient admissions.
- We classified care fragmentation by the number of facilities an individual received inpatient care (1, 2, 3-4 or ≥5 unique facilities) during their time in each age group.
- SCD specialty care centers (SCD SC) were determined using all SCD inpatient admissions over the period of the study; facilities in the top 5% based on number of unique SCD patients seen were considered SCD SC. Patients were classified as always receiving their care at a SCD SC, sometimes, or never during their time in each age group.
- Poisson regression was used to identify risk factors associated with fragmented care. Fragmented care was defined as receiving care at multiple facilities.
- Multivariable Cox regression was used to determine the impact of fragmented care, frequency of admission and care at SCD SC on all-cause mortality, conditional on surviving to 26 years of age for the YA group.

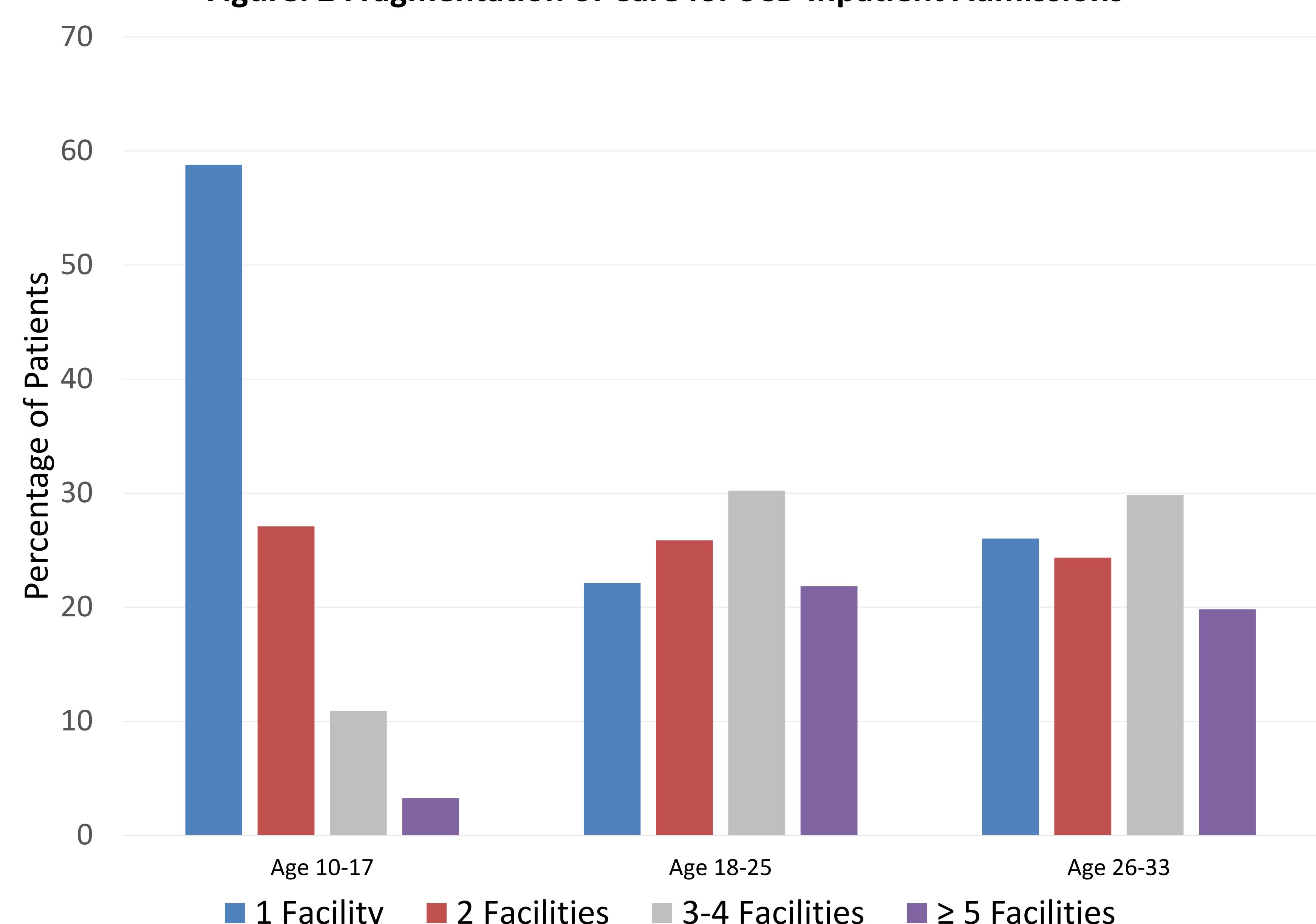
**Figure 1: Number of Sickle Cell Patients by Age Cohort**  
Patient Discharge (PDD), Emergency Department (EDU), and Ambulatory Surgery (AS)



