Development of the Sickle Cell Program at the Center for Special Health Care Needs

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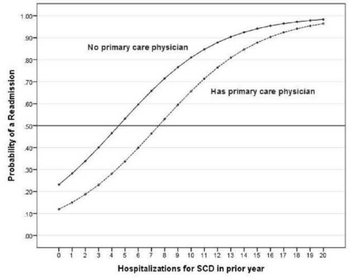
BACKGROUND

- Sickle cell disease (SCD) is the most common inherited red blood cell disorder and can cause a variety of complications over the lifespan.
- It is estimated that there are 100,000 people living with SCD in the U.S. and 700 people in Delaware.[1]
- Patients with SCD are known to have less access to comprehensive team care compared to those with other genetic disorders.[1]
- Improvements in care for pediatric patients with SCD has significantly decreased their mortality rates, but no change has been seen in adolescent and adult patients.[2]
- Research has shown that as patients with SCD transition from pediatric to adult health care systems, their acute care utilization increases.[3,4]
- In Delaware, the majority of pediatric patients with SCD receive care at Nemours Center for Cancer and Blood Disorders
- No comprehensive program for adult patients with SCD existed within a major health system in the state prior to September 2018.

READMISSION RISK FACTORS

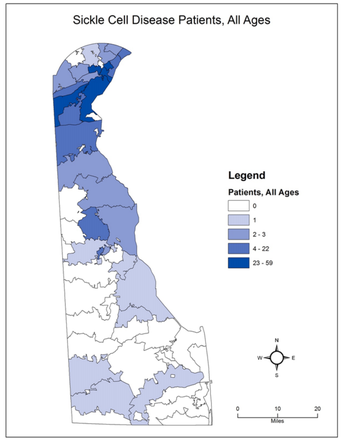
- Having a primary care physician was associated with significantly fewer readmissions for patients with sickle cell disease[5]
- In ChristianaCare data set, fewer than half of patient s had an accurately identified primary care physician



PROGRAM DESIGN

	AYA Cohort	Older Patients	All Patients
Number of encounters	343	207	550
Number of patients	149	173	322
Age (%)*			
18-29	62.1		38.7
30-39	37.9		23.6
40-49		31.9	12.0
50-59		51.2	19.3
60+		16.9	6.4
Sex (%)*			
Male	51.6	64.3	56.4
Female	48.4	35.7	43.6
Encounter Type (%)*			
ED only	63.8	77.3	68.9
Observation Admit	5.8	4.8	5.5
Inpatient Admit	30.3	17.9	25.6
Encounter Location (%)*			
Christiana	47.2	31.4	41.2
Wilmington	44.3	66.2	52.5
Middletown	8.5	2.4	6.2

- July 1, 2016- June 30, 2017 all adult patients with ICD D57.XX in Emergency Department or Inpatient at any Christiana Care Health System acute care site



- September 7, 2018- First patient seen at Center for Special Health Care Needs (CSHCN) at Wilmington Hospital
- Sickle Cell Program Clinic held bi-monthly in conjunction with primary care clinic at CSHCN
- Infusion Center appointments offered at Christiana Care and Wilmington Hospitals pending availability during Monday-Friday business hours
- Inpatient and Emergency Department consultations for new and affiliated patients, often with in-person visit by team members including Hematologist, Social Worker, Nurse Case Manager
- Aerial case management support to allow close follow-up and monitoring of patients
- Collaboration with Nemours Center for Cancer and Blood Disorders Sickle Cell Program through joint visits to support patients in the transition period as they move into adult care

FUTURE DIRECTIONS

- Expand research collaborations and clinical trial availability through American Society of Hematology Clinical Trials Network
- Implement standardized protocols for care of vaso-occlusive crisis in Emergency Department and Inpatient settings
- Expand infusion center availability and evaluate effects on cost and quality of care
- Evaluate non-pharmacologic pain management strategies, including peer-led pain support groups

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