The Critical Role of Community Health Workers (CHW) and Health Navigators (HN) in Access to Care for Individuals with Sickle Cell Anemia

Report by Avalon Health Economics
Commissioned by the Sickle Cell Disease Association of America

April 11. 2022

Submitted by:
Katherine Dick
John E. Schneider, PhD
Cara Scheibling

Project Director:

John E. Schneider, PhD
CEO, Avalon Health Economics
26 Washington Street, 3rd Floor
Morristown, NJ 07960
862.260.9191 (office)
319.331.2122 (mobile)
John.Schneider@avalonecon.com

Submitted to:

Ashley Clark, MPH, MAHS
Sickle Cell Disease Association of America, Inc.
7240 Parkway Drive, Suite 180
Hanover, MD 21076
aclark@sicklecelldisease.org

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services(HHS) grant number U38MC28326. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

1. EXECUTIVE SUMMARY

Sickle cell disease (SCD) is a genetic blood disorder that affects approximately 100,000 Black, African American, and Hispanic-Americans in the United States. The disease is progressive and causes life-threatening complications that require comprehensive healthcare to manage. The first objective of this analysis was to identify barriers to SCD healthcare and to assess their impact on a state level. The second purpose was to evaluate the current research on Community Health Worker (CHW) interventions, and estimate the economic impact that CHW programs could have on SCD patients' overall healthcare costs. Community health workers (CHWs) are trained community members who can support SCD patients, reduce barriers to care, foster connections with the healthcare system, and provide health education.

After a thorough review of the literature, we determined that the key healthcare access barriers for SCD patients include provider shortages, economic factors, ability to consistently access specialist and preventative care, and healthcare disparities. Though these barriers to care occur nationally, we found that SCD patients are more likely to experience difficulty accessing healthcare in the southern states of Mississippi, Louisiana, Arkansas, Georgia, Alabama, Texas, and Florida.

A review of the research on CHW programs showed that these programs are both effective and cost-saving when designed to serve disadvantaged patients with different types of chronic illness. This research was analyzed to estimate the potential healthcare cost savings from the Sickle Cell Disease Association of America's (SCDAA's) CHW program. We found that intervention by CHWs could save upwards of $5,900 per patient per year through reduced hospitalizations, shorter hospital stays, fewer ER visits, and better adherence to medication and preventative care recommendations. Our research also illustrated possible targets for future advocacy, including SCD screening for immigrants to the United States, CHW programs targeted at high-risk young adults, and expanded programs into underserved, rural areas with higher barriers to care.

2. BACKGROUND

Sickle cell disease (SCD) is a genetic blood disorder that causes red blood cells to deform into a sickle shape, resulting in serious pathophysiological issues, including anemia and a variety of other problems.[1-6] An estimated 100,000 Americans live with SCD, and the majority are African American or Hispanic.[7] One out of every 365 Black or African American newborns have SCD, and 1 out of every 16,300 Hispanic-Americans have SCD.[6] Although infant and child mortality related to SCD has decreased, a sickle cell patient's typical life expectancy is 25 years shorter than the average American.[8]

The distorted red blood cells associated with SCD are more likely to rupture prematurely, which leads to anemia. The sickle-shaped blood cells can also stick together and cause painful blockages

in vessels that carry blood to vital organs. These blockages can cause acute and chronic pain[9-14] and acute lack of blood flow to cause pulmonary, neurologic, ophthalmic, and cardiovascular complications.[15-25] The disease is chronic and progressive and can result in organ damage and failure, neurocognitive impairment, renal disease, acute chest syndrome, pulmonary hypertension, stroke, and other complications that require comprehensive, multidisciplinary care to manage.[26] SCD is a significant emotional and financial burden on patients and their families.[26]

While there is no cure for those with SCD, there are treatments that can relieve pain and prevent complications. As with many chronic conditions, successful management and treatment depends in large part on the amount of community-based health care workers available to offer support for individuals in need.[27-29] SCD patients face many barriers to quality healthcare because of the chronic and debilitating nature of the disease and its relative rarity.

Managing care for SCD and its comorbidities can be challenging, particularly in areas of the United States where barriers to care are elevated, and many patients lack the support needed to manage the disease.[26, 30-32] Community health workers (CHWs) are generally defined as "non-clinicians who work with medically and socially complex individuals from underserved communities to help bridge to medical services to improve patient healthcare engagement, self-management, treatment plan adherence, and health outcomes."[33] CHWs are critically important for improving health care and health outcomes for many chronic conditions including the management and treatment of SCD.[31, 33-43] As recent experiences with COVID-19 have demonstrated, CHWs are a critical but "endangered" part of health care infrastructure,[29] and as the CHW network is weakened, concerns for individuals with SCD rise.

3. OBJECTIVES

This report's overall objective is to provide an overview of the supply, demand, and scope for CHWs and health navigators (HNs) regarding access to care for individuals with SCD. Specifically, the study has four aims: (1) conduct an overview of literature about barriers to care in SCD; (2) provide an overview of the existing CHW landscape concerning SCD; (3) conduct a "gap analysis;" and (4) estimate potential cost savings of a CHW program for SCD patients. The report is divided into six remaining sections: Section 4 provides a detailed overview of access barriers; Section 5 describes the role of CHWs in bridging some of these barriers; Section 6 describes the methods and results of the supply-demand gap analysis; Section 7 discusses CHW training and regulation; Section 8 discusses the role and benefit of the Sickle Cell Disease Association of America (SCDAA); and Section 9 describes opportunities for advocacy and change.

4. BARRIERS TO CARE

A comprehensive literature review was conducted to determine the key barriers to care for sickle cell patients in the United States. Some barriers occur on a patient level, including economic factors, insurance, and family or community support. Other obstacles are related to the health system and the biases of providers toward SCD care. Key literature sources were identified in

PubMed. Additional sources, including reports from national and state-level health organizations and CHW programs, were identified via a more general search. The review focused on the past ten years of published material, including materials published in peer-reviewed journals and reports and other unpublished materials identified via searches roughly corresponding to the sub-headings shown below.

4.1 Access to Comprehensive Care

Pediatric SCD patients often receive care in comprehensive sickle cell care centers, but there is a shortage of comprehensive care for adults with SCD in the United States.[44, 45] Patients with SCD benefit from access to hematologists and other specialists who can initiate and monitor hydroxyurea and blood transfusion treatments to prevent subsequent disease complications. Access to these specialists is limited, and it significantly impacts hospitalization and mortality associated with SCD-related complications.[44]

SCD patients without access to consistent, high-quality care from hematologists, primary care physicians, and comprehensive care centers have significantly higher hospital utilization rates than patients with access to these resources.[46] A 2012 study showed that patients living farther from comprehensive SCD care providers had higher emergency department rates than those located in closer proximity to comprehensive care providers.[47] Young adult patients experience additional challenges when transitioning to adult care, including increased rates of SCD complications and acute care utilization, less preventative care, higher mortality risk, and financial stressors.[48-52]

A 2015 study compared medical records of SCD patients five years before and five years after the establishment of a comprehensive SCD care center. After the SCD center was established, annual hospitalizations per patient dropped from 2.4 per year to 1 per year. The length of hospitalization decreased by 50%, and readmission rates were reduced by 33%. The proportion of eligible patients receiving appropriate hydroxyurea treatment increased from 30% to 90%.[45] This is one example of evidence that interventions improving access to care can positively impact patients' lives and reduce high-cost emergency care utilization.

4.2 Insurance Coverage and Economic Factors

Insurance coverage also affects access to care. A considerable proportion of SCD patients are insured through Medicaid and Medicare programs.[44, 53] Patients who are publicly insured through Medicaid or Medicare have more difficulty accessing specialist care. Lack of specialist care leads to higher inpatient hospital admission rates.[44, 54] Publicly insured SCD patients have more emergency room visits than SCD patients with private insurance, and account for over 75% of SCD hospitalizations.[46, 47] Publicly insured patients also had the highest rehospitalization rate among these patient groups.[53] SCD was the fifth most common diagnosis associated with Medicaid super-utilization, defined as four or more hospital stays per year.[55] SCD patients

residing in states with a higher percentage of publicly insured individuals are likely to experience more difficulty accessing specialist care.

4.3 Provider Knowledge and Education Gap

Even when SCD patients are able to access care, providers often lack disease-specific education and guidelines for how to appropriately treat SCD, in part because sickle cell is relatively rare.[56-59] There were no comprehensive, evidence-based guidelines for the management of SCD until 2014 when the National Heart, Lung and Blood Institute (NHLBI) published guidelines.[57] These guidelines appear to have had a relatively small impact on provider knowledge and behavior. A 2019 study by Masese et al. found that many hospitals do not have standardized protocols for managing sickle cell-related pain, and 67% of providers were not aware of the NHLBI guidelines published five years prior. Some primary care providers and hematologists provide individualized care plans with patient-specific instructions for opioid dosing in the emergency department, but only 50% of providers reported using these protocols, and these protocols simply do not exist in most institutions.[58, 60]

Although some treatments are available to prevent SCD-related complications, they are often underutilized. Rates of severe SCD complications can be reduced by hydroxyurea treatment, but it is often under prescribed, and disease-modifying therapy like chronic transfusion has many limitations.[52, 61] Hematopoietic stem cell transplant and gene therapy have great promise but are costly and not universally available.[26, 61] Three new medications that can reduce the severity of SCD have been approved by FDA since 2017, but they have been slow to gain wide utilization.[61, 62]

4.4 Opioid Restriction and Regulation

The opioid crisis has also affected access to care for SCD patients. Many hospitals have policies limiting access to pain medications, and doctors are hesitant to prescribe opioids due to concerns surrounding the opioid epidemic and fears of enabling opioid addiction.[26, 58, 59, 63] Healthcare providers dismiss sickle cell patients as drug seekers and assume that patients are overstating their pain level.[64] These factors lead to delayed or inadequate treatment of pain, contributing to the high rate of hospital readmission and distrust in medical providers among SCD patients.[48, 58, 59] Doctors' assumptions about the high probability of opioid addiction in sickle cell patients are largely unfounded. A 2016 analysis of the CDC's Multiple Cause of Death database found only 95 opioid-related deaths among SCD patients between 1999 and 2013.[64]

