

*“We di woman den, na we di suffer”:*  
**A report on sickle cell in Sierra Leone.**



Berghs, Maria;

Gabba, Amelia Eva;

Nyandemo, Sia Evelyn;

Dyson, Simon. M.;

Fadlu-Deen, Gbrilla; and Tregson-Roberts, George.

## Acknowledgements

In 2017, we participated in a Newton funded project that De Montfort University (DMU) supported in Freetown, the capital city of Sierra Leone. The Sierra Leone Sickle Cell Society (SLSCS) with Dr. Maria Berghs was adapting Professor Simon Dyson's 2016 school policy guide for children who had the sickle cell condition with several schools in Freetown that had sickle cell school clubs. Amelia Eva Gabba of SLSCS stated that sickle cell was very much a women's issue and noted that all the school girls who we talked to informally had experiences that had a strong gendered dimension. Under the guidance of Professor Simon Dyson, who stated that more qualitative research on women and sickle cell in West-Africa was needed, Dr. Maria Berghs, Mrs. Amelia Gabba and Mrs. Sia Evelyn Nyandemo of Sickle Cell Carers Awareness Network (SCCAN) began a research project in June 2018 with women who were mothers of children with sickle cell and women who had the condition.

First and foremost, we wish to thank all the women who participated and kindly shared their experiences with us. We hope that we have done justice to the spirit in which they shared their stories, which is to enact social change and educate.

We also have to thank Iyamide Thomas of Sickle Cell Society-UK, Grace Macauley, Samuel O. J. Macauley, Rev. Solomon Van Kanei of the Methodist Church of Sierra Leone and the Community Evangelism programme, the British Council, Dr. Mary Hodges of Helen Keller International, Dr. James Bunn of the World Health Organisation, the volunteers at SCCAN and SLSCS and the Sickle Cell Technical Working Group in Sierra Leone for their support and advice given to this project.

This research was made possible thanks to funding from De Montfort University's VC2020 programme.

*"I want to say thanks to you, the nurses here, (name of Dr.). Thank you. Why? They did not take up a programme around religion or tribe. They took up a programme to help lives, to save lives."*

Djenabou, 30, Koidu

## Abstract

Sierra Leone is thought to be one of the West African countries most affected by sickle cell disorders. Estimates state that one in four people carry the gene for sickle cell and between 1 to 2% of births are of children with the condition. Despite this, there has been a general public health and social neglect of the condition, so that prevalence is poorly understood and policy non-existent. This participatory qualitative research project, conducted in 2018 in two districts in the country, sought to understand both women's experiences caring for children with the condition, as well as what the needs were of women who had the condition. The findings illustrated that a historical memory of the condition and its effects exists in the intergenerational memories and practices of people. This is important to learn from to combat stigmatisation of women and people who have the condition. However, past expertise and medical knowledge currently co-exist in isolation from each other, with access to proper healthcare unavailable in most parts of the country. This has led to an inability to get a correct medical diagnosis, no advice about how to live with the condition and an inability to access specialized medical and rehabilitative services. These failures in care have led to early deaths and disablement, with the result that the general public fear the condition. A neglect of reproductive justice and the relational implications for women with the condition was also apparent in the high number of deaths of women and infants with sickle cell. Lastly, due to the work of the voluntary and medical sector, there is increasing awareness in parents, schools and communities of how the total environment is crucial for holistic management of sickle cell conditions in a low-income country. However, it is women who are still mostly responsible for ensuring that their children access a better quality of life and women who still incur moral blame and shame for their ill-health and that of their children.

**Keywords:** sickle cell; Sierra Leone; women; gender; reproduction

## Table of Contents

|   |    |
|---|----|
| 1. Introduction.....  | 4  |
| 2. Background.....  | 5  |
| 3. Methodology.....   | 8  |
| 4. Findings.....  | 9  |
| 5. A historical memory of a condition and its effects.....                  | 11 |
| a. Signs and symptoms of sickle cell.....                                   | 12 |
| 6. Witches, traditional healers and blame.....                              | 13 |
| 7. Lack of social and public health education.....                          | 16 |
| a. Incorrect medical diagnosis .....  | 17 |
| b. Late diagnosis and incorrect advice.....                                 | 19 |
| c. Real fears of testing: creating a stigmatised condition? .....           | 20 |
| 8. Neglect of reproductive and relational health.....                       | 22 |
| a. Lack of choices.....   | 23 |
| b. Family planning.....   | 24 |
| c. Safe births.....   | 25 |
| d. Relational health, employment and wellbeing.....                         | 27 |
| 9. Environment and management of condition allows it to become chronic..... | 30 |
| a. Good care: Family and school environment.....                            | 31 |
| b. Access to medicines and specialist knowledge.....                        | 34 |
| c. Access to transfusions and hospital care.....                            | 36 |
| d. Access to rehabilitative services and surgery.....                       | 37 |
| 10. Conclusion: A need for future services.....                             | 37 |
| 11. Recommendations.....  | 41 |
| 12. Appendix One: A National Policy on Sickle cell: A five-point plan.....  | 50 |
| 13. Appendix Two: Participant Sampling.....                                 | 51 |

## 1. Introduction

Sickle cell disorder (SCD) is an inherited multi-system condition that affects millions of people worldwide (Serjeant & Serjeant, 2001; Piel et al., 2017). In people who carry the gene, it provided profound resistance to malaria in early childhood, and was positive for survival (Dyson, 2019). SCD is primarily found in populations in West and Central Africa, Southern Europe, India, Saudi Arabia and due to migration of these populations in Latin America, the United States and the United Kingdom (UK) (Piel et al., 2017; Dyson, 2019). As many as 400,000 children with SCD may be born globally each year (Piel et al., 2013). Of these, over 80% are born in Africa, mainly in West and Central Africa (Modell & Darlison, 2008). This makes SCD an important, but relatively neglected public health issue in West and Central Africa (WHO, 2010). Grosse et al. (2011) suggest that since SCD might be responsible for 5-16% of under-five mortality in parts of Sub-Saharan Africa, it is important for African governments to ensure that they make SCD a priority. In terms of achievement of the 2030 United Nations (UN) Sustainable Development Goals (SDGs), SCD thus becomes correlated to SDG 3 on good health and wellbeing, in ensuring life-saving measures for people born with the condition. The World Health Organisation (WHO) also advocates adopting a national public health strategy in the African countries most affected, by 2020 (WHO, 2010). The WHO (2010: 7) has also called for more research on the condition to be undertaken and has noted that, 'children under five years, adolescents and pregnant women' are most affected by 'organ damage and premature death.'

Despite being one of the major chronic illnesses of West and Central Africa, SCD has received relatively little attention in terms of social science research (Fulwilley, 2011; Dennis-Antwi et al., 2011; Ola et al., 2016) and none of these studies specifically examines the experiences of West-African women living with SCD itself. Although, we know from previous research that Sierra Leonean attitudes to disability are gendered (Berghs & Dos Santos-Zingale, 2011; Berghs, 2018), to date there have been no social studies examining the experiences of people living with one of Sierra Leone's major chronic disabling illnesses. Most research concentrates on attitudes and perceptions of SCD in the population or communities (i.e. Senesie, 2010). We know that having both severe and milder forms of SCD can lead to impairment and hence, disability identity in Sierra Leone which can lead to experiencing stigma (Berghs, 2018). Yet, we know very little about how gender, disability, socio-economic status and ethnicity interact together for women as patients and care-givers (Dyson & Berghs, 2018).

With some of the highest mother and child mortality rates in the world, the priority of the government is rightly on reducing maternal and child mortality rates, improving anaemia and nutrition, sanitation and hygiene, and issues that lead to child death like malaria (SSL & ICF, 2014; WHO, 2017). Post-Ebola, Sierra Leone's President Julius Maada Bio has also focused on gender issues and declared a national emergency on sexual violence against women, which studies have argued has risen post-Ebola (Onyango et al., 2019). Yet, we know very little about how these policies interact with women's everyday lives, aspirations and reproductive experiences. We know that women undertake paid work in the formal and informal sector, for example, linked to agriculture or fishing (i.e. Frausin et al., 2014; Thorpe et al., 2014), unpaid work in the household, and are held almost entirely responsible for everyday child care, impacting on educational and other opportunities (Abdullah et al., 2016; Novelli & Higgins, 2017). Development policy in Sierra Leone also focuses on economic empowerment of women and human rights, a post-conflict legacy for women and children (Denney & Fofana Ibrahim, 2012; Miller, 2015), and is now examining UN SDGs 4 on education and 5 on gender equality in terms of multi-sectorial action on health challenges facing the country (WHO, 2017; Garrett et al., 2018).

In Sierra Leone, we know that there are longstanding issues in gaining access to government run health-care services, in non-payment of healthcare workers and with corruption (Berghs et al., 2016; WHO, 2017). Likewise, access, costs, as well as information on healthcare for women with disabilities are all issues correlated with socio-economic status (Trani et al., 2011; Berghs, 2016, 2018). There are also associations between having a disability or looking after disabled children, which bring extra costs and, in turn, can limit access to education, employment, healthcare, savings, politics and justice for women (Berghs et al., 2016). Socio-economic status and living in chronic poverty are also correlated to developing additional impairments through inability to access nutritious food, safe sanitation, proper housing, and exposure to violence, having to carry out dirty and difficult jobs, and having limited or no access to education (Berghs et al., 2016). The experience of living with SCD or caring for a child with SCD is gendered in North America and particularly impacts on women (Hill, 1994; Hill & Zimmerman, 1995). It is highly likely, then, that the experience of living with SCD in Sierra Leone is one characterised not only by context of possible violence, low-income and disability discrimination, but is also gendered, affecting women in particular. It is the implications for women that this report outlines.

## 2. Background

Sierra Leone is one of the countries in West Africa most affected by SCD. Estimates have fluctuated from 19 out of 1,000 births affected (WHO, 2017) to 3,000 infants with SCD being born each year, that is, approximately 1.3% of all new-borns in Sierra Leone (Roberts et al., 2015). It is estimated that around one in four people carries a variant of the sickle cell trait (Wurie et al., 1995), but that this differs by ethnic group (Livingstone, 1958; Knox-Macaulay, 1983) and there are differences between rural and urban settings (Roberts et al., 2015). The last prevalence study dates from the 1990s and indicates that different variants of SCD exist in the population (Wurie et al., 1995) but we do not know at what levels (Wirth et al., 2018). Recent small sample studies investigating anaemia in the population have found a prevalence in children of both sickle cell and trait of 21% but this decreased by half when examining women (Wirth et al., 2018). If one out of four people are carrying the gene, a figure of 25% would be representative (Roberts et al., 2015) but indicates that children with SCD are dying before they reach adulthood. In Liberia, a small-scale pilot of screening in a hospital setting found SCD in 1.5% of infants (Tubman et al., 2016). In Guinea-Bissau, SCD was found in 0.2% of the population, which might be indicative of low survival rates of children with SCD into adulthood or even where screening occurred.

SCD is a disorder affecting red blood cells. It is caused by a recessively inherited abnormal haemoglobin, HbS, which, under low oxygen conditions, forms crystals that distort the shape of the red blood cell from the normal round shape to that of a sickle. This irregular sickle shape can cause blockages in the blood vessels of the body leading to tissue and organ damage, as well as induction of pain. The pain can be managed by over-the-counter pain killers, and/or may be intense enough to need medical intervention. When pain is severe, it is often referred to as an 'attack' or 'crisis'. It can be so serious that it can completely incapacitate a person or even lead to death if not treated properly (Wailoo, 2017). Certain factors, such as cold temperatures, dehydration, excessive physical exertion, mental stress and high altitude with low oxygen, predispose to acute pain crises. Over time, SCD progresses to organ damage and functional impairment, such as: avascular necrosis of the hip requiring hip-replacement surgery; stroke; cardiovascular and kidney issues (Sickle Cell Society, 2018).

An individual with SCD inherits the condition from their mother and father. The most severe version of SCD is sickle cell anaemia with the genotype HbSS that indicates that a sickle cell gene (HbS) has

been inherited from each parent to give to a child (HbSS). There are other milder versions such as HbSC in which the sickle cell gene and another variant, HbC have been inherited. Other variations are also possible, and in Sierra Leone, sickle-beta thalassaemia (thalassemia is another haemoglobinopathy or blood disorder) has also been reported (Wirth et al., 2018). Persons who have just one gene for sickle cell are referred to as 'carriers' of the sickle trait (HbAS). This means that if they have a child with another person who has the trait, they have a 1 in 4 chance of having a child with SCD in each pregnancy. If a couple has a child with SCD they need to know this as soon as possible, because even though the child may be fine at birth because of the protection afforded by their foetal haemoglobin, over a period of 4-6 months after that, it may begin to show symptoms of disease, some of which may be severe or life-threatening. This change can permit complications of SCD to manifest (e.g. swelling in hands or feet, fever, or rapid enlargement of the spleen) and treatment is urgently required. There are also dangers to infants in greater risks of infection, and having malaria is known to be linked to going into crisis.

There is, currently, no generally available cure for SCD and, in African contexts, like Sierra Leone, curative treatments are simply out of the question. Like elsewhere, the only common symptomatic treatments are pain-killers and exceptionally, blood transfusions. Other treatments like hydroxyurea, which has been recommended in Sub-Saharan African countries (Tshilolo et al., 2019) (because it can limit the amount of crisis in some people with SCD), is not readily available and there are no protocols. Likewise, procedures like Transcranial Doppler Screening for detecting impending strokes in children are not available, and other less reliable procedures have to be used. Additionally, SCD is often highly variable, with two people who may have the same HbSS genotype, having very different clinical profiles. In Sierra Leone, according to the voluntary sector, variation in life outcomes can be partly explained by socio-economic status, including whether or not there is access to private healthcare, a regular supply of medicines, surgery or even stem cell transplantation abroad. Yet, they explain, medical access can be delivered through low-cost interventions such as vaccinations, pain-killers, and oral rehydration (See also Dyson, 2019). Medical access is, thus, not the only factor to survival and environment is also crucial to living well with the condition as it becomes chronic. Similarly, members of the sickle cell voluntary sector note how they do not understand why SCD changes across the life-course and why it affects genders differently, both as a physical and mental health condition.

In public health policy, it is often naively assumed that if people are aware of SCD, and know that they have the trait or carry the sickle cell gene, that they will avoid having children with another person with the trait (Dyson & Atkin, 2012). This is often gender discrimination, as there are many presumptions about women's agency contained in such policy, such as the ability of women to control their reproductive choices, that they don't experience sexual violence like rape, that they can ask their partners to be tested and that they want their partners to undertake such a test (Chattoo et al., 2014). Research from a long-term Jamaican study in schools has indicated that awareness raising and education, even over years, often does not have much of an effect in terms of encouraging screening for SCD, and in subsequently preventing births of children with SCD (Mason et al., 2016). They noted that the imperative for screening of the man was accepted by the woman, who then, while remaining morally and socially blameless because she willingly took a test, mostly report reluctance of partners to get tested for SCD (Mason et al., 2016). There may also be many complex reasons for men's reluctance to take a blood test, from fears over what else the blood test might reveal, to not wanting to have that knowledge because it implies a 'fault' in themselves, or even acceptance of the trait and of child/ren with SCD (Atkin et al., 2015; Dyson et al., 2016; Berghs et al., 2017).

