

# Community Health Workers as Support for Sickle Cell Care



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Community health workers are increasingly recognized as useful for improving health care and health outcomes for a variety of chronic conditions. Community health workers can provide social support, navigation of health systems and resources, and lay counseling. Social and cultural alignment of community health workers with the population they serve is an important aspect of community health worker intervention. Although community health worker interventions have been shown to improve patient-centered outcomes in underserved communities, these interventions have not been evaluated with sickle cell disease. Evidence from other disease areas suggests that community health worker intervention also would be effective for these patients. Sickle cell disease is complex, with a range of barriers to multifaceted care needs at the individual, family/friend, clinical organization, and community levels. Care delivery is complicated by disparities in health care: access, delivery, services, and cultural mismatches between providers and families. Current practices inadequately address or provide incomplete control of symptoms, especially pain, resulting in decreased quality of life and high medical expense. The authors propose that care and care outcomes for people with sickle cell disease could be improved through community health worker case management, social support, and health system navigation. This paper outlines implementation strategies in current use to test community health workers for sickle cell disease management in a variety of settings. National medical and advocacy efforts to develop the community health workforce for sickle cell disease management may enhance the progress and development of “best practices” for this area of community-based care.

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## Introduction

Sickle cell disease (SCD) is a set of genetic hemoglobinopathies characterized by hemolytic anemia, severe pain, and multi-organ compromise. As a result of dramatic improvements in care and longevity,<sup>1–3</sup> SCD increasingly has become a lifespan disease, from childhood to adulthood.<sup>4</sup> However, approaches to managing SCD encounter problems at multiple levels that challenge both the patient and healthcare system. The purpose of this paper is to summarize the potential for community health workers (CHW) in the care of people with SCD, offer practical guidance for the development of new CHW programs for SCD through current examples, and highlight evaluation and policy opportunities.

## **Sickle Cell Care Highlights Gaps in a Socioecologic System**

Though considered a rare disease by U.S. standards, SCD has come to be regarded a significant target for U.S. healthcare reform efforts, such as Healthy People 2020.<sup>5</sup> Much recent attention to SCD has arisen from the high morbidity, healthcare utilization, and cost associated with SCD, both for individuals and healthcare systems.<sup>6–16</sup> Although SCD therapies have led to improved life expectancy, many outcome goals remain unmet, not only because of the biological burden of end-organ failure or acute complications but also because of the complex burden of SCD patients' interaction with the socioecologic system.<sup>17–19</sup> This system emphasizes the inter-relationship among individual, interpersonal, organizational, community, and public health factors in relation to health behavior change.<sup>20</sup> Like other chronic conditions, SCD is influenced at all of these levels by varying factors, and by interactions between these factors. Interaction between disease manifestations and health behavior is only one part of the challenges to the individual within the socioecologic system.

Regardless of management or adherence, pain and other disease manifestations can be acute or chronic, incapacitating, and unpredictable.<sup>21–24</sup> Thus, patients and caregivers must learn disease self-management, how to access healthcare systems, and how to make healthcare decisions. Unfortunately, mismatches between the needs of the SCD population are often entwined with health disparities associated with race/ethnicity in the U.S.,<sup>17–19</sup> including those at primary<sup>25</sup> and specialty care levels.<sup>26</sup> Contrary to best practices for care of chronic health conditions,<sup>27</sup> only a fraction of Americans with SCD receive regular medical care for scheduled preventative care and evaluation. SCD care is often delivered in resource-intense medical settings, such as emergency departments and in-patient hospital stays, especially after childhood.<sup>28,29</sup> Even hematologists might not prescribe hydroxyurea,<sup>30–32</sup> the only U.S. Food and Drug Administration–approved disease-modifying drug for SCD.<sup>31,33</sup>

At the community level, impediments to helping people with SCD maximize function at school and work contribute to high unemployment and disability.<sup>34,35</sup> Social isolation may be compounded by cognitive impairment and stigma of SCD.<sup>36,37</sup> In total, these multilevel issues lead to high variability in patient satisfaction, quality of life, and adherence to prescribed medical regimens and appointments. These multilevel barriers should be addressed to improve care and outcomes for people with SCD.<sup>38</sup>

