J Community Genet (2016) 7:195–202
DOI 10.1007/s12687-016-0267-3

ORIGINAL ARTICLE

Community engagement to inform the development of a sickle cell counselor training and certification program in Ghana

Kofi A. Anie[1,11] · Marsha J. Treadwell[2] · Althea M. Grant[3] · Jemima A. Dennis-Antwi[4,5] · Mabel K. Asafo[6] · Mary E. Lamptey[5,7] · Jelili Ojodu[8] · Careema Yusuf[8] · Ayo Otaigbe[9] · Kwaku Ohene-Frempong[5,7,10]

Received: 27 November 2015 / Accepted: 10 April 2016 / Published online: 18 April 2016

Abstract Sickle cell disease (SCD) and sickle cell trait (SCT) are highly prevalent in Africa. Despite public health implications, there is limited understanding of community issues for implementing newborn screening and appropriate family counseling. We conducted a 3-day workshop in Kumasi, Ghana, with community leaders as lay program development advisors to assist the development and implementation of a Sickle Cell Counselor Training and Certification Program. We employed qualitative methods to understand cultural, religious, and psychosocial dimensions of SCD and SCT, including the advisors' attitudes and beliefs in relation to developing a culturally sensitive approach to family education and counseling that is maximally suited to diverse communities in Ghana. We collated advisors' discussions and observations in order to understand community issues and potential challenges and guide strategies for advocacy in SCD family education and counseling. Results from the workshop revealed that community leaders representing diverse communities in Ghana were engaged constructively in discussions about developing a culturally sensitive counselor training program. Key findings included the importance of improved knowledge about SCD among the public and youth in particular, the value of stakeholders such as elders and religious and traditional leaders, and government expectations of reduced SCD births. We submitted a report to the Ministry of Health in Ghana with recommendations for the next steps in developing a national sickle cell counselor training program. We named the program "Genetic Education and Counseling for Sickle Cell Conditions in Ghana" (GENECIS-Ghana). The first GENECIS-Ghana Training and Certification Program Workshop was conducted from June 8 to 12, 2015.

✉ Kofi A. Anie
kofi.anie@nhs.net

1 Haematology and Sickle Cell Centre, London North West Healthcare NHS Trust, Central Middlesex Hospital, London NW10 7NS, UK

2 University of California San Francisco Benioff Children's Hospital Oakland, Oakland, CA, USA

3 Centers for Disease Control and Prevention, Atlanta, GA, USA

4 International Confederation of Midwives Investing in Midwives Program, Accra, Ghana

5 Sickle Cell Foundation of Ghana, Kumasi, Ghana

6 Ashanti Region Health Promotion Office, Kumasi, Ghana

7 National Newborn Screening Program for Sickle Cell Disease, Accra, Ghana

8 Association of Public Health Laboratories, Silver Spring, MD, USA

9 Sickle Cell Foundation Nigeria, Lagos, Nigeria

10 Children's Hospital of Philadelphia, Philadelphia, PA, USA

11 Imperial College London, London, UK

Introduction

Sickle cell disease (SCD) comprises a group of inherited red blood cell conditions that result from production of abnormal hemoglobin (Hb) S. SCD results from inheritance of the sickle gene (for Hb S) from both parents (Hb SS), or the sickle gene from one parent and from the other parent, another abnormal hemoglobin gene such as C or beta thalassemia, which contributes to the pathological effect of the sickle gene. Asymptomatic sickle cell trait (SCT) results from the inheritance of the sickle gene from one parent and the normal version (for Hb A) from the other.

SCD has been acknowledged to have a global public health impact by the World Health Organization (WHO 2006) and United Nations (UN General Assembly 2008). Over 300,000

babies are born worldwide annually with the Hb SS type of SCD mostly in low and middle income countries, and about 75 % or more of these births are found in sub-Saharan Africa, posing an increasing health burden (Piel et al. 2013). SCD has remarkable public health implications, contributing to early childhood mortality if undiagnosed at birth, and appropriate healthcare interventions for under-5-year-old children are not implemented (Modell and Darlison 2008; Grosse et al. 2011).

