Feasibility of establishing a network of community health workers to support care of people with sickle cell disease in Kumasi, Ghana

Julie M. Buser¹ · Ashura Bakari² · Cheryl A. Moyer³

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Abstract

Globally, sickle cell disease (SCD) is a common, yet often neglected, non-communicable disease. Community health worker (CHW) interventions have been shown to improve outcomes for chronic diseases but have not been evaluated with SCD. This study assessed the interest in and feasibility of establishing a network of CHWs to support care of people with SCD in Kumasi, Ghana. Using in-depth interviews with key stakeholders ($N = 15$) identified through purposive and snowball sampling from January to March 2020, we gathered focused information about interest in and feasibility of establishing a network of CHWs. Respondents were chosen for their knowledge and oversight of health services for people with SCD. Latent content analysis was used to examine the data. Participants expressed interest in establishing a network of CHWs to better support care for people with SCD. Three primary themes emerged from the data: (1) support by CHWs could be beneficial for people with SCD; (2) using existing CHW networks for SCD services would be best; and (3) funding of expanded CHW network might be a problem. We advocate for the mobilization of resources to expand the current network of CHWs to include a focus on SCD in Kumasi, Ghana. Participants believe that it is feasible to use CHWs to improve care outcomes of people with SCD. There is potential for findings from this exploratory project to be adapted and implemented in other settings throughout sub-Saharan Africa, as well as areas of higher income countries where there are higher proportions of people living with sickle cell.

Keywords Community health worker (CHW) · Sickle cell disease (SCD) · Ghana · Sub-Saharan Africa

✉ Julie M. Buser
jbuser@umich.edu

Ashura Bakari
abakari@yahoo.com

Cheryl A. Moyer
camoyer@med.umich.edu

- ¹ Fogarty International Center, National Institutes of Health, Global REACH, University of Michigan Medical School, Victor Vaughan Building, 2nd Floor, 1111 East Catherine Street Ann Arbor MI 48109 USA
- ² Ghana Health Service, Suntreso Government Hospital, Kumasi Ghana
- ³ Departments of Learning Health Sciences and Obstetrics & Gynecology, Global REACH, University of Michigan Medical School, Victor Vaughan Building, 2nd Floor, 1111 East Catherine Street Ann Arbor MI 48109 USA

Introduction

Sickle cell disease (SCD) is a neglected non-communicable disease of growing global importance (Lopez et al. 2014) and is among the most prevalent inherited disorders worldwide (Ribeil et al. 2017). Globally, over 300,000 babies are born with SCD every year (Piel et al. 2013). The disease is characterized by recurrent painful episodes of vaso-occlusion and inflammation resulting in progressive damage to most organs, including the brain, kidneys, lungs, bones, and cardiovascular system (Rees et al. 2010).

The majority of children with SCD are born in sub-Saharan Africa (Lopez et al. 2014) where the burden of disease is aligned with that of malaria (Piel et al. 2010). In some parts of the continent, SCD affects up to 3% of births (Grosse et al. 2011). While the disease is common, established life-saving public health programs for sickle cell have not been implemented in most African countries (Wonkam and Makani 2019).

Our study took place in the West African nation of Ghana, where 2% of newborns have sickle cell disease (Ohene-Frempong et al. 2008). Based on the yearly number of births in Ghana, (United Nations 2019) and given that 2% of newborns in the country have SCD, we estimate that approximately 17,424 babies are born in Ghana each year with SCD, or an average of 48 every day. Despite the high prevalence of SCD in Ghana, the extent of the burden of the disease in adults is uncertain and the life expectancy of the Ghanaian SCD patient is unknown, though more children with the disease survive into adulthood (Asare et al. 2018).

Recognizing that public health action is needed in Ghana and other low- and middle-income countries, community health workers (CHWs) may offer an intervention to improve care and care outcomes for people with SCD (Hsu et al. 2016). A CHW is a frontline public health worker with a trusting relationship and close understanding of the community that enables them to serve as a liaison to facilitate access to services and improve the quality and cultural competence of service delivery (American Public Health Association 2020). They also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities, including outreach, community education, informal counseling, social support, and advocacy (American Public Health Association 2020).

