Sickle Cell Care Coordination Initiative: Community Based Needs Assessment to Inform Strategies to Reduce Healthcare Disparities in Northern California

Executive Summary

"People with sickle cell are Black…
and Black pain is never as valuable as White pain."
Young adult with sickle cell disease

OVERVIEW

The Sickle Cell Care Coordination Initiative (SCCCI) is one of eight programs funded by the National Heart, Lung and Blood Institute (NHLBI) using implementation science to reduce sickle cell disease (SCD) healthcare disparities. We conducted the SCCCI needs assessment in Northern California in 2017 – 18 with the goal to gather perspectives from sickle cell stakeholders about challenges faced by adolescents and adults with SCD that contribute to early mortality and dramatically increased visits to hospitals and emergency rooms, with a corresponding decrease in preventive care, compared with children with SCD. Although SCD does not exclusively affect African Americans, the perception that adults affected by the disease are not valued is pervasive, and unfortunately is reflected in their limited access to knowledgeable and compassionate providers, inadequate treatment for acute pain and seemingly ignored decline in quality of life. We sought to identify facilitators and barriers to preventive and acute care for adolescents and adults with SCD, with the ultimate goal to inform the development of interventions to improve their healthcare.

NEEDS ASSESSMENT PARTICIPANTS AND METHODS

The SCCCI covers five counties in Northern California – Alameda, Contra Costa, Sacramento, San Francisco and Solano – with 1,120 unique individuals with SCD identified in the region ages 15 – 45 years. Figure 1 shows there are four sickle cell special care centers within the

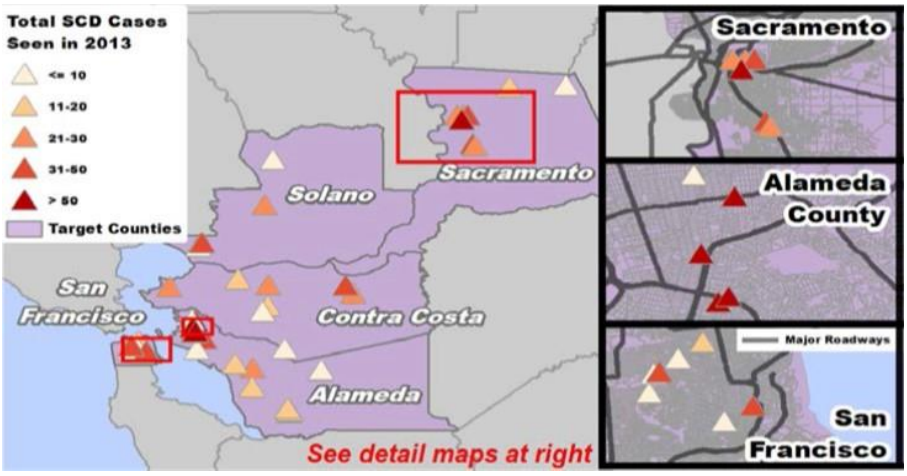

Figure 1. Sickle Cell Care Coordination Initiative 5 county catchment area. N = 1120 unique individuals with sickle cell disease ages 15 – 45 years.Sickle Cell Special Care Centers lie within the red rectangles.

SCCCI, but a number of individuals live up to 50 miles from these centers. Fifty-eight individuals with SCD (average age 31 ± 9 years, 57% female) completed our survey and interviews gathering information about socio-demographics, clinical characteristics, barriers to care, health metrics, self-efficacy, quality of care and pain experiences. Fifty-six providers (57% sickle cell specialists, 25% emergency department providers) and key informants (2 leaders of sickle cell community based organizations and 3 healthcare administrators) completed surveys and interviews that also asked about their perceptions of barriers individuals with SCD might face in accessing healthcare, pain control, provider management practices and barriers that providers might face in delivering care. Individuals with SCD, their providers and key informants also discussed potential approaches that might lead to improvements in care.

Findings

A striking 84% of individuals with SCD in the needs assessment reported that they had severe pain at home in the past six months that they did not seek health care for, with 59% reporting four or more of these episodes, and downtime of one week or more in the past six months.

84% of adolescents and adults with sickle cell disease surveyed reported they had severe pain at home in the past sickle months that they did NOT seek healthcare for

The burden of SCD itself (pain, fatigue, emotional responses) were barriers to health care cited by more than 60% of adolescents and adults responding. The range of transportation barriers (not having a vehicle, costs, accessibility of public transit) were cited by more than half of respondents. More than half of respondents also cited provider knowledge and attitudes, including being accused of drug-seeking, as problematic to accessing care, as well as insurance issues (e.g., co-pays, limitation in coverage).