Newborn screening (NBS) allows early identification and effective management of infants with SCD, which includes the following: administration of penicillin prophylaxis; immunizations against streptococcus pneumonia, hemophilus influenza, and meningococcus; prevention of malaria; and parental education for timely recognition of SCD complications (Brousse et al. 2014). Although national NBS programs for SCD are not established in Africa at present, several pilot schemes in different countries have demonstrated the significance of NBS and early management (Mutesa et al. 2007; Ohene-Frempong et al. 2008; Kafando et al. 2009; Rahimy et al. 2009; Tshilolo et al. 2009; McGann et al. 2013a). Furthermore, one of these pilot NBS and treatment programs implemented in Angola was shown to be cost effective. The cost of treating a child with SCD for 5 years, including penicillin prophylaxis and 3-monthly clinic visits, was $332, with the cost per DALY averted estimated to be $150 to $190 (McGann et al. 2013b) and a cost per health life-years gained of $1380–$3565 during the first 5 years of life based on WHO criteria (McGann et al. 2015). Another study in Kenya reported an annual cost of care for a child with SCD in a rural hospital clinic of about $150 (Amendah et al. 2013).

Genetic counseling and health education are essential components of any NBS program for SCD to ensure that results are effectively communicated by healthcare workers to those affected and their families. These are also important within the context of culture and religion because health beliefs and attitudes of the general public have a significant impact on outcomes, and community leaders substantially influence reproductive decisions made by individuals and families (Bhogal and Brunger 2010; Toni-Uebari and Inusa 2009).

In Ghana, a pilot NBS project for SCD was conducted in Kumasi (the second largest city) and Tikrom (a nearby rural community) from 1993 to 2008 as an international collaborative study, with funding from the US National Institutes of Health (Ohene-Frempong et al. 2008). Babies identified with SCD from this NBS venture were enrolled into a specialist clinic at the Komfo Anokye Teaching Hospital in Kumasi. The Sickle Cell Foundation of Ghana (SCFG) was inaugurated in 2004 and assumed administrative leadership of the NBS project in 2005. The Government of Ghana supported the NBS project from 2008, and in 2010 the National NBS Program was launched with the intention to scale up the pilot project into a national universal public health program. The SCFG was selected by the Ministry of Health to coordinate this NBS program. One of the central goals of the SCFG was to develop a sickle cell counseling and health education curriculum to complement the NBS program, and for young people of pubertal age. This initiative aimed to allow continuity of the education and counseling component of the pilot NBS project, which led efforts to creating patient and public awareness about SCD and the need for NBS, while keeping healthcare providers updated about SCD management (Dennis-Antwi et al. 2008). Endeavors to introduce the counseling component of the pilot NBS project began in early 2000 with the formation of an advisory committee that included religious and traditional leaders, healthcare workers, a gender specialist, a legal adviser, and a parent. The committee recommended that a counseling program for SCD should be established to train marriage counselors and others in genetic counseling skills. The first counselor training in SCD for marriage counselors from churches in Kumasi was organized by one of the authors (JD-A) in 2007. This provided education about the genetics of SCD and counseling skills in relation to SCD issues to these marriage counselors. Pursuant to this early work, implementation of the national NBS program involved a two-stage approach to community engagement for the development of a sickle cell counseling and health education program.

In the first stage, we conducted formative research using focus groups and qualitative methodology to gain better understanding of SCD and SCT within a cultural context from a representative sample of 32 healthcare providers and health educators (Treadwell et al. 2015). These healthcare workers, selected by the ten Regional Health Directors of Ghana, participated in group sessions to explore health beliefs, cultural and religious practices, and societal attitudes that may influence people with SCD. Participants highlighted the importance of engaging community leadership representing a broad range of stakeholders in planning a sickle cell counselor training program.

This report describes the second stage of community engagement for the program development through an advisors' workshop. The objectives were to obtain information from community leaders about appropriate goals and strategies for counseling following NBS and to identify potential barriers to achieving a counseling program.

Methods

A selection of 15 community leaders, representing religious, traditional, and relevant civic organizations, were invited as advisors to explore scientific, cultural, and religious issues around SCD education, testing, and genetic counseling in a 3-day developmental workshop. This was facilitated by a faculty of ten international and local experts with extensive clinical, research, and educational experience in SCD from the

USA, UK, Nigeria, and Ghana. This group included psychologists, a midwifery advisor, a health promotion officer, a health scientist, epidemiologists, programmatic and nurse coordinators of the National NBS Program for SCD in Ghana, and a senior nurse manager/genetic counselor from the Sickle Cell Foundation Nigeria.