4.5 Healthcare Disparities

In addition to other care barriers, sickle cell patients experience discrimination stemming from misconceptions about SCD and racial bias. A vast majority of SCD patients are non-white because

of the hereditary origin of the disease. A 2013 study of nationally representative ED data found that sickle cell patients experience wait times 25% longer than the general population, most of which was attributable to race.[65] African American SCD patients perceive a significantly higher level of racial discrimination than African Americans with other conditions and report feeling that racial bias has an adverse effect on the quality of care received.[66, 67] Misconceptions about SCD often lead physicians to underestimate the severity of a patient's pain.[26, 68] ED providers with strong negative attitudes toward sickle cell patients were 20% less likely to re-dose opioids to address uncontrolled pain.[69]

5. COMMUNITY HEALTH WORKER PROGRAMS

5.1 Community Health Workers

Community health workers (CHWs) are trained community members who act as liaisons between healthcare providers, social services, and patients in the community.[20, 70] Their primary role is to facilitate access to healthcare and health information to improve community members' health outcomes. CHWs are also referred to as community health advisors, patient navigators, and lay health advisors.[33, 71] The scope of practice for a CHW varies depending on the needs within the community. The role can include providing culturally appropriate health education, acting as mediators between communities and health systems, making home visits, coordinating patient care, and improving access to community resources.[70, 72]

CHW programs are often targeted toward underserved, disadvantaged patient populations with the goal of improving prevention or management of chronic conditions. There is considerable evidence supporting CHW programs' effectiveness in assisting with management and prevention of diabetes, hypertension, asthma, and cancer.[72-87] To date, research on the significance of CHWs has predominantly focused on the management and prevention of common chronic diseases, but patients with other complex, chronic diseases like sickle cell disease can also benefit from CHW programs.[33] In the context of the barriers to care described above, the approximate alignment between barriers to care and the role of CHWs is shown in Figure 5-1.

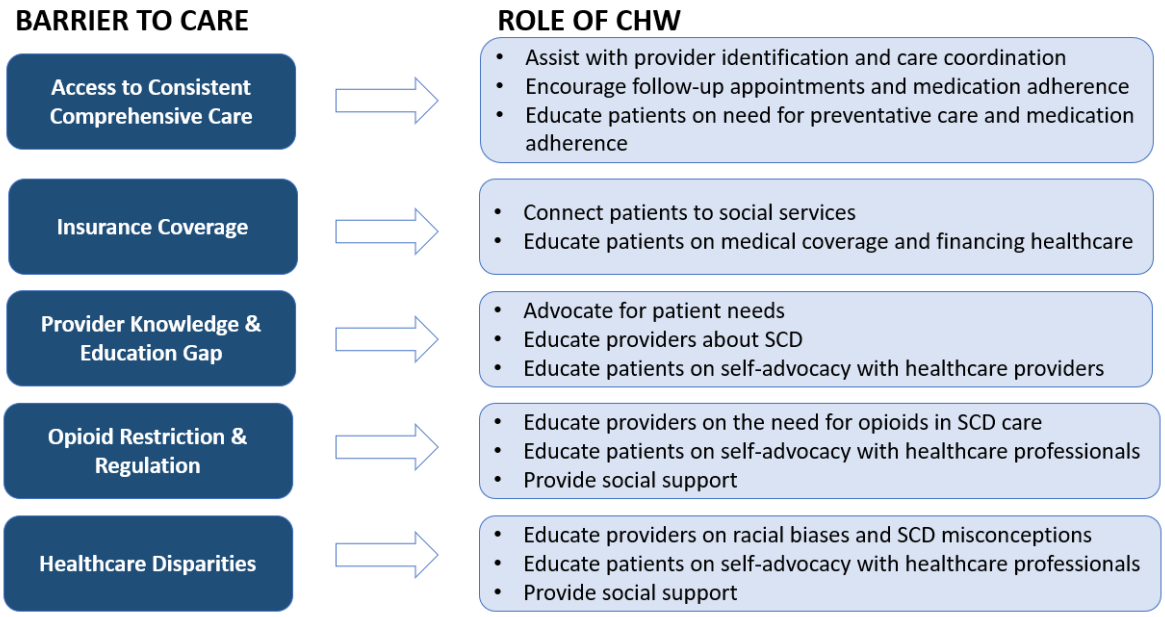

Figure 5-1. Role of CHWs in addressing barriers to sickle cell disease care

5.2 Health and Cost-Benefit of CHW Programs

CHW programs create tangible and significant improvements in glycemic control in diabetic patients, cancer screening rates among high-risk populations, pediatric asthma management, and hypertension control. These interventions also provide cost benefits by preventing the progression of chronic diseases and reducing preventable ER visits, hospitalizations, and hospital readmissions.[72, 74, 83, 84, 86, 87] CHW intervention drives care from high-cost urgent care and emergency settings to lower-cost primary care and specialist care settings.[72, 86]

There is considerable variation in the estimated cost-benefit of CHW programs, due mainly to heterogeneity in the target population, program structure, and resources available to CHWs.[88-90] Despite differences in study design and economic perspective, evidence to date indicates that CHW programs are cost-effective for both adults and children (**Table 5-1**). Critical studies of return on investment (ROI)[1] include: $1.80 ROI for cardiovascular disease prevention for every dollar invested;[91, 92] $2.28 saved per dollar invested annually for CHW program aimed at improving care management and access for underserved residents in Denver;[86] $1.84 – $3.09 ROI for every dollar invested in CHW programs supporting chronically ill Medicaid patients;[90] $1.09 return on investment for every dollar invested in a pediatric asthma management CHW program;[93] and $2.30 ROI for every dollar invested in CHW-led cancer outreach.[94] Overall, across all types of programs, CHWs appear to be associated with ROIs in the neighborhood of 2.0,

[1] Defined here as the return associated with $1.00 investment or expenditure.

which implies that one can expect to achieve benefit of about double the cost. However, some studies have also suggested that CHW program ROIs are associated with a "ramp up" time, with ROIs generally increasing in each following implementation.[95] Thus, CHW programs require sustained investment over time to achieve higher ROIs.

Table 5-1.
CHW Programs Return on Investment (ROI)

Patient Population	ROI
Underserved & chronically ill	$1.84 – $2.28
Cancer screening & prevention	$2.30
Asthma	$1.09
Cardiovascular disease prevention	$1.80

Though not specific to SCD, the studies cited above show the benefit of CHW programs for managing complex health conditions for high-need individuals across the lifespan. SCD patients are high-need, chronically ill patients with complex needs, many of whom are publicly insured. SCD patients also need consistent disease management and appropriate preventative care to avoid or delay the development of potentially fatal organ failure, acute chest syndrome, and stroke.[26]

6. DEMAND AND SUPPLY GAP ANALYSIS

6.1 Demand for Sickle Cell Care

The demand for sickle cell care varies by state, and a key objective of the analysis was to determine which states are "hotspots" for the disease. The most recent available state-level SCD population estimates were provided in a 2010 study by Hassell et al., which estimated the number of individuals with SCD based on the 2008 Census.[7] To generate an updated SCD population approximation, we estimated the number of individuals born with SCD and who died of SCD complications in the intervening years between 2008 and 2016. The annual birth rate of newborns with SCD by state was extracted from a study by Therrell et al.[96] The number of SCD-related deaths was approximated from the Centers for Disease Control (CDC) WONDER mortality database.[97]

The exact prevalence of SCD among immigrants to the United States is difficult to estimate because of the lack of SCD screening upon entry. Though immigrants with SCD enter the United States from many countries, this analysis focused on estimating the number of SCD patients immigrating from Africa, representing much of the population requiring care.

A 2008 United Nations report estimates that 15 million people in Africa suffer from SCD, representing 1.25% of the total African population.[98, 99] Immigration statistics from 2016 showed that approximately 618,000 newly arrived immigrants entered the US in 2016, and about 10% of those individuals were from Africa.[100, 101] Assuming that 1.25% of the African immigrants entering the United States in 2016 had SCD, about 740 individuals with SCD entered the United States and required care. This may be a slight overestimation because mortality rates among children with SCD reach 50-90% in some African communities. The majority of

immigrants are adults, and prevalence in this age group is lower than in younger patients.[102, 103]

The distribution of demand varies considerably across states, as shown in Figure 6-1. The ten states with the largest population of individuals with SCD are Florida, New York, Texas, Georgia, California, Maryland, New Jersey, North Carolina, Louisiana, and Illinois.[7, 96]

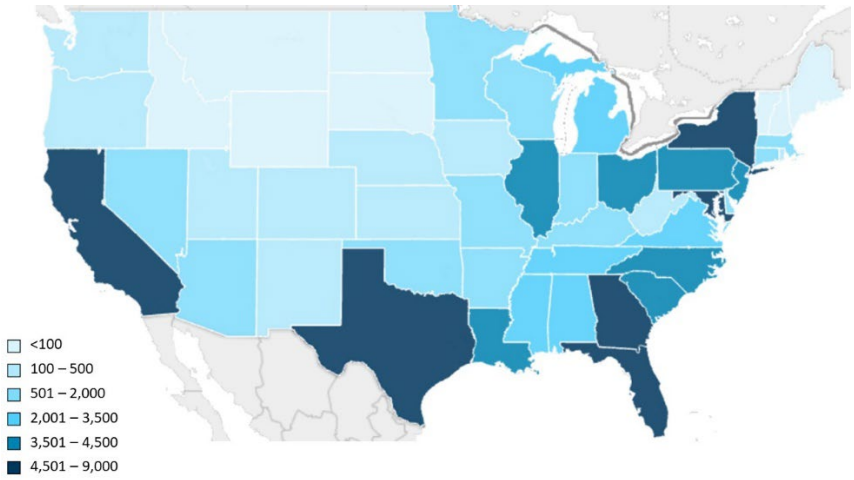

Figure 6-1. Estimated Population with sickle cell disease by state.