Eight of nine participating emergency department providers echoed the issues with provider attitudes and several were themselves unaware of NHLBI recommendations for the treatment of vaso-occlusive pain. Sickle cell and primary care providers were concerned that the behavioral and mental health needs of individuals with SCD were not being met. Many participating providers indicated that they were not entirely comfortable with managing sickle cell related co-morbidities or with providing preventive care, and none of the providers expressed complete comfort with managing chronic pain. Individuals with SCD and their providers were consistent in their assessment of the issues with hydroxyurea – worry about side effects and challenges with adherence (i.e., concrete barriers to laboratory monitoring and the need for support with remembering to take the medicine).

We were able to compare ratings of quality of care (Adult Sickle Cell Quality of Life Measurement Information System – ASCQ-Me) from our participants with SCD, with results from other populations. Fifty-one percent of participants in our needs assessment in Northern California rated their overall healthcare as poor, compared with only 16% of adults with Medicaid surveyed in 2017 and 37% of a sample of 556 adults with SCD from across the U.S. completing ASCQ-Me in 2008 – 09 (Figure 2).

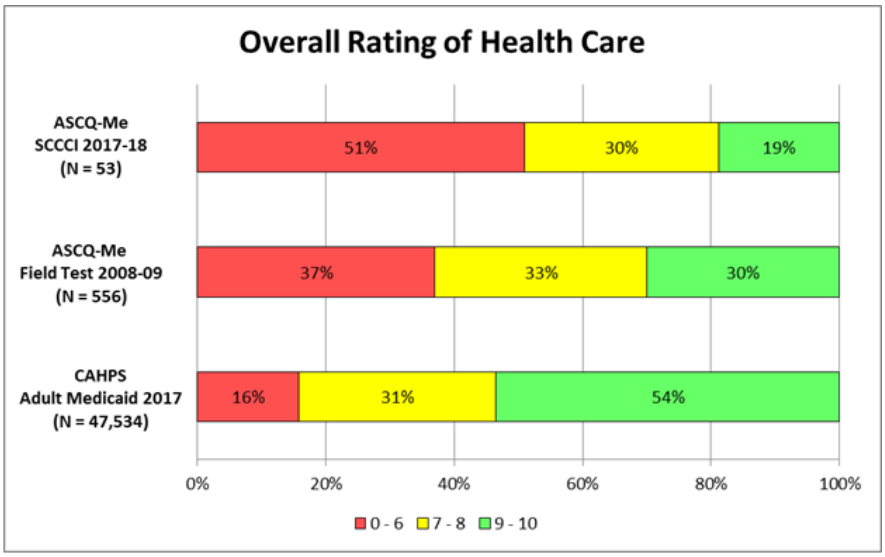

Figure 2. ASCQ-Me Quality of Care measure, overall ratings of quality of care

The majority (61%) of our participants with SCD never or only sometimes felt that their ED physicians really cared about them and 37% felt they were not believed about the severity of their pain. Only 11%, compared with 63% of adults with Medicaid, rated their access to emergency department care as the best possible (Figure 3). Sixty-three percent of survey participants rated their sickle cell providers positively, comparable with other adults completing ASCQ-Me (65%), and the general population with Medicaid (74%).

When we looked at how different variables were related, we found that participants from all counties reported about the same number of barriers to care, on average, with no county with more or fewer barriers compared to the other counties. Individuals who reported more barriers to care also reported lower satisfaction with care and less confidence in their ability to manage their sickle cell disease (self-efficacy). Female participants reported more barriers to care on average compared with male participants. Finally, participants with higher self-efficacy reported lower pain ratings.

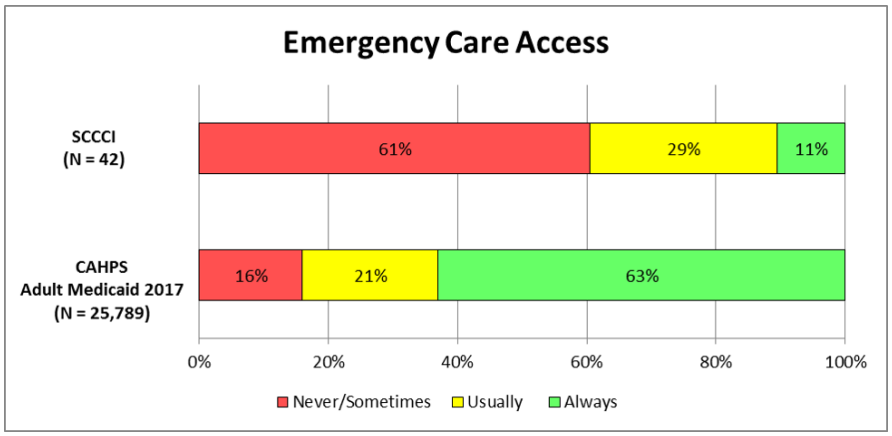

Figure 3. ASCQ—Me Quality of Care measure, timely access to emergency department care

