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Using Formative Research to Develop a Counselor Training Program for Newborn Screening in Ghana

Marsha J. Treadwell,

Hematology/Oncology Department, UCSF Benioff Children's Hospital Oakland, 747 52nd Street, Oakland, CA 94609, USA

Kofi A. Anie,

Haematology and Sickle Cell Centre, North West London Hospitals, National Health Service (NHS) Trust, Central Middlesex Hospital Acton Lane, London NW10 7NS, UK

Althea M. Grant,

Epidemiology and Surveillance Branch, National Center for Birth Defects and Developmental Disabilities, Division of Blood Disorders, Centers for Disease Control and Prevention, 1600 Clifton Road, MS E64, Atlanta, GA 30333, USA

Solomon F. Ofori-Acquah, and

Center for Translational and International Hematology, Vascular Medicine Institute, University of Pittsburgh, 200 Lothrop Street, Pittsburgh, PA 15262, USA

Kwaku Ohene-Frempong

Sickle Cell Foundation of Ghana, 4 Harper Road, 3rd Floor Adum, Kumasi, Ghana

Marsha J. Treadwell: mtreadwell@mail.cho.org; Kofi A. Anie: kofi.anie@nhs.net; Althea M. Grant: agrant@cdc.gov; Solomon F. Ofori-Acquah: sfo2@pitt.edu; Kwaku Ohene-Frempong: ohene@sicklecellghana.org

Abstract

Sickle cell disease (SCD), sickle cell trait (SCT) and related conditions are highly prevalent in sub-Saharan Africa. Despite the public health implications, there is limited understanding of the unique needs regarding establishing and implementing extensive screening for newborns and appropriate family counseling. We sought to gain understanding of community attitudes and beliefs about SCD/SCT from counselors and potential counselors in Ghana; obtain their input about goals for counseling following newborn screening; and obtain guidance about developing effective counselor education. Five focus groups with 32 health care providers and health educators from 9 of 10 regions in Ghana were conducted by trained facilitators according to a

Correspondence to: Marsha J. Treadwell, mtreadwell@mail.cho.org.

Conflict of Interest Marsha J. Treadwell, Kofi A. Anie, Althea M. Grant, Solomon F. Ofori-Acquah, Kwaku Ohene-Frempong declare that they have no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 2000. Institutional Review Board approval for the study was obtained through Noguchi Memorial Institute of Medical Research at the University of Ghana (051/10–11). Informed consent was obtained from all participants included in the study (Williams, 2008).

Animal Studies No animal studies were carried out by the authors for this article.

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structured protocol. Qualitative data were coded and categorized to reflect common themes. Saturation was achieved in themes related to genetics/inheritance; common complications of SCD; potential for stigmatization; marital strain; and emotional stress. Misconceptions about SCT as a form of SCD were prevalent as were cultural and spiritual beliefs about the causes of SCD/SCT. Potential positive aspects included affected children's academic achievement as compensation for physical limitations, and family cohesion. This data informed recommendations for content and structure of a counselor training program that was provided to the Ministry of Health in Ghana.

Keywords

Genetic counseling; newborn infant screening; formative research; counselor training; sickle cell disease; Ghana

Introduction

Sickle cell disease (SCD), a group of inherited red blood cell conditions, results from the production of structurally abnormal hemoglobin (Rees, Williams, & Gladwin, 2010). The hemoglobin S (HbS) mutation leads to polymerization and precipitation of hemoglobin during deoxygenation or dehydration, resulting in sickling, abnormal adhesion of leukocytes and platelets, and microvascular obstruction. In turn, inflammation, hypercoagulation, hemolysis and hypoxia, and ultimately organ damage, are induced. Sub-Saharan Africa carries the greatest global burden of SCD with 79 % of the over 300,000 annual births worldwide (Piel et al., 2013). Childhood mortality in sub-Saharan Africa is believed to be 50 – 90 % for children born with SCD (Grosse et al., 2011) with 70 % of these deaths estimated as preventable (WHO, 2006). Newborn screening (NBS) allows early identification of SCD, making possible simple and cost-effective interventions that dramatically impact early morbidity and mortality (Quinn, Rogers, & Buchanan, 2004; Telfer et al., 2007).

In developed countries, newborn screening with appropriate follow-up and care of affected children in specialized centers, has resulted in a reduction in the SCD mortality rate to <1 % for children under five years of age (Frempong & Pearson, 2007; Telfer et al., 2007). Similarly, in the Republic of Benin, the under-five mortality rate for infants diagnosed with SCD was 15.5 per 10,000 following neonatal screening and follow up. This figure is 10 times lower than the general infant mortality rate in the country (Rahimy, Gangbo, Ahouignan, & Alihonou, 2009). More recently in Angola, it was shown that adherence with clinic follow-up for families of infants newly diagnosed with SCD was excellent and calculated first-year mortality rate for the infants with SCD compared favorably to the national infant mortality rate (McGann et al., 2013).