## **Community Health Workers**

Intervention by CHWs can target barriers to improved health and well-being for people with SCD on multiple levels. CHW programs aim to address the needs of underserved populations by providing trained community members as educators, supporters, and advocates who can effectively reach their neighbors.<sup>3–41</sup> In health care, CHWs are 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.<sup>42</sup> CHWs are called varying terms, including lay health worker, outreach worker, health advocate, *promotora de salud*, patient navigator, and guide. Such terms convey the concept that CHWs can effectively connect to multiple levels of a system. CHWs often share responsibility for patient education, support, and social services with clinic staff, and they have been successful in engaging and sustaining comprehensive disease care.<sup>39–41</sup>

Seven core roles in improving patients' health can be served by CHWs, who provide:

1. cultural mediation;
2. informal counseling and social support;
3. culturally appropriate health education;
4. advocacy for individual and community needs;
5. assurance that people receive needed medical and social services for which they are entitled;
6. direct social and supportive services; and
7. support for building individual and community capacity.<sup>41</sup>

The contributions these core CHW roles make to behavior change are supported by social cognitive theory.<sup>43,44</sup> This construct states that behavior is shaped and maintained by consequences, particularly by immediate feedback from both objective sources (such as blood results) and an individual's social network (beliefs and traditions of family and friends).<sup>45</sup> CHWs could also help patients move between stages of the transtheoretical model of behavior change for self-care and chronic disease self-management. In this model, processes for adoption of positive behaviors are linked to enhanced decision making and self-efficacy.<sup>46,47</sup>

Examples of the multilevel functions of CHWs can include the level of coaching the individual with SCD in adaptive behavior.<sup>48</sup> At the healthcare system level, CHWs can be integrated into the clinical setting as patient navigators to assist the patient with access to medical care. CHW integration with the medical team is

highly effective in adult diabetes<sup>49–51</sup>; pairing CHWs with nurses improves outcomes more so than nurses working alone.<sup>52</sup> On the community level, CHWs can engage, support, and advocate for families through schools and social service agencies.

The evidence for CHWs to impact these multiple levels in other disease areas is strong, as reflected in several systematic reviews.<sup>53–55</sup> CHW programs have existed for more than a century in developing countries for infectious disease management<sup>56</sup> and maternal child health.<sup>57–59</sup> Among the adult chronic diseases, CHWs have been shown to improve health outcomes for asthma, hypertension, heart disease, diabetes, and HIV, as well as improve disease self-management, disease prevention, pregnancy outcomes, and healthcare utilization.<sup>52,60–63</sup> For children with chronic disease, evidence of the benefit of CHWs is particularly strong for asthma.<sup>44,64–66</sup> In addition, studies indicate that CHW interventions are cost effective, especially when taking a longitudinal view of the return on investment.<sup>54,67–71</sup> CHW interventions have specifically been shown to lower hospital readmissions.<sup>72,73</sup> Because of the critical role CHWs play in health and the emerging needs of the workforce, the American Public Health Association established a specific section on CHWs.<sup>74</sup>

The diversity of CHW roles and terminology shown in the SCD projects listed in [Table 1](#) is similar to the published literature on CHWs in other fields. Many CHWs have a role that can be called “patient navigator,” whereas other CHWs focus on home visiting and improving access to community resources. Generally, CHWs are viewed as non-clinical professionals, as opposed to a healthcare professional like a nurse, social worker, or physician providing home visits or community outreach. CHWs may also participate in tasks such as coordinating medical care and providing assistance for diverse needs such as health insurance enrollment, immigration, or housing. These types of efforts serve to improve not just the medical but also the social health of the individual.

Social and cultural alignment of CHWs with their communities is a major aspect of effective intervention. They can be community-based or hospital-based, but regardless of their point of patient interaction, they are most effective when they share common cultural, social, and linguistic aspects with the clients they serve. For comprehensive, culturally appropriate SCD care, CHWs can address many of the barriers to access, communication, support, and disease self-management while reinforcing healthy behavior. Culturally aligned CHWs are an accepted mode of outreach by community members, sometimes in the context of community-based organizations for improving the health of underserved communities.<sup>69,77,78</sup>