Ghana formally launched a national CHW program in 2014, to augment the pre-existing Community-Based Health Planning and Services (CHPS) (Schwarz et al. 2019) that was formed in 1999 as the key primary health care strategy to deliver essential community-based health services involving health planning and service delivery with the communities (CHPS 2016). Ghana has made several efforts at achieving universal health coverage using CHPS and other interventions, including national health insurance (Kweku et al. 2020). There is considerable variability in the type of activities performed by CHWs and the degree of availability of each activity, across the different regions of Ghana (Schwarz et al. 2019). Activities of CHWs in Ghana include community mobilization, health education, outreach for loss to follow-up, disease surveillance, clean water and sanitation counseling, enrolment in health facilities, family plan counseling and provision, and antenatal care counseling (Schwarz et al. 2019).

Although CHW interventions, such as those focused on cancer prevention and cardiovascular disease risk reduction (Kim et al. 2016), improve patient-centered outcomes in underserved communities, such interventions have not been evaluated with SCD (Hsu et al. 2016). Community health workers bridge cultural, social, and linguistic barriers to chronic disease treatment and improve health outcomes (Hsu et al. 2016). Perhaps, the same can hold true for CHWs and SCD. As we strive to better address the management of SCD symptoms, there is a wide gap in knowledge about the interest in and feasibility of establishing a network of CHWs to support care of people with SCD in Kumasi, Ghana. The purpose

of this study was to gather focused information about interest in and feasibility of establishing a network of CHWs to support care of people with SCD in Kumasi, Ghana.

Methods

Sample and setting

We conducted the qualitative study from January to March 2020 using purposive and snowball sampling with individual interviews on the interest in and feasibility of creating a network of CHWs for SCD in Kumasi, Ghana. The West African nation of Ghana is on the Gulf of Guinea and the Atlantic Ocean (World Population Review 2020). The city of Kumasi, in the Ashanti Region, is Ghana's second city and has a population of over two million (World Population Review 2020).

The sample ($n = 15$) included key decision makers and community stakeholders who spoke English (official language in Ghana) or Asante Twi (local language spoken most commonly spoken in Kumasi). Key decision maker participants included 5 pediatricians, 3 nurses, 1 CHW, and 1 social worker with the Ghana Health Service, Komfo Anokye Teaching Hospital, National Health Learning Material Centre, and Regional Public Health Officials. Additional community stakeholders included a mother of a child with SCD, an adult with SCD, a local assemblyman, a chief, and a religious leader. Participants were recruited via face-to-face interactions, phone, and email methods by research team members based on their direct or indirect SCD care. All who were approached agreed to participate. No incentives were given to participate in the study. Individual interviews were conducted in person at a mutually convenient location while maintaining privacy and confidentiality. In a given interview, the only people present were the participant, one research assistant, and the principle investigator.

Data collection

We developed a semi-structured interview guide based on domains from the Tailored Implementation for Chronic Diseases (TICD) checklist (Flottorp et al. 2013). The checklist helps both implementation researchers and people responsible for quality improvement in healthcare (Flottorp et al. 2013). The TICD checklist encompasses potential determinants of practice in seven domains: guideline factors, individual health professional factors, patient factors, professional interactions, incentives and resources, capacity for organizational change, and social, political, and legal factors (Flottorp et al. 2013). Determinants of healthcare professional practice are factors that might prevent or enable improvements in that practice (Flottorp et al. 2013). The initial TICD project assessed programs improving healthcare for people with chronic diseases, while contributing knowledge on concepts and methods of tailoring interventions (Wensing 2017). We constructed our

interview guide around the TICD checklist because of its usefulness for assessing feasibility, barriers, and facilitators influencing the success of implementation interventions. Table 1 displays interview questions and probes. The interview guide was pilot tested with two physicians and one community stakeholder for context in meaning, and no changes were deemed necessary.

Ethical approval was obtained from the Kwame Nkrumah University of Science and Technology Committee on Human Research Publication and Ethics (CHRPE/AP/001/20) and the University of Michigan (HUM00175765) and cleared by the Ghana Health Service (GHS/ASH/AD4/Vol.6). Two researchers from the USA, a pediatrician, and three research assistants in Ghana comprised the team. The primary investigator and a research assistant explained the study goals and gathered informed written consent. Interviews were audio recorded and transcribed verbatim. Four interviews were conducted in Twi and translated while the remaining interviews were done in English. The primary investigator took field notes during and after the interviews. Fifteen individual interviews, lasting approximately 30 min, were performed and basic demographic characteristics were collected.