The workshop was held from February 25 to 27, 2013, in Kumasi (Ashanti Region), situated geographically in the center of the country, and the main location for the pilot NBS project for SCD. Kumasi was the preferred venue where previous surveys on genetics, genetic counseling, and SCD were conducted with 237 parents of affected and unaffected children (JD-A, unpublished observations, 2000, 2001). Moreover, several advisors had previously served on a Genetic Counseling Task Force for the NBS project in Kumasi.

The workshop format included brief formal lectures on a variety of topics delivered by the local and international faculty, followed by questions from the participants to the faculty, questions from the faculty to the advisors in order to address specific issues, and discussions with the whole group. In addition, small group discussions were held. Advisors were encouraged to be candid with their responses and discussions in a relaxed and open atmosphere. A health educator transcribed the proceedings, and advisors completed a questionnaire evaluating the workshop.

Two central questions were asked by participants regarding the purpose of counseling and the counselor training program:

1. "*Are we looking at training counselors so that people will*

   a. *receive information only,*
   b. *use the information to make decisions concerning marriages, or*
   c. *for some other reason?*"
2. "*Is the aim of the counselor program that we intend to put in place to reduce the number of children born with sickle cell disease?*"

Small group discussions were based on the following structured questions posed by the faculty:

1. *What are some of the advocacy strategies that can be used for the Sickle Cell Disease Counseling Program in Ghana?*
2. *What are some of the potential challenges for the introduction of the Sickle Cell Disease Counseling Program in Ghana?*
3. *How will the Sickle Cell Disease Counseling Program be evaluated?*

The transcripts were initially categorized into themes by the lead author (KA). Subsequently, all the other authors assessed the themes and statements to arrive at consensus about the final categories of themes.

Results

The formal lecture topics are presented in Table 1. All 15 invited participants attended the development workshop, which was composed of the following: 12 community leaders (8/67 % female, 4/33 % male); one academic (male); and one clinical nurse (female) and one nurse/health educator (male), both of whom had substantial years of experience in working with people with SCD and their families (Table 2). Discussions based on the structured questions and additional topics are summarized by themes generated below.

Provision of general information

1. Information for young people

   Advisors suggested that young people in secondary schools (aged 12–19 years) should be targeted and tested for their SCT status; this would enable them to make informed marital and reproductive decisions without directing these decisions and choices. The counseling program should also ensure that counselors educate young people about pertinent information regarding SCD.
2. Information for potential couples and family members

   Advisors noted that education for prospective marriage couples, family members, and significant others of these couples would improve understanding of the implications of SCT status and improve attitudes and behaviors towards people with SCD in general and children of the couples, if affected. Information could help reduce stigma and stress in people with SCD.

Reduction of sickle cell disease population

The advisors debated whether the government in Ghana should fund a genetic counseling training program with the expectation that there will be a reduction in the number of children born with SCD. Most advisors favored the model where reduction of SCD births would be a long-term goal, probably 10–15 years after the commencement of a counseling and certification program. The most immediate objective of the program would be directed at providing people with correct information for them to make informed decisions about their reproductive choices. Government involvement would not reduce the number of children per se, although morbidity may be minimized. Some of the advisors favored using public information about SCD to help reduce the number of children born with

Table 1 Formal lectures and specific objectives of the sickle cell counselor training community advisory development workshop, Kumasi, Ghana, February 25 to 27, 2013