## **Reported Use of Community Health Workers in Sickle Cell Disease**

The use of CHWs for SCD has been limited. In the U.S., CHW programs have focused on common diseases. By contrast, based on population prevalence, SCD is considered rare. In the global public health sphere, WHO recognized SCD as a priority topic in 2006,<sup>79</sup> but many countries with the highest incidence of SCD still struggle to balance prioritization of non-communicable and communicable diseases in low-resource settings. To the best knowledge of the authors, CHW interventions dedicated only to SCD have been published in only three reports. In Ghana, home visits by CHWs help families cope with new diagnosis of SCD in a newborn screening program.<sup>80</sup> In a peer-mentoring pilot program at St. Christopher’s Hospital for Children, older adult volunteers who raised a child with SCD advise new families on medical and child-rearing practices.<sup>75</sup> In St. Louis, CHW home visitors promote early cognitive development, promote clinic attendance, and medication compliance.<sup>76</sup> A recent systematic review of CHW interventions for children with chronic health conditions listed SCD as appropriate for CHW intervention and research.<sup>57</sup> [Figure 1](#) lists possible roles for CHWs in SCD. Multiple SCD CHW demonstration projects are underway ([Table 1](#)).

## **Conceptual Bases and Potential Roles for Community Health Workers in Sickle Cell Disease**

Social cognitive theory can guide CHW interventions at the individual and family levels.<sup>45,81</sup> Behavior is shaped and maintained by consequences and an individual’s social network (beliefs and resilience of family and friends).<sup>82,83</sup> For example, repeated clinic visits may not be perceived by patients and families as addressing pressing psychosocial needs. Poor alignment with provider–patient needs may lead to patient frustration and perceived gaps in addressing needs. By contrast, in home visits, CHWs can check for potential triggers of acute problems: disorganized medications, inadequate hydration or nutrition, physical barriers, family stress, and household chaos. The SCD CHW must support the positive behaviors and social networks using self-management skills.

Interventions by CHWs for SCD can be viewed through the socioecologic model. At the individual level, lifestyle, medication adherence, and coping are important issues for individuals with SCD, and CHW interventions have demonstrated impact in these areas for other chronic diseases. Aspects of self-management for