Data analysis

From April to May 2020, themes about the interest in creating a network of CHWs for SCD in Kumasi were derived using latent content analysis following a process of decontextualization, recontextualization, categorization, and compilation (Bengtsson 2016). Data were managed using Microsoft Word and uploaded to a password-encrypted Google Doc for all coders to access and make updates in real time. The principal investigator reviewed transcripts for accuracy and completeness. Each transcript was read by at least three members of the research team. Four researchers worked together to create a preliminary coding structure and codebook. All team members deliberated the meaning and application of codes. We revised and consolidated similar codes into categories. Data saturation was achieved in coding after four interviews but researchers continued to code each interview. There was no occurrence of divergent views that could challenge generalizations. Themes were defined when they recurred numerous times in the transcripts. Participants provided feedback and verification on findings about the feasibility, barriers, and facilitators influencing the viability of a network of CHWs in Kumasi, Ghana.

Table 1 Sample interview questions and probes

Sample questions	Probes
Is it feasible to use community health workers to support care of patients with sickle cell disease, in your opinion?	If yes, why do you think it would work? If no, why not?
Do you and your friends/colleagues believe that establishing and using a network of community health worker will lead to better sickle cell disease outcomes (for patients, providers, the health system)?	Can you think of any immediate improvement in sickle cell disease care by establishing a network of community health workers? Do you or your colleagues intend to use community health workers to support care of sickle cell patients? What concerns do they have about establishing a network of community health workers?
What resources would be helpful in getting you or your colleagues to establish a network and use community health workers fully?	Include human resources, facilities, equipment and supplies, technical capacity, patient information, other ideas.
What leadership or management support is needed to assist you or your colleagues in using community health workers for sickle cell?	In your opinion, is this available, and do clinicians know how to access it?
How do internal and external rules, regulations, policies, or procedures help or hinder establishing and using community health workers?	
What barriers do you anticipate in the establishment of a network of community health workers for sickle cell care in this area?	What solutions do you think could address these barriers?
What will the community do to sustain the network of community health workers for sickle cell care once it is established?	What factors are associated with the sustainability? What income-generating activities could you see associated with the community health workers? Who do you think could pay for the maintenance and ongoing activities of the community health worker network?

Results

Table 2 displays the demographic characteristics of the fifteen individual interview participants. The average age of the participants was 41 years. Most participants obtained a tertiary level of education ($n = 12$). All of the participants were Christian and half worked for the Ghana Health Service ($n = 7$). Participants expressed unanimous interest in establishing a network of CHWs to better support care and care outcomes for people with SCD in Kumasi, Ghana. All of the key decision makers and community stakeholders backed the idea of using CHWs to support people with sickle cell and viewed it as a health system strengthening intervention. One of the people with sickle cell stated:

I think it will be a good thing if community health workers come and support with the care of sickle cell patients. That will help us a lot and it will even improve

Table 2 Individual interview participant characteristics

Demographic characteristic	Individual interview ($n = 15$)
Age (years)	% (n)
Range, mean (SD)	28–60, 41 (11)
Missing	6.7% (1)
Sex	
Female, male	46.7% (7), 53.3% (8)
Education level	
Junior secondary (8–9)	6.7% (1)
Senior secondary (10–12)	13.3% (2)
Tertiary	80% (12)
Marital status	
Married	60% (9)
Single	26.7% (4)
Widowed/separated/divorced	13.4% (2)
Number of living children	
Range, mean (SD)	0–6, 2.5 (1.6)
Ethnicity	
Akan	86.7% (13)
Ga Adangbe	6.7% (1)
Ewe	6.7% (1)
Occupation	
Community leader	13.3% (2)
Ghana Health Service	46.7% (7)
Government organization	13.3% (2)
Non-government organization	6.7% (1)
Religious leader	6.7% (1)
Sales/commerce	6.7% (1)
Unemployed	6.7% (1)

SD standard deviation

our way of life and also enable us to be sociable to everyone around us which will promote unity among the neighbors and ourselves. It will also help the people living in our community to know more about the disease as well through education. This will permit us not to live a lonely life.

