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# SICKLE CELL DISEASE AWARENESS AND PERCEPTION AMONG CHRISTIAN RELIGIOUS LEADERS IN ACCRA METROPOLIS: A QUALITATIVE STUDY

**Authors:**

Rebecca Okyere1, Menford Owusu Ampomah2, Gloria Achempim-Ansong2, Luke Laari3, Lillian Akorfa Ohene3,Karl Atkin4

**Authors Address:**

1 Rebecca Okyere(MPhil, RGN), Pentecost University, Faculty of Health and Allied Sciences, Department of Nursing and Midwifery, Accra-Ghana. rebecca.okyere86@yahoo.com

2 Menford Owusu Ampomah (PhD, RGN) Department of Adult Health Nursing, School of Nursing and Midwifery, University of Ghana, Legon, P.O Box LG 43, Accra-Ghana mowusuampomah@ug.edu.gh

2 Gloria Achempim-Ansong (PhD, RGN), Department of Adult Health Nursing, School of Nursing and Midwifery, University of Ghana, Legon, P.O Box LG 43, Accra-Ghana. gachempim-ansong@ug.edu.gh

3 Luke Laari (PhD, RN), Department of Public Health Nursing, School of Nursing and Midwifery, University of Ghana, Legon, P.O Box LG 43, Accra-Ghana llaari@ug.edu.gh

3 Lillian Akorfa Ohene (PhD, RGN), Department of Public Health Nursing, School of Nursing and Midwifery, University of Ghana, Legon, P.O Box LG 43, Accra-Ghana. lohene@ug.edu.gh

4 Karl Atkin (DPhil, FAcSS) Department of Sociology, Law and Sociology Building. Heslington East Campus, University of York, YORK. YO10 5GD. United Kingdom. karl.atkin@york.ac.uk

**CorrespondingAuthor:**

2Menford Owusu Ampomah (PhD, RN), Department of Adult Health Nursing, School of Nursing and Midwifery, University of Ghana, Legon, P.O Box LG 43, Accra-Ghana. mowusuampomah@ug.edu.gh

# Abstract

**Introduction**

Sickle Cell Disease (SCD) is a severe hemoglobin gene mutation disorder inherited from both parents. Two percent of Ghanaian newborns are affected by SCD; one in three Ghanaians has the hemoglobin S gene. Christian religious leaders may play a role in the prevention of SCD through the promotion of genetic counseling, genotype screening for premarital couples, and offering counseling to couples on prenatal screening and diagnosis for SCD. However, little is known about the awareness and perception of SCD among Christian religious leaders in Ghana, and this study aims to explore these.

**Methods**

This study adopted a qualitative descriptive design to explore the awareness and perception of SCD among Christian religious leaders in the capital city of Ghana. A purposive sampling technique selected 16 participants from churches under the main Christian groups. The participants were chosen based on their roles and responsibilities within their respective churches. Data was collected using a semi-structured interview guide, which included open-ended questions to encourage participants to share their thoughts and experiences. The interviews were conducted in a private setting to ensure confidentiality. The data was then analyzed using a thematic analysis approach, which involved identifying recurring themes and patterns in the participants' responses.

**Results**

The study's findings are crucial. They reveal a high awareness of SCD among Christian religious leaders, but also some misconceptions. Most of the religious leaders knew SCD was a genetic disease, although a few associated SCD with superstitious beliefs, poor dietary intake, and lifestyle. Some also stated that SCD was a disease of the blood group instead of the defective haemoglobin gene. They perceived SCD to be burdensome, disruptive, and draining, and they associated the disease with burnout in Persons Living with SCD (PLWSCD) and their families. The religious leaders had a good social network with PLWSCD, including family, friends, colleagues, and congregants.

**Conclusion**

These findings underscore the need for intense education about SCD, especially among Christian religious leaders. It is crucial to engage all stakeholders to intensify public awareness and education about SCD while improving the management and social support systems available to PLWSCD and families. This includes the religious institution's leadership, PLWSCD and families, the Ministry of Health, Ghana Health Service, and the Ghana Education Service. As active stakeholders, religious leaders can play a vital role in supporting PLWSCD if they are equipped with the necessary knowledge about the condition.

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Keywords**:** *Awareness, Perception, Religious leaders, Sickle cell disease.*

# Introduction

Sickle Cell Disease (SCD) is among the most prevalent hereditary conditions worldwide (Buser et al., 2021; NIH, 2014; Piel et al., 2017). About twenty-five million people are estimated to have SCD globally (WHO, 2023). Up to fifteen million people out of the total estimate inhabit sub-Saharan Africa (SSA), including Ghana (Edwin et al., 2011; WHO, 2023)**.** About 1000 children with SCD are born daily in Africa, making it the region's most widespread genetic disease. Nearly 50-80% of these children die before their fifth birthday due to challenges in the management of SCD arising from limited resources in primary health care (Piel, 2017; Dua, 2022; WHO, 2022).