**Table 1.** Current Programs of Community Health Worker Efforts in Sickle Cell Disease as of 2015

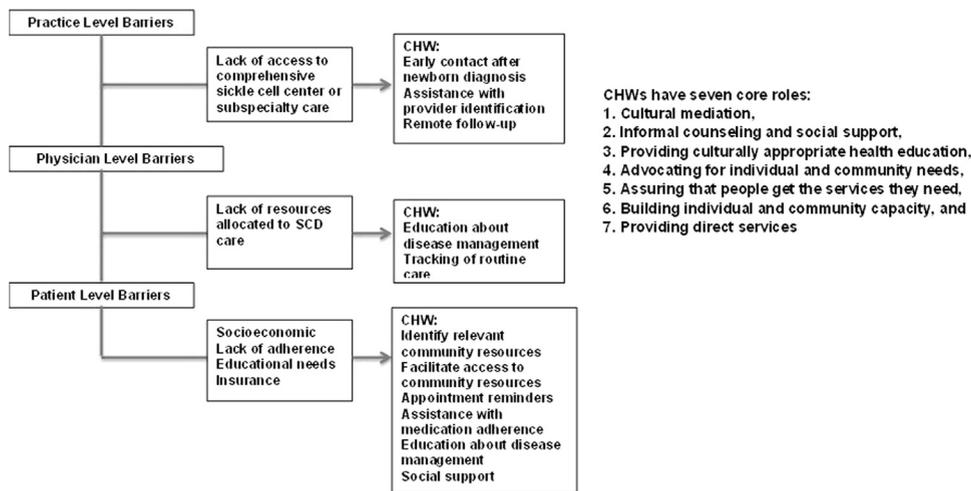
<b>Programs</b>	<b>Region, target population, estimated no. of patients</b>	<b>Source of CHW, program outline</b>	<b>Notes about training CHW</b>
PI, project name, goal(s)			
Wally Smith Shirley Johnson Project: Enhancing Use of Hydroxyurea in SCD Through Patient Navigators. Goals: Improve the percentage of adults who are in SCD specialty care and increase hydroxyurea compliance (NIH R18 funded)	Richmond (urban) and Tidewater area (rural) Virginia adults >15 years old, n=270	Utilize patient navigators (PNs) to overcome patient access barriers to SCD care and to test the efficacy of PNs for overcoming barriers to acceptance of and adherence with hydroxyurea therapy	Didactic, experiential CHW group meetings
Nancy Green Arlene Smaldone Project: Hydroxyurea Adherence for Personal Best in Sickle Cell Treatment: HABIT. Goals: Hydroxyurea adherence; Utilization of acute care; improved quality of life (NIH R21 funded)	New York City (urban) Children 10–18 years old, n=30 dyads	CHWs have scheduled interactions with subjects at home, by telephone, or at a partner community-based organization CHWs send customized text message reminders for taking hydroxyurea to each youth and parent	Didactic, experiential CHW group meetings, built upon a very strong asthma CHW program in Manhattan
Ben van Voorhees Molly Martin Lewis Hsu, CHECK program Goals: Reduce acute hospital visits	Chicago region (urban) Child, AYA, n>500	Experienced CHW from other programs, such as asthma	Builds on basic training for CHW and adds specific training didactic modules for SCD, followed by experiential training in sickle cell center
Jerry Krishnan PARTNER program Goals: Reduce readmissions to hospital within 30 days, increase social support, improve self-efficacy, and reduce anxiety	Cook County, Illinois (urban), 18 years old and up, n>85 SCD	Experienced CHW from asthma programs Assist transition from hospital admit to outpatient care for SCD, asthma, and other chronic diseases Visit patient in hospital and at home, plus phone follow-up	Training on assessing barriers to care, confidentiality, community resources
Rosalyn Stewart, J.J. Strouse, iHOMES, Goals: improve health and outcomes through improved adherence to ambulatory care plans, improve access to care, and improve utilization of community resources to overcome hindrances to care	Baltimore metropolitan area, adults, n=104	CHWs from the community as employees of Johns Hopkins University, worked with patients to improve adherence to care plans and overcome social barriers to care	Standard training program for CHW at Johns Hopkins with addition of specific sickle cell content
Gladys Robinson Sickle Cell of Piedmont Goal: Integrate primary care and specialty care	North Carolina federally qualified health center	CHW cross-trained for several chronic diseases	Promote health care for SCD, HIV/AIDS, diabetes, other chronic conditions
TaLana Hughes Sickle Cell Disease Association of Illinois Goal: Coordinated care	Chicago and Peoria, IL (urban, suburban, rural)	Home visits for families who missed follow-up for newborn screening diagnosis of SCD They also serve as parent-to-parent advisors on resources Follow-up in 1 year to check knowledge and behavior	SCD care for infant

(continued on next page)

**Table 1.** Current Programs of Community Health Worker Efforts in Sickle Cell Disease as of 2015 (*continued*)

<b>Programs</b>	<b>Region, target population, estimated no. of patients</b>	<b>Source of CHW, program outline</b>	<b>Notes about training CHW</b>
Trevor Thompson Sickle Cell Foundation of Tennessee. (SCFT) Goal: Improve adherence to medical care	Tennessee	Community-based group Transportation assistance for clients/patients to medical, dental, or mental health appointments related to their SCD	Patient navigator trained by SCFT
Stanley Simpkins Sickle Cell Disease Association of America (SCDAA), Philadelphia/Delaware Valley Goal: Improve access to care	Philadelphia, PA (urban and suburban)	Community-based group. Transportation assistance for pediatric families Locate children who were lost to follow-up and assist them to come to appointments	Navigator trained by SCDAA-Philadelphia/ Delaware Valley
Health Resources and Services Administration Sickle Cell Disease Newborn Screening Program demonstration project, SCDAA Mid-Atlantic Regional Advisory Committee (MARAC)	5 regional clusters, with lead sites in Illinois, California, Tennessee, North Carolina, Maryland (Figure 2)	Lay workers, parents of children with SCD, some staff from sickle cell community-based organizations Systematic community engagement recruitment process CHW canvasses a rural area to find SCD patients not enrolled in comprehensive sickle cell care Home visits and SCD care coordination	MARAC and SCDAA developing a national CHW certification for sickle cell, as special training to augment “basic training” for CHW
Kisha Hampton Indiana Newborn screen follow-up Goal: Educate about SCD and improve clinic attendance	Indiana (divided into regions, a nurse for each region), newborns and children	Community health nurse Home visits and phone calls to educate about SCD and encourage clinic compliance	Nurse for new diagnosis SCD from newborn screen
M. Renee Robinson The Grandparent Program. Goal: Improve caretaker knowledge as measured by knowledge quiz <sup>75</sup>	Philadelphia (urban) Newborns to 2 years old, <i>n</i> =9	Older adult volunteers who have raised a child with SCD Educational and social support on both medical and child-rearing practices Assess success with knowledge quiz	Didactic training on SCD knowledge, child care, and home visitation, adapted from “Family Friends” inter-generational program
C. Hoyt Drazen, Allison King Goal: Promote clinic education attendance, medication compliance, cognitive development <sup>76</sup>	St, Louis Newborns to preschool, <i>n</i> =39	Home visitors for early cognitive development, patterned after “Born to Learn,” promote clinic attendance and medication compliance	Patterned after “Born to Learn” curriculum from Parents as Teachers National Center
Examples of community health worker programs for SCD outside the U.S.			
Kwaku Ohene-Frempong Health educators for newborn screening program Goals: Home visits and local training for families of newborns, increase understanding of SCD medical care	Ghana, Kumasi, and other regions Parents of newborns	Healthcare providers, health educators	Didactic sessions, curriculum developed for Ghana with local focus groups by psychologist
Clarisse Lobo Goals: Help patients access regional center for care of blood diseases (“Hemo Center”)	Brazil HEMORIO blood center, Rio de Janeiro	Lay public health worker, “agente de saude” responsible for regular visits to 100–150 households	Family Health Strategy is part of a nationally scaled model of primary care services

