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Permalink

<https://escholarship.org/uc/item/1z60d825>

Journal

Journal of Genetic Counseling, 28(1)

ISSN

1059-7700

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Publication Date

2019-02-01

DOI

10.1007/s10897-018-0296-7

Peer reviewed



HHS Public Access

Author manuscript

J Genet Couns. Author manuscript; available in PMC 2020 March 01.

Relation between religious perspectives and views on sickle cell disease research and associated public health interventions in Ghana

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Authorship Contributions

Dr. Dennis-Antwi made substantial contributions to the conception of the work; the acquisition, analysis, and interpretation of data for the work; and drafting and revising the work critically for important intellectual content. Drs. Treadwell and Anie made substantial contributions to the conception, design, analysis and interpretation of data for the work, and drafting and revising the work critically for important intellectual content. Drs. Ohene-Frempong and Wonkam made substantial contributions to the conception and design of the work, and to revising the work critically for important intellectual content. Ms. Dzikunu, Agyare, Asafo, Anim-Boamah and Mr. Okyere Boadu, JSarfo Antwi and Agyei made substantial contributions to the acquisition of the data for the work and revising of the work critically for important intellectual content. Mr. Asubonteng made substantial contributions to the analysis of the data and revising of the work critically for important intellectual content. All authors gave final approval of the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflict of Interest

Authors Dennis-Antwi, Ohene-Frempong, Anie, Dzikunu, Agyare, Okyere Boadu, Sarfo Antwi, Asafo, Anim-Boamah, Asubonteng, Agyei, Wonkam and Treadwell declare that they do not have conflicts of interest.

Human Studies and Informed Consent

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 2013 (World Medical Association, 2013). Informed consent was obtained from all participants for being included in the study.

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Abstract

Sickle cell disease (SCD) is highly prevalent in Africa with a significant public health burden for under-resourced countries. We employed qualitative research methods to understand the ethical, legal, and social implications of conducting genomic research in SCD under the Human Heredity and Health in Africa (H3Africa) initiative. The present study focused on religious and cultural aspects of SCD with the view to identifying beliefs and attitudes relevant to public health interventions in Ghana. Thematic analyses from individual and group interviews revealed six key areas of importance, namely: Reliance on a Supreme Being; Religion as a Disruptive Influence on Health Behaviors; Role of Religious Leaders in Information Sharing and Decision-Making; Social, Religious and Customary Norms; Health and Religious/Supernatural Beliefs; and Need for Social Education and Support through Church and Community. Findings suggest that public health programs in Ghana should not only aim at increasing knowledge and awareness about SCD and its management but also create an understanding of the relevance of genomics and alternative technological advancement to diagnosis and ethical decision making around available options for health seeking. Future research should engage communities to help address the ethical and social implications of a persuasive religious influence on SCD related health decisions.

Keywords

sickle cell disease; religion; spirituality; genetic counselling; genetic testing; prenatal diagnosis

Introduction

Sickle cell disease (SCD) is a serious condition caused by a single gene mutation that affects the hemoglobin (Makani, Ofori-Acquah, Nnodu, Wonkam, & Ohene-Frempong, 2013). SCD is highly prevalent in sub-Saharan Africa where approximately 300,000 babies are born annually with the disease (Weatherall, 2011). SCD has devastating consequences in relation to infant mortality; morbidity including stroke, kidney damage and pulmonary hypertension; and diminished quality of life (Grosse et al., 2011; Makani et al., 2011; Makani et al., 2013). Public health interventions with demonstrated value in high resource settings, such as newborn screening, are beginning to be introduced in low and middle- income countries in Africa (Wonkam, Ngo Bitoungui, & Ngogang, 2015). The high burden of SCD in sub-Saharan Africa provides a compelling reason for advancing genomics research, research that holds the promise for discoveries and new technologies that will inform personalized therapeutics and development of novel biological targets for intervention. The Human Heredity and Health in Africa (H3Africa) initiative has the specific mission to advance the study of genomics and environmental determinants of common diseases in order to address health disparities and improve health for populations in Africa (Rotimi et al., 2014). Effective utilization of resources requires an understanding of unique aspects of settings in Africa that could facilitate or pose challenges to the uptake of research and public health interventions for SCD.

Since 1995, newborns in Kumasi and Tikrom in the Ashanti region of Ghana have been screened for SCD through an international demonstration project originated by one of the authors (KO-F). This project has been conducted in collaboration with the Ministry of Health and the Ghana Health Service, and screened 479,837 babies from February 1995 to October 2016 with 8,155 (2%) testing positive for SCD (K Ohene-Frempong & M Lamptey, personal communication, 2017). Although SCD affects about 2% of all newborns annually in Ghana (~18,000 births), it is not considered of critical public health importance (J. A. Dennis-Antwi, Culley, Hiles, & Dyson, 2011; Ross et al., 2011; M. J. Treadwell, Anie, Grant, Ofori-Acquah, & Ohene-Frempong, 2015). Support services for SCD are limited in access and scope with a few SCD Associations existing nationwide to provide social and psychological support to patients and families. Genetic counseling in relation to sickle cell trait and SCD is not well integrated into the health system in Ghana. Genetic counseling is provided by nurses, midwives and physicians as opportunistic interactions that arise when a couple planning marriage seeks consultation, in order to understand the meaning of their sickle cell status upon voluntary screening. Nurses, midwives or physicians may provide genetic counseling to parents when an infant is diagnosed with SCD on newborn screening. Within Christian faith-based organizations, internal policies are often in place that compel would-be-couples to receive marital counseling and testing for their sickle cell status (Anie et al., 2016). These lay counselors or religious leaders who generally do not have training in genetic counseling then provide counseling. Ghana does not have an established profession of Master's degree trained genetic counselors at this time.

Empirical data on perceptions about genomics research, and the utility and potential impact of SCD-related public health strategies in Africa is emerging (Anie et al., 2016; J. A. Dennis-Antwi et al., 2011; Marsh, Kamuya, & Molyneux, 2011; M. J. Treadwell et al., 2015). However, a number of practical and ethical challenges to the implementation of this research and these interventions remain. In Africa, as in other modernizing traditional societies, public perceptions and cultural factors are particularly relevant to genomic research and uptake of public health interventions because of beliefs, traditional practices, and religious values.

Religion may be defined as the set of attitudes and beliefs that fulfill specific functions or roles in people's lives such as providing frameworks of meaning and resources for coping. Religion also reflects a peoples' belief in a god or gods and includes spiritual explanations of human place in the world, worship of deities and supernatural or spiritual entities (Pargament, Koenig, & Perez, 2000). Religious beliefs can empower people by association with a community and a 'supreme being' that may in turn offer psychological stability (Oman & Thoresen, 2003). For populations with SCD, prayer, high church attendance and reliance on spirituality to cope with the physiological and psychological effects of the illness have been found to be common (Bediako et al., 2011; Clayton-Jones & Haglund, 2016; Cotton et al., 2009).