Counseling is a critical component of NBS programs as parents of children with SCD are educated on how to promote health and recognize signs necessitating immediate treatment. Preliminary experiences of NBS in Africa revealed that capacity building and training provide local healthcare workers with skills needed for a functional screening program and clinic. However, tracking and contacting families of all affected infants remains a challenge (McGann et al., 2013; Ohene-Frempong, Oduro, Tetteh, & Nkrumah, 2008).

NBS for SCD also identifies carriers, namely sickle cell traits (SCT) and other abnormal hemoglobin genes. All couples planning families should be offered testing and counseling, given that the prevalence of SCT in sub-Saharan Africa ranges from 20–40 % (Piel et al., 2010). Parents of children with SCT should also be referred for additional family testing and receive non-directive counseling to support future reproductive decision-making. SCD is a recessive genetic disorder, therefore when both partners in a couple are carriers for SCT, they have a 25 % chance with each pregnancy of having a child with SCD. Prenatal diagnosis is usually offered in developed countries, and this should be considered in Africa if available (Wonkam, Ngongang Tekendo, Zambo, & Morris, 2011). Effective counseling, including health education/promotion and genetic counseling must be provided in a respectful manner compatible with an individual's culture, health beliefs, and language (Whaley & Davis, 2007).

Ultimately, parents make their own reproductive decisions, but healthcare providers vary tremendously when discussing risks and benefits that inform such decisions (Blaine et al., 2008). Meanings of risk, disability and normality vary within and between individuals and cultures (Bhogal & Brunger, 2010). It is critical to gather maximum information about cultural, religious, economic, educational and political dimensions of communication prior to implementing national NBS for SCD and its associated counseling program (Oliver, Dezateux, Kavanagh, Lempert, & Stewart, 2004).

In low-resource settings, professionally trained genetic counselors are rare. Instead, physicians, nurses, social workers, non-health professionals, and lay counselors discuss complex and often emotion-laden genetics information with families. There are two genetic counseling training programs available in South Africa, which are seldom accessible to other sub-Saharan African students (Beighton, Fieggen, Wonkam, Ramesar, & Greenberg, 2012). Another two-week genetic counselor training course is offered specifically for SCD and SCT counseling by the Sickle Cell Foundation of Nigeria (http://www.sicklecellfoundation.com/). This course has been conducted for several years with financial support from non-governmental and charitable organizations. Trainees are mostly selected from the country to represent the various states in Nigeria, although there have been some foreign participants and invited international faculty.

Ghana is a lower-middle income country with a population of about 25 million, 48 % rural, and some 75 ethnic groups (IndexMundi 2014). Most healthcare is provided by the government and largely administered by the Ministry of Health and Ghana Health Service. The healthcare system is well structured with five levels of providers: health posts which are first level primary care for rural areas; health centers and clinics; district hospitals; regional hospitals; and tertiary hospitals. The Christian Health Association of Ghana also provides healthcare services through hospitals and clinics. There are about 200 hospitals, and some private (for-profit) clinics that provide less than 2 % of healthcare services. Healthcare is quite variable across the country. Urban areas are well served, and have most of the hospitals, clinics, and pharmacies in the country. Rural areas usually have no modern healthcare patients in these areas either rely on traditional medicine, or travel long distances to access hospitals and clinics.

The first NBS for SCD pilot program in sub-Saharan Africa was conducted in Kumasi, Ghana's second largest city, led by one of the authors (KO-F), from 1993–2008. The Ministry of Health of Ghana has supported the project since 2008, pursuant to a national program plan. By 2013, the screening program had tested 368,164 babies, with SCD diagnosed in 6,450 (1.8 %). The majority of diagnosed infants were enrolled in the second SCD clinic to be established in the country at Komfo Anokye Teaching Hospital in Kumasi. About 13.5 % and 8.8 % of the newborns were found to have hemoglobin AS and hemoglobin AC (SCTs) respectively (Ohene-Frempong et al., 2008).

Recent studies examining community awareness about SCD/SCT in Sub-Saharan Africa (Adeola Animasahun, Nwodo, & Njokanma, 2012; Animasahun, Akitoye, & Njokanma, 2009) have used structured questionnaires as a primary research methodology. A notable exception is the work of Dennis-Antwi and colleagues (Dennis-Antwi, Culley, Hiles, & Dyson, 2011) who studied lay perceptions of SCD in Ghana by conducting individual interviews with fathers of children with SCD and focus groups with the mothers and a group of health professionals. The researchers concluded that perspectives on SCD are embedded both within stable aspects of culture such as the high value of children, and within a societal transition to greater access to health insurance and a SCD population living beyond the newborn years. These researchers also commented on the importance of understanding how families live with SCD, rather than just how they react to the diagnosis.