Yet, women too may not want their partners to get tested and morally deflect this by reporting reluctance, refusal or state they did not understand risks, when other priorities, such as being a mother and having children, are more vital and crucial to identity as a woman (See Hill, 1994, 2018). Women will use acceptance of screening as a means of 'moral positioning' to ensure that screening works for them, the situations they find themselves in and that they can remain 'morally blameless' about having children with SCD. Other studies have found that women and men have been receptive to screening and genetic testing, so they can use it 'biopolitically' to 'pragmatically calculate the value genetic testing, may hold or may not hold for their lives' (Fulwilley, 2004: 157). In some African countries, like Nigeria, an implicit policy of prevention exists in people being tested to understand their genotype, often at university or during pre-marital counselling. Religious counselling by churches is directive and aims to stop people with the trait from having a relationship to prevent births of children with SCD. Yet, this will not lead to a reduction of births of children with SCD and increases stigmatisation of people with trait and SCD (Ola et al., 2016), thereby increasing potential for discrimination against them (Berghs et al., 2017; Dyson, 2019).

What has been given less attention in public health debates on screening for SCD, is the importance of access to cost-effective contraception and information to enable reproductive choices for women and men. Screening also ignores the fact that women and men having children, may themselves also have SCD and may want to have their partners tested. They will also need counselling services and information about the risks of pregnancy and likelihood of having children with SCD, if they have a partner who carries the gene, which they may want to avoid or accept (Sickle Cell Society, 2018). In particular, clinical services for managing pregnancy for women with SCD need development but have been shown to be successful with multi-disciplinary teams, despite challenges, in other West-African settings (Olugbenga, 2019).

Policy has to ensure equity and if prevention is emphasised through individual screening, this ethically cannot be at the expense of ensuring better care for people with SCD (Dyson & Atkin, 2012; Chattoo, 2018; Dyson, 2019). In countries in Africa, like Sierra Leone with high rates of teenage pregnancy (WHO, 2015a,b) and where illegal abortions cause maternal and infant deaths (Paul et al., 2015), it is essential that there is education and affordable access to family-planning alongside counselling for testing. Similarly, if informed choices are to be made and non-directive counselling services implemented as a matter of equity (Anie et al., 2016), new-born screening programmes should also be instigated. New-born screening for SCD has been shown to be both medically and economically cost-effective in other sub-Saharan African countries (McGann et al., 2015; Hsu et al., 2018; Dyson, 2019) and West-African neighbours like Liberia have begun small pilots (Tubman et al., 2016). Improved survival of people living with SCD into adulthood, is likely to become a feature of SCD prevalence in West African countries like Sierra Leone in the decades to come. In Sierra Leone, there have been many public health programmes, free health care and other initiatives on various aspects of improving maternal health and child survival. Under-five mortality rates, while still high, have fallen since the country's ten-year civil war ended in 2002 (SSL & ICF, 2014). Post-Ebola with sustained healthcare systems strengthening, mortality rates should continue to fall and the proportion of children with SCD surviving will increase. Awareness and capacity, within both the public health and education sectors, will need to evolve. One area in which we know that considerable complementary expertise exists, is in the voluntary sector and in knowledge that parents and people with SCD have (Sickle Cell Society, 2018).

Being a mother of a child or children with SCD is all consuming, especially when dealing with a healthcare system that is inaccessible because of cost, discriminates or does not understand SCD (Hill & Zimmerman, 1995). Mothers are often at the frontlines of the impact of the condition on their children, in care-giving, in seeking medical diagnosis, seeking various treatments for various ailments



and during long and sometimes life-threatening hospital stays or emergencies linked to their child going into crisis. For both mothers and fathers, this ‘fighting’ for their children remains constant, unpredictable, sometimes with no relief and often becomes correlated to individual and relational psychosocial impacts (Hill, 2018). Parenting a child with SCD requires hypervigilance about signs and symptoms of SCD and passing on that knowledge in terms of ‘strategies’ and ‘tactics’ to their children so they can manage the condition themselves (Keane & Defoe, 2016; Dyson, 2018). This parental knowledge or ‘praxis’ is often very important for survival of children with SCD and includes both the local and global understandings of SCD (Dennis-Antwi et al., 2011; Dyson, 2019). One area where we know that this parental knowledge has played a big role in improving life-chances of children with SCD, with help of the voluntary sector and research, has been in accessing primary and secondary education (See Dyson et al., 2010, 2011). While we have a lot of medical knowledge about health of people with SCD, the importance of voluntary organisations, parental support groups and the roles of people with SCD have often been neglected in research. One aspect of this neglect has been a lack of knowledge of how best to support families, and especially women caring for children with SCD or women with SCD. This report hopes to contribute to such knowledge in Sierra Leone, by describing some of the barriers that women face in their daily lives living with SCD and what enables mothers to care for their children with SCD.

### **3. Methodology**

This project was participatory, working with two different sickle cell non-governmental organisations (NGOs), Sierra Leone Sickle Cell Society (SLSCS) and Sickle Cell Carers Awareness Network (SCCAN), being led by women who had children with SCD. The project proposal was co-written and all possible ethical issues were discussed beforehand. This was inclusive of how data would be safely managed and stored inside and outside the country. Ethical approval for this study was given by the Allied Health Sciences Governance Board at De Montfort University. We selected two different regions of Sierra Leone to recruit our participants. We wanted to ensure that we captured the differences between the rural and urban context by selectively recruiting from the capital of Freetown and urban Western Area District, and the more rural north in Koidu located in the Kono District. Sampling was purposeful and was focused on ensuring maximum diversity (Barbour, 2014; Bryman, 2015). While recruitment was voluntary, we ensured a range of ages, ethnicities, socio-economic circumstances, relational backgrounds, type of SCD and impairment were included (See Appendix Two).

Interviews were conducted in June 2018. Verbal information briefings about the project were given to women who belonged to the organisation before recruitment. All interviews were voluntary in nature and could be stopped at any time. NGO workers were present before and after the interviews to deal with any questions. Before any interviews took place, information sheets were given and read out if the women were illiterate. All participants signed (by signature or thumb print) a consent form and were assured of the confidentiality of the interview. They have all been given pseudonyms in this report. Almost all interviews took place in the lingua franca, Krio, and were digitally recorded after permissions were given.

The interviews were led by the Sierra Leonean heads of the NGOs, Mrs. Gabba and Mrs. Nyandemo. As mothers of children with SCD they had the appropriate sensitivity, trust of the participants and counselling skills to undertake the interviews if women got upset. Dr. Berghs was also present but in a secondary role to act as support, probe issues in more depth from an outsider’s perspective and ask follow-up questions to confirm meaning. These further questions were mostly linked to ensuring diversity in sampling by checking data saturation and actively seeking disconfirming cases through

insights generated in earlier interviews, often around sensitive topics like family planning (Bryman, 2015). They also had another role, in keeping with anthropological principles (Hammersley & Atkinson, 2007), Dr. Berghs made sure that she did away with any idea of herself as having expertise and instead tried to emphasise that she needed to be taught by all the women, inclusive of main interviewers, about SCD. This lack of expertise was emphasized through illustrating lack of command of the Krio language, openly deferring to Mrs. Gabba and Mrs. Nyandemo by asking them to explain issues, often openly getting the participants to join in by getting meaning wrong, thus needing to be corrected.

In total 36 women were interviewed; 18 women in Western Area Urban District and 18 women in the Kono District. 20 of the women were literate and 16 were illiterate. All women who had SCD (either sickle cell anaemia, HbSS or haemoglobin SC disorder, HbSC) were aged 18 and over). Of the 18 women with SCD, six of those women also had children with SCD and one had a child who did not. Inclusive of the sample of women with SCD were three with HbSC but not everyone knew the specifics of what kind of SCD they had. We interviewed 12 women with SCD who had no children yet and 16 mothers of children with SCD. Two interviews were undertaken with grandmothers who had responsibility caring for a child/ren with SCD. Most women were actively involved with the NGO and some in Koidu were also involved a research study where they were accessing free healthcare and medications. This did affect the sample and there is a possible bias towards participants who have links to the NGOs and participants with connections to other researchers. However, their inclusion did reveal how SCD could be managed, why research is important and what treatment was effective, as well as why treatment was lacking. We also did not interview any women who were in highly paid formal employment, and while we accessed a range of ethnicities (e.g. Temne, Mende, Mandingo, Limba, Maraka), no Krio women took part in our research (See Appendix Two). These are important limitations to consider and made any comparisons across socio-economic status and ethnicities difficult.

We ensured that interviews were accessible, paid for transport and made sure that mothers could also bring their children and breastfeed if needed. After each interview, a small payment was given to the participants for their time. We discussed themes together with the NGO staff after the interviews to ensure context and transparency. Interviews were transcribed in full and then further checked by a Sierra Leonean for correct meaning. Analysis was conducted using the qualitative software programme NVivo, using an adaptive approach (Layder, 1998). Adaptive theory was appropriate as it situates particular human life accounts in relation to broader contextual resources and historically-given social structures.

#### **4. Findings**

In Sierra Leone, women's lives were affected by two major historical moments. First, a ten-year civil war that lasted from 1991 to 2001 which led to massive loss of lives, familial displacement, sexual and other forms of violence, interrupted educations and meant hardship during the conflict and in the post-war years. Second, from 2014 to 2016, the country was also part of the largest Ebola epidemic that the world has ever seen, which led to thousands of deaths; again, affecting women and leading to familial loss, unemployment, resurgence of sexual violence and interrupted educations.

These moments are interwoven in the stories that women told of the past and how they were related to their present struggles, mainly associated with living in times of austerity in 2018 with what they viewed as a serious illness and/or caring for children with that illness. Most of the women

were mothers or saw having children as important to their futures. It was this identity that structured the way in which they fought for and tried to access healthcare for their children (Hill, 1994). They often gave a religious dimension to explain the reasoning behind their caring roles and relationships to children with SCD.

*“What is giving me power, for this child? For a woman the first thing is to have a child. If a woman does not give birth to a child, then God has deprived her of something. So, if God gives you a child, and one has an illness, you do not blame God because he knows the reason why that happened. God doesn’t do anything that is bad. He knows why. That is why I go anywhere I hear of treatment or medicines or help, so that my child could grow up to be somebody in the future. That is why I wake up at night and pray for her. I raise my hands up and pray for God to solve my problems; and to solve the problems of others. I don’t have any power only God does. Anything that humans are able to do is from God. That is my belief that is why I have the heart to take care of my child.”*

Djenabou, 27, Koidu

Historically, the interviews revealed local and global inter-generational knowledge and medical expertise about SCD in Sierra Leone that exists side by side and goes back decades. This expertise is gradually being scaled-up, since the health sector is being rebuilt with the help of international agencies. However, participants related that this knowledge can exist in silos and that they often have to travel for correct medical services, still consult traditional healers or herbalists in rural areas (with miss and hit results), and often cannot find good hospital treatment in emergencies.

It was related that men and women, as parents, were involved in trying to find a diagnosis and correct treatment for their children with SCD. The extended family also struggled to pay for that treatment during difficult government austerity measures. Tough years post-conflict and now during austerity, was having an impact on families staying together and led to men, who could not access employment, feeling they could not always care for children or wives if they had a long-term condition. It was women (i.e. mothers, grandmothers, aunties and sisters) who mostly took on caregiving responsibilities. Moreover, it was women with SCD who suffered the embodied consequences of a lack of healthcare combined with neglect of national standards of care and public health education on SCD. Sierra Leone has one of the highest rates of maternal and child mortality in the world (WHO, 2015b) and moreover lost many skilled healthcare workers during the Ebola epidemic (Evans et al., 2015). This meant that there was a history of female embodied reproductive loss of children and ‘suffering’ that women took the opportunity afforded by this study to give voice to.

*“I do think of the woman, she lost twins and gave birth again, lost them, next birth was through a caesarean section and they asked her not to give birth again. Now the grandmother died. I sometimes think of the little children and wonder how they will be in the future with all these pains and illness on and off. Sometimes, I feel sorry for my son and it makes me feel so sad.”*

Khadija, 54, Freetown

This report gives an overview of key themes that arose from the research which are addressed in turn. First, a historical memory of the condition and its effects exists, which is important to learn from and understand to combat stigmatization of people with SCD. Second, past expertise and local knowledge is being lost because of the lack of social and public health education. That has had dangerous effects in incorrect medical diagnosis, in inappropriate advice and in the general public

fearing the condition. Third, there has been a neglect of the reproductive and relational implications for women which can lead to deaths. Fourth, due to the work of the voluntary and medical sector there is awareness in parents, schools and the community. This can ensure that a child with SCD thrives and that their SCD develops into a long-term chronic condition. The report gives some further recommendations and argues that it is time for a five-step National Policy on Sickle Cell. It begins by situating why a historical memory matters.

## 5. A historical memory of a condition and its effects

A record of diagnostic training, medical resources and laboratory testing of SCD has a long history in Sierra Leone, West Africa and in the diaspora but which has been lost. People know about SCD and related family histories of screening as well as knowing people with SCD. This lost history came out in several interviews with older participants, especially in the north of the country, where testing of men and women had been normal. For example, Finda, who was 45 and interviewed in Koidu, explained that they knew about SCD in her family.

*Finda: My father was tested in 1976.*

*Interviewer 1: 1976. Where was he tested?*

*Finda: In Tombodu.*

*Interviewer 1: He was tested at the Tombodu Hospital? (...)*

*Interviewer 2: Was there a lab at Tombodu?*

*Finda: Yes. At that time nurse (name) was working at the hospital.*

Women often shared intergenerational memories of family members who had died or had the condition. Dejenabou, who was the 27-year-old mother of a daughter with SCD and possibly had the illness herself, was told by her aunt that one of her aunt's sisters had SCD and had died of it. Likewise, similar to the Nigerian conception of *ogbanje* (spirits who come and go) (Schneider, 2016; Dyson, 2019), SCD was described in similar terminology.

*"People felt that the child won't live. They say it's the same child. He or she comes and goes in death."*  
Sally, 46, Freetown

Older women with SCD also related how foreign healthcare workers in hospitals, or who they came in contact with before the war, or expats, also knew what SCD was. For instance, Harietu, who was 65 years old and interviewed in Koidu, said that she understood how to care for herself, for example, by staying hydrated, because her father's boss gave that advice to him. "He told him that I should not drink coffee. He told my father that every morning I should have a cup of tea, eat cucumber, pear... my father did not have that experience." Mabinty, who was 36 years old and interviewed in Freetown, remembered feeling afraid when people told her she had SCD because she said, "I remembered a lady in our compound who had 'the sick'. It used to disturb her in the rainy season and harmattan." Similarly, Dawa, who was 30 years old and interviewed in Koidu, explained how

during the civil war when she had to flee with her family, her uncle used his raincoat to keep her dry so she would not get an ‘attack’.