Religion appears to be important within African cultures, and the effects of religious practices on health outcomes are important. Ghanaians are a religious people, largely identified as Christian (74.9%). Over 15% of the population is Muslim and about 5% practice traditional religions (Pew Research Center, 2017). At the same time, it is reported

that people combine beliefs and practices of traditional religions with the tenets of Christianity and Islam, i.e., syncretism (Kasomo, 2012). Studies have demonstrated significant relationships between religious beliefs and healthcare in Ghana. Gyimah and colleagues found that religious beliefs, teachings, doctrines, and church regulations could negatively influence healthcare utilization such as by impeding follow-up with antenatal care visits by pregnant mothers (Gyimah, Takyi, & Addai, 2006). Other studies revealed that among “charismatic” church congregations (Gifford, 2004), beliefs that some illnesses or diseases could only be cured by a prophetess led to rejection of modern health services (Sackey, 1999). The disruptive effects of religious practices on reproductive behaviors, family planning (e.g., spouses preventing women from accessing family planning services) and other health promoting behaviors such as childhood immunizations have been documented in Ghana (Addai, 1999).

Despite its importance, there have been only a few reports of community perspectives about SCD within the context of religion in Africa, including Ghana. One recent study concluded that in addition to medical treatment, patients with SCD in Ghana attended church to seek help from a ‘supernatural being’ when they had severe sickle cell pain episodes, and a significant number relied on their personal faith in God to cope with an “unbearable SCD condition” (Adzika, Glozah, Ayim-Aboagye, & Ahorlu, 2017). Research in Nigeria showed that religious beliefs played a positive role in coping with the psychosocial burden of the disease and limitations to social functioning, including prayer, faith in God and doctors, and an optimistic approach to health problems (Ohaeri, Shokunbi, Akinlade, & Dare, 1995; Uwakwe, Kofie, & Shokunbi, 2001). Another study reported that people with SCD living in Nigeria employed prayer more often as a means of coping, compared with individuals with SCD in the United Kingdom, owing to their faith in God, but also because of superstition and stigma associated with the disease (Anie, Dasgupta, Ezenduka, Anarado, & Emodi, 2007).

When confronted with hereditary implications of a disease such as in SCD, individuals in Ghana may seek guidance from their orthodox, unorthodox, and/or traditional religious leaders. While religious leaders are held in tremendously high regard, the advice given by them may not be consistent with the goals of genetic counseling that are to “increase understanding of genetic disease, discuss disease management options, and explain the risks and benefits of (genetic) testing” (Genetic Alliance 2017). Genetic counseling focuses on giving fundamental, balanced information and non-directive assistance in the decision-making process (LeRoy, 2006; Stern, 2012). In contrast, couples-at-risk for having children with SCD can be prevented from marriage by Christian churches in Ghana (Anie et al., 2016; J. Dennis-Antwi, Dyson, & Ohene-Frempong, 2008; M. J. Treadwell et al., 2015). Further, traditionalist religions and cultural practices, based on supernatural beliefs, can stigmatize individuals with SCD. They may be denounced as witches or as being cursed and of being the source of family hardships and poverty (J. A. Dennis-Antwi et al., 2011; Nzewi, 2001). Treatment of the disease may then include rituals designed to relieve the individual and family of the curse (Abad et al., 2014).

We conducted an ethical, legal and social implications (ELSI) research pilot project within the H3Africa consortium that 1) explored perspectives and attitudes regarding genomic

research and its implementation and implications in Cameroon, Ghana and Tanzania; and 2) assessed perceptions about public health interventions aimed at increasing awareness, early detection and prevention of SCD related complications (M. Treadwell et al., 2017). The goal of the current project, drawn from the larger study, was to use qualitative research methods to identify perceptions and attitudes of stakeholders in Ghana about 1) the appropriateness of biological specimens that might be used in SCD related genomic research and 2) SCD public health interventions that would appropriately be accompanied by genetic counseling. We viewed these perceptions and attitudes specifically in relation to religious beliefs in Ghana, and from the perspectives of individuals/families directly affected by SCD, religious leaders, marriage counselors, health care providers and other community stakeholders. Our research questions were: What is the relation between religious perspectives and views of one aspect of SCD-related genomic research, the use of biological specimens? What is the relation between religious perspectives and SCD public health interventions that may best be accompanied by genetic counseling in Ghana? Our research aims to inform policies and practices in relation to some aspects of genomic research and SCD public health interventions, within the context of religious institutions that are so central to everyday life.

Methods

Institutional Review Board (Ethics Committee) approval for the study was obtained in April of 2015 through the Committee on Human Research, Publications and Ethics, Kwame Nkrumah University of Science and Technology, School of Medical Sciences & Komfo Anokye Teaching Hospital. Informed consent was obtained from all participants included in the study. Details of the study's methodology have been published elsewhere (M. Treadwell et al., 2017) so will be reviewed only briefly.

We used qualitative methods in a cross sectional research design, conducting semistructured interviews to gain in-depth understanding of cultural influences on thoughts and views about genomic research and perceptions about public health interventions for SCD in Cameroon, Ghana and Tanzania. Participants were men and women, 18 years of age and older, from urban and rural areas in the participating countries. We used purposive sampling of individuals and families affected by SCD, health professionals and community opinion leaders including traditional leaders, marriage counselors, and religious leaders. Our goal was to ensure that participants were knowledgeable informants (Matthie, Hamilton, Wells, & Jenerette, 2015; Matua & Wal, 2015) and reflected a range of characteristics of individuals potentially impacted by genomic research and public health interventions (Tuckett, 2004). This publication is focused only on the Ghana arm of the larger study.

Procedure

Trained researchers in Ghana conducted semi-structured interviews using vignettes featuring a fictitious couple, Mr. and Mrs. Nti. The researchers used the vignettes and standardized probes to guide discussion, asking participants to weigh in as to how comfortable Mr. and Mrs. Nti would feel with participating in research that would require a sample of blood from their baby with SCD. Specific questions asked about the acceptability of blood versus other specimens including hair and saliva. Participants were also asked their views on the

acceptability of public health interventions for SCD that Mr. and Mrs. Nti might be offered, including premarital testing, genetic counseling, prenatal diagnosis and newborn screening. Finally, participants were asked to generate ideas about strategies that might be effective in informing the general public about SCD related genomics research and public health interventions. The interview guide is available from the correspondence author (MJT).

All interviews were conducted between April and December 2015. Group interviews took between 90–120 minutes to complete, while individual interviews took about 60 minutes to complete. Participants were assured confidentiality, as much as possible, by referring to individuals interviewed in groups with identification numbers rather than their names. All interviews were digitally recorded and transcribed verbatim. Standardized interview guides were translated into Twi to allow data collection to be conducted in English or Twi, as needed.

Data analyses

Digital recordings from individual and group interviews were cleaned of identifying information and transcriptions were translated into English as needed. Transcriptions were reviewed for accuracy then imported into NVivo 11 qualitative data management program (www.qsrinternational.com). Responses that specifically evoked themes related to religion and spirituality were extracted from the transcripts and coded for the present analysis. We began with text searches for words including faith, prayer, God, minister, pastor, spiritual, church and religion. Passages that contained these words were coded initially by two authors (JDA and MJT) who settled any discrepancies in assigning themes by consensus. The remaining transcripts were coded by an additional team member (AKA) and themes were further discussed with KA to refine the final coding scheme.

We used thematic analysis (Braun & Clarke, 2012) to identify patterns of meaning across the dataset, both within-case and between-cases as we read through the transcripts. Analysis involved search for understanding of similarities and differences among stakeholders with regard to views of religion and spirituality as related to SCD. These views were further classified and summarized. In addition to the text searches, sections of every transcript that emerged as sensitive to religious themes were reviewed: responses to questions about use of body tissues (blood, saliva, hair) for research and the sections on genetic counseling, newborn screening, premarital screening, prenatal diagnosis and follow-up and recommendations on public education about sickle cell trait.