SCD is a genetic disorder and chronic. It is a complex condition and involves the pathological breakdown of red blood cells (haemolysis), and occlusion of a blood vessel, leading to a lack of oxygen to organ cells (hypoxia) (Tshilolo et al., 2019; Piel, Steinberg, and Rees, 2017). SCD may result in a multiplicity of complications like severe anaemia (acute or chronic), bacterial infections, severe painful crises, multiple organ injuries, and much more (Piel, Steinberg, and Rees, 2017). SCD is inherited as an autosomal (meaning: the gene is not linked to a sex chromosome) recessive condition, whereas sickle cell trait (SCT) (the "carrier" state) is inherited as an autosomal dominant trait. It means that the gene can be passed on from a parent carrying it to their children. Haemoglobin is created by a pair of genes, one of which is inherited from one’s mother and the other from one’s father, i.e. inheritance of the haemoglobin-S gene from both parents results in a homozygote state of the condition sickle cell anaemia (Hb SS). Hb SS tends to mainly be the common form with its accompanying severe clinical manifestations, and therefore a serious outcome (Serjeant, 2001; Dyson, 2005). The person who carries a trait (Hb AS, Hb AC, Hb AE, Hb A β thalassaemia, etc.) has inherited the normal Hb A gene from one parent, and an abnormal Hb gene (S, C, D, E, β thalassaemia, etc.) from the other parent (Sears, 1994).

The condition causes acute and chronic debilitating pain for people living with SCD (PLWSCD), especially during vaso-occlusive crises. Severe crisis of SCD contributes to recurrent disruption in academic work for school-going individuals, absenteeism at the workplace for workers, poor quality of life, caregiver pressure, patient and family stigmatization, the financial burden on patients and families, and eventually death (Buser et al., 2021; Kato et al., 2018; Okoibhole & Ebenso, 2023; Ampomah, et al., 2022).

The diagnosis of SCD and carrier status can be made at different stages of one's life; for example, neonatal testing, testing for young people, premarital, preconception, and antenatal screening of expectant mothers (followed by partner testing and prenatal diagnosis). Consequently, the genetics of SCD can mediate the setting of counselling from Christian religious leaders and informed decision-making by at-risk parents, as it provides context to the difficulties parents are likely to face when bringing up a child with SCD. However, it is difficult to know how severe the condition will be in individual cases and uncertainty continues to be a primary characteristic of SCD prognosis.

Christian religious leaders, ordained by religious institutions, are mandated to lead their congregants and influence family formations through their operations and activities. They uniquely indoctrinate their congregants with their perception and understanding of spiritual and physical issues around them through their sermons and the influence they wield (Anshel & Smith, 2014; Campbell, 2021). In the context of SCD prevention, they can play a crucial role in promoting genetic counseling and screening. While they may not be qualified genetic counselors themselves, they can facilitate the process by inviting qualified professionals to conduct these services within the church premises or by referring their congregants to external counseling centers. Additionally, evidence suggests that religious institutions, predominantly churches, disseminate evidence-based health activities for non-communicable diseases such as SCD (Bopp & Fallon, 2013; Heward-Mills et al., 2018; Hopoi & Nosa, 2020; Osafo et al., 2021). It is essential to prevent SCD, and Christian religious leaders may be active stakeholders in SCD prevention through their involvement in awareness creation activities with their congregants, the promotion of genetic counseling, and genotype screening for the entire congregants, specifically among premarital couples. They may be uniquely positioned to offer counseling to couples on prenatal diagnosis (PND), as well as informed reproductive decision-making and other community engagements to promote health in the population.

The World Health Organization (2018) emphasizes the importance of collaborative efforts in SCD prevention. They recommend intense public education, genetic counseling, and screening for carriers and PND as primary preventive measures. Many affected countries, including Ghana, have introduced premarital counseling and screening programs (Dennis-Antwi et al., 2018; Kisanga et al., 2021; Osei-Tutu et al., 2020). Scholars have also highlighted the role of individual and community awareness and collaborative partnerships in strengthening primary prevention prenatal screening to reduce disease incidence, morbidity, and mortality and improve quality of life (Ampomah et al., 2022; Dennis-Antwi et al., 2018; WHO, 2010).

One of the ways to increase SCD awareness and screening is to involve religious leaders such as Priests, Imams, and other religious leaders. The extant literature has established those religious leaders, because of their position in civil society, play a role in the delivery of programs that promote positive health outcomes (Anshel & Smith, 2014; Bopp & Fallon, 2013; Campbell, 2021; Heward-Mills et al., 2018). However, it is important to acknowledge that there may be challenges and limitations to this approach. For instance, some religious leaders may lack the necessary knowledge and skills to effectively communicate health information, or they may face resistance from congregants who are skeptical about medical interventions. Despite these potential challenges, the unique position and influence of religious leaders make them valuable partners in SCD prevention and management. It is, therefore, imperative to explore the awareness and perception of SCD among religious leaders who, with their social influence, can support and educate the masses they reach.

# Methods

## Design

This qualitative study, which holds invaluable insights at its core, employed an exploratory, descriptive design to investigate the awareness and perception of SCD among Christian religious leaders in Accra, Ghana. This study is crucial because Ghanaians identified as Christian leaders uniquely influence their congregants and society cannot be overstated. This design allows researchers to explore religious leaders' sickle cell disease awareness which allows them to share their expertise, ideas, experiences, and misconceptions. Again, a qualitative study was chosen because it can provide a holistic understanding, explore diverse perspectives, describe the phenomenon in detail, contextualize beliefs and behaviors, and capture the unique voices of the participants. This design allows researchers to assess religious leaders' sickle cell disease awareness. They can share their expertise, ideas, experiences, and misconceptions.

## Research Location

The Greater Accra region, the capital city of Ghana was chosen as the research location, is the most populous region in Ghana and serves as the home to diverse Christian inter-denominations. The Christian Council (CC), the Ghana Pentecostal Council of Churches (GPCC), and the National Association of Charismatic and Christian Churches (NACC) were selected because most churches within the Metropolis predominantly belonged to these Christian organizations. This choice was made to ensure that the research is conducted within a context that is familiar and relevant in the Ghanaian religious context.