However, post-war and post-Ebola, participants recounted that SCD had been neglected by the national and international community. These inequalities, in how many people SCD affects and the lack of resources for the condition were often starkly alluded to. Women could not understand why the condition was labelled in the same terms as other ‘diseases’ with no cure but then neglected. These inequalities continued during the Ebola epidemic, as people with SCD were affected as patients and became Ebola survivors. They also got involved in fighting the Ebola virus, for instance, in activities such as community sensitisation work or with religious organisations. Especially in Koidu, where women had formed an active parent’s group, several participants were clear about the lack of material benefits, for their SCD illness, in terms of vehicles, medicines and specialised clinics which had been mobilised for other conditions. For example, Harietu, who knew how sickle cell had been treated in the past and had seen the resources being built up around different illnesses over decades, related:

*“Dry cough-TB, they are bringing medicines for it; they are bringing vehicles for it. Also, leprosy, they are bringing vehicles, medicines and have a hospital, but they do not care for this disease. The white people are fighting for malaria, for leprosy, HIV, but they do not care much for sickle cell.”*

#### a. Signs and symptoms of sickle cell

Part of this historical memory was correlated to understanding the signs and symptoms of SCD. Most participants related that the condition is typically known as affecting the bones or causing ‘bone pain’ or ‘pain inside of the bones’ as main symptom. In Koidu, Finda, who was 45, explained, “They call sickle cell, *mengeh*; they do not know sickle cell. It affects the bones, like arthritis.” They noted similarities to arthritis and malaria that people could articulate, in terms of feeling pain. Other signs and symptoms of SCD, like becoming ill all the time, having swollen hands or/and feet as well as crying a lot were often described as being identified early in infancy, often a few months after birth, if medical expertise was there.

*“While I was still a suckling baby, during (name) time, I was crying a lot. My mother took me to the (name) hospital in (place). (...) My hands and feet were swollen. According to what my mother told me, that is when they told us that I had sickle cell.”* Dawa, 30, Koidu

People with SCD were described as being very thin, ‘sickly’, and, because they had anemia, they sometimes had yellow eyes. We also heard that the words ‘bone’ and humoral states of the body like ‘dry’ were being used to bully children with SCD due to their thinness. Dawa said that she was called names because she used to be so thin. This was before she accessed medical care that allowed her to gain weight. She explained how people made fun of her for being ‘thin’ and ‘dry’. She stated: “Yes, dry. Sometimes they call you *gbagbakuru bonga*. Isn’t it?” The signs of yellow eyes were also misunderstood in relation to contemporary suspicions.

*“Yes, they provoked me calling me ‘bone’. They asked if I smoked marijuana since my eyes are always yellow.”* Fatima, 23, Freetown

Some mothers spoke of their children having ‘attacks’, meaning that the bone pain was extreme to the point that were in severe life-threatening pain, requiring immediate pain relief and/or hospital visits. In the Temne language, SCD was referred to as ‘*gbalan gbalan*’ or ‘*gbalam gbalam*’. Sally who was 46 years old and interviewed in Freetown, stated how it was her grandmother who explained that her mother had the condition. She said that during the last ‘attack’ (*Kaa gbakpai* in Mende) she had died. In explaining cause of these ‘attacks’, some women made allusions to ‘traditional’ beliefs around illness and unexplained deaths.

### **b. Witches, traditional healers and blame**

In the historical consciousness and popular imagination in Sierra Leone, there is a child figure of a witch with a distended stomach (See Shaw, 2002). One of the signs of SCD can be a swollen spleen.

*“Anybody who has witch, or a child that has witch especially in Sierra Leone, is said to be able to destroy, kill and hurt people. So, when they see a sickle cell child with swollen (big) stomach, ...Yes, a child whose eyes are always yellow and changing colours, who doesn’t like looking directly into the eyes of the next person because he doesn’t want the eyes to meet, especially when that child is losing weight, is thin and has a big protruding stomach, they say that the person has witch. And it is the witch that makes the child looks ‘korshi’ [malnourished]. That is the reason why people are afraid to help. They believe that the money or help received would be taken into the witch kingdom enabling the child to destroy, kill or harm the giver and destroy their resources, and they will not be able to regain their resources.”*

Siabanda, 19, Koidu

We found that the witchcraft accusation was affecting women with SCD in Koidu and Freetown. Mimicking both the colonial history of the Atlantic slave trade and the present neoliberal realities in Sierra Leone, the witchcraft accusation focuses on a bodily exchange having been made (often resulting in impairment or illness) for riches or political power (Shaw, 2002; Berghs, 2018). Generally speaking, witchcraft accusations tend to be made when there has been disharmony in kinship relationships or patriarchal power is under threat (Shaw, 2002; van de Grijsparde et al., 2014). The accusation is usually aimed at a woman (i.e. a wife as outsider to a kinship group) or women’s actions that threaten the kinship group or relations (Schneider, 2016). Impairment and illness are constructed in terms of misfortune, social defect and moral blame, which need social actions to engage in moral repair, by for example, consulting a traditional healer and/or doctor (Berghs, 2018).

In Koidu, Keima, who was 18 years old and had SCD, explained that none of her peers wanted to play with her when she was small and called her a witch. She said that she was taken by her mother to places where they could ‘cook’ her stomach. She said. “The Konos call it *kundaba*. That *kunda* is in my stomach.” This is similar to the idea of the spleen or liver distending into the stomach as ‘witch’s cauldron’ found in Ghana by Dennis-Antwi et al. (2011). In Kono, *gbonda* was the name given to the witch but in differing contexts it also meant spleen as will be illustrated below. Witches were also associated with the night (Shaw, 2002) and children who do not sleep, like children with SCD being kept awake by pain, were under suspicion. If a child with SCD had a chest infection this was also linked to witchcraft and for example, a witch rope tied around the child that had to be cut.

*“When I fell ill, the man cut my body with razor blades (...) he cut around my waistline but still the illness persisted. Another country medicine man told us that they had tied me with ropes*

*so as not to have children and that was affecting me. He pulled out a rope from my body and showed it to us; they said that the illness was over.”* Amie, 23, Koidu

Women with SCD related how they had to be released from ‘witches’ ropes preventing wellness and reproduction, by the ropes being ‘cut’ from their bodies. However, ropes and lappas (a traditional African cloth) were also used to tie them down to stop the severe bone-pain. Due to pain being felt in the bones, people related asking people to put pressure on the bones by tying them, sitting on them, and having blocks of cement or heated stones placed on them. A mother related the treatment for her child, which was very dangerous in terms of dehydrating him and making the pain worse.

*“He is inside the hole. They put sticks across the hole, spread fresh leaves on top of it, not dry ones, green fresh ones, and light it. It smokes, not burns, with the heat meeting him down there and making him sweat.”* Kumba, 30, Koidu

More often than not, especially in the rural areas, people related being tied with lappas or bandages. Sally who had told us about her mother having the condition explained how she had been tied (*ta ngie ngie lo*) with cloth to combat the pain she was feeling in her bones. However, this was recounted by people in Freetown too.

*“When one of them had the attack (crisis) recently the neighbours came and assisted us to get transport to go to the centre. They tied their bones hand and foot (...) this is because of the pain to reduce the pain and help them stop crying.”* Sarah, 42, Freetown

Mabinty too, remembered the lady who lived in her compound and who used to get ‘the sick’ having to be tied. In the Temne language, the word for tying was related as *ashakteko* and in the Kono language, people mention *anachi*. In Freetown, Isha who was 25 years old, clarified how signs of SCD were someone being ill all the time and having yellow eyes before they went into a crisis. She explained, “She gets severe bone pains on and off. We do tie them when she is in pain.” While being tied with lappas was not helpful (because tying might further constrict blood vessels and ultimately aggravate the pain), staying warm with blankets, having a massage and or using a hot towel or water bottle was. However, the tying was not always with cloth and was also linked to herbs being ‘tied’, especially in one instance when relatives refused to pay medical and traditional healers. Instead, country medicine was accessed (Bakshi et al., 2013) and knowledge of pain relief as handed down by her grandmother.

*“Sometimes, when my bones ached, they did not care much. They said to me that they were tired. They had tried so much to get treatment for me but were now tired. That if I wished to die then I should. I cried a lot. I tied my body with country leaves (country medicine). My grandma would go to the bush to pick the herbs and tie my bones. When I felt better, I would go back to doing housework.”* Fatou, 35, Koidu

Harietu too related how crushing certain herbs gave her relief from pain.

*Interviewer 1: Wait... the spice drink given to us after delivery. What is its name? Kandi koneh?*

*Harietu: Kandi, yes. I crush it and apply it to the joints. I feel free [from pain] afterwards.*

*Interviewer 2: I don't know what Kandi is?*

*Interviewer 1: Koneh korgbor is the bark of a tree. It is dry.*

There were a few good local healers or herbalists, who seemed to have an understanding of the cause of bone pains and used a tree called 'bone to bone' (*kookai* in Kono) to treat it. For instance, Patricia, who was 24 years old and interviewed in Koidu, related:

*Patricia: There is also a plant that grows in the swamp called, Gbwe-gbweh. They cut a stem, take off the bark, chop and steam it in a pot until it was hot. They then wrap it in cloth and lay it here...*

*Interviewer 1: On the spleen?*

*Patricia: Yes, because it was enlarged. It scalded my skin around the spleen (Gbonda), but the scar faded. The [country medicine] was for drinking, washing and laying it on my side; I did it all but... "*

The same stories were related in Freetown but not in as many interviews by women. For example, Fatima who was 23 said, "*Gbangba and sheku turay*. They boil the roots and leaves respectively and give it to me to drink for pain and malaria." These herbal remedies did sometimes seem to work for malaria and so women did access them. However, women also encountered charlatans and crooks who claimed they were 'native healers'. Especially in the more rural areas where medical care was less readily available, women were desperate for a diagnosis.

*My mother had tried [to help] and I was so ashamed because my child was always sick. I would hide my clothes and sell them so that I could have money to take my child to the native doctors for treatment."*  
Dejanbou, 27, Koidu

The costs of going to see traditional healers were vastly more expensive than going to seek medical advice but women *had* to morally try everything, especially if SCD was not helped by traditional medicine and if SCD was being incorrectly medically diagnosed, a point we will return to later.

*"Another man, a Limba, charged me Le 550,000 (five hundred and fifty thousand Leones) and told me that the child was tied up [through witchcraft]. He collected some herbs. Later he told me that witches had visited him during the night. I couldn't see any change for the better in the child's condition. So, I stopped going to him. I went to different people and many places with this child. Some of the food she was given to eat and medicines they tied around her body made her choke. It continued and weakened her."*  
Suma, 30, Koidu



## 6. Lack of social and public health education

The moral blame that women felt, compounded with current lack of social and public health education about SCD, was also causing a culture of secrecy linked to SCD. This was enabling the stigmatisation of SCD and people with SCD (Dyson, 2019). It was also leading to the social invisibility of the condition.

*"The information was very bad. The time I knew, was when people regarded sickle cell as a terrible illness. Nobody came close to my child. I was always tormented. I didn't know it was not the type of illness I should run away from. I didn't know it was something that my husband or myself could have passed down to my child. We thought it was witch. It was believed that sickle cell could be transferred from person to person. No one wanted the disease transferred to them. We had no peace from the time we knew that it was sickle cell. I came back and told my parents. I told papa that the child had sickle cell. My dad cried. He said it was a dreaded disease and I should not tell anyone about it because it would not be good. He said that the disease was killing people and killing children. From that time, I kept it as a secret."*

Kumba 30, Koidu

When there was information it was often faulty and sometimes linked to hearsay. In both Freetown and Koidu, people with SCD and mothers were often told that a person with the condition would not live past 21 years old. This had a detrimental mental health and relational effect on women with SCD and families. Such stories were pervasive, both in the past and present histories we heard. Mothers, grandmothers and women with SCD all related fears about people with SCD not living long lives.

*"I was discouraged and used to cry. I felt sad especially for all the things I used to hear about sickle cell. Then some say you grow with it until 21; when they can be strong or die."*

Bintu, 55, Freetown

*"When I was told that she had sickle cell, people were saying that anyone with sickle cell did not get well. That they would die by 21 years and her condition made me very unhappy."*

Suma, 30, Koidu

There was also a dangerous lack of public health education in schools about what SCD was and how it was caused. This was despite excellent initiatives such as the SCD school clubs that have been running for several years in certain schools in Freetown (Dyson, 2017). This also affected women with SCD, who did not know that their condition was genetic and inherited from their parents.

*Interviewer 1: Could you tell us how one gets sickle cell? What causes it?*

*Isatu: No idea.*

When women did have information, it was very medicalised or given in biomedical terminology that most people did not understand. In a country with some of the highest illiteracy rates in the world,

where only around 25% of women aged 15 years and older are literate (UNESCO, 2019), more thought needs to be given how to make SCD accessible in awareness, education and training. While SCD is often described in terms of round blood cells forming a sickle cell shape, this does not always translate to women with minimal education. Amie, who was 23 and interviewed in Koidu, explained, “We are told that people who have sickle cell have something that looks like a banana in their blood. Those without sickle cell, theirs is round.” While mothers and the people affected may not have understood the causes of SCD, the signs and symptoms were not understood by healthcare professionals either.

#### a. Incorrect medical diagnosis

In 2010, Sierra Leoneans began the Free Health Care Initiative that aimed to give pregnant and lactating mothers and children under five, access to free healthcare in government hospitals. While this programme had some success, poorly resourced healthcare facilities, inadequately trained staff and lack of infrastructure meant that women and children did not always have the resources or capital to access this ‘free’ care (Diaz et al., 2013; Witter et al., 2016). The programme was also interrupted by the Ebola epidemic, which led to a rise in maternal deaths and reduced accessibility to healthcare. In 2017, the WHO began a new five-year strategy for Reproductive, Maternal, Newborn, Child and Adolescent Health in Sierra Leone (WHO, 2017) but it remains to be seen how successful this initiative will be. We found limited impact of such initiatives in our study which we outline later. The first issue that women brought up, was incorrect medical diagnosis and treatment due to limited medical and nursing education.

*“It is only now they have included sickle cell in their (nursing) studies. Even in school it is only now that it is a topic. We never studied it or knew about it. Even in the hospital it is only (name) that will give you the correct treatment. Most of the others will make some mistakes. Sometimes, due to our experience, we the patients will refuse some of the wrong treatments and show them the correct treatment and they will make a note of what is good for sickle cell patients and what is not good for them.”*  
Susan, 30 years, Freetown

People who carry the sickle cell trait are mostly healthy. As stated earlier, a father and mother both have to carry the trait in order to pass it on genetically to their child. In each pregnancy the woman, with the same man, will have a one in four chance of having a child with SCD. It is very important to identify children with SCD in infancy, so that they can be vaccinated and antibiotics can be administered to prevent life-threatening infections or diseases (Sickle Cell Society, 2018). Despite the importance of early identification of infants, most mothers related that it took several years for their children to get diagnosed in primary care. Most people with SCD and mothers of children with SCD noted histories of incorrect medical diagnoses. It is very important to identify children with SCD in infancy, so that in postnatal care, they can be vaccinated and that antibiotics can be administered to prevent life-threatening infections or diseases (Sickle Cell Society, 2018). Early interventions like folic acid and ensuring that the babies sleep under a net from six months onwards can save lives. The signs of SCD begin very early and mothers stated it could start from as early as two months with the child becoming ill frequently up until two years.

*“After I gave birth, from about four months, the child was always very ill.”* Djenabou, 27, Koidu

Inability to diagnose SCD was the same in the urban and rural settings. The signs of hand-foot syndrome were not understood by medical professionals nor mothers especially if they had not heard of SCD.