Results

Participants were 149 individuals: 34 were interviewed individually, 115 in focus groups. Demographics of participants can be found in Table 1. Individuals with SCD, their family members, and health care providers (primarily nurses and midwives) who participated in focus groups were primarily female (74.8%) while key informants were primarily male (76.5%). Key informants were also older than focus group participants at 51.8 years compared with 35.1 years. Participants were primarily from urban settings (69.1%), from the Akan ethnic group (90%), and with Twi as their primary language (89.3%). Individuals with

SCD and family members were less likely to be married compared with key informants (55% versus 21.3% not married). Health care providers and key informants were more likely to have completed tertiary education (90%) compared with individuals with SCD and family members (20%). The predominant occupation of individuals with SCD/family members was small-scale business (38%) while key informants were predominantly educators, health professionals, and community and religious opinion leaders (41%).

We identified 6 overarching themes in the data:

1. ‘With God All Things are Possible’: Reliance on a Supreme Being
2. ‘Testing will not help - Let’s just pray’: Religion as a Disruptive Influence on Health Behaviors
3. ‘Should I consult my Pastor, Counsellor or Doctor?’: Role of Religious Leaders in Information Sharing and Decision-Making
4. ‘We don’t encourage them to marry’: Social, Religious and Customary Norms
5. ‘No blood, no hair’: Health and Religious/Supernatural Beliefs
6. ‘Let the people know it is not a curse’: Need for Social Education and Support through Church and Community

We describe key findings, including sub-themes, under each thematic area below.

‘With God All Things Are Possible’: Reliance on a Supreme Being

Across all stakeholder groups, the most frequent reference to religion was in relation to the importance of faith and reliance on prayer for coping with SCD and decision-making around potential interventions. These references came up most frequently around issues of pre-marital screening for sickle cell trait and prenatal diagnosis that might lead to the decision to terminate an affected pregnancy.

I believe that with God all things are possible and I believe that no matter how bad it is, God is still faithful so they have to take it. Sometimes God is trying your faith and you should be strong and go through it and he will also show his goodness to you. (Urban Healthcare Provider, Group 1)

Strong faith often translated to the idea that a miracle could occur, as stated by a rural marriage counselor - “The disease tormented me until I was 35 years when someone prayed for me. Since then I was healed forever.” An urban religious leader echoed that longevity in SCD should be considered a miracle:

I know there are people who can survive and actually grow to maturity and so why not encourage them to work hard and ensure that they have a child that grows....they should be able to have faith in God for the things that are impossible with God are possible. (Urban Religious Leader, Key Informant)

Faith was regarded as sustaining, not only of the life of the child with SCD, but in the knowledge that God will take care of the child and of the family:

My thought is you shall not kill...there are godly interventions that God can sustain the person to live long like any other human being. Apart from having the thought that the child will be ill you must have a second thought that God is a working miracle God and may take care of you. – (Urban Religious Leader, Key Informant)

Reliance on a supreme being was aligned with belief in a God-controlled destiny that cannot be altered, as stated by an urban teacher "...you can be AA and die young so it is in the hands of God." There were cautionary elements in this theme of relying on faith, as couples were warned against moving ahead with a marriage without premarital screening if their faith was not strong enough. An additional cautionary element urged using wisdom in approaching healthcare and public health interventions, even when relying on God to perform a miracle:

Even though God can work miracles he also expects us to use wisdom. The love factor can prevent people from coming and superstition and other things you know are factors that can hinder people from taking the (trait) test. (Rural Healthcare Provider, Group 2)

'Testing will not Help - Let's just Pray': Religion as a Disruptive Influence

At its extreme, reliance on faith and on the powerful Creator, could lead to lack of self-knowledge and informed healthcare decision-making:

There are some Christians who do not want to find out even things about themselves. They believe that nature takes care of everything about them and when they refer to nature they are referring to their creator. They will only depend on God and they would not want to do any test. (Urban Religious Leader, Key Informant)

Health care providers, religious leaders and marriage counselors commented more often than individuals with SCD and family members on the potential for inaction in relation to health behaviors, or lack of acceptance of some medical interventions when faith was strong. They noted that couples would conclude, "*(prenatal) testing will not help*" and "*(we can only) pray that God delivers them safely.*" A few individuals with SCD and their family members added the sentiment that faith is important in knowing that one can bear any trial presented by God:

I think most couples wouldn't like to know, even if they want to know, what will they do? They can't do anything about it and most of them wouldn't want to abort it... maybe by faith it will change so people may have that faith. Some will even say that God knows that I can take care of the child that is why he has given him or her to me. (Group member, Urban Individuals with SCD/Families)

Finally, informants commented on an underlying cause of SCD as lack of faith for Christians or the manifestation of superstitions among those of traditional religions. Such constructions were seen as contributing to inaction in relation to health, as stated in a rural healthcare provider focus group: "*What will prevent the community members from not accepting the*

education may be their religious background and superstition because they associate each condition to (something) spiritual.”

‘Should I consult my Pastor, Counsellor or Doctor?’: Role of Religious Leaders in Information Sharing and Decision-Making

The stakeholder groups were unanimous in their endorsement of the importance of newborn screening, of parents’ autonomy in making decisions about newborn screening apart from their religious leaders/institutions and about parents directly receiving newborn screening results. The driving factor in this universal acceptance of newborn screening was the wellbeing and immediate health of the child.

If they are informed that there is the need for the test, otherwise the child will die, they will surely do it. Assure them the result will be delivered to them soon and a promise that they will be supported to treat the child. (Rural Religious Leader, Key Informant)

I think it is good to seek different opinions ... but if the baby is your only child I do not think it will be an easy thing discussing with your pastor and I therefore think the parents should decide alone. (Rural Focus Group, Healthcare Providers)

Views about the role of religious leaders in advising about other public health interventions for SCD, return of clinical results and consultation in decision making about such results diverged among the stakeholders. Individuals with SCD or their family members, and marriage counselors were more likely than other stakeholders to favor consultation with their religious leaders when deciding about the uptake of public health interventions other than newborn screening.

By contrast, religious leaders themselves stated that couples should be autonomous in most decision-making about health interventions, while health care providers endorsed this perspective most strongly. When stakeholder groups expressed that there was a need for consultation in decision-making, they recommended a range of advisors, including health care providers and extended family, as a rural traditional leader key informant stated “The church priest or counselor should help AS/AS couples decide what to do about their results. The priest or counselor and the doctors (should receive the results). All of these can help.” An urban religious leader key informant advised that genetic counselors should “ask the couple to go and ponder over the issue at stake.” Knowledge about SCD was an important factor in deciding whom to consult, with religious leaders singled out as sometimes lacking sufficient knowledge about SCD and the interventions asked about in the study:

If we give the results to the doctor, who have more knowledge on the sickle cell he can counsel them before they leave the facility so that they have some knowledge before going to the pastor. (Rural Focus Group, Individuals with SCD/Families)

Religious leaders were also cited as not objective in counseling individuals and couples, if an intervention is clearly in contravention to their doctrines, e.g., termination of an affected pregnancy. Autonomy of the individual/couple was strongly endorsed, in that case: “Why should you tell them (religious leader)? ... you must decide on your own. It’s a decision you

have to make on your own you don't have to consult anyone." (Urban Healthcare Providers, Focus Group) and:

The couple should take that decision. For instance, I am a Catholic and Catholics are against abortion but I have a different perception about it. If the pregnancy is going to disturb you then you do away with it. If you go to the priest he will tell you no, leave it there. (Urban Civil Servant, Key Informant)