6.2 Supply of Community Health Workers

An estimated 54,760 CHWs are employed in the United States.[104] CHWs are most commonly employed in California, New York, Massachusetts, Texas, and Florida (Figure 6-2). CHWs are employed by social advocacy organizations, community relief organizations, and social assistance services, outpatient care centers, and family services.[104] These estimates are provided by the Bureau of Labor Statistics, but it should be noted that the lack of uniform terminology for CHW makes labor statistics difficult to estimate accurately.[74] These services can significantly reduce the challenges that SCD patients face. CHW programs specific to SCD have been implemented in a limited number of locations, but the expansion of these services has the potential to improve patient outcomes and reduce costs.[33]

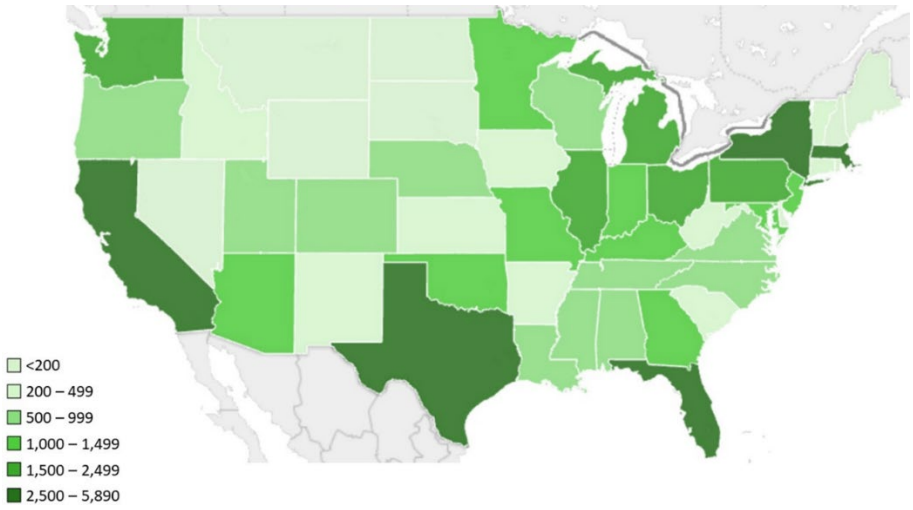

Figure 6-2. Employed CHWs by State.

6.3 State-Level Gaps in SCD Care

Ten key indicators of gaps in SCD care were selected based on the barriers to care described above. The goal of selecting these indicators was to choose metrics that can be quantified and compared across states. These metrics can be combined to provide an overall assessment of deprivation, indicating the degree to which there may be a greater need for care.

1. *Ratio of SCD patients to employed CHWs.* Patients living in states with a higher patient to CHW ratio likely have little to no access to CHW support. CHW support can address barriers to care on all levels (see Figure 5-1).[104]

2. *Ratio of SCD patients to hematologists.* Patients living in states with a higher patient to hematologist ratio may have more difficulty connecting with a specialist and will likely have to travel farther to access a provider. The approximate number of hematologists in each state was extracted from provider listings compiled by the American Society of Hematology.[105] This metric will be an overestimate of expert resources, because many hematology providers actually treat SCD.

3. *Licensed physicians per 100,000 population.* The availability of licensed physicians provides a picture of how the supply of licensed physicians matches up with the demand for care. In states where the number of licensed physicians per 100,000 population is lower, patients may have to travel further or wait longer for preventative, specialist, or emergency care.[106]

4. *Percentage of population living in rural areas.* In states with a high percentage of the population living in rural areas, patients will likely have to travel farther to find primary

care and specialist providers. Rural areas are more likely to have a scarcity of clinics and hospitals and are less likely than urban counterparts to have access to telehealth services.[107, 108]

5. *Percentage of high need and multimorbid patients without care due to cost.* Care is less affordable for high need and multimorbid patients in some states than others. High need individuals are more likely than the average adult to have insurance but are more likely to forgo doctor visits and prescription medication than average adults due to cost. High need patients report the most difficulty affording care in states that did not expand their Medicaid programs under the Affordable Care Act.[109] Though this metric is applicable to all high need and multimorbid patients, it also applies more specifically to SCD patients because a high percentage of publicly insured SCD patients live with comorbid illnesses.[26]

6. *Percentage of high need and multimorbid patients without a source of usual care.* This metric provides a picture of whether patients with complex health needs are likely to lack a source of usual care.[109] Though this metric is applicable more generally to high need and multimorbid patients, we assume that access to care difficulties will also apply to the subset of SCD patients

7. *Official Poverty Measure (OPM).* The OPM is a Census poverty metric that compares income to a poverty threshold determined by family size and other factors.[52] A higher proportion of population below the poverty line suggests that patients will likely have more difficulty affording care.

8. *Multidimensional Deprivation Index (MDI).* The MDI is a metric recently developed by the United States Census Bureau that includes six dimensions: standard of living, education, health, economic security, housing quality, and neighborhood quality. This metric includes aspects of lifestyle that also impact healthcare access not captured in our other indicators. Housing quality, neighborhood quality, and standard of living can affect an individual's proximity to care, the ability to afford care, the amount of social support for adherence to medication, and other factors. Education can impact an individual's health literacy.[110]

9. *Percent of population publicly insured.* Patients who are publicly insured are more likely to seek high-cost emergency care and less likely to have a consistent source of care.[46, 109]

10. *Percent of population uninsured.* Uninsured patients are more likely to avoid seeking any type of healthcare and seek high-cost emergency care when urgent complications arise.[46] They are also less likely to have a primary source of care than their insured counterparts.[109]

State-level data on each metric was compiled for all 50 states. Only 25 states have an estimated SCD population over 1,000, so the care gap analysis focused on only the states with over 1,000

SCD patients. In order to compare this data across states, thresholds were created to differentiate states where barriers to care were likely to be considerably higher than in other states. These thresholds were determined for each metric based on reviewing the data and identifying where data appeared to be materially different from the state nearest in number (Table 6-1). For example, the proportion of the population qualifying as deprived on the Multidimensional Deprivation Index scale ranged from 10%-22% among the states with the top 25 largest populations of sickle cell patients. 18%-22% of the population was considered deprived on the MDI in the nine states with the highest deprivation. The remaining 16 states have a materially lower proportion of the population below the threshold and range from 10%-16%. Full results are shown in Appendix A.

Table 6-1
Thresholds defining gaps in care.

Metric	Threshold	Source of Data
Patients/CHW	>4	Bureau of Labor Statistics [104]
Patients/Hematologist	>100	American Society of Hematology [105]
Physicians/100,000 Population	<350	Young et al., Census of Actively Licensed Physicians in the United States [106]
Percentage of population living in rural areas.	>25%	United States Census 2010 [111]
High Need Patients without Source of Usual Care	>23%	Behavioral Risk Factor Surveillance System (BRFSS), Radley (2017) [109]
Uninsured	>10%	American Community Survey, Kaiser Family Foundation [112]
Publicly Insured	>35%	American Community Survey, Kaiser Family Foundation [112]
Population below official poverty measure (OPM)	≥ 20%	American Community Survey 2017 [110]
High Need Patients Skipping Visits Due to Cost	>15%	Behavioral Risk Factor Surveillance System (BRFSS), Radley (2017) [109]
Multiple Deprivation Index (MDI)	>16%	American Community Survey 2017 [110]

These thresholds enabled comparison of probable gaps in care across the states. Each metric for which a state met the definition of a potential care gap counted as a single point on the "care gap" scale. Total care gap scores ranged from 1 to 10 and are presented in Figure 6-3**.** States with a higher score and, therefore, more gaps in healthcare for SCD patients can reap greater benefits from connecting patients to CHWs. According to this scoring system, the states predicted to have the most significant gaps in care are Mississippi, Louisiana, Georgia, Arkansas, Texas, and Alabama. Louisiana, Georgia, and Texas are also among the top ten states with the most SCD patients and include over 8,000 SCD patients who are predicted to have difficulty accessing care. The full results are shown in Appendix A.

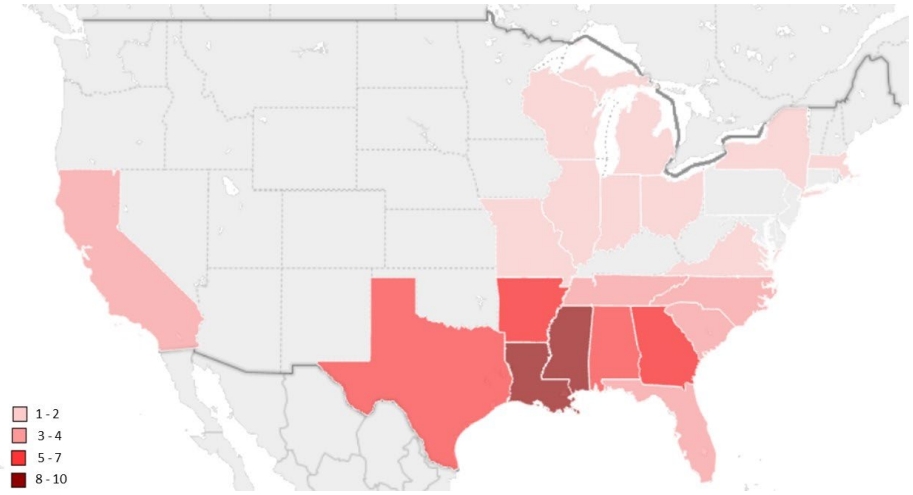

Figure 6-3. SCD healthcare gaps by state.

A key limitation of this predictive scoring system is that it does not include the effects of provider-level barriers, such as lack of SCD-specific knowledge and racial biases. It is difficult to assess provider-specific barriers on a state level because they are unique to each provider. Not surprisingly, research indicates that more exposure to SCD patients and education on SCD management is associated with greater comfort managing SCD care.[56] This predictive scoring system also does not include the effects of opioid restriction and regulation because policies and laws regarding opioid prescriptions vary considerably by state, hospital, and provider.

7. TRAINING AND OCCUPATIONAL REGULATION

Though CHW programs have proven effective in many settings, legislation and occupational regulation are limited.[44] Inconsistent funding and training policies make it much harder to develop and sustain a CHW workforce. A 2015 policy brief published by the CDC emphasizes the importance of policies that formalize funding, CHW training, and CHW certification. High-quality training programs, clearly defined scope of practice, systems for supervision, and continuing education are critical elements of successful and sustainable CHW programs. The integration of CHW programs into healthcare systems and creating a reimbursement structure will help make CHW programs more sustainable.[71, 113] These recommendations are echoed throughout CHW research.[114]

As of December 2015, 15 states are developing or have established formal training and certification programs for CHWs. Requirements for certification vary across the state, and certification is not mandatory in all states. Common requirements for CHW certification include: (1) developing a knowledge base on healthcare, health behaviors, and disease-specific concerns;

(2) developing communication, advocacy and interpersonal skills; and (3) understanding professional ethics and responsibilities.[71, 115]

8. BENEFITS OF SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA)

8.1 SCDAA CHW Program

The Sickle Cell Disease Association of America (SCDAA) is a key part of the effort to improve the care and quality of life of individuals with sickle cell disease. Supported by a grant from the U.S. Department of Health and Human Services, SCDAA's Sickle Cell Disease Newborn Screening Follow-up Program connected 7,600 individuals with core and supportive services between 2018 and 2020.[116] SCDAA's CHW program is a significant part of the effort to connect patients with care. Between 2018 and 2020, SCDAA trained 160 CHWs across 17 states (Table 8-1). CHWs were trained in 60% of the top 10 states with the greatest predicted gaps in care, and 80% of the states with the greatest estimated number of SCD patients (Table 8-2).