*“The child was crying very often. One day I observed and found out that his hands and fingers were swollen but I did not know about sickle cell and did not understand.”*

Mariama, 39, Freetown

In a country with a high infant mortality rate, with priorities focusing on immunisation of children and prevention of major childhood diseases, malaria, diarrhea and encouraging breastfeeding (WHO, 2017), SCD is commonly missed in antenatal and primary care.

*“He used to be sick so frequently, but each time they said it was jaundice, and never sickle cell. This was despite the fact that his eyes were turning yellow. This second child, the girl, she was never getting frequently sick but by the time she was preparing for her WASSCE she fell sick and that’s when we did the test and confirmed it. Her eyes also used to turn a yellow colour, but they said it was malaria.”*

Hawa, 38, Freetown

While it is important to treat such illnesses, incorrect diagnosis was impacting on children and people with SCD, and this could have dangerous outcomes, for example, in terms of misdiagnosis of issues with the spleen, of abdominal pain and inability to link SCD to strokes, which is an outcome of SCD in many children.

*“His eyes were yellow and they told us to do hepatitis test, which we did. The result was negative. They asked us to repeat the test. The boy’s stomach was swollen and they said to do that test?”*

Mariama, 39, Freetown

However, mothers did not relate stories about strokes but instead how incorrect diagnosis and treatments were again making people more ill.

*“When we went to the hospital, they would tell us it was typhoid, malaria; those were the sicknesses they would say. They gave us medicines which when I took only made me get worse. At a point my stomach was swollen, my body was also swollen.”*

Siabanda, 19, Koidu

Most mothers related that they had to strategically learn what the outward bodily signs were of SCD in terms of yellow eyes, tiredness due to anemia, distended stomach because of swollen spleen, breathlessness or rapid heartbeat. Generally speaking, due to training linked to nutrition and multi-sectorial focus on anaemia (MoHS, 2018), anaemia or, as stated above, typically jaundice was being picked-up by healthcare professionals (Wirth et al., 2016). However, no links were being made to SCD and no training was given on the association between anaemia and SCD to healthcare workers (Wirth et al., 2018). Mothers who had children with SCD often told tragic stories of children who they had lost in birth or early infancy.

*"I came and they gave me paper for the blood test for the two children, then it was proven that they are SS. By then, I had lost my first child when I came here." Mabinty, 36, Freetown*

*"Yes, six children are alive and some are living with sickle cell. Of the four who died, three had sickle cell. They are now dead and gone." Bintu, 55, Freetown*

## **b. Late diagnosis and incorrect advice**

Worryingly, all mothers and women with SCD related that there had often been a very late diagnosis of SCD due to diagnostic overshadowing, especially when children had another form of disability, for example, like epilepsy. The lack of understanding of the condition in primary and secondary care workers was explained in most interviews. While evidence would mount that a person might have SCD, patient histories were not being adequately studied and healthcare workers did not have enough training. Suma explained:

*Interviewer 1: No, he did not know he had it. What was he being treated for?*  
*Suma: Malaria. Whenever he was ill, he was told that he had malaria.*  
*Interviewer 2: Malaria?*  
*Suma: He had malaria every month.*  
*Interviewer 2: Every month? He had malaria every month?*  
*Interviewer 1: How old was he when both of you got to know that he had sickle cell?*  
*Suma: He knew last year.*  
*Interviewer 1: Last year?*  
*Suma: Yes.*  
*Interviewers: How old is the man?*  
*Suma: The man? He is 32."*

While bone pain and treatment of pain was recognised, organ damage, chest infections and common complications like ulcers or issues with vision were not understood to be linked to SCD, and all were incorrectly diagnosed. Diagnosis was almost always late in most participants, and incorrect advice was being replicated in urban and rural contexts. It was noted that there had not been any thought given to the varieties of SCD that exist and corresponding advice to give. SCD is a variable condition and will affect people differently. There were also women with milder versions of SCD like HbSC but this medical advice was not always related to them by healthcare workers. We come back to why we think this was the case later. What did get attention was serious pain requiring hospitalisation and issues needing specialised secondary and tertiary care, like blood transfusions, abdominal and hip 'pain', which we discuss later.

### c. Real fears of testing: creating a stigmatised condition?

When SCD was correctly medically diagnosed, the fear of blame for women was compounded with fear of inability to care for a child that they believed would have extra costs and die young. This mentally affected some mothers and children negatively.

*“When my mother gave birth to me, they took me to the hospital and the doctor told them that I had sickle cell. I was told that they checked my bones. My veins were so pronounced. That is why my mother ran away from me. She left me with this my aunt’s mother. She is the one who brought me up.”*

Fatu, 27, Koidu

The lack of knowledge and fears around the condition, which was always mentioned as ‘sickle cell disease’, meant that there was also stigma being built up around testing for a ‘disease’. SCD was also becoming linked to other incurable diseases, as the first thing that healthcare workers did was mention that the condition was incurable which was not always understood by parents or their patients.

*“She felt bad because the nurse had told her that there is no cure available. She told me that by then I was very young, about five years. That the nurse had told her that no medicine would cure it. The medicine I was taking was just to help me manage my life. It is not like taking Panadol and getting cured. She [my mother] gave up hope and thought that I will die.”*

Patricia, 24, Koidu

If SCD was a disease and ‘incurable’, for many people, this implied that you could catch it. The second thing that professionals told mothers, was that this ‘incurable’ disease was passed through the mother and father.

*“They said it’s in a family (hereditary), that if a man has trait and wife also have trait you can have children with SS.”*

Mabinty, 36, Freetown

This explanation was not really understood. It often led to men and women blaming each other for the birth of a child with the condition.

*Suma: He thought that I was responsible for giving birth to children with sickle cell.*

*Interviewer 1: Did you believe that?*

*Suma: When I came here, we were told that this illness is passed through the blood, either transferred through the blood of the mother or father. So, I accepted it as I gave birth to them. Even if it was through my blood, I accepted it.*

*Interviewer 1: They could get it through the mother and father.*

*Suma: I am aware now. If he didn't have it and if it wasn't for my blood all the children would not have been born with it.*

Diagnostic tests were very expensive for ordinary people and not always reliable. The diagnostic test can cost up to 200,000 Leones which parents often did not have the ability to pay. They are more expensive in private hospitals and clinics, making testing inaccessible for most people. The average national minimum wage in Sierra Leone, per month, is 500,000 Leones which is around £40 pounds.

*"We went to a private hospital called (name) where they did his tests. We had to pay before the test was done. We paid two million five hundred thousand Leones for the test."*  
Fanta, 25, Koidu

While it might be important for a child to be tested, in terms of accessing treatment, parents often struggled with understanding why they needed to have the test (See Dyson et al., 2016; Dyson, 2019). People who carry the trait are told they healthy and they do not need treatment. Men often refused to be tested, as for some, the blood test was linked to other blood tests for infectious diseases like HIV. This meant that women, who were mostly in contact with healthcare workers, were the ones who were approached and got tested. The healthcare workers were sometimes connected to the voluntary sector that was providing them with medicine and advice, further adding to possible pressure to test in order to access emotional and material resources. Yet, in Sierra Leone, testing positive for the sickle cell trait, meant that mothers had to accept the moral responsibility and thus blame for their children with SCD. This complicated testing even further and changed how it was perceived.

*Fanta: If I had known that the man had sickle cell, I would not have married him.*  
*Interviewer 1: Why?*  
*Fanta: Because of the manner in which he treated me when we didn't know that the child has sickle cell.*  
*Interviewer 2: How did he treat you? Did he beat you? What did he do?*  
*Fanta: He didn't want to know about the child; he didn't feed us, nothing. He didn't want to know.*  
Fanta, 25, Koidu

These women wanted their husbands or partners to take the test, in order to guarantee that they were not solely blamed for the illness of their child, for example, in terms of witchcraft. Women also explained that after women were found positive for trait, men often contested their paternity which they felt a test could confirm. Jenneh, who was 37 years old and had access to laboratory services in Freetown, explains the difficulties in understanding what it meant to be 'negative' but be told you are carrying the gene for sickle cell.

*Interviewer 2: If they have a child with sickle cell, what's the point in doing the test? Both of*

*you have it?*

*Jenneh: My husband denies always, so there is need to prove that he is the father. While my husband denies, he is the only man in my life. I went to (laboratory for testing) and they tested me but the result was negative. They told me to go again after 3 months but I never did."*

When men got tested or admitted they had the trait or SCD, this often led to 'peace' for women and their acceptance by the extended family. Yet, it could also have unintended consequences for men. Fanta goes on to explain that she would not have married her husband had she known his status because she would not have wanted a child with SCD. Women with SCD also related fears of having children with SCD because of the guilt, in terms of how much pain the child would experience. There is a danger that testing people who carry the SCD gene will lead to greater stigmatisation of people. There are signs that this is already happening and testing is not preventing culture of blame and shame of SCD. Letting people identify with their genotype as 'status' did not help matters either, as it was still linked to fears of witchcraft or had shifted the stigma to an incurable disease.

*"Some people don't play with us and don't accept things from us like food etc., because they say we have SS. That's why I only have one friend."* Kadie, 19, Freetown

Fears linked to SCD often had relational effects in the breakdown of a marriage, abandonment of women or children, and affected women's position in a kinship group and community. Even in present day Sierra Leone, women with SCD are being incorrectly told they will die early.

*Interviewer 1: You were heart-broken because you were told that you will die?*

*Patient: Yes.* Keima, 18, Koidu

## 7. Neglect of reproductive and relational health

The focus of UNSDGs and WHO initiative in Sierra Leone, is on combating maternal and child mortality and early marriage (WHO, 2017). Despite this, there was not much of an impact yet for women with SCD, who often recounted struggles with costs of healthcare and access to reproductive health. The most harrowing and distressing stories from mothers, were linked to experiences of childbirth. Mothers and fathers of women with SCD expressed fears and worries that their daughters would die in childbirth; which was already fraught with dangers for women (WHO, 2017). Furthermore, this was correlated to a lack of choices that women had linked to their reproductive healthcare and family planning (WHO, 2015a).

*"Interviewer 2: How old were you when you got your first child?"*

*Isha: I was 14 years."* Isha, 25, Freetown

Early marriage and teenage pregnancy are common in Sierra Leone (WHO, 2017), and most parents related trying to protect their girls from consequences of this. Yet, what this resulted in was a lack of choices and enforced ignorance of women with SCD. We explain how this is linked.

#### a. Lack of choices

Women were being advised to plan their pregnancies after they had been educated and/or married but not given adequate medical reproductive nor relational advice about how this would be achieved (WHO, 2015a). The advice to plan pregnancies often presumed a level of choice that was not present in the life stories that we heard in the interviews. Many women with SCD were actively encouraged not to have boyfriends, to concentrate on their educations and to engage in premarital screening. We heard different versions of healthcare professionals recommending that women with SCD have their children in their late twenties. For example,

*"(...) if you get pregnant it is a problem. Around twenty-eight or thirty it's alright to have baby so I am not thinking about family planning for now."* Fatima, 23, Freetown

*"They told me since I was small that I should be 25 to 26 years before getting pregnant."* Patricia, 24, Koidu

Despite counselling needing to be non-directive (Sickle Cell Society, 2018), it was becoming directive and not giving women informed choices. Counselling was actively telling women when and what they should do with their bodies but not explaining the medical evidence. Women with SCD were also being told that they should only marry men if such men had been screened for SCD. These men had to be found to be AA or not a carrier for the sickle cell gene.

*"They told us that when you want to get married, you should go with your partner to the government hospital for testing. If the man has it [sickle cell] both of you should not get married; but if he doesn't have it, then both of you can get married."* Patricia, 24, Koidu

*"We were also told that if you have sickle cell, you should not have a man who has it or else all the children you give birth to will be SS."* Amie, 23, Koidu

The above presumes that women have a lot of power and agency in sexual or other relationships and that men will want to get screened, which we have illustrated was not always the case. Many interviews with women explained how they had to create this choice secretly because of unequal balances of power in relationships.



## b. Family planning

Despite directive counselling and the importance of family planning for women with SCD so they did not get pregnant, they did not always understand where to access such healthcare, nor were given adequate counselling. Mothers with children with SCD were being advised to space their pregnancies by healthcare professionals and the voluntary sector. However, some women were being advised not to have any further pregnancies too.

*"Pieces of advice were given not to give birth again but to raise this one. My husband was happy that no more children would be born."*  
Sally, 46, Freetown

Despite advice on not getting pregnant, women with SCD were often confused if they could get pregnant because of their light or missing periods. Women with SCD related that they often had light periods that lasted for three days and when anaemic could have no periods. One girl told us that she believed her period was heavy but when told that this would mean having to change a pad every two to three hours said that it was very light. Some women had no periods due to anemia but did not understand that they could still get pregnant. Fatima related how she was only '18 to 19' years old before her period started which lasted only 3 days and only gave her light abdominal aches.

In a country with early marriage, some of the highest rates of teenage pregnancy and women experiencing high rates of sexual violence (WHO, 2017), we assumed that family planning would be discussed as a matter of healthcare and women's rights if a woman had SCD. This was often not the case and influenced by religious beliefs, counselling was becoming prescriptive. Yet, while counselling was prescriptive it was ignoring family planning with unintended consequences.

*"Interviewer 2: Do you know types of methods used, the injection and other types?"*

*Fatima: Yes, I heard of it but I have not joined. I know of abstinence. When you want pregnancy or children that's when you take it. "*

Fatima, 23, Freetown

The voluntary sector and healthcare professionals rarely discussed periods, sex, menopause or options of family planning with women who had SCD. Most women related that they heard about family planning through radio, via nurses or female friends. Often, they explained they had discussed such decisions with their husbands who were supportive of family planning. However, women noted that the onus of responsibility fell to themselves not to their husbands or partners. In some cases, they made those decisions autonomously, especially when there had been marital strife or a man refused to get tested. In those instances, family planning has to remain secret and it may be important to talk about it to a medical professional or receive counselling.

The most common NGO that they accessed was Marie Stopes but several women related how they had to keep this quiet from others. Shame still existed around contraceptive use, despite its importance to health of women who have a serious condition like SCD (WHO, 2015a; Sickle Cell Society, 2018). We also found that women were using methods to prevent getting pregnant but not to prevent sexually transmitted infections like HIV. It was also not clear that organisations, like Marie Stopes, were giving women with SCD the correct birth control and advice that they needed.

*“Yes, I have asked at Marie Stopes and told that nothing will happen to me. So, I took the injection once but had very heavy periods. It also came multiple times during the month, so I went back to them. They gave me medicine to stop the bleeding. I haven’t taken the injection again.”*  
Yenor, 23, Koidu

Women related a lot of confusion about birth control methods and no clear advice existed for women with SCD. For example, Patricia used the injection which made her bleed so she moved to taking pills. Gladys explained that the implant worked best for her but that she was not sure about the other methods. If in a relationship, women related issues in persuading their partners to use a condom, so one lady recounted accessing the morning after pill several times.