The fact that it will be the couple/family who has to care for an affected child was frequently cited as the reason decisions should be left up to them, as a group of urban healthcare providers noted "When problems come (i.e., a child with SCD is born) none of the pastors will come to solve the problem," as well as key informants:

Oh I think the issue confronting the parents is difficult and sad, so it's not everybody that should get to know of this. The two parents will have to decide, bearing in mind that they have to help the child so as to become important person in future. Nobody knows the future of the child. There are some religious groups that forbid blood transfusion. If you belong to such group what kind of good advice do you anticipate from the members and the minister? The parents should decide on their own. (Rural Religious Leader)

The case against consulting with religious leaders and providing them with results from premarital sickle cell trait testing could even be more strongly stated, usually by healthcare providers:

... if the couple decided to do the test and came themselves for the test to be done, they are entitled to their results but you see in the case where the counselor asks them to come and do and even like I was saying the counselor gives a letter to the couple to give to you... in that case the best thing is to give it to the counselor who requested the test because he/she may be experienced in dealing with such matters but not withstanding we have some of these modern day quacks who call themselves pastors. They've never been to school because he is a pastor and people are passing through his hands they ask people to go and do a test he cannot even interpret the test. He cannot even understand the test he is requesting. (Rural Focus Group)

Some healthcare providers stressed the importance of considering the results of premarital screening away from the religious setting, to truly inform decision-making:

(The minister should not receive the results) I think it should be a doctor or a counselor. Some churches request for their members to take (the test) but if you don't have a counselor then you have a problem. (They) need to be counseled before the test. We shouldn't just ask them to go and take it and when it comes then you are now going to counsel them. They have to prepare their mind before. (Urban Healthcare Provider, Key Informant)

A rural traditional leader echoed the sentiment that decisions about healthcare should be made in only in the healthcare setting, "The pastor ... does not come in here at all, the doctor is the only person (the couple) should consult" in discussion of prenatal testing and the possibility of termination.

In addition to stressing the importance of knowledge about SCD when providing counseling, the importance of appropriate counseling techniques, including assurance of confidentiality, and accuracy of results was touched upon.

If we give them good counseling in relation to the test, they will do it. We should also give them accurate results. For example if today the test is positive and tomorrow it becomes negative then it will discourage them. If we are not sure we confirm and then counsel them well. I think the technical staff should handle it, not pastors, catechists etc. (Urban Healthcare Provider, Key Informant)

We have clinical counselors - before you do the test you're counseled, so you will have the courage to get the test. If you prefer minister too it's better. Ministers have (an) oath of allegiance and oath of secrecy, so until thy kingdom comes no one will hear it. Even my wife shouldn't know it. So people confide in us ... seriously! (Urban Religious Leader, Key Informant in discussion of return of results and counseling following sickle cell trait screening)

Seemingly in contrast to the idea of the individual's autonomy in decision-making, religious leaders were most likely, of all of the stakeholder groups, to suggest that the actual results of testing should come to them first, although a few religious leaders favored the individuals/ couples being the direct recipients of their results:

Eeh when it comes to the church, it's the minister who handles (for the) couple. If the minister asked for the test, then automatically the minister should have the result for review and to know the outcome. Then he will present to the couple what the outcome is. So whoever is requesting for the test should get the results. For example, I am a minister and if a couple wants to marry, then I will request that they go for test. This is secret and confidential. No one is supposed to know the result. The minister should hand over the results. That of the man goes to him while the woman also gets her own separately. Apart from the couple, no one should get it. (Rural Marriage Counselor, Key Informant)

Yes, couples should be required to take this test so that they do away with this problem in future, so they don't go for children who have sickle cell disease. If they do the test, they should know the result. After all it's meant to help them get the information so that they can take decision. If you do and somebody else gets the result, it's not good, so they should get it direct. (Urban Religious Leader, Key Informant)

A number of individuals with SCD/family members expressed a discrepant sub-theme to statements cited earlier about the importance of consulting with religious leaders about test results. In the case of premarital screening, they were the most likely of respondent groups to actually say that people might circumvent their religious leaders if tests results were "unfavorable," or more directly "Pastors need to see the results because the couple can destroy the result." (Rural Focus Group)

Alternatively, if couples' results showed that both carried a sickle cell trait, the couple might not return to the religious leader for further counseling, nor to the church to be married:

I know from experience from the churches, the pastor and the counselors who encourage and advise the couple to go for the test. They bring the couple to me then I do the test on the patient. They ask me is it positive or negative? (I say) your minister requested for it so see him. Because sometimes if they know the results they will go and marry without going back to the pastor then the pastor will not know. (Rural Healthcare Providers, Focus Group)

If the results are given to the couples only, and they are the type who won't pay heed to any advice - deeply involved in love - they will tear the result into pieces and move on with the relationship. So copies should be given to the parents or the minister who is leading the marriage. (Rural Marriage Counselor, Key Informant)

Religious leaders and health care providers noted, in fact, that individuals/couples had been known to alter results so that they could proceed to have their marriage approved: "The woman is (already) pregnant, but they want to get married. By the time the test results get to the church it has been....already tampered upon so it can be given to the pastor." (Urban Healthcare Providers, Focus Group)

Of note, the concept of prevention of the birth of a child with SCD for an AS/AS couple was almost exclusively not to marry, versus some other form of reproductive planning. An urban religious leader provided this representative statement - "People should be aware from the beginning before they become couples. It's in their own interest not to come together if such union will produce such a problem." Some religious leaders suggested that extended family members should also be the recipients of results from premarital screening tests, consistent with Ghanaian traditions. This, and other social conventions are discussed in the next section.

'We don't encourage them to marry': Social, religious and customary norms

Religious communities in Ghana have norms around marriages that are often implemented by church based marriage committees assigned to counsel the would-be-couple in preparation for the ceremony and for life as a married couple. Marriage committees are therefore mandatory recipients of sickle cell trait screening results, as per urban individuals with SCD/families in one group: "Since the test results will be discussed with the marriage committee of the church, I think a member of the committee should go with the couple to take the results and given to them in the presence of all three of them." A rural marriage counselor key informant also described the role of the marriage committee with regard to sickle cell trait screening results, noting that "counseling" means that couples who both have sickle cell trait are encouraged not to marry:

In our case - I'm using my church as an example - we are the ones that make the request from the couple to go for the test. They're instructed not to open the sealed result but rather submit them to the marriage committee. We then review the result and if there is no problem we allow them to proceed with their marriage. But if we identify any problem, then we offer counseling to the couple. (Rural Marriage Counselor, Key Informant)

This informant went on to describe how religious and medical institutions work together, with the health care provider actually doing the testing and returning the results to the minister.

Families/individuals with SCD, health care providers, religious leaders and marriage counselors were consistent in describing the social norm that individuals who both have sickle cell S trait (AS) should be discouraged to proceed to marry in Ghanaian society:

Eeh ... I don't encourage them to marry because of impending problems, since we already (know) there is problem. The bible tells us to run when we see things we don't appreciate. Once you've seen a danger I think it's better to run from it. Marriage is a lifelong process, so if you fail to do this test to know your status and how to handle it. You'll not enjoy your marriage, not enjoying your child's upbringing and care and all other things will get out of hand. But if you did the test and after realizing you're both AS, and they agree to separate so that we go for a partner who are not AS. To be happy in life, that will help. (Urban Religious Leader, Key Informant)

In the midst of these discussions about the social and religious norms discouraging AS/AS marriages, there was also the essence of the limitation of the power and influence of the leaders over the two who may be deeply in love. However, there was the expectation that if the counsel of the opinion leaders were not accepted, then the two people will have to bear the consequences of their actions in the future.