Aims of the Study

We found no published studies describing the systematic development of a counselor-training program for NBS in Africa. We therefore aimed to gather input from healthcare providers - including health educators, clinicians providing counseling and health administrators - regarding the development of the counseling component of the Ghana National NBS Program for SCD. These professionals were either current or future providers of counseling to families of infants diagnosed with SCD or SCT. Objectives included obtaining their input about: 1) community attitudes and beliefs about SCD and SCT; 2) the most appropriate goals for counseling after newborns are identified with SCD or SCT and barriers to achieving the stated goals; and 3) developing an effective counselor education program.

Methods

Institutional Review Board (Ethics) approval for the study was obtained through Noguchi Memorial Institute of Medical Research at the University of Ghana. Informed consent was obtained from all participants included in the study.

Research Design

The research design was cross sectional, using a qualitative phenomenological approach.

Participants

Sampling Method

The study used purposive sampling of professionals with varying experiences with sickle cell counseling (Sandelowski, 2000; Tuckett, 2004) to capture the heterogeneity of this population of professionals while ensuring a representative variation in conclusions (Maxwell, 1996). Purposive sampling was used because there are a limited number of individuals with expertise in the area of sickle cell counseling. The Sickle Cell Foundation of Ghana wrote letters of invitation to each of the Regional Directors of Health representing the 10 regions of Ghana, asking them to identify three untrained potential counselors from each region who should be invited to participate in the groups. In addition, five previously trained sickle cell disease counselors from Kumasi, where the pilot NBS program was implemented, were invited. These counselors practiced in the Ashanti region, where more than half of the population resides in urban areas.

Population and Eligibility Criteria

Inclusion criteria were healthcare providers, educators, and administrators who could potentially provide counseling pursuant to the NBS program. No exclusions were based on age, gender or education. All participants were fluent in English although language was not an exclusion criterion.

Setting and Sessions

The study was conducted at the University of Ghana in Accra. Participants provided informed consent. Seating was arranged in a semi-circle with two flip charts and an audio recorder in the middle of the room. Each focus group lasted for about three hours. Each group had two facilitators, a scribe and was digitally recorded for transcription by a research assistant.

Five focus groups were conducted in English by three investigators (KA, AG, MT) and three locally trained facilitators. Assignment to each group was random, with the exception that we assigned the experienced counselors to one group. Focus group participants were provided with accommodation, meals and were reimbursed for travel.

Materials

Each focus group was conducted using a structured protocol (see supplementary information). Participants completed a questionnaire to provide participant demographic information including age, gender, education, and counseling experience.

Procedure

Each group began with group leaders presenting a general overview of the group's purpose and ground rules. Focus group leaders next asked, “When I say sickle cell disease, what comes to mind?” so that participants could freely generate attitudes, thoughts and feelings about SCD. Participants were asked the same question about SCT and similar unstructured questions about community health beliefs i.e. causes of ill health in general and about SCD

in particular. Next, focus group leaders used the Critical Incident Technique (CIT) to gather information from focus group participants about positive or negative effects on individuals or families of SCD/SCT (Butterfield, Borgen, Amundsen, & Maglio, 2005; Fitzgerald, Seale, Kerins, & McElvaney, 2008). Focus group participants were asked to narrate stories about the impact of SCD/SCT on individuals or families in response to the questions “Tell me about a recent time when an individual learning that their child had sickle cell disease had a positive (negative) effect on that person or his/her family.” Focus group leaders used a series of probes to insure that participants talked about specific events, rather than in general terms, and to insure that the described behaviors were responsible for the positive or negative effect on the individual/family.

Focus group leaders returned to an open-ended format to ask group participants to generate a list of counseling goals and barriers. The scribe recorded the list on the flip chart in front of the group. When participants completed their list, the focus group leaders and scribe referred to a list of potential goals identified by the investigators from the literature, also on a flip chart, and asked group participants to compare the group's list to the list of goals from the literature. Next, participants prioritized the contents of both lists combined by voting on the relative importance of each goal or barrier. Each participant was allowed five “votes” that they could distribute among each potential goal on the list in whatever way that they chose (i.e., if they considered a goal to be very important, they could give more than one “vote” to the goal).

The focus group leaders returned again to the open-ended format, asking participants to provide input about desired topics for a counselor training program and ongoing training and consultations following certification. Finally, participants responded to open-ended questions to describe what kind of messages might encourage community members to seek counseling. At the end of the group, participants completed the demographics questionnaire.