AYA, adolescent and young adult; CHW, community health workers; PI, principal investigator; SCD, sickle cell disease.



**Figure 1.** Multiple barriers can be addressed by community health workers (CHW) for sickle cell disease (SCD).

SCD can be promoted by coaching in community-based mentoring programs, peer groups, and others. At the family level, multiple social determinants of health can benefit from CHW programs, including maternal health and economic self-sufficiency.<sup>59</sup> CHWs may also be able to help the family understand reproductive choices relevant to the sickle gene, which can be passed along to future children of the patient with SCD and by any family members who have sickle cell trait. At the healthcare system level, CHWs can help the SCD patient navigate multiple appointments, provide reminders of appointments, and organize transportation. At the level of schools or jobs, CHWs can coach the SCD patient in requesting accommodations for their disease, using the appropriate resources under existing rules for people with disabilities.

Application of limited resources may require CHW services for SCD to draw upon other CHW programs. For example, home visitor programs for early childhood can benefit academic readiness for children with SCD.<sup>59</sup> SCD early childhood home visitor programs might effectively address the neurocognitive impairment<sup>84,85</sup> and frequent school absences associated with SCD.<sup>86</sup> Improving control of asthma as a comorbidity of SCD would address the increased risk of SCD complications in preschool children with asthma as a high-risk group,<sup>87</sup> and many CHW programs have shown benefits for asthma.<sup>46,81</sup> In the socialized medical system of Brazil, one report describes the network of neighborhood CHWs who assist everybody with healthcare needs, and their main role in SCD care is ensuring that patients go to subspecialty care at the regional center for blood diseases.<sup>88</sup>

### Evaluating the Impact of Community Health Workers on Sickle Cell Disease

Impact of CHW and other workforce interventions should include improvement in four primary domains (Table 2):

1. outcomes related to health and quality of life for the patient and family;
2. access and utilization of standardized preventative care and acute care services;
3. patient satisfaction with communication and care; and
4. long-term medical, psychological, and social metrics of well-being.<sup>89</sup>

Metrics often used for quality of SCD care involve utilization of acute care services, for example, number of acute care visits, length of hospital stay, or hospital readmissions within 30 days. However, cost considerations may inadvertently push CHWs to drive these cost-based, organization-focused outcomes, potentially placing CHWs in conflict with their patients.<sup>38,90</sup> Accordingly, the benefit of interventions to educate patients or coordinate care with the goal of reducing acute care utilization might require alternate approaches.