Topic of lecture	Specific objectives
Community messaging about sickle cell disease in Ghana: a. Kumasi and Tikrom Pilot Newborn Screening Project b. General community	To gain understanding of community messaging strategies for sickle cell disease that have been used following newborn screening for sickle cell disease and in the wider community
Counselor training and community messaging: a. Formative research on counselor training in Ghana b. Formative research on knowledge gaps of parents in Ghana	To share findings from formative research (2011) on issues and topics that may serve as the basis for developing effective strategies for culturally appropriate and scientifically accurate sickle cell counselor training
Strategies and challenges with community messaging used in different countries: UK, Ghana, USA, Nigeria	To familiarize participants with strategies and challenges faced by existing counselor training, public education, and certification programs in and outside Ghana
Small break-out group discussions, group reports, and open discussions	To identify and discuss potential challenges that may be faced in establishing counselor training and certification in Ghana
Models for counselor training programs: UK, USA, Nigeria	To highlight examples of programs for counselor training and certification from other settings in order to identify key components that could be adapted to the design of a program for Ghana
Objectives of genetic counseling for hemoglobin disorders: a. Personal, community, or national b. International examples from Cyprus, Thailand, Bahrain, Cuba	To outline the objectives of genetic counseling for hemoglobin disorders (using examples from other countries) in order to inform discussion of potential objectives appropriate to Ghana
Knowledge and attitudes about sickle cell disease in Ghana: a. Genetic survey results b. Results of regional workshop on sickle cell disease and newborn screening	To share findings on the knowledge and attitudes about sickle cell disease in Ghana based on the results of a survey (2001) and workshop (2011)
Best model for counselor training in Ghana: Open group discussion of strategies and challenges for rolling out counselor training	To discuss and outline a model for counselor training and certification in Ghana
Steps in establishment of professional certification program: Program ownership, curriculum development, certifying board, and cost implications	To identify the essential steps in the establishment of counselor training and certification program in Ghana
Open group discussion of counselor training next steps: a. Short-term goals (low hanging fruit) b. Long-term goals	To discuss strategies for design and implementation of a counselor training and certification program in Ghana
Strategies for evaluation: a. Evaluation 101 b. Logic Modeling 101	To familiarize participants with selected strategies for the systematic collection of information about the activities, characteristics, and outcomes of program
Human resource needs for national sickle cell disease program in Ghana: Open group discussion of opportunities for training of nurses and midwifes for specialized careers in sickle cell disease programs	To discuss and identify other potential human resources needs for Newborn Screening Program in Ghana and opportunities for redress
Open group discussion of research that complements newborn screening	To discuss and identify potential research topics that are complementary to the evaluation of the Newborn Screening Program in Ghana

SCD. Advisors stated that knowledge acquired should be used to minimize new SCD cases (by informed decision making) and manage those who have already inherited this condition.

Testing and counseling for sickle cell conditions

Advisors and faculty discussed the importance of testing and counseling for two different sets of people, new parents and infants, and prospective couples. Advisors recommended that testing and counseling should be considered at all transitional periods be it academically (school age) or traditionally (premarriage).

Access to test results was an important issue. For example, if testing is made compulsory at high school level, or is part of marriage counseling, there could be issues of stigma if results are given to church leaders, traditional leaders, or imams, thereby reducing choices of marriage and children. Marriages in Ghana are generally a family affair: by tradition, couples cannot get married without the approval of both families. Most people within the Ghanaian traditional setting may ask for some time to carry out their own investigation into suitability of the other partner after a man has asked for the hand of a woman in marriage. Their investigation into health issues, such as SCD, may reveal results that are perceived as not favorable for the marriage to proceed. A good understanding of SCD or SCT through counseling for a couple and other family members by trained marriage counselors could help to remove myths and modify beliefs.

Table 2 Participants of the sickle cell counselor training community advisory development workshop, Kumasi, Ghana, February 25 to 27, 2013

Gender	Role and institution
Male	Department of Children, Regional Coordinating Council, Ashanti Region
Female	Department of Women, Regional Coordinating Council, Ashanti Region
Female	Centre for Development of People (Non-Governmental Organization)
Male	National Youth Authority
Female	Christian Marriage Counselor (Orthodox Church)
Male	Christian Marriage Counselor (Charismatic Church)
Female	Women Aglow Ministry (Christian Women's Organization)
Female	Private Lawyer (formerly with International Federation of Women Lawyers—FIDA)
Female	Midwife and Counselor (Moslem)
Female	Parent of child with sickle cell disease diagnosed through newborn screening
Male	Moslem Imam
Female	Traditional Queen
Male	Professor, Department of Behavioral Sciences, Kwame Nkrumah University of Science and Technology
Female	Nurse, Sickle Cell Clinic, Komfo Anokye Teaching Hospital
Male	Nurse and Health Educator, Regional Health Promotion Team

Small group discussions

Emergent themes based on the structured questions about the strategies, potential challenges, and evaluation of counselor training in Ghana from the small group discussions are summarized below.