Table 8-1.
SCDAA Coverage in States with Greatest Predicted Care Gaps

States	Member Organizations	Trained CHWs
Mississippi	No	No
Louisiana	Yes	Yes
Arkansas	No	No
Georgia	Yes	Yes
Alabama	Yes	Yes
Texas	Yes	Yes
Florida	Yes	No
North Carolina	Yes	Yes
South Carolina	Yes	No
Tennessee	Yes	Yes

Table 8-2.
SCDAA Coverage in States with Greatest Estimated Number of SCD Patients

States	Member Organizations	Trained CHWs
Florida	Yes	No
New York	Yes	Yes
Texas	Yes	Yes
Georgia	Yes	Yes
California	Yes	Yes
Maryland	Yes	Yes
New Jersey	Yes	Yes
North Carolina	Yes	Yes
Louisiana	Yes	Yes
Illinois	Yes	No

Although there are no nationally consistent training programs, certain elements have been proven to improve outcomes for the populations they serve. SCDAA training aligns well with state recommendations and evidence-based training frameworks presented in the research. Key elements highlighted in research and SCDAA's training program include: (1) Development of technical competency including general and disease-specific health knowledge;[71, 89, 115, 117] (2) development of social competency, including cultural competency, communication, and advocacy skills;[71, 115, 117] and (3) understanding professional ethics and responsibilities.[71, 89, 115] SCDAA's training program provides modules of disease-specific training on SCD issues in childhood, adolescent transition, and adulthood.

Research also emphasizes the importance of supportive and collaborative supervision for training and retention of CHWs.[118, 119] SCDAA provides specialized training to supervisors to help them develop management skills and further the professional development of the CHWs under

their management. The training also includes a discussion of appropriate workload, barriers to CHW effectiveness and success, and ways to make supervision collaborative.[120]

8.2 Estimated Annual Healthcare Cost Savings Per Patient

Estimating anticipated healthcare cost savings from literature is challenging given the dearth of economic studies of CHW programs, particularly in SCD. In this section, we identify studies with similar patterns of care and interventions, and estimate the healthcare costs that could be saved by CHW intervention for individuals with SCD.

SCD-related healthcare costs are considerable. A 2020 claims study of healthcare resource utilization among patients with SCD estimated the average annual cost of SCD care to be $20,206.[121] Using this study as an estimate of baseline cost, we sought to estimate the savings that CHW support could provide in terms of reduced hospitalization, fewer ER visits increased adherence to hydroxyurea treatment and monitoring.

Inpatient Hospitalization
To our knowledge, there are no economic studies of CHW intervention for SCD. To approximate this population and the benefits of a CHW program, we searched for studies of CHW programs treating a similar chronically ill population of primarily African American individuals who were publicly insured. A 2020 study by Vasan et al. assessed the impact of a CHW program on hospitalization rates of disadvantaged patients with multiple chronic health conditions. The study pooled the results of three clinical trials and found that two weeks to six months of CHW intervention reduced hospitalizations by 25% and length of hospitalizations by 15%.[122] This results in an estimated cost savings of $4,876 per patient per year.

Emergency Department
A 2009 study found that CHW support decreased ED visits by 23% in among urban African Americans with diabetes.[123] Shah et al. (2020) found that average ER costs totaled $402 per year.[121] Assuming that CHW intervention could decrease ED visits by 23%, ER costs will reduce to an average of $310 per year, which results in an average savings of $92 per patient per year.

Preventative Care & Hydroxyurea Treatment
In addition to preventing hospitalizations, CHWs advocate for appropriate hydroxyurea treatment and monitoring. Treatment with hydroxyurea will increase pharmacy and outpatient monitoring costs, but has been shown to decrease SCD-related hospitalizations.[124, 125] Appropriate adherence to hydroxyurea treatment and monitoring has been shown to reduce hospitalizations related to sickle cell crises by as much as 32% and overall crisis rates by as much as 68%.[125, 126] A pediatric study found that hydroxyurea increased outpatient costs by $1,376 per patient, but decreased inpatient costs by 31%. The study also speculated that these savings would only grow with patient age.[124] Assuming that CHW programs could improve hydroxyurea adherence by 30%, cost savings would reach an average of $1,004 per patient.

Total Estimated Healthcare Cost Savings

CHW intervention has the potential to impact many areas of a patient's health and life. The cost savings described above show several avenues of cost savings that the average patient with SCD might experience with CHW support. The total cost savings per patient are estimated to be $5,973 per patient (Figure 8-1). Notably, even if the CHW program was 80% less effective than we anticipate in these estimations, cost savings would still total over $1,000 per patient.

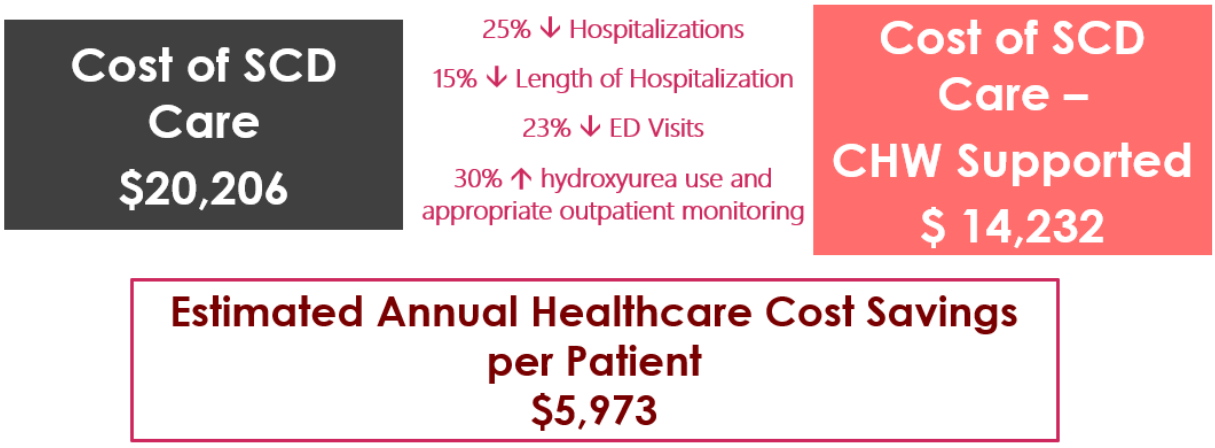

Figure 8-1. Estimated healthcare savings per patient.

9. OPPORTUNITIES FOR ADVOCACY AND CHANGE

9.1 SCD Screening for United States Immigrants

The immigrant population is particularly vulnerable because these individuals often do not have a connection to the United States health system upon arrival.[127] There are often language or cultural barriers that make it more difficult for immigrants to enter the US healthcare system. CHWs are uniquely equipped to assist immigrant populations because of their shared culture. Chronic disease management and prevention programs led by CHWs have proven to be effective in many immigrant communities.[127-130]

Immigrants with SCD pose an additional challenge because many have not been diagnosed. The majority of the incident population of individuals with SCD immigrate from Africa. Over 75% of all infants born globally with SCD are born in Africa, but the mortality rate for children with SCD under the age of 5 is over 50%.[15] The accuracy and extent of data on individuals with SCD in Africa are limited by the fact that many individuals remain undiagnosed or are born outside of a hospital setting.[131]

Immigrants with SCD have unique needs because they must be screened, diagnosed, and directed toward healthcare practitioners to assist them with managing care. Immigrants to the United States

are required to undergo medical examination upon entry to the United States, though the exact protocol for examination varies by state.[132] This includes screening and vaccination for communicable diseases that may require follow-up care such as tuberculosis, HIV, and hepatitis.[133, 134] Immigrants are not screened for SCD, which delays diagnosis.

The impact of failure to screen for SCD is illustrated in a study of individuals immigrating to Italy. The study found that most immigrants were diagnosed with SCD only due to an acute clinical event that required emergency care. The remainder were identified as a result of non-emergent SCD symptoms or SCD-related pregnancy complications. Screening of high-risk individuals could prevent life-threatening SCD-related acute events and pregnancy complications before they occur.[135] Screening is particularly important for infants, who should be treated with prophylactic antibiotics to reduce SCD-related mortality.[96] Screening programs for SCD are both low cost and effective for identifying individuals with SCD.[136]

In addition to a national immigrant screening program, CHW programs targeted toward immigrants with can improve their understanding of their SCD diagnosis and connect them with resources to effectively manage the disease. Early diagnosis allows immigrants with SCD to make informed decisions about the state that they choose to settle in. New York, California, Texas, Maryland, New Jersey, Virginia, Massachusetts, Georgia, Minnesota, and Florida receive the largest number of immigrants from Africa each year.[137] Our analysis indicates that immigrants may experience higher barriers to care in Texas and Georgia than in other states, so immigrants may prefer not to settle in those states. CHWs can help immigrants with these important decisions through health education and support.

9.2 Specialized Programs for High-Risk Young Adult Patients

A significant gap in healthcare exists for young adults with SCD transitioning from pediatric to adult SCD care. The transition from pediatric care requires connecting with new providers and sources of care when many patients also experience an increase in SCD complication rates. Difficulty accessing new providers leads to a gap in preventative care with corresponding higher acute care utilization, greater mortality risk, and financial stress.[48-52]

The extent of this gap is difficult to quantify for all states because of the lack of comprehensive data collection on SCD in the United States. Therefore, a smaller subgroup analysis was conducted for two states with a high burden of SCD: California and Georgia. Since 2015, the CDC has collected detailed data on healthcare resource utilization for different patient age groups. When data from Georgia and California were combined, the sample included 12,706 SCD patients, representing about 13% of SCD patients in the United States.[138] The data summarized in Figures 5-1 and 5-2 show that hospital admissions per patient and the number of emergency department visits per patient increase dramatically when patients enter the 20-29 age group.