We derived three major themes including (1) support by CHWs could be beneficial for people with SCD; (2) using existing CHW networks for SCD services would be best; and (3) funding of expanded CHW network might be a problem. All of the themes were associated with each category of participant. Healthcare providers of people with SCD more often mentioned using existing CHW networks.

Support by CHWs could be beneficial for people with SCD

All study participants mentioned how CHWs are in positions to bring unique support that could benefit people with SCD including health education to families, communities, and schools; medication adherence; tracing of defaulters; and stigma reduction messages. According to a nurse:

Community health workers should educate about the condition and ensure understanding. They should educate about pain management of SCD, particularly vaso-occlusive pain episode, so if a child is in pain what you are going to do. They should also educate them on nutrition, how to prevent infection through hand washing, educate them on sleeping in insecticide treated mosquito net, advise them on the importance of taking the prophylaxis.

Along this line, a physician commented:

The services by CHWs would be teaching the parents about how to look for danger signs, anemia, jaundice, fever, pain and also what they should be doing to manage symptoms. Also telling them to drink enough water and all that. This can be some of the services the CHWs can be taking them through. People in the community know the health workers so whenever there is a crisis they can easily approach them for assistance with easy referral to the hospital.

A chief commented:

Yes, it is a wonderful idea to have CHWs for sickle cell! One reason why it will work is that many of the parents of the sickle cell patients usually do not want people

around to know that their children have sickle cell because of the stigma attached to the disease. This usually makes people who have children living with SCD hide the health state of their children from people so if there is a CHW within the community that they trust, they could easily approach them.

Using existing CHW networks for SCD services would be best

Participants involved in overseeing or providing SCD care frequently mentioned the belief that a new network of CHWs should not be created. Instead, participants expressed an interest in incorporating a focus on SCD into the existing CHW network, provided the CHWs receive additional training about sickle cell. A chief stated that, “Since the CHWs that are already in place have much knowledge about the communities, they can move through the various areas to educate and sensitize the people about SCD. It would be better than bringing new people.” A physician commented:

You see, already the Ghana Health Service system has the CHWs in the communities so the community members are aware of their presence. The CHWs are people who have always been coming to them so if they start working on the SCD it will not be difficult since they have already established the rapport between themselves and the community members. I am suggesting we fall back on the Ghana Health Service so we can ride on that to execute this program and not necessarily reinventing new ways to go about it.

Another physician echoed the sentiment that a focus on SCD should be incorporated into existing CHW networks:

A CHW already situated within the community will be the best approach to support care for sickle cell patients because the CHWs are already working and are familiar to community entries and tracking of patients in the various communities. This is better than bringing a whole new person because they will not be willing to give that much information as they would to the CHW that they have known within the community for a long time.

Funding of expanded CHW network might be a problem

Despite the overwhelming interest and support for expanding the current network of CHWs to support care of those with SCD, participants often mentioned that securing funding

could be a challenge to feasible implementation. All categories of participants anticipated the financial cost of training and sustaining an expanded CHW network could be a problem. Many participants suggested that the Ministry of Health, Ghana Health Service, and/or the Ghana National Health Insurance Scheme should be tapped to pay for the expanded CHW network. A religious leader pointed out, “The only barrier will be finding financial resources because Ghana Health Service may not have much to use for this program.” A parent suggested:

We would wish for the government will support this project so that community health workers can come to our homes and help us care for the sickle cell patients but I don’t know if they have the money for it. Well, maybe, the community leaders like the chief can help and talk to the people on the need for the community health workers to come and support the care of the members but the barrier is the same because the funding is not coming.

A nurse proposed:

There should be a team with a merger of health staffs, government and the community leaders to pull resources together. It should be the health management and directors, ministry of health, Ghana health service and others to fund the workers. The government will have to agree on training CHW on SCD and also can involve the already employed nurses and CHW in training on SCD for them to work in that aspect. The challenge will be how to finance the whole program.