Strategies

1. Educational institutions
   The advisors recommended that an educational policy for SCD information should be incorporated into the school curriculum and into training for teachers, health workers, and genetic counselors.
2. General public information and education
   The advisors saw the development of SCD materials as essential to the training program. The SCD materials should focus on genetic aspects of SCD and be provided in different languages, such as Twi, Ewe, and Ga, with gender differences considered. Community centers that provide public health information should have these SCD materials. Text messaging could be another resource for public education. Peer to peer and education for prospective couples was advised and could be achieved within existing youth groups.
3. Education in religious and traditional settings
   There was a consensus among advisors that marriage counseling should include SCD information. Youth engagement in SCD issues within churches, mosques, and traditional places of worship, in addition to community engagement in SCD programs with traditional leaders, such as chiefs, should be considered. Furthermore, SCD messaging at religious and special traditional events, such as confirmation, baptism, and puberty rites, was proposed.
4. Media and entertainment
   The role of the media in broadcasting SCD information was discussed. Suggestions by advisors were as follows: inclusion in favorite television programs, such as "Chokor Trotro," and interactive theater with role play; documentary movies; and animated cartoons. Popular presenters on FM radio stations also could be enlisted to improve awareness.
5. Healthcare
   The advisors believed that it is imperative to incorporate SCD into clinical and hospital systems and introduce SCD in preconception care and prenatal diagnosis. In addition, cultural and religious issues need consideration in this process.

Challenges

The advisors agreed 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. Major stakeholders for the program need to be targeted with a youth-friendly approach where required. Also, community leaders could distract potential beneficiaries of the counseling program by giving them inaccurate SCD information.

Evaluation

Evaluation of the counseling program could be achieved through various methods, for example, surveys on general public attitudes and misconceptions about SCD, quiz competitions in schools, the number of telephone calls received

during or after a live television or radio program about SCD, or the number of people using a program website, if available. Furthermore, the impact of counseling could be determined by the number of people who seek counseling prior to marriage and the number of people attending SCD clinics.

Discussion

The 3-day developmental workshop for a sickle cell genetic counselor training program in Ghana identified key issues for consideration. Knowledge and education of the general public about SCD with special emphasis on the youth appeared to be essential. The idea was to target young people around puberty and empower them with adequate information for reproductive decision making. A study in Nigeria revealed a poor level of knowledge related to a low perception of the risk of SCD in prospective children of youth corps members (Olatona and Odeyemi 2010). However, public health education improved knowledge and SCD screening and counseling uptake among them (Olatona et al. 2012). These studies support the workshop participants' views on youth education and counseling, as well as a key objective of goals and strategies of the proposed counseling program, although there is no evidence to suggest that women with SCD or SCT in particular would change their reproductive decisions. For example, some studies have shown that regardless of their SCD or SCT status, women generally placed a high value on motherhood and their ability to have children, and this could be influenced by culture and religious beliefs (Asgharian et al. 2003; Gallo et al. 2010). On the other hand, stigmatization is quite common in African communities where patrilineal societies tend to blame mothers for their child's ill health. A study in rural Kenya revealed that fathers attributed "bad spirits (pepo mchafu) that comes to attack the child" to mothers, who then became economically disadvantaged as a result of their child's SCD (Marsh et al. 2011). Therefore, community education about SCD and interventions to address underlying economic and social disparities could potentially alleviate stigmatization and negative misconceptions. For example, knowledge and acceptance of SCT status prior to marriage could empower women and build trust between the couple (Marsh et al. 2013). As faculty, we explained to the advisors that the Government of Ghana did not have a universal screening policy for adolescents, and the proposed counselor training program was intended to provide accurate and non-directive information for those young people who may be tested for SCD or SCT.

Advisors postulated that the government of Ghana may have expectations for a reduction in the babies born with SCD to warrant financial support, with examples cited from the lectures provided by faculty about Bahrain and Nigeria. In Bahrain, government initiatives for 16–18 years of screening and follow-up of all pregnant women, premarital counseling, and a student-screening project reported a 60 % reduction in the birth rate of newborns with SCD (Al 2005). By contrast, in Nigeria there was no government policy to reduce SCD births and no evidence to suggest that, since genetic counseling started in 1986 (with some interruption), and prenatal diagnosis initiated in 1993, there has been a decline in SCD births, although this was not the intended outcome (AO, personal communication, 2013). Moreover, advisors assumed that a counseling program solely would result in reduced SCD births, albeit long term (10–15 years). The faculty stressed that there was no such evidence in SCD and dispelled this view. In Italy, for example, genetic counseling with the view to reduce severe thalassemia births was unsuccessful (Barrai and Vullo 1980). Furthermore, the faculty re-emphasized that the counselor training program in Ghana is not planned to reduce SCD births but to support informed decision making with a non-directive approach (National Society of Genetic Counselors 2006).