Programs supporting the transition of care for SCD patients can improve adolescent patients' health outcomes and quality of life. A 2019 study by Smith et al. reports on the implementation of a transition program for adolescents with SCD. Patients were connected with a team of adult and pediatric practitioners, an educational coordinator, and a clinical psychologist. Patients over the

age of 15 were also assigned a CHW, referred to in this study as a patient navigator. Before implementing the program, only 50% of patients visited an adult provider within six months of high school graduation. After implementing the program 100% of patients visited an adult provider within six months of graduation, and 78% continued care in the adult clinic after the first visit.[139] This study showed that elements such as health education, assistance with care coordination, and individualized support and reinforcement significantly improved the number of young adults continuing care. CHWs are trained in all of these areas and can play a crucial part in the transition from pediatric to adult care.

Support is particularly important for young adults who move out of their current area of care to enter the workforce or continue their education. These patients lack connections within their new community. A shortage of comprehensive sickle cell care for adults and a high likelihood of being uninsured makes it more difficult for young adults to access adult care providers, increasing the probability of failing to transition to adult providers.[140, 141] CHW programs linked with colleges and trade schools would prevent young adult patients who choose to continue their education from losing contact with the healthcare system.

Successful transition to adult care has a positive impact on healthcare costs. Adherence to preventative and connection to the healthcare system reduces short-term reliance on high-cost emergency room visits and hospitalizations. It also prevents future SCD-complications that might have been prevented by consistent SCD care.[48-52]

Young adult SCD patients have unique needs that require additional support. CHW programs designed to target this population can ensure that patients remain connected to the health system and prevent costly hospital admissions and ER visits. Empowering young adults with SCD to manage their condition can also lead to long-term health and cost benefits as they move into adulthood.

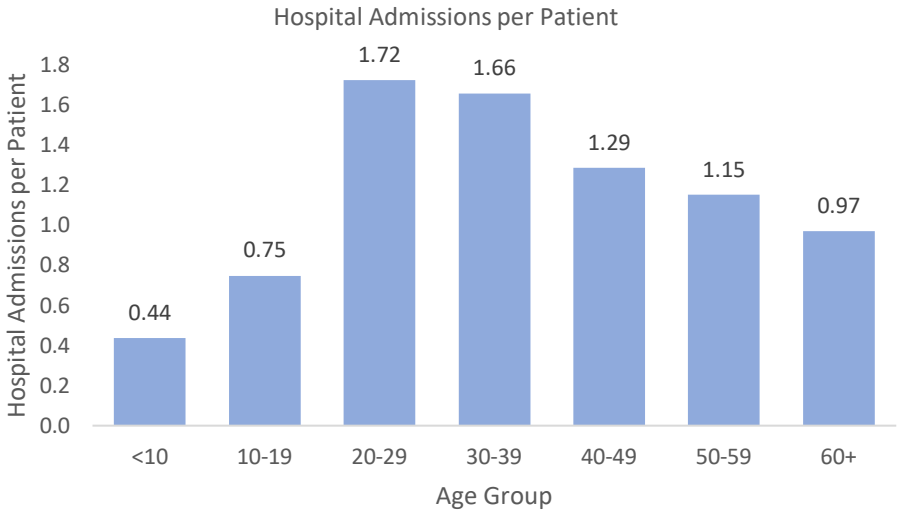

Figure 9-1. Hospital admissions by age group in SCD patients.

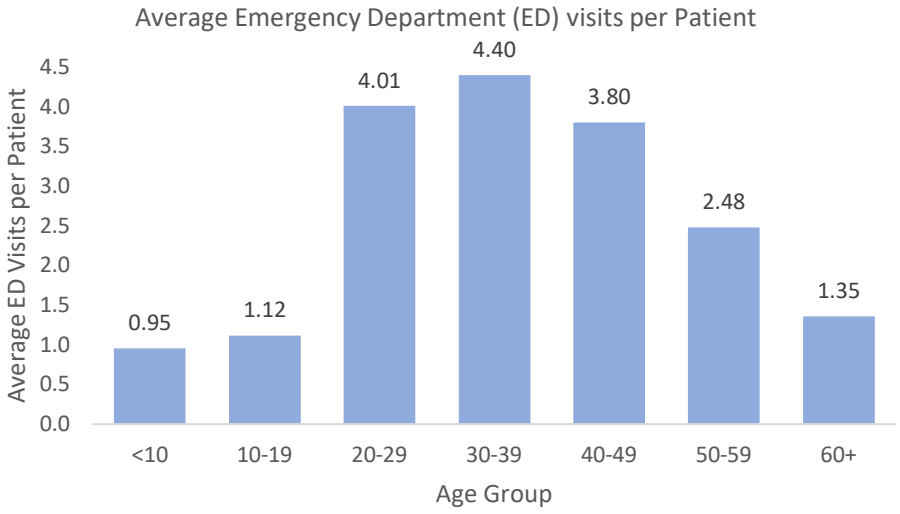

Figure 9-2. Emergency department visits per SCD patient by age group.

9.3 Patients in Rural Areas with Provider Shortages

Rural areas generally have higher rates of chronic illness and a larger number of elderly residents than urban communities and a corresponding higher demand for care. Unfortunately, rural areas also have the lowest supply of licensed physicians.[142] Rural communities often have difficulty attracting and retaining physicians due to lower salaries, urban-centric healthcare training, and other factors. Rural areas are also more likely to have a scarcity of clinics and hospitals and provision of emergency services is left to primary care physicians. Consequently, healthcare providers, particularly primary care physicians, are both scarce and overburdened. The limited number of locations for care force patients to travel further to visit a provider, which is made more

difficult by the lack of public transportation options in rural communities.[107, 117, 143-145] Rural patients are also less likely than their urban counterparts to have access to telehealth services.[107, 108]. However, the major expansion of access to telemedicine during the COVID pandemic includes a broad range of ordinary electronic devices and holds promise for reducing the rural disparity in access to SCD care.

CHW programs can address these barriers to care because they are a uniquely flexible and widespread workforce. CHWs can relieve provider shortages by shifting tasks from other overburdened healthcare workers, including primary care physicians and nurses, and enable more efficient use of available resources, which is especially important in under-resourced areas.[117] CHWs are trained and trusted community members, which can be an important factor in communities that are more socially isolated. CHWs have a unique understanding of the patients' cultural values and special needs, which translates to better program adherence and greater receptiveness to health education.[143] The future of CHW programs lies in the expansion of programs into underserved populations where barriers to care are highest.

10. ANALYSIS LIMITATIONS

This study has several limitations. The focus of this analysis was on predicting possible gaps in SCD healthcare and on estimating possible cost savings associated with an SCD CHW program. These care gaps were estimated from SCD data where possible, but the accuracy of the analysis is limited by the accuracy of the data on which it is based. As noted previously, there is a lack of recent state-specific data on individuals living with SCD, which made linear extrapolation from older data necessary. This is unlikely to significantly impact the results of the analysis because SCD rates in the United States have remained fairly stable over the twenty-year period between 1991 and 2010.[96] The estimated number of immigrants with SCD only considered individuals immigrating from Africa, though this neglects individuals with SCD from other countries.[15] This choice was justified by the fact that the 85% of people with SCD are born in Africa.[146] Immigrants represent less than 1% of the total estimated individuals with SCD, and are unlikely to effect the overall demand for SCD care across the United States.

Estimates of SCD care resources are similarly uncertain. State estimates of licensed physicians and hematologists are likely correct on the order of magnitude, but not all licensed physicians or hematologists are available or prepared to treat SCD patients. CHW employment statistics are difficult to accurately assess due to the lack of uniform terminology and use of alternative names such as "patient navigator."

Due to the lack of studies on SCD-specific CHW programs, cost savings were estimated from studies of non-SCD CHW programs or from SCD studies investigating other interventions to improve patient care. These cost savings represent a ballpark estimation of likely per-patient savings from the implementation of an SCD CHW program. Though these savings represent a rough estimate, the estimated reduction healthcare utilization and related costs are consistent with benefits of disease-modifying therapies like hydroxyurea, glutamine, and crizanlizumab.[62, 124, 147]

11. CONCLUSION

SCD is a complex, chronic condition that requires consistent management by comprehensive care, but patients in many states face challenges to accessing care. These challenges are worsened by factors such as distance from comprehensive care, the ability to afford care, insurance coverage, education, and housing. Patients living in states with a high proportion of publicly insured individuals who live in areas that are rural and impoverished will have more difficulty accessing care. CHW programs have proven effective in addressing barriers to care for other chronic diseases in disadvantaged populations by linking the community with healthcare resources, educating patients and providers, and advocating for the needs of the community. This research demonstrates that SCD patients have a clear need for additional support in managing their chronic disease and that CHW support can reduce the barriers to receiving healthcare.

Appendix A.
Demand and Supply Model Results

Table A1.

STATE	PREVALENCE			
	Est. Number of SCD Patients (2016)	Births/Year	Deaths/Year	Estimated Immigration/Year (2016)
Florida	9,009	224	49	28
New York	8,567	152	40	77
Texas	7,520	157	31	63
Georgia	6,159	163	36	35
California	4,904	99	33	73
Maryland	4,762	73	17	56
New Jersey	4,121	61	17	40
North Carolina	4,024	88	22	7
Louisiana	3,908	73	19	7
Illinois	3,808	86	24	10
Pennsylvania	3,725	75	15	4
Ohio	3,649	72	18	10
South Carolina	3,574	65	24	7
Michigan	3,272	59	16	10
Mississippi	3,194	62	14	7
Virginia	3,115	74	17	38
Alabama	2,845	57	19	7
Tennessee	2,108	48	12	7
Missouri	1,948	36	10	10
Massachusetts	1,945	39	4	37
District of Columbia	1,639	0	3	4
Connecticut	1,281	26	4	4
Indiana	1,250	34	7	10
Arkansas	1,230	24	9	4
Wisconsin	1,119	25	5	4
Sources	[7, 96, 97]			[99-101, 137]

Table A2.