**Table 1: Baseline Characteristics of Young Adult Cohort (n=1,122)**

Characteristics	N	%
<b>Gender</b>		
Male	492	43.9%
Female	630	56.1%
<b>Number of Admissions</b>		
< 10 Admissions	494	44.0%
10-19	226	20.1%
20-29	125	11.1%
≥ 30	277	24.7%
<b>SCD High Volume Facilities (Top 5% by patients)</b>		
Always	259	23.1%
Sometimes	557	49.6%
Never	306	27.3%
<b>1<sup>st</sup> Health Insurance Payer (at entry into cohort)</b>		
Medicare	57	5.1%
Medi-Cal/Government	476	42.4%
Private	300	26.7%
Self Pay	31	2.8%
Other	2	0.2%
Unknown (Pre-1999)	256	22.8%
<b>Vital Status (as of 2013)</b>		
Living	1,023	91.2%
Deceased	99	8.8%

**Figure 2 Fragmentation of Care for SCD Inpatient Admissions**



- Most children (nearly 60%) received their care at just one facility, compared to 22.1% of YAs and 26.0% of older adults. More than half of YA (52.0%) and adults (49.7%) were seen at ≥3 facilities with at least 20% in the adult age groups receiving care at ≥5 hospitals over seven years.
- Table 2 shows risk factors associated with fragmentation of care for YAs included lack of insurance, more frequent admissions, and not receiving all care at an SCD SC
- Table 3 shows risk factors for mortality for YAs: in a multivariable model more frequent admissions was associated with increased risk of mortality.

## Results

**Table 2: Risk factors for Fragmentation of Care for Young Adults with SCD**

Variables	Hazard Ratio	95% Confidence Interval	p-value
<b>Gender</b>			
Female	1.04	(0.97-1.11)	0.2728
Male	Reference		
<b>Health Insurance</b>			
Medi-Cal/Medicare/Government	Reference		
Private Insurance	0.58	(0.78-0.93)	0.0002
No Insurance	1.45	(1.22-1.72)	<.0001
<b>Number of Admissions</b>			
<10 Admissions	Reference		
10-19	1.42	(1.29-1.57)	<.0001
20-29	1.49	(1.33-1.67)	<.0001
≥ 30	2.13	(1.95-2.32)	<.0001
<b>SCD Specialty Center</b>			
Always	Reference		
Sometimes	2.19	(1.98-2.43)	<.0001
Never	1.29	(1.15-1.46)	<.0001

**Table 3: Risk factors associated with mortality for Young Adults with SCD**

Variables	Hazard Ratio	95% Confidence Interval	p-value
<b>Gender</b>			
Female	1.01	(0.67-1.52)	0.9651
Male	Reference		
<b>Health Insurance</b>			
Medi-Cal/Medicare/Government	Reference		
Private Insurance	0.88	(0.45-1.74)	0.7123
No Insurance	0.63	(0.09-4.61)	0.6445
<b>Fragmentation of Care</b>			
< 3 Facilities	Reference		
3-4 Facilities	1.03	(0.58-1.83)	0.9149
≥ 5 Facilities	1.5	(0.78-2.88)	0.2204
<b>Number of Admissions</b>			
< 10 Admissions	Reference		
10-19	2.36	(1.13-4.91)	0.0217
20-29	4.25	(2.03-8.92)	0.0001
≥ 30	7.79	(4.09-14.83)	<.0001
<b>SCD Specialty Center</b>			
Always	Reference		
Sometimes	0.63	(0.34-1.18)	0.1517
Never	1.04	(0.57-1.90)	0.8975

## Conclusions

- Most YA SCD patients (78%) received inpatient care at >1 facility. Children were most likely to be seen at only 1 facility, suggesting that fragmentation begins in early adulthood
- Young adults without insurance, patients with more frequent admissions and those who did not always receive care at an SCD SC were at higher risk of fragmentation
- More frequent inpatient admissions between the ages of 18-25 were associated with increased mortality

## Acknowledgements

I would like to thank the ASH Minority Scholars who funded this project. I would also like to specially thank all of my mentors including Dr. Mahajan and Dr. Wun.