....(laughing) heart desires and love. Apart from love what else? They are deeply in love and are damming the consequences. If they decide to continue despite the education, what can you do? We have to allow them because that is their choice. They will have to live with their decision and pray that they don't have a child with the traits. (Urban Civil Servant, Key informant)

A related social and religious norm mentioned by participants was the high value placed on children in Ghanaian society. Couples that married despite both having AS status, thereby risking that the child would have SCD could be seen as “specifically against God.” Some religious leaders estimated incorrectly that all children of an AS/AS couple would always be affected with SCD.

Termination of an affected pregnancy was consistently viewed as not an option among all stakeholder groups, with the most common reason cited that “abortion is a sin.”

In Ghana our three main religions will not support termination. If the doctor encourages termination then it's up to him, unless the woman's health is at risk. Even the doctor, unless a wicked doctor, will not support abortion. (Rural Marriage Counselor, Key Informant)

A rural religious leader specifically noted that couples with an affected pregnancy diagnosed using prenatal diagnosis should consult with “the pastor or health person whose ethics is to save life” so that the couple would not even consider termination.

Respondents consistently discussed the birth of a child with SCD as part of God's plan for the family, and even society. As often, respondents noted that "SCD can be managed," therefore, in the absence of inevitable suffering and early death, there was no need to terminate, as illustrated by this quote from a rural group of individuals with SCD and families: "I don't think they should end the life of the baby because we have seen some people who are SS but they are alive and working and grownups so they should leave that one to God."

One urban religious leader commented on the benefits to society of premarital screening, prenatal diagnosis and the view that termination of an affected pregnancy should not be an option in Ghana.

Yes, Ghana is developing ... now we are saying we're developing the economy and so we need healthy people to develop the country. So when we are pregnant we need to take good care of the pregnancy so that children that are born are in good health to give us our peace. Financially the children should be able to grow and work to make money. This will help us to plan for them medically. (Urban Religious Leader, Key Informant)

Occasionally, stakeholders except for individuals with SCD and family members brought up the idea that termination was not always the inevitable consequence of prenatal diagnosis. Rural healthcare providers in one focus group commented on the potential knowledge that could be gained from prenatal diagnosis:

Participant 6: *I have been thinking of the essence of the prenatal diagnosis, is it to help mothers know the status of their babies or to terminate babies who test positive to SCD. I do not see why the pregnancy should be terminated because I know a SCD patient who has lived to even marry to have three children and is still living very well* Participant 8: *I agree with number 6, none of us is God to know the destiny of the child. The pregnancy should not be terminated.*

Another rural marriage counselor key informant added:

Because God has given the doctors knowledge to do their work, if the doctor confirms for abortion then no problem. But if the doctors do not confirm that, if it's just sickle cell disease you have to deliver the child. If he lives for 1 year or 10 years, allow him to live until his time is up. But if you want to push him out, ahaa, before God you're a murderer.

A limited number of respondents within each stakeholder group did say that termination could be acceptable, given how much an affected child and family might suffer, as stated by a participant in an urban focus group of individuals with SCD and families: "They should terminate the pregnancy. It will give them a lot of problems. It will even cause, how do you call it, divorce....so the better way is to terminate."

A participant in an urban focus group of individuals with SCD and families cited an alternative interpretation of the bible to actually support the idea of terminating an affected pregnancy:

I will really agree to terminate the pregnancy so that we end the problems associated with it. It is not a matter of being a Christian, the Bible says if your one arm is making you sin, cut it off.

‘No blood, no hair’: Health and religious/supernatural beliefs

Although our discussion guide specifically asked about body samples for research, all stakeholder groups responded to the question by naming specific organized religions that did not allow blood transfusions. Respondents cited “religious beliefs” as sometimes being the reason that families might not find donating blood samples for research acceptable “Some groups of people (Jehovahs) may prefer other tissues (saliva, hair) being used rather than blood because of some religious beliefs.” (Rural Healthcare Providers Focus Group). Superstitions about blood in particular, but hair as well, were cited often as potential barriers to giving samples for genomic research, including the possibility that these materials might be used for rituals: “People think that their blood is sacred and then if somebody takes their blood it can be used for any other thing so people are very hesitant when it comes to blood” (Urban Health Care Providers Focus Group) and

African(s) believe the use of human blood for performing spiritual things or rituals. So the couple may fear that their baby’s blood may be used for rituals than for the purpose of the research... Using human hair is also scary - people use hair for rituals. (Rural Marriage Counselor, Key Informant)

From a religious standpoint, participants felt that saliva might provide acceptable samples for research, as a rural educator noted “Saliva and hair... people will feel okay, especially for Jehovah witness.” However, unfamiliarity with providing samples other than blood were noted as potential barriers to research and some, including a rural civil servant wondered if saliva would actually be an adequate sample given that SCD is a blood disease - “The sickle cell trait is in the blood so the blood should be used for the study because I don’t think saliva will help in any way, it is only requested from people who cough but this is in the blood so the blood sample should be used.”

Religious leaders and individuals with SCD/families also noted that some religious beliefs would preclude certain families and individuals in Ghana from any research participation.

Yes perhaps there are many but if we talk of religion, religion plays some roles in taking decisions about some of these things. One’s beliefs often have some effect on the person’s decisions to take part in such things or such programs. So that is why I also have a feeling that if we want to address issues concerning genetic type of education and research it will be very good to make the religious leaders aware and perhaps let them talk to their people about what is taking place whether it is a research or medication for them to readily accept it because there are many people who do not talk about things connected with blood and other things and because of what they believe in they may not even listen to you. (Urban Religious Leader, Key Informant)

Supernatural beliefs, including perceptions that individuals with SCD were bewitched or witches, might also influence willingness to participate in genomic research.

(Participation in SCD research may be affected by) our cultural beliefs that such people are bewitched ... because they think that they're (sickle cell patients) even witches themselves, so we don't have anything do with them. (Urban Healthcare Provider, Key Informant)

Nevertheless, stakeholders for the most part expressed that the community would participate in research and would trust healthcare providers and researchers to use samples with proper informed consent, i.e., with assurances that the samples would be used only for the purposes for which consent had been given.

Blood means a lot and people who request for blood sometimes have other reasons why they request for the blood and so there are many people who will not feel comfortable giving out their blood for any test. But we have a medical researcher or a doctor or anything of that sort or anything that is recognized people should feel comfortable. When you go to, when you come to the spiritual aspect of things that is why these come up. When we get to the hospital we put these things aside and respond to whatever the man has to say because he is a health personnel you know. We should trust him. (Urban Religious Leader, Key Informant)

In fact, ascribing a spiritual meaning to research, might encourage the faithful to participate:

...in Christianity, someone suffered - Jesus Christ was crucified and all people are benefiting. So maybe the baby's blood that is going to be used for the research will help future generations to benefit from it. So in a way, it's good for the researchers to get the blood of the baby for the research to help find better ways to protect future generation from sickle cell disease. (Rural Marriage Counselor, Key Informant)

'Let the people know it is not a curse': Need for Social Education and Support through Church and Community

When asked "how might we go about educating the community about SCD...?" all stakeholder groups frequently named churches as important vehicles for public education in relation to SCD screening, clinical care and research.