STATE	CARE GAP METRICS		
	Patients/CHW	Patients/ Hematologist	Licensed Physicians/100,000 Population
Florida	3	85	359
New York	2	36	476
Texas	2	55	280
Georgia	5	121	349
California	1	24	380
Maryland	4	64	502
New Jersey	3	55	416
North Carolina	5	49	382
Louisiana	6	301	361
Illinois	2	37	387
Pennsylvania	2	32	441
Ohio	2	47	401
South Carolina	11	223	383
Michigan	2	54	476
Mississippi	5	1,597	343
Virginia	5	54	450
Alabama	4	158	328
Tennessee	3	50	346
Missouri	1	46	423
Massachusetts	1	17	512
District of Columbia	2	86	1,838
Connecticut	3	39	487
Indiana	1	32	426
Arkansas	4	154	334
Wisconsin	2	23	463
Sources	[104]	[105]	[106]

Table A3.

STATE	CARE GAP METRICS			
	% Rural* Pop.	% Uninsured	% Publicly Insured	Official Poverty Measure (OPM)*
Florida	9%	13%	36%	14%
New York	12%	6%	38%	14%
Texas	15%	17%	28%	15%
Georgia	25%	13%	30%	15%
California	5%	7%	38%	13%
Maryland	13%	6%	30%	9%
New Jersey	5%	8%	30%	10%
North Carolina	34%	10%	33%	15%
Louisiana	27%	10%	38%	20%
Illinois	12%	7%	33%	13%
Pennsylvania	21%	6%	35%	13%
Ohio	22%	6%	36%	14%
South Carolina	34%	10%	35%	15%
Michigan	25%	5%	38%	14%
Mississippi	51%	12%	38%	20%
Virginia	25%	9%	25%	11%
Alabama	41%	9%	35%	17%
Tennessee	34%	9%	35%	15%
Missouri	30%	9%	30%	13%
Massachusetts	8%	2%	36%	11%
District of Columbia	0%	4%	36%	17%
Connecticut	12%	5%	33%	10%
Indiana	28%	8%	32%	14%
Arkansas	44%	8%	42%	16%
Wisconsin	30%	5%	32%	11%
Sources	[111]	[112]		[110]

Table A4.

STATE	CARE GAP METRICS			CARE GAP
	High Need, Multimorbid Patients w/o Source of Usual Care	High Need, Multimorbid Patients Skipped Visit Due to Cost	Multidimensional Deprivation Index (MDI)**	Care Gap Score
Florida	24%	18%	14%	4
New York	18%	14%	18%	2
Texas	33%	18%	18%	5
Georgia	28%	19%	16%	6
California	25%	13%	19%	3
Maryland	17%	10%	14%	0
New Jersey	18%	14%	12%	0
North Carolina	24%	16%	14%	4
Louisiana	25%	17%	22%	8
Illinois	18%	12%	21%	1
Pennsylvania	15%	12%	15%	0
Ohio	20%	13%	15%	1
South Carolina	23%	18%	15%	4
Michigan	16%	15%	16%	1
Mississippi	26%	19%	20%	10
Virginia	24%	13%	11%	2
Alabama	23%	17%	21%	5
Tennessee	24%	16%	16%	4
Missouri	21%	13%	13%	1
Massachusetts	10%	8%	12%	1
District of Columbia	25%	11%	22%	3
Connecticut	16%	11%	11%	0
Indiana	20%	15%	15%	1
Arkansas	22%	18%	19%	6
Wisconsin	18%	10%	10%	1
Sources	[109]	[109]	[110]	

REFERENCES

1. Buchanan, G., et al., *Severe sickle cell disease--pathophysiology and therapy.* Biol Blood Marrow Transplant, 2010. **16**(1 Suppl): p. S64-7.
2. Malowany, J.I. and J. Butany, *Pathology of sickle cell disease.* Semin Diagn Pathol, 2012. **29**(1): p. 49-55.
3. Rees, D.C., T.N. Williams, and M.T. Gladwin, *Sickle-cell disease.* Lancet, 2010. **376**(9757): p. 2018-31.
4. Serjeant, G.R., *The natural history of sickle cell disease.* Cold Spring Harb Perspect Med, 2013. **3**(10): p. a011783.
5. Sundd, P., M.T. Gladwin, and E.M. Novelli, *Pathophysiology of Sickle Cell Disease.* Annu Rev Pathol, 2019. **14**: p. 263-292.
6. Ware, R.E., et al., *Sickle cell disease.* Lancet, 2017. **390**(10091): p. 311-323.
7. Hassell, K.L., *Population estimates of sickle cell disease in the U.S.* Am J Prev Med, 2010. **38**(4 Suppl): p. S512-21.
8. Lubeck, D., et al., *Estimated Life Expectancy and Income of Patients With Sickle Cell Disease Compared With Those Without Sickle Cell Disease.* JAMA Netw Open, 2019. **2**(11): p. e1915374.
9. Aguilar, C., E. Vichinsky, and L. Neumayr, *Bone and joint disease in sickle cell disease.* Hematol Oncol Clin North Am, 2005. **19**(5): p. 929-41, viii.
10. Ballas, S.K., K. Gupta, and P. Adams-Graves, *Sickle cell pain: a critical reappraisal.* Blood, 2012. **120**(18): p. 3647-56.
11. Gupta, K., O. Jahagirdar, and K. Gupta, *Targeting pain at its source in sickle cell disease.* Am J Physiol Regul Integr Comp Physiol, 2018. **315**(1): p. R104-r112.
12. Howard, J., V.J. Thomas, and H.M. Rawle, *Pain management and quality of life in sickle cell disease.* Expert Rev Pharmacoecon Outcomes Res, 2009. **9**(4): p. 347-52.
13. Merlet, A.N., et al., *How Sickle Cell Disease Impairs Skeletal Muscle Function: Implications in Daily Life.* Med Sci Sports Exerc, 2019. **51**(1): p. 4-11.
14. Naseer, Z.A., et al., *Osteonecrosis in Sickle Cell Disease.* South Med J, 2016. **109**(9): p. 525-30.
15. Piel, F.B., M.H. Steinberg, and D.C. Rees, *Sickle Cell Disease.* N Engl J Med, 2017. **376**(16): p. 1561-1573.
16. Caboot, J.B. and J.L. Allen, *Pulmonary complications of sickle cell disease in children.* Curr Opin Pediatr, 2008. **20**(3): p. 279-87.
17. Farooq, S., M. Abu Omar, and G.A. Salzman, *Acute chest syndrome in sickle cell disease.* Hosp Pract (1995), 2018. **46**(3): p. 144-151.
18. Farooq, S. and F.D. Testai, *Neurologic Complications of Sickle Cell Disease.* Curr Neurol Neurosci Rep, 2019. **19**(4): p. 17.
19. Gladwin, M.T. and V. Sachdev, *Cardiovascular abnormalities in sickle cell disease.* J Am Coll Cardiol, 2012. **59**(13): p. 1123-33.
20. Gordeuk, V.R., O.L. Castro, and R.F. Machado, *Pathophysiology and treatment of pulmonary hypertension in sickle cell disease.* Blood, 2016. **127**(7): p. 820-8.
21. Khoury, R.A., et al., *Pulmonary complications of sickle cell disease.* Hemoglobin, 2011. **35**(5-6): p. 625-35.
22. Lawrence, C. and J. Webb, *Sickle Cell Disease and Stroke: Diagnosis and Management.* Curr Neurol Neurosci Rep, 2016. **16**(3): p. 27.
23. Noubouossie, D., N.S. Key, and K.I. Ataga, *Coagulation abnormalities of sickle cell disease: Relationship with clinical outcomes and the effect of disease modifying therapies.* Blood Rev, 2016. **30**(4): p. 245-56.

24. Prengler, M., et al., *Sickle cell disease: the neurological complications.* Ann Neurol, 2002. **51**(5): p. 543-52.
25. Scott, A.W., *Ophthalmic Manifestations of Sickle Cell Disease.* South Med J, 2016. **109**(9): p. 542-8.
26. Adams-Graves, P. and L. Bronte-Jordan, *Recent treatment guidelines for managing adult patients with sickle cell disease: challenges in access to care, social issues, and adherence.* Expert Rev Hematol, 2016. **9**(6): p. 541-52.
27. Gorman, D., *Developing health care workforces for uncertain futures.* Acad Med, 2015. **90**(4): p. 400-3.
28. Rees, G.H., et al., *The promise of complementarity: Using the methods of foresight for health workforce planning.* Health Serv Manage Res, 2018. **31**(2): p. 97-105.
29. The, L., *No health workforce, no global health security.* Lancet, 2016. **387**(10033): p. 2063.
30. Carey, P.J., *Addressing the global health burden of sickle cell disease.* Int Health, 2014. **6**(4): p. 269-70.
31. Islam, N., et al., *Integrating community health workers within Patient Protection and Affordable Care Act implementation.* J Public Health Manag Pract, 2015. **21**(1): p. 42-50.
32. Lee, L., et al., *Reducing Health Care Disparities in Sickle Cell Disease: A Review.* Public Health Rep, 2019. **134**(6): p. 599-607.
33. Hsu, L.L., et al., *Community Health Workers as Support for Sickle Cell Care.* Am J Prev Med, 2016. **51**(1 Suppl 1): p. S87-98.
34. Freiermuth, C.E., et al., *Shift in Emergency Department Provider Attitudes Toward Patients With Sickle Cell Disease.* Adv Emerg Nurs J, 2016. **38**(3): p. 199-212.
35. Jenerette, C. and A. Leak, *The role of oncology nurses in the care of adults with sickle cell disease.* Clin J Oncol Nurs, 2012. **16**(6): p. 633-5.
36. Tanabe, P., N. Dias, and L. Gorman, *Care of children with sickle cell disease in the emergency department: parent and provider perspectives inform quality improvement efforts.* J Pediatr Oncol Nurs, 2013. **30**(4): p. 205-17.
37. Allen, C.G., et al., *Strategies to Improve the Integration of Community Health Workers Into Health Care Teams: "A Little Fish in a Big Pond".* Prev Chronic Dis, 2015. **12**: p. E154.
38. Collinsworth, A., et al., *Community health workers in primary care practice: redesigning health care delivery systems to extend and improve diabetes care in underserved populations.* Health Promot Pract, 2014. **15**(2 Suppl): p. 51s-61s.
39. Hartzler, A.L., et al., *Roles and Functions of Community Health Workers in Primary Care.* Ann Fam Med, 2018. **16**(3): p. 240-245.
40. Johnson, S.L. and V.L. Gunn, *Community Health Workers as a Component of the Health Care Team.* Pediatr Clin North Am, 2015. **62**(5): p. 1313-28.
41. Kwon, S., *Community health workers improve outcomes, reduce costs.* Manag Care, 2018. **27**(11): p. 20-21.
42. Singh, P. and D.A. Chokshi, *Community health workers: an opportunity for reverse innovation - Authors' reply.* Lancet, 2013. **382**(9901): p. 1327.
43. Stiles, S., et al., *Deploying Community Health Workers to Support Medically and Socially At-Risk Patients in a Pediatric Primary Care Population.* Acad Pediatr, 2020.
44. Dampier, C., et al., *Access to Care for Medicaid and Commercially-Insured United States Patients with Sickle Cell Disease.* Blood, 2017. **130**(Supplement 1): p. 4660-4660.
45. Andemariam, B. and S. Jones, *Development of a New Adult Sickle Cell Disease Center Within an Academic Cancer Center: Impact on Hospital Utilization Patterns and Care Quality.* J Racial Ethn Health Disparities, 2016. **3**(1): p. 176-82.