Data Analysis

Specific steps in the thematic analysis of the open-ended data on SCD, SCT and health beliefs included: 1) review of transcriptions to ensure accuracy; 2) open coding of each transcript to identify salient issues by three investigators (KA, AG, MT); 3) independent analysis of major categories derived from step 2 and; 4) identification and description of unifying contextual themes (Bernard & Ryan, 2010; Saldana, 2012). The investigators worked in pairs to assess agreement with the themes generated and differences in how statements were coded were resolved by consensus. Data from established counselors were compared with data from the groups not yet trained for similarities and differences in content. Both the existence of themes and the frequency of themes were coded.

We used the CIT (Butterfield et al., 2005; Fitzgerald et al., 2008) to categorize the “stories” that the focus group participants told about positive and negative effects of SCD and SCT on individuals or families. The CIT has been used cross-culturally (Emusu et al., 2009; Griffiths et al., 2001) to assess patient experiences in healthcare settings (Grant, Reimer, & Bannatyne, 1996; Kemppainen 2000; Mallak, Lyth, Olson, Ulshafer, & Sardone, 2003) and to determine patient responses to chronic illness and treatment (Janson & Becker, 1998;

Kemppainen, Levine, Mistal, & Schmidgall, 2001). The CIT has thus been used for both practical and research applications.

Each critical incident was reviewed to ensure standards for adequate critical incidents were met (Kemppainen 2000). Incidents were separately categorized based on similarity of content, by identifying the key behavior responsible for the positive or negative outcome. The preliminary categories from the initial grouping were consolidated where possible. Additional sets of incidents were then categorized, with new domains, categories, and sub-categories developed as needed and discrepancies in coding resolved by consensus. Incidents were classified until no further categories could be identified. A research psychologist, independent of the original project team, with knowledge of SCD and qualitative research methodology, coded the final set of categories. Inter-rater reliability at the category and sub-category levels between the psychologist and the original coders was assessed using percent agreement (Hayes & Hatch, 1999).

Results

Focus group participants were 20 women and 12 men representing 9 of the 10 regions of Ghana, (Table 1). The Upper East Region was unrepresented, and there were three untrained and five trained counselors from Ashanti Region. The mean age of the focus group participants was 40.6 years, with education ranging from General Certificate of Education - Advanced Level through Medical School. Years of counseling experience ranged from 6 – 16 years, and those with more experience were primarily sickle cell disease counselors working in the Ashanti region. Twelve (38 %) participants were nurses and 14 (44 %) were health educators or health promotion officers.

Sickle Cell Disease and Sickle Cell Trait

In response to the open ended query “When I say sickle cell disease, what comes to mind?” the most prevalent theme was the clinical complications of SCD, followed by genetics/ inheritance, and the cellular pathology of the disease (Table 2). Next were stigmatization within the community; community beliefs in shortened lifespan; and psychosocial aspects. Experienced counselors commented more frequently than other groups on misconceptions about SCD among community members. They also commented more frequently on the belief that SCD is incurable, and on prevention of SCD complications and subsequent births.

Genetics/inheritance was the most prevalent theme across all five groups in relation to SCT (Table 2) followed by community misconceptions about SCT as a form of SCD, rather than a benign carrier state. Experienced counselors reported some individuals with SCT attributed any rheumatic pain to SCD and some took folic acid (a treatment for SCD not beneficial for SCT). All five groups frequently commented on the importance of screening or testing as the only way to be sure (one carries the trait). An infrequent theme included challenges associated with having thalassemia or hemoglobin C trait, given that community knowledge and testing was often limited to hemoglobin S trait. Additional infrequent themes included phenotype (absence of crisis); protective effects (some immunity against malaria); cellular pathology (the person has some normal hemoglobin and sickle hemoglobin);

prevention (people with SCT should marry those who do not have a hemoglobin trait to avoid having children with SCD) and superstitions (caused by witches in the family).

Health Beliefs

Cultural and spiritual beliefs about SCD were the most prevalent health beliefs (Table 3) across all groups. Sub-categories of cultural and spiritual beliefs included: witchcraft; impact on marriage, family and relationships; and the concepts of stigmatization, curse and punishment. Experienced counselors most often cited misconceptions about SCD including beliefs that parents should not invest in education because the child with SCD would die early. Group participants noted that formally educated community members know SCD is inherited. One group of not-yet-trained counselors described the belief that SCD is a disease of the poor. A less frequently cited health belief in relation to SCD was no cure.