When you teach a primary six something it sticks so you teach everybody who has been to school, every church should try and have a health week or a health day. One day in a month to talk about certain diseases and sickle cell disease should be one. A lot of us go to church and the mosque. That is for the adults but we have to catch the children young. (Urban Health Care Providers, Focus Group)

We have different communities such as school community, church community and many more. So it should be done through the communities. You can visit the church and inform and ask permission from the minister to organize the church members for sensitization and education, that this disease is everywhere and we want to research into it in order to eradicate it. (Rural Marriage Counselor, Key Informant)

In our setting, as you said earlier, the superstitions that we have around make people think that some of those things are curses and other things so once we are able to free the mind of the people on some of these thinking I think is a

breakthrough in the first place. So we should through the churches and the mosque and other areas make the people aware that this thing is not a curse. It is a genetic something or issue that anybody can have it once you have it in the family and then like I said you tell me this is what you have discovered, what is the solution to it. If I can't have treatment what is the essence of even doing it if you are able to identify the problem and provide the necessary solution, I think people will accept it so the fact that people are not seeing the way forward in some of these things that is why they wouldn't accept. (Rural Healthcare Providers, Focus Group)

A related common dialogue among all stakeholder groups was that various categories of community and religious leaders are critically positioned to provide or create opportunities for relevant social education to facilitate decision-making, uptake of services, home management or attitudinal change.

In our society, there is respect for leaders so much....so we think that we should always get the leaders to champion them. So when we say the leaders we mean the church leaders, by the chiefs and other opinion leaders. We are talking about school heads and the rest so in the community, the chief opinion leaders and the religious leaders we should get them to be emphasizing these things and be teaching in their areas. One thing I have come to know about community education is that people in the community accept their people more than the outsider....so if you get the leaders educate them and let them get the understanding and willingness to go ahead to do the education you will achieve far than you alone going. I mean from outside. (Urban Civil Servant, Key Informant)

Religious leaders noted that their respected standing in the community could lend needed weight to community education efforts. Some religious leaders also suggested that religious institutions should partner more closely with the medical community, by locating counseling centers in churches, as did healthcare providers:

Yes, people in the community accept to take the test. There should be advocacy in the churches. Based on instructions of the pastors couples planning for marriage should know their status. There is the need to open a center where people can walk in, have counseling and have a test done for them. (Healthcare Provider Key Informant)

The importance of religion, faith, and being part of a religious community for social support and SCD self-management came up across all stakeholder groups although not as frequently as other themes. Some religious leaders also suggested that their church communities could and should provide financial support for families with a child with SCD. For example, a rural religious leader key informant suggested: “the couple should consult a religious member who is wealthier and has empathy ... and who will be willing to support financially and socially.” An urban religious leader noted:

This illness is one of the illnesses that is very devastating... (People with SCD) are virtually helpless people who are not able to do many, many things on their own. ... government can come in to assist them then the churches too they should also be

able to help such people if they know that some church members are in this type of trouble.

Other approaches to social education were also mentioned by the stakeholders emphasizing the need for youth with SCD to educate their peers at church and community to prevent SCD, teach how to live with SCD and also the use of radio and social media to create awareness.

I think the youth in our various churches should be educated mostly so they know who they can date to prevent giving birth to babies with SCD, they should be told not to follow love but test and know their status for informed decision. (Urban Individuals/Families with SCD, Focus Group)

A key point that most stakeholders agreed upon was that education about SCD must occur early, often and in multiple venues, including churches.

Discussion

To our knowledge, this is the first study eliciting perspectives from a broad range of stakeholders about the relation between religious beliefs and perspectives on SCD and associated research and public health interventions in sub-Saharan Africa. Our research questions were framed specifically in relation to religious perspectives and views of SCD public health interventions in Ghana that may require genetic counseling and one aspect of SCD-related genomic research, the use of biological specimens.

We organized our findings into a model for influences and interactions between religion/spirituality and sickle cell related health behaviors and research participation in Ghana (Figure 1), and have framed our discussion in reference to this model. Central to the model is faith, a resource for coping and empowerment or autonomy that can support informed, active decision-making in relation to participating in health enhancing behaviors such as newborn screening, trait testing and prenatal diagnosis, as well as in research. Faith could also lead to disruption of or inaction in relation to health behaviors when associated with belief in a God controlled destiny and/or a reliance on miracles.

We found that questions of religion could not be considered separately from cultural and societal norms in Ghana. The high value placed on children in Ghana was intertwined with the universal acceptance of newborn screening, a public health intervention that was regarded by all stakeholders as primarily about the wellbeing and immediate health of the child. The value placed on children was also intertwined with the strong prohibition with regard to the termination of a pregnancy affected by SCD by all religions referenced by stakeholders. Opposition to termination of pregnancy for SCD by medical students and doctors has also been reported in Cameroon (Wonkam et al., 2011). Discouraging couples where both carried the sickle cell trait from marriage was a cultural norm implemented through religious bodies. On the one hand, this may represent both an efficient strategy to avoid suffering in potential newborns affected by SCD and their families, and also to avoid the ethical challenges related to the question of prenatal diagnosis and subsequent highly ethically challenging issue of medical abortion. On the other hand, this could be viewed as

societal stigma regarding SCD that is enhanced by religious leaders (J. A. Dennis-Antwi, 2006; J. A. Dennis-Antwi et al., 2011).

Stakeholders reported that couples were likely to resist their religious leaders in particular, by altering trait testing results, failing to return to their church to be married, or failing to obtain trait testing at the outset. Of note, both in the case of prenatal diagnosis and premarital screening, participating stakeholders, including healthcare providers, tended to see only one outcome in relation to each intervention – termination of an affected pregnancy following prenatal diagnosis or proscription of marriage of couples where both have sickle cell trait (AS/AS). Only rarely did a stakeholder comment on the value of prenatal diagnosis as a strategy to prepare a couple for the birth of an affected child or of premarital screening as informing family planning strategies.

Studies evaluating the acceptability of such sickle cell related interventions as newborn screening, prenatal diagnosis and trait testing have only recently been implemented in Ghana (Anie et al., 2016; J. Dennis-Antwi et al., 2008; M. J. Treadwell et al., 2015). In contrast to the strong prohibitions against marriage of AS/AS couples and termination of SCD affected pregnancies in Ghana, adult patients with SCD in Cameroon (Wonkam, de Vries, Royal, Ramesar, & Angwafo, 2014) and parents of children with SCD in Cameroon (Wonkam et al., 2011) indicated in response to a survey that they would find prenatal diagnosis highly acceptable (89% of adults; 90% of parents) and would even consider termination of affected pregnancies (41% of adults; 62.5% of parents). Respondents in Cameroon were largely Christian urban dwellers (95.5% of adults; 93% of parents) as they were in Ghana. In both Cameroon and Ghana, respondents cited the future wellbeing of the child and family as paramount, but appeared to come to different conclusions about the appropriate health behavior to achieve that outcome. These differential views could be a consequence of the differential health systems in the two countries: contrary to Ghana, there is not yet a newborn screening program with subsequent preventative care for SCD in Cameroon, resulting in a high prevalence of severe manifestations of SCD, including stroke, neurocognitive challenges and kidney dysfunction (Geard et al., 2017; Njamshi et al., 2006; Ruffieux et al., 2013).