## Sampling Strategy and the Process of Selection

A purposive sampling method was used to recruit Christian religious leaders of the CC, GPCC, and the NACC Churches within the Accra Metropolis, the capital of Ghana. This method was chosen to ensure that the sample included religious leaders who have been in leadership for at least a year, thereby having the experience to offer premarital and genetic counseling services, as well as providing physical and spiritual support to congregants with SCD and their families. The research team approached and discussed the recruitment process and data collection with the heads of the various denominations, ensuring their support and cooperation. The participant information sheet was given and explained to them individually. They were also given the chance to ask all questions before giving informed written consent. Participants who required time to make informed decisions were given three days to decide whether to partake in the research or decline participation. The Christian leaders were then contacted to confirm participation in the study, and those who were willing to participate gave oral and written consent. Participants scheduled a meeting at their convenience for the interview to be conducted with the researcher.

## Data collection

Data was collected through semi-structured interviews conducted with participants in person. An interview guide developed and agreed upon by the researchers was used to guide conversations (Fielding, 1993). The interviews, which lasted 40 to 60 minutes, included questions such as (A). *Please can you tell me what you know about SCD?* (B). *What causes SCD*? (C). *Do you get congregants coming to you for counseling on SCD, and what is the experience like*? (D). *In your perspective, how does SCD affect the lives of the patients and their families*? Various probes were used to elicit extensive information from participants. Interviews were conducted by the first and second authors (RO) and (MOA) in the English language with a few in a Ghanaian local language, Twi (n=6) at preferred venues of the participants, and all interviews were audio recorded with their permission. Interviews that were conducted in Twi were translated into English before transcription.

## Data analysis

All interviews and field notes were transcribed and analyzed using thematic analysis by Braun and Clarke (2006). Interviews that were conducted in Twi (n=6) were initially translated into English by RO and reviewed by MOA and GAA, who have proficiency in the Twi language. This was to ensure that the true meaning of what participants were communicating was not lost during the translation process before transcription. Some priori codes were established from the interview guide by two of the researchers (KA and LAO) who are experts in qualitative analysis. The initial empirical analysis focused on generating themes and showing how often a characteristic pattern was identified from the participants’ views (Braun & Clarke, 2006), where themes and subthemes were developed and labeled. The organization and improvement in themes and subthemes for each transcript continued until saturation. This process generated key concepts that informed the basis of the study findings.

## Ethical considerations

Ethics approval was received from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana (NMIMR-IRB CPN 066/22-23 IORG 0000908). Also, an introductory letter was submitted to the Christian Council of Ghana, the Ghana Pentecostal, and Charismatic Council, and the National Association of Charismatic and Christian Churches for researchers’ introduction and permission from Christian denominational leadership engagement. The participants’ right to make personal choices was respected throughout the process. The participants who agreed to partake in the study were given consent forms to sign. Participation was voluntary, and all the participants were assured of confidentiality and anonymity without coercion on the part of the researchers (Schaefer & Wertheimer, 2010).

# Findings

# Demographic data of Participants

A sample of sixteen Christian religious leaders participated in the study. 10 of the participants were males and 6 were females. The ages of the study participants ranged from 32 to 70 years. Overall, 13 of the participants were married, 2 were widowed and 1 was single. Over half of the study participants (9 out of 16) were associated with the Ghana Pentecostal and Charismatic Council (GPCC) Churches, 5 belonged to the Christian Council of Ghana (CC) Churches, and the remaining 2 were members of the National Association of Charismatic and Christian Churches (NACCC). The participants had varied years of Christian leadership experience with the longest serving years of leadership pegged at 38 and the least at 4 years. 3 were retired religious leaders and the remaining 13 were in active leadership roles. 7 leaders were full-time ministers while the remaining 9 were lay church leaders. Participants were assigned pseudonyms to ensure anonymity from Religious Leader 1= RL1 to RL16 (see Table 1).

## Table 1: Demographic Data of Religious Leaders

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Pseudo Name | Gender | Age | Marital Status | Years of Service |
| RL 1 | Female | 60 | Married | 32 |
| RL 2 | Male | 68 | Married | 34 |
| RL 3 | Male | 67 | Widowed | 3o |
| RL 4 | Male | 43 | Married | 12 |
| RL 5 | Male | 70 | Married | 38 |
| RL 6 | Female | 37 | Married | 9 |
| RL 7 | Male | 34 | Married | 8 |
| RL 8 | Male | 47 | Married | 6 |
| RL 9 | Male | 40 | Married | 12 |
| RL 10 | Female | 53 | Widow | 13 |
| RL 11 | Male | 38 | Married | 7 |
| RL 12 | Female | 32 | Single | 4 |
| RL 13 | Female | 39 | Married | 6 |
| RL 14 | Male | 47 | Married | 11 |
| RL 15 | Female | 48 | Married | 4 |
| RL 16 | Male | 50 | Married | 23 |

# Themes and Subthemes

This study focuses on the awareness and perception religious leaders have towards SCD in Ghana. The analysis of this study presents two themes, underpinned by seven subthemes (Table 2). The main themes forming the basis for this analysis are the Understanding of SCD and the religious leaders’ social network with PLWSCD.