Health professionals, religious and traditional leaders, and family elders were considered to be important stakeholders for the training of lay counselors. Suggestions in this workshop were corroborated by previous research (JD-A, unpublished observations, 2000, 2001) that health workers should refer people who test positive for SCT to their customary counselors in churches, mosques, or traditional settings, and family elders supervising preengagement negotiations should know about the genetic status of a couple before marriage. Nevertheless, the faculty stressed that people diagnosed with SCD should be referred to a healthcare facility. Additionally, advisors emphasized targeting cultural and religious gatherings with SCD information to help dispel any myths and stigma. This is consistent with previous findings that health workers considered misconceptions and cultural and spiritual beliefs about SCD to be prevalent in Ghana and these must be addressed in a culturally sensitive counseling and health education program (Treadwell et al. 2015). Finally, the advisors supported the need for resources and appropriate facilities for an effective counseling program.

There were some limitations of the advisory workshop. A majority of the participants were female, although faculty did not observe any differential contribution, recommendations, or insights based on gender. While the selection of participants was intended to represent their roles within diverse communities, there could have been a selection bias of participants given that culture and religion appeared to influence their views. That is, other community leaders may have made different recommendations. Furthermore, results may not be generalizable across all settings, and merely within an African cultural context.

In conclusion, the workshop achieved its key objective, to engage the community in developing a culturally sensitive counselor training program. There was active participation of community advisors, who had very constructive comments,

and their impression was that the meeting was successful and enlightening. Faculty members also found the contribution of advisors to be informative and valuable. Recommendations for the next steps to developing a national counselor training and certification program were made to the Ministry of Health in Ghana and mainly stated that it is intended solely for education and non-directive counseling of parents of newborns, and others who are tested for their sickle cell status. No recommendations were made to the Ministry of Health about using this program to reduce the number of people born with SCD.

The national program was established and named "GENECIS-Ghana" (Genetic Education and Counselling for Sickle Cell Conditions in Ghana), and the first GENECIS-Ghana Training and Certification Program Workshop was conducted from June 8 to 12, 2015.

Acknowledgments We are extremely grateful to all the participants of the 3-day advisory workshop that was held in Kumasi, Ghana, from February 25 to 27, 2013, for the development of the Sickle Cell Counselor Training and Certification Program.

Compliance with ethical standards

Funding This manuscript is supported by Cooperative Agreement no. U60HM000803 funded by the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC or the Department of Health and Human Services.

Conflict of interest Kofi A Anie, Marsha J Treadwell, Althea M Grant, Jemima A Dennis-Antwi, Mabel K Asafo, Mary E Lamptey, Jelili Ojodu, Careema Yusuf, Ayo Otaigbe, and Kwaku Ohene-Frempong declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent Informed consent was not required since this is a report of proceedings of a workshop and not a study of human participants.

References

Al AS (2005) Campaign to control genetic blood diseases in Bahrain. Community Genet 8(1):52–55

Amendah DD, Mukamah G, Komba A, Ndila C, Williams TN (2013) Routine paediatric sickle cell disease (SCD) outpatient care in a rural Kenyan hospital: utilization and costs. PLoS One 8:e61130

Asgharian A, Anie KA, Berger M (2003) Women with sickle cell trait: reproductive decision-making. J Reprod Infant Psychol 21(1):23–34

Barrai I, Vullo C (1980) Genetic counselling in beta thalassemia in Ferrara. J Genet Hum 28(2):97–104

Bhogal AK, Brunger F (2010) Prenatal genetic counseling in cross-cultural medicine: a framework for family physicians. Can Fam Physician 56(10):993–999

Brousse V, Makali J, Rees DC (2014) Management of sickle cell disease in the community. Br Med J 348:g1765

Dennis-Antwi JA, Dyson S, Ohene-Frempong K (2008) Healthcare provision for sickle cell disease in Ghana: challenges for the African context. Divers Health Soc Care 5:241–254