Similarly, women who had children with SCD or mothers with SCD were medically advised to space their pregnancies to make sure they could recover from difficult pregnancies. If women are to wait to have children or being advised to have children later in life, for their health, they need to learn about family planning and the different methods (e.g. implant, pill, condoms and coil). Currently, it seems that the responsibility falls to the women but that they are unaware of risks to their health and that they could still contract sexually transmitted infections. This is an important consideration for women with SCD as any infection could be potentially dangerous. Our interviews indicated that mothers and people with SCD were accessing Marie Stopes or Planned Parenthood in Sierra Leone. Yet, it was not clear that these organisations understood the complexities of the condition to be able to give correct reproductive advice.

### c. Safe births

While under-age marriage still occurs in Sierra Leone, despite it being illegal (WHO, 2017), one of the reasons it is discouraged, is because of the complications that occur during pregnancy. While this kind of pregnancy is actively discouraged, family planning for men and women, as mentioned above is completed neglected. Hence, 18 year old Isatu explained:

*Interviewer 1: Have you heard anything about family planning?*  
*Isatu: Not to have sex, and not to give birth under-age or I will die.*  
*Interviewer 2: Why would you die?*  
*Isatu: Under-age pregnancy can cause it.*  
*Interviewer 1: Anything on family planning?*  
*Isatu: No.*

Women with SCD did not understand how they could give birth safely, only that they would have high risk pregnancies. The consequences often also meant impairment and it caused one woman to become paralysed in a wheelchair. While they understood the dangers, they did not know how this

risk to themselves and their child would be medically managed. They were also scared of the pain of childbirth, believing it would mean more crisis.

*"The constraints; when you are having a baby, they have to give you something, so you don't feel the pain. You cannot give birth to your children in the same way that your peers give birth to their children."*  
Amie, 23, Koidu

Often, they had witnessed their peers go through difficult births, resulting in comas, needing multiple blood transfusions, losing children and/or dying.

*"It was very bad, it was the worst in fact as she always had pains, swollen feet and so on. Then she got married and became pregnant but died and lost the baby as well."* Isatu, 18, Freetown

*"Yes. One of the women was pregnant and admitted in hospital. We went to see her. She was in so much pain that I said that I would not have children. She was suffering so much. Dr (name) said that caesarean would be good for sickle cell patients, so they can take out the child."*  
Yenor, 23, Koidu

Many women also had experiences of difficult pregnancies and births. Dawa had one of the worst experiences of natural childbirth. She cried as she related how she needed 17 units of blood and how she fell unconscious after giving birth. Several women related losing large amounts of blood and needing several units of blood. Gladys whose mother had SCD and who she had lost when she gave birth to a sibling had an especially tough time.

*Gladys: Before I gave birth, they gave me more than seven units.*  
*Interviewer 2: Seven units?*  
*Gladys: Yes. The second child I had four units.*  
*Interviewer 1: The second child?*  
*Gladys: Yes.*  
*Interviewer 1: You went through the same pain?*  
*Gladys: Yes. I lost the child after one month and two weeks. It was after I lost the second child that we were directed here, and I joined. Since I have been here, I haven't taken blood even during my third pregnancy. They advised me and I followed the advice. I haven't taken blood since.*

Harietu also related having to spend very long periods of time in hospital and that after having four children, she felt as if her health had been compromised. Several women related experiences of having gone into a coma while giving birth.

*"...the first pregnancy I got, I was sick and admitted at (name) hospital. I was anaemic. At the time of delivery, I went into comma for 3 days. I did not even know when I delivered and God spared my life. My parents told me that I had given birth to twins and that I will see them when I leave the ward. However, I lost the children and they did not want to tell me."*

Aminata, 33, Freetown

The above examples of loss of life did not have to be the case. If women with SCD are given specialised multidisciplinary care, are monitored early throughout their pregnancies, obtain pain relief, blood transfusions and are provided with access to caesareans under a gynaecologist if natural birth is not possible, they can have safe pregnancies (see Olugbenga, 2019). Several women talked about how affirming such experiences were.

*"It made me happy because the pain I went through during my first pregnancy was not the same with my other child. Being in hospital for three months before I delivered and then having that experience when they trying to find a vein, while I was suffering in pain. With this child, I thank God. I did not go through that pain."*

Gladys, 23, Koidu

Overall, pregnancy was viewed as a risky for all women. Yet, for women with SCD it meant possibly losing a child as well as having their health compromised both during and after giving birth.

*"Yes, I was not attacked by the disease when pregnant but as soon as I delivered the baby I couldn't work with water. I couldn't bathe or wash anything. Other people helped to take care of me and the babies until they walked."*

Finda, 45, Koidu

#### **d. Relational health, employment and wellbeing**

Relational health and wellbeing were often neglected in health and social care services, but they were having a critical impact on ability of women to manage their conditions and those of their children. Physical and mental health are often mentioned together by women with SCD. For them, it was important to understand both physical and emotional causes of 'attacks' or crises when pain becomes severe.

*"How to be in a home with a sickle cell child ... A child with sickle cell doesn't need stress, worries and should not be beaten. The child needs lots of rest. He should eat well and should not be washed late."*

Siabanda, 19, Koidu

One of the issues that came out in our interviews was both the positive and negative impacts of relationships with the opposite sex. We heard many stories of happy marriages to caring and kind

men. In fact, advice about premarital screening often mentioned these ‘caring’ characteristics alongside the needed genotype HbAA. Often fathers acted as examples for young women of what kind of man they wanted to marry.

*“I pray to God to have someone to care for me like my father. He is very caring. Even yesterday when sitting outside some ladies came and asked me what type of man I want. I said someone like my dad. When I have an attack at midnight, it is him that will get up. He will use hot water and heats me up with a towel.”*  
Kadie, 19, Freetown

Women related stories about caring husbands and fathers but also experiences with partners who still beat women, had girlfriends, bullied, rejected and neglected them. These experiences of violence were linked to women with both SS and SC going into sustained and repeated crises.

*Interviewer 1: Yes. Was he boxing you?*  
*Gladys: He was ‘blowing at me like [you would at] flour’. It is not a joke, mama. He was really beating me.*  
*Interviewer 1: What do you mean by that?*  
*Gladys: Like he was beating another man.*  
*Interviewer 1: Hm...*  
*Gladys: It is here that I have learned that someone should not be beaten, not to stress someone; to wash with warm water; take your bath before it is dark and cold. When I didn’t know about that, I had frequent crisis.*

In Sierra Leone, women’s rights have been enshrined into what is known as three gender acts which were passed in 2007-8: 1) Domestic Violence Act making domestic violence a crime; 2) Devolution of Estates Act allowing women to inherit property and land; and 3) Registration of Customary Marriages and Divorces Act which meant that a marriage could only happen after the age of 18 and had to be registered. In 2012, the Sexual Offences Act was also passed ensuring sexual violence was a crime. While some women we interviewed experienced a lot of physical violence from men (Schneider, 2019), protective mechanisms existed in the caring acts and words from their children, supportive extended families; as well as legislation and services such as Family Support Units at the police.

*“He had done it once when I was pregnant with this child. A man at the FSU (Family Support Unit), Mr (name) called him after I complained that he didn’t feed me and didn’t want to know. Mr (name) called him on the phone and addressed him. He told him that the next time I go to [the Unit] with such a complaint they will not talk much to him but will detain him. Since that time, he stopped doing it.”*  
Fanta, 25, Koidu

Living in an unhappy marriage was something that some women just had to ‘bear’ because of the austere economic consequences, but staying in such marriages affected their health. Most of the women related difficulties managing formal and informal employment with caring for their children,

especially if they had SCD themselves. While the female networks of religious and other organisations such as *osusu* or savings clubs offered them some protections, they were still very dependent on men. There were some female activities from which they were excluded due to their health conditions, such as collective female work in farming in the villages during planting or harvesting seasons.

*"I cannot join in farming during the rainy season. The rainy season is planting season in the swamp and women hold 'boma'. Today, they go to someone, tomorrow they may come to you, if you belong to their group. You will not be able to go [work in the swamp] because you cannot go in swampy water."*

Patricia, 24, Koidu

Sometimes, the men who they lived with were the main breadwinners and trying to do their best. Yet, they were often living from day to day and unable to save money for emergencies.

*"Sometimes, my brother doesn't bring money home because the police had arrested him. We go without that day. Our grandma too is unemployed; she doesn't work."*

Amie, 23, Koidu

Even if a marriage was good, times were very difficult and required that a woman engage in informal work to look after her children. This was causing stress and causing ill health.

*"It is difficult. I have children and my husband is not working. I am not working and getting regular pay nor doing business to get money. I want to do something but when I try it, I get ill. When I am stressed, even small, it brings on the pain."*

Gladys, 23, Koidu

In terms of women's empowerment programmes or microcredit schemes, we found that there were no adjustments made if you had a sick child, so women opted out of those while still staying in savings clubs or women's religious organisations. More than one woman explained that microcredit programmes were discriminating against women and children with disabilities.

*"I asked for micro-credit but was refused because of the health of my child. I went to the micro credit office on the main road for a loan to expand my business to take care of my family, but I was told that I have a child who is always sick, and in hospital every month. If they give me their money, I will use it to pay for my child's medical bills and will be unable to pay back."*

Kumba, 30, Koidu

## 8. Environment and management of condition allows it to become chronic

The environmental and household management of the condition was related by mothers and women with SCD as critical to understand. As mothers who were looking after children with SCD, they felt it was part of their task to manage the condition of their child through tactical actions, for example, ensuring they were not over-exerting themselves, took their medications, ate well and stayed hydrated with water.

*"I give him fruits, small rice and lots of plasas [local vegetables]. If I cannot get sardines, I buy fresh mackerel from the market, steam, de-bone and give it to him to eat."* Fanta, 25, Koidu

Due to austerity, some families were not eating three times a day and for most mothers, providing meat for their children was out of reach. One of the oldest participants related how she looked after herself and was cared for by her family members. This was inclusive of her family ensuring that she would not have to do hard manual labour nor wash clothes. She explained how to live a long life.

*"What should people do? In the morning, what they should do first is to drink warm water. If they want to pass urine, take warm water in a bathroom kettle when you go to the toilet. Wear cardigan in the morning. Avoid going in the rain. Don't wash with cold water. If you want to live long wear clothes that covers up your body. Tie your head or wear your hijab. Take your medicines every day- take one Pen VK; take one Folic Acid plus that multivitamin tablet. Take ORS."* Harietu, 65, Koidu

In family life, children with SCD were sometimes described as 'spoilt' because they got extra food and were not always required to do chores in the home or did lighter chores like cooking or sweeping. This could cause jealousy in their siblings but parents felt that this extra care and attention was necessary for their health. People with SCD related how, for example, it was important not to walk in the rain without an umbrella, not to do laundry, not to go swimming, and not go fishing or work in the rice fields or 'swamps'. The Harmattan winds or colder months around December and January were mentioned as being linked to periods of extended illness especially in the provinces. There were certain months when the rainy season typically falls in Sierra Leone, which were also correlated to increased hospital stays and having 'attacks' or going into crisis.

*"The months are fast approaching – June, July and August. If you are not careful during those three months you would go into a crisis."* Patricia, 24, Koidu

Just as they were being managed, people living with SCD had to manage themselves on the outside (physically) and inside (emotionally). Women also explained emotional management of SCD was needed, as getting too excited or depressed were dangers too. They often had to walk a fine line because following the rules too strictly meant you became an outsider but engaging in too much fun with your peers could result in a crisis.

*“For example, when your peers are having a programme and are being happy, you do not even have the ability or the strength to join in. When they are having fun, you know that if you join them, you will likely go into crisis. Except you go the other way. They will laugh at you that you do not take part in any of the activities; that you are a HP (house pikin) or you do not know anything.”*

Amie, 23, Koidu

One way of controlling emotions as well as helping with daily life, was linked to belonging to a religion and engaging in religious practices like prayer. As stated above, women noted the importance of religion in their lives and belonging to different types of religious fellowships and women’s clubs. Some women belonged to savings clubs, also linked to their religious associations. These were accessible to women with health conditions or who had children who were ill. Women also related how religious experiences were being made accessible to them. The pastors or Imans were good about giving advice about combining religious life with a serious health condition. They advised against fasting with a medical condition where hydration and/or medication was important. They also advised against all night prayers but prayed over medicines and visited people in hospital. They also noted ways in which people with SCD could partake in fasting.

*“No, but when they are fasting and if I am able to get bananas and oranges, I take them to church for those who are fasting and ask them to pray for me.”*

Siabanda, 19, Koidu

*“Every day, I give someone what I should eat so they will fast for me. I make small rice pap and also rice and plasas [vegetables] and give out.”*

Harietu, 65, Koidu

When washing with water became difficult for Harietu, her Iman advised her to use a clean and round stone instead, ensuring that she could take part in prayer five times a day in keeping with her Muslim faith which gave her peace. The above are examples of religion being enabling but we also heard reports about Christian churches advising women, for example, that they would go to hell if they had sex before marriage. Another troubling development was pastors getting involved in directive counselling to women linked to SCD, by for example, explaining who they should marry. Hill (1994) also makes a distinction between the social support aspects of integration into a church, which was found to be helpful for women but repetition of religious doctrines, which was not. These are issues illustrating a need for policy development and the importance of informed, sensitive and ethical counselling services.

#### **a. Good care: Family and school environment**

Good care was seen as extending from family household to the school and community environment. In Sierra Leone, children are legally required to attend six years of primary school and three years of junior secondary school until they are 15 years old. This consists of the basic education that each citizen is entitled to have according to the 2004 Education Act. The 2004 Education Act stipulates that there should be no discrimination which could prevent a child in attaining this basic education. The 2007 Child’s Rights Act also states that children are entitled to basic education. An important part of school inclusiveness is recognising the importance of offering care to young people with long standing illness, particularly since a major part of childhood is spent in attending school. The 2006



UN Convention on the Rights of Persons with Disabilities (CRPD) also states that school inclusion is a right for children with serious health conditions and disabilities. While it should be the government and school authorities that take leadership in drafting school policies for inclusion, this was not the case.

It was outreach activities by voluntary organisations, whether it was on radio, visiting schools or on television that was recounted as being very important. First, these outreach activities comprised raising awareness to understand the condition and how to look after children, as well as gain access to medicine. Second, these activities involved educating the schools and teachers about how they should treat their children with SCD. This management of SCD was especially important as children with the condition were repeating years. There were also several cases of girls dropping out of the education they had a right to access.

*“When I was going to school, I had to walk in the early hours of the morning to get to school because there was no transportation available. The cold air in the morning made here to ache. Sometimes, I went to the hospital for two weeks. When it was examination time that was when I would be admitted in hospital. I tried over a long period and then gave up. I decided I wasn’t going to go to school any longer.”*  
Patricia, 24, Koidu

If the condition becomes severe, children’s education is affected thus limiting their chances in life. As Sarah said, “This child who is getting frequent crisis - no longer goes to school.” However, getting involved in informal work early, may also be detrimental to a child’s health and prevent any further educational attainment. In families, children were also being involved in care-giving for siblings or mothers with SCD which also affected their futures.