Table 1: Organization of Major Themes and Subthemes

**Theme Subtheme**

|  |  |
| --- | --- |
| 1. Understanding and perception of SCD
 | * Religious leaders’ insight on SCD
* Source of information on SCD
* Causes and Misconceptions about SCD
* Social network with People living with SCD and families
 |
| 1. Perceived influence of SCD on patient/family.
 | * Socioeconomic burden
* Psychological burden
 |

# Understanding and Perception of SCD

Awareness of SCD is the first step in recognizing that a condition (Sickle cell disease) exists, and the perception of religious leaders towards SCD may inform stakeholders on developing strategies to help educate these leaders on genetic diseases and equip them with preventive measures to promote health among their congregants.

## Religious leaders’ insight on SCD

All sixteen (16) participants, who are active leaders in their respective Christian communities, stated that they had heard about SCD and recounted what they knew about the disease. They shared their insight as follows:

*“What I know is that sickle cell disease is an inherited disorder, something in the family. And normally, they have this kind of painful joints and so on”.* ***RL 5***

*“It is inherited because the genes are inherited, and it is alarming”* ***RL 16***

PLWSCD experiences a range of signs and symptoms that serve as evidence of the disease. The knowledge of Christian religious leaders about these signs and symptoms can help them better understand the condition and contribute to policies addressing the challenges of SCD management and prevention. All 16 respondents demonstrated a level of understanding of the clinical manifestations of SCD. Most participants identified body and joint pains, swellings, and stunted growth as common signs and symptoms of SCD. Their comments included:

*“…They show signs like swollen arms and legs, loss of appetite, crying due to body pains among others…”* ***RL 1***

*“…They have this kind of painful joints and other painful body parts…”* ***RL 5***

*“…When we were growing together, that guy never grew up; he looked small for his age. He complained of joint pains and headaches, and he always appeared anemic. Also, after a short time, he was admitted to the hospital for Malaria and always feeling cold, so you always see him wearing a lot of things around him. Sometimes he felt bad to even play with some of us…”* ***RL 14***

While the respondents showed a commendable level of awareness about SCD and their knowledge about the clinical manifestation was good, there is an undeniable need for further education. This was not just a suggestion, but a crucial requirement to equip religious leaders with the necessary knowledge to effectively address genetic diseases like SCD.

## Sources of information on SCD

The path to understanding SCD for the participants was deeply personal, each sharing a unique journey to knowledge about the disease, often intertwined with their own family’s experiences with the condition. For example, one participant had a child with SCD, which prompted him to learn more about the disease. Another participant’s nephew was frequently getting sick and was later diagnosed with SCD, leading to their awareness of the condition. Their narratives, such as the ones below, vividly illustrate the emotional depth of their journey:

“*I have a sickle cell child, and that’s how come I came to know more about them”* ***RL1***

*“…My sister’s son, who was frequently getting sick, was diagnosed as having SCD, and that’s how l heard about the condition…”* ***RL 10***

The participants’ paths to knowledge about SCD were diverse, reflecting the multitude of information sources available in today’s world. From traditional media like books, newspapers, radio, and television to modern platforms like the Internet, each participant had a unique learning journey about the disease. Their comments, such as the ones below, provide a glimpse into this diversity, inspiring healthcare professionals, researchers, policymakers, and stakeholders to explore various channels for disseminating SCD information:

*“…I remember reading books and the newspapers…”* ***RL 2***

*“…I read the mirror or the graphic newspaper, or sometimes on the radio and television, I sit there and watch…”* ***RL 5***

*“…because of the internet now, you read about some of these things, and your knowledge about it also is broadened…”* ***RL 6***

Also, public lectures by health professionals during church services, where they provided comprehensive information about SCD and answered questions, served as a significant source of information on SCD. These health professionals, often invited by the church, played a crucial role in disseminating accurate and up-to-date information about the disease. One leader who is a Pentecostal had this to say:

*“…I learned about it through health professionals invited to come and educate our youth members…”* ***RL 14***

Another participant, a science student who had learned about genetics at university, indicated that his source of information on SCD was through the secondary and tertiary education systems. He had this to say about his experience:

*“… OK, so I was a science student during secondary school days, and back in the university, l did a bit of genetics as well, so I can say I gathered the knowledge there…”* ***RL 9***

While performing his leadership duties of home visitation of church members, a participant learned about the condition and recounted the experience in the following words. His role as a church elder allowed him to interact closely with the community and identify health issues. This highlights the unique role that religious institutions can play in disseminating health information:

*“…I got to know he has SCD during one of my home visits as a church elder…”* ***RL 12***

These findings underscore the crucial role of stakeholders in disseminating information about SCD. The participants’ narratives, rich with their personal experiences, provide clear guidance on the channels that should be prioritized for creating awareness about the disease and highlight the significant impact of this knowledge on their decision-making. This insight should inspire all healthcare professionals, researchers, policymakers, and stakeholders involved in preventing and controlling SCD to take proactive steps in this direction.