Critical Incidents

Eighty-three critical incidents were put forward in response to the queries: “Describe a recent time when an individual learning that their child had SCD/SCT had a positive effect on that person or his/her family” and “Describe a time when learning that their child had SCD/SCT had a negative effect.” While participants' initial reactions were to state “there are no positive effects,” upon reflection, they commented on some positives. The most common positive effect (9 critical incidents – Table 4) reflected a theme not generated from the open ended query about SCD – children with SCD seem to be more intelligent and with better educational attainment, as they compensate for physical limitations. Eight critical incidents reflected greater family cohesion following diagnosis, as well as pride in the child's accomplishments in the face of adversity. Seven incidents reflected knowledge about diagnosis leading to better self-care. Less common themes were prevention of sickle cell births given knowledge of trait status and opportunities to advocate for the affected child and other families.

The most often cited negative effects of SCD were impacts on families and relationships (21 critical incidents – Table 4). Individuals with SCT or SCD were advised not to marry, and marital strain was common when a child was affected. Negative psychosocial influences (emotional stress; depression; hopelessness) were cited next most often (12 critical incidents). Financial burden, including loss of employment for parents and for affected adults, were reflected in 7 critical incidents. Misconceptions about the disease were cited in five incidents; clinical complications in three. Stigmatization and curse were the final categories.

Theoretical saturation was achieved when new data were repetitive and offered little further insight into topics (Corbin & Strauss, 2008). Percent agreement between the independent and the original coders ranged from 63 to 100 %. There was 91 % agreement between the independent and the original coders for 39 themes and 100 % agreement for 44 of the themes.

Goals of Counseling

Focus group participants predominately generated goals of counseling consistent with goals in the literature (Biesecker, 2001)(Table 5). Group members also were consistent in prioritizing the goals of creating awareness; educating parents about SCD; and helping parents to make informed decisions/choices. Group participants generated additional goals including: teaching parents how to manage finances; helping parents to encourage children to be positive minded about the condition; and building up confidence in children. Other important goals of counseling included: promoting healthy choices; empowering (families) – about how to handle situations related to illness; preventing SCD births; providing information about inheritance; providing psychosocial support; and correcting misconceptions. Lower priority goals included: providing information about resources, including health facilities; reducing stigmatization; promoting healthy choices; promoting acceptance of the child; and making testing accessible for early detection.

Barriers to Counseling

The focus groups agreed common barriers to counseling include: language barriers; lack of information (about counseling) or ignorance of counseling resources; lack of qualified counselors; families have too many other problems; not understanding the importance of knowing screening results; stigmatization; cultural and religious barriers (including confiding in religious leaders only and relying on traditional practices); and geographic accessibility. They identified and prioritized barriers to counseling in their settings including: counselors not knowledgeable about SCD; facilities not ensuring privacy/ confidentiality; and parents having less confidence in young counselors. Problematic counselor characteristics were prioritized, including poor attitudes, i.e., judgmental, lacking in empathy, unfriendly; and counselors imposing cultural and religious beliefs. Other cultural barriers cited were a counselor's societal status (i.e., high status counselees not being comfortable listening to lower status counselors). Long waits, either in the clinic to obtain counseling or screening results; and emotional barriers – worry, fear, frustration or anger on the part of the family - were also cited.

Counselor Training

Participants in the five groups were consistent in recommendations for topics for initial counselor training, including basic facts and management of SCD; prevention of complications; informed reproductive decision-making; effective communication; customer care, i.e., counselor attitudes, confidence, approachability and availability; providing family support and managing emotions; ethical and cultural issues; services and resources. Participants indicated the need to learn how to provide education about SCD and SCT in a variety of venues including churches, mosques, markets and schools. They requested strategies to address misconceptions and language barriers and updated information about research and clinical innovations. Less frequent requests were for information on helping mothers who need time off work to care for children; families managing finances; and parents develop coping skills for supporting their children with SCD.

Focus group members requested annual refresher courses after initial training, and resource persons such as researchers and clinicians for ongoing consultation. They requested aids for counseling sessions, including cue cards, flip charts, manuals and visually based materials for low literacy counselees. Focus group participants suggested strategies to maintain and sharpen skills: mentoring across sites; sharing best practices; having experienced counselors train new counselors; training in report writing; and performance/peer review.

Diverse strategies were suggested regarding training formats. While noting the value of on-line information and strategies, participants indicated that sometimes on-line information is not practical in areas where internet connections are slow or non-existent. Suggested formats for trainings ranged from 2-week workshops, 2–3 day seminars, 3–6 month short courses and 6–12 month on-line courses. Opportunities for regional and centralized trainings were also requested.