Adherence to preventive care, including prescribed medication use and attending scheduled visits, is recognized as a key measure of quality care.<sup>91</sup> Some of these adherence measures could be well-suited efficacy measures for SCD. CHW contact with the family shortly before a well-child visit has resulted in fewer missed appointments, fewer sick and acute visits, better understanding of anticipatory guidance,<sup>92</sup> and transition readiness.<sup>93</sup>

**Table 2.** Potential Outcome Measures for Community Health Workers to Address in Sickle Cell Disease

Acute care utilization = costliest part of care for SCD ED visits, hospital days, 30-day readmissions “Potentially preventable” ED visits Surrogate measure—Patient Activation Measure (PAM-13) to assess self-efficacy
Adherence to longitudinal care Appointments, medications, control of comorbidities Knowledge of sickle cell genetics and reproductive implications Pediatric to adolescent/adult care
Quality of life Child development/academic readiness Lifestyle (PROMIS, ASQ-ME) and function (SF-36) Social determinants of health
Process measures, QA/QI for fidelity of intervention and training

ASQ-ME, Adult Sickle Cell Quality of Life Measurement Information System; ED, emergency department; PROMIS, Patient Reported Outcomes Measurement Information System; QA/QI, quality assurance/quality improvement; SCD, sickle cell disease; SF-36, 36-Item Short-Form Health Survey.

At the interpersonal level, CHWs operate as a vehicle for delivering educational content and encouraging behavior change. Pain-related poor quality of life in people with SCD<sup>94</sup> and social isolation are frequent concerns.<sup>35,36</sup> The Patient Reported Outcomes Measurement Information System (PROMIS) question bank was developed by NIH to assess quality of life across multiple populations ([www.nihpromis.org](http://www.nihpromis.org)). The Adult Sickle Cell Quality of Life Measurement Information System (ASQ-ME) question bank was developed specifically for quality of life in SCD, using PROMIS methodology.<sup>95,96</sup> Quality of life in SCD has been reported using the 36-Item Short-Form Health

Survey.<sup>97,98</sup> Unfortunately, behavioral change promoted by CHW does not guarantee quiescent symptoms of SCD, even with complete adherence to care plans.<sup>21–24</sup>

Finally, intervention process measures are useful for defining essential and satisfactory elements of CHW interventions.<sup>99</sup> Quality assurance measures and quality improvement processes are also important to assure ongoing intervention.

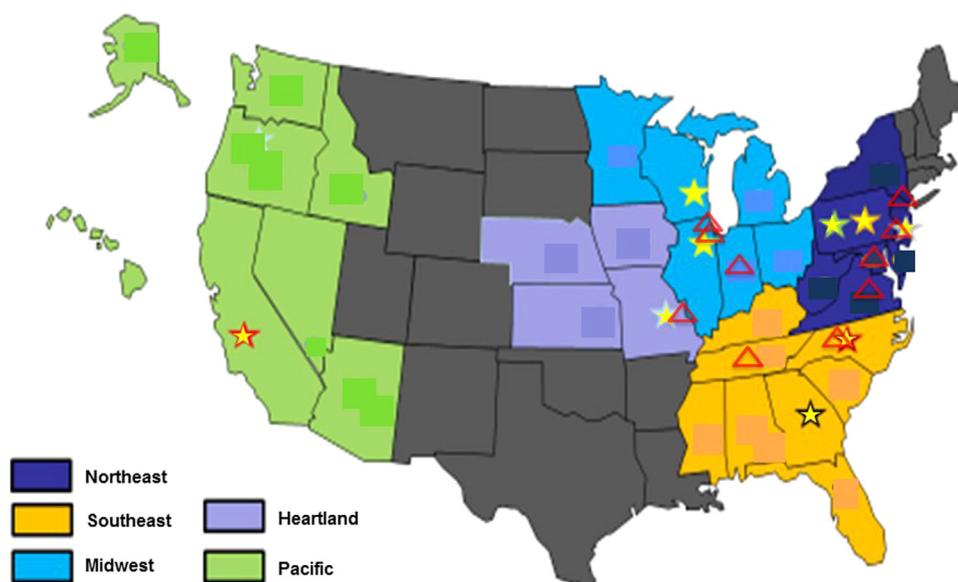
## Community Health Worker Certification and Training

As with other powerful tools for improved health, critical selection of CHW personnel, training, goal setting, reporting, and other structure are crucial for success.<sup>100,101</sup> CHWs must be selected for excellent interpersonal skills, experience, empathy, and problem solving. Training curricula could be suitable for adapting flexibly to trainees of different backgrounds. CHW training generally features role playing and problem solving, experiential training, and meetings between CHW trainees and SCD providers.