## Causes and Misconceptions about SCD

SCD is a severe hemoglobin gene mutation disorder inherited from both parents (WHO, 2006). SCD is a genetically inherited disorder, common in West Africa. Most of the participants explained that SCD was a genetic disease and shared their perspectives on the causes of SCD:

*“…What I know is that when one’s father and mother have some traits of the disease when they give birth, the children are likely also to inherit it or have the same condition…”* ***RL 6***

*“…Okay, sickle cell, I know, is a disease in the blood. So, I know one gets it through genetics, which affects red blood cells. That’s what I can say about the disease”* ***RL 8***

However, a few respondents who identified SCD as a genetic disease mistakenly attributed it to the blood group, rather than the defective hemoglobin gene. This misconception underscores the nuanced understanding of SCD causes within the population. Here are some of their statements:

*“…When the couple has AS and SS blood groups, and they marry, their produce is likely to be a sickle cell disease patient. So is a blood group problem…”* ***RL 3.***

“…*Okay, sickle cell, I know, is a disease in the blood. So, I know one gets it through genetics, which affects the blood group. That is what I can say about the disease…”* ***RL 10***

Nevertheless, two out of the sixteen participants associated SCD with a spiritual disease.

*“Spiritual causes like evil spirits cause some of these diseases.”* ***RL 7***

*“I used to think SCD was a case of malediction or sorcery because his mother was rich, so we thought she had used her son for money rituals. Some do not believe it is a sickness but a curse from the ancestors (Nananom yare); they do not believe it is a medical condition.”* ***RL 14***

One respondent was uncertain if there were causes of SCD other than genetic factors and made this remark:

*“…I know it is genetic, but as to whether a lifestyle, one’s lifestyle, can cause it, I do not know much about that…”* ***RL 4***

Another retired GPCC leader believed that SCD could be caused by poor dietary habits and certain lifestyles, such as smoking cigarettes, as captured below.

 *“…So l think parent’s blood group can cause SCD as well as poor dietary intake and lifestyle like cigarette smoking…”* ***RL 3***

Participants exhibited a wide range of understandings and also misconceptions about the causes of SCD. While the majority correctly identified SCD as a genetic disease, some misinterpreted the defective hemoglobin as a blood group issue. A few even attributed SCD to supernatural causes, poor dietary habits, and smoking. This prevalence of misconceptions highlights the urgent need for healthcare professionals to address and correct these misunderstandings, as a high level of awareness about the condition does not necessarily mean a detailed understanding of SCD.

## Social network with People living with SCD and families

Religious leaders, deeply empathetic and understanding, connect with families, friends, church members, and community members, serving as trusted confidantes during times of difficulties and health challenges. Nine religious leaders shared that members often confide in them about SCD and its related issues. Out of the nine participants who have had some direct contact with PLWSCD and their families, one participant had a son with SCD, one had a nephew, and the remaining seven either had friends, church members, or work colleagues diagnosed with SCD.

A religious leader, drawing on 32 years of leadership experience, shared a poignant insight into her connection with PLWSCD:

*“Mmm, we need to get time for them. We need to get time for SCD patients. Some of these patients may need help financially, and physically among others which we need to assist in providing for them as church leaders. Also, we need to constantly visit them. This is because some SCD patients feel emotionally down and unhappy and with the regular visitation, they may be encouraged and feel loved. When they feel they can’t do it, get closer to them, encourage them, and rekindle their faith in God as well as revive the l can-do spirit in them. So, for me, I don’t give up on SCD patients in my church but rather encourage them. I put myself in the shoes of their parents or relative or friend and encourage them to be the best of themselves daily*.” **RL 1**

Among the study participants, prayer and counselling times were seen as appropriate moments to interact with persons with SCD and their families. Some of the religious leaders remarked:

*“I have some knowledge about it because of the interactions with some members who come for prayers and counselling. Some tell us “We’ve been diagnosed with this sickness.” Some also don't know, but through interactions, through counselling when we get to know the symptoms then we advise them to go to the hospital for assessment and treatment.”. (...). So, as a religious leader, I started advocating for that in the church, that before a couple get married or would-be couples get married, they should test and figure out if they are carriers, if both are carriers, then they should be encouraged not to go ahead.”* ***RL 16***

*“I know of people with SCD. As a church Leader, they come to seek spiritual support. l pray with them as the bible says in James 5: I5-16 and Exodus 23:25. Prayer is very important, and then l counsel them as well. This often relieves them of the fear of the unknown. We believe doctors report but l believe God's report is supreme, so l encourage them to have faith in God, because He can heal all diseases and this helps them to cope with the disease.” RL3*

A 40-year-old religious leader recounted his experience with a person with SCD back in school and another youth member. He said:

*“…Hmmm, my best friend in Junior high school had SCD, and one of my youth members currently also has it.* *I got to know he has SCD during one of my home visits as a church elder. I advised that he judiciously follow his doctor’s appointment and get enough rest, eat well, and pray with him.”* ***RL 9***

However, it is important to note that not all religious leaders have had direct interactions with PLWSCD or their families. Seven out of the 16 participants shared that they have not been approached by individuals or families affected by SCD. They offered various explanations for this, shedding light on potential barriers to engagement.