*“Yes. One remains with me while the other goes to school. The next day, the other one stays. They assist one at a time.”*  
Hawa, 38, Freetown

The voluntary sector also gave advice to families about how to treat their children in the home and were involved in creation of good family and school management of the condition for parents (Dyson, 2017). Fatmata who was 23 and interviewed in Freetown explained:

*Interviewer 2: What did the society tell you? What new information did they give you?*  
*Fatmata: That Sickle Cell would not be cured. To maintain my blood pressure (BP), I should eat carrot, mango, vegetables and take Hb12 syrup, Bco and folic acid.*

Women clarified that they were also personally affected by the extra costs of taking care of child with SCD. Suma, who was 30 years old and interviewed in Koidu, noted how other women looked down on her because often she did not have enough money to buy nice clothes for herself. Most of her money went to fees for school, transport, medical treatment and medicines. Her husband had left her for another woman and her 11-year-old son with SCD had to work in a market alongside studying at school. This was necessary to help support the family. In this context of sacrifices having

to be made for school fees, most mothers of children report having to go to primary and secondary schools to educate principals and teachers about their children's condition and to explain absences.

*"Sometimes, when he says he is feeling unwell, I give him medicines, take him to school and inform his teachers. I do that for both of them."* Yara, 35, Koidu

This education was often about the necessity to allow children to drink water, go to the toilets when needed, prevent 'flogging' or beating of the children and to call the parents in case of a crisis or other emergency. While schools were beginning to understand how to make physical accommodations, this was not perfect as no adjustments were made for exams.

*"No. There is no help. If they miss an exam, they miss it. Nothing else. No other help, no support on that side. If he misses his first term exams, he doesn't get a report for the first term. That's it; no other support. Not a teacher who can help him to catch up on what he had lost. We do not get such help. All he does is to join the class."* Kumba, 30, Koidu

Despite education of the schools, very little was actually done to change practices, and parents still faced constraints in looking after their children in terms of accessing the resources to provide the best care in schools.

*"They have a plastic bucket with drinking water in class. But I have to give him water to take to school. It is not every day because sometimes I do not have money. I give it to him because we have been told that they should drink water often."* Yara, 35, Koidu

Perhaps impacted by the voluntary sector, as well as new caring regimes, parents and women with SCD were highly invested in gaining an education in order to secure a formal job that would not tax their health, for example in a bank or as an accountant. Another issue was that few teachers and schools understood how both physical exertion as well as stressful excitement could act as triggers to children having a crisis. Mothers often learned by experience.

*"I went to a party once on the school campus at night. When I came back the thing [disease] hit me so badly that my mum never allowed me to go out at night."* Yenor, 23, Koidu

Yet, some schools were also becoming proactive about SCD education and awareness-raising. Fatmata explained that her child was re-tested at her school to confirm a SCD diagnosis. It was also noted how mothers will often get involved in aiding other mothers to understand how to care for their children, often as a matter of urgency. For instance, one mother related having to stop her child going to dangerous all-night study sessions. Mothers related knowing how their knowledge was life-saving, especially in the early years.

*"Not long ago, one of my mother's neighbours had a child who was ill. I visited them at the hospital and was told that the child had sickle cell. They took the child home. I was unable to*

*visit them early at home. Then I learned that the child had another crisis and was taken to the Government Hospital. I went to their house yesterday just to be told that the child had died about two days ago.”*

Kumba, 30, Koidu

## **b. Access to medicines and specialist knowledge**

While medicines are supposed to be free for children under five years old, many participants did not know this or were asked to pay. This was especially dangerous with young children with SCD reportedly getting pneumonia and malaria regularly. A simple preventative treatment exists in getting them to sleep under a net to avoid malaria and vaccinations to prevent infections but this was not mentioned by mothers. A lack of knowledge around treatment of ulcers, their care and use of antibiotics was also noted with life threatening results. This indicates that there is a lack of general and specialist knowledge of SCD in healthcare professionals. Despite this, women became experts of their own conditions and related knowing when they would need to access such medicines.

*“How do I know that sickle cell is beginning to affect me? My eyes turn yellow, my urine changes colour, my stomach swells up, I feel pain and sweat a lot. I am constantly thirsty, drink frequently and breathe fast.”*

Siabanda, 19, Koidu

Women with SCD and mothers of children with SCD, both related that a routine of access to simple pain relief, penicillin, folic acid and vitamins was aiding in management of the condition. However, they would often have to be educated about this and if illiterate did not understand the use of medications.

*Patricia: Yes. I thought the medicine the nurse had given to me was very small and that it would not cure me.*

*Interviewer 1: Folic acid tablet is very small so you thought it would not cure you?*

*Patricia: Yes.*

*Interviewer 1: If it was large, you would have trusted that it would cure you? It will be able to travel in your body?*

*Patricia: Yes.*

It was also important for mothers to have an understanding of the extent of the pain that their children were going through, so they could give the right dose of medications.

*“I did not feel good about it and I felt awful for my child as I know the pain he must have been going through. When they explained it all to me, I was able to appreciate the degree of pain that child suffered. Auntie, when the pain started that child cried and cried, and I also cried as the child was crying. I did not feel good at all.”*

Fanta, 25, Koidu

The access to medicine, vitamins and pain relief was often recounted by women involved in a research study in Koidu and by those in Freetown who were accessing free medicine through an NGO. However, it also had an unintended effect of causing more stigma as the community members realised the medicines they were accessing were free.

*Gladys: When they see me going to collect my medicines, they laugh at me that I am collecting medicine for HIV.*

*Interviewer 1: Do you think it will help if we go to that community and educate them, it will help?*

*Gladys: Yes, so they will know that I do not have HIV. I have sickle cell. Any condition that comes my way I will know because anytime we go there [Jericho], we get tested. If I wasn't having tests, I wouldn't know that I have diabetes, isn't it? I told her to continue laughing at me. I know my status, but she doesn't know hers because she is not going to hospital.*

When women with SCD and mothers of children with SCD were not involved with a voluntary organisation or research study, access to medicines like pain-killers was a concern. Medications were a valuable commodity and women often had to share medicines with family members.

*“Interviewer 2: Do they sometimes use your medicines?”*

*Fatu: Yes, they take the Panadol when they have headaches.”*

Knowledge about medicines was also valuable to people. Mariama related that she would often buy the same prescriptions for her relatives who lived in Bonthe. Hawa explained that sometimes pharmacies would run out of stock so she tried to understand which pharmacies or hospitals would continue to have access to medications. Women also related that they knew that they had to use more of their pain-killers when they were experiencing more pains, for example, during their periods. That is never mentioned by healthcare professionals but some women said they experienced effects of crisis during their periods. When that support to buy medicines did not exist or if they needed to access hospital treatments they could not afford, the consequences could be detrimental for women. The effect of blame and guilt for women with SCD was reported as leading to mental health issues like depression.

*“Yes, her business broke down because of my illness. All the money she got from the business was spent in hospital. Every two weeks we were in hospital for blood and other things. Each time I had a crisis, I would be short of blood and she would use the money from her sales. Every time we went to the hospital, she would spend about one hundred or two hundred thousand Leones for my sake. That made my sister to also drop out of school because our parents could not pay her school fees on time. She was asked out of school; so that year she didn't sit her BECE exams as we had no money and no help. Our family had abandoned us because they said our mother has a child who is a witch.”*  
Siabanda, 19, Koidu

### c. Access to transfusions and hospital care

People with SCD may need to have blood transfusions, some women every month and others from time to time. Yet, women related that there were very few blood banks in Sierra Leone and no blood drives for people to donate their blood. Instead it fell to relatives to give blood or payment to strangers to get access to blood needed for life-saving treatments. Often people paid to access private clinics, believing they might be better in terms of access to specialised treatment. However, management of the condition was also important in limiting admissions and limiting the need for blood transfusions in the first place.

*“I have admitted twice, got drip, but no operation, never had blood transfusion. I have stopped going to the private clinics.”*

Fatima, 23, Freetown

Women related a possible correlation between factors such as the correct medical management of the condition, a diet of fruit and green leafy vegetables, a peaceful environment and a reduction in the need for transfusions. This however only went so far as services were not developed to deal with complications of the illness nor acute episodes. Transportation in the evening hours, when most people said that their crisis or attacks would usually become severe, remained a barrier to access emergency pain medication and care.

*“The disease attacked him during the night, and they tried to get him to the Government Hospital. It was during the Ebola crisis. There were no motor bikes (...) The crisis started at night, about twelve o’clock. They tried to get a motor bike, but they could not find one. They woke up one of the neighbours who took him to the Government hospital. He was there until the next morning, when he died (...)”*

Keima, 18, Koidu

The hospitals themselves were also very rudimentary with parents expected to pay for care and medicines. Parents were also aware of the dangers of infection to their children with SCD and they noted unsafe and undignified hospital practices.

*“We were there while they dressed and wrapped up the child [the child that had died]. Another parent was there also. Not long after taking that child away, and while they were attending to this child [my child], another sick child was brought in and they laid him on the same bed. You see the problem? Our children have sickle cell which is very difficult for them. If they are exposed to other diseases from other children? You see. That really affected my child.”*

Djenabou, 30, Koidu

People with SCD, who were patients, also mentioned the need for appropriate pain relief and training when they got to hospitals in the middle of a serious crisis. The pain they felt was often indescribable but meant they could lose complete control over themselves from ability to walk and even to talk.

*“Yes, it was so bad, even when I wanted to go toilet, I couldn’t get up to go to the bathroom and I would wet myself.”*

Gladys, 23, Koidu

#### d. Access to rehabilitative services and surgery

There were some participants who related gaining access to rehabilitative services like physiotherapy and massage. Often these services seemed to be very basic or improvised.

*"I was still in pain and they were pulling my legs. My people did not take me to hospital. I was in Bo; they pulled my legs and suspend me."* Fatu, 27, Koidu

Harietu explained that when massage and physiotherapy were done well, they were beneficial for people with SCD. She had accessed 'massage' in Freetown and found it very helpful to managing her condition. However, we noted that there did not seem to be sufficient investment in rehabilitative services even post-Ebola when incidence of disability was known to increase (Berghs, 2016). It seemed as if rehabilitative services were seen as separate from healthcare services and a part of disability NGOs (Berghs, 2018). Yet, women explained how crucial prosthetic services were, as the reality of the condition in a resource-poor setting like Sierra Leone was impairment.

*"I was always listening to the radio where they taught us about the disease and how to treat it. But we didn't have the right medicines because those we were told to buy only made the child worse. His hands and feet were swollen. At a point I took him to (name). He couldn't walk. People ran away from us; his foot rot and he lost a bone. They took it out at (name). He couldn't walk. There was a white man at (name) who helped him to use his legs again. He helped him until he walked again."* Kumba, 30, Koidu

There was no access to surgical interventions that women needed, like hip-replacement surgeries, meaning that impairments would worsen and become more disabling as time went on. Several participants told us that in order to access surgery they had to travel nearly 1,000 miles to Ghana and needed funding from ministries or private donors to access such surgical services. If they could not access these services, more disability and early death were in their futures.

## 9. Conclusion: A need for future services

Everyone related how essential it was that holistic services were scaled up for SCD in Sierra Leone because when parents and patients were given guidelines they could follow, their health and wellbeing in terms of quality of life improved. This is why parents often asked for specialised schools, clinics and even nurses that had knowledge of the condition. Yet, at the same time authorities and medical institutions in Sierra Leone did not understand the prevalence of SCD, so did not know how many people exactly the illness affected or who would use those services. Not understanding prevalence meant neglect, which was then translated into disavowal which trickled down into social and public misunderstanding of the condition. Social and public health neglect were leading to devaluation of people with SCD and their exclusion from social life, particularly affecting women. There was also evidence of missed diagnoses, deaths and lack of clinical understanding of SCD which was leading to break-up of families, loss of education and abandonment in one woman's case. We also noted that the testing and counselling that was being carried out for SCD was directive. There were no clear counselling guidelines, nor understanding if clinical standards were appropriate, nor

policies that could be followed by medical or educational institutions and NGOs. Primary care was very basic, secondary care was lacking and there was often neither surgical care nor rehabilitative services specialised in dealing with SCD.

This has to change and the first thing that should be done is to **pilot a new-born screening programme** to estimate **prevalence** of SCD. This would also allow clinicians and public health policy makers to understand if a **National New-born Screening Programme** should be implemented. Early diagnosis of sickle cell is being missed despite the fact that early clinical intervention can lead to better life outcomes and clinical expressions of the condition. Mothers related that they were not given much advice and that in many cases the community were suspicious, indifferent or hostile towards children with SCD by accusing them of witchcraft.

There needs to be more **community education and awareness** of the condition, which the voluntary sector was described by participants as undertaking with some success. Having advice which was non-medical, or translated medical advice into practical steps to take in everyday life, was allowing parents and patients to manage their conditions.

*“Yes. But since we came here and yes, they’ve told us it has no cure, but you can manage your life if you follow the advice. That has given me the courage to manage my life and to carry on with living.”*  
Amie, 23, Koidu

All interviews mentioned a lack of awareness and need for different kinds of information via personal outreach, radio, TV and in print, to sensitise communities or in schools to educate teachers and head teachers. It is essential that the condition is not solely viewed in medical terms but culturally sensitive social resources are also developed. It is also important to learn from and include women with SCD and mothers of children with SCD in such efforts by co-producing resources with them. They have shared a lot of knowledge about household management and care they give their children which can be learnt from. People with SCD also related how the condition was linked to physical and emotional environment which needed to be managed carefully. In particular, the report noted that resources need to be created for a population group that is illiterate and may not understand basics of biology or biomedicine.

#### **Example of culturally sensitive resources: *The Family Legacy***

The Sierra Leonean diaspora with UK’s Sickle Cell Society has been involved in the creation of resources about sickle cell such as the film, *The Family Legacy*. The film tells the story of a child being born with sickle cell in an African family. It goes through narratives of blame and shame before it is understood nobody is at fault. It is an illness that is on both the mother’s and father’s side of the family. It is also not an illness that should be feared because children can live a good life, if it is medically managed and children cared for. Members of Sickle Cell Society-UK, like Iyamide Thomas, have used this in the UK and Sierra Leone to raise awareness with success.

Part One: <http://www.youtube.com/watch?v=JAv1Ja2AYhw>

Part Two: [http://www.youtube.com/watch?v=7QNFR\\_MSMocP](http://www.youtube.com/watch?v=7QNFR_MSMocP)

Part Three: <http://www.youtube.com/watch?v=L8bhJivddpQ>

The voluntary sector and diaspora represent imperative resources in planning for future services that might be needed if screening is implemented. One of those resources will be genetic counselling which should occur in a non-directive fashion. This means that information is given in a neutral way to people, who are then free to discuss with their families and/or make their own informed choices for example, with regards to family planning about when and if they want another child. Guidelines will have to be developed, healthcare professionals trained, laboratory testing improved and educational services implemented. It is ethically imperative that people with SCD and people who carry the trait are not stigmatised - neither in the present nor in the future.

Education was viewed as a means to 'become someone' in Sierra Leone but schools while slowly improving, were not always inclusive for children with SCD. There needs to be an **educational policy** on sickle cell that is nationally implemented in primary, secondary and tertiary education. Education is a right for children, and parents articulated that it was correlated to the future health and wellbeing of their children. Yet, one important issue still affecting people with SCD is that exams occur during the rainy season when they have attacks or crises meaning long periods of hospitalisation. In the future, a way in which children can re-sit exams or have exam schedules moved earlier in the year to accommodate them, should be considered by educational boards.