We gained an in-depth understanding of the survey results by interviewing 55 of the participating adolescents and adults, and the 56 providers and key informants. Individuals with sickle cell disease confirmed the physical and emotional burden of the disease but

indicated that perceived lack of compassion in relation to seeking pain management was pervasive and contributed to their decisions to not seek acute care. The foundation of the stigma in unconscious bias or overt racism was frequently articulated by

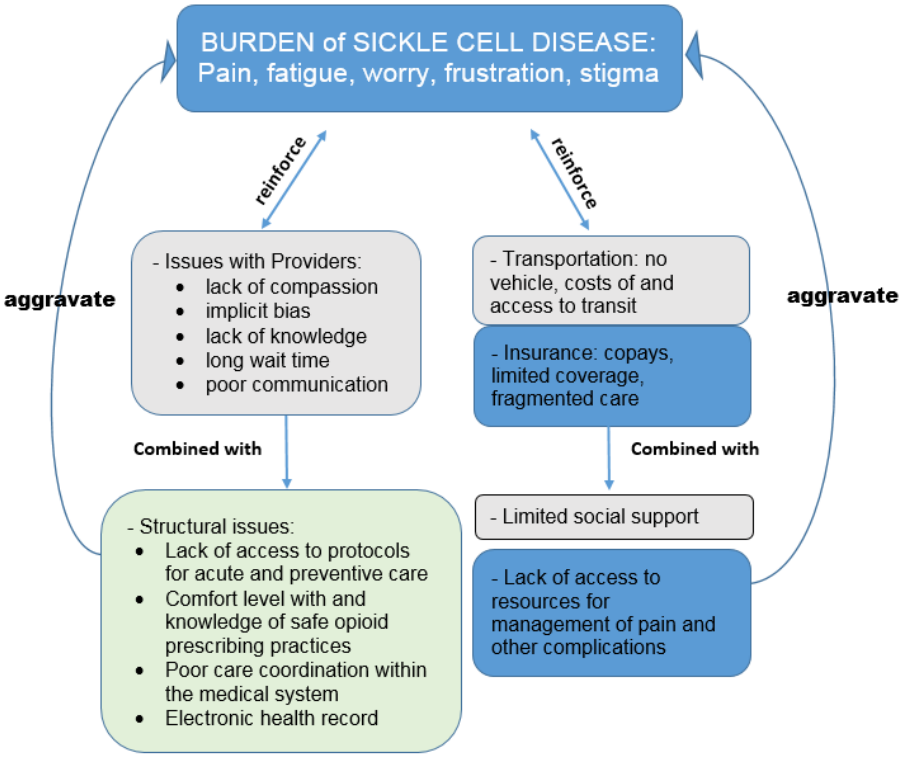

Figure 4. Information from surveys and interviews organized to show inter-relationships among factors identified as barriers to healthcare within the SCCCI. Factors shown in the grey boxes denote issues identified by adolescents and adults with SCD. The blue boxes denote issues identified by both individuals with SCD and their providers. Providers' issues are found in the green box.

interviewees with SCD. Providers were less in tune with these issues, focusing on concrete barriers to care such as insurance and poor care coordination. Providers expressed that they wanted to take care of individuals with SCD, but they needed such support as better access to protocols for care. Both providers and participants with SCD expressed the need for resources for pain management other than opioids and support for managing other complications, including education for providers and adherence supports for patients (Figure 4). The breakdown of access to quality healthcare at the juncture of transition from pediatric to adult care was described by all participants.

RECOMMENDATIONS AND NEXT STEPS

Our assessment of the needs of adults and adolescents with SCD, the needs of their providers and barriers to SCD care is the first of its kind in Northern California and our participants provided a number of recommendations for improving care. Case management services to improve care coordination and access to transportation were

seen as important by all. Both providers and individuals with SCD also wanted to consolidate complementary resources for pain management (e.g., meditation, acupuncture, virtual reality) as well as education and support for adherence with hydroxyurea. Providers wanted to be able to partner with community health workers, as well as with pain management specialists, particularly with regard to managing chronic pain. Providers also expressed the need for clinical decision support tools for the prevention and management of SCD complications, including safe opioid prescribing.