*“…No! you know, through all my life about these 38 years in ministry, I have heard about it, but personally, nobody has come to me with such a problem…”* ***RL 5***

*“…Not really, because I have one member of our church whose child has a sickle cell disease. They did not know, but it was later confirmed, and they are still in the church. That is what I know. But I have not encountered someone coming to confide in me about it…”* ***RL 13***

Some participants attributed reasons why PLWSCD and their families did not discuss SCD. The reasons given for the refusal to share the SCD status are captured as follows:

*“…No, I think we do not have SCD patients in the church. On the contrary, maybe they feel too shy to talk about it, to even disclose to others to seek help even when in pain. Some also may be ignorant of the disease so that they may be attributing their signs and symptoms to spiritual or superstitious beliefs…”* ***RL 12***

*“…I think that most youth will not disclose their SCD status because they are scared; they may not get suitors because of the stigma attached to the disease…”* ***RL 4***

*“…I think it is a cultural thing. Some also do not want to expose their family shortcomings…”* ***RL 16***

It is strikingly diverse that more than half of the participants are interacting with PLWSCD, each bringing their unique perspectives and insights to health issues. Conversely, some participants reported having little or no social network with PLWSCD and their families, highlighting the varied experiences within religious communities. It could be that PLWSCD is not declaring their status because of the stigma associated with the disease, fear of losing suitors for marriage, and other forms of stigmatization, or they may be ignorant of the disease and attributing it to spiritual causes. It could also be that participants are not initiating conversations about SCD within the church setting.

# Perceived influence of SCD on patient/family

PLWSCD and their families, while managing the realities of SCD, also navigate their daily life activities with remarkable resilience. In this context, religious leaders, who are not just integral parts of these communities but also crucial pillars of support, frequently interact with patients and their families and play a significant role. Their understanding and perception of the disease can significantly influence the community’s response to SCD. All 16 participants in our study shared the negative impact of the disease on the overall well-being of PLWSCD and their immediate family, including the socioeconomic and psychological burdens that significantly affect their quality of life.

## Socioeconomic burden

SCD is not just a health issue but also a significant socioeconomic burden that demands immediate and concerted attention. The high cost of care associated with SCD often leaves PLWSCD and their families financially strained. This financial burden extends beyond medical expenses, disrupting routine activities such as school and work schedules. As a result, we see socioeconomic consequences such as school dropout and termination of employment offers. Our participants shared their experiences of the economic and financial burden of SCD, highlighting its urgent impact on PLWSCD families and the community at large.

A 60-year-old female religious leader with a son living with SCD stated that:

*“…It is financially draining that frustrates you as the caregiver…”* ***RL1***

Other participants shared their perceived financial impact associated with SCD with the following statements:

*“…In my estimation, SCD hurts society. Firstly, it causes financial problems because of the high medical bills associated with the treatment…”* ***RL 12***

*“…The impact on the family is a monetary pressure, when they go into crises, the medicines and all that, its monetary issues, so if the family does not have money, they may lose the person…”* ***RL 15***

## Psychological burden

Uncertainty, anxiety, and depression are emotional challenges that significantly impact the psychological well-being of PLWSCD and their families. The constant fear of a crisis, the stress of managing the disease, and the emotional strain of seeing a loved one in pain are just a few examples of these psychological burdens. Participants shared their experiences, emphasizing the need for emotional support, such as counseling or peer support groups, to help them cope with these challenges. This highlights the emotional toll that SCD can take on individuals and their families and the crucial role of religious leaders in providing this support.

*“…Secondly, patients and family experience burnout because of the in and out of hospital admissions and finally some stigma or tag on the family…”* ***RL 12***

*“…It is a very devastating sickness because when a child has SCD, the parents are emotionally, financially, and employment-wise unstable and drained. When the child is unhappy, you are unhappy as a parent as well…”* ***RL 2***

*“I even have a colleague at work who has two children with it, and I get to know what she goes through occasionally. The children were going on admission, one going, the other coming, and the stress she goes through—the psychological state and how it affects her work.  Not being able to come to work.  Being absent here and there, Hmm, the disease is disruptive”* ***RL 6***

Participants stated that PLWSCD and their families are negatively affected by physically disrupting one’s usual routine. For instance, frequent hospital visits or the need for constant monitoring can disrupt school or work schedules, leading to absenteeism or reduced productivity. Comments like:

*“…You can sometimes juggle between the hospital and your activities for about two weeks, three weeks, and even a month. It’s not an easy task to carry…”* ***R L7***

*“…The child is currently paralyzed, and so it has prevented the mum from coming to church because she has to stay home and take care of the child, and also, they visit the hospital frequently…”* ***RL 13***

# Discussion

This study explored the awareness and perception Christian religious leaders have about SCD in Accra, Ghana. The finding indicates a high awareness of SCD among the religious leaders interviewed. All 16 participants had heard about the existence of SCD, and the majority stated that SCD is a genetic disease. Most participants could correctly state some signs and symptoms of SCD, indicating their understanding of the condition. The findings were consistent with the literature, as some studies conducted on religious leaders found a high level of awareness and knowledge of SCD among the participants (Abubakar et al., 2019; Awe, 2018). It was also observed that out of the majority who said SCD was a genetic disease, a few said SCD was a disease of the blood group instead of a defective haemoglobin gene. This implies that although Ghanaian Christian leaders may have a high awareness of SCD, some may have some vital details distorted about the condition, such as the specific genetic mutation that causes SCD or the potential complications it can lead to. This may include leaders of other religious organizations in the country. It is also an indication that when a religious leader is knowledgeable about a health condition, it makes it easier for them to engage their followers and advise on its control or prevention. Therefore, awareness creation and education on health issues should be done among religious leaders in clear and concise language so that these leaders can have a fundamental understanding. This may help reduce misinformation about health conditions, including SCD, and empower these leaders to apply the gained understanding in their social interaction with PLWSCD and their families on the condition and its associated community impact during premarital counseling in the churches.