The high perceived burden on parents and adult patients (Wonkam, Mba, et al., 2014a, 2014b), may thus have shaped views regarding termination of pregnancy for SCD in Cameroon (Wonkam, de Vries, et al., 2014; Wonkam et al., 2011). Further, SCD in Ghana is characterized by a higher proportion of HbSC (30% (K. Ohene-Frempong, Oduro, Tetteh, & Nkrumah, 2008)), that is only present in 1% of the SCD population in Cameroon (Wonkam, de Vries, et al., 2014; Wonkam, Ngo Bitoungui, et al., 2014). SCD-HbSC is generally associated with less severe clinical severity and higher life expectancy. Views expressed by the stakeholders interviewed in Ghana are consistent with an article on ethics and options for the control of SCD in Ghana that emphasizes preconception genetic testing and holistic management of individuals born with SCD (Kyerewaa Edwin, Edwin, & Etwire, 2011). However, Kyerewaa and colleagues support premarital screening and prenatal diagnosis as important to inform reproductive options, in contrast with the stakeholders interviewed in the present study.

We expected that religious leaders in Ghana would play an integral role as mediators in decision-making about SCD public health interventions for couples and families and we found that they played a positive role in supporting coping and couples' autonomy in decision-making (Figure 1). Religious leaders could equally be disruptive influences on health behaviors, particularly when couples might hide or alter screening results. Accurate knowledge about SCD and the interventions being considered seemed to be a key – stakeholders, including religious leaders themselves, noted that healthcare providers were the most appropriate professionals to consult with in decision making, and religious leaders clearly held such incorrect views as all children born of an AS/AS couple would inevitably have SCD.

The strong faith that many of the stakeholders ascribed to could support positive coping and autonomy, aside from trust and confidence in religious leaders. However, strong faith could also lead to inaction when it came to health behaviors, as individuals might decide to “just pray” for a hoped for outcome, rely on a miracle, and accept their God controlled destiny, rather than taking steps to learn more about managing their own and/or their child's health. These findings are consistent with those with other populations that suggest that the strong faith that can come with religion/spirituality can be associated with both positive (improved mental health, sense of wellbeing and quality of life (Puchalski, 2001) and negative (avoidance of health promoting behaviors) (Gyimah et al., 2006) outcomes.

Stakeholders in the present study commented on the potential negative influence of religion and spirituality in relation to health behaviors and SCD, including superstition, supernatural beliefs and stigma. Traditional beliefs that diseases are caused by attacks from evil or bad spirits and that when ancestors are not treated well, they may punish people with disease (White, 2015) were described in the present study as common. These findings are consistent with other research highlighting the importance of supernatural beliefs in conceptualizations of SCD in Ghana (J. A. Dennis-Antwi, 2006). Supernatural and religious beliefs were viewed as affecting decisions about participating in research, primarily in relation to the potential use of biological specimens in studies. Concerns for the use of blood or hair for rituals has been reported by other researchers in Africa (Boahen et al., 2013; Coetzee, Kagee, Tomlinson, Warnich, & Ikediobi, 2012). Interestingly, the scenario posed to focus group participants and key informants specifically asked if parents might have issues with a sample of their baby's blood, already drawn for clinical purposes, being used for research. Respondents in the current study mistakenly cited religions that might oppose the use of blood for research (e.g. Jehovah's Witnesses), even though the religious prohibition is about blood transfusions, not about donating blood. However, stakeholders consistently expressed that if families were approached about research participation by trusted clinicians and researchers who explained the purpose of the study thoroughly and understandably, that families and individuals would likely agree to participate.

Stakeholders in the present study cited churches, schools and traditional gatherings such as durbars as strong entry points for SCD-related public education, health promotion and research. They expressed that public education will go a long way to ameliorating public discourses around SCD as a curse or punishment and allow for conventional medical management of SCD while allowing individuals to practice their faith to cope with the

complications of the disease. Previous researchers have cited the importance of embedding SCD public health and health education interventions within faith based communities (Anie et al., 2016; J. A. Dennis-Antwi et al., 2011; M. J. Treadwell et al., 2015).

Our findings present opportunities for elevating community awareness, knowledge and interest not just about the current discourses around SCD but also the relevance of genomics in early detection and effective SCD management to improve the quality of life of affected individuals and families in Ghana. These findings may also have the potential for generating more interest in prenatal diagnosis and genetic counselling, challenging community perceptions of the irrelevance of these procedures. Finally, knowledge about current technologies can be enhanced as community members become familiar with the use of samples other than blood (saliva, hair) for research.

Practice Implications

The findings from the present study suggest that health programs in Ghana should aim at a strong public campaign for increasing knowledge and awareness about SCD and the options available for care and improved health for those affected. A perceived focus on providing knowledge that supports only one outcome when a pregnancy is affected, termination, is resoundingly rejected by the predominantly Christian Ghanaians who are certain that “God will provide.” Close collaborations between religious institutions and the medical community were strongly supported by participants in the present study. This would include concerted efforts to educate religious leaders and correct common misconceptions about SCD and sickle cell trait, as many leaders are already involved in requiring sickle cell trait screening prior to marriage for their congregants, without an adequate knowledge base for the provision of counseling. With a broader knowledge base, religious leaders might be persuaded to take a less directive approach to counseling, leaving counseling about informed reproductive decision making to healthcare providers. Healthcare providers themselves in Ghana have lacked adequate knowledge and training in nondirective counseling about SCD and sickle cell trait, but we were able to expand their understanding and awareness of these techniques with our short course for nurses and health educators - Genetic Education and Counseling for Sickle Cell Conditions in Ghana (GENECIS-Ghana – (Anie et al., 2016)). We found that participants embraced this education, recognizing the importance of empowering individuals and couples to weigh options and make informed decisions that they deem appropriate for themselves or their families. We intend to offer GENECIS-Ghana for lay counselors, including those embedded in religious institutions, in the future.

The findings from this study can also be used to strengthen the current H3Africa ethics and community engagement guidelines. We worked closely with our collaborators in each country as they advised us on refinement of qualitative research strategies for our African context. For example, we took extra care to ensure confidentiality for participants and created vignettes for participants to respond to in relation to decision making about genomics research and SCD public health interventions. We engaged the broadest range of community perspectives to date to fill a void in our understanding of African perspectives about genomic research. We have demonstrated the importance of pursuing themes that arise

in the initial stages of qualitative analysis, here perspectives on religion and spirituality in relation to genomic research and SCD public health interventions.

Our findings provide guidance for optimal integration of community perspectives into the design and implementation of research and the most effective strategies to implement public health policies and regulations informed by research as we engage with a range of stakeholders (including traditional and religious leaders) from rural and urban settings. We contribute to the growing literature describing ethical considerations for genomics research, the majority of which is not yet empirical in nature (e.g., Tindana & de Vries, 2016; Tindana et al., 2015). Our findings provide insight into challenges that need to be addressed to appropriately plan genomic research, health resources and services, and provision of necessary support for individuals affected with genetic disorders.

Study Limitations

We conducted an analysis of religious perspectives about research with and interventions for SCD and sickle cell trait in Ghana. We derived our analyses from a larger ELSI study designed to explore perspectives and attitudes regarding genomic research and its implementation and implications in Cameroon, Ghana and Tanzania and assess perceptions about public health interventions aimed at increasing awareness, early detection and prevention of SCD related complications. Our focus group guide was not specifically written to collect information about religious perspectives but as we conducted the larger analysis, we observed the strong emergence of these themes in Ghana.