Discussion

Community stakeholders and key decision makers are extremely interested in using CHWs as a health system strengthening intervention to improve care and care outcomes for people with SCD in Kumasi, Ghana. Participants believe that it will be feasible to establish a network of CHWs to better support care of people with SCD. Most participants recommended incorporating a focus on SCD into existing CHW networks. They anticipated that funding of an expanded CHW network to support care of people with SCD in the community might be challenging.

There are few studies done on CHWs and SCD on which to compare our findings. In 2015, researchers in Kumasi conducted a 3-day workshop with community leaders to assist

the development and implementation of a Sickle Cell Counselor Training and Certification Program and submitted a report to the Ministry of Health in Ghana with recommendations to develop a national sickle cell counselor training program for education and non-directive counseling of parents of newborns and others who are tested for sickle cell status (Anie et al. 2016). To date, the proposed genetic counseling program has not been implemented. Similar to our study, Anie et al. (2016) concluded that funding for a sustainable counselor training program is crucial. Without this, provision of adequate resources, including settings for privacy and one-to-one counseling, electronic materials, and quality of training, would be compromised (Anie et al. 2016).

In Brazil, Gomes et al. (2015) gave an educational intervention to CHWs about care and monitoring of people with SCD and assessed the perception of CHWs afterwards. The educational intervention changed attitudes and improved quality of care provided by CHWs to individuals with SCD (Gomes et al. 2015). In a related study, researchers evaluated the effectiveness of a training program about childhood SCD aimed at CHW testing knowledge and found a significant increase in correct answers to questions about SCD management in the intervention compared to the control group (Gomes et al. 2017).

There are some ongoing projects exploring CHWs for SCD. Smaldone et al. (2019) shared a protocol for a study aiming at testing the efficacy of an intervention delivered to youth/parent dyads by CHWs, augmented by tailored text messages on medication adherence. In their feasibility study, CHWs worked with people and families for improved understanding of SCD and medication adherence, identified and addressed barriers to medication adherence, built youth–parent disease self-management partnerships, and identified a cue on which a medication habit could be built (Green et al. 2017). The Patient-Centered Outcomes Research Institute (2020) is funding a study exploring CHW and mobile health programs to help young adults with SCD transition to using adult healthcare services. Finally, the Sickle Cell Disease Association of America (2019) is offering a training program to cover the core competencies of CHWs, and includes additional concentration on SCD.

Participants suggested similar roles for how CHWs can benefit people with SCD and help address barriers as those proposed by Hsu et al. (2016) through case management, social support, and health system navigation. In Ghana and other countries, possible roles for CHWs in SCD include informal counseling and social support, providing culturally appropriate health education, advocating for individual and community needs, assuring that people get the services they need, building individual and community capacity, and providing direct services (Hsu et al. 2016).

This was the first qualitative gathering of focused information about interest in and feasibility of establishing a network

of CHWs as an intervention to improve care and care outcomes for people with SCD in an urban low-resource setting in West Africa. The study is innovative and timely as we strive to better address SCD symptom management to improve quality of life for people, strengthen health systems, and bring down medical costs.

Limitations

We only performed interviews from invited individuals without the perspective of others. Also, we collected data in the Ashanti Region of Ghana and results cannot be generalized to other areas of the country. Additionally, there is potential for loss of nuances in meaning for the four interviews conducted in Twi and translated to English.

Conclusions

As next steps, we advocate for the mobilization of resources to expand the current network of CHWs to include a focus on SCD in Kumasi, Ghana. An exploration of the feasibility of establishing a network of CHWs in other regions of Ghana to assess a wider spectrum of cultural and social determinants or barriers to implementation is warranted. Additionally, further economic evaluation, along with a cost–benefit assessment, could be useful for the advocacy, on a stakeholder level, for routine training of CHWs in the existing network about SCD. There is potential for findings from this exploratory project to be adapted and implemented in other settings throughout sub-Saharan Africa as well as areas of higher income countries where there are higher proportions of people living with SCD. Future research should explore the impact on health outcomes (i.e., pain crises, anemia, infection) along with the cost-effectiveness of establishing a network of CHWs to better support care of people with SCD.

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Compliance with ethical standards

The authors declare that they have no conflict of interest. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants before being included in the study.

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