Again, although most participants in this study attributed SCD to be a genetic disease, a few also associated SCD with a spiritual disease caused by evil spirits, poor dietary intake, and lifestyle habits such as smoking cigarettes. These misconceptions, such as the belief that evil spirits cause SCD, highlight the need for accurate information dissemination among religious leaders (Dennis-Antwi et al., 2011; de Montalembert et al., 2019; Okoibhole & Ebenso, 2023). A religious leader’s misconceptions about SCD, its management, and prevention may translate to the wider context of society because many of them are in a social relationship with their members in Ghana (Okoibhole & Ebenso, 2023). Furthermore, getting Christian leaders to understand the causes of SCD may help broaden their knowledge of SCD, which may translate to communal and societal beliefs about the disease because many of the followers of these leaders and their families form the basic unit of society (Makiwane & Kaunda, 2018). Health education among Christian leaders could help bridge the knowledge gap and increase the public’s understanding of SCD.

It is suggested that health educators, in their engagement with these leaders, should consider utilizing a socioecological approach as such leaders are in social interactions and are seen as social figures with the individual, families, institutions, and communities while considering the societal norms, religious values, and policies (Ibemere et al., 2021; McLeroy et al., 1988). Most participants became aware of SCD through friends, relations, and church members within their social network.  This is understandable because religious leaders often socialize with families, friends, and congregants and are often consulted on almost every matter for spiritual and physical direction. This corroborates a study that cited family and friends as a source of information on SCD in Uganda (Tusuubira et al., 2018). Others learned about SCD through public lectures by health workers during church services and other programs. This is congruent with the findings that churches can be used as health promotion avenues for awareness creation and education on health matters (Anshel & Smith, 2014). The sources of information for SCD must be strengthened within the churches and communities so that information on health issues can be disseminated effectively. Social institutions such as churches and religious organizations can set up health information desks within the facilities manned by trained health personnel to disseminate accurate health information to congregants and users of such facilities. Health education and awareness creation should be culturally appropriate and written with the appropriate consideration of literacy levels for laypersons. This will empower the population, including religious leaders, on health matters, including SCD.

Social network with PLWSCD, referring to individuals who have been diagnosed with sickle cell disease and their family leaders relate with family, friends, church, and community members and act as confidantes in times of difficulties and health challenges. These people are important sources of influence in individuals’ health-related behaviors. Social relationships affect how individuals cope with stress. A little over half of the participants confirmed that people confided in them about SCD and its related issues. Participants had an excellent social network with PLWSCD and families within their catchment areas. Some participants had family members, friends, church members, and colleagues diagnosed with SCD, and they were constantly interacting with them. These findings are analogous to those in literature, which suggests that religious leaders inhabit the communities forming part of society, and they are seen as confidantes in times of distress (Campbell, 2021; Campbell & Szaflarski, 2021; Osafo et al., 2021).

Derlega et al. (2018) identified some reasons for sickle cell disease disclosure to specific persons; self-related reasons (receiving support and venting feelings), others-related reasons (educating others about sickle cell disease, forewarning others about sickle cell disease-related problems), and situational reasons (mainly focusing on another person being physically close or available to talk to. It is therefore not surprising that the Christian religious leaders in this study became aware of SCD based on the social relationships with such individuals and their families and, more importantly, their ability to provide the necessary support, be it spiritual, physical, or financial, when the need arises. McPherson et al. (2006) also found that people preferred to discuss sensitive matters only with people who are very close and vital in their lives. These could be domestic, wellbeing, professional, or business issues. This is in contrast with the findings of Small (2013), who found that people do not always reserve intimate matters for their confidantes or people with strong ties. Instead, it is a combination of the people we are close to, people we are not close to but knowledgeable about the matters we regularly find essential, and people we are not close to but who are available because of our routine activities.  Secondly, people tend to discuss important matters with knowledgeable people, regardless of whether the latter are close or not. It is a reminder that this is a two-way process. Religious leaders must be knowledgeable about the causes of SCD and its clinical consequences along with its social, economic, and emotional impact. This is two different sets of knowledge and understanding. People then must trust them to seek advice and see them as a source of information and comfort. This is, therefore, a negotiated relationship. Thus, according to Small (2006), the strength of a tie is neither a necessity nor a sufficient condition for the pursuit of confidence. This implies that when religious leaders are seen as available, approachable, and knowledgeable on issues bothering individuals or families, they may be consulted on such matters irrespective of their relationship. Religious leaders should, therefore, commit themselves to lifelong learning and should not be limited to only theological tenets so that their socioecological impact can be fully harnessed, more so when it comes to a health condition like SCD, where in the Ghanaian context, individuals with the condition and their families are often stigmatized and discriminated against.

Findings from this study also suggest that some people do not disclose their SCD status to others, including their religious leaders, but rather, they prefer to keep it to themselves. This is consistent with literature that has indicated that people do not disclose their SCD status because they fear stigmatization (Bulgin et al., 2018; Leger et al., 2018).  Similarly, Derlega et al. (2018) found that some reasons for SCD nondisclosure were self-related (fear of denunciation, being labeled, maintaining privacy) or other-related (lack of assistance, not disturbing someone). Religious leaders can, therefore, use their social influence to encourage PLWSCD and families to verbalize their apprehensions about the disease and encourage them to seek treatment and comply with their treatment regimen. Religious leaders can also initiate conversations about SCD in the churches and communities to increase public awareness about the disease while ensuring that the families, friends, church, and community accord PLWSCD the necessary social support they need to improve their health and quality of life.