The results of this needs assessment in Northern California and across the broader Sickle Cell Disease Implementation Consortium (SCDIC) have informed the development of two sets of interventions that we will participate in, along with other SCDIC sites, beginning in 2019. The first set of interventions utilize mobile phone apps to support adherence with hydroxyurea for individuals with SCD, and hydroxyurea management by their providers. The second set of interventions is still under development but focuses on ensuring that ED providers have access to adequate information about treatment of vaso-occlusive events (both individualized and guidelines) when adolescents and adults with SCD present for acute pain management.

In addition to these interventions that will be rolled out across the consortium, we are investigating a number of local interventions that we believe should be implemented to improve care in our region:

Improving provider knowledge and attitudes

Concerns about stigma and lack of provider compassion were resounding in the SCCCI needs assessment, therefore we propose carrying out quality improvement projects in individual EDs throughout our five counties to explicitly address these issues. We are establishing a group of adolescents and adults with SCD who will educate ED providers about patient experiences in the format of panel discussions. We will also incorporate short video segments of adults with SCD discussing their experiences into provider education that will include didactics on cultural humility and SCD pain and symptom management, to directly address implicit bias and the failure to provide compassionate care. We will create QuickTips Sheets about SCD and pain management for providers that incorporate all of these elements, to improve not only knowledge but attitudes.

We have instituted a “Sickle Cell Boot Camp” at UCSF Benioff Children’s Hospital Oakland for providers. The goal of this intensive week is to give interested providers the skills, knowledge, and attitudes for providing in-depth evaluation, treatment, and long term management of individuals living with SCD. During the week, Sickle Cell Center team members and affiliated specialists provide didactics and practical demonstrations about treatment of common and health-threatening conditions for adults with SCD. Clinical structure, needed resources, and preventive and longitudinal screening is addressed, as are quality of life and disparities in care. Adults with SCD present their experiences on panels and in individual interviews and demonstrations. Philanthropic support allows us to provide funding for participating providers who are taking time away from their clinical practices. We have trained other sickle cell specialists and hospitalists, but hope to provide this training to primary care providers who can then partner more effectively with sickle cell specialists. Our goal is to create a robust

network of care for adults with SCD in Northern California, and to provide ongoing support for providers who in turn can serve as resources for their colleagues and their health organizations.

Improving pain management

We will work to identify resources to consolidate integrative approaches to pain management, that support improved self-management outside of the healthcare setting, access to needed complementary approaches within the healthcare setting and establishment of pain action plans. We anticipate that a concerted integrative approach to pain management will require additional funding. We will work with health systems to evaluate the feasibility of establishing “fast-track” protocols in emergency departments within the SCCCI, as well as units that allow individuals with SCD to bypass the ED and receive acute care from knowledgeable providers.

Self-management and preventive care

We have recently added an embedded psychologist within one of the Sickle Cell Special Care Centers in the Bay Area (with philanthropic support). This new model provides for screening for self-efficacy and coping with the burden of the disease, as well as for addressing mental health symptoms and self-management. The additional support also provides for a patient navigator who can assist with improving access to preventive care such as by addressing insurance and transportation barriers. We will share lessons learned from this endeavor with other health systems that might want to pursue funding to utilize this approach.

Sustainability

We are working with systems in the Bay Area to increase access to existing patient navigator and behavioral health support for our adults with SCD. Our needs assessment was focused on facilitators and barriers to sickle cell care in Northern California within the context of a lack of infrastructure that is contributing to preventable, early mortality for adults with SCD. SCD is a complex disease that requires a coordinated approach to its management and our implementation grant allows us to focus on interventions to improve SCD care using targeted approaches. However, we must also pursue commitments from insurers, health systems, policy makers, administrators and other community groups to improve the context for SCD care in our region. This might include a supplemental health plan guaranteeing payment for recurrent SCD care, transition of care between providers and settings and chronic pain management. Healthcare providers who participated in our needs assessment indicated that they would be willing to care for individuals with SCD but Medi-Cal payments do not currently cover the complicated care needs of this population

CONCLUSION

Our needs assessment was focused on facilitators and barriers to sickle cell care in Northern California within the context of a lack of infrastructure that is contributing to preventable, early mortality for adults with SCD. SCD is a complex disease that requires a coordinated approach to its management and our implementation grant allows us to focus on interventions to improve SCD care using targeted approaches. However, we must also pursue commitments from insurers, health systems, policy makers, administrators and other community groups to improve the context for SCD care in our region. The pervasive and longstanding disparities in SCD care must be addressed, to improve the quality of life, productivity and longevity of those affected. A healthcare system that is transformed to provide adequate SCD care would benefit the broader population with improved access to services and ultimately to the best health outcomes.

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