46. Benenson, I., Y. Jadotte, and M. Echevarria, *Factors influencing utilization of hospital services by adult sickle cell disease patients: a systematic review.* JBI Database System Rev Implement Rep, 2017. **15**(3): p. 765-808.
47. Wolfson, J.A., et al., *Sickle cell disease in California: sociodemographic predictors of emergency department utilization.* Pediatr Blood Cancer, 2012. **58**(1): p. 66-73.
48. Renedo, A., et al., *Not being heard: barriers to high quality unplanned hospital care during young people's transition to adult services - evidence from 'this sickle cell life' research.* BMC health services research, 2019. **19**(1): p. 876-876.
49. Blinder, M.A., et al., *Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs.* Pediatr Blood Cancer, 2013. **60**(5): p. 828-35.
50. Porter, J.S., et al., *Pediatric to Adult Care Transition: Perspectives of Young Adults With Sickle Cell Disease.* Journal of pediatric psychology, 2017. **42**(9): p. 1016-1027.
51. Bemrich-Stolz, C.J., et al., *Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease.* Int J Hematol Ther, 2015. **1**(1).
52. Lanzkron, S., et al., *Transition to adulthood and adult health care for patients with sickle cell disease or cystic fibrosis: Current practices and research priorities.* Journal of clinical and translational science, 2018. **2**(5): p. 334-342.
53. Brousseau, D.C., et al., *Acute Care Utilization and Rehospitalizations for Sickle Cell Disease.* JAMA, 2010. **303**(13): p. 1288-1294.
54. Ndumele, C.D., M.S. Cohen, and P.D. Cleary, *Association of State Access Standards With Accessibility to Specialists for Medicaid Managed Care Enrollees.* JAMA Intern Med, 2017. **177**(10): p. 1445-1451.
55. Jiang, H.J., M.L. Barrett, and M. Sheng, *Characteristics of Hospital Stays for Nonelderly Medicaid Super-Utilizers, 2012: Statistical Brief #184*, in *Healthcare Cost and Utilization Project (HCUP) Statistical Briefs*. 2006, Agency for Healthcare Research and Quality (US): Rockville (MD).
56. Mainous, A.G., 3rd, et al., *Attitudes toward Management of Sickle Cell Disease and Its Complications: A National Survey of Academic Family Physicians.* Anemia, 2015. **2015**: p. 853835-853835.
57. Yawn, B., MD and G. Buchanan, MD, *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014*. 2014, US Department of Health and Human Services, National Heart, Lung and Blood Institute.
58. Masese, R.V., et al., *Barriers and facilitators to care for individuals with sickle cell disease in central North Carolina: The emergency department providers' perspective.* PloS one, 2019. **14**(5): p. e0216414-e0216414.
59. Haywood, C., Jr., et al., *A systematic review of barriers and interventions to improve appropriate use of therapies for sickle cell disease.* J Natl Med Assoc, 2009. **101**(10): p. 1022-33.
60. Sinha, C.B., et al., *Management of Chronic Pain in Adults Living With Sickle Cell Disease in the Era of the Opioid Epidemic: A Qualitative Study.* JAMA Netw Open, 2019. **2**(5): p. e194410.
61. Salinas Cisneros, G. and S.L. Thein, *Recent Advances in the Treatment of Sickle Cell Disease.* Frontiers in physiology, 2020. **11**: p. 435-435.
62. Riley, T.R., et al., *Review of Medication Therapy for the Prevention of Sickle Cell Crisis.* P & T : a peer-reviewed journal for formulary management, 2018. **43**(7): p. 417-437.
63. Zempsky, W.T., *Treatment of sickle cell pain: fostering trust and justice.* Jama, 2009. **302**(22): p. 2479-80.
64. Ruta, N.S. and S.K. Ballas, *The Opioid Drug Epidemic and Sickle Cell Disease: Guilt by Association.* Pain Med, 2016. **17**(10): p. 1793-1798.

65. Haywood, C., Jr., et al., *The impact of race and disease on sickle cell patient wait times in the emergency department.* The American journal of emergency medicine, 2013. **31**(4): p. 651-656.
66. Haywood, C., Jr., et al., *Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease.* J Pain Symptom Manage, 2014. **48**(5): p. 934-43.
67. Nelson, S.C. and H.W. Hackman, *Race matters: perceptions of race and racism in a sickle cell center.* Pediatr Blood Cancer, 2013. **60**(3): p. 451-4.
68. Fearon, A., et al., *Pediatric residents' perceived barriers to opioid use in sickle cell disease pain management.* Pediatric blood & cancer, 2019. **66**(2): p. e27535-e27535.
69. Glassberg, J.A., et al., *Emergency provider analgesic practices and attitudes toward patients with sickle cell disease.* Ann Emerg Med, 2013. **62**(4): p. 293-302.e10.
70. Corder-Mabe, J., et al., *Development of a Framework to Describe Functions and Practice of Community Health Workers.* Journal of Continuing Education in the Health Professions, 2019. **39**(4): p. 265-269.
71. *Addressing Chronic Disease Through Community Health Workers: A Policy and Systems-Level Approach*. 2015, Centers for Disease Control and Prevention.
72. Johnson, D., et al., *Community health workers and medicaid managed care in New Mexico.* J Community Health, 2012. **37**(3): p. 563-71.
73. Palmas, W., et al., *Community Health Worker Interventions to Improve Glycemic Control in People with Diabetes: A Systematic Review and Meta-Analysis.* J Gen Intern Med, 2015. **30**(7): p. 1004-12.
74. Allen, J.K., et al., *Cost-effectiveness of nurse practitioner/community health worker care to reduce cardiovascular health disparities.* J Cardiovasc Nurs, 2014. **29**(4): p. 308-14.
75. Aponte, J., et al., *Health effectiveness of community health workers as a diabetes self-management intervention.* Diab Vasc Dis Res, 2017. **14**(4): p. 316-326.
76. Battaglia, T.A., et al., *The impact of patient navigation on the delivery of diagnostic breast cancer care in the National Patient Navigation Research Program: a prospective meta-analysis.* Breast Cancer Res Treat, 2016. **158**(3): p. 523-34.
77. Brownstein, J.N., et al., *Community health workers as interventionists in the prevention and control of heart disease and stroke.* Am J Prev Med, 2005. **29**(5 Suppl 1): p. 128-33.
78. Brownstein, J.N., et al., *Effectiveness of community health workers in the care of people with hypertension.* Am J Prev Med, 2007. **32**(5): p. 435-47.
79. Carrasquillo, O., et al., *Effect of a Community Health Worker Intervention Among Latinos With Poorly Controlled Type 2 Diabetes: The Miami Healthy Heart Initiative Randomized Clinical Trial.* JAMA internal medicine, 2017. **177**(7): p. 948-954.
80. Gary, T.L., et al., *Randomized controlled trial of the effects of nurse case manager and community health worker interventions on risk factors for diabetes-related complications in urban African Americans.* Prev Med, 2003. **37**(1): p. 23-32.
81. Islam, N.S., et al., *Evaluation of a community health worker pilot intervention to improve diabetes management in Bangladeshi immigrants with type 2 diabetes in New York City.* Diabetes Educ, 2013. **39**(4): p. 478-93.
82. Lim, S., et al., *A Culturally Adapted Diabetes Prevention Intervention in the New York City Sikh Asian Indian Community Leads to Improvements in Health Behaviors and Outcomes.* Health Behav Res, 2019. **2**(1).
83. Margellos-Anast, H., M.A. Gutierrez, and S. Whitman, *Improving asthma management among African-American children via a community health worker model: findings from a Chicago-based pilot intervention.* J Asthma, 2012. **49**(4): p. 380-9.