Our goal for the larger ELSI study was to interview a range of stakeholders in each of the three countries but we obtained the largest sample of religious leaders in Ghana. These results should therefore not be generalized beyond implications for Ghana, and this sample of religious leaders was heavily weighted towards Christian ministers, as well. It is worth noting that our study sample was predominantly from the Akan ethnic group and spoke Twi, out of proportion to the distribution of the range of ethnic groups in Ghana. The present findings might therefore only be relevant to this group until more diverse samples in Ghana are interviewed. However, we also acknowledge that inter-cultural interactions due to living and experiencing SCD in similar environments may offer the potential for similar perspectives among different ethnic groups in Ghana.

Given the focus of our interview guide, we may also have missed important beliefs in relation to other aspects of research beyond specimen collection. We did not find striking differences in perspectives between rural and urban environments, but the rural environment where we conducted data was in close proximity with Kumasi, where the pilot SCD newborn screening for Ghana was launched over 20 years ago. If we were to conduct the study in a different rural locality in Ghana, it is possible that we would find more concerns about the SCD public health interventions that we inquired about, as well as perhaps more mistrust of researchers and clinicians. The educational levels of patients with SCD and their families were much lower than that of other stakeholders interviewed in this study, likely reflecting the impact of the disease on the ability of both patients and parents to attain higher education. However, as with the rural/urban perspectives, we did not find striking differences in perspectives about religion/spirituality between individuals directly affected by SCD and

other groups that appeared to be based on their educational levels. Similarly we did not ascertain influences on responses based on how the data was collected, i.e., individuals interviewed in both groups and individually were quite forthcoming about their perspectives.

Research Recommendations

Interventions informed by these qualitative research findings should be implemented and systematically evaluated. As previously noted, we have piloted GENECIS-Ghana, a short training curriculum for nurses and health educators. Trainees demonstrated immediate improvements in knowledge about SCD, sickle cell trait and observed skills in nondirective counseling strategies, but we have not evaluated the impact of the program on longer-term work processes. We also have not evaluated the impact of the program on the individuals and families counseled about their satisfaction, perceptions about the effectiveness and appropriateness of the counseling, and on their sense that they feel more empowered to make autonomous decisions in relation to their health. Our goal is to introduce GENECIS-Ghana within the faith-based community and the program should be evaluated rigorously, as well.

Finally, we developed a model of the influence of religious perspectives on the uptake of public health interventions related to SCD based on our qualitative findings and the interrelations among different aspects of the model should be evaluated, so that modifiable aspects of the model can be identified and targeted for intervention. Future research needs to engage communities in the evaluation of this model, and further develop the ELSI component of ongoing SCD genomic research in Africa.

Acknowledgements

Research reported in this publication was supported by the National Human Genome Research Institute of the National Institutes of Health under Award Number U01HG007459 (Wonkam PI). The authors wish to thank Natasha Dean for her assistance with the preparation of the manuscript.

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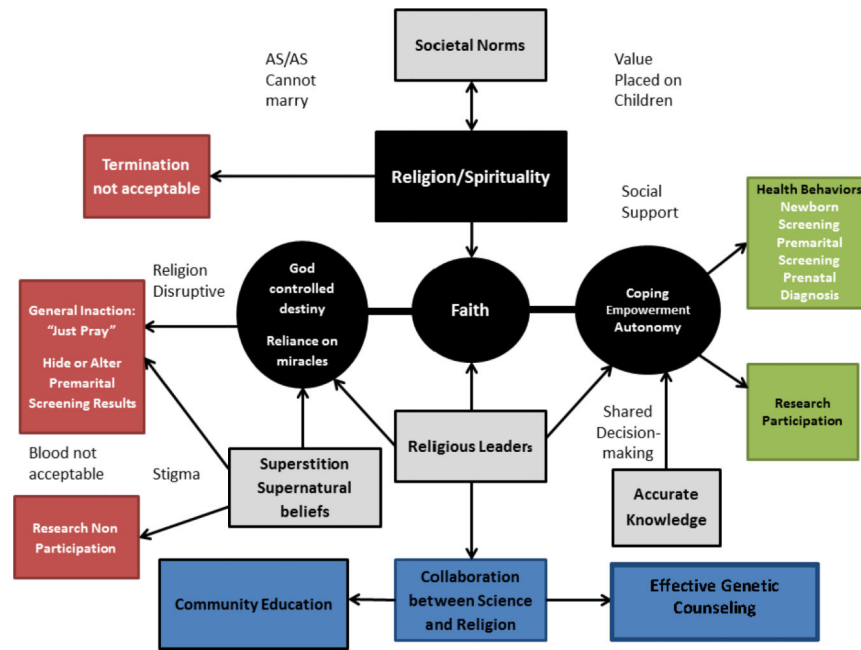


Figure 1. Model of relationships between religion/spirituality and sickle cell related health behaviors and research participation in Ghana. Faith is central (black shading), as a resource for coping, empowerment and autonomy, leading to informed decision making about health behaviors and/or research participation (green shading). Faith can also lead to disruption of or inaction in relation to health behaviors and/or research participation (red shading) when primarily associated with belief in a God controlled destiny or reliance on miracles. Additional influences on beliefs and behaviors are indicated in gray. Interventions that should be informed by cultural and religious norms/values are shown in blue. Interspersed throughout the model are details about the potential influences (i.e., discouragement of marriage of partners with AS, the value placed on children and extended family support are important societal norms; superstitions and some spiritual beliefs can lead to stigma and views such as the unacceptability of the use of blood samples in research; accurate knowledge is essential to families trusting their religious leaders to engage in shared decision making).

Table 1.

Demographics and Characteristics of Participants in Ghana - (n = 149)^a

	Individuals with sickle cell disease and family members (n = 60)	Health care providers (n = 55)	Key Informants and Sickle Cell Disease experts (n = 34)
Gender			
Female	37 (62%)	49 (89%)	8 (23.5%)
Male	23 (38%)	6 (11%)	26 (76.5%)
Age in years (SD)	34.5 (11.1)	35.7 (10.3)	51.8 (12)
Marital status			
Married	27 (45%)	38 (69%)	31 (91%)
Not Married	33 (55%)	17 (31%)	2 (6%)
Location (Rural)	11 (18%)	26 (29%)	9 (26%)
Ethnic group			
Akan	58 (97%)	44 (80%)	32 (94%)
Other (Dagarti, Dagoma, Gonja, Ga, Ewe)	2 (3%)	11 (20%)	2 (6%)
Education			
Tertiary (University Polytechnic, Professional)	12 (20%)	51 (92%)	29 (85%)
Secondary (High School, Vocational)	44 (73%)	3 (5%)	5 (14%)
Primary	4 (7%)	1 (3%)	
Occupation			
Business	23 (38%)		1 (3%)
Student	6 (10%)		3 (9%)
Government/Policy	2 (3%)		7 (20.5%)
Education	2 (3%)		7 (20.5%)
Health Professional (Physician, Nurse, Midwife, Researcher,		55 (100%)	

	Individuals with sickle cell disease and family members (n = 60)	Health care providers (n = 55)	Key Informants and Sickle Cell Disease experts (n = 34)
Other Medical)			7 (20.5%)
Community/ Religious Opinion Leader			
Other	2 (3%)		3 (9%)
Unemployed	13 (22%)		9 (26%)
<hr/>			
Primary language			
Twi	58 (97%)	42 (76%)	33 (97%)
Other	3 (5%)	11 (23%)	1 (3%)

^a All participants did not provide a response in every category so percents in each category do not always add up to 100%.