Messaging to the Community

The focus group participants generated a range of messages important to the community, including preventing births of children with SCD - “Know your status (before marriage)” and preventing complications - “Get early treatment”; and “People with SCD can live long if well managed”. The simple message “SCD is not caused by witchcraft” was frequently suggested. Experienced counselors indicated that screening newborns needed coupling with education about the true meaning of the screening results. Powerful and succinct messages included: “Anyone can get it”; “It is not a new disease”; “A child's death can be prevented”. Encouraging and motivating individuals and families, highlighting the importance of community and family support for those affected and combating stigma were other messages. Finally, the importance of assuring affordable, accessible and confidential counseling was noted.

All groups agreed that a range of message formats was important, including radio and television; presentations at churches, mosques and schools; dramas and role-plays; and videos, billboards, t-shirts, leaflets, posters and stickers. Group participants emphasized the importance of messages tailored to target audiences and early education in schools. They also emphasized the need to not only educate the general public but health promoters, opinion leaders and advocates. Specific strategies included using community cinema vans in rural areas and durbars for dissemination.

Discussion

Current or future providers of counseling to families of infants diagnosed with SCD or SCT in Ghana provided insights into perceptions about SCD/SCT and about the impact of SCD/SCT on families and affected individuals in a series of focus groups. Focus group participants commented most frequently on genetics/inheritance and common clinical complications of SCD. They also highlighted stigmatization about SCD and the psychological burden the diagnosis can bring to individuals and families. Community misconceptions about SCT as a form of SCD was a prevalent theme as were cultural and spiritual beliefs about the causes of SCD and SCT. Potential positive aspects of SCD that

were elicited with probing included an enhancement in affected children's academic achievement when they compensate for physical limitations. Greater family cohesion was cited as a potential positive outcome in relation to the diagnosis, but marital strain and emotional stress were cited more frequently.

Practice Implications

The findings from the present research and other studies in Africa suggest that potential sources of stigma must be considered when developing the content and context of counseling programs. We did not find the level of stigma directed towards women, as has been found with other studies of SCD in Africa (Marsh, Kamuya, & Molyneux, 2011). However, we did find that the presence of a child with SCD could exact a major toll on family relations. Beliefs that a child with SCD reflects a curse or punishment on the family may be powerful (Allotey & Reidpath, 2001; Nzewi, 2001). Focus group participants recommended addressing stigmatizing beliefs head-on with such messaging as “SCD is not caused by witchcraft”. Counselor training programs for SCD and SCT must take cultural and familial health beliefs into consideration when supporting family adjustment to the diagnosis and reproductive decision making by families.

Our use of the CIT, in contrast with previous studies using structured questionnaires (Adeola Animasahun et al., 2012; Animasahun et al., 2009), allowed us to glean potential positive aspects of SCD/SCT from our participants. Participants noted the potential for increased family cohesion and advocacy and enhanced achievement by some children with SCD. Use of the CIT generated information about specific psychological, social and economic influences of SCD/SCT that should be included in counselor training curriculums in Ghana. This includes focus on bringing parents, siblings and other family members together in the care and support of the affected child; taking pride in accomplishments in the face of adversity; and planning for financial challenges as parents may have to miss days of work and pay for medicines and medical care.

Our qualitative approach can inform counselor training programs in the inclusion of strategies to increase individual and family resiliency. Counselors must foster holistic practice and collaboration with the medical care team, in addition to assisting families in the interpretation of genetic science and therapeutic options. Counselors provide a critical link to community resources for families and can strengthen positive family processes and coping. Counselor training curricula can include conceptualizations of family resilience and implications of the constructs of risk and protective factors within an ecological perspective (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013).

Specific recommendations were generated from these data for the Sickle Cell Foundation of Ghana, the Ghana Health Service, and the Ministry of Health of Ghana, regarding the need to implement a counselor training component of the Ghana National NBS Program for SCD. We recommended training lay counselors as well as enhancing the role of providers involved in counseling and health education (e.g., nurses) to specifically focus on SCD and SCT. Table 6 includes recommendations for specific content of the counselor training curriculum, including counselor knowledge, skills and other considerations. Many of the

recommendations are aligned with the extant literature on genetic counseling training. Our focus group participants provided insight into sources of stigma in Ghana, including the physical appearance of some individuals with SCD and beliefs about punishment and curse. They also provided insights into the complexities of spirituality as a source of strength and stress for families. Supernatural mechanisms and traditional healing are juxtaposed with Christian and Muslim beliefs. Families can draw comfort and hope from any of these beliefs, or a sense of despair – e.g. “If you pray hard it can be cured. If you are not a good Christian, you will not be cured”. Perceptions and health beliefs should be evaluated within each community, so that the structure and content of the SCD counselor/educator training is best suited to the needs of varied groups.

Study Limitations

A limitation of the present study is that it does not provide information from the general community about what they would like addressed in counseling sessions about SCD and SCT. While our data gathering was enriched by some participants' direct experience with SCD and SCT within their families and social circles, future comparisons are planned between these provider views and those of the general community and affected families, to better inform the development of a training program. Group members were men and women and they varied in educational levels, but the group leaders did not observe, nor hear reported, issues with any member feeling that s/he could not speak up or that his/her voice was not attended to.

Research Recommendations

There is limited social and behavioral research in relation to genetics and genetic counseling in Africa. There is a need for systematic evaluation as genetic counseling programs are implemented, with the goals of delineating effective processes and outcomes in relation to knowledge gained, and to consumer assessments of support provided that enhanced coping and adjustment. Strategies for, and content of community messaging need to be evaluated, particularly messages that directly address stigma. We are developing a curriculum for training lay counselors, and providers such as nurses who are already providing counseling, specifically in relation to SCD and SCT. There is a need to determine what relative benefits and challenges are associated with providers of counseling at the two levels.

There is also a need for genetic counselors to be included on translational research teams, as such enterprises as the Human Heredity and Health in Africa (H3Africa) initiative evolves (Adoga, Fatumo, & Agwale, 2014). Genetic counselors can assist with engaging various community stake-holders and with traversing ethical and practical challenges of genomics research (Zierhut & Austin, 2011). This formative research provided perspectives from healthcare providers, many with both personal and professional experiences with the impact of SCD and SCT. In the next phase of our research, we plan to gather perspectives from a broad representation of lay individuals directly affected by SCD and SCT.

Conclusion

There is an urgent need to address the public health impact of SCD in Sub-Saharan Africa. Comprehensive programs must be established with the utmost regard for social, cultural, economic and spiritual contexts and diversity within populations. Goals of counseling must be well defined to generate empirical data on its effectiveness and the essential elements of the process (Biesecker, 2001). To our knowledge, this is the first publication to describe the use of formative research to inform development of a counselor training program in Africa as a national NBS program for SCD is being implemented. This use of qualitative strategies to lay a foundation for developing a counselor training program maximally suited to the diverse communities in Ghana provides a model for developing similar programs in other countries.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographics and Characteristics of Focus Group Participants (n =32)[a]

Characteristic	
Gender	20 Female; 12 Male
Age	Mean=40.6 (26 – 58 years)
Counseling Experience - Years	Mean=8.6 (6 – 16 years)
Location - Region	8 Ashanti (3 untrained)
	3 each Brong-Ahafo, Central, Eastern, Greater Accra, Volta, Western
	2 each Northern, Upper West
	0 Upper East
Ethnic Background	6 Akan
	5 Ewe
	3 each Ashanti, Fante, Ga, Krobo
	1 each Akwapim, Akyem, Bono, Dagaabe, Dagaare, Dagomba, Kassena, Sissala
Education	16 Nursing (Diploma, BA, BSc PHN)
	12 Health Education (Diploma, BA, BEd, MS)
	2 GCE A Levels
	1 PharmD
	1 Medical School - Pediatrics
Job Title	14 Health Educator or Health Promotion Officer
	12 Nurse or Public Health Nurse
	1 Specialist in Pediatrics
	1 Pharmacist

[a] All participants did not provide a response in every category so numbers in each category do not always add up to 32

Table 2

Common Themes – Sickle Cell Disease and Sickle Cell Trait[a]

Category	Sample Statements
Sickle Cell Disease	
Clinical Complications	Two common symptoms are pain and anemia
Distinct Physical Appearance	Slim/thin; Yellow eyes
Chronic/Recurrent Illness	Child falls sick often
Genetics/Inheritance	Genetic disorder
Cellular Pathology	Red blood cells sickle under certain conditions
Misconceptions	They think they can't go to school; They think they cannot give birth; They…think it is from one parent only
Stigmatization	Women with SCD are not advised to be married
Superstition	Evil forces or spirits
Psychosocial Aspects	They just start crying. They know they are going to suffer with their babies
Risk of early death	It's a deadly disease – die by age 5 or 18… maximum age you will live is 32 years
Potential for cure	It cannot be cured but can be managed
Prevention	If detected early it can be prevented
Sickle Cell Trait	
Misconceptions	A portion of the condition is in you; AS is a trace of SCD
Genetics/Inheritance	(They) can pass (the gene for) sickle hemoglobin on to offspring
Screening/Testing	Many do not even know they have the trait
Phenotype/symptoms	They do not have crisis
Superstition	Caused by witches in the family

[a]Themes presented in order of prevalence

Table 3

Health Beliefs in Relation to Sickle Cell Disease[a]

Category	Sample Statements
Cultural and Spiritual Beliefs	If you pray hard it can be cured. If you are not a good Christian, you will not be cured
Witchcraft	Leg ulcers and splenomegaly associated with witchcraft
	Bewitchment by relatives
Curse/Punishment	…family members have offended the deities/gods
	Family may have offended someone and that person may have cast a spell on them
Impact on Family and Relationships	Some believe one should not marry if the person has SCD
	Feeling remorseful - questioning why this happened in their family
Misconceptions	They are not strong – and should not work or play
	If you eat more groundnut oil you get it
Behaviors of Others	(Investing in their education) is a waste of money because they will die
Education	Educated people think it is hereditary
	There is a (general) lack of education about SCD
Socio-economic factors	Disease of the poor
Longevity	They do not live long

[a]Themes presented in order of prevalence

Table 4
Critical Incidents – Positive and Negative Effects of Sickle Cell Disease

Category	Number of Incidents (%)	Sample Statements
Positive Effects		
Impact on Family and Relationships	15 (18.5 %)	
Family Cohesion		…the parents managed the child together…the siblings also help… it brought the family together
Pride in Accomplishments		I told her (when she was accepted for senior high school) “we are going to inspire them…even with SCD you can do anything.”
Improved Intelligence/Scholarship	9 (11 %)	…she spent more time at home and studying, leading to academic achievement
Advocacy	4 (5 %)	…they know how to manage their child's condition… and now they give advice to other people
Negative Effects		
Impact on Family and Relationships	21 (26 %)	There was this couple…both were SS. They got married and their first child had to go to the hospital every moment. Eventually the couple got tired of the marriage and the child expired
Psychosocial Aspects	12 (15 %)	(After the deaths of two children with SCD) they are now left with one child with SCD. They are still mourning their children… they don't have the joy they had.
Socioeconomics/Resources	7 (9 %)	The parents are out of work to take care of their child. The person (with SCD) was sick most of the time and not able to work
Misconceptions	5 (6 %)	…she had her first menarche at 24 or 25… she was told it was not possible for her to give birth They are told “you don't live above 25 years” if you have SCD
Clinical Complications	3 (4 %)	…she had joint pain and inflammation
Stigma	2 (2.5 %)	…the family prevented her fiancé from marrying her …they put the blame on the woman, said SCD is from the maternal family
Curse/Punishment	1 (1 %)	…they thought witchcraft was upon them

[a]Themes presented in order of prevalence

Table 5

Prioritization of Counseling Goals[a]

Goal of Counseling	Number of Votes
Educate parent about SCD and inheritance	33
Help family to make informed decisions	20
Provide emotional support/empathy/encouragement	19
Create awareness about SCD	17
Empower families in how to handle situations related to illness/to remain positive	15
Educate parent about SCD management	11
Reduce the number of sickle cell births	9
Correct/defeat misconceptions about disease	7
Provide information about resources, including where trait testing is available	7
Provide health promotion strategies	6
Reduce stigmatization	5
Linking families to other patients and families who are doing well	3

[a]Participants were allotted five votes each and could distribute the votes however they saw fit, i.e. they did not have to have just one vote per topic

Table 6

Focus Group Participant Recommendations for Sickle Cell Counselor Training Curriculum in Ghana

Counselor Knowledge
SCD clinical complications, genetics/inheritance, pathophysiology, life expectancy
Evidence-based treatments, health promotion, research updates
SCD/SCT – screening and testing
Common misconceptions about sickle cell trait and sickle cell disease
Psychosocial aspects of sickle cell disease
Impact on family relationships
Importance of fostering positive coping in family and affected individual
Health beliefs and impact on coping
Potential stressors, including financial
Counselor skills
Educate family on risk for future affected birth
Support family in informed reproductive decision-making
Assess and address common misconceptions
Evaluate family coping, including spirituality, self-advocacy, stress management
Educate family on positive coping and strategies for fostering positive coping in affected children
Evaluate family's beliefs about causes and treatments for SCD, including supernatural mechanisms and traditional healing
Evaluate potential for stigma, beliefs about curse/punishment
Provide emotional support/empathy/encouragement
Provide families with community resources, including where to obtain trait testing
Working with challenging counseling scenarios – language barriers; family uninformed about counseling or reluctant to participate in counseling; counselor younger or lower status than counselee
Other Counseling Topics
Establishing the counseling setting – ensuring confidentiality, accessibility
Counselor characteristics – friendly, approachable, nonjudgmental, empathetic, avoids imposing cultural and religious beliefs
Provision of Community Education
Address misconceptions and beliefs about witchcraft head-on
Use succinct messages such as: Anyone can get it; It is not a new disease; A child's death can be prevented.
Highlight importance of community and family support for those affected
Provide assurances of affordable, accessible and confidential counseling