84. Norris, S.L., et al., *Effectiveness of community health workers in the care of persons with diabetes.* Diabet Med, 2006. **23**(5): p. 544-56.
85. Spencer, M.S., et al., *Effectiveness of a community health worker intervention among African American and Latino adults with type 2 diabetes: a randomized controlled trial.* Am J Public Health, 2011. **101**(12): p. 2253-60.
86. Whitley, E.M., R.M. Everhart, and R.A. Wright, *Measuring return on investment of outreach by community health workers.* J Health Care Poor Underserved, 2006. **17**(1 Suppl): p. 6-15.
87. Wilson, F.A., et al., *Cost-effectiveness analysis of a colonoscopy screening navigator program designed for Hispanic men.* J Cancer Educ, 2015. **30**(2): p. 260-7.
88. Rush, C.H., *Return on investment from employment of community health workers.* J Ambul Care Manage, 2012. **35**(2): p. 133-7.
89. Scott, K., et al., *What do we know about community-based health worker programs? A systematic review of existing reviews on community health workers.* Hum Resour Health, 2018. **16**(1): p. 39.
90. Kangovi, S., et al., *Evidence-Based Community Health Worker Program Addresses Unmet Social Needs And Generates Positive Return On Investment.* Health Affairs, 2020. **39**(2): p. 207-213.
91. Jacob, V., et al., *Economics of Community Health Workers for Chronic Disease: Findings From Community Guide Systematic Reviews.* Am J Prev Med, 2019. **56**(3): p. e95-e106.
92. Walls, T. *Integrating Community Health Workers on Clinical Care Teams and in the Community*. 25 June 2020 13 September 2020]; Available from: https://www.cdc.gov/dhdsp/pubs/guides/best-practices/chw.htm.
93. Campbell, J.D., et al., *Community Health Worker Home Visits for Medicaid-Enrolled Children With Asthma: Effects on Asthma Outcomes and Costs.* Am J Public Health, 2015. **105**(11): p. 2366-72.
94. Diaz, J., *Social Return on Investment: Commmunity Health Workers in Cancer Outreach*. 2012, Wilder Research.
95. van der Goes, D.N., et al., *An iron triangle ROI model for health care.* Clinicoecon Outcomes Res, 2019. **11**: p. 335-348.
96. Therrell, B.L., Jr., et al., *Newborn screening for sickle cell diseases in the United States: A review of data spanning 2 decades.* Semin Perinatol, 2015. **39**(3): p. 238-51.
97. Prevention, C.f.D.C.a., *Compressed Mortality File 1999 - 2016 on CDC WONDER Online Database Series 20 No. 2U, 2016*. 2016, National Center for Health Statistics.
98. Aliyu, Z.Y., et al., *Sickle cell disease and pulmonary hypertension in Africa: A global perspective and review of epidemiology, pathophysiology, and management.* American Journal of Hematology, 2008. **83**(1): p. 63-70.
99. *The Demographic Profile of African Countries*. 2016, United Nations Economic Commission for Africa.
100. *Table 7. Persons Obtaining Lawful Permanent Resident Status By Type And Detailed Class Of Admission: Fiscal Year 2016*, Y.o.I. Statistics, Editor. 2016, Department of Homeland Security.
101. *Table 3. Persons Obtaining Lawful Permanent Resident Status By Region Of Birth: Fiscal Years 2014 To 2016*, Y.o.I. Statistics, Editor. 2016, Department of Homeland Security.
102. Grosse, S.D., et al., *Sickle cell disease in Africa: a neglected cause of early childhood mortality.* American journal of preventive medicine, 2011. **41**(6 Suppl 4): p. S398-S405.
103. *Table 8. Persons Obtaining Lawful Permanent Resident Status By Age: Fiscal Year 2016*, Y.o.I. Statistics, Editor. 2016, Department of Homeland Security.
104. *Occupational Employment and Wages, May 2019 - Community Health Workers*. 2020 06 July 2020 [cited 2020 27 October 2020]; Available from: https://www.bls.gov/oes/current/oes211094.htm#(9).

105. *Find A Hematologist*. 2020 08 July 2020]; Available from: https://www.hematology.org/education/patients/find-a-hematologist.
106. Young, A., PhD, et al., *A Census of Actively Licensed Physicians in the United States, 2016.* Journal of Medical Regulation, 2017. **103**(2): p. 7 - 21.
107. Douthit, N., et al., *Exposing some important barriers to health care access in the rural USA.* Public Health, 2015. **129**(6): p. 611-20.
108. Ratcliffe, M., et al., *Defining Rural at the US Census Bureau: American Community Survey and Georgraphy Brief*. 2016.
109. Radley, D., S. Hayes, and D. McCarthy, *Assessing State Variation in High-Need Adult Populations and Their Care Experiences*. 2017, The Commonwealth Fund.
110. Glassman, B., *Multidimensional Deprivation in the United States: American Community Survey Report*. 2019, United States Census Bureau.
111. *Urban and Rural - Table P2*. 2010, United States Census Bureau.
112. *Health Insurance Coverage of the Total Population, 2016*. [cited 2020; Available from: https://www.kff.org/other/state-indicator/total-population/?currentTimeframe=3&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D.
113. *Including Community Health Workers (CHWs) in State Health System Transformations*. 2019 28 February 2019 30 August 2020]; Available from: https://www.cdc.gov/dhdsp/pubs/toolkits/chw-ta-including.htm.
114. Rosenthal, E.L., et al., *Community health workers: part of the solution.* Health Aff (Millwood), 2010. **29**(7): p. 1338-42.
115. London, K., M. Carey, and K. Russell, *Community Health Worker Requirements by State*. 2016, Connecticut Health Foundation.
116. *Sickle Cell Disease Newborn Screening Follow-up Program Progress Report*. 2020, Sickle Cell Disease Association of America.
117. Celletti, F., et al., *Can the deployment of community health workers for the delivery of HIV services represent an effective and sustainable response to health workforce shortages? Results of a multicountry study.* Aids, 2010. **24 Suppl 1**: p. S45-57.
118. Kane, S., et al., *Limits and opportunities to community health worker empowerment: A multi-country comparative study.* Soc Sci Med, 2016. **164**: p. 27-34.
119. Jaskiewicz, W. and K. Tulenko, *Increasing community health worker productivity and effectiveness: a review of the influence of the work environment.* Hum Resour Health, 2012. **10**: p. 38.
120. *Community Health Worker Supervision Training*. Sickle Cell Disease Association of America.
121. Shah, N., et al., *Medical Resource Use and Costs of Treating Sickle Cell-related Vaso-occlusive Crisis Episodes: A Retrospective Claims Study.* Journal of health economics and outcomes research, 2020. **7**(1): p. 52-60.
122. Vasan, A., et al., *Effects of a standardized community health worker intervention on hospitalization among disadvantaged patients with multiple chronic conditions: A pooled analysis of three clinical trials.* Health services research, 2020. **55 Suppl 2**(Suppl 2): p. 894-901.
123. Gary, T.L., et al., *The effects of a nurse case manager and a community health worker team on diabetic control, emergency department visits, and hospitalizations among urban African Americans with type 2 diabetes mellitus: a randomized controlled trial.* Arch Intern Med, 2009. **169**(19): p. 1788-94.
124. Wang, W.C., et al., *Hydroxyurea is associated with lower costs of care of young children with sickle cell anemia.* Pediatrics, 2013. **132**(4): p. 677-83.

125. *Systematic Review: Hydroxyurea for the Treatment of Adults with Sickle Cell Disease.* Annals of Internal Medicine, 2008. **148**(12): p. 939-955.
126. Brandow, A.M. and J.A. Panepinto, *Hydroxyurea use in sickle cell disease: the battle with low prescription rates, poor patient compliance and fears of toxicities.* Expert Rev Hematol, 2010. **3**(3): p. 255-60.
127. Islam, N., et al., *Evaluating community health workers' attributes, roles, and pathways of action in immigrant communities.* Preventive medicine, 2017. **103**: p. 1-7.
128. Islam, N., et al., *Protocol for the DREAM Project (Diabetes Research, Education, and Action for Minorities): a randomized trial of a community health worker intervention to improve diabetic management and control among Bangladeshi adults in NYC.* BMC Public Health, 2014. **14**: p. 177.
129. Islam, N.S., et al., *A randomized-controlled, pilot intervention on diabetes prevention and healthy lifestyles in the New York City Korean community.* J Community Health, 2013. **38**(6): p. 1030-41.
130. Islam, N.S., et al., *Diabetes prevention in the New York City Sikh Asian Indian community: a pilot study.* Int J Environ Res Public Health, 2014. **11**(5): p. 5462-86.
131. Mulumba, L.L. and L. Wilson, *Sickle cell disease among children in Africa: An integrative literature review and global recommendations.* International Journal of Africa Nursing Sciences, 2015. **3**: p. 56-64.
132. Pezzi, C., et al., *Health screenings administered during the domestic medical examination of refugees and other eligible immigrants in nine US states, 2014-2016: A cross-sectional analysis.* PLoS medicine, 2020. **17**(3): p. e1003065-e1003065.
133. *General Refugee Health Guidelines*. 2016 21 June 2016; Available from: https://www.cdc.gov/immigrantrefugeehealth/guidelines/domestic/general/index.html.
134. *Summary Checklist for the Domestic Medical Examination for Newly Arriving Refugees*. 2019 07 August 2019 13 September 2020]; Available from: https://www.cdc.gov/immigrantrefugeehealth/guidelines/domestic/checklist.html.
135. De Franceschi, L., et al., *Access to emergency departments for acute events and identification of sickle cell disease in refugees.* Blood, 2019. **133**(19): p. 2100-2103.
136. Venturelli, D., et al., *Sickle cell disease in areas of immigration of high-risk populations: a low cost and reproducible method of screening in northern Italy.* Blood transfusion = Trasfusione del sangue, 2014. **12**(3): p. 346-351.
137. Gambino, C., E. Trevelyan, and J. Fitzwater, *The Foreign-Born Population from Africa: 2008-2012*, in *American Community Survey Briefs*. 2014, United States Census Bureau.
138. *Sickle Cell Data Collection (SCDC) Program Data*. 30 June 2020]; Available from: https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc-data.html.
139. Smith, W.R., et al., *Lessons Learned from Building a Pediatric-to-Adult Sickle Cell Transition Program.* South Med J, 2019. **112**(3): p. 190-197.
140. Darbari, I., et al., *Correlates of successful transition in young adults with sickle cell disease.* Pediatric Blood & Cancer, 2019. **66**(12): p. e27939.
141. Andemariam, B., et al., *Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care.* Pediatric Blood & Cancer, 2014. **61**(4): p. 697-701.
142. Goodell, S., C. Dower, and E. O'Neil, *Primary care workforce in the United States*. 2011, Robert Wood Johnson Foundation.
143. Feltner, F., et al., *Community health workers improving diabetes outcomes in a rural Appalachian population.* Soc Work Health Care, 2017. **56**(2): p. 115-123.

144. Snell-Rood, C., F. Feltner, and N. Schoenberg, *What Role Can Community Health Workers Play in Connecting Rural Women with Depression to the "De Facto" Mental Health Care System?* Community Mental Health Journal, 2019. **55**(1): p. 63.
145. Physicians, A.A.o.F., *Rural Practice, Keeping Physicians In*. 2015.
146. Piel, F.B., et al., *Global burden of sickle cell anaemia in children under five, 2010-2050: modelling based on demographics, excess mortality, and interventions.* PLoS Med, 2013. **10**(7): p. e1001484.
147. Ataga, K.I., et al., *Crizanlizumab for the Prevention of Pain Crises in Sickle Cell Disease.* The New England journal of medicine, 2017. **376**(5): p. 429-439.