Women are also encouraged to become educated but too often were still dropping out of schools or aiding with care-giving tasks or informal work. This does not have to be the case as there are examples of inclusive practices at schools in Sierra Leone, allowing young women to remain in schools.

#### **Example of culturally sensitive resources: A Sierra Leonean Approach to Sickle Cell and Inclusion in Schools**

The Sierra Leonean Sickle Cell Society with several schools in Freetown has been involved in the creation of policy guidance for schools on inclusion for children with sickle cell.

[http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER114b\\_Simon-Dyson-Guide-for-Schools\\_11April17.pdf](http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER114b_Simon-Dyson-Guide-for-Schools_11April17.pdf)

They have also developed a national school song in the lingua franca, Krio especially important where parents might be illiterate or to reach more rural areas of the country. The song can be freely used to educate people about sickle cell and promote inclusion of children in educational and social settings.

<https://www.sicklecellsociety.org/resource/sikul-sel-song-sierra-leone/>

The report pointed to the lack of **empowerment of women** in Sierra Leone and the fact that there is often talk of women's rights but institutions are not implementing those rights in terms of **mainstreaming gender equality in education, healthcare, employment, justice and politics**. Institutions and policy should also take into account that SCD affects women and men differently through the creation of gender specific resources and practices. The most urgent was the need for **better health and reproductive care** for mothers and their children whose deaths and impairment we have documented. Structural change is needed if women report lack of access to good and basic healthcare that they still need to pay for. Women with SCD also need information to understand where they can get family planning, how they can give birth safely and what they can do if their relationships become violent. Men also need to be involved in understanding that they also have



responsibilities towards their families in terms of family planning. Difficulties in life should be given other expressions than violence, and men need to be sensitised that for women with SCD this can lead to impairment and possible death if she goes into a crisis. Generally, we felt that women with SCD had been neglected in thinking about how to impact greater agency and autonomy, for example, by making micro-credit programmes and schools inaccessible to them. An important aspect of the lives of many girls with SCD is the need to use toilets in schools. This was never discussed in terms of gender equity but if a school does not have safe sanitation for girls, their education is disrupted.

How can we ensure empowerment for women? Fatu, a young shy woman with SCD in Koidu, who had been abandoned and severely stigmatised, spoke slowly but gave nine points that she felt were imperative to support women like herself: 1) Encouragement; 2) Befriending; 3) Education and skills training; 4) Faith; 5) Life partnerships, marriage and children; 6) Good nutritious food; 7) Warm clothes when needed; 8) Suitable housing which is cool in summer and dry during the rainy season. This environment needs to include a foam mattress to sleep on and malaria net which people can sleep under; and lastly 9) Travel for a holiday so they could rest, see family and relax. These points were a world away from the actual conditions in which Fatu was living; where she had no encouragement, no friends, was taken out of school, not allowed to work, kept away from church, told she would never get married or have children, not fed any food some days, had to beg to buy clothes and was left in store room to sleep on the floor with no contact with anyone. When she told the interviewers that the one thing that she wanted in her life was some joy, everyone was in tears.

A year later, despite efforts to support her by the NGO, we found out that Fatu had sadly died. A total lack of care and respect for her basic human rights definitely lead to her early demise. We can do better and ensure that other women like her have access to a better quality of life. A report on gender and sickle cell is a first step in this direction to educate and call for reproductive justice on sickle cell.

*“Right now, we the women suffer the most from this crisis.”* Finda, 45, Koidu. Person with SCD and mother of child who also has SCD.

## Recommendations

### Sierra Leone Government

*“She didn’t feel good about it at that time but when we came here, she was told that it doesn’t mean her child would die soon because of sickle cell. That as long as she follows the advice given, the child could live longer. Right now, she is saying that she gives thanks to God for my life. The illness is not attacking me as it used to.”*

Keima, 18, Koidu

- SCD is an important public health and social issue in the country. It particularly affects women, yet seems completely neglected. This neglect is also a form of violence against women and children. It contributes to gender inequalities and needs to urgently be tackled by understanding the scale of the issue. A pilot prevalence new-born screening study is needed to understand how many people this public health issue affects presently and cost-effectively plan for the future.
- The development of a national programme to ensure life-saving and cost-effective treatment for people with SCD should be started via a new-born screening programme.
- Historically, this public health neglect of sickle cell was not always the case and the international community is also at fault. There are now pockets of medical as well as social expertise that exist in the country and Sierra Leonean diaspora. It is essential to build upon these networks of knowledge and ensure more capacity building in laboratories, imaging and medical education. This will be necessary to prepare for the future.
- SCD should be a matter of public health policy and there should be a National Sickle Cell Act.
- Encourage medical and applied social science research on SCD.
- SCD has to be on the curriculum in primary, secondary and tertiary educational schools and universities. It is critical that this education is not just biological or medical but also socially just in combating any discrimination against people with SCD or people who have the trait.
- Development of rehabilitative, prosthetic and surgical services should be invested in.
- People with SCD, their families, the voluntary sector, academics and medical professionals have built up a lot of expertise on SCD, and it is essential to involve them in creation of policy, public awareness and improvement of practice guidelines.
- More community awareness needs to be invested in about SCD.

### Medical professionals

*“Yes. If we have qualified nurses for sickle cell, I don’t think the children would die as they are doing now. That will be support for the children.”*

Suma, 30, Koidu

- SCD needs to be a part of medical and nursing training in Sierra Leone. This should include patients as experts of their conditions explaining how the condition can affect them.

- Medical professionals need clinical education and training on SCD with a gender-sensitive dimension across the life-course.
- It is essential that community healthcare workers, nurses and doctors are given training about diagnosis of early signs of sickle cell in infants; stroke in children; correlated ailments and why pregnancies for women with SCD are high risk. These basics are currently missing.
- It is crucial to understand if someone has SCD before an operation and preoperative screening is necessary. Counselling afterwards should also be planned for.
- Clinical standards for the care for women and men with SCD need to be developed with linked protocols.
- Rehabilitative services, prosthetics and surgical treatments should be developed and invested in.
- Non-directive counselling resources need to be further developed if advice is being given about genetic testing.
- Robust data collection, development of laboratory services and clinical research should be developed on SCD.

## Schools

*“Support our education for advancement and help us to go to schools and talk about this illness.”*  
Kadiatu, 18, Freetown

- SLSCS has created a guide for sickle cell policy and national school song about sickle cell in Krio to raise awareness. This school policy should be implemented nationally in primary, secondary and higher educational institutions.
- Schools should have policy on how to ensure lessons and exams are accessible for children with SCD.
- Schools are an extension of community-based care for people with SCD and the combatting of stigma of people with SCD and the trait. Lessons on sickle cell should reflect this.
- Schools should create inclusive spaces for all children and not make the child with SCD feel as if they are different or an outsider. This is achieved by, for example, ensuring that all children can have access to water and toilets and nobody is made to feel different.
- Encourage awareness of how bullying can affect children negatively and should not be tolerated.
- Instead of using corporal punishment or flogging children think of other punishments to discipline children.
- Encourage girls with SCD to stay in schools by ensuring safe and accessible sanitation.
- Allow pregnant girls to access education.
- Ensure education for girls and boys on consent in relationships, non-violence and family planning.

## Awareness

*“Yes. The advice is more [valuable] than the medicines. At school, I told them not to allow her to play too much or take part in sports. She does not wash with cold water and she knows when to rest. She knows when she is feeling weak and would go to bed.”* Suma, 30, Koidu

- More awareness raising linked to SCD needs to be under-taken in Sierra Leone in print, on the radio, on TV and in communities using song, dance and theatre for literate and illiterate audiences.
- Parents should receive training about signs of SCD and especially danger signs like enlarged spleen causing the stomach to become big, how to spot strokes or how to reduce the risk of malaria to children with SCD.
- More needs to be done to empower people with SCD through the creation of patient and parent support groups.
- Mothers and women with SCD should be involved in creating research that they need on topics that affect them.
- Awareness should ensure that people with SCD and people who carry the condition are not stigmatised.

*“They continued the provocation at school. I also told SCAN about it. The nurses at SCAN went to the area where I lived and sensitised the people. They also went to my school and talked to them about sickle cell, how it affects people, how to get medication and how to live with people who have sickle cell. They talked to people in my area, my neighbours and my school friends.”* Siabanda, 19, Koidu

## References

- Abdullah, H., Ibrahim, A. F., & King, J. (2016). Women's Voices, Work and Bodily Integrity in Pre-Conflict, Conflict and Post-Conflict Reconstruction Processes in Sierra Leone. *IDS Bulletin*, 47 (1A).
- Atkin, K., Berghs, M., & Dyson, S. M. (2015). 'Who's the guy in the room?' Involving fathers in antenatal care screening for sickle cell disorders. *Social Science & Medicine*, 128: 212-219.
- Anie, K. A., Treadwell, M. J., Grant, A. M., Dennis-Antwi, J. A., Asafo, M. K., Lamptey, M. E., ... & Ohene-Frempong, K. (2016). Community engagement to inform the development of a sickle cell counselor training and certification program in Ghana. *Journal of community genetics*, 7(3): 195-202.
- Bakshi, S. S., McMahon, S., George, A., Yumkella, F., Bangura, P., Kabano, A., & Diaz, T. (2013). The role of traditional treatment on health care seeking by caregivers for sick children in Sierra Leone: results of a baseline survey. *Acta tropica*, 127(1): 46-52.
- Barbour, R. (2014). *Introducing Qualitative Research: A Student's Guide*. London and New York: Sage.
- Berghs, M. (2018). Ethical (Dis)enchantment, Afflictive Kinship and Ebola Exceptionalism. *Disability and Everyday Worlds*. Thomas, G. & Sakellariou, D. (eds.) New York: New York University Press.
- Berghs, M. (2016). Neoliberal policy, chronic corruption and disablement: biosecurity, biosocial risks and the creation of 'Ebola survivors'?. *Disability & Society*, 31(2): 275-279.
- Berghs, M., & Dos Santos-Zingale, M. (2011). A comparative analysis: everyday experiences of disability in Sierra Leone. *Africa Today*, 58(2): 18-40.
- Berghs, M., Dyson, S.M., & Atkin, K. (2017). Resignifying the sickle cell gene: Narratives of genetic risk, impairment and repair. *Health*, 21(2): 171-188.
- Berghs, M., Atkin, K.M., Graham, H.M., Hatton, C. & Thomas, C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. *Public Health Research*, (4) 8.
- Batty, F. & M'Cormack-Hale, F. (2019). "Do not Disturb the Peace!" Identities, Livelihoods and the Politics of Post-War Discontent in Sierra Leone. *Journal of Asian and African Studies*, DOI: 0021909618825355.
- Bryman, A. (2015). *Social Research Methods*. Oxford: Oxford University Press.
- Chattoo, S. (2018). Inherited blood disorders, genetic risk and global public health: framing 'birth defects' as preventable in India. *Anthropology & Medicine*, 25(1), 30-49.
- Chattoo, S., Atkin, K. M., Dyson, S. M., Ahmad, W. I., & Anionwu, E. (2014). *Living with Sickle Cell or Beta Thalassaemia Trait: implications for identity and social life: summary of research findings for health and social care professionals*. York: University of York.
- Denney, L. & Fofana Ibrahim, A. (2012). *Violence against women in Sierra Leone: How women seek redress*. London: Overseas Development Institute.
- Dennis-Antwi, J.A., Culley, L., Hiles, D. and Dyson, S.M. (2011). "I can die today, I can die tomorrow": Lay perceptions of sickle cell disease in Kumasi, Ghana at a point of transition. *Ethnicity and Health* 16 (4-5): 465-481.

Diaz, T., George, A. S., Rao, S. R., Bangura, P. S., Baimba, J. B., McMahon, S. A., & Kabano, A. (2013). Healthcare seeking for diarrhoea, malaria and pneumonia among children in four poor rural districts in Sierra Leone in the context of free health care: results of a cross-sectional survey. *BMC public health*, 13(1), 157.

Dyson, S.M. (2017). A Sierra Leonean Approach to Sickle Cell and School Inclusion. Available at: [http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER114b\\_Simon-Dyson-Guide-for-Schools\\_11April17.pdf](http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER114b_Simon-Dyson-Guide-for-Schools_11April17.pdf)

Dyson, S.M. (2016). *Sickle cell and thalassaemia, education, health and social care: A guide to school policy*. Leicester: De Montfort University. Available at: [http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER112b\\_Simon-Dyson-Guide-for-Schools\\_V2\\_June-2016.pdf](http://sicklecellanaemia.org/wp-content/uploads/2017/11/SCOOTEROER112b_Simon-Dyson-Guide-for-Schools_V2_June-2016.pdf)

Dyson, S.M. & Atkin, K. (eds.) (2012) *Genetics and Global Public Health: Sickle Cell and Thalassaemia*. London: Routledge.

Dyson, S.M., Berghs, M. and Atkin, K., (2016). 'Talk to Me. There's Two of Us': Fathers and Sickle Cell Screening. *Sociology*, 50(1), pp.178-194.

Dyson, S.M., Atkin, K., Culley, L.A., Dyson, S.E. & Evans, H. (2011) Sickle cell, habitual dispositions and fragile dispositions: young people with sickle cell at school. *Sociology of Health and Illness*, 33 (3): 465-48

Dyson, S.M., Atkin, K. Culley, L.A., Dyson, S.E. Evans, H. & Rowley, D.T. (2010). Disclosure and sickle cell disorder: a mixed methods study of the young person with sickle cell at school. *Social Science & Medicine*, 70 (12) 2036-2044.

Evans, D. K., Goldstein, M., & Popova, A. (2015). *The next wave of deaths from Ebola? The impact of health care worker mortality*. New York: The World Bank.

Frausin, V., Fraser, J. A., Narmah, W., Lahai, M. K., Winnebah, T. R., Fairhead, J., & Leach, M. (2014). "God made the soil, but we made it fertile": Gender, knowledge, and practice in the formation and use of African dark earths in Liberia and Sierra Leone. *Human Ecology*, 42(5), 695-710.

Fulwiley, D (2011). *The Enculturated Gene: Sickle Cell Health Politics and Biological Difference In West Africa*. Princeton, NJ: Princeton University Press.

Fullwiley, D. (2004). Discriminate biopower and everyday biopolitics: views on sickle cell testing in Dakar. *Medical Anthropology*, 23(2), 157-194.

Gaston, M.H., Verter, J.I., Woods, G., Pegelow, C., Kelleher, J., Presbury, G., Zarkowsky, H., Vichinsky, E., Iyer, R., Lobel, J.S., Diamond, S., Holbrook, T., Gill, F.M., Ritchey, K., Falletta, J.M. (1986). Prophylaxis with oral penicillin in children with sickle cell anemia: a randomized trial. *New England Journal of Medicine* 314: 1593-1599.

Garrett, L., Barr, A., Kadandale, S., & Marten, R. (2018). Sustainable Development Goals in Sierra Leone: Multisectoral Action to Address Persistent Health Challenges. *Global Health Governance*, 12(2).

Grosse, S. D., Odame, I., Atrash, H. K., Amendah, D. D., Piel, F. B., & Williams, T. N. (2011). Sickle cell disease in Africa: a neglected cause of early childhood mortality. *American journal of preventive medicine*, 41(6): S398-S405.

- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice*. London: Routledge.
- Hill, S. A. (2018). Caregiving in African American Families: Caring for Children with Sickle Cell Disease. In *The Black Family*, Logan, S.L.M. (ed.), (pp. 39-52). New York: Routledge.
- Hill, S.A. (1994). *Managing Sickle Cell Disease in Low Income Families*. Philadelphia: Temple University Press.
- Hill, S.A. & Zimmerman, M.K. (1995) Valiant girls and vulnerable boys: the impact of gender and race on mothers' caregiving for chronically ill children. *Journal of Marriage and the Family*, 57: 43-53.
- Hsu, L., Nnodu, O. E., Brown, B. J., Tluway, F., King, S., Dogara, L. G., ... & Gordeuk, V. R. (2018). White Paper: Pathways to Progress in Newborn Screening for Sickle Cell Disease in Sub-Saharan Africa. *Journal of tropical diseases & public health*, 6(2).
- Keane, B., & Defoe, L. (2016). Supported or stigmatised? The impact of sickle cell disease on families. *Community practitioner: the journal of the Community Practitioners' & Health Visitors' Association*, 89(6): 44-47.
- Knox-Macaulay, H. H. M. (1983). Sickle cell disease in Sierra Leone: a clinical and haematological analysis in older children and adults. *Annals of Tropical Medicine & Parasitology*, 77(4): 411-419.
- Layder, D. (1998). *Sociological practice: Linking theory and social research*. London: Sage.
- Livingstone, F. B. (1958). Anthropological Implications of Sickle Cell Gene Distribution in West Africa. *American Anthropologist*, 60(3): 533-562.
- Masmas, T. N., Garly, M. L., Lisse, I. M., Rodrigues, A., Petersen, P. T., & Birgens, H. (2006). Inherited hemoglobin disorders in Guinea-Bissau, West Africa: a population study. *Hemoglobin*, 30(3): 355-364.
- Mason, K., Gibson, F., Gardner, R. A., Serjeant, B., & Serjeant, G. R. (2016). Prevention of sickle cell disease: observations on females with the sickle cell trait from the Manchester project, Jamaica. *Journal of community genetics*, 7(2): 127-132.
- McGann, P.T., Grosse, S.D., Santos, B., de Oliveira, V., Bernardino, L., Kassebaum, N.J., Ware, R.E., & Airewele, G.E. (2015) A Cost-Effectiveness Analysis of a Pilot Neonatal Screening Program for Sickle Cell Anemia in the Republic of Angola *Journal of Pediatrics* 167(6): 1314-1319.
- Modell, B. & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators *Bulletin of the World Health Organization*. 86 (6): 417-496.
- Maclure, R., & Denov, M. (2009). Reconstruction versus transformation: Post-war education and the struggle for gender equity in Sierra Leone. *International Journal of Educational Development*, 29(6), 612-620.
- Ministry of Health and Sanitation (MoHS), UNICEF, Helen Keller International, and WHO. (2015) Sierra Leone Micronutrient Survey, 2013. Freetown: MoHS.
- Ministry of Health and Sanitation (MoHS) (2018). Sierra Leone National Multi-Sectoral Strategy to Prevent and Control Anaemia, 2018-2025. Freetown: MoHS.

Novelli, M., & Higgins, S. (2017). The violence of peace and the role of education: insights from Sierra Leone. *Compare: A Journal of Comparative and International Education*, 47(1): 32-45.

Olugbenga, A.O. (2019). Managing sickle cell disease in pregnancy, the success and the challenges: Our experience in a semi-urban tertiary health-care facility, Southwest, Nigeria, *Tropical Journal of Obstetrics and Gynaecology*, 35: 342-7.

Ola, B.A., Yates, S.J. & Dyson, S.M. (2016). Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study. *Social Science and Medicine*, 161: 27-36

Onyango, M. A., Resnick, K., Davis, A., & Shah, R. R. (2019). Gender-Based Violence Among Adolescent Girls and Young Women: A Neglected Consequence of the West African Ebola Outbreak. In *Pregnant in the Time of Ebola* (pp. 121-132). Springer, Cham.

Piel, F. B., Steinberg, M. H., & Rees, D. C. (2017). Sickle cell disease. *New England Journal of Medicine*, 376(16): 1561-1573.

Piel, F. B., Hay, S. I., Gupta, S., Weatherall, D. J., & Williams, T. N. (2013). Global burden of sickle cell anaemia in children under five, 2010–2050: modelling based on demographics, excess mortality, and interventions. *PLoS medicine*, 10(7), e1001484.

Paul, M., Gebreselassie, H., Samai, M., Benson, J., Kargbo, S. A. S., & Lazzarino, M. M. (2015). Unsafe abortion in Sierra Leone: an examination of costs and burden of treatment on healthcare resources. *J Women's Health Care*, 4(1000228): 2167-0420.

Roberts, G.T., Gabba, A.E., Roberts, T.L., Deen, G. and Wurie, I. (2015). Sickle cell disease in Sierra Leone *Ghana Medical Journal* 49(4): 258-265.

Sarkar, D., Murphy, H., Fisseha, T., Koroma, A. S., Hodges, M. H., Adero, N., ... & Namaste, S. M. (2018). Understanding the process of strengthening multi-sectoral efforts for anemia reduction: Qualitative findings from Sierra Leone and Uganda. *The International journal of health planning and management*, 33(4): 1024-1044.

Sensie, J. V. (2010). Investigating knowledge, perceptions and attitudes regarding sickle cell disease in Mattru, Bonthe District, Southern Sierra Leone. Dissertation in partial fulfilment of the requirements for the degree of Master of Public Health, Faculty of Health and Sciences, Staffordshire University, UK.

Schneider, L. T. (2017). The ogbanje who wanted to stay: The occult, belonging, family and therapy in Sierra Leone. *Ethnography*, 18(2): 133-152.

Schneider, L. T. (2019). Partners as possession: A qualitative exploration of intimate partner sexual violence in Freetown, Sierra Leone. *Journal of Aggression, Maltreatment & Trauma*, 28(2): 127-145.

Shaw, R. (2002). *Memories of the Slave Trade: ritual and the historical imagination in Sierra Leone*. Chicago: University of Chicago Press.

Sickle Cell Society (2018). *Standards for the clinical care of adults with sickle cell in the UK*. London: Sickle Cell Society.



Statistics Sierra Leone (SSL) and ICF International (2014). Sierra Leone Demographic and Health Survey 2013. Freetown, Sierra Leone and Rockville, Maryland, USA: SSL and ICF International.

Thorpe, A., Pouw, N., Baio, A., Sandi, R., Ndomahina, E. T., & Lebbie, T. (2014). "Fishing Na Everybody Business": Women's Work and Gender Relations in Sierra Leone's Fisheries. *Feminist Economics*, 20(3): 53-77.

Trani, J. F., Browne, J., Kett, M., Bah, O., Morlai, T., Bailey, N., & Groce, N. (2011). Access to health care, reproductive health and disability: a large scale survey in Sierra Leone. *Social Science & Medicine*, 73(10): 1477-1489.

Tshilolo, L., Tomlinson, G., Williams, T. N., Santos, B., Olupot-Olupot, P., Lane, A., ... & Ware, R. E. (2019). Hydroxyurea for Children with Sickle Cell Anemia in Sub-Saharan Africa. *New England Journal of Medicine*, 380(2): 121-131.

Tubman, V. N., Marshall, R., Jallah, W., Guo, D., Ma, C., Ohene-Frempong, K., ... & Heeney, M. M. (2016). Newborn screening for sickle cell disease in Liberia: a pilot study. *Pediatric blood & cancer*, 63(4): 671-676.

UNESCO (2019). Sierra Leone. Available at: <http://uis.unesco.org/country/SL>.

van de Grijspaarde, H., Voors, M., Bulte, E., & Richards, P. (2013). Who believes in witches? Institutional flux in Sierra Leone. *African Affairs*, 112(446): 22-47.

Wailoo, K. (2017). Sickle cell disease—a history of progress and peril. *New England Journal of Medicine*, 376(9): 805-807.

Wirth, J. P., Ansumana, R., Woodruff, B. A., Koroma, A. S., & Hodges, M. H. (2018). Association between sickle cell and  $\beta$ -thalassemia genes and hemoglobin concentration and anemia in children and non-pregnant women in Sierra Leone: ancillary analysis of data from Sierra Leone's 2013 National Micronutrient Survey. *BMC research notes*, 11(1): 43.

Wirth, J. P., Rohner, F., Woodruff, B. A., Chiwile, F., Yankson, H., Koroma, A. S., ... & Shahab-Ferdows, S. (2016). Anemia, micronutrient deficiencies, and malaria in children and women in Sierra Leone prior to the Ebola outbreak-findings of a cross-sectional study. *PLoS One*, 11(5), e0155031.

Witter, S., Brikci, N., Harris, T., Williams, R., Keen, S., Mujica, A., ... & Renner, A. (2016). The Sierra Leone free health care initiative (FHCI): process and effectiveness review. Available at: <https://eresearch.gmu.ac.uk/bitstream/handle/20.500.12289/4358/eResearch%204358.pdf?sequence=1>

World Health Organisation (WHO). (2018). Genes and human disease. Genomic resource centre. Available at: <http://www.who.int/genomics/public/geneticdiseases/en/index2.html>

World Health Organisation (WHO). (2017). *Sierra Leone Annual Report. A Year in Focus 2017*. Freetown: WHO.

World Health Organization (WHO). (2015a). Medical eligibility criteria for contraceptive use. Available at: [http://www.who.int/reproductivehealth/publications/family\\_planning/MEC-5/en/](http://www.who.int/reproductivehealth/publications/family_planning/MEC-5/en/).

World Health Organisation (WHO). (2015b) *Trends in Maternal Mortality: 1990 to 2015*. 2015. Estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division. Geneva: WHO.

World Health Organisation (WHO). (2010). *Sickle Cell Disease: A Strategy for the WHO African region*. Malabo: WHO.

World Health Organisation (WHO) (2006) *Sickle Cell Anaemia Report of the 59<sup>th</sup> World Health Assembly*. Available at: [http://apps.who.int/gb/archive/pdf\\_files/WHA59/A59\\_9-en.pdf](http://apps.who.int/gb/archive/pdf_files/WHA59/A59_9-en.pdf)

Wurie, A. T., Wurie, I. M., Gevao, S. M., & Robbin-Coker, D. J. (1996). The prevalence of sickle cell trait in Sierra Leone. A laboratory profile. *West African Journal of Medicine*, 15(4): 201-203.

## APPENDIX ONE

### GOVERNMENT POLICY ON SICKLE CELL: A FIVE POINT PLAN

1. To understand prevalence of sickle cell by engaging in a pilot newborn screening programme.



2. A national newborn screening programme is needed to save lives. This requires a simple blood spot test in infants.



3. Community awareness of sickle cell through sensitization by outreach, radio and television programmes to educate and combat stigma.



4. Policy in all primary, secondary and tertiary education to insure inclusion.



5. Empowerment of women so they can give birth safely, access family planning and can look after their children.



| No. | Pseudonym | Location | Person with SCD or Mother? | Age | Ethnicity | Religion  |
|-----|-----------|----------|----------------------------|-----|-----------|-----------|
| 1   | Estelle   | Freetown | Mother                     | 32  | Loko      | Christian |
| 2   | Susan     | Freetown | Mother and person with SCD | 30  | Sherbro   | Christian |
| 3   | Aminata   | Freetown | Mother and person with SCD | 33  | Temne     | Muslim    |
| 4   | Fatmata   | Freetown | Person with SCD            | 23  | Temne     | Muslim    |
| 5   | Sarah     | Freetown | Mother                     | 42  | Limba     | Christian |
| 6   | Mariama   | Freetown | Mother                     | 39  | Sherbro   | Christian |
| 7   | Hawa      | Freetown | Mother                     | 38  | Susu      | Muslim    |
| 8   | Jenneh    | Freetown | Mother                     | 37  | Susu      | Muslim    |
| 9   | Isatta    | Freetown | Person with SCD            | 18  | Temne     | Muslim    |
| 10  | Mabinty   | Freetown | Mother                     | 36  | Mende     | Muslim    |
| 11  | Zainab    | Freetown | Mother                     | 45  | Mende     | Muslim    |
| 12  | Sally     | Freetown | Mother                     | 46  | Mende     | Christian |
| 13  | Kadie     | Freetown | Person with SCD            | 19  | Limba     | Christian |
| 14  | Khadija   | Freetown | Grandmother                | 54  | Temne     | Muslim    |
| 15  | Isha      | Freetown | Mother                     | 25  | Temne     | Muslim    |
| 16  | Fatima    | Freetown | Person with SCD            | 23  | Temne     | Muslim    |
| 17  | Bintu     | Freetown | Mother                     | 55  | Temne     | Muslim    |
| 18  | Ella      | Freetown | Mother                     | 29  | Temne     | Muslim    |
| 19  | Siabanda  | Koidu    | Person with SCD            | 19  | Kono      | Christian |
| 20  | Finda     | Koidu    | Mother and person with SCD | 45  | Kono      | Christian |
| 21  | Kumba     | Koidu    | Mother                     | 30  | Kono      | Muslim    |
| 22  | Suma      | Koidu    | Mother                     | 30  | Kono      | Christian |
| 23  | Djenabou  | Koidu    | Mother                     | 27  | Fula      | Muslim    |
| 24  | Yara      | Koidu    | Mother                     | 35  | Kono      | Muslim    |

|    |          |       |                            |    |         |           |
|----|----------|-------|----------------------------|----|---------|-----------|
| 25 | Fatu     | Koidu | Person with SCD            | 27 | Limba   | Christian |
| 26 | Yenor    | Koidu | Person with SCD            | 23 | Kono    | Christian |
| 27 | Barbara  | Koidu | Mother and person with SCD | 32 | Kono    | Muslim    |
| 28 | Isata    | Koidu | Grandmother                | 67 | Limba   | Muslim    |
| 29 | Sera     | Koidu | Person with SCD            | 22 | Limba   | Christian |
| 30 | Amie     | Koidu | Person with SCD            | 23 | Mende   | Christian |
| 31 | Dawa     | Koidu | Person with SCD            | 30 | Kono    | Muslim    |
| 32 | Patricia | Koidu | Person with SCD            | 24 | Kono    | Christian |
| 33 | Gladys   | Koidu | Mother and person with SCD | 23 | Kono    | Christian |
| 34 | Fanta    | Koidu | Mother                     | 25 | Maraka  | Muslim    |
| 35 | Keima    | Koidu | Person with SCD            | 18 | Kono    | Christian |
| 36 | Harietu  | Koidu | Mother and person with SCD | 65 | Madingo | Muslim    |

## RESOURCES

### **The Sierra Leonean Sickle Cell Society**

Mrs. Amelia Gabba

Provides advice, counselling, pain medicine and referrals for medical treatment.

25 Thomas Street or

86 Kissy Road, Freetown, Sierra Leone.

amy\_gabs3@ymail.com

<http://www.sleonesickle.org>

### **Sickle Cell Carer's Awareness Network (SCCAN)**

Provides advice, counselling, pain medicine and referrals for medical treatment.

Mrs. Sia Evelyn Nyandemo

konosccan@yahoo.com