All the study participants perceived SCD to harm the overall well-being of the patients with SCD and family. This includes the socioeconomic, psychological, and financial burdens adversely affecting the well-being of PLWSCD and their families. This perception could have been formed because of the religious leader’s characteristics, such as knowledge and beliefs about SCD, and the social interaction between the religious leader and the individuals, families, church, community, and society. This is in line with the findings of the study, which found that when making sense of chronic illness, people generate their true-life experience within the framework of their broader social and cultural context, and this results in multiple discourses operating (Dennis-Antwi, 2011; Kahissay, 2017). Similarly, another study found that people uneducated about SCD form a belief about the disease from their own conceived ideas, beliefs, and cultural and social interactions, which may result in an undesirable perception of PLWSCD (Royal et al., 2011). Consequently, where religious leaders do not have much understanding of SCD, this may have some implications on how they perceive PLWSCD, as they may have negative attitudes toward the patients and their families. Therefore, continuous education of religious leaders about SCD and other health-related disabilities is essential to dispel all preconceived ideas, myths, and misconceptions surrounding the disease among such individuals of influence within the society in the context of Ghana.

Apart from the negative socioeconomic impact of SCD, most participants reported that they perceived that SCD has a psychological burden on people diagnosed with the condition. Several studies have documented fear, indecision, apprehension, and depression to impact the psychological well-being of PLWSCD and families (Buser, 2021; Mumuni, 2023; Quasie-Woode, 2021). Religious leaders can offer psychological support to assist PLWSCD and families as they navigate their health. The churches can also financially support them to meet the financial demands of quality care by setting up a support fund from the church’s internally generated funds.

**Practical or social implications**

Creating awareness and developing education on SCD (and broader health issues) is an important priority. This would improve the current understanding of religious leaders and reduce misinformation. It would also empower these leaders to apply this improved understanding, during their social interaction with PLWSCD, their families, and the broader community, when offering premarital counseling in the churches.

Health education among Christian leaders could help bridge the knowledge gap and increase the public’s understanding of SCD. Health education and awareness creation should be culturally appropriate and written with the appropriate consideration of literacy levels for laypersons. This will empower the population, including religious leaders, on health matters, including SCD. This would also encourage greater community confidence in spiritual leaders.

When religious leaders are seen as available, approachable, and knowledgeable on issues bothering individuals or families, they may be consulted on such matters irrespective of their relationship. Religious leaders should, therefore, commit themselves to lifelong learning and should not be limited to only theological tenets so that their socioecological impact can be fully harnessed, more so when it comes to a health condition like SCD, where in the Ghanaian context, individuals with the condition and their families are often stigmatized and discriminated against.

Therefore, continuous education of religious leaders about SCD and other health-related disabilities is essential to dispel all preconceived ideas, myths, and misconceptions surrounding the disease among such individuals of influence within the society in the context of Ghana.

**Conclusion**

This study explored Christian religious leaders’ awareness and perception of SCD in Accra, Ghana. The finding indicates a high awareness of SCD among religious leaders. The majority knew SCD was a genetic disease, but a few associated SCD with superstitious beliefs, poor dietary intake, and lifestyle habits such as cigarette smoking. Social networking with PLWSCD/families revealed that most participants were in contact with PLWSCD as family, friends, colleagues, or congregants. Findings revealed that some PLWSCD and families talked about the disease with their religious leaders, while others did not. Also, participants from their socialization with PLWSCD perceived the disease harms the lives of patients and families. These findings disclose the urgency for intense education about SCD, especially among Christian religious leaders. Also, engagements between religious leadership, PLWSCD and families, and the Ministry of Health should be made to intensify awareness and education of the public on SCD while improving the management and social support systems available to SCD patients and families.

# Strengths and Limitations

This study occurred in one setting with a homogenous sample of participants. Therefore, the findings must be considered in that light, limiting the generalization of the findings to other populations in similar contexts. The study was also undertaken in an urban area; the findings may differ from the perspectives of religious leaders living in rural and deprived areas. Translation of the interview data from the local dialects may threaten trustworthiness as the specific meaning of some statements may be lost. However, intense efforts were made to use words as close to the translated words as possible. This study complements our understanding and awareness of Christian religious leaders towards SCD. Given the small number of studies in this area, more research would be helpful to develop strategies to increase the awareness of SCD among religious leaders.

**Declarations**

# Ethics Approval and consent to participate:

Ethics approval was received from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana (NMIMR-IRB CPN 066/22-23 IORG 0000908). An introductory letter was also submitted to the Christian Council of Ghana, the Ghana Pentecostal, and Charismatic Council, and the National Association of Charismatic and Christian Churches for researchers’ introduction and permission from Christian denominational leadership engagement. Signed consent was obtained from each participant, to participate in the study. All methods were carried out consistent with appropriate practices and guidelines.

# Consent for publication:

Not applicable to this study.

# Availability of data and materials:

# The datasets generated and analyzed during the study are available from the corresponding author upon reasonable request and permission from study participants.

# Competing interest:

The authors declare that they have no competing interests.

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**Authors’ contributions:**

Rebecca Okyere and Menford Owusu Ampomah conceptualized the study and data collection. Rebecca Okyere and Menford Owusu Ampomah wrote the main manuscript text. Menford Owusu Ampomah and Gloria Achempim-Ansong supervised the initial draft of the manuscript. All authors participated in the data analysis. Gloria Achempim-Ansong, Luke Laari, Lilian Akorfa Ohene, and Karl Atkin took turns reviewing and finalizing the final manuscript. All authors approved the manuscript for submission.

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