Gallo AM, Wilkie D, Suarez M, Labotka R, Molokie R, Thompson A, Hershberger P, Johnson B (2010) Reproductive decisions in people with sickle cell disease or sickle cell trait. West J Nurs Res 32(8): 1073–1090

Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB et al (2011) Sickle cell disease in Africa: a neglected cause of early childhood mortality. Am J Prev Med 41(6 Suppl 4):S398–S405

Kafando E, Nacoulma E, Ouattara Y et al (2009) Neonatal haemoglobinopathy screening in Burkina Faso. J Clin Pathol 62(1):39–41

Marsh V, Kamuya DM, Malyneux SS (2011) "All her children are born that way": gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya. Ethn Health 16(4–5):343–359

Marsh V, Kombe F, Fitzpatrick R, Williams TN, Parker M, Molyneux S (2013) Consulting communities on feedback of genetic findings in international health research: sharing sickle cell disease and carrier information in coastal Kenya. BMC Med Ethics 14:41

McGann PT, Ferris MG, Ramamurthy U, Santos B, de Oliveira V, Bernardino L, Ware RE (2013a) A prospective newborn screening and treatment program for sickle cell anemia in Luanda. Angola. Am J Hematol 88(12):984–989

McGann PT, Santos B, de Oliveira V, Bernardino L, Ware RE, Grosse SD (2013b) Cost-effectiveness of neonatal screening for sickle cell disease in the republic of Angola. Blood 122(21):421

McGann PT, Grosse SD, Santos B, de Oliveira V, Bernardino L, Kassebaum NJ, Ware RE, Airewele GE (2015) A cost-effectiveness analysis of a pilot neonatal screening program for sickle cell anemia in the republic of Angola. J Pediatr 167(6): 1314–9

Modell B, Darlison M (2008) Global epidemiology of haemoglobin disorders and derived service indicators. Bull World Health Organ 86(6):480–487

Mutesa L, Boemer F, Ngendahayo L et al (2007) Neonatal screening for sickle cell disease in Central Africa: a study of 1825 newborns with a new enzyme-linked immunosorbent assay test. J Med Screen 14(3):113–6

National Society of Genetic Counselors: NSGC Code of Ethics. [http://nsgc.org/p/cm/ld/fid=12] Published 2006. Accessed February 22, 2016

Ohene-Frempong K, Oduro J, Tetteh H, Nkrumah F (2008) Screening newborns for sickle cell disease in Ghana. Pediatrics 121:S120–S121

Olatona FA, Odeyemi KA (2010) Knowledge and attitude of youth corps members in Lagos to sickle cell disease. Trop J Health Sci 17(2): 60989

Olatona FA, Odeyemi KA, Onajole AT, Asuzu MC (2012) Effects of health education on knowledge and attitude of youth corps members to sickle cell disease and its screening in Lagos state. J Community Med Health Educ 2(7):163

Piel FB, Patil AP, Howes RE et al (2013) Global epidemiology of sickle haemoglobin in neonates: contemporary geostatistical model-based map and population estimates. Lancet 381(9861): 142–151

Rahimy MC, Gangbo A, Ahouignan G, Alihonou E (2009) Newborn screening for sickle cell disease in the Republic of Benin. J Clin Pathol 62(1):46–48

Treadwell MJ, Anie KA, Grant AM, Ofori-Acquah SF, Ohene-Frempong K (2015) Using formative research to develop a counselor training

program for newborn screening in Ghana. J Genet Couns 24(2): 267–77

Tshilolo L, Aissi LM, Lukusa D et al (2009) Neonatal screening for sickle cell anaemia in the Democratic Republic of the Congo: experience from a pioneer project on 31204 newborns. J Clin Pathol 62(1):35–38

Toni-Uebari TK, Inusa BPD (2009) The role of religious leaders and faith organisations in haemoglobinopathies: a review. BMC Blood Disord 9:6. doi:10.1186/1471-2326-9-6

United Nations General Assembly. Recognition of sickle-cell anaemia as a public health problem. Sixty-third General Assembly, 2008. [www.worldlii.org/int/other/UNGARsn/2008/277.pdf] Published 2009. Accessed February 22, 2016

World Health Organisation. Sickle-Cell Anaemia Report by the Secretariat. Fifty Ninth World Health Assembly 2006. [http://apps.who.int/gb/ebwha/pdf_files/WHA59/A59_9-en.pdf] Published 2006. Accessed February 22, 2016