Several training components have been identified by projects with SCD CHWs:

1. basic training for CHWs for any disease condition;
2. specific training material on SCD;
3. experiential learning by shadowing in the SCD clinic; and
4. continuing education.

Experienced trainers of CHWs emphasize person-to-person skills, such as respect, patient centeredness, and

**Figure 2.** Map of community health worker projects for sickle cell disease.

Note: Shown are current lead sites for multi-state SCDA-HRSA programs (star) and other programs serving children and/or adults (triangle).

communication. Practice and application of new knowledge are essential. Role play, teach backs, and other adult education strategies could help prepare CHWs for the complexities of interpersonal interactions that may arise in their work.<sup>40,102</sup> Effective use of adult education methods in training emphasizes both practical skills and theoretic frameworks, such as social cognitive theory.

Despite the advantages of state or national standards for CHW workforce development, as of this writing, no national certification for CHWs yet exists.<sup>100</sup> Several states are developing legislation and protocols for CHW training and certification.<sup>103</sup> In the absence of state certification programs, training tends to be designed by the organizations that employ CHWs, primarily to focus training on specific tasks. Hence, CHWs may require additional training if they move to other organizations or disease-associated populations.

An approach to help garner broad support, alignment, standardization, and recognition with widely recognized workforce training would be to collaborate with institutions such as the American Public Health Association, Health Resources and Services Administration within the U.S. DHHS, and major SCD community organizations. A common training curriculum would create a national standardized pool of knowledgeable and skilled CHWs to support the work for SCD care, supplemented by components that address unique populations of, or goals for, SCD. Beginning in 2015, a CHW-focused Health Resources and Services Administration–funded project through the SCD Association of America spans four regions and at least nine states (Figure 2).<sup>104</sup> This program would be a fine opportunity to test the concepts of centralized, multisite training and implementation.

## Conclusions

As a rare but socially costly condition that increases health disparities, SCD is in need of alternative interventions for improving short- and long-term outcomes and quality of life. CHWs are an accepted model for improving healthcare outcomes in underserved communities and populations at high risk for poor outcomes. For chronic conditions, CHWs have been shown to bridge cultural, social, and linguistic barriers to chronic disease treatment and improve health outcomes.

Projects underway by members of this group are currently examining the impact of CHW involvement in different dimensions and outcomes of CHW intervention for SCD with diverse targets for specific populations (e.g., adolescents), settings (e.g., community; urban or rural), and specific healthcare outcomes (e.g., medication adherence). Although results are not yet available, the high rate of patient acceptance of CHWs is

an early indicator that CHW interventions can be feasible. Partnership with local and national community-based organizations is emerging as a strong emphasis for SCD, and the SCD Association of America is planning to officially endorse the use of CHWs for SCD.

A CHW SCD intervention research agenda is needed to move the field forward. The authors recommend that efforts to optimize CHWs in SCD be aligned in terms of training, intervention design, and outcomes measurement as well as culturally appropriate alignment with patient medical, social, and mental health needs. The authors propose a national effort to develop best practices for CHWs in SCD and to demonstrate outcomes on the key indicators described here for medical, social, mental health, and family well-being.

A new consensus on roles, training, and certification for CHWs is currently under development by the National Area Health Education Center Organization, funded by the Amgen Foundation, with support from the American Public Health Association. CHWs will be ranked in tiers based upon level of formal education (high school, college), disease-specific education, experience serving as CHW, and experience as supervisor or trainer of other CHWs. These tiers will also correspond to levels of certification and compensation. The report from the Community Health Worker Core Consensus Project is expected in 2016 (at: [www.chrllc.net/id12.html](http://www.chrllc.net/id12.html)).<sup>100</sup>

Elements of this proposal include the following strategies for expanding capacity and evaluating impact:

1. developing standard curricula for training SCD CHWs;
2. creating a registry of SCD CHWs in local/regional demonstration programs;
3. organizing SCD Association of America certification and registration of CHW training;
4. promoting consistency in outcome measures for CHW interventions in SCD;
5. establishing a “learning collaborative” of CHW efforts in SCD, with opportunities to exchange information about challenges and successes in CHW programs and facilitate refinements to these programs; and
6. developing a model to reimburse CHW services.

These advances should be studied as implementation and evaluation for public health impact, and to better define metrics for successful